Hope and Hubris

JAMES A. TULSKY, M.D.

**hope**: n 1: TRUST, RELIANCE 2a: desire accompanied by expectation of or belief in fulfillment b: someone or something on which hopes are centered c: something hoped for

Ask a patient with advanced cancer why he is visiting the oncologist and more likely than not he will respond, “I’m hoping that this round of treatment will stop the cancer.” Ask the oncologist why she continues to offer chemotherapy despite little evidence of benefit and she may say, “I don’t want to take away this patient’s hope.” Admittedly oversimplified in this example, conspiracies of hope frequently underlie the difficulties faced by patients, families and physicians choosing curative versus palliative approaches at the end of life. To help uncover the role that hope plays, I will explore the definition of hope, its societal meanings, and the role of physicians.

The Webster’s definition above offers two somewhat competing interpretations of hope. The first—trust or reliance—implies faith and dependence. Such a conception of hope does not depend on a particular outcome. Rather, the hopeful person trusts that whatever the outcome, good or bad on first glance, will ultimately be for the best. For many people, such trust is embodied in their notions of religious faith. A person may hope for God’s intervention in a serious illness or a life crisis, yet accept that whatever the outcome, God’s intercession serves a higher purpose, and is therefore good. For others with a secular outlook, their trust and reliance may be on a community whose presence allows them to face their darkest hours.

The second definition offers a different per-
spective. It states that what separates hope from desire is the expectation of fulfillment. In some cases, such expectations can be rational. For example, a patient with low-grade germ cell tumor may review the clinical trials outcome data and expect to be cured. This patient’s hope is dependent on a particular outcome that is very likely to occur. In contrast, the expectation may be irrational and rooted entirely in faith. For example, the patient with widely metastatic non-small-lung cancer may expect to be cured, despite few or no examples of this ever occurring previously.

Hope defined as trust or reliance is not dependent on a belief in fulfillment of specific expectations, such as cure. For such a conception of hope, the outcome may be less important than the experience of being hopeful. Hope defined as trust and reliance protects the person from loneliness and feeling abandoned. Such hope can be tremendously comforting and strengthening for the patient facing a life-threatening illness. In contrast, hope defined by expectations requires a fulfilled outcome to be successful, and risks greater disappointment.

Society helps construct our definitions of hope. I sense that our society, mistakenly, focuses on the second definition of hope and, by doing so, loses the benefits of the first. This is seen keenly on television, where hope is frequently associated with cure. The eponymic program, Chicago Hope, is not about trust or reliance, but rather about expectations for cure. Cardiopulmonary resuscitation (CPR), one of the most dramatic but least successful medical procedures, is routinely portrayed in ways that overstate the likelihood of fulfilled expectations. CPR survival rates on television programs such as Chicago Hope, ER, and Rescue 911 far exceed those in real life. The public views these data on television and incorporates them as facts into its own conceptualization of the procedure.

As problematic as these images may be, leading to a misinformed public, misperceptions of fact are amenable to education. Physicians can sit down with patients, discuss do-not-resuscitate (DNR) orders and correct their misunderstandings about the likelihood of survival with CPR. If trust is present, and physicians communicate their explanations well, patient will learn, incorporate the new knowledge, and make different decisions.

More insidious is the other message promulgated in our society that “miracles happen.” Whether it is the motto of a major medical center, or a testimonial on talk radio or a television documentary, the message is that even when the data would suggest an outcome is extraordinarily unlikely, continued hope may help achieve such an outcome. In the previous example, patients are misinformed, but when they are educated about the low CPR survival rate they change their treatment plans based on this new information. In contrast, society’s focus on miracles encourages distrust of physicians that attempt to provide realistic data. An episode of the television program Rescue 911 serves as a wonderful example of this. The program portrayed the story of a young man struck by lightning outside his home who initially received CPR from his wife. The paramedic said, “It didn’t look good . . . he was in a rhythm called asystole, otherwise known as flatline. We felt the patient would probably not survive.” The physician commented, “He was not likely to make any useful recovery.” However, the wife heroically stated, “I never gave up hope . . . they were talking about, if he lived, he had a 1% chance of being a functional human being.” After they describe the man’s “miraculous” recovery, the physician recognizes his shortcomings. “The most amazing thing to me about J’s recovery is that we were wrong. We had given up hope. His wife did not . . . I think there’s no question that if she had lost hope, there might have been a different outcome.” The wife, with the final word said, “It truly is a miracle that he is alive.” The message was clear. Miracles happen, and hope, embodied in expectations—however unrealistic—creates miracles.

Such societal constructions of hope also permeate medical practice. Physicians view the management of hope as a critical component of their care. They attempt to instill hope through treatment decisions such as continuing anticancer therapy, and worry that their words may take hope away. Depending on the definition one chooses, the perception that physicians influence hope may be misplaced, guided by hubris, or worthy of exploration.

In the case of the patient who defines hope in terms of expectations of fulfillment but responds rationally to outcome data, physicians influence hope only inasmuch as they tell the truth. Such a patient’s hope will change when she learns that her prognosis is worse than she previously understood. Yet, in general, patients do not wish to be deceived, and this patient’s change in hope is
an appropriate response to the facts. Hope in this context is not really a source of strength or help to the suffering patient. It is simply a rational coping mechanism that is no longer effective in certain settings. This patient now needs to access other more effective resources.

For the patient who defines hope as fulfillment of desire, but has faith that he will be cured despite the prognosis, it is hubris to believe that we can influence such hope. The entire notion of faith and belief in miracles is based on irrationality—that something will occur despite the laws of science. Do we physicians really believe that communicating more information about outcomes and data can override longstanding faith? How the physician chooses to work with a patient or family that makes faith-based decisions with which the physician disagrees is another issue. Yet, to presume that logical argument will prevail is truly irrational(!) and potentially disrespectful.

In contrast to these two cases, physicians may play a role influencing hope defined as trust or reliance, yet in unexpected ways. One study of hospice patients found that physicians engender hope by being present, giving information and demonstrating caring. How one communicates is apparently more important than what one communicates. This makes sense as these same physician behaviors engender trust. The physician who spends time with the patient, is honest but compassionate, and expresses empathy offers a hopeful presence even in the face of bad news. Such a physician will also recognize that for many patients, their capacity to hope is independent of the health care provider. Herth studied terminally ill patients who defined hope as an “inner power directed toward enrichment of being.” Such an expression of hope deserves awe and honor, and is certainly not something that any of us can take away.

As we care for patients facing life-threatening illness, and hear the language of hope, we should explore the underlying meaning, and allow it to direct our response. When the meaning is unclear, we have an opportunity to articulate a definition of hope that speaks about trust and reliance rather than expectations and outcomes. And, if we cast our behaviors to instill trust rather than avoiding “taking away hope,” we may find ourselves providing a very different type of care.

REFERENCES


Address reprint requests to:
James A. Tulsky, M.D.
VA Medical Center (11C)
508 Fulton Street
Durham, NC 27705

E-mail: jtulsky@duke.edu