
The Physician's Role in Maintaining Hope and Spirituality

by Thomas Warr

This paper examines several areas that health care providers may find difficult in the care of patients near the end of their lives. It looks at society's denial of death and at ways physicians and their patients use ongoing active treatments to maintain that denial. It suggests that as active treatment fails to be effective and hope fades, physicians must find ways to care for those they cannot cure. It explores the function of hope to help physicians, their patients, and their patients' families redirect their thinking. Finally, it describes how the physician may support a patient's spirituality by becoming more comfortable with his own.

To address the clinical barriers to achieving high-quality end-of-life care, physicians and other health care professionals must develop specific skills. Physical, psychological, social, and spiritual care must be part of a patient's treatment from the outset and continue through all phases of the illness (American Society of Clinical Oncology 1998). The healing powers of modern medicine are vastly superior to any time in history. Life expectancy has doubled in the last 100 years. Yet, as Bernie Seigel says:

[O]ur power to heal people and their lives seems to have diminished as dramatically as our power to cure diseases has increased. This is because the knowledge of human nature, which used to be the doctor's principal resource, has been abandoned as irrelevant in an age of science (1989, p.121).

We need to learn how to provide better care for the dying. We use science but not art to the benefit of our patients; we treat illness but not the person who is ill. Denial of death is very prevalent in our culture; it is facilitated by our dependence upon medical technology. Continued active treatment of patients who are dying can contribute to this denial, and can block opportunities for spiritual growth. This paper examines this attitude of denial, provides some guidance toward maintaining hope

in patients with limited treatment options, and suggests that we offer psychological and spiritual support to help terminal patients cope with dying.

Denial of Death

The bias toward ongoing active treatment is an attempt to deny death. It illustrates our dependence on medical technology to allow us to ignore the threat of our mortality. Denial is an ego-defense mechanism that protects us from unpleasant situations. As a short-term adaptive mechanism, it is healthy and useful; but continued denial, or denial to an inappropriate degree, is pathological and destructive. One must ask in each case whether the denial is protective and beneficial or excessive and contributory to unrealistic expectations and false hopes.

In his book, *The Experience of Dying* (1977), E. Mansell Pattison describes the emotional work that is precipitated for most patients in the interval between the crisis knowledge of impending death and the point of actual death. The disclosure of life-threatening illness precipitates an acute crisis that is relieved somewhat by treatment.

The following case offers an example of this theory. A forty-two-year-old woman presented with a two month history of shortness of breath, cough, right lower chest pain, abdominal pain, and

occasional vomiting. She also had low back and right hip pain. X-rays and a biopsy demonstrated widespread metastatic lung cancer. Though she had experienced no weight loss, the patient was weak and her functional performance was impaired.

She underwent palliative surgery to remove fluid from around the heart and lungs, and initially responded well to aggressive chemotherapy given over four months. The patient was able to be awake during the day, was ambulatory, stable in weight, and independent in self care. She was able to do only light, if any, housework; had shortness of breath with exertion, chronic hoarseness, and a persistent cough. The pain in her right hip initially improved, then gradually recurred requiring narcotics for control.

Ongoing active treatment at this stage may contribute to some degree of inappropriate denial. It can make patients unrealistic about the goals of treatment, interfere with their acceptance of mortality, and prevent opportunities for growth.

At this stage, the patient has begun the emotional work that Pattison describes. Her initial anxiety and her family's anxiety were relieved by active treatment. Though the strictly palliative (and not curative) goals of chemotherapy were emphasized repeatedly, both she and her family assumed that the treatment would be curative, and initial clinical improvement seemed to encourage that point of view.

After four months of chemotherapy, its toxicities became more prominent. She began to lose weight and to experience nausea and fatigue. Increased hip pain suggested tumor progression. Chemotherapy was stopped; a two week course of palliative radiation was given along with dexamethasone

and narcotics; and the patient's pain control, anorexia, and fatigue all improved. Again, the success of the palliation led the patient and her family to assume that the cancer was cured.

Pattison's theory predicts that when this palliative care is exhausted, the patient will experience yet another period of heightened anxiety. At this point, those in charge of the treatment plan explain that no further active treatment is available; her condition is "terminal," and death is imminent. At this point, the family made inquiries about referral to a tertiary medical center for experimental therapy, and investigated "clinics" that offer unproven or untried treatments.

Ongoing active treatment at this stage may contribute to some degree of inappropriate denial. It can make patients unrealistic about the goals of treatment, interfere with their acceptance of mortality, and prevent opportunities for growth. McCormick and Conley (1995) interviewed six patients to ascertain their knowledge and attitudes regarding the goals of the anticancer treatment they had received. All six patients assumed that when a treatment plan was described as potentially curative, a cure would be achieved. This assumption allowed them to develop a positive outlook toward the future, thus reducing their anxiety.

For these patients, the potentially curative therapy appeared to distance them from the acute crisis stage of facing a life-threatening illness. These patients chose to think of themselves as cured. Unfortunately, the goals and expectations of treatment can be misinterpreted. In McCormick and Conley's study, two of the six patients interpreted palliative treatment following the recurrence of their cancer as curative.

There is value in having patients overcome denial and come to acceptance regarding their terminal illness. According to McCormick and Conley:

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.

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 (1995, p. 242).

Maintaining Hope in the Terminal Setting

A major argument against trying to get beyond a patient's denial and helping them accept their prognosis is that such truthfulness takes away their hope. Bernie Siegel says, "There is no such thing as false hope, only false no hope."

Active treatment can be abused as a way to offer hope to patients when there is little to offer. In a questionnaire regarding the goals of radiation therapy for treating lung cancer, 85 percent of Americans, but only 40 percent of Canadians would use radiation with curative intent, although all respondents agreed that the probability of cure is less than 10 percent. Americans were more than twice as likely as Canadians or Europeans to include "giving hope" as an important part of therapy (Porzswolt, Tannock 1993).

The major goal is relief of symptoms, according to Porzswolt and Tannock in their article "Goals of Palliative Cancer Therapy" (1993). Since patients are felt to be the best judge of symptoms, and tumor response is not a direct endpoint of palliation, these authors went on to discuss the ethics of giving or withholding anticancer therapies that are known to be minimally effective, when these therapies are requested by the patient or family. The general consensus was that administering treatment for this reason is often a way to avoid difficult problems in communication. The patient's request for treatment should be considered a serious signal that requires analysis. The optimal management of such patients will depend on whether pain, anxiety, or the potential loss of hope is the major reason for treatment demands.

Patients and their physicians may be forced to consider limiting active treatment as a criterion for referral to a hospice program. This requirement may seem cruel or hope destroying. Its effect can be lessened, however, if the hospice discussion is not

the first opportunity that patients and their physicians have had to discuss the matter openly. Conversations to help seriously or chronically ill patients and their families determine when enough is enough should not be delayed. For some, the fear associated with treatment abatement can be replaced by the comfort in knowing that caring resources are available and that the patient will

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not be abandoned. For many, a safe place, time, and manner in which to discontinue aggressive therapies can be the most important consideration.

To return to my earlier example, the young woman with metastatic lung cancer lived with her family on a ranch, roughly 100 miles from the community medical center that administered the therapy. Hospice services were not available in that remote location. Fortunately, her symptoms were well controlled. She was able to stay awake during the day and interact with her family and two young children. Though she was short of breath with exertion and unable to do any cooking or housework, monthly visits to the clinic seemed adequate to maintain her condition. The physician made it a point at each visit to discuss how she and her family were coping.

Her family, however, continued to inquire about other therapies, because they "didn't want to give up hope." Ultimately, second opinions locally and a telephone consultation with a tertiary cancer treatment center convinced them that no realistic benefits could be expected from further active treatment. Only then did the family begin its long trek from denial to acceptance.

Siegel (1986) points out that our ability to predict the course of a disease is notoriously inaccurate:

"In the face of this uncertainty, hope is always warranted." However, hope is not eliminated by the certainty of impending death, but takes on new dimensions. As Kubler-Ross says, dying patients are still alive and have unfinished business they must address. Their hope is to be able to finish it. Cicely Saunders says that one's hope may be to have physical and spiritual comfort, to be free from pain, to be in control, and to have a sense of self. Hope can be redefined: hope for loving times, for good moments, for sweet experiences with loved ones. The more willing we are to accompany our patients through this process, the more likely we are to bolster their hope rather than allow it to wither in denial. We can provide candor and hope at the same time.

Just so, in our example. The patient and her family began at last to realize how fortunate she was that she could enjoy her family and children for the last several months of her life. She seemed, in fact, content with her situation, enough at least to decide that traveling around the country searching for a cure was not the best way to spend her remaining time. Acceptance of death and a redefinition of hope empowered her to choose the way she wanted to die — to express in her manner of dying the same values she had lived in health.

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About four months after chemotherapy was discontinued, the patient presented with rapidly progressive shortness of breath. There was evidence of cancer progression to the lungs. She was hospitalized to provide aggressive palliation and treated with parenteral morphine and supplemental oxygen. The patient was peaceful. She deteriorated quickly and died less than twenty-

four hours after admission. Her family was at her bedside. The input of social workers, clergy, and specialists in children's anticipatory grief were helpful resources to her family, as hospice or another home care agency would have been to her, had it been available on the ranch.

Transforming Our Notions of Hope

Supporting our patient's hopes and spirituality is the physician's best way to counter the fear of, and consequent denial of death in our patients, ourselves, and our society. Indeed, conversations with terminal patients facing death must pass beyond the realm of scientific proof to encompass truth of the spirit. Death cannot be measured, and life after death cannot be proved. The inevitability of death cannot be corrected. There is no more information available.

Medicine or the medical profession is, in many ways, in the forefront of this culture's need to control and conceptualize things as clearly as possible. No wonder, then, that we have trouble dealing with patients who are dying: their condition is not something we can correct by writing a prescription or imparting some form of information or education. Other than symptom management, the dying experience eludes the type of problem-based medical model through which we usually view patient care. It calls, instead, for an openness to the mystery of suffering, and the possibility of transcending suffering in life and death.

Eric Cassell, author of "The Nature of Suffering and the Goals of Medicine" (1991), feels suffering involves a threat to the person. To Cassell, the person is composed of body and body image, cultural background, beliefs, preferences and aversions, families, politics, and a sense of meaning in life. A person also has transcendent dimensions and a sense of connection to something that endures, that will live beyond. The person usually perceives the self as being present into the foreseeable future.

Suffering results from one or more aspects of the person being threatened or coming under attack. Suffering continues until that threat has passed or,

in the case of a terminal patient, until the person's sense of integrity can be restored in some other manner. Physical suffering can be relieved with morphine, but psychological suffering may require that one find a new sense of life's meaning or a more solid conviction about one's spiritual reality.

To counsel patients and their family adequately, physicians need to point out that they need not give up hope, rather they should shift their hope to other goals. One can hope for a longer life, cured of a disease that appears terminal, as one can hope for a miracle to appear. But in so hoping, we cannot deny reality either. Physicians must not contribute to false hope by misleading patients about the benefits of marginally active treatments. They must eliminate bias, and avoid denying death in conversation and attitude.

As active treatment fails, hope can now take on another form. Hope is that the remaining days of life will be happy ones, that tasks at the end of life can be addressed, relationships mended and finalized, and every moment treasured. Under these

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conditions, efforts to palliate symptoms take on extreme importance. No one should have to suffer physically at the end of life; rather, each patient should be helped to reach the end peacefully.

As patients approach death, hope can change again from hope for a cure to hope that one's symptoms will be eased and one's spirit nourished.

Patients and families can now hope that the dying experience will bring them on a journey into a new world much better than the one they were in before. For many this hope is supported by religion; for others, it is a world view that may be characterized as spiritual but not religious; and, for still others, this hope is a way of finding themselves incorporated into their families and community in new or transcendent ways. It is this hope, however it may be described, that allows other people to say goodbye and to get on with life, even though a beloved has been taken from their midst.

Supporting Spirituality

The highly technical world in which we live sometimes leaves us with a spiritual void, which often becomes apparent as we provide support to patients near the end of their lives. In these situations, all that we can offer is our presence, our caring, and our love. By exploring one's own self-awareness and spirituality, a physician can more comfortably discuss these issues with patients. The following case example illustrates this.

A forty-two-year-old woman with metastatic breast cancer had progressive disease despite all treatment. Palliative efforts were effective in controlling nearly all symptoms, and she was alert, eating, and fully aware despite being weak and nearly bed-bound. The patient was very familiar with death and dying. She was very well read in these areas. As a nurse specializing in oncology, she had been very inspirational to many of her patients. She was married to a minister and very religious. She was very loving and giving. She was familiar with all the past and current theories and approaches to developing spirituality.

Nonetheless, she was very frightened of dying, and had been refusing to give up. Convincing her that further attempts at chemotherapy would do more harm than good was difficult. When she developed a problem or symptom related to her cancer, it reminded her of her mortality, and she became frightened.

Her doctors found it curious that this very sensitive, spiritual person would have such difficulty accepting her own mortality. Clearly, a

problem existed that wasn't being addressed, despite the support she was receiving from family, friends, clergy, and hospice. She seemed to have lost faith in her spirit.

The first thing that her physician did was address his attitude toward her care. The patient's worry seemed to stem in part from a fear that the doctors had given up on her. But doctors do continue to care for patients when active treatment is no longer available. The idea is to continue the best care they can give, and never give up. Don't continue ineffective chemotherapy, but don't ever give up on supportive care, appropriate diagnostic tests, and above all, concern. It is a matter of philosophy and attitude; it is how the physician sees the world and the patient. The physician's attitude is a very real thing to the person on the receiving end of care.

That seemed to help this patient a bit, but there was still a problem.

Her primary physician also reminded her of ways she could realize her spiritual self — the self that was intimately connected to her body, but also separate from her body. Her badly diseased body will die, but her spirit, which is also separate and is in fact God, will live on. It will live on in the love others have for her, in her wonderful legacy of her children, and in all the people she has inspired and helped. In this case, the physician even reminded her of a passage in the movie, *Jacob's Ladder*: "If you're frightened of dying and holding on, you'll see devils tearing your life away. But, if you've made your peace, the devils are really angels freeing you from the Earth."

Soon after this conversation about holding on less tight to living, she dreamed of an angel — a patient she had taken care of years ago. The suggestion apparently worked. When she toned down the ego that was working so hard to protect her physical self, an angel appeared to remind her of her spiritual self. This and other examples, helped support her belief in her spiritual self.

Her physician also talked to her about his own beliefs (emphasizing that they were his). She appreciated the support this sharing gave her, and

they had a nice debate. She seemed very reassured, and much less afraid of dying. Mainly, she was mad at not being able to live. She said later, "It's like a different world now from where I was. I am more peaceful." By accepting that her life was in God's hands, and worrying less about the future, she was more open to the present, and much more content. Her physician was able to support her spiritual side and make her more aware of the part of her that will live on forever.

Our religious background has a powerful effect on our adult spiritual life. Religion can be defined as the human institution that carries spiritual traditions and practices across time and space. The purpose of religion is to foster, nourish, and sustain the life of the spirit. Yet, because it is a human institution, religion does this imperfectly. For many of us, this imperfection proved so painful or confusing that we adamantly rejected religion, and now we steadfastly steer away from any "religious" spiritual path.

Many patients cannot accept religion as a way to help them sustain their spiritual beliefs because of bad experiences in the past, or whatever. Yet, they are very spiritual and believe in God. Bernie Seigel (1986) views spirituality as including the belief in some meaning or order in the universe. He views

the force behind creation as a loving, intelligent energy. For some, this is labeled God, for others it can be seen simply as a source of healing. From this there comes the ability to find peace, to resolve the apparent contradictions between one's emotions and reality, between internal and external. Spirituality means acceptance of what is (p. 177).

It is probably sufficient for us to be truly compassionate, to continue to care, and to show true concern for them in their time of greatest need. Yet, if we can be in touch with our own spirituality we can more effectively support patients in theirs.

Perhaps it is because physicians touch on the boundary of body and soul that we have an ability to obtain a special insight. For a patient to discuss

Recommendations for End-of-Life Care Providers

1. Maintain a close doctor-patient relationship, and frequently review the goals and expectations of treatment. Become comfortable discussing how the patient is coping psychologically, socially, and spiritually.
2. Evolve back to a caring rather than an exclusively curing philosophy. Endeavor to heal your patients, rather than treat their diseases. Instead of active treatment, try caring humanness.
3. Do not abandon your dying patients in their time of greatest need — continue to care for and about them. Never say, “there’s nothing more I can do for you.”
4. Explore your own self-awareness and spirituality so that you can comfortably discuss these issues with your patients.
5. If a doctor would be a physician and not merely a body technician, he must also be a knower of souls, those of his patients and, not least, his own (Kass 1980).

Figure 1. — Five ways to support patients who are dying.

issues of spirit with us is as natural as when, at the point of facing serious illness or death, he or she comes to see or feel that the boundaries of body and soul dissolve and are actually one. We are no longer just specialists but persons, individuals, whom the patient has entrusted, because of our unique knowledge, to help provide guidance at a critical time.

Conclusion

Physicians cannot provide anything but the best care they know how to offer. It is not our role to provide hope that cannot be there. Only God can provide us with miracles and these miracles are signs for us to know God’s existence and mercy. The important thing at these times is how one expresses to the patient and family their remaining options. A cold, unfeeling matter of fact presentation does little to help the family grieve. Nor do unrealistic expectations of possible cures. A simple expression of concern, however, along with one’s continuing professional presence (see Fig. 1), offers a different hope, a hope of love and compassion.

Such hope is a basic concept because it recognizes that mortality is a dimension of living, not merely a negation or an end that cancels out

everything else. Hope is, indeed, a basic aspect of living and dying, but it sickens in an atmosphere of persistent, ill-founded deception and denial (Weisman 1972).

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