Quality End-of-Life Care
Patients’ Perspectives

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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 "standardized measurements are applied to metrically defined units [of text] and these are used to characterise 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 acceptability 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.

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.

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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 form and interviewed 6 months later. 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 with-...
lidity in quantitative research. 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.

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-

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 any-

ways. 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.

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Table 2. Participant Characteristics

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

*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*

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

*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 stressful 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 conceptual 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 al 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 al found that 47% of incurably ill patients with advanced dementia and metastatic cancer received nonpalliative treatments. Solomon et al found that 78% of health care professionals surveyed reported that they sometimes felt the treatments they offered patients were overly burdensome. Hanson et al 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 Tulsky et al, 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.” 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. 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.

**Achieving a Sense of Control**

When participants said they wanted to achieve a sense of control, they seemed to have in mind a psychosocial outcome rather than a precise specification of what treatments would be received. Although the SUPPORT study 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. As noted by Byock, 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, 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 beginning 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. 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.

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