

## PERSPECTIVES

## A Physician's Guide to Talking About End-of-Life Care

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**A large majority of patients and close family members are interested in discussing end-of-life issues with their physician. Most expect their physician to initiate such dialogue. End-of-life discussions, however, must go beyond the narrow focus of resuscitation. Instead, such discussions should address the broad array of concerns shared by most dying patients and families: fears about dying, understanding prognosis, achieving important end-of-life goals, and attending to physical needs. Good communication can facilitate the development of a comprehensive treatment plan that is medically sound and concordant with the patient's wishes and values. This paper presents a practical 4-step approach to conducting end-of-life discussions with patients and their families: (1) Initiating Discussion, (2) Clarifying Prognosis, (3) Identifying End-of-Life Goals, and (4) Developing a Treatment Plan. By following these 4 steps, communication can be enhanced, fears allayed, pain and suffering minimized, and most end-of-life issues resolved comfortably, without conflict.**

**KEY WORDS:** advance directives; communication barriers; decision making; end-of-life care; patient-doctor communication.

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Physicians are trained to maintain health and fight illness, but typically receive little guidance on how to communicate with dying patients and their families.<sup>1-3</sup> Thus, in our death-averse society,<sup>4</sup> it is not surprising that many physicians find it difficult to engage in end-of-life discussions.

Death has long been regarded as tantamount to medical failure, which implies that physicians have nothing to offer a dying patient and family.<sup>2</sup> Physicians must recognize that quite the contrary is true. Good communication can help allay fears, minimize pain and suffering, and enable patients and their families to experience a "peaceful death."<sup>4</sup> Poor communication can result in suboptimal care, and patients and their families may be subjected to undue mental or physical anguish.

A large majority of patients are interested in discussing end-of-life care with their physician,<sup>5-10</sup> and most believe that physicians should introduce the topic.<sup>7,8</sup> Physicians must therefore accept responsibility to initiate timely dialogue, as many patients will wait for their physician to raise the subject.

End-of-life discussions should address a broad array of issues central to the dying patient and family. Discussions that focus solely on resuscitation fail to recognize important physical and psychosocial concerns.<sup>11</sup> Most patients, as they near death, contend with similar fears, needs, and desires. Dying patients experience fear of pain, fear of indignity, fear of abandonment, and fear of the unknown.<sup>4,11,12</sup> Open and direct discussions can ease many of these fears. By involving family members in these discussions, relationships within the family can be strengthened, and can reduce the isolation experienced by the dying person.<sup>13-17</sup>

As death approaches, many patients have relatively modest needs and desires. When curative treatments are no longer effective, most patients and families desire that aggressive interventions be avoided.<sup>5,18,19</sup> They want the last days, weeks, and months to pass without pain, to be spent harmoniously with family and close friends, preferably at home in familiar surroundings. In rare instances, patients and family members may have major disagreements, or futile treatments may be demanded. But in the vast majority of cases, patients and family members are aligned, and end-of-life care can be managed in a sensible and conflict-free manner.<sup>11</sup>

This article provides physicians with practical tools for addressing fundamental end-of-life issues with patients and their families. I have formulated a 4-step approach, based on structured interviews at a major university hospital with five faculty clinicians experienced in the care of dying patients. Italicized dialogues in the following sections are actual wordings used by these clinicians in caring for their patients. They offer a useful script that can help physicians become more at ease in conducting these crucial end-of-life discussions.

### TYPICAL INPATIENT DISCUSSION

During training, medical residents are often taught to address resuscitation status with language similar to the following:

I need to ask you some questions that we ask all patients who are very sick. These questions are about CPR,

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or cardiopulmonary resuscitation. I need to know your preferences.

If your heart stops beating, do you want us to use electrical shocks and chest compressions to try to get your heart beating again? Or if you stop breathing, do you want us to put a tube down your throat into your lungs and attach you to a breathing machine to help you breathe?

Although this wording is familiar, it is woefully inadequate. It is devoid of empathy, thereby limiting the physician-patient alliance. It does not address prognosis; thus, patients may request CPR with unrealistic expectations. Undue emphasis is placed on *possible* interventions, while ignoring mention of the ongoing care that *will* be provided. Finally, the burden of decision making is thrust on the patient and family—the physician provides no guidance in addressing these complicated issues.

## COMMUNICATION GUIDELINES

A pragmatic 4-step approach to discussing end-of-life care is outlined in Table 1. The physician sensitively initiates the discussion so as to create a forum for ongoing dialogue. Subsequent discussion serves to clarify prognosis, identify end-of-life goals, and finally to develop a treatment plan. The 4 steps are progressive; each step provides a necessary foundation for further discussion.

At each of the 4 steps, the physician should seek a common understanding with the patient and family. When disagreements arise, overt conflict can often be avoided by reviewing what was discussed previously. For example, if a patient has unreasonable expectations regarding the *treatment plan*, it is helpful to revisit his perceptions of *prognosis* and his *end-of-life goals*.

### Step 1. Initiating Discussion

A supportive physician-patient relationship provides an important foundation for end-of-life care. Patients and families speak more openly and are more trusting when they feel their doctor's empathy and compassion. A caring connection can be enhanced by recognizing the stresses that illness imposes on a patient and family.

*I know this is a very difficult time for you and your family. You have never been this sick before, and I know that it must be frightening to you. I want you to know that as bad as it is, we will deal with it together.*

As an illness progresses, the physician is challenged to respond to the pains and fears a patient and family are experiencing. In this context, Emanuel talks about "fearless healing . . . to heal, one must witness pain without fear. Healers can hear pain, healers give people permission to show pain, healers are not afraid to see pain."<sup>20</sup>

Fearless healing can mean initiating an end-of-life discussion with a terminally ill patient or discussing a worsening prognosis with a failing, hospitalized patient.

**Table 1. A Physician's Guide to Talking About End-of-Life Care**

#### Step 1. Initiating discussion

- Establish a supportive relationship with patient and family.
- Appoint a surrogate decision maker.
- Elicit general thoughts about end-of-life preferences. Go beyond stock phrases with probing questions.

#### Step 2. Clarifying prognosis

- Be direct, yet caring.
- Be truthful, but sustain spirit.
- Use simple everyday language.

#### Step 3. Identifying end-of-life goals

- Facilitate open discussion about desired medical care and remaining life goals.
- Recognize that as death nears, most patients share similar goals; maximizing time with family and friends, avoiding hospitalization and unnecessary procedures, maintaining functionality, and minimizing pain.

#### Step 4. Developing a treatment plan

- Provide guidance in understanding medical options.
- Make recommendations regarding appropriate treatment.
- Clarify resuscitation orders.
- Initiate timely palliative care, when appropriate.

Sometimes fearless healing means listening to a patient talk about his physical decline, his emotional and spiritual suffering. Even when curative therapy is no longer effective, the physician's involvement can be a powerful source of comfort.

*While I can't cure you, there are still many things I can do for you. I want you to be able to speak openly with me, so I can best help you. No matter what happens, I can be here for you—you are not alone.*

By encouraging a patient to speak openly, the subject of death can become less of a taboo. Patients and families may feel comfortable continuing conversations outside the doctor's office.<sup>17</sup> When the patient becomes sicker, all parties find it easier to reopen the discussion.<sup>7,21</sup>

Appointing a surrogate decision maker is an important early task and can be an effective way to direct the conversation.

*I would like to take a few minutes for us to begin discussing an important topic—I'd like to know how I should care for you if you were to become very ill.*

*First, I want to assure you that I am not raising this subject because of any new concerns I have about your health. As I have previously said, your condition is stable, and I have every expectation that you will remain so in the near future. However, I believe it's best if we begin these discussions when you are stable, so we don't have to raise these issues for the first time in an emergency situation.*

*There are several things that would be helpful for me to know. First, if you ever became so ill that you were unable to speak for yourself, who would you want to make decisions regarding your medical care?*

Early discussions may also provide opportunities to elicit a patient's general thoughts about end-of-life care.

*We cannot predict exactly what medical treatment you might need at the end of your life. But it's important for me to know your thoughts about what type of medical care you would like to receive. How do you imagine spending your last days, weeks, and months?*

Try to go beyond stock phrases with probing questions.<sup>10</sup>

*You said that you don't want to suffer—what type of suffering are you talking about?*

*You said that you don't want to be a burden to your family—what do you mean by that?*

*You said that you don't want to be kept alive as a vegetable—what does that mean to you?*

The preferences of terminally ill patients trend toward less-aggressive care as their illnesses progress. Most patients believe that, at some point, life-prolonging interventions should be limited.<sup>5,18,19</sup> We can support this important notion by asking:

*Are there any treatments that you might not want to receive? Are there any circumstances in which you believe life-prolonging treatment would not be desirable?*

**Why the First Discussion Should Not Be the Last.** Although general thoughts can be explored in initial discussions, several factors mediate against making detailed end-of-life decisions significantly in advance of one's death.<sup>22</sup> First, patients' preferences may not be durable over time. Although some have concluded that advance directives can be stable for months to years,<sup>5</sup> others have noted significant preference changes, even over short periods of time as severity of illness worsens.<sup>23</sup> Other investigators have found that preferences can fluctuate depending on how outcomes of therapy are described.<sup>24</sup> Thus, one must respect that an advance directive should never supercede the currently stated interests of a patient.<sup>22</sup>

Second, early discussions, by definition, must focus on the hypothetical as it is impossible to anticipate all relevant medical decisions of a particular case.<sup>22</sup> Hypothetical discussions, however, are hampered by real limitations in communication.<sup>25</sup> In one study, patients left routine advance directive discussions with serious misunderstandings about life-sustaining treatments—67% of patients who had just discussed mechanical ventilation did not understand that a patient cannot speak while on a ventilator.<sup>26</sup> The same study also reported that physicians had limited understandings regarding their patients' preferences. After engaging in end-of-life discussions, physicians were unable to predict their patient's treatment preferences any better than by chance in 18 of 20 hypothetical scenarios.<sup>26</sup>

Discussing hypothetical scenarios may be an effective way to elicit general thoughts or to initiate end-of-life discussions. But the important decisions need to be made as the situation arises. Maintaining open communication is key to allowing physicians, patients, and families to respond to changing medical and psychosocial needs.

## Step 2. Clarifying Prognosis

There is a natural inclination to equivocate about bad news, to downplay the seriousness of a patient's condition. When no viable therapeutic options exist, the physician must acknowledge this with directness and compassion. There must be no chance for misunderstanding; when terminal patients are not fully aware of their prognosis, they tend to overestimate their survival, which influences their preferences regarding medical treatment.<sup>27,28</sup>

*This cancer is getting the better of you. The treatments that have helped you in the past are no longer working. I understand your desire to feel better and to be better—but it is not realistic.*

Patients and families often require repeated explanations in order to understand a medical problem. Comprehension is enhanced with each repetition. With all medical discussions, it is best to use simple, everyday language and to avoid technical wording. Most patients best understand new information when it is presented at a sixth to eighth grade level.<sup>29,30</sup> During times of high anxiety, concentration and comprehension may be further limited. It is frequently helpful to ask:

*I want to be certain that I have clearly explained your medical situation. Can you give me your understanding about what is ahead for you?*

Prognostic discussions are bounded by epidemiologic shortcomings: statistics speak for groups, not for individuals. Should we focus on the small number of patients who outlive the average, or those who follow the usual course? Can we be a source of both truth and hope to our patients?

*Most people with multiple myeloma who are at your stage of the disease, continue to do very well for 3 to 5 years. But that is the average patient, and I cannot predict exactly how you will do. I certainly hope that you will do better than average, but it is also possible that you may do worse.*

Although uncertainty complicates decision making, many patients want to know about the uncertainties of their medical condition as well as the established facts.<sup>31</sup> By honestly acknowledging our prognostic limitations, we can build trust.

## Step 3. Identifying End-of-Life Goals

Once a patient and family acknowledge that death is approaching, the physician's role is to facilitate an open discussion about desired medical care and remaining life goals.

*As your doctor, I want to make sure we are always doing the things that might help you, and that we never do anything that either can't help you, or you wouldn't want. So I need to know what things are most important to you, given your illness. How do you want to spend your remaining time?*

As death nears, most patients share similar goals: maximizing time with family and friends, avoiding hospitalization and unnecessary procedures, maintaining functionality, and minimizing pain. Some patients have special requests, such as important visits, desired conversations, or the wish to involve hospice or religious counsel in their final care. Earlier discussions about general desires need to be revisited, as the immediacy of a worsening illness may modify one's feelings and thoughts.

*A few months ago we spoke about what kind of care you would want if you were to become very ill. We're now facing that situation. I want to know if your thoughts are the same, or if they have changed in any way.*

When death is imminent, the discussion is more limited in scope:

*When people get to this stage, some people feel like they want to keep fighting, and other people feel like they just want to be comfortable and let things happen as they may. How are you feeling now?*

Occasionally, a patient or family will say they want "everything done" to prolong life, regardless of prognosis. In such cases, it is essential to understand the patient's or family's underlying motivation. Sometimes the futility of a treatment may not be recognized, and the issue of prognosis needs to be reexamined. Sometimes patients state: "I know my children would not want me to give up. I have to keep going for them." Other patients may feel bound by religious beliefs. These situations can provide difficult ethical challenges, but fortunately represent a small minority of cases.<sup>18,19</sup>

#### Step 4. Developing A Treatment Plan

Given the bewildering array of medical technology, patients look to their physicians for guidance. Comprehensive treatment plans will include, but not be limited to, site of care, effective pain control, the use of CPR and other aggressive treatments, and implementation of palliative care.

*From what you have said, let me suggest the following plan. Please tell me if I am correctly representing your views. Given that being at home and spending time with your grandchildren are most important to you—that is what we will focus on. We can organize your radiation treatments on an outpatient basis. I can also arrange to have visiting nurses see you at home as needed. Let's make sure that we design your medical care so that you can accomplish what you want with your remaining time.*

Preferences regarding resuscitation must also be overtly clarified, as most patients wish to have some limits imposed on life-prolonging interventions.<sup>5,32</sup> If a patient has stated earlier her preference to forgo invasive treatment, it is important to reconfirm such decisions.

*You have previously said to me that when your time comes, we will let nature take its course. I will make sure that you*

*are comfortable at all times, and that ultimately, you are able to die comfortably. We will not plan to use cardiopulmonary resuscitation or breathing machines or an intensive care unit. Am I correctly stating your preferences?*

If resuscitation has not been addressed, an explicit discussion is necessary. An appreciation of the limitations of CPR is necessary to make an informed decision regarding its use. Most people gain at least some of their knowledge about CPR from television, where the majority of resuscitation attempts are successful. Thus, patients frequently overestimate the utility of CPR,<sup>33-35</sup> and are particularly unaware of the poor outcomes for the chronically ill.<sup>34</sup> Patients need to know that the likelihood of survival is related directly to one's underlying illness. With patients in the terminal stages of chronic disease, CPR is rarely, if ever, successful in prolonging meaningful life.<sup>36-39</sup>

*There are some other medical interventions that are available—but interventions that I think would not be helpful to you, and we need to talk about these as well.*

*With some patients we use cardiopulmonary resuscitation. This means that if your heart stops beating, we would try to use electric shock and chest compressions to get your heart beating again. If you stopped breathing, we would attempt to assist your breathing with a tube in the lungs. I know on television that these treatments usually work, but in real life, these treatments are rarely successful.*

*For someone in your condition, with widespread cancer, these treatments are almost never successful. Most patients die in spite of resuscitation efforts, or may live for a few more hours or days before dying. The people who do survive resuscitation are generally people who are relatively healthy to begin with.*

*We have talked about your illness and your poor prognosis. You have told me about how you want to spend your final months. I also need to know your thoughts about using cardiopulmonary resuscitation.*

All parties must be entirely comfortable with writing a do not resuscitate (DNR) order. If there are any doubts, further discussion must ensue.

*You look uncertain about this. We don't need to decide today, at this moment. Let's talk more about this at our next meeting.*

Physicians attend to the experience of death many times, but a family goes through it only once with a loved one. Patients and families need time to reflect, to feel certain they are making the best choices. During this difficult time, patients and families may harbor seemingly irrational hopes for an improbable reversal. Supportive, unpressured discussions increase the likelihood that sensible and humane decisions are ultimately made.

As an inevitable death nears, family members must understand that aggressive intervention changes only the time and conditions of death, but not the patient's ultimate fate. In these instances, forgoing aggressive resuscitation allows for a more comfortable and humane death, and represents an act of love, not one of abandonment.

*I am making recommendations to you as if your mother were my mother. I know that you want to give her every possible chance to get better. And I also know that you don't want her to suffer through painful procedures that won't be helpful to her.*

*We have done everything possible to help your mother recover, but her body is no longer responding to our treatments. Her heart is so weak and has suffered so much damage—I don't believe she is going to get better.*

*Continuing aggressive treatments is not going to be helpful to her, and may actually cause her to suffer. What we can do now is to make sure that she is comfortable and that she suffers no more pain.*

Patients and families desire appropriate, caring treatment. If resuscitation and other aggressive interventions will not meaningfully extend life, such care will usually not be requested. The focus then changes to palliation, which offers comprehensive treatment to alleviate pain and to provide maximal comfort.

## CONCLUSIONS

Providing good end-of-life care requires both an understanding of how patients and families experience the dying process and a sensitive communication style. With these skills, physicians are able to conduct thoughtful discussions in which most decisions evolve comfortably and without controversy.<sup>11</sup>

Many physicians want to become more comfortable and skilled in addressing the needs of dying patients and their families.<sup>3,40</sup> Ongoing professional training in end-of-life care requires a commitment to work through personal discomfort and fears and can be supplemented in several ways. First, we all benefit by observing experienced clinicians address these issues with their patients. Conversely, clinicians should strive to include residents and medical students when these vital discussions take place. Second, we must recognize that our skills and comfort level increase only through repetition and practice. Third, we must be open to feedback from mentors, and from our patients and their families.

Finally, we must reshape our views to acknowledge death as a natural last step in the progression of aging and of disease.<sup>40</sup> Providing care for a dying patient is challenging and, when done well, a meaningful and gratifying experience for the physician. To help someone die in comfort, in peace, and with dignity is to give one final gift of life.

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