

# Good and Bad Dying From the Perspective of Terminally Ill Men

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**Background:** Understanding the range of patients' views about good and bad deaths may be useful to clinicians caring for terminally ill patients. Our current understanding of good and bad deaths, however, comes primarily from input from families and clinicians. This study aimed to learn how terminally ill men conceptualize good and bad deaths.

**Methods:** We conducted semistructured interviews with 26 men identified as having terminal heart disease or cancer. Participants described good and bad deaths in a section of open-ended questions. Participants also answered closed-ended questions about specific end-of-life scenarios. The open-ended questions were tape recorded, transcribed, and analyzed using grounded theory methods. The closed-ended questions were analyzed using descriptive statistics.

**Results:** We found heterogeneity in responses to questions about good deaths, bad deaths, and preferred

dying experiences. Participants voiced multiple reasons for why dying in one's sleep led to a good death and why prolonged dying or suffering led to a bad death. Participants did not hold uniform views about the presence of others at the very end of life or preferred location of dying.

**Conclusions:** In discussing the end of life with terminally ill patients, clinicians may want to identify not only their patients' views of good and bad deaths but also how the identified attributes contribute to a good or bad death. The discussion can then focus on what might interfere with patients' attainment of their preferred dying experience and what may be available to help them achieve a death that is most consistent with their wishes.

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**T**O HELP THOSE WITH TERMINAL illness achieve the best possible experience of dying, clinicians need to know what their patients want and what they want to avoid at the very end of life. Previous attempts to define good and bad deaths have relied on input from family members,<sup>1-3</sup> a combination of patients, family and/or clinicians,<sup>4,5</sup> and end-of-life experts.<sup>6</sup> Other studies, however, have illustrated that patients, families, and clinicians may all interpret the experience of dying differently.<sup>7-12</sup> Several studies have focused on patients' perspectives of good and bad deaths.<sup>13-15</sup> Only 1 of these studies limited enrollment to individuals who were actively facing a terminal illness with an estimated life expectancy of 6 months or less, and that study examined relatively young patients with advanced AIDS.<sup>15</sup> Our goal was to study the perspective of older patients with common terminal illnesses, cancer, and end-stage heart disease.

A primary goal of this study was to learn how a group of terminally ill men described good and bad deaths. We also were interested in how components from these descriptions contributed to a good or bad death. To obtain rich data that were not influenced by any investigator's precon-

ceived ideas of good and bad deaths, we opted to use open-ended questions. To obtain additional information about preferences for the very end of life, we also asked several closed-ended questions.

## METHODS

### DESIGN

The design was a qualitative study involving one-on-one interviews with terminally ill men to determine the components of a good and a bad death.

### PARTICIPANTS

Participants were enrolled in a study to identify the components of quality of life at the end of life. Physicians from geriatrics, general internal medicine, oncology, and cardiology clinics at 2 university-affiliated medical centers identified potential participants with estimated life expectancies of 6 months or less from either cancer or heart disease from their panels of patients. Patients with these illnesses were chosen because cancer and heart disease are the most common causes of death in the older adult population.<sup>16</sup> Physicians were provided with reference material to help them estimate prognosis of 6 months (ie, criteria for a Karnofsky performance scale score of  $\leq 50$  for patients with cancer<sup>17</sup> and the hospice eligibility criteria of the National Hospice Organization for heart disease<sup>18</sup>).

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Potential participants received a letter from their physician, introducing the study and providing a telephone number if no further contact was desired. During a telephone contact from a member of the research team (E.K.V.), potential participants learned about the study and, if interested in participating, gave verbal consent to be screened for eligibility. Screening exclusion criteria included moderate or severe cognitive impairment reflected by 5 or more errors on the Short Portable Mental Status Questionnaire<sup>19</sup> and failure to acknowledge that they were seriously ill.

In designing this study, we believed that those with significant cognitive impairment and those who did not acknowledge that they were seriously ill might not be able to provide in-depth descriptions of good or bad dying experiences. Those eligible and interested in participation gave written consent at the start of the face-to-face interview. Of 41 individuals solicited to participate, 33 were eligible. Those who were not eligible had either died or were reported to be too ill to participate. No potential participant was excluded because of a low Short Portable Mental Status Questionnaire score or failure to acknowledge that his illness was "serious."

Of the eligible potential participants, 26 (79% of the eligible subjects) agreed to participate.

The participants included 13 men with cancer and 13 men with heart disease. All but 1 participant were veterans. The mean age of both groups was 71 years. All participants with cancer were white; 5 participants with heart disease were African American. Twelve participants with cancer and 10 with heart disease were married or partnered. New subjects were enrolled until "theoretical saturation" was reached, that is, until no new themes emerged from answers to the open-ended questions in the interview.<sup>20(pp61-62)</sup> The Human Subjects Division of the University of Washington approved all study materials and procedures.

#### DATA COLLECTION

Subjects participated in semistructured interviews. One interviewer (E.K.V.) conducted all interviews at the most convenient location for the subject. First, participants were asked to describe a good death and a bad death. Responses to these questions were tape recorded and transcribed verbatim. Second, participants rated the importance of end-of-life issues such as presence of others while dying and location of death. These questions were answered using a 5-point Likert scale ranging from "not important" to "very important." Participants also answered demographic questions, completed the Yesavage Geriatric Depression Scale,<sup>21</sup> and were asked if they were depressed.<sup>22</sup> Any spontaneous comments in response to the closed-ended questions were transcribed verbatim by the interviewer.

#### DATA ANALYSIS

Themes emerging from the interviews were incorporated into a coding scheme. Transcripts were coded by 2 investigators independently, the assigned codes were compared, and discrepancies in coding were resolved through discussion. The coded text was entered in a qualitative analysis database and analyzed using the grounded theory methods.

Grounded theory uses a systematic method to divide and reorganize qualitative data and to facilitate interpretation. It includes 3 levels of coding (open, axial, and selective) with the ultimate aim of developing a new theory about a phenomenon.<sup>20</sup> During open coding, researchers categorize data from sources such as interview transcripts into broad categories or themes. During axial coding, the properties of each category are characterized and the relationships between categories are examined. Finally, in selective coding, the categories are organized into a framework to explain the phenomenon.

In this study, we used open and axial coding methods. This process of analysis was used to categorize the components of a good and a bad death, to learn how themes contributed to a good or bad death, and to compare the content of responses given by participants with cancer and heart disease.

Steps taken to ensure the trustworthiness of the qualitative data included theoretical saturation<sup>20</sup> (no new themes emerged during interviews with the last 3 participants enrolled), an evaluation of intercoder reliability<sup>23</sup> (assignment of codes by 2 investigators across 3 transcripts was 77%), and theoretical verification<sup>24</sup> (the results were presented to 2 end-of-life researchers familiar with qualitative methodology). The quantitative data were analyzed using descriptive statistics. These data provide complementary information to the qualitative results and are included for descriptive purposes only.

## RESULTS

Of the 26 participants, 6 with cancer and 6 with heart disease described their health as "poor" or "very poor." Eight participants with cancer and 8 with heart disease described their quality of life as "best possible" or "good." Two participants with heart disease and 1 with cancer were mildly depressed (6-8 "depressed" answers on the Geriatric Depression Scale). One participant with heart disease and 2 with cancer were more depressed (>8 "depressed" answers on the Geriatric Depression Scale).

Participants did not hold a uniform view of a good or bad death. **Table 1** and **Table 2** list the themes mentioned by at least 3 participants in descriptions of good and bad deaths and the number of participants identifying each theme. Sample quotations illustrating each theme are also provided. No participant mentioned every theme. Responses of participants with cancer contained similar themes to the responses of participants with heart disease. The results, therefore, have not been divided into illness category. Participants with and without depression mentioned similar themes.

In addition to identifying components of good and bad deaths, analysis of the qualitative data yielded 2 additional findings. First, although participants used many of the same terms in their descriptions, multiple reasons emerged for how these themes contributed to a good or bad death. Second, past experiences with death and with inadequately controlled symptoms often influenced participants' views of good and bad deaths.

Probing participant responses with further questions provided information on how a theme contributed to a good or bad death. Participants offered several reasons why dying in one's sleep was associated with a good death, for instance. Explanations included that the dying individual would (1) not know death was imminent, (2) not be in pain at the moment of death, and (3) die quickly, peacefully, or easily. As one individual described, "Oh, just going to sleep one night and not waking up. It would be a very easy, fast way to go, no drugs, no side effects, so to me that would be real easy."

Eleven participants identified prolonged dying with a bad death. To some, prolonged dying meant having prolonged pain. Several others believed that prolonged dying would cause their families to suffer. They expressed concerns about the emotional, financial, and caregiver

**Table 1. Components of Good Deaths and Illustrative Quotations**

"In my sleep" (n = 14)	"A good death, for me, would be to slip away quietly in my sleep, by and large, with no pain or to speak of or I just—when the time comes, I'd see the Lord and just like stepping off a platform and says, Here I am. That's about it."
Quick (n = 11)	"A good death? 85 [years old] of a heart attack in—walking through the trees and I was out before I hit the ground. Other than that, I think're all kind of bad."
Painless (n = 11)	"But I guess if you get a lot of pain like I had before, death would have been kind of a welcome—welcome sight because I was hurting pretty bad."
Without suffering (n = 5)	"Good death is like my buddy that I ran around with for many, many years . . . he woke here a couple years ago, and he told his wife, you know, I feel kind of funny. And he went in, and he got down on his knees . . . and died. Boom. Never suffered a day, never suffered an hour even."
Peace with God (n = 3)	"I would say that a good death would be a death where you were sure that . . . you've made your peace with God; you've made sure your family's taken care of, and there's no need to worry."
Peaceful (n = 3)	"A good death? Well, to just leave this world in the peaceful manner, of course, naturally. I know that I'll have pain and somewhat—a little suffering, but I can endure that if I just leave this earth well thought of."
Without knowledge of impending death (n = 3)	"Go quietly in sleep, I guess. I think that would be the nicest way to go. . . . Well, I guess you don't know it until you get there, you know."

**Table 2. Components of Bad Deaths and Illustrative Quotations**

Painful (n = 12)	"To be in severe—ultra severe pain under whether there's no control. . . . And it goes on and on and you can't control it or do anything about it . . . it's just awful, awful. That to me would be the worst kind."
Prolonged (n = 11)	"Oh, to linger and drag on and take a long time. It would make it hard on people and everything. People more or less accept that you're going to die, but if you prolong it, it just makes it harder on them."
Dependent (n = 8)	"Being hooked up with those monitors and then laying there for days and stuff and you hurt; you can't complain, you can't do anything. That's a bad way to go. I don't want that. That's the reason I says no resuscitation."
Suffering (n = 7)	"And I really don't want to suffer, but I've done a lot of that, and I'm not totally afraid of it. . . . Well, going to the hospital is suffering for me. And I've been through some torture that I consider pretty terrible."
Burdening others (n = 5)	"If I were bedridden and had to have my wife and some other people take care of me, I wouldn't want to stick around a minute."
"Drowning" or shortness of breath (n = 4)	"Maybe, maybe before I lose all my breathing, some other organ will take—take me. And I've prayed for that."
"Not right with God" (n = 3)	"Not being with—with the Lord would be a bad death. Not being right in the Lord and with your family."

burdens to loved ones that would be associated with prolonged dying. One explained,

I don't want to hang around. That just makes it miserable for everybody around you. You know, your kids and everything come to see you, and they say, I wonder how long Dad's got now. They put their arms around Mom and console her, let her know that they're with her when the time comes.

Those participants who identified suffering with a bad death were asked to explain why. To some, "suffering" meant being dependent on others. One participant described the end of his aunt's life as he explained how suffering, to him, meant being dependent:

Just laying and suffering or not being able to do something would be bad . . . She couldn't feed herself. She couldn't do nothing. Then toward the end, they even had to feed her intravenously to keep her alive.

To others, suffering meant being in pain. For example, another participant explained, by describing the end of his mother's life, how suffering meant having pain:

And my mother seemed to suffer at the end. She was losing her legs from diabetes, and she was in a lot of pain, or at least she felt like she was. She was in a coma, but she could—she would moan and all if anybody touched her, especially her legs. So you knew that she was—if she was conscious, she was suffering . . .

Participants' definitions of good and bad deaths were often influenced by past experiences. As illustrated in the previous paragraph, some participants' descriptions of bad deaths were influenced, in part, by deaths of loved ones. One participant described a good death:

. . . my granddad, he just sat down in a chair one morning, a rocking chair, and he said he felt a little cool. And she [participant's grandmother] said, I'll get you a blanket. And when she came back with the blanket, he was gone.

Another participant recalled the death of a hospital roommate when he had been a patient in an intensive care unit. He described listening to his roommate die with shortness of breath as, "the worst thing that ever happened to me." This participant had also experienced shortness of breath firsthand:

. . . you're on one of these ventilators, if you're in the hospital, when they—when they don't work quite right. And I've had that happen to me. And you can't get enough oxygen quite.

Because of his past experiences with the death of his hospital roommate and with his own dyspnea, this participant described a bad death as one with shortness of breath, "I hope I don't die like that, when you're fighting to get your breath."

**Table 3** gives the participants' responses to the closed-ended questions. Although most participants (20

**Table 3. Importance Ratings of End-of-Life (EOL) Issues**

	Not Important	A Little/Somewhat Important	Quite Important	Very Important
Family/friends in current life	0	1	4	20
Presence family/friends at the very EOL	4	5	7	10
Religion/spirituality in current life	5	4	1	16
Presence of religious/spiritual leaders at the very EOL	6	7	4	8
Dying at home	5	6	5	6
Dying in the hospital	13	6	1	2
Physical contact with loved ones at the very EOL	2	9	5	8

[77%]) rated family as “very important” in their current lives, fewer than half of these participants (10 [45%]) also rated the importance of family presence at the very end of life as “very important.” As one participant described, “It would be nice [to have family present], but I’d hate to put them through it.” Another commented, “I’ll travel the road myself.” Participants’ views of dying at home were heterogeneous. Although some preferred to die at home, many voiced concerns about the effect of this on their families. As one explained, “If it’s a burden on my family, I’d rather go elsewhere.”

#### COMMENT

A primary goal of this study was to learn how terminally ill men described good and bad dying experiences. We found heterogeneity in terminally ill men’s views about good deaths, bad deaths, and preferred dying experiences. The heterogeneity of views even extended to the reasons provided for how attributes contributed to the good or bad death. For example, dying in one’s sleep could lead to a good death because the dying individual would not know that death was imminent or because the death would be painless. Prolonged dying could lead to a bad death because it burdened the family or because the dying individual would have prolonged pain. Suffering could lead to a bad death because the dying individual was dependent on others or because that individual was in pain. Furthermore, our study provides empiric evidence for the multifaceted nature of suffering as previously described in theoretical discussions.<sup>25,26</sup> Finally, participants held differing opinions about preferred location of death and presence of others at the very end of life.

Our results bear some similarities to previous studies.<sup>5,15,27</sup> Heterogeneity of views about good deaths has been found in medical students<sup>26</sup> and persons with advanced AIDS.<sup>15</sup> Four components of a good death (in one’s sleep, painless, quick, and peace with God) identified by participants in our study also were mentioned in a study of palliative care cancer patients.<sup>5</sup> The palliative care patients also

identified the quiet (dignified) death and the death without fear or fatalism. The components of a good death identified both in our study and a study of patients with advanced AIDS<sup>15</sup> were symptom control, quick, without suffering, and in one’s sleep. The patients with AIDS also identified themes such as patient control of treatment and role of physician-assisted suicide. Interestingly, some participants with AIDS explained that knowing that death was imminent contributed to a good death. In contrast, those in our study who mentioned this theme believed the opposite—that a good death occurred when one did not know that death was imminent.

In another qualitative study, Steinhauser et al<sup>4</sup> conducted focus groups with patients (with cancer or human immunodeficiency virus infection), bereaved family members, and health care workers to describe good deaths. The issues contributing to a good death identified in the study by Steinhauser et al<sup>4</sup> included pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person. Only 1 theme, pain and symptom management, was noted in our study. The difference in issues identified between the study by Steinhauser et al<sup>4</sup> and ours may be explained, in part, by a difference in perspective about what constitutes the end of life. The focus groups in the study by Steinhauser et al<sup>4</sup> described experiences in the weeks and months prior to death that contributed to a good death. Those in our study identified attributes of a good death occurring at the very end of life. The themes identified in the study by Steinhauser et al<sup>4</sup> may also differ from ours because the work was conducted within a research program entitled Program on the Medical Encounter and Palliative Care, which may have introduced a recruitment bias.

We also asked participants to describe a bad death. Participants in our study voiced concerns about being dependent and burdening others. Payne et al<sup>3</sup> asked health care workers this question, but not patients. Of the 7 themes identified by the participants in our study and the 5 identified by the health care workers in the study by Payne et al,<sup>3</sup> only 1 theme overlaps—presence of uncontrolled symptoms. The health care workers identified different themes such as lack of acceptance and the dying person being young. This finding may lend credence to previous studies, which have found that patients, caregivers, and clinicians have different concerns regarding the end of life.<sup>7-12</sup>

The closed-ended questions contributed additional findings. Currently valuing family did not automatically translate into wanting family present at the very end of life. Two participants in the present study, in fact, stated that they wanted to die away from their loved ones. This range of preferences about presence of loved ones at the very end of life has been previously noted with older patients<sup>13</sup> and patients with AIDS.<sup>15</sup> Our participants did not voice a uniform preferred location of death. This heterogeneity of preferred location of death has been noted previously in terminally ill patients,<sup>28</sup> patients with AIDS,<sup>15</sup> and older patients.<sup>13,29</sup>

In addition to the similarities to previous studies, there is further evidence that the results may be credible. First, we found consistencies between descriptions of good and

bad deaths. The opposites of several themes mentioned in descriptions of good deaths were noted in participant descriptions of bad deaths. A painless and quick death was considered good, while a painful and prolonged death was considered bad. Dying having made "peace with God" was considered good, and dying while "not right with God" was considered bad. This consistency indicates some internal validity of the results. Second, the process of theoretical verification of the results, in which 2 experts in end-of-life research were asked to respond to the plausibility of the preliminary results, indicates that the results have a measure of external validity.

This study has limitations. First, the small study population may limit the generalizability of the results. Theoretical saturation, however, was achieved. The similarities between the themes found in our study and in previous studies<sup>5,13,15</sup> indicate that our findings may be generalizable, and help, in part, to validate the findings of the previous studies in a different patient population. Second, participants knew that they would be talking about the end of life and all acknowledged that they were seriously ill, introducing a potential for selection bias. Patients who are unaware of or in denial of the severity of their medical illness might offer different descriptions of good and bad deaths. Third, because most of the participants were male veterans, the results should not be extended to women, to nonveterans, and to those who are not white or African American.

The results of this study have implications for clinicians caring for terminally ill patients. Because individuals define good and bad deaths differently, clinicians may want to ask each patient to describe each of these. To truly understand a patient's views about the end of life, the clinician will need to probe certain answers to find out what "suffering" means to that individual, for example. Clinicians may not want to assume that wanting to avoid suffering equates to wanting to avoid pain. Clinicians may also want to ask patients about the presence of others at the very end of life and preferred place of death.

Once the clinician has obtained information about a patient's preferences for the end of life, the discussion then can focus on how a patient's clinical course may fit with the stated preferences. Situations that might preclude a patient from being able to attain his preferred death, for instance, could be discussed and alternative options reviewed. If a patient without family, who lives alone, states that a good death would be one in which he or she dies at home, the clinician's response might include a review of alternative settings for care if adequate in-home care could not be arranged. Engaging in these conversations before death is imminent may help patients achieve a better quality of life while they are dying and may reduce emotional stress on loved ones.

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