

Patients' Perspectives on Dying and on the Care of Dying Patients

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Dying patients have much to teach us about their preferences for care. Although caring for dying patients is a major responsibility of physicians, the current curriculum in medical education emphasizes the pathophysiology and treatment of disease, with scarce time and emphasis for developing attitudes and skills essential to caring for persons in the final stage of life. Barriers to satisfactory communication may arise from either the physician or the patient, or both. Patients and physicians sometimes attach different meanings to words that are commonly used in discussing treatment. Barriers can be diminished or resolved by applying good communication skills, including attending to both verbal and nonverbal signals, exploring incongruent affect, and empathically eliciting patients' perspectives about illness, treatment plans, and end-of-life issues. The competent care of dying patients must extend beyond the management of physical symptoms because patients may experience their gravest suffering from fears and anxieties that go unaddressed in conversations with their physician. Conflicts arise when the disease progresses and the end of life approaches if the physician and patient have not reached agreement on their expectations. Physicians may initiate life-prolonging mechanisms when patients actually prefer palliative care.

Patients experience a reduction in both physical and psychological aspects of suffering when physicians use good communication skills, are sensitive to patients' perspectives, and actively work to reduce barriers to mutual understanding.

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Despite the medical profession's ambitious goals of healing the injured and curing the ill, death is a natural and inevitable end of human life. All will die. Therefore, another important goal of medicine is caring for the dying. Fortunately, some physicians perceive it a special privilege to be able to participate with patients in the last stage of life's journey. These physicians are perceived by patients and families as competent, warm, and caring communicators who are willing to be involved at a personal level in the provision of care.

Many physicians feel uncomfortable when a patient is dying and nothing of a curative or technical nature can be offered. Feelings of discomfort may lead physicians into a variety of unplanned behaviors that create a safe emotional distance from their patients. When dying patients experience their physician as distant or uncomfortable, they feel depersonalized and inhibited in openly discussing their most important concerns in the final phase

of life. Patients' questions can be an opportunity to provide information that could reassure them about comfort measures that would be implemented as their condition worsens and how their dying could occur with appropriate support.

Patients are also sensitive to the nonverbal language of their physician. For example, an alert, competent 66-year-old man with bladder cancer tried to elicit information about the progression of his disease from two different physicians assigned to his care. In response to the question, "How is my disease responding to treatment?" the first oncology fellow lowered his eyes to the chart, flipped through the pages, and mumbled an answer so loaded with medical jargon that the patient could not understand the physician's response. He correctly concluded from this behavior that the physician was reluctant to discuss his condition. When the patient posed the same question to the second fellow, she offered reassur-

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The University of Washington is one of ten medical schools engaged in a study designed to evaluate and improve methods of teaching medical students the art of caring for dying patients and their families. Dr McCormick, who teaches death education for University of Washington School of Medicine students, serves on the National Advisory Panel for Choice in Dying, sponsored by a grant from the Greenwall Foundation.

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ance as tears welled up in her eyes. The patient later told his wife that he believed her tears more than her words.

Patients are usually most satisfied when they can get information about their condition and care directly from their physician. When the patient in the previous paragraph finally learned from his adult daughter that his prognosis was grim and he was expected to die in the near future from his rapidly progressing tumor, he was further chagrined that the information had been shared with his daughter before it was disclosed to him. Effective communication plays an important role in patient satisfaction and response to treatment and can actually reduce patients' suffering by recognizing their personal needs, feelings, and expectations.¹

Dying is a normal part of living. No single way of dying is ideal, yet there are some general principles that can guide us in providing care for the dying. Persons tend to die in character, so an important goal in working with dying patients is to allow or assist a person in the integration of dying into his or her lifestyle. Weisman describes this as an "appropriate death," living out our dying in a manner consonant with our values and coping mechanisms.² Dying is person-specific, and the "final agenda" of every person will be unique when it comes to reconciling death with life and appropriately maintaining relationships as death approaches. For example, Cassell describes a 35-year-old patient who had received extensive treatment for widespread metastatic breast cancer. Cassell observed three facts about her situation^{3(p31)}:

The first is that this woman's suffering was not confined to physical symptoms. The second is that she suffered not only from her disease but also from its treatment (it was disfiguring). The third fact is that one could not anticipate what she would describe as a source of suffering; like other patients, she had to be asked.

In an elective class on death and dying, we ask medical students to write two paragraphs, the first describing their concept of a bad death and the second describing their concept of a good death, the kind of death they would want for themselves. These descriptions are shared with the class, and it is common for one person's "good death" (for example, sudden, unexpected death from massive heart attack) to be another's perception of a "bad death" and vice versa. This exercise helps reinforce the principle that we avoid projecting our values onto patients, but that we put forth the effort to understand patients' perspectives.

Patients' Perspectives

Although the literature is replete with research into the attitudes and practices of physicians in caring for dying patients, until recent years, little research has been directed specifically toward patients' perspectives on communication during a life-threatening illness and patients' perceptions of support from the physician-patient relationship.⁴ In the not-too-distant past, physicians typically withheld the fact that a patient was expected to die. As recently as the 1960s, most physicians in the United States (90%) did not directly inform patients of the diagnosis of a life-threatening illness, particularly cancer.⁵

Furthermore, the person in the "sick role" in this era, as described by Parsons, was viewed as a passive participant who was expected to cooperate with the physician-expert and comply with the physician's advice.⁶ A pioneer in patient communication, Kübler-Ross broke the taboo of speaking directly with dying patients about their feelings.⁷ She reported that most patients found relief in being able to talk openly about the process of dying. In current practice, the emergence of new therapies and the requisite demand for informed consent has further reversed this practice. Most patients are now informed of the nature of their diagnosis, their prognosis, and the preferred course of medical treatment.⁸

Despite these advances, much work is still needed in improving the communication between physicians and patients surrounding end-of-life issues. A recent study of 228 adults found that 40% of the terms used by physicians were not understood by their patients.⁹ Many physicians withhold information, fearing that full disclosure of an incurable illness will rob the patient of all hope for the future. Textbooks like *Harrison's Principles of Internal Medicine* still advise that physicians should decide how much information to convey based on factors such as the financial and business status of the patient, the religious beliefs of the patient, and the wishes of other family members.^{10(p5)} These factors might militate against providing information that patients desire to know. Waitzkin's research indicates that patients wanted to know as much information about their situation as possible and thought it was helpful, whereas physicians underestimated their patients' desire for information in 65% of study cases, overestimated in 6%, and estimated correctly in 29%.⁴ The principle of

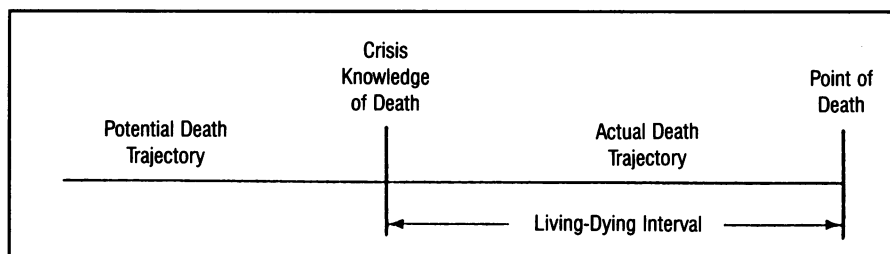


Figure 1.—Living with the awareness that life will be foreshortened precipitates a crisis.

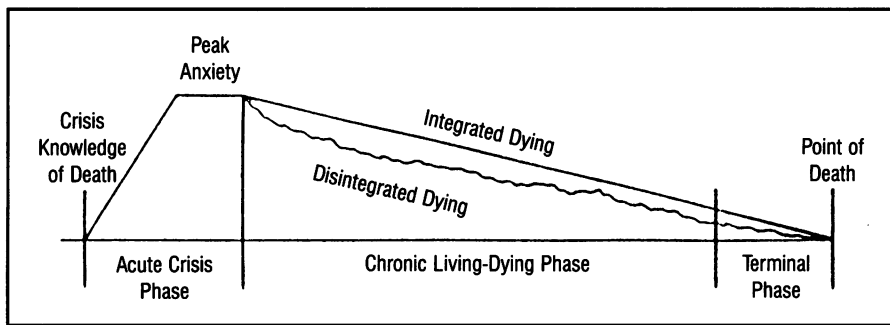


Figure 2.—With appropriate support, patients can use the awareness of their dying to integrate their values by responding to relationships and revising goals in the time that is left to them. Without such support, patients may experience a disintegration at the psychological and social levels in the chronic living-dying phase before death.

open communication should allow patients to have their questions answered in a compassionate and unhurried manner, with assurance by their caregivers that their emotional, physical, and spiritual needs will be provided for or arranged.

Living With Denial

Human beings live with an awareness of mortality and the potential for death at any time, although we ordinarily project a picture of ourselves as alive in the foreseeable future. Becker describes the mechanism of normal denial that removes the idea of death from our everyday deliberations and conveniently stores it just out of sight or consciousness.¹¹ Thus, the discovery that our future life span will be foreshortened by illness or accident precipitates a crisis—the crisis of the knowledge of death.^{12(p44)} When our potential life span is shortened by the threat of illness, all anticipated activities must be recast within a changed time frame.

To teach empathy with patients in a class on death and dying designed for medical students, we ask students to write down their current age, then the age at which they expect they will die, and then to list their important priorities in the time that is left. Later in the same session, we invite them to imagine that they have just learned they have six months to live and, in the light of this shortened time frame, to make any desired adjustments to their priority list. In most cases, the priority lists change dramatically, and most students claim they would withdraw from medical school, spend more time with their families, travel, and seek pleasures deferred for medical studies.

Crisis of Disclosure

When a physician discloses the diagnosis of a life-threatening illness, the door of awareness is jarred open for a patient. The usual habit of allowing thoughts of death to remain in the background is now impossible. Death can no longer be denied. This awareness precipitates a crisis for most patients, who are suddenly faced with addressing, and most likely rearranging, their priorities in the time they now anticipate is left.

Pattison offers two diagrams that illustrate the emotional work that is precipitated for most patients in the living-dying interval between the crisis knowledge of death and the point of actual death (Figures 1 and 2).¹²

In this perceptual model, the awareness that death is near leads to an acute crisis phase, followed by a chronic living-dying phase, and, finally, the terminal phase leading to the point of death (Figure 3). Health care professionals have much to offer in helping patients to cope during each of these phases. Kübler-Ross observed that patients in a hospital often experienced feelings of shock, numbness, denial, and anger in this acute crisis phase after learning they will die.⁷ In a personal conversation with one of us (T.M., February 12, 1985), Kübler-Ross expressed regret that she had referred to these as “stages” of dying, as some came to believe that patients should progress through these stages in a step-like manner. Rather, she had intended to describe patterns of emotional response that she had observed in many patients to help others recognize the naturalness of these feelings and to provide emotional support for patients experiencing these feelings.

Likewise, in the chronic living-dying phase, patients may need help and support in integrating their dying into the activities and circumstances of daily living and adapting to the limitations brought about by the illness and its symptoms. Kübler-Ross observed that some patients enter into a bargaining process, often experience depression, and may move toward the acceptance of their death as they integrate the inevitability of death in this period.^{7,12}

When patients learn that no curative treatment is available for their illness, they often have a number of fears and anxieties. These may arise in any of the three phases described earlier, following the knowledge that death is inevitable. Patients may fear the onset of pain that cannot be managed, the loss of bodily control, the loss of function, and a growing dependence on others. Patients may also fear the unknown, the loss of family and friends, and, ultimately, the loss of self.¹² Health care professionals have a moral duty to provide adequate pain management and symptom control. Fear of inade-

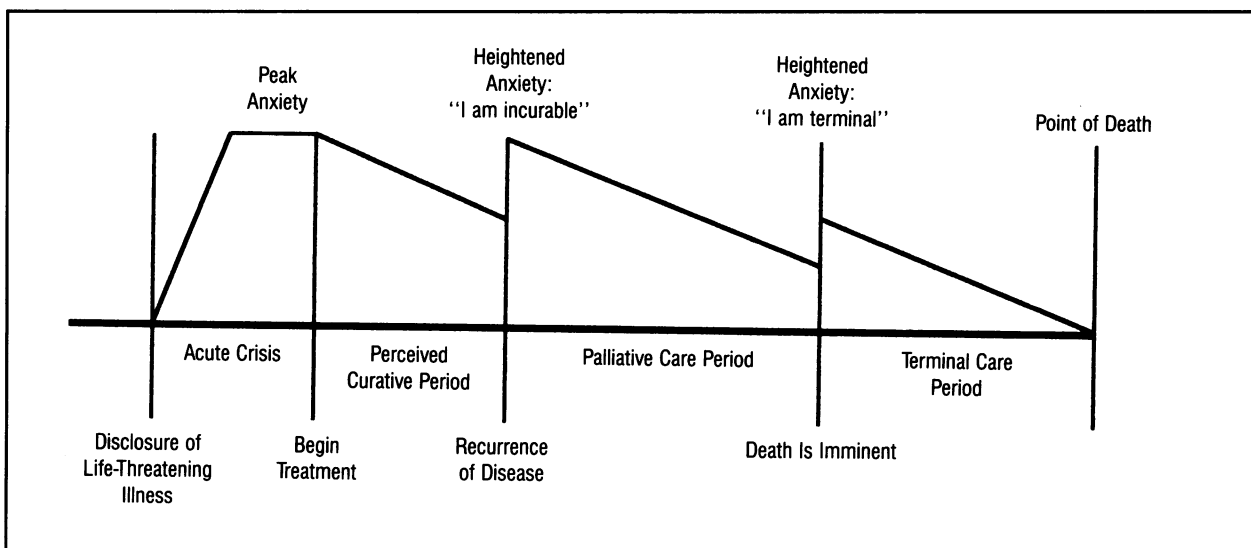


Figure 3.—This diagram from the patients' perspective shows heightened anxiety at the time of diagnosis, when the disease recurs, and when it appears death is imminent. Communication and psychological and social support are especially important at these times.

quate pain management has contributed substantially to the recent interest in physician-assisted suicide. Fortunately, there is a growing movement in pain management that is actively teaching and carrying out comfort measures appropriate to the needs of patients.* We need to go beyond pain management to address the suffering of patients, however. Only a portion of suffering is attributable to physical pain; other aspects are psychological and emotional and can be ameliorated and assuaged by caregivers who remain responsive to the patient as a person.

A Small Qualitative Study

To better understand the needs of dying patients from their own perspective, we interviewed six patients with life-threatening illness. Having noted patients referring to a "transition" from curative measures to palliative measures, we were interested to learn more about how physicians can help patients recognize this transition and provide support in this process. As described previously, patients have notable levels of awareness in their perceptions of their illness and its treatment and the meaning that they attach to these changes. Physicians, possessing a greater body of knowledge of the nature of disease and its treatment, often form their own perceptions and assumptions about the likely future course of any particular patient. The disparity of information and beliefs held by physicians and patients often leads to problems in communication.¹³ It is important that physicians take time to listen to their patients' stories and to ask about their thoughts, feelings, and concerns throughout the changing circumstances of treatment and care.

Here we describe the cases of six patients who, having accepted hospice assignment, were clearly aware

that their illnesses were no longer responsive to curative measures and that death was fairly imminent. Patients who are aware of their impending death are able to share something that others cannot—their experience of dying. These patients were willing to share experiences from all aspects of their care over the course of their illness, and several near death claimed to find a new source of meaning and purpose at the end of life by sharing their stories.

Patient interviews addressed the patient's illness history, treatment history, personal perception of the treatment plan, perceived needs and desires regarding communication with physicians, and other thoughts or feelings they wished to volunteer. We were particularly interested in examining patients' perspectives on their communications with physicians and their perceptions of obstacles to their receiving the best care for their terminal illness. Our protocol was reviewed by the Department of Medical History and Ethics at the University of Washington School of Medicine and accepted by Hospice of Seattle. All patients provided informed consent before participating in the interviews. The thoughts and feelings of patients are identified, often by quoting patients' exact words. Pseudonyms have been used to protect the confidentiality of the participants described briefly in this report.

Case Histories

"Ann," a 34-year-old divorced woman, was diagnosed with breast cancer four years earlier. Surgical therapy was thought to have achieved a cure. A year ago, she had a recurrence with advanced metastatic disease for which she received palliative chemotherapy. In the past five months, she has had an abdominal operation for debulking of tumors and for lysis of adhesions, heart failure due to pericardial effusion caused by tho-

*See also "Clinical Management of Dying Patients" by J. Gavrin, MD, and C.R. Chapman, PhD, on pages 268-277 of this issue.

racic metastases, and surgical placement of a permanent pericardial drain.

"Bob," a 61-year-old retired seaman who lived alone, was diagnosed with colon cancer 5½ years earlier. His treatment with surgical and radiation therapy was thought to have achieved a cure. Two years ago, the cancer recurred with advanced metastatic disease in the liver, lungs, and bones.

"Fay," a 65-year-old woman diagnosed with colon cancer 2½ years earlier, had thought her irradiation and chemotherapy had achieved a cure. A year ago, she was found to have metastatic liver disease.

"Jon" is a 75-year-old retired electrician who is widowed and living with his son. Two years earlier he was diagnosed with lung cancer. Surgical treatment was thought to have achieved a cure, but seven months ago he was found to have advanced metastatic disease. He suffers from insomnia and cachexia.

"Ken," a 72-year-old married, retired aeronautical engineer, was diagnosed with cancer of the left vocal fold 11 years ago. Treatment was thought to have achieved a cure. He had a recurrence six years ago, and laryngectomy was thought to be curative. A year later cancer was found in his pharynx. He refused curative radical surgical therapy and instead underwent several courses of palliative chemotherapy. Four months ago he chose to stop all chemotherapy for his advanced disease. He has a tracheostomy, a gastrostomy (for feeding), and tracheoesophageal fistulas. He communicates only through writing and facial gestures. His wife, Nan, is able to interpret his expressions and at Ken's request assists him in communicating.

"Tom" is a 66-year-old retired electrician who is widowed and living alone. Seven years ago over the course of a year he underwent an operation, radiation therapy, hormonal therapy, chemotherapy, and surgical castration for prostate cancer. He thought he had achieved a cure. Two years ago he was found to have advanced metastatic disease. Complications included spinal tumors that have left him paraplegic and several hospital admissions for life-threatening gastrointestinal bleeding episodes of unknown origin.

Disclosure—A Crisis

Each of these patients described the disclosure of their original diagnosis as a critical event. The knowledge that they were living with a life-threatening illness raised questions about whether they would die of the illness, whether they would suffer greatly from the disease or its treatment, and whether they would become dependent on others for their care. All of these patients were advised of treatment plans tailored to their particular needs, and each thought that caregivers had a strong and supportive interest in assisting them. This helped ameliorate the acute crisis phase. When the treatment plan was described as a possibly curative measure, these patients seemed to assume that a cure would be achieved and developed a positive outlook toward the future, thus reducing their anxiety.

Curative Care Period

The illness profile of each of the participants was initially similar. After the cancer diagnosis, all of the patients experienced a curative care period perceived at the time as a cure, followed by a period of time in which they were able to resume premorbid activities. For many physicians, these patients were not necessarily thought to be cured of cancer, but might better be described as currently not manifesting any signs of cancer and possibly cured. For these patients, the curative therapy appeared to remove them from the acute crisis stage of facing a life-threatening illness. These patients chose to think of themselves as cured.

This disparity of perception raises perplexing questions regarding physician-patient communication. How explicit should physicians be about the possibility of recurrence? What if a patient does not ask about recurrence? Is it better to allow patients to proceed through therapy with the highest level of hope? Can the power of suggesting that the cancer might return be a self-fulfilling prophecy by weakening the immune system of patients through the stress of worry and anxiety? Physicians in other cultures such as Italy and Japan are far less candid with patients to encourage a hopeful spirit in battling against illness.¹⁴⁻¹⁶ In the pluralistic culture of the United States, we hold that physicians should be truthful and provide any information that is requested by patients and should also be respectful of patients who choose to limit the disclosure of possible future complications.

The recurrence of cancer defined the beginning of a new period in the illness. At this point, five patients entered the palliative period, or the chronic living-dying phase of their illness. Their experiences varied, however, in how and at what point in the palliative period they came to the awareness of their true status. Two, Ann and Fay, became aware of being in the palliative period at almost the same time their physicians did. Two, Jon and Tom, interpreted treatment following the diagnosis of recurrence as curative, only to learn at a later time that the treatment of recurrent disease was palliative. Ken refused a radical operation that was presented to him as a curative therapy. He understood that "cure can only come from surgery." On his own initiative, he gathered information (through visiting a patient who had undergone a similar procedure and procuring a professional second opinion) and decided that a surgical procedure would result in a level of functioning that was unacceptable to him. Therefore, with the support of his wife, he chose to reject his primary physician's recommendation for surgical intervention. He relates, "As long as there was hope for a cure, I was willing for anything, until the point I learned the surgery would take away too much." With this decision, Ken knowingly entered the palliative period. One patient, Bob, received a single dose of chemotherapy followed by only palliative care.

The Early Palliative Care Period— 'I Am Incurable'

When relating their experiences during the transition period from curative to palliative care, these five

patients described two distinct levels of awareness, each holding separate and important meanings for them. Ann was best able to articulate the difference between these two levels of awareness. She chose the terms "incurable" and "terminal" to describe the two levels in the palliative period that seem to coincide with the living-dying phase and the terminal phase described earlier. She defined the meaning of being incurable and terminal as follows:

Being incurable meant that I would have to live with it. I knew that I was going to die, but I regarded that as something in the future. I didn't know when that would happen. I was more concerned with living as much as I could, getting as much done with the amount of illness and discomfort that I had. Incurable meant that I had to face dying, but I could face it in the same sense that everyone does. We're all incurable, everybody dies, and I'm going to die just like everybody else. Terminal meant that I had less time. It meant that dying was now countable. It was now time to prepare myself to die.

Ann picked up the terms incurable and terminal from health care professionals as they defined her status in the palliative care period. Although no one defined these terms, she felt she had an intuitive awareness of their meaning. Yet, terminal illness, from the perspective of medicine, refers to an irreversible disease process that will lead to death, more synonymous with incurable. Ann seemed to use terminal to signify the imminence of death. Pumphrey and Eisman remind us of the following^{17(p227)}:

[T]he clinician can expect patients to tune in to the verbal and nonverbal messages of those around them. These messages may be distorted in reception, hence the need for clarifying dialogue on a continuing basis.

We found in these interviews that patients and health care professionals often attached different meanings to the terms incurable and terminal.

Like Ann, the other four patients referred to a time during their illness when they knew that their cancer could not be cured but did not consider themselves "terminal" or imminently dying. Only Fay understood that death was imminent. Tom suspected that he had entered the palliative period as he was more frequently admitted to the hospital with various complications. His suspicions were later confirmed through explicit conversations with his physicians in response to his questions about the imminence of death.

Ann was the only one of the six who learned that she was incurable as the result of an open discussion that was initiated by her primary physician with whom she met after her recurrence was diagnosed by an orthopedist. Ann: "That's one of the things that I like my doctor for, because he was plain with me that I was incurable."

As a consequence of learning that their disease was incurable but not yet terminal, two patients chose a course of aggressive chemotherapy. Both justified the debilitating side effects of therapy with the belief that they were in more control of the disease process, and they could achieve greater longevity and decreased symptoms. Ann: "I was able to make a trade-off. I exchanged a year of my life in chemo for about seven months of fairly good quality of life." These patients appeared to accept the inevitability of death and to inte-

grate this reality appropriately in their decision making. The patients' descriptions of being incurable in the early palliative period seem to match our earlier description of the chronic living-dying phase. It is clear that good communication is essential to assist patients in understanding their situation and making appropriate choices in keeping with their values.

The Late Palliative Care Period— 'I Am Terminal'

To all these patients, the most important event in the illness was the point at which they understood that death was imminent. Each of the six was able to describe a particular conversation with health care professionals in which they became aware that death was near. Their experiences varied as to whether the information was conveyed in an explicit or oblique manner, whether the discussion was initiated by the physician or the patient, and whether the patient chose to actively pursue further information than was initially offered. Three of the patients (Bob, Tom, and Jon) were informed of the imminence of death in an explicit manner. Bob: "I was given one treatment of chemotherapy. One treatment only, then they stopped. A little after that, in an office visit, my nurse told me that they couldn't do anything. He said, 'You are a terminal patient.'" Tom's awareness came when his physician enrolled him in a hospice program.

Tom: Basically, my doctor didn't tell me very much to start with. The doctor who covers for him told me "this isn't the same as before, you could go at any time." He told me in about four different ways the same thing. And then my physician basically told me to get things in order. He said, "You may have up to two years. . . ." but he didn't really mean that I could have up to two years. *Question:* He didn't? How did you pick that up? *Tom:* Because he'd talked to me before. . . . He had told me that this was much more serious than the others [hospitalizations]. Then he said, "Well, I'm going to call in the hospice nurses, and they'll be able to give you some help." And it's my understanding that they don't come in until you have about six months.

After a course of chemotherapy followed by irradiation, Jon chose to ask his physicians "point blank" what his current prognosis was. At the time, he did not realize that his treatment regimen was palliative rather than curative.

Jon: I did think my radiation oncologist was uncomfortable when I asked her . . . there was a hesitation, a little reluctance. I told her, "Now, I'm going to ask you the \$64 question. How much time do I have left? What am I looking forward to?" And she said, "Six months to two years." I don't think my primary doctor was uncomfortable. He was the one that said 90% of the patients in my condition don't, ah, last over six months. *Question:* You seem to be keenly aware of what was happening around you, and you responded by asking direct questions? *Jon:* It just kind of seemed to me that things fell naturally into place as we went along. As questions occurred, I asked them.

Fay's realization that death was imminent followed a single conversation with her physician. Although he had been explicit about the need for a palliative approach, he had never actually explained that her death was now imminent.

Fay: It happened so quickly. I just heard him talking to a nurse in the hall, and he said, "Let's call and see if we can get her into the program." That's the first I ever knew of hospice being around. *Question:*

After you heard them visiting in the hall, did he then come in and talk to you? *Fay*: Yes, he did. He explained the whole program. Instead of curing, going palliative. I didn't see what good any more chemo would do, or radiation or anything else. I figured that was it. So, here I am, in hospice. It's still hard to believe that this is available; it's great.

Ann described how she began to realize that she was terminal during a recent hospital stay.

Ann: Well, this last time that I went into the hospital, it was made plain to me that I was terminal. I mean, I knew that I was incurable, but I stepped over the line to terminal. *Question*: Was it any one physician that approached you and explained? *Ann*: No, the only way it was introduced to me, that I was terminal, was very obliquely through getting my codes. This doctor asked me, "What code do you want to be?" And I said, well, what does that mean? And he explained it [do-not-resuscitate order, or DNR code] to me. So I began to realize, even though it wasn't clear to me until a few minutes later, after the doctor had left, when I asked the nurse who had been there, why are they coding me? She said, "Well, you are terminal now." So the realization was partially there, but the nurse made it concrete, and that helped me.

We learned from patients like Ann that it is important to be informed of this change in their status so they can make plans for their remaining time.

Ken and his wife, Nan, chose to end chemotherapy when it seemed ineffective, leading to an increased awareness that the end of life was near.

Ken: I quit chemo because it was making me sick three days a week and there was no change in the tumor. I told my oncologist, and she agreed that my decision was valid because we weren't accomplishing anything. She had been proposing more and different types of chemo, but without too much enthusiasm. *Nan*: I think that the medical profession knows it's the end of the line, but they don't come out with it. They feel that they have to keep going or they aren't doing their job.

Ken and Nan describe a kind of technologic imperative, the pressure to use any therapy available, even if it may provide little or no benefit. At this point Ken decided to enter the hospice program.

Ken: I said to the nurse, "Is this the time to go to hospice?" The nurse said, "We think that's a very good idea!" In the end, Nan had to sign the papers because the doctor was unavailable. One of his staff told me, "He's very uncomfortable with patients who are dying."

Nurses were seen by these patients as more comfortable talking about death and dying:

Ann: Talking with nurses has helped a lot. I get tremendous support from them, but I don't think it makes up for talking to my doctor. It's frustrating, because these are excellent doctors, yet they can't talk about dying. . . . It's great being able to talk with the nurse, and I appreciate it, but she's not my doctor officially telling me, "You're terminal, you have to deal with this."

An awareness of imminent death encourages patients to put their affairs in order, provides an opportunity to openly communicate with those most dear, and allows treatment decisions congruent with patients' values.^{18,19} All the patients interviewed were able to describe activities of a personal, practical, or interpersonal nature that they chose to undertake as a result of having become aware that death was near. Tom described working through his thoughts with the help of a friend, claiming, "I made peace with my life." Jon traveled to spend time with each of his children and their families while he still had the strength. After Ann became aware that death was imminent, she wrote her will and proclaimed,

"Death is a practical business, as well as an emotional one." She went on to say

I was very grateful to know that I was terminal because it allowed me to spend some precious time with my family and friends that I might not have had if I hadn't known I was under the gun. My friends would ask when they should visit, and I could say, come as soon as possible because I don't know how long I'll be coherent. I'd rather have you with me now.

These patients described their need for candor on the part of their physicians, particularly at that point when the physician becomes aware that death is imminent. All preferred to learn this information from their physicians and wanted the information to be given in an explicit manner. They were unanimous in feeling that once the basic information had been provided, the physician should "open the door" for them to talk about any questions or issues they deemed important. Ann provided an example of how she would like to have been told:

He might say, "The cancer has moved into your chest. Do you realize that this means you have a shorter time? You're now regarded as terminal. Do you have any feelings about that or any questions? Is there anything you'd like to tell me?"

Each patient reported that accepting information about the imminence of death would be easier if it were presented with sensitivity and compassion. All acknowledged the difficulty of becoming aware of their impending death. As *Fay* said, "You hate to face that day." As *Bob* pointed out, however, "You can tolerate that difficult situation if you have a doctor who can sit down and explain and tell you where you are." These patients affirm the point that the psychological suffering of patients in the terminal phase of illness can be mitigated in part by the honest, open, and caring attitude of caregivers.

Summary

Although health care professionals possess an understanding of the pathophysiology of illness, its treatment and progression, patients often do not, and they look to their attending physician for appropriate and timely disclosures of information. Our discussions with patients confirmed that the initial disclosure of a life-threatening illness precipitates a crisis as the patient begins to contemplate an untimely death. We found ample evidence, however, that with compassionate support, comfort measures, and palliative care, patients move into a chronic living-dying phase that they often describe as "living with an incurable illness." Patients uniformly wanted to know when treatment modalities were no longer efficacious and that the approach had turned the corner to a palliative model.

Further along, in the late palliative period, patients also wanted to know when death was imminent. The patients discussed here are much like other patients we have cared for facing death from heart disease, lung disease, the acquired immunodeficiency syndrome, or any other life-threatening illness. Most admit to having particular tasks to achieve in bringing closure to life as death draws near. Others describe the spiritual richness

they experience in their last days, savoring the moments and living with the intensity of knowing their time is limited. Physicians who manifest genuine interest in their patients as persons, who use appropriate touch in conveying empathy, and who provide adequate and timely information are regarded as an important source of social support. Conversely, patients experience barriers to communication if a physician is anxious when discussing dying, resorts to medical jargon and intellectualization to avoid a more personal contact, or when care is so fragmented that a consistent source of communication is absent. Further qualitative and quantitative research into patients' perspectives regarding their care and the quality of their communication with caregivers in the process of dying can enhance our efforts in providing better care.²⁰ Further efforts must be made to teach medical students and resident physicians about the care of dying patients.

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