SOME THOUGHTS ON HONESTY AND HOPE

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*Hope is the thing with feathers/That perches in the soul.* ---Emily Dickinson

**Early Impressions**

Early on in medical school, I began to consider training as a medical oncologist. Initially, I was drawn to the scientific and research aspects of hematology and oncology, and pursued clerkships which would acquaint me with the clinical aspects of this field. I had opportunities to observe a fairly broad spectrum of oncologists— with varied educational and cultural backgrounds, years in practice, and treatment philosophies—who saw patients in a variety of settings: private clinics, large research hospitals, veterans hospitals, intensive care units. I began to realize, and was drawn to, the very intimate nature of the relationship that can develop between a trusted oncologist and her patient, coming at a time when that patient becomes focused on what is most important in life. It seemed these doctors were often privileged to have their patients share their sincerest dreams, goals, and values and to enable them to overcome fears and live longer or more fully—often both—than they would otherwise.

Because of the nature of medical oncology and my interest in it, I was privy to many conversations between doctors and patients when poor prognostic information or other bad news had to be relayed. I took an interest in the way in which various doctors approached and carried out this difficult task. I began to feel that the complicated nature of this interaction derived largely from the conflicting interests of hope and honesty. Is it okay for physicians not to completely disclose information to a patient, to avoid causing that patient mental distress? Does this prevent a patient from preparing for death physically and emotionally? Is there value in allowing a patient to have hope? How much
information do patients want? What is the most ethical course for a physician to take?

Honesty

Few would dispute that honesty is a core concept for an ethical physician to embrace. Deontologically, it is a principle of divine origin embraced by many of the world's religions, and is a commonly valued virtue of most societies. Given this, and assuming that most physicians attempt to act ethically, the number of physicians who fail to fully inform their patients regarding aspects of their illnesses is unsettling. Over $\frac{1}{4}$ of patients are not told of the incurable nature of their disease, more than $\frac{1}{3}$ of patients with metastatic cancer believe that palliative treatments which they are receiving are meant to be curative, and about $\frac{1}{4}$ of patients are not told of the side effects they should expect with the treatments they are receiving (1). More than 40% of oncologists withhold prognoses if not specifically asked or if patients' family members request that the patient not be given this information (2). One reason cited for not fully disclosing to patients the severity or progress of their disease is a desire to allow patients to hold on to hope. This seems a noble justification, and perhaps complete honesty does not require that details not specifically requested are relayed, provided that information that is given is at least technically true.

Analyzing this type of patient-physician encounter and the ethical tensions involved may begin with a discussion of autonomy. What do patients want? A study of outpatient cancer patients in Britain found that all patients interviewed wanted information about their diagnoses, treatment options, and common side effects of those treatments (3). A large, recent study survey given to terminally ill in-patients and their families at five tertiary care hospitals across Canada attempted to address this question. Each participant in the study was given a list of 28 elements of end-of-life care and asked to rate each element for its level of importance to them, on a one-to-five scale, with five indicating "extremely
important." The items most frequently rated as five by the patients were "To have trust and confidence in the doctors looking after you" and "That information about your disease be communicated to you by your doctor in an honest matter." Family members of patients placed these same elements of care at the top of their ranked lists (4).

Physicians may use the principle of nonmaleficence to defend their failure to be completely honest with patients regarding bad news. However, it is often the uncertainty associated with their diagnoses that distresses patients the most. Patients may harbor unexpressed fears or anxieties, anger or sadness. They may put off or question such preparations as making a living will, naming a health care proxy, clarifying priorities and strengthening relationships, which may prevent them from experiencing peace and, eventually, a good death (5,6). A doctor may be unwilling to admit that medicine has nothing curative to offer; he may see himself as having failed. Whatever the reason, physicians who do not discuss bad news with patients may feel dishonest and have difficulty maintaining a trusting, strong relationship with those patients. They may eventually withdraw from patients, leaving them feeling abandoned (7).

Thus, discussing possible outcomes with patients and their families is truly acting with beneficence. As geriatrician and writer Paul Rousseau put it: "Physicians are characteristically hesitant to deliver devastating news and may abstain from truth telling in an effort to sustain and bolster hope...Such misguided hope may involve telling patients about futile treatments such as chemotherapy, radiotherapy, and surgery, which can create false expectations." He further notes that in honestly discussing prognosis with a patient, he has seen that "The false hope of a relatively futile medical intervention (chemotherapy) was replaced with an appropriate and humane hope of reconciling, . . . resolving familial discord, and experiencing an improved quality of life" (8). In view of the above, it can not be deemed just for a physician to deny his patient information.
Hope

Perhaps at the outset a working definition of hope is in order. While many meanings exist, I will consider hope to be holding on to an objective or desired ends, looking to the image of this outcome and working towards these goals, and deriving a sense of meaning in life, of individual worth, and an increased ability to cope through this focus. There can be multiple simultaneously held hopes, the outcomes hoped for may shift through the course of an illness, and both sources and objects of hope for each individual or patient are influenced by that person’s unique faith, culture, circumstances, and values.

It is interesting to approach the idea of hope from the perspective of consequentialist ethical theory, focusing on aspects of the outcome of allowing patients, and physicians, to maintain hope in the face of terminal, potentially devastating illness. It is easy to accept that hope is a critical element for coping with illness (9) allowing patients some degree of emotional comfort. But addressing hope from a biologic standpoint, looking at its physiologic and possible therapeutic effects is somewhat more foreign.

In his book *The Anatomy of Hope: How People Prevail in the Face of Illness*, Dr. Jerome Groopman, a researcher and clinician in hematology and oncology at Harvard Medical School and the Beth Israel Deaconess Medical Center in Boston, and staff writer in medicine and biology for *The New Yorker*, explores the biology of hope in some detail. He describes research which indicates that belief and
expectation can block a patient's perception of pain by releasing natural forms of morphine-endorphins and enkephalins, in hopeful patients. He also relates research related to the consequences of a patient's emotional state on functions of the autonomic nervous system, including heart rate, blood pressure and respiration. These functions impact a patient's illness and response to treatment. Fear, pain, and emotional distress can elevate the heart rate and blood pressure and make breathing more difficult; furthermore, studies have shown that there is a correlation between hopefulness and recovery. Groopman cites the work of Nobel Prize winner Dr. Eric Kandel of Columbia University revealing the "plasticity" of the human brain—that environment has an influence on neural circuits, experiences cause structural and synaptic changes. Of this, Groopman writes, "We will likely discover genes that contribute to the very complex feeling we know as hope, but the circuits in the brain that stem from this feeling are not static. Rather, events in our lives modify them, and I would posit that the words spoken and the gestures made by physicians...influence the synaptic connections" (10).

From an altruistic standpoint, then, hope may improve outcomes. But what about the egoistic outcome? Is hope beneficial for the physician? It seems reasonable that medical oncologists must have some degree of hope to practice in their field. They deliver toxic drugs day-after-day, see the ravages of their treatments on patients they have come to know and care for, experience therapeutic failure and patient deaths with regularity. What but hope can motivate their work? There are long-term recoveries, continual new and promising treatment strategies, successes. They must hold to these. But also, physicians who develop trusted relationships with long-term patients can come to frame hope, not in terms of potential for cure, but in terms of helping a patient meet his goals, to live pain-free and fully, and to enjoy moments with loved ones to a greater degree than ever before. As stated by a group of instructors in hematology-oncology at Massachusetts General Hospital, "In order to maintain a healthy practice, physicians must also be optimistic about their patients' treatment plans and course. By sharing a sense of hope, doctors align themselves with the patient and provide critical support" (1).
This alignment surely helps a doctor fighting terminal disease to find accomplishment and satisfaction in what might otherwise seem an often futile exercise.

Some Conclusions

Hope is also beneficial if one looks at outcomes from a utilitarian perspective. This may at first seem not to be the case at all. Indeed, patients with more optimistic assessments of their own prognosis are more likely to choose aggressive therapies at the end of life (11), therapies which may be both futile and extremely costly thereby draining resources which may otherwise be used for improving the health of others while benefiting no one. However, it is important to distinguish between true hope and false hope; doing so, in fact, facilitates resolution of the seeming conflict between hope and honesty, or more accurately, perhaps, allows one to incorporate both into an optimal approach for discussing difficult news with a patient. Of false hope, Dr. Nicholas A. Christakis an internist and professor at Harvard Medical School said, "If one patient in a thousand will live with pancreatic cancer for 10 years and doctors hold out that patient as a realistic example, we have harmed 999 patients" (12). False hope ignores reality and leaves patients and their loved ones unprepared for foreseeable tragedy.

I first heard the phrase "hope for the best, and prepare for the worst," uttered by a doctor with whom I saw patients during my first year of medical school; this doctor later became my mentor. At the time, he was speaking to a patient with advanced cancer, discussing all possible outcomes, including worst-case scenarios. He was completely honest and forthcoming, providing detailed information in a comprehensible form, and inviting patients and their families to ask questions, to repeat back what they understood the situation to be. But in the same conversation, and in numerous others like it, I observed him then joining forces with his patient to find and explore avenues for true hope: hope for many happy days ahead, for continued productivity and fulfillment, for building new relationships and strengthening
old ones, for being free from pain and preparing fully for the death that all eventually experience, but not all have the luxury of carefully and completely planning for.

I have heard and read this mantra in discussions of the best way to approach delivery of distressing findings to patients, and picture this seasoned oncologist seeking out a path for real hope with each patient and then walking with him, turning or backtracking as needed. And beyond this, I have decided that it is okay to allow patients to hope for a miraculous cure, to even hope for that oneself as a practicing, fully aware physician. To simultaneously uphold honesty, the key is to realize that such a cure would, indeed, be miraculous- it is not to be expected, but may be a common hope.

Very thoughtful discussion from Hell's perspective from analysis & discussion from biology & ethics of Rick's experience & the lessons you've drawn from them.
The issue of whether or not it is our duty as physicians to actively ensure that all people have access to health care, irrespective of their economic status or country of residence/nationality is an ongoing debate fraught with guilt, frustration, anger, and I would argue most especially confusion. Confusion because most physicians truly do possess an altruistic desire to see the end of suffering but have very little knowledge of how to make-good on such an overwhelming task. This then becomes a point of contention and guilt, even something to argue against, ironically, despite our fundamental desire to heal. Physicians are not mentored in these skills. Though we are deeply conscious of the disparities that exist, we are frequently uninformed of the root causes and are not encouraged to consider solutions. We are not trained in how to treat the masses, and we are not trained to feel responsible to do so. Herein lies one of the fundamental flaws of medical education.

As trained clinicians we should be taught the epidemiology of important, widespread diseases. In US medical schools it is deemed imperative that the epidemiology and treatment of cardiovascular disease be taught, and well it should. The same is true for diabetes, lung and colon cancer to list only a few. If the justification for this lies in the numbers of people affected and therefore the numbers who may be helped by a thorough understanding of such diseases, then how can a substantive medical education rationally not include training future physicians about the largest cause of premature death and suffering: poverty. Poverty has been shown over and over as the primary underlying cause of most illness in the world today.(3,4,5,6,7) The World Health Organization now acknowledges that poverty is the world’s greatest killer.(6) Given the inextricable ties established between poverty and poor health, there is an implied link between a physician’s commitment to health and a commitment to reducing poverty and helping those most impacted by it. Why then is this not emphasized in US medical schools?

We have made strides in recognizing and teaching about inequities that exist in our health care system. Recognition of health care disparities and the resultant disease burden among minority populations in the US is only the first step towards understanding a deeper and more uncomfortable truth—that these disparities lie along class lines.(4,5,7) They result from material deprivation and the multiple social disadvantages associated with it. Premature death and illness are two of the leading causes of suffering in the world, and the poor statistically bear the brunt of both the world-over. That race is often used as a substitute for class allows us to attribute illness to something inherent, unchangeable, and beyond our control. To admit so many do without due to economic factors in which we all play a part is far more difficult. In particular this may strike a painful cord amongst physicians, all of whom share the traditional class parameter of being highly educated, and most of whom share a second class parameter, above average income. The very individuals responsible for teaching the next generation of physicians must face the confusing challenge of disparity and allocation in a society that does not want to be implicated. Indeed many physicians do not want to be implicated. Equity then becomes the central challenge to modern medicine, even more so given the growing
global society. How can physicians resolve the moral dilemma of the 'have and have nots'?

Cultural differences, though used by anthropologists and ethicists alike, do not provide an answer or an excuse for why so many of the world’s poor suffer health inequity. We pride ourselves in becoming culturally competent in medicine today, and yet we use the concept of cultural relativism as a tool to relieve our own guilt. We look outside and note “they are different” and hence “live differently”, with different standards that can be explained away as “part of their culture.” (7) Rather than calling a spade a spade and acknowledging poverty for what it is, namely inequality often in the setting of extremely inegalitarian social structures, we choose to see it as unconquerable—a given like culture itself. Does a mother in Chiapas in a small village feel differently than a father in suburban Houston when a child becomes ill? No, the difference is only that the poverty in the former prevents treatment of the illness and the child dies. Being culturally sensitive does not include accepting this form of relativism. As long as we use this measuring stick poverty and the abject suffering it brings can be viewed as unpreventable.

Conventional medical ethics does not provide answers to this dilemma either as it is mired in individualism and for the most part speaks to cases that would never apply to the masses of the world’s sick. Wealthy nations ethicize over how best not to administer excess while the world’s majority die from malnutrition and infections, diseases that result from too little. There is no current bioethical principle to grapple with the obscene fact that over the next year more than six million people will die from AIDS, TB and malaria, diseases that are completely treatable. Cultural relativism may erase the guilt for some, but it does not erase the plain truth. Even if physicians choose not to undertake an analysis of the forces that create such extremes of economic disparity, they may still take issue with the results of that disparity. What is needed is an understanding of ethics that emphasizes responsibility to others and a desire and obligation to uphold moral principles of the medical tradition.

What is my duty as a physician in terms of healing the sick and suffering? It is generally accepted that in choosing a profession, a person should understand and accept the obligation to conduct himself in accord with the ideals of that profession. In 2001 the American Medical Association wrote the Declaration of Professional Responsibility in order to reaffirm and uphold the ideals that inspire many people to pursue medicine as lifework and which afford physicians society’s trust and respect. In it physicians are asked “to use their skills beyond the bounds of the traditional patient-physician relationship in responding to exceptional global conditions and need for care.” The Preamble to the Declaration concludes by stating, on behalf of all physicians that "humanity is our patient." (8)

The honored ideals and morals of the medical profession imply that the responsibilities of the physician extend not only to improving the health and well-being of the individual but to the community and greater society as well. I would argue that in today’s global economy this includes other countries as well. The AMA upholds such ideals and calls
upon the profession to act in accordance in its 2005 Principles of Medical Ethics which states: (9)

I. Article VII. A physician shall recognize a responsibility to participate in activities contributing to the improvement of the community and the betterment of public health.

II. Article IX. A physician shall support access to medical care for all people.

In the case of allocating limited resources, the AMA code of ethics calls upon physicians to use their expertise in order to safeguard the interests of patients when decisions are made at the societal level regarding allocation or rationing of health resources. Additionally, ethically appropriate criteria are established to use in decisions regarding allocation that include likelihood of benefit, urgency of need, change in quality of life, and duration of benefit.(10) It emphasizes that non-medical criteria, such as ability to pay should not be considered in allocation decisions. The code goes on to state that the greater the disparities, the more justified the use of the criteria becomes, and that patients should be prioritized so that death and extremely poor outcomes are avoided, and then, patients should be prioritized according to change in quality of life. Since we have established that the poor suffer the greatest disparity in health and clearly bear the greater burden of death and extremely poor outcomes, surely these criteria apply in spades. If we as physicians are to uphold the ethical principles our profession dictates over and over in the literature and in our society, then the poor above all deserve our care. We need look no further than our own codes of ethics and professional conduct to paint a clear picture of a physician’s responsibility to ensure access to health care. Since it is established that it is our professional responsibility to aid those most in need, teaching physicians to uphold this moral principle is an implicit duty of medical schools.

If humanity is our patient and we acknowledge a duty to adhere to the explicit moral obligations of our profession as well as the implied then the physician must view the issue of health care access as an inalienable responsibility. Does this assume that health care is a right then? The overall ethical paradigm in which the medical profession’s code falls is that of a human rights perspective. In fact this is laid out explicitly in the article IX of the AMA’s Principles of Ethics above.(9) Multiple references to health care as a basic human right are seen throughout international treatise on human rights. Health care is a global public good to which all have a right (11); the Tavistock document on ethics goes further and states that health care is a human right (12); the Universal Declaration of Human Rights goes on to state that everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including medical care. (13)

Those who argue health care is not a right often use the argument that because it is a need that requires something of someone else any “right to medical care imposes on someone the obligation to provide care to those who cannot provide it for themselves.” (14) They argue that any right in itself necessarily sacrifices our genuine rights of liberty because individuals are an end in themselves and not instruments of society. One can
argue that the profession of medicine mandates looking beyond such individualism to a
moral code of altruism that affords physicians a unique position of responsibility, and
with it, respect. Dr. Edmund Pellegrino has asserted in an article for JAMA, "A medical
need in itself constitutes a moral claim on those equipped to help." (15)

International human rights instruments essentially provide a framework within which
medicine may more explicitly lay down expectations of its members.(1) Though
superficially theses guidelines exist, they must be emphasized throughout medical
training in order to establish that they are fundamental to the profession rather than
optional and only of secondary importance. This should not be taught as an afterthought,
on a cursory level whereby students sense its status as ‘second tier’, but as a consistent,
integral part of core professional attributes to which they are expected to adhere, no less
so than equally important standards of professionalism such as integrity and honesty
towards patients and colleagues. The vast majority of medical students adhere to and
more importantly believe that falsifying physical findings, lab values or research data is a
professional crime. This code of professionalism has been ingrained in them, mentored
over and over. In this vein human rights as it applies to medicine must be similarly
institutionalized.

Studies show mentors or consistent training increases the likelihood of adherence to
certain principles.(15,16,17) So why isn’t this emphasized? Attend a curriculum planning
meeting and one will see the struggle to encompass the entirety of necessary subjects a
future physician must be taught. Surely the concept of true altruism can be underscored in
each of these areas however. It would be blind to argue that it isn’t applicable in virtually
every realm of medical education. The problem is not in its applicability but in first, the
level of awareness of our mentors, and second in their willingness towards the
commitment of developing future physicians that believe these issues matter. How
difficult or time consuming would it be to discuss the mortal risk of childbirth that still
exists for millions of women during the reproductive organ block? Or, that millions of
people still die from measles each year when we teach the childhood immunization
schedule. Rather than educating about the gruesome oddities of parasitology, why not
instead focus on the devastating impact schistosomiasis and echinococcus have in the
developing world?

Why does it matter? It’s obvious. 46 million in our own country have no health care
coverage. Even more poignant is the mass suffering due to treatable disease in most of
the world. Can we as physicians sit back and enjoy immunity from such pain when we
have the tools to change it? We cannot sit by and declare treatment is not ‘cost-effective’,
’sustainable’ or ‘feasible’ when we speak of human lives and simultaneously adhere to
the morals of our profession. If as a profession we are doing more than paying lip service
to ending disparities in health, a necessary acknowledgment of the root causes of such
inequity is paramount. Given the present state of health care in our own country, let alone
the developing world, it behooves us to mentor future health care leaders that understand
the evidence based, fundamental causes of such disparity rather than leaving them
confused, defensive and impotent. This requires a dedication to do so on the part of
medical education regardless of social pressures to the contrary. Paul Farmer states, “It is
only if unnecessary sickness and premature death don’t matter that inegalitarian systems
can be considered efficacious.” (7) The moral and ethical codes of the medical profession and international human rights establish that these issues do matter. We must then do a better job of instilling these values. The ‘bottom line’ in medicine comes back to the individual physician. Each physician must be systematically trained in the morals the profession demands in order to establish a strong enough base upon which a health care system that acknowledges basic human rights may be built.

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