Perspectives

The Perils of Hope

LAWRENCE J. SCHNEIDERMAN

One of the most entrenched commandments in medicine is: "Never take away a patient's hope!" Often it is issued during the treatment of a terminally ill patient to spur and justify the continuation of aggressive life-prolonging efforts. Hope has been called one of a patient's "most powerful internal resources,"[1] and "a powerful ally, our last defense against despair."[2] One editorialist confidently stated: "[C]ommunicating hope can improve patients' prognosis."[3]

Advocates claim that hope, optimism, and a "will to live" prolong life.[4] By contrast, a sense of hopelessness about the future is alleged to increase mortality,[5] and a self-described "realistic acceptance" in AIDS patients to shorten survival time.[6] Even unrealistically optimistic beliefs, one group of researchers declared, might be life prolonging.[7]

In fact, none of the above claims stand up to careful scrutiny with respect to serious illness.[8] Greer et al. first claimed that survival rates in breast cancer patients were linked to a hopeful outlook.[9] Later, however, in a larger and more detailed study, researchers, including Greer, found only a modest association between helplessness/hopelessness and diminished survival, an inconclusive effect of depression, and no effect of "fighting spirit."[10] Cassileth et al. found no evidence of a connection between several highly touted psychosocial factors, including hope, and improved survival in advanced cancer.[11] Similarly, Petticrew et al. concluded that there is "little scientific basis for the popular lay and clinical belief that psychological coping styles have an important influence on overall or event-free survival in patients with cancer."[12] They further caution: "People with cancer should not feel pressured into adopting particular coping styles to improve survival or reduce the risk of recurrence."[13] Angell states bluntly that "our belief in disease as a direct reflection of mental state is largely folklore."[14]

The belief in the medical value of hope[15] may impose on the physician contradictory obligations: to maintain hope while at the same time to be honest. Patients themselves may impose this contradictory demand. In one study, terminal cancer patients receiving hospice-type palliative care unanimously preferred that their doctors be "honest." At the same time more than 90% said they wanted their doctors to be "optimistic."[16] How to achieve this? Tell the truth "in the most optimistic way," one physician advises.[17]

Referring to what are acknowledged to be overlapping psychological states, some psychologists have tried to distinguish hope, an "'emergent property' engendered by serious, or persistent illness and other profound

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life challenges," from optimism, which mediates "more routine or minor hassles."[18] If hope really was a beneficial or—at worst—a harmless psychological state enabling patients to cope with "profound life challenges," there would be little reason to deny it. But what about the possibility that hope might actually cause harm?

Optimistic bias, the tendency to believe that one is immune from laws of chance, might "seriously hinder efforts to promote risk-reducing behaviors."[19] "Highly optimistic" patients, who are "less likely to report being bothered by symptoms,"[20] might tend to ignore or deny early symptoms of cancer and thus lose the chance to obtain curative treatment.[21] Unreasonable hope by the physician or the patient or the parents of a child in the face of imminent death might deprive the patient of more beneficial palliative care.[22] Delaying hospice referral might cause needless suffering and give providers "inadequate time to learn [a patient's] needs and develop an optimal plan for care."[23]

These are only speculative concerns, of course. But there is also empirical evidence to suggest that unrealistic hope in a dying patient does cause harm. For example, SUPPORT researchers found that critically ill patients whose own prognostic estimates exceeded their physicians' prognostic estimates demanded more aggressive and invasive life-sustaining treatments than did patients with more realistic estimates of their prognoses. Increasing these aggressive and invasive treatments only increased burdens and harms—rather than maximizing comfort—without improving hospital survival in the slightest.[24]

Grasping at hope is understandable—patients want to be cured. Unfortunately, most patients obtain their hope from dubious sources, particularly television and the misinformation highway known as the Internet. For example, success rates for CPR on popular shows like *ER*, *Chicago Hope*, and *Rescue 911* are "significantly higher than the most optimistic survival rates in the medical literature."[25] And several studies have shown that elderly patients who request CPR in the event of cardiac arrest have an inflated view of its ease and success. When such patients are informed about the true nature of the technique and the probability of survival their desire for the procedure plummets.[26]

Lack of knowledge and denial, perhaps "reinforced unwittingly by the physician," may also account for unrealistic hope of cure and belief in quack therapies by many patients with metastatic cancer.[27] Patients undergoing bone marrow transplantation have higher expectations for "returning to normal" than do their medical providers, whose expectations are more modest.[28]

Several research groups report that physicians hold more pessimistic prognoses than do their seriously ill patients.[29] Others find physicians to be overly optimistic.[30] Such variations in the framing of decisions and prognostic estimates by physicians can have significant consequences on diagnostic strategies, healthcare utilization, and costs.[31]

Physicians sometimes intentionally mislead their patients,[32] usually by being unduly optimistic.[33] For example, 86% of internists responding to a national survey expressed the view that it was best to have an "upbeat attitude" with patients; 75% reported that they sometimes found it helpful "to shade prognoses to the positive"; and 64% reinforced patient optimism as opposed to only 5% who stated that they reinforced patient pessimism.[34]

Several explanations have been offered for this tendency of physicians to accentuate the positive, including a

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reluctance "to acknowledge that patients they know well are close to death;"[35] "ego bias," namely, a "systematic overestimation of the prognosis of one's own patients compared with the expected outcome of a population of similar patients";[36] and "enthusiasm for new treatments."[37] Also, one cannot discount the embarrassing possibility that an erroneously pessimistic prognosis may make the physician an object of mockery. ("That dumb doc gave me only a month to live, and here I am going strong a year later!")

As already noted, hope is almost always promoted for its impact on a single dimension—life prolongation. In a thoughtful commentary, Christopher suggests "we distort the meaning of hope when we make it depend on the possibility of physical survival,"[38] tracing this view back to Judaic and Christian traditions. Indeed, one has to wonder whether the central role of miracles in Christian mythology may not underlie the contemporary expectation, or at least hope, for medical miracles.

A oft-cited testimonial to the life-prolonging effect of hope is Viktor Frankl's description of his experiences in the Nazi concentration camps.[39] However, what Frankl actually propounded was not hope but rather "man's desire to find and fulfill a meaning in his life, or for that matter in the individual life situations confronting him."[40] He went on to suggest that "what underlies the attempt to establish faith, hope, love, and the will by command is the manipulative approach. The attempt to bring these states about at will, however, is ultimately based on an inappropriate objectification and reification of these human phenomena: They are turned into things, into mere objects."[41]

Ezzy explored this notion of hope-as-meaning in the narratives HIV patients use to make sense of their life-threatening illness.[42] Drawing upon interviews with patients and a variety of narrative theorists, he defines three categories of narratives: linear restitution, linear chaotic, and polyphonic.

Linear restitution narratives are characterized as clinging to normal life goals and expectations in spite of the disease. Hope for these patients focuses on specific future objectives, like seeing a child grow up and get married, and depends on an optimistic bias that empirically derived prognostic probabilities do not apply to them. Their expectation (and hope) is that normal life will go on for many years by means of successful—and sometimes miraculous—medical interventions. These patients, often in unpremeditated collusion with their physicians, maintain their hope by denying the possibility of death.

Linear chaotic narratives, as the name implies, are characterized by anger and despair because their promising, often idealized, life has been fractured and destroyed by illness. These patients have no hope for the future, no explanatory narrative, no simple organizing principle around which to integrate their experience. To them reality is a meaningless chaos. But, as Ezzy points out, underlying that chaotic narrative is an implied belief in a lost and longed-for linear narrative "as an ideal, or an imagined solution that would resolve the chaos of the present."[43]

Neither of the above two narratives serves their owners well. Seemingly at opposite poles, both are, in the most important sense, unrealistic, and therefore unhelpful. The most beneficial form of hope is based on a polyphonic narrative. As the name implies, patients who discover and accept this form of narrative are "many voiced." Rather than focusing on preexisting milestones, these patients are open to "uncertainty about the future, a more

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communally oriented morality and politics, and an acceptance of the reality of death at some stage in the future."[44] Their notion of hope seeks "mystery, surprise and creativity."[45]

I believe that the difficult but essential task for physicians in the modern medical era is to discard the conventional, narrow view of hope as a means to prolong life. That version of hope is perilous. Rather, hope should provide a wider illumination. For the physician that means revealing to the patient the best in the life that is left and assuring that when it is inevitable the exit will be a good death. Is that not the hope we all hope for?

Notes

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