Hope is essential in every field of medicine - **by Shannon Casey*

A man in his fifties is wheeled into the emergency department on a gurney hoping he'll still be around to cheer from the sidelines at his daughter's next soccer game. A little girl on the pediatric floor upstairs simply hopes her tummy stops hurting. A woman in the clinic explains her puzzling symptoms and hopes that this is the specialist who will finally be able to ascertain why she hasn't been feeling well.

Our patients' hopes are as varied as their medical conditions, and as their health care providers, we often support them in these hopes. Holding hope for our patients is part of our duty. However, hope is inherently complex, and sometimes it is in conflict with another duty - our responsibility to tell patients difficult truths that will extinguish their hope. It is these circumstances that call for a renewed understanding of hope.

The word "hope" generally has positive connotations, but we must also recognize that it can sometimes be an unexpectedly powerful source of unintentional harm. There are two main kinds of hope - *what Dr. Harpham calls "healing hope"* and *false hope* — and part of our role is to help patients distinguish between the two. False hope is, of course, the harmful kind because it sets patients up for distressing disappointment; it encourages them to maintain unrealistic expectations that inevitably go unmet. For patients navigating end-of-life care, a sense of false hope may lead them to proceed with ineffective treatments that keep them from enjoying what time they have left. Healing hope, on the other hand, can help patients live life to the fullest, even in the midst of the challenges they face.

Unfortunately, there are no clear criteria or committee-approved guidelines that help us navigate the nuances of hope. How can we deter patients away from false hope and help guide them toward healing hope instead? The first step is to help our patients expand their definition of hope. In the book Hope in the Dark, activist and author Rebecca Solnit writes, "It's important to say what hope is not: it is not the belief that everything was, is, or will be fine." Rather, she goes on to assert that true hope requires two things: clarity and imagination. Clarity is essential because one cannot avoid reckoning with reality. Imagination follows closely behind because it empowers one to turn towards the future with a new perspective that embraces uncertainty.

Julie Church, a registered dietitian who works with patients struggling with eating disorders, also comments on the uncertainty implicit in hope. She says that the professional therapeutic team she is a part of "hold[s] a lot of mystery and ambiguity about what one's body will do when one is pursuing health […] for some bodies, some weight loss could occur as they pursue health and for others it may be maintenance and [for] others it may be weight gain." This orientation around hope typically requires that patients let go of certain specific and potentially false hopes they have been clinging to. The process of adopting a new definition of healing hope is not always easy; it often involves a significant amount of grief, but there is also relief on the other side. Rebecca Solnit notes, "Inside the word emergency is emerge; from an emergency new things come forth."

Healing hope equips patients with the tools to see that their hopes are actually the means to living life to the fullest rather than the end in and of themselves. For example, a young man with epilepsy conveys his hope to the neurologist that his medications can be adjusted so he doesn't experience the nearly incapacitating side effect of irritability. His hope to not feel so irritable is not the end in and of itself; rather, it is the means by which he will be able to connect better with his classmates and build meaningful relationships.

Having conversations with patients about hope is essential not only in oncology or palliative care, but in every field of medicine. After all, all of our patients are hoping for something.

What cancer taught this physician about hope - **By Wendy S. Harpham, MD*

As an internist, I strived to give patients hope by prescribing therapies that increased their chance — their hope — of the best outcome and by encouraging them with hopeful words. My own hope was to care for patients until I was old.

Just weeks after celebrating my 36th birthday, I was diagnosed with non-Hodgkin lymphoma. Throughout the ups-and-downs of my chemotherapy, I felt the kind of hope I'd wanted my patients to have. Clear scans and 10 months later, I traded in my patient gown for my more comfortable white coat and reopened my office, hoping I was cured. I wasn't. Six months later, my need for more treatment forced me to close my practice. What could I hope for now?

Friends and family kept urging me to have hope, as if it were simply a matter of choice — and all hope was good. Try as I might, I couldn't switch on "hope" like a light. Of the hopes I had, many were not helpful, even when realistic.

Understanding the complexity of hope

My medical training, which enhanced my ability to communicate with my health care team and comply with therapies, didn't help me understand hope. So, I began studying it. The first thing I learned was that hope is far more complex and controversial than I'd imagined. It is more powerful, too, because it shapes patients' perception of their world and drives their actions.

I began to see hope like a potent medicine that can heal or harm, depending on what patients hope for. Unlike prescribed therapies, though, hope arises within. That realization launched my quest to find hope. Not just any hope, but healing hope — namely "hope that helps me get good care and live as fully as possible."

Searching took time and effort. It took courage, too, as I learned after my cancer recurred a second time. I struggled briefly before rejecting the promises of mail-order cures and limiting my treatment choices to the few science-based options, none of which I liked. That experience opened my eyes to the vital role clinicians play in helping patients find healing hope.

For starters, patients can't simply decide to have hope and — voilà — they have hope. One of the many reasons is that anything affecting brain chemistry might affect the brain cells, which must fire properly to experience what we call hope. That could help explain why patients might find it more difficult to find hope if, say, in pain, on certain medications or haunted by memories of others' poor outcomes.

Although saying "I want to hope" might not make it happen, patients can always choose to set the stage for hope to emerge. In my case, I decided to work with my health care team to optimize my physical and emotional well-being; read writings by exceptional survivors, hang out with people who lifted my spirits, and avoid people who dragged me down. I painted the drab walls of my study bright rose and the doors grape purple. Visitors rolled their eyes. I didn't care. Pink and purple helped me. Setting the stage for hope has been a never-ending work-in-progress because hope is fleeting and circumstances change constantly.

Healing vs. harmful hopes

The tougher challenge for me was learning to distinguish healing and harmful hopes. In search of a hope-o-meter (scans and blood tests are useless), I had an insight while leaving for the airport to participate in a clinical trial to treat my second recurrence. My then-seven-year-old daughter waved from the back door, saying, "Bye, Mom. It's not going to work." For her, the distress caused by the possibility of disappointment outweighed the emotional lift of believing the third time might be the charm.

The image of hope as an inner tug-of-war between fear and inspiration led me to a metric for assessing each of my hopes: I could ask whether it was helping me think and act in healthy ways. “Is this hope helping me take proper action or, if there’s no more I can do, is it helping me wait?” Whenever the answer was “no,” I let go of that hope and invested in other, more healing hopes.

For example, patients undergoing evaluation naturally hope for good news. Unfortunately, that hope only exacerbated my anxiety. If the results were what I’d feared, I felt somewhat responsible, as if I hadn’t hoped right.

I found a more healing hope. Now while undergoing an evaluation, I repeatedly tell everyone, “I’m hoping for accurate news.” That hope motivates me to hold still in the scanner to help get clear pictures. It helps me wait for results because I want my doctors to take their time scrutinizing the findings. It lessens the shock of upsetting news. It prevents despair by framing upsetting results as “useful” news. And it quiets a voice that might try to blame me.

Guiding patients toward healing hope

Share your hope, separating hope and expectation. By saying “I’m hoping for the best,” you show compassion by expressing your feelings about their situation. Adding “I’m prepared for whatever happens,” reminds — or teaches — your patients they can expect one thing and hope for another.

Discuss short-term hopes. By saying “While I’m hoping the treatments work, I’m also hoping to improve your … (pain, fatigue, etc.),” you encourage patients to focus on short-term hopes that motivate them to action — the key to complying with health-promoting behaviors.

Today, marveling at my 28-year survival, I think about the many ways healing hope has helped me overcome the challenges of recurrences and after-effects — and helped me raise my children through my illness. Even if I hadn’t survived, I would have benefited. Healing hope would have guided me to wise decisions and motivated me to live as joyfully as possible in whatever time I had.

Let’s change the conversation about hope. If nothing else, ask patients to share their hopes unrelated to illness, such as hope to attend a special event. Their answers may enrich your understanding of your patients’ values and goals of care, which will help you advocate for them. Most important, talking about such hopes reminds everyone that clear scans, low tumor markers, and optimal pain control are not the goals — they are only a means to our shared mission of helping each patient live his or her best life today, tomorrow and every day.