

In search of a good death: observations of patients, families, and providers.

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# In Search of a Good Death: Observations of Patients, Families, and Providers

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## Abstract

Despite a recent increase in the attention given to improving end-of-life care, our understanding of what constitutes a good death is surprisingly lacking. The purpose of this study was to gather descriptions of the components of a good death from patients, families, and providers through focus group discussions and in-depth interviews. Seventy-five participants—including physicians, nurses, social workers, chaplains, hospice volunteers, patients, and recently bereaved family members—were recruited from a university medical center, a Veterans Affairs medical center, and a community hospice.

Participants identified six major components of a good death: pain and symptom management, clear decision making, preparation for death,

completion, contributing to others, and affirmation of the whole person.

The six themes are process-oriented attributes of a good death, and each has biomedical, psychological, social, and spiritual components.

Physicians' discussions of a good death differed greatly from those of other groups. Physicians offered the most biomedical perspective, and patients, families, and other health care professionals defined a broad range of attributes integral to the quality of dying.

Although there is no “right” way to die, these six themes may be used as a framework for understanding what participants tend to value at the end of life. Biomedical care is critical, but it is only a point of departure toward total end-of-life care. For patients and families, psychosocial and spiritual issues are as important as physiologic concerns.

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Professional organizations and the public have recently made care of the dying a national priority (1-7). Despite this, however, we remain confused about what constitutes a good death (8). Some patients with terminal illnesses choose to leave the conventional medical setting and receive hospice care in their home, surrounded by family. Others seek experimental chemotherapy in an intensive care unit. In each of these vastly different scenarios, the perception of the quality of death is constructed by family, friends, and health care providers, not solely by the dying person. However, little empirical evidence exists to document these varied perspectives (9, 10).

We conducted this study to describe the attributes of a good death, as understood by various participants in end-of-life care. To evaluate the relative importance of these attributes, we compared the perspectives of different groups of persons who had experienced death in their personal or professional lives.

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# Methods

## Design

We used focus groups and in-depth interviews to identify the attributes of a good death. These qualitative methods, which are common in exploratory studies, generate hypotheses and provide rich descriptive information about a phenomenon (11–13). Researchers do not impose theoretical assumptions a priori but instead let participants frame questions from the “ground up.”

## Participants

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 (Table 1) (12). Groups were stratified by role. Participants were recruited from Duke University Medical Center, Durham Veterans Affairs Medical Center, and a local community hospice in Durham, North Carolina. Nonphysician providers were recruited from convenience samples generated by e-mail and departmental advertising. Physicians were recruited from the attending staff of the Duke University Medical Center, Department of Medicine. We stratified physicians by level of appointment (assistant, associate, or full professor), randomized the lists, and recruited potential participants in order, ensuring that the final group represented each career level. Patients were recruited by telephone from an ethnically stratified sample enrolled in oncology and HIV clinics. Family members were recruited from a stratified random sample of recently bereaved relatives of Veterans Affairs patients who had died 6 months to 1 year earlier. For each group, we continued to call potential participants until

we obtained 6 to 8 participants per group.

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## Table 1. Focus Group Composition

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We conducted separate groups for African-American and white patients, with trained facilitators from the respective ethnic groups. Participants were compensated for their time. The institutional review boards of the Durham Veterans Affairs Medical Center and the Duke University Medical Center approved the study.

## Data Collection

We asked focus group participants to discuss their experiences with the deaths of family members, friends, or patients and to reflect on what made those deaths good or bad. When necessary, we asked probing questions to clarify a comment or obtain more detail ([Appendix](#)).

We took several steps to ensure reliability and validity, which are often called “exhaustiveness” and “trustworthiness” in qualitative research (11). First, we conducted focus groups until the same themes were repeated and no new themes emerged. Theme exhaustiveness is reached when similar themes are generated by participants from very different social backgrounds. Next, after repeatedly analyzing focus group transcripts, we conducted in-depth interviews with two members from each group—the most and least talkative participants. The most talkative participants were usually willing to provide information; the least talkative participants were interviewed to elicit possible silent but dissenting viewpoints. No new themes emerged through these interviews, thereby confirming exhaustiveness. The interviewees were presented with our analyses and were asked to evaluate our interpretations. Trustworthiness is noted when participants respond affirmatively to researchers' interpretations (12).

# Statistical Analysis

Focus groups and interviews were audiotaped and transcribed. We did not use quantitative methods of inter-rater agreement. Instead, we followed a grounded theory approach with a “constant comparisons” method and its related open and axial coding techniques (10, 11). During open coding, four investigators independently read an example of a transcript and analyzed it for common and recurrent themes pertaining to qualities of a good death. These summaries were compared for theme agreement and disagreement. One coder used qualitative software (NUDIST, Scolari Sage Publications Software, Thousand Oaks, California) to apply the coding scheme to the remaining transcripts. Throughout the coding process, all four investigators reviewed theme exemplars as a check on coding validity. During axial coding, the investigators developed further conceptual domains by comparing themes within and between transcripts (11). After identifying more than 70 attributes, we collapsed the full list into 6 broad domains. Although the 6 themes are presented as conceptually distinct, attributes overlapped between domains. For example, attention to spiritual concerns may be primarily associated with a process of “completion” but may also affect patients' physical pain.

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.

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## Results

Focus group participants ranged in age from 26 to 77 years (mean age, 47 years) (Table 2). 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 (Table 3).

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**Table 2. Characteristics of Focus Group Participants**

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**Table 3. Components of a Good Death**

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## Pain and Symptom Management

Many focus group participants feared dying in pain. Portrayals of bad deaths usually mentioned inadequate analgesia during cure-directed therapies that were perceived as too aggressive. One nurse, discussing a patient, said:

His disease was very widespread. One of the interns or residents said, “We don't want you on morphine. You're going to get addicted.” I said, “You must be joking. This guy is having pain, and he's not going to make it out of the hospital.” He stayed on the surgical service and he died in 4 days, in pain.

Participants were concerned with both current pain control and control of future symptoms. Intrusive thoughts of breakthrough pain or extreme shortness of breath produced anxiety that could be relieved with appropriate reassurance. One man with AIDS said, “I don't want to be in pain, and I've discussed it with my doctor. He said, ‘Oh, don't worry about pain. We'll put you on a morphine drip.’ That sort of eased my mind.”

## Clear Decision Making

Participants stated that fear of pain and inadequate symptom management could be reduced through communication and clear decision making with physicians. Patients felt empowered by participating in treatment decisions. One patient said:

This is *my* medical problem. Sometimes I don't want to stay on the rigid schedule, and he [the physician] would say, "I would like for you to stay on that, but you are the manager of your ship. You decide how fast you want to paddle, if you want to go backwards, sideways, or make a 360° turn."

Alternately, descriptions of bad deaths frequently included scenarios in which treatment preferences were unclear. Patients felt disregarded, family members felt perplexed and concerned about suffering, and providers felt out of control and feared that they were not providing good care. Decisions that had not previously been discussed usually had to be made during a crisis, when emotional reserves were already low.

One social worker, speaking about her mother, said:

I had never talked to her about end-of-life issues. I'm trying to communicate with my family over the phone. "What do we do? She's intubated, her labs are worse." The doctor said, "We really don't think that she's going to make it, and we have to consider withdrawing life support." I said, "I'm sorry, but that's not a decision I can make."

One physician spoke about the anticipatory conversations she usually had with patients who had advanced disease, using one particular patient as an example:

This person had mets everywhere. I explained to him, “There's nothing that's going to bring your bones back. In this situation, somebody would do CPR [cardiopulmonary resuscitation]. That involves pumping on your chest, and it would likely fracture your bones.” I was very simple about it. I said, “The alternative, which I would recommend, is we make sure we give you enough pain medication that you will not suffer.” I find that the more up-front I am, most people are appreciative of that.

## **Preparation for Death**

Participants voiced a need for greater preparation for the end of life. Patients usually wanted to know what they could expect during the course of their illness and wanted to plan for the events that would follow their deaths. One patient said, “I have my will written out, who I want invited to the funeral. I have my obituary. That gives me a sense of completion that I don't have to put that burden on someone else. It's to prepare myself for it.”

Family members felt a need to learn about the physical and psychosocial changes that would occur as death approached. Participants spoke of scenarios in which a lack of preparation adversely affected patient care. One nurse said:

I can't tell you how many times, working in the emergency room, [that I saw] families [take a patient home]; this patient was going to die at home. And, when the last breath came, the families panicked. They brought the patient into the emergency room and went through the whole process [resuscitation]. Preparing the family, assessing what they actually know, and figuring out what you have to teach them is essential.

Finally, the most experienced nonphysician providers spoke about the

importance of exploring one's own feelings about death and the ways in which these feelings influence the ability to care for terminally ill patients. One nurse said:

When I was in nursing school, my older sister was killed in a car accident. I never had to think about death before that. It sent me on a personal quest. I developed a comfort with it that sometimes made it very frustrating to work with people who didn't have that understanding, who still looked at death as the enemy. You all know which attendings can and can't go in and talk to the patients because it's too uncomfortable.

Most of the personal preparation described by health care providers had occurred individually, outside the context of their formal training. Only one physician in our study had received residency training in palliative medicine.

## **Completion**

Participants confirmed the deep importance of spirituality or meaningfulness at the end of life. Completion includes not only faith issues but also life review, resolving conflicts, spending time with family and friends, and saying good-bye. A family member of a recently deceased patient recalled the following:

He got home, and they got him out of the ambulance. I remember him saying, "Oh, can I wait just a minute, to remember the sunshine." This for somebody who hadn't seen the sun in ... It was almost like we had a party that evening. Everybody was there, and we sang songs. He died that night, at home, and everybody was there.

In western culture, completion may primarily be a process of individual life review that is subsequently shared with family and friends. For patients from other cultures, completion may be more explicitly communal and may involve rituals that are important to the family during the dying process and after death. A nurse described her experiences with the family of one such patient:

They asked to bring in their religious representative. It was important to them that the patient be completely bathed as she was dying as well as when she was dead. I had some weird looks from physicians who were saying, "You're wasting your time. This wasn't an effective intervention." But it was, because when all was said and done, they [the family] had accepted it.

Issues of faith were often mentioned as integral to overall healing at the end of life and frequently became more important as the patient declined physically. However, we also heard that such issues are highly individualistic and that cues about their particular expression must be taken from the patient.

## **Contributing to Others**

Several focus groups mentioned the importance of allowing terminally ill persons to contribute to the well-being of others. A hospice volunteer told the following story:

They [patients] have the ability to help someone else through me. One fellow liked to go out for rides. He couldn't walk around very well, but he invited another patient to come out. She was very debilitated too. So, the three of us would drive around the community. As debilitated as some

patients get, they're still capable of helping someone else or making someone else laugh.

Contributions can take the form of gifts, time, or knowledge. As death approaches, many patients reflect on their successes and failures and discover that personal relationships outweigh professional or monetary gains. They are anxious to share that understanding with others. One family member said, "I guess it was really poignant for me when a nurse or new resident came into his room, and the first thing he'd say would be, 'Take care of your wife' or 'Take care of your husband. Spend time with your children.' He wanted to make sure he imparted that there's a purpose for life."

## **Affirmation of the Whole Person**

Participants repeatedly declared the importance of affirming the patient as a unique and whole person. Patients appreciated empathic health care providers. One patient said of his caretakers, "There's no question that they make me feel I can't ask." Family members were comforted by and spoke with great respect about those who did not treat their loved ones as a "disease" but understood them in the context of their lives, values, and preferences. One family member related the following:

The residents always approached my father as if he was a person and there weren't any divisions between them. They didn't come in and say, "I'm Doctor so and so." There wasn't any kind of separation or aloofness. They would sit right on his bed, hold his hand, talk about their families, his family, golf, and sports.

Health care providers' descriptions of good deaths also focused on their personal relationships with patients and families. They were touched by

the fact that these relationships were present even in the most dire medical crises. One physician told the following story about a patient:

That last day I saw him in the emergency room, he was looking at me with those roving eyes and gasping for breath. I leaned over him and stroked his hair. He looked at me and said, “How's that new house of yours?” I said, “I'm not really moved in.” And he said, “You make sure you decorate it nicely.” It was a very personal interchange. He was dying, and his last interaction with me was as a person, not as a doctor.

## **Distinctions in Perspectives of a Good Death**

These six themes reflect the common ground shared by participants. However, we also saw differences between groups. Social and professional roles substantially shaped the views of our discussants. In fact, professional role distinctions were more pronounced than sex or ethnic differences. For example, all social workers spoke from a case management perspective and were highly attuned to the needs of the family as the unit of care. Chaplains eloquently discussed ethical issues and were the only group to relay the tension between individual and community rights. Family members spoke from the unique role of both patient advocate and recipient of care. All six themes were present in patient, family, and nonphysician health care provider focus groups. In contrast, physicians' discussions were uniformly more medical in nature, and no physicians spoke of “contributing to others.” One physician made a brief comment about completion, but other members of the group did not expand on it.

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## **Discussion**

Although death is a rite of passage in which we will all participate—as family member, provider, or, eventually, patient—we understand little of what is valued at the end of life. Our study confirmed the importance of four themes found in the palliative care literature: pain and symptom management, clear decision making, preparation for death, and completion. Two new themes, contributing to others and affirmation of the whole person, were unexpected and add to our understanding.

Every provider group offered regret-filled stories of patients who died in pain. Such findings are concordant with studies showing that 40% to 70% of Americans have substantial pain in the last days of their lives (14). Concern about undertreatment of pain is consistent across surveys of physicians, nurses, and recently bereaved family members (10, 15, 16). Our study also revealed a new dimension to this theme: anticipatory fears about pain and symptom control. Many dying persons are terrified of waking in the middle of the night with intense pain or air hunger. For them, a good death includes providers who anticipate these fears.

Providers and families in our study also identified the need for improved communication and clear decision making and feared entering a medical crisis without knowledge of patient preferences. Despite the recent attention devoted to advance care planning, this remains a source of great consternation (2, 17, 18). Medicine will never remove all uncertainty from the decision-making process (19). However, if values and preferences are clarified, tolerance for that uncertainty may increase.

Focus group members were concerned about our society's tendency to deny death and demanded greater preparation for dying. We heard many examples in which providers avoided end-of-life discussions because they did not want to remove hope. However, patients and families feared bad dying more than death. Bad dying was characterized by lack of opportunity

to plan ahead, arrange personal affairs, decrease family burden, or say good-bye. For dying patients and their families, preparation does not preclude hope; it merely frames it. After a new diagnosis, patients usually hope for a cure. However, they also hope for lack of pain, lucidity, good quality of life, and a physician who is committed to being with them throughout the care process.

We heard extensive discussion of the need for “completion,” a process involving meaningful time with family and close friends and attention to religious or spiritual beliefs. Terminally ill patients are often able to view their current experience as part of a broader life course trajectory. This may explain why they often rate their quality of life higher than observers, who often do not give appropriate weight to patients' emotional and spiritual development during the dying process (20-24). Traditional measures used to assess end-of-life quality do not usually account for this growth potential (20).

Our study introduced two novel components of a good death. First, a surprising number of participants spoke of the importance of terminally ill patients' contributions to the well-being of others. We fully expected to find that dying patients needed care, but we did not consider the extent to which they also needed to reciprocate. Social psychologists describe this need for “generativity” as one of the great emotional tasks of human development, particularly during later life (25). Dying patients need to participate in the same human interactions that are important throughout all of life. Second, focus group participants continually discussed the need to appreciate patients as unique and “whole persons,” not only as “diseases” or cases. We were struck by the very personal language of this theme and by participants' desire to simply be known.

These six themes add to our understanding of what constitutes a good death and also generate hypotheses that have implications for both medical education and clinical practice. The culture of death changed dramatically during the 20th century. When people died primarily at home, family, community, and clergy assumed responsibility. As the location of death shifted to the hospital, physicians became the gatekeepers (26, 27). As a result, death is now viewed through the lens of biomedical explanation and is primarily defined as a physiologic event (26, 28). Most medical education and training reinforces this framework.

However, a strictly biomedical perspective is incomplete. For most persons involved with care at the end of life, death is infused with broader meaning and is considered a natural part of life, not a failure of technology. All focus groups, except physicians, spoke extensively about the need for life review and subsequent completion. This is not to suggest that these themes are unimportant to physicians; rather, they are not a usual focus of treatment. It may be useful to recognize that for most patients and families who are confronting death and dying, psychosocial and spiritual issues are as important as physiologic concerns. Patients and families want relationships with health care providers that affirm this more encompassing view.

In an economic environment that substantially limits physicians' time, developing such relationships may seem unrealistic. However, in a previous study, we noted that the median time for advanced directive discussions is less than 10 minutes, with no apparent correlation between length of discussion and discussion quality (29, 30). Furthermore, an initial investment of time may improve the patient–physician relationship and save time in future conversations. Time may also be used more efficiently if providers have an a priori list of themes to touch on, such as the six discussed here.

There is no single formula for a good death. Many participants cautioned health care providers against implying, “You're not dying the right way because you're not dying the way we think you should.” As one author has written, people die “in character” (31). Professional providers who meet a dying patient for the first time are at a disadvantage because they catch only a cross-sectional glimpse of the lifetime of experiences that are shaping the dying process. Our data suggest that the quality of dying is related to acknowledgment of that lifetime context.

We heard many stories of health care providers' discomfort with death and dying. Whether such discomfort is caused by feelings of failure, a desire for professional distance, or inexperience, it can adversely affect care. Delivering bad news or discussing other end-of-life issues is a skill that is rarely natural; like other procedures, it must be learned (32). Furthermore, providers must be able to acknowledge and process the feelings that arise when caring for dying patients (33). Programs designed to facilitate this process are now common in police departments and crisis intervention programs, two occupational settings in which trauma and death are always present (34-36). However, such programs have not yet become a usual part of medical training or practice.

Physicians should also be reminded that they are not alone when caring for dying patients; many other health care providers (nurses, social workers, and chaplains) are available for comprehensive care. For example, physicians may ask a screening question (such as “What role does faith or spirituality play in your life?”) that displays awareness of these important aspects. Physicians can then ask whether the patient would like to speak in greater depth with a chaplain. Although physicians may not be responsible for resolving the psychosocial and spiritual needs of patients, acknowledging the presence and complexity of these needs is a way of

actively affirming the whole person.

Our study has several limitations. Most patients were recruited from a Veterans Affairs medical center, and therefore our findings may not be generalizable to other groups. Although our patients were mostly men, they represented a broad range of ages, educational levels, and socioeconomic backgrounds. Many also received care in the private sector, and their comments reflected experiences in many settings. Family focus group members were also recruited from the Veterans Affairs system. However, we collected extensive discussions of family perspectives during discussions with the hospice volunteer group and follow-up interviews with patients. Discussions were limited to deaths from chronic illness and did not include deaths caused by accident or trauma. However, participants described deaths that had occurred in hospices, hospitals, and at home. Good and bad deaths occurred in all settings.

Our study has implications for clinicians, educators, and researchers. Although there is no “right” way to die, the six themes identified here provide an initial framework for addressing topics that are important to patients and families. In addition, biomedical aspects of end-of-life care are crucial but merely provide a point of departure toward a good death. When physical symptoms are properly palliated, patients and families may have the opportunity to address the critical psychosocial and spiritual issues they face at the end of life.

## **Appendix: Protocol for Focus Group Discussions**

### **Focus Group Ground Rules**

We're all here to discuss a topic of great interest to you. But before we begin our discussion, I'd like to review a few important points.

1. Please say exactly what you think. Don't worry about what I think or what your neighbor thinks.
2. Talk about your experience and feelings, and not about what you have heard others say about this issue.
3. Express your opinions, but do not argue with other participants.
4. This discussion is being taped, so please speak up and speak clearly.
5. Let's try to have only one person talking at one time. I will try to ensure that everyone gets a turn to share their opinions.
6. Finally, we're here to have fun. I hope everyone will leave this group having had a worthwhile and stimulating experience.

Today we want to talk about what constitutes a “good death.” We are interested in finding out what you think would make a death good and what would make a death bad. We're interested in this because we want to try to improve people's experiences at the end of life. In order to do that, we need to understand what people feel are the important things that would make a death good.

Many of you have been present for someone's death. We're interested in finding out what kind of things you think make a death good or bad.

### **Focus Group Questions**

First, let me start by asking, has anyone seen someone die in a way that you thought was particularly good or bad?

Do you mind telling us about it?

Do you think it was a good death?

Do you think it was a bad death?

Why? What made it a good/bad death?

What kind of things do you think would make a death a good death?

### **Probe Questions**

Would it be important not to have pain at the time of death?

Who do you think you want to be with you when you die? Would you like to be with others or alone?

How important would it be to have friends and family nearby?

What kind of role would you like your friends and family to have in your death?

How important would it be to have clergy/religious figures nearby?

How important do you think it would be to say good-bye to people?

Where do you think it would be good to die? Would you prefer to die at home, at a hospital, at a hospice?

How do you feel about being sedated?

How important would it be to know in advance what is likely to happen when you die?

How can health care providers affect the quality of death?

What do you think are the roles of nurses, doctors, and social workers in affecting the quality of death?

Imagine if you were to measure good compared with bad deaths. Can you give two things you would measure?

How much control do you want over your death?

How do you feel about assisted suicide/euthanasia?

Do you think about how much money will be spent related to your death?

What do you consider to be proper financial preparations related to your death? This might mean making wills and planning for a funeral.

What are your feelings about the uncertainty that surrounds death?

What are your feelings about the communication between the dying person, the person's family, and the person's caregivers around the time of death?

What kinds of emotions do you think are normal around the time of dying?

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