Hope and the Care of the Patient

Introduction

From the early 19th century American Codes of Medical Ethics have emphasized the physician’s responsibility to sustain hope in patients. This is a perennial aspect of the “art of medicine.” Thomas Percival famously described the physician as “minister of hope and comfort to the sick.”

How can you as a physician respect the dynamic of hope in patients? Harvard hematologist-oncologist Jerome Groopman, in his *The Anatomy of Hope*, writes that hope is “the elevated feeling we experience when we see – in the mind’s eye – a path to a better future. Hope acknowledges the significant obstacles and pitfalls along the path. True hope has no room for delusion” (p. xivi). Without endorsing the exaggerated popular literature on hope and healing, Groopman notes that belief and expectation, two aspects of hope, are fundamental to the placebo effect, and activate brain circuits that release endorphins (natural opiates) and dopamine (a feel good chemical). A careful assessment of the existing research compels Groopman to conclude, “Hope, I have come to believe, is as vital to our lives as the very oxygen that we breathe” (p. 208). Current researchers focus on the neurobiology of optimism, psychological resilience, physical health and optimism, and the promotion of optimism and hope. Significant NIH-funded investigations link hope to longevity, enhanced wound healing, stress reduction, dopamine release, and endorphin release. Hope for patients is about the uncertain expectations around which they constitute their lives in time of serious diagnosis or illness. It is a passion for the possible and a way of staying afloat in uncertain times. Hope is often thought of as deeper than optimism, and may be grounded in spirituality and religion for many patients. Hope is often deemed virtue in hard times, while optimism is a dispositional personality trait more conditioned by circumstances. The opposite of hope is despair – an unhappy resignation, an admission of defeat, a giving up of expectations. The skilled clinician must handle hope empathically, and be able to redirect patient hopes from one goal to another in order to circumvent despair – e.g., from cure of cancer to the comfort care of hospice, from an earlier vision of a flourishing life to a modified vision, etc. Redirecting hope can be challenging in a high-tech era with real possibilities for miraculous new cures.

Perspective matters in the ethics of hope. The oncologist may believe that a last-chance new chemotherapy like the plant alkaloid taxol will work, while the ICU intensivist feels that this is an unwelcome manipulation of the patient in the name of “false hope”. It turned out that taxol really was a miracle drug for women with gynecological cancer. In one study of women who participated in the early taxol trials (1990), they gave reasons such as, “My husband passed away last year and I cannot bear the idea of our two young daughters not having one of us around,” or “I know that this is keeping my hopes alive.” Yet hope can be manipulated in destructive ways that harm rather than help patients, and that burden them with expensive but ineffective treatments.

Persons with major spinal cord injuries navigate the choppy waters of hope and despair. Often physicians who care for such individuals will not allow the patient who wishes to throw in the towel to do so. Christopher Reeve, for example, initially wanted to give up on treatment, but with the encouragement of many friends (including Robin Williams) and loved ones, over time, he came to accept his new life and even became an outspoken advocate for persons with spinal cord injuries. He spoke up for stem cell research at the Democratic National Convention in 2004. He was a dear friend of Stony Brook’s Brooke Ellison, who will speak with us this afternoon.
Brooke has worked as an advocate for stem cell research for nearly a decade. In 1990, at the age of 11, Brooke was in an accident on Nicols Road about a half mile from where we sit. It left her paralyzed from the neck down and dependent on a ventilator to breathe. However, not letting her physical circumstances limit her life, Brooke graduated with honors from Harvard University in 2000 with an undergraduate degree in cognitive neuroscience and from Harvard’s Kennedy School of Government in 2004, with a Masters degree in public policy and a thesis on our topic, hope. In 2002, Brooke published an autobiography, *Miracles Happen*, which was later made into a movie directed by Christopher Reeve. For more than a decade, Brooke has worked across the country as a public speaker, delivering her message of hope, optimism and strength in the face of obstacles, using her own experiences as a vehicle to convey the message. In 2006, Brooke was a candidate for New York State Senate, focusing on the need for New York State to embrace funding for stem cell research. Brooke continues her work in the field of stem cell research, serving as a gubernatorial appointee on the Ethics Committee of New York State’s Empire State Stem Cell Research Board. In July of 2007 formed a non-profit organization, *The Brooke Ellison Project*, to educate and mobilize on behalf of the research. Through this organization, Brooke has worked with many leading scientists and advocates in the field to create a documentary, *Hope Deferred*, to provide the necessary information on stem cell research.

**Objectives**

At the end of this session:

1. Students will become more conscious of their responsibility to treat the patient not as “the kidney” in room 6, but as a human person navigating through the peaks and valleys of hope and despair.
2. Students will be able to explain a scientifically informed perspective on the mind-body and emotion-body connections that make the dynamic of hope essential to patient well-being and to clinical outcomes.
3. Students will be encouraged to think through the nature of being a good doctor, and even partner in health, at a deeper and more holistic level.

**Competencies**

Professionalism, communication

**Preparation**

1. Write a brief definition of hope
2. Write a brief (several sentences) statement on hope and the illness experience as they or someone they know has experienced it
3. Read the assigned article on hope and reduced mortality.

**Process**

We begin in lecture. Dr. Post will briefly discuss the topic, and then introduce Brooke Ellison. Ms. Ellison will describe her experiences with hope over the course of her lifetime after her accident. How did doctors treat her? Were they at times destructive of her hope, and how does she maintain hope today? How did Ms. Ellison
translate challenge into hope and what ways were doctors instrumental in that? There will be ample time (at least 15 minutes) for students to question Ms. Ellison.

In Section discuss the power of hope in Ms. Ellison’s experience, and reflect on students own experiences of hope and health.

Explore the role of hope in two cases provided.

**Study Questions**

1. Why is hope important in patient care?
2. Is there ever a time when there is no hope?
3. What might be some biological mechanisms by which hope impacts physical health?
4. What can you learn from the Brooke Ellison case?
5. How might hope be related to patient spirituality?
6. Is it justifiable to disclose diagnosis, but not a clear prognosis, in order to sustain hope?
7. Is there a difference between optimism and hope?
8. Among Arab Muslims, as long as the patient has faith in Allah and His power, hope is never false. How do culture and worldview play into hope?
9. In research trials, subjects must sign informed consent forms that detail potential benefits to the subject, as well as potential harms or inconveniences. Often, researchers exaggerate potential benefits and have to reword their forms after IRB analysis. How does hope fit into the content of research? How can it be used well, rather than abused?

**Articles on File**


**Resource Links**

www.stonybrook.edu/bioethics
www.brookeellisonproject.org