The Breadth of Hopes

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HOPE is a fundamental human activity. As a pediatrician who cares for children with life-threatening, complex chronic conditions, I hear the word “hope” on a daily basis: “I hope we can come up with the definitive diagnosis”; “I hope the treatment makes the disease go away”; “I hope we can relieve his pain”; “I hope we can go home today.” Indeed, the word is uttered so frequently in clinical medicine that the underlying phenomenon is widely presumed to be well understood, a shared point of reference. Our understanding of hope, however, is not based on much empirical evidence about how hope actually does whatever it does in shaping our lives. Moreover, as with many everyday phenomena, when our conceptions of and assumptions about hope are examined carefully, they prove to be extremely varied. In this case, they are also limited, radically affecting — and too often curtailing — our approach to hope as a force in our lives.1,2

To make the most of hope’s benefits, it would help to replace four prevalent presumptions about hope with alternative propositions. First, we often speak of hope as a single entity — big, blooming, and beckoning — with no internal architecture. Within this conceptual framework, which is related to the notion of “feeling hopeful,” hope is alluring but vague, revered but ineffable, aloof from daily life and mostly inactionable. In contrast, we also frequently mention specific hopes, of “hoping for” something in particular. Unlike the broader concepts of hope and feeling hopeful, these discrete acts of hoping — smaller, salient, and steady — provide motivation and direction toward a desired goal.

What happens if we shift away from the monolithic vision of hope and toward the proposition that hope in the big sense is actually composed of multiple hopes in the smaller sense?3 This perspective casts several common concerns about hope in a new light and suggests some important corollaries for clinical practice.

Second, when clinicians discuss the prospect of delivering bad news to patients or their families, we often speak imperatively about not “taking away” or “killing” or “destroying” their hope. Yet if hope writ large is in fact a collection of smaller hopes, to which of the various possible hopes does the imperative refer? Usually, the focus of paternalistic concern is on the distinct hopes of cure or long-term survival, which are exactly the types of hope that are most threatened by bad news. Indeed, such news often elicits feelings of intense sadness or anger in patients and families. But as countless patients and par-

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ents have taught me, although these feelings may signify the receding of a particular hope, other hopes remain or emerge: the process of hoping endures.

All of which is not to make light of the effects of bad news. For some time after such news is shared, the act of hoping strains under its load, and people suffer. Although my patients and their families have an unequivocal right to the forthright and compassionate disclosure of the information that I have, I always wish that the news had been different, and I usually say so. But after sufficient time has passed for them to assimilate the information, part of my job is to help illuminate the hopes that remain. To do so, I cannot presume to understand their goals and expectations; instead, to take the best care of each patient, I have to ask a crucial question: Given what you are now up against, what are you hoping for? And then I must be patient as I wait for the answers.

Third, some clinicians fear that discussing hope with patients or the families of patients who are facing grave or terminal illness will only engender false hope and thereby impair decision making and care. And, true enough, when I ask what people are hoping for, I often learn about hopes of miracles and cures, of waking up from bad dreams. These hopes are often shared first, quickly and nervously. I try to probe further, gently asking, “Do you mind telling me what else you might be hoping for?” The subsequent answers tend to be qualitatively different from the initial hopes: they are more oriented to pain or suffering and the hope of relief, to the longing for home and the hope of homecoming, or to surviving not in a physical but in a spiritual sense and the hope of finding meaning and connection.

This breadth of hopes, ranging from the miraculous to the mundane, reveals the internal architecture of hope—a framework complete with ceiling, floor, and diverse supporting pillars. I have observed that within this structure, the maintenance of a “miracle” hope can be adaptive, enabling people to cope with adversity and loss, as well as affirmative, conveying the abiding commitment of relationships and love. Judging such a hope as either realistic or false misses the point; rather, we should judge ourselves as clinicians by the degree to which we can help nurture our patients’ collection of diverse hopes.

Fourth, some physicians and ethicists argue that emotions should take a backseat to data and reason when decisions are made about medical care: emotions are too mercurial and inevitably bias people’s judgments; talking about hopes just stirs the emotional pot; when tough choices must be made, we need to be level-headed. But this seemingly objective perspective begs the answer to a vital question: level-headed about what? When confronted with the need to make any complex decision, we often have to figure out what we care about, explore the values that provide the foundation for our choices, and then prioritize our hopes. There are good reasons to believe that emotions play a fundamental role in these undertakings, and I have found that discussing hopes, and the spectrum of emotions that these hopes represent and evoke, can help to identify the guiding principles for making difficult decisions. Even in the midst of heartache, focusing on specific hopes provides invaluable, orienting points of reference for sustaining hopeful engagement with the future.

An ethic of respecting the breadth of hopes hints at the contours of a larger set of empirical and ethical questions regarding the management of hope and other emotions. What would the world of clinical medicine look like if we had, in addition to techniques of managing cognitive information, the ability to assist with emotional management, for ourselves and for the patients and families that we serve? And what if these techniques not only provided support in making these difficult decisions but also helped to fortify the motivation to carry out those decisions? At the same time, as clinicians, we need to more carefully work through what separates the appropriate management of hopes from their inappropriate manipulation, because whether we want the responsibility or not, we constantly interact with our patients’ hopes. Let us all hope that we can learn to do so more compassionately and effectively.

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