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Deep hope: A song without words

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Abstract Hope helps alleviate suffering. In the case of terminal illness, recent experience in palliative medicine has taught physicians that hope is durable and often thrives even in the face of imminent death. In this article, I examine the perspectives of philosophers, theologians, psychologists, clinicians, neuroscientists, and poets, and provide a series of observations, connections, and gestures about hope, particularly about what I call "deep hope." I end with some proposals about how such hope can be sustained and enhanced at the end of life. Studies of terminally ill patients have revealed clusters of personal and situational factors associated with enhancement or suppression of hope at the end of life. Interpersonal connectedness, attainable goals, spiritual beliefs and practices, personal attributes of determination, courage, and serenity, lightheartedness, uplifting memories, and affirmation of personal worth enhance hope, while uncontrollable pain and discomfort, abandonment and isolation, and devaluation of personhood suppress hope. I suggest that most of these factors can be modulated by good medical care, utilizing basic interpersonal techniques that demonstrate kindness, humanity, and respect.

Keywords Hope · Palliative care · End-of-life care · Physician-patient relationship

The great American humorist Mark Twain (Samuel Clemens) once quipped, "save us from old age, broken health, and a hope-tree that has lost its faculty of putting out blossoms" [1, p. 244]. Endowment with a "hope-tree" appears to be a natural human characteristic. The tree's blossoms energize our existence and enable us to cope with life-threatening crises, including serious and progressive illness. Since

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hope helps to alleviate suffering, physicians have long believed that instilling hope is an important feature of medical treatment [2]. In fact, when a person's hope-tree fails to blossom, as occurs, for example, in deep clinical depression, the situation may become life-threatening, even in the absence of so-called physical disease.

The Oxford English Dictionary's definition well captures our everyday use of the word: hope is the "expectation of something desired, a feeling of expectation and desire combined."[1] The basic elements seem incontrovertible: expectation, goal, desire, and feeling. Yet, it only takes a little probing to identify a number of questions. For example, can we hope for something that is improbable and we don't actually expect? Since setting goals is a cognitive process, how can we define hope exclusively in terms of feeling? Moreover, given the wide array of "somethings" that might be desired, is every act of hope equivalent, or are there different varieties or levels of hope?

This essay serves as a meditative exploration of themes and meanings associated with the word "hope" as it arises in the discourse of terminally ill patients and their caregivers. Rather than providing an analytical philosophical perspective, the essay sketches the contours of hope from the perspective of a clinician, triangulating among the experience of practice, the learned literature on hope, and the voices of the dying and their loved ones. As such, the ideas presented here are best understood not as closely argued theses but as a series of observations, connections, and gestures that may prove helpful to philosophers, theologians, and other scholars interested in the topic, and above all, to the clinicians and patients who grapple with the meaning of hope in the setting of terminal illness. I draw together the perspectives of philosophers, theologians, psychologists, clinicians, neuroscientists, and poets. These explorations lead me to suggest that there is a difference between the commonsense hoping-for-something-desired that is so much a part of our conscious everyday experience and the layer of hope that underlies this experience and may continue to exist, or even thrive, during a time when the patient has very few "somethings" left to hope for. I call the latter *deep hope*.

Medical beliefs about hope

The following two statements summarize traditional medical beliefs regarding hope in patient care. First, *hope is beneficial*. As Claudio observes in Shakespeare's *Measure for Measure*, "the miserable have no other medicine, but only hope" [3, act 3, scene 1]. Like Claudio, doctors have long considered hope as a universal balm. Patient welfare (or at least "do no harm") is the primary moral duty of physicians. This duty, firmly embedded in the ancient Hippocratic tradition, generally trumps other, competing moral values, like respect for self-determination or autonomy. Second, *hope is relatively fragile.* Disclosure to a patient that he or she has a terminal illness, especially with detailed information about prognosis, will diminish or destroy the patient's hope and, therefore, enhance suffering. Thus, the doctrine of informed consent, which requires disclosure of prognosis, options,

[1] Shorter Oxford English Dictionary, 1993 ed., s.v. "hope."

benefits, risks, and so forth, is subject to medical veto if the physician deems it to be in the patient's best interests ("therapeutic privilege"). Given hope's fragility, medical practice in the past usually involved manipulating the truth, or telling outright lies, about the patient's condition. Clinicians argued that candor with terminally ill patients was usually unethical because "the most disastrous results may follow a tactless warning" [4, p. 98]. The profession's narrative was full of stories about patients who lost hope and became depressed and suicidal upon learning their prognoses.

These attitudes toward truthfulness have changed radically during the last four or five decades. While 90% of oncologists surveyed in 1961 reported not disclosing cancer diagnoses to their patients [5], less than two decades later, 97% of physicians acknowledged that it was preferable to disclose a diagnosis of cancer [6]. There are many reasons for this reversal of belief, some of them external to medicine, such as changes in social mores and patient expectations [7]. We now know that most people do, in fact, want to know the extent and prognosis of their disease. Moreover, experience in palliative medicine has shown that most patients remain deeply hopeful, even in full awareness of impending death.

The development of palliative medicine as a medical specialty and the growth of hospice and palliative care services have generated a more scientific and humane approach to treating terminal illness [8, 9]. Palliative care clinicians have reframed the traditional medical approach to hope in light of two important realizations. First, the goals of therapeutic hope need not involve disease remission or cure, or even prolongation of life, but rather, they may include smaller, more focused objectives, like resolving a family conflict or going on a picnic with friends at a cherished location. Thomas Warr writes, "as active treatment fails, hope can take on another form. Hope that the remaining days of life will be happy ones, that tasks at the end of life can be addressed, relationships mended and finalized, and every moment treasured" [10, p. 34]. In other words, as one approaches death, hope may endure, but its goals may become more immediate and circumscribed. The physician's role, then, is to set goals to maintain hope [11].

In their article "Hope for the Best, and Prepare for the Worst," Anthony Beck, Robert Arnold, and Timothy Quill [12] outline a useful way of analyzing this situation. They argue that terminally ill patients may inhabit a state of "middle knowledge" that allows them to alternate very rapidly between planning for continued life and preparing for death [13]. This dynamic creates a fluid situation in which physicians can encourage agendas that appear contradictory: hoping for the best (gently supporting a milieu of hopefulness) and, at the same time, preparing for death (providing information, addressing fears, encouraging relationships).

The second realization of palliative care clinicians is that hope has a more complex and resilient quality than physicians previously believed. By accompanying terminally ill patients on their journey, palliative care clinicians have learned that hope usually bounces back after being struck down by bad news and disappointment, even after repeated disappointment. In fact, they have discovered a form of hope that underlies the tree's seasonal "blossoms" and endures—or even thrives—when seemingly few attainable objectives remain. In the remainder of this essay, I explore the basis and characteristics of this quality. First, however, it is

important to distinguish this *deep hope* from another, superficially similar, phenomenon that physicians refer to as *false hope*.

False hope

Palliative care physicians often use the term "false hope" in cases where a patient's treatment goals are so unrealistic that the embrace of those goals causes additional suffering for the patient and family. For example, a person suffering from terminal pancreatic cancer might choose to undergo repeated courses of aggressive chemotherapy that generate violent side effects, rather than accepting a palliative regimen that could minimize symptoms and maximize quality of life. Moreover, this patient's apparently hopeful perspective might also create severe psychological and financial stress for his family. Finally, the patient's demands might generate tension and anger among hospital or clinic personnel. While genuine hope is therapeutic, physicians argue, this sort of behavior exemplifies false hope that, they believe, is damaging. But what, precisely, is the distinction between genuine and false hope?

The most obvious criterion one might use is the probability of attaining the hoped-for goal, i.e., hope is false when the attainment of its goal is objectively far-fetched or even impossible. However, the word "false" is not synonymous with "inappropriate" or "unreasonable." If a patient genuinely hopes for a cure of his cancer, even though such an outcome is virtually unprecedented, it seems inaccurate to say that his hope is *false*. It would be far more accurate to call it unreasonable or neurotic. Take, for example, a person who buys a lottery ticket and hopes to win the grand prize of sixty million dollars. We might say her avowed hope of winning the money is unwarranted because the chance of winning is infinitesimal. However, I doubt that many would call the lottery player's hope false. Foolish, yes; false, no.

In reality, the distinguishing features of false hope relate more to the purported adverse effects created by the hope, than to the probability of its goal. The judgment that hope is "false" is based on an antecedent assessment of its harmfulness. Practitioners do not identify hope, however unrealistic, as false unless they believe it is somehow harmful—i.e., the hope-tree produces rotten fruit. In some cases the patient's behavior generates the harm, at least from the physician's perspective. For example, one physician expressed approval of a terminal leukemia patient's "endless hope," writing that the patient "had a tremendous amount of optimism… and he inspired the oncology team" [14, p. 2]. In this case, the physician visualized himself as an advocate for that person, whose narrative he considered noble and life-affirming. However, a different narrative may lead to a completely opposite assessment. When the patient is demanding and manipulative, the family is disruptive, and clinical interactions are fraught with tension and confrontation, "endless hope" might well be reinterpreted as a negative, rather than a positive, characteristic, i.e., false hope. In other cases, the physician's behavior might generate harmful false hope as a result of miscalculation, overly optimistic promises, and/or manipulation of prognostic or therapeutic information. In other words, clinicians themselves might be responsible for false hope through misguided or unskillful attempts to shield the patient from reality [15].

Thus, the pernicious aspect of false hope is not the mere fact of going for the long shot but, rather, the patient's seeming inability to cope with his situation. Beck, Arnold, and Quill's "hoping for the best, preparing for the worst" provides a practical framework for understanding this issue [12]. In this framework, optimal end-of-life care does not require scaling down hope itself. What's wrong with hoping for a miracle cure? Why not inspire yourself and others with endless hope? Rather, optimal care is impaired, and "falseness" arises, only when the patient does not also prepare for the more likely outcome, i.e., when hoping for the best is pursued to the exclusion of preparing for the worst. This exclusionary principle is nicely encapsulated in Benjamin Franklin's aphorism, "he who lives on hope will die fasting."

Deep hope

Poetic dimension: The song without words

Emily Dickinson, a poet whose life was full of shattered hopes, wrote several poems on the topic, of which one of the best known is "Hope" [16]:

> Hope is the thing with feathers
> That perches in the soul
> And sings the tune—without the words,
> And never stops at all,
>
> And sweetest in the gale is heard;
> And sore must be the storm
> That could abash the little bird
> That kept so many warm.
>
> I've heard it in the chilliest land,
> And on the strangest sea;
> Yet, never in extremity,
> it asked a crumb of me.

Dickinson's observations that hope has "kept so many warm" and seems "sweetest" during the worst of times coincide with traditional medical beliefs. But she also highlights hope's endurance: a bird that "perches in the soul" and continues singing despite the storms and extremities of life. Hope never asks for payment in return for its faithful service. Interestingly, the bird metaphor suggests an additional insight about hope: its sweet song is wordless, a melody without lyrics. What can this possibly mean? Is the Amherst poet implying that the cognitive content of hope (i.e., the object hoped for) is not essential? Indeed, she suggests that hope arises from a living interior source (the bird) whose natural outpouring (the melody) underlies whatever words we may later attach to it. This is analogous to Mark Twain's hope-tree and its recurring blossoms.

Clinicians, philosophers, and theologians have recognized that hope is deeper and more enduring than are its blossoms and songs. The existentialist philosopher

Gabriel Marcel distinguished between hope as expressed in the statement, "I hope that…," and the more profound utterance, "I hope," which need not have an object [17]. The former corresponds to the usual understanding of hope as having a specific goal, whether it be superficial ("I hope that it doesn't rain tomorrow") or profound ("I hope that the bone marrow transplant will cure my leukemia"). However, the latter statement is "a more general cosmic conviction affirming human life or being in general… hope about the meaningfulness and purpose of human existence" [15, p. 97].

Edmund Pellegrino and David Thomasma employ the term *transcendental hope* for Marcel's deeper utterance, and they relate it closely to religious, specifically Christian, belief [15, p. 64]. The theologian Paul Tillich captured the seeming paradox of hope without a necessary *that*-object in these words: "where there is genuine hope, there that for which we hope already has some presence. In some way, the hoped for is at the same time here and not here. It is not yet fulfilled, and it may remain unfulfilled. But it is here, in the situation and in ourselves, *as a power which drives those who hope into the future*" [18, p. 1065].

Viktor Frankl offers an immanent, as opposed to a transcendent, formulation of deep hope. In *Man's Search for Meaning*, he directly confronts the problem of suffering. We experience suffering when illness or catastrophe threatens the integrity of our world. We encounter our vulnerability to destruction and the negation of everything that is meaningful to us. Yet, Frankl claims that suffering also provides us with a profound opportunity to *discover meaning* in our lives. Thus, the destroyer of preconceived meaning can become a harbinger of new meaning. As he writes, "there are situations in which one is cut off from the opportunity to do one's work or enjoy one's life; but what never can be ruled out is the unavoidability of suffering. In accepting this challenge to suffer bravely, life has a meaning up to the last moment…" [19, p. 114]. Superficially, this may sound similar to the belief that suffering is beneficial because it helps make us better persons (mold character, etc.), but Frankl doesn't dress up suffering in that way. Rather, he calls attention to the *will to meaning*, which he considers the primary motivation in human life, in contradistinction to Freud's will to pleasure or Adler's will to power [19]. For Frankl, Thomasma and Pellegrino's *transcendent hope* might be recast as *having-agency-to-discover-meaning.*

The clinical literature includes numerous analyses of the distinction between hoping for a specific outcome and a deeper, more existential form of hope. Like Frankl, Judith Miller characterizes the deepest level of hope as the experience of finding meaning in loss or suffering [20]. Karin DuFault and Benita Martoocchio contrast *particularized hope*, which is related to specific desired objectives, to *generalized hope,* which is the "intangible inner experience of hope" [21]. In a longitudinal study of 30 dying patients, Kaye Herth defined deep hope as an "inner power directed toward enrichment of being" [22, p. 1250]. In a study of eleven palliative care patients in Sweden, Eva Benzein et al. [23] described them as experiencing continuous tension between the states of "hoping for something" and "living in hope."

Every one of these dichotomies appears to point in roughly the same direction, although different terminologies highlight different aspects of the comparison. The

first term, "I hope that…," "I hope for…," or particularized hope refers to the everyday sense of hoping for the fulfillment of a specific desire. The second term refers to what I call *deep hope*. Frankl, Miller, and Pellegrino and Thomasma conceptualize deep hope as the agency by virtue of which we discover or rediscover meaning in our lives, even in the face of radical loss. Tillich views deep hope as a "power" that drives us into the future, while Herth speaks of it as an enriching "inner power" and DuFault and Martoocchio as an "intangible" experience. Every one of these formulations imply durability or sustainability, which Benzein's "living in hope" makes explicit. In his phenomenological analysis, Anthony Steinbock [24] argues that one of the distinguishing characteristics of deep hope is its sustainability. He writes, "in hope, I have a future orientation. But when I hope, I do not 'expect' something…. In hope, the future orientation is qualified uniquely as an 'awaiting' (as Marcel might say), because the ground of hope encourages patience. I can 'await' in hope…" [24, p. 11]. Steinbock's convoluted language is a bit off-putting, but the notion I derive from his analysis is that the future-directedness of hope is inherent, and it neither requires a particularized object ("I hope for X") nor is extinguished when a given object becomes objectively unattainable ("I not longer expect X").

Back to Emily Dickinson's metaphor: if deep hope is the wordless song that sustains us through difficult times, what can we say about the bird that produces it? More prosaically, what are the psychological and biological bases of enduring hope?

Psychological dimension

Some psychologists view hope as fundamentally a cognitive process, while others believe it is best considered an emotional phenomenon. C. Richard Snyder, the leading cognitive theorist, considers hope to be a characteristic way of *thinking*. He defines it as "a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal directed energy) and (b) pathways (planning to meet goals)" [25, p. 250]. According to this formulation, the primary features are cognitive rather than affective. Hopeful thinking requires both identified goals and conscious awareness of a method (i.e., pathways) of achieving those goals. People who lack hope do so "because they were not taught to think in this manner, or forces intervened to destroy such hopeful thought during their childhoods" [25, p. 253]. Alternatively, the more a person has learned to think about the future in terms of agency and pathways, the better he is at hoping. Thinking, not emotion, generates the "positive motivational state." According to this theory, emotions are reactive, reflecting the person's response "to perceptions about how one is doing (or has done) in goal pursuit activities" [25, p. 252]. The more successful one is in achieving his hoped-for goal, the happier he feels, and vice versa.

Other writers argue that hope is primarily affective rather than cognitive [26]. From their perspective, hope as an emotional trait antedates the construction of a cognitive framework around achieving a particular goal. The fact that people can strongly hope for an outcome even in the absence of identifying realistic pathways or creating reasonable plans to achieve that outcome tends to support the primacy of the emotional realm. While cognitive theorists may label this situation as having

false hope, there are (as noted above) numerous cases where hopefulness for an unlikely outcome may be considered natural or beneficial, rather than harmful, as the term false hope implies.

The emotion versus cognition debate reflects, in part, the traditional belief that thinking and feeling are completely different mental functions. Functional neuroimaging studies lend some support to this belief, although neural networks are far too complex to be reduced to such a dichotomy. At this point in our understanding, it seems most plausible to conclude with Richard Davidson, director of the Laboratory for Affective Neuroscience at the University of Wisconsin, who explained in an interview with Jerome Groopman, "I understand hope as an emotion made up of two parts: a cognitive part and an affective part…. Hope also involves what I would call affective forecasting—that is, the comforting, energizing feeling that you experience when you project in your mind a positive future" [2, p. 193]. Even Snyder acknowledges that "emotional sets influence dispositional hope levels," e.g., a high-hope person would have "a sense of affective zest about the pursuit of goals," while a low-hope person may have their motivation blocked by negative emotions. He concludes that "emotions shape and inform the cognition of the person in the throes of goal attainment" [25, p. 254]. Given all this, it seems arbitrary to stipulate that the *core* of hope is cognitive or that pathways thinking is essential. Would not it be more accurate to say that hope is a complex mental quality or trait that involves interaction among affective, cognitive, and motivational pathways?

Psychologists have also studied the relationship of hope to life meaning, which Feldman and Snyder define as "a global way of assessing or understanding one's life." A higher level of such meaningfulness "is associated with lower levels of negative emotions (especially anxiety and depression) and lower risk of mental illness" [27, p. 402]. Based on their empirical studies, as well as various psychological theories, these authors conclude that hope is an important component of life meaning. Other investigators have reached similar conclusions [28–30]. One group has proposed a multidimensional model of hope based on factor analysis of empirical data [28]. Life meaning is integral to this model, which also includes interpersonal factors that can be utilized by clinicians to enhance their patients' hope (see below).

The term "trait" suggests a relatively stable and enduring mental quality. While hope may be characteristic of the human condition ("hope springs eternal"), its penetrance or strength clearly varies along a continuum based on innate neurological and developmental factors. The view that hope is a psychological trait raises the question of its relationship to personality and, in particular, to optimism.

A common definition of optimism is the inclination to put a favorable construction on actions and events or to anticipate a good outcome in any situation [31]; it is considered to be the generalized expectancy that the future will be positive. While psychologists tend to agree that optimism differs from hope, its distinguishing characteristics vary somewhat among theorists. For Snyder, whose cognitive theory of hope requires a person to conceptualize how he or she might achieve desired goals (i.e., pathways thinking), optimism is the tendency to believe

that everything will turn out well, even though one does not have a specific idea of how to pursue and accomplish the goals [32]. Others argue that hope is directed primarily toward goals with important personal resonance, while optimism covers a much broader range of outcomes [33]. A similar, but more textured, position holds that optimism appraises the expected quality of future outcomes in general and the cognitive features of personal outcomes, whereas hope focuses more directly on "the personal attainment of specific goals or dispositional beliefs about personal capabilities" [34]. I believe this means, in plain English, that hope selects outcomes that are especially important to us, while optimism gives us a general perspective on the future.

Nonetheless, a number of studies have shown that people who score highly on optimism scales tend to have better health outcomes. For example, in the Women's Health Initiative, those who scored highly for optimism on the Life Orientation Test experienced fewer new cases of coronary heart disease and lower total mortality than their more pessimistic peers [35]. Other studies demonstrate that optimists are more likely to adopt healthy lifestyles [36] and less likely to suffer from depressive symptoms [37], and are less likely to have progression of carotid atherosclerosis [38] than their less optimistic peers. Thus, although optimism is not identical to hope, it appears to be a beneficial attribute in itself. It also stands to reason that the more optimistic (general worldview) a person is, the more disposed he is to experience hope (specific personal goals).

Another important distinction is that between hope and *expectation*. While hope may have little or no relationship to probability, one usually reserves the statement "I expect…" for outcomes that one has reason to believe are likely to occur. However, one can still expect something when one's reasons for doing so are mistaken. For example, I may have *hoped* that someday my wealthy uncle, who has been estranged from me for decades, might nonetheless leave me a large inheritance. After I reconciled with my uncle, and he told me that I would receive his fortune, I then *expected* the inheritance. Unfortunately, he dies and leaves his entire estate to the Audubon Society. My expectation of an inheritance was valid and reasonable (based on available evidence), but incorrect.

In this case, in addition to saying, "I didn't get what I expected," would it not also be correct to say, "my hopes were dashed"? Or did my expectation of an inheritance replace my hoping for one at the moment my uncle made his promise? Expectation relies on an assessment of the outcome's likelihood. Hope, as has been shown, is more complex, involving affective as well as cognitive elements, with personal meaning and emotional investment as important features. The world is a risky place. The most secure plans may suddenly unravel, or the improbable event may happen. For example, there was always the chance that I might die before my uncle, that he would marry his beautiful young secretary, or that he had simply lied to me (as he did). It seems unreasonable, then, to claim that just because I had reason to expect the inheritance, I no longer hope for it. In fact, I continued to be hopeful. One can continue to hope for an expected outcome, as long as a subjective element of risk remains, which is generally the case. I suspect that the more personally meaningful an objective is, the higher the level of certainty needed before expectation entirely replaces hope. Perhaps our tendency to think of hope

only in relationship to unlikely outcomes arises from the prominent role of hope in progressive or terminal illness where cure is improbable.

It is, of course, also possible to expect or anticipate negative outcomes that one strongly hopes will not happen. For example, I may expect to be fired next week because my company is laying off 25% of its workforce and I am the most recently hired employee, but, of course, I do not hope to be fired. In fact, I hope for quite the opposite.

In general, there are at least three important differences between hope and expectation. First, no matter what level of probability one sets as a threshold for being able to say, "I expect this to happen," it is possible to hope for an outcome that is far less probable. Second, expectation can have a positive, neutral, or negative emotional valence; hope is always positive. Finally, expectation, which relates to any probable event, has a far different "feel" from hope, which requires personal investment, in addition to (or even in spite of) probability appraisal.

Biological dimension

Alexander Pope's "hope springs eternal from the human breast" is clearly an overstatement, but, like Emily Dickinson's bird and Mark Twain's hope-tree, his vision of an eternal spring—or perhaps catapult—conveys well the concept that hope is a characteristic and enduring human quality [39]. However, the poet's anatomy is quite mistaken. Hope, in fact, springs from the human brain.

In the last decade or so, remarkable progress has been made in identifying the neurological correlates of human qualities that were once solely the province of theology, philosophy, and, more recently, psychology. Advancements in neuroscience, especially functional neuroimaging, like positron emission tomography (PET) and functional magnetic resonance scanning (fMRI), combined with the development of sophisticated attribute-associated mental tasks, have permitted scientists to explore the neurobiology of the placebo effect, empathy, altruism, compassion, spirituality, and wisdom [40–48]. While remarkable, these studies remain in their infancy. A preliminary understanding of neural patterns and networks has emerged, but the most strikingly consistent finding has been the brain's extraordinary complexity and plasticity.

In his popular book on the power of hope, Groopman devotes a chapter to its biology and neuroanatomy [2]. He bases the discussion on an analogy between hope and expectation, arguing that expectation of a desired outcome plays a major role in the placebo response, and, since the functional biology of the placebo effect has been extensively investigated [43–45, 49–52], clues to the biology of hope may be found in our limited understanding of placebo healing. However, while this may well be true, it is important to acknowledge, first, the distinction between expectation and hope, as outlined in previous paragraphs, and, second, the likelihood that conscious expectation is not the sole factor in generating placebo responses. Nonetheless, I agree that some aspects of placebo biology may provide a useful starting point.

Unfortunately, the terms "placebo" and "placebo effect" often evoke an ambivalent response among clinicians. While practitioners are well aware that

patients can and often do experience significant and sometimes dramatic symptomatic improvement as a result of non-specific factors in treatment (e.g., setting, beliefs, clinician-patient interactions), many physicians have difficulty incorporating such observations into their belief systems, which tend to hold that mental phenomena have no great influence on "real" physical disease. Thus, these physicians are inclined to minimize the importance of placebo-induced relief and to suggest, when it does occur, that the original symptoms were questionable or exaggerated.

I will not attempt to summarize here the extensive evidence demonstrating the ubiquity and power of the placebo effect in research and clinical medicine [43–45, 49–55].[2] However, four features of placebo studies are of particular interest. First, the severity of underlying symptoms appears to be positively correlated with the magnitude of the placebo effect. Thus, in studies of pain, as well as in conditions like depression and Parkinson's disease, the more severe the symptom, the more likely that patients will experience placebo relief and the more substantial that relief will be [58]. In other words, patients experiencing severe pain are more likely to report significant analgesia (e.g., decrease from a 9 to a 4 on a 10 point pain scale) than are patients experiencing only modest pain (e.g., decrease from a 4 to a 2 on the 10 point scale). The second interesting feature is that the more dramatic the placebo intervention, the more potent its effect. For example, a sham acupuncture device, which involves mechanical manipulation that appears similar to actual acupuncture, is a more effective symptom reliever than less dramatic forms of placebo, like oral tablets [59].

Third, placebo responses are probably additive. For example, in one study of patients with irritable bowel syndrome, there were three groups of subjects: one group received no treatment, one was treated with a sham acupuncture device (pure placebo), and the third received both sham acupuncture treatment and a supportive clinician-patient relationship (placebo-plus). After 3 weeks, 28, 44, and 62% ($p < 0.001$) of the groups, respectively, experienced adequate relief on a standard symptom scale [52]. This, and other studies, suggests that the total therapeutic placebo effect in clinical situations results from multiple inputs, e.g., setting, communication style, empathy, and trust, as well as "pure placebo, that influence the patient's overall expectancy."[3]

The fourth point about placebo response actually relates to its opposite, the nocebo effect. Negative expectations about treatment may result in worsening of symptoms and/or new symptoms [51]. This nocebo effect appears to be the mirror image of a placebo effect, although for ethical reasons the biology of the nocebo effect has not been systematically investigated [51]. Clinical experience suggests that interactional and environmental factors may also promote nocebo responses, e.g., poor communication, distrust, dissatisfaction, and previous negative experiences or bad outcomes.

[2] Meta-analyses by Asjborn Hrobjartsson and Peter Gotzsche question the overall clinical importance of the placebo effect [56, 57]. Miller et al. respond to these claims based on additional information provided by Hrobjartsson and Gotzsche [53].

[3] Classical conditioning may also play a role in placebo responses, but the extent of its effect and its relationship to conscious expectancy are unknown.

Functional neuroimaging studies of the placebo analgesic effect consistently demonstrate activation of the anterior cingulate cortex (ACC), although a number of other neural centers (e.g., orbitofrontal cortex, anterior insula, medial prefrontal cortex, ventrolateral prefrontal cortex, and periacquaductal gray matter) are also activated in various studies using either PET or fMRI imaging [43, 44, 49–52]. In terms of neurochemistry, the μ-opioid system is involved in pain reduction; dopamine probably mediates symptom relief in neurological disorders like Parkinson's disease; and cholecystokinin appears to diminish or inhibit placebo responses [50–52, 60].

Given the ambiguous connotations of placebo, some investigators have proposed replacing the term with a more descriptive (and less emotionally laden) name. Moerman suggests *meaning response*, a label that highlights the centrality of interpretation and expectation in this form of healing [61]. Moermann argues that context has meaning for the patient who understands the elements of the situation—persons, items, practices—to constitute a healing process. Physiological alterations result from the meaning the patient attributes to the event and her expectation of symptomatic relief. The concept of placebo effect as meaning response is consistent with deep hope's relationship to the meaning of one's life [19, 20, 27, 28].

Alternatively, Franklin Miller, Luana Colluca, and Ted Kaptchuk offer the term *interpersonal healing*, which they define as "a generic name for the various direct causal pathways from clinician-patient interaction to therapeutic outcomes relating predominantly to symptomatic relief and coping with illness" [53, p. 529]. They distinguish interpersonal healing from technological healing, i.e., response to specific therapy, and natural healing, i.e., resolution as a result of the expected course of the disease. Their definition highlights the fact that placebo responses normally result from human interactions (past and present). It also frames the possibility that clinicians can actively mobilize placebo healing in their relationship with patients. Finally, the definition, with its clause about symptom relief, acknowledges that interpersonal healing is most often experiential—decreased symptoms and improved coping skills—rather than an alteration of underlying disease processes.

Both *meaning response* and *interpersonal healing* have the advantage of more closely linking the phenomenon they describe to clinical methods of enhancing hope, as discussed in the next section. Consequently, as Groopman suggests, the neurophysiologic basis of hope's influence on health may lie in placebo or related mechanisms [2]. Moreover, the fact that the affective-cognitive experience of hope may be associated with these natural self-healing pathways supports both the "normality" and persistence of human hope.

Nurturing deep hope

Physicians and other clinicians who treat seriously ill patients aim to relieve suffering by (1) curative or remissive measures, i.e., directed toward curing or diminishing the disease process, and (2) palliative measures, i.e., directed toward relieving symptoms and enhancing quality of life. Yet suffering may, and often

does, elude these medically-oriented approaches because they often fail to address the existential core of suffering. Physicians have long recognized the role of hope in relieving suffering and considered it their duty to instill hope and, in particular, to avoid diminishing it. To quote from the original Code of Ethics of the American Medical Association (1847):

> For, the physician should be the minister of hope and comfort to the sick; that, by such cordials to the drooping spirit, he may smooth the bed of death, revive expiring life, and counteract the depressing influence of those maladies which often disturb the tranquility of the most resigned, in their last moments. The life of a sick person can be shortened not only by the acts, but also by the words or the manner of a physician [62, art. 1, sec. 4].[4]

In that document and, until recently, in practice, a major component of the medical approach to hope has been to withhold prognostic information and, when necessary, to tell lies. These practices were based on the belief that the deep hopefulness that alleviates suffering necessarily entails the goal of being cured. Therefore, awareness that one will certainly die within a short time seemed inconsistent with genuine hope. However, hope is more flexible and resilient than it was thought to be. More recently, palliative care physicians have adopted the practices of (1) "setting goals to maintain hope," which encourages the patient to substitute discrete, immediate, and achievable goals for more global, remote, and unrealistic goals and (2) "hoping for the best, but preparing for the worst," which encourages the patient to set his house in order and prepare for dying while, at the same time, maintaining a sense of hopefulness. These approaches, which can and should be synergistic, facilitate deep hope while maintaining the patient's dignity and respecting her self-determination.

Several investigators have explored the personal and situational factors associated with higher or lower levels of deep hope. Herth, who defined deep hope as an "inner power directed toward enrichment of being," conducted a longitudinal study of the hoping trajectory in 30 terminally ill patients [22]. She identified seven "hope-enhancing" strategies or characteristics: meaningful shared relationships with other persons (interpersonal connectedness); attainable intermediate goals; spiritual beliefs and practices; personal attributes of determination, courage, and serenity; lightheartedness; recollection of positive events or moments; and a sense of one's individuality being affirmed [22, p. 1254]. As the patients moved closer to dying, several of these characteristics appeared no longer to be significant, but interpersonal connectedness, having a spiritual base, and setting attainable goals continued to be highly associated with hope. Herth also identified three "hope-hindering" characteristics in patients: uncontrollable pain and discomfort; abandonment and isolation; and devaluation of personhood, i.e., being treated as a nonperson of little value [22, p. 1256].

In a later study of 32 oncology patients, Post-White et al. observed similar clusters of hope-enhancing and hope-hindering features. Among hope-enhancing

[4] It should be noted that the American Medical Association borrowed this quotation virtually intact from Thomas Percival's *Medical Ethics*, which was first published in 1803 [63].

strategies, they discovered finding meaning in life, affirming relationships, and "living in the present." [64]. Benzein et al. found that cancer patients' hope was positively correlated with good nurse-patient relationships [23]. Herth also studied two groups of geriatric patients, one group living in institutions and the other in community settings [65]. Several hope-enhancing features among these patients were similar to those found among terminally ill patients (interpersonal connectedness, spiritual beliefs and practices, lightheartedness, uplifting memories, and attainable intermediate goals), but aside from uncontrolled pain and discomfort, hope-hindering factors were different: experiencing hopelessness in others, depleted energy, and impaired cognition [65, 66].

These studies are, of course, only suggestive, and the observed correlations do not necessarily imply causal relationships. However, it is striking that a substantial number of the situational factors can be influenced, either positively or negatively, by the behavior of physicians and other health care professionals. Obviously, appropriate medical treatment can control pain and other uncomfortable symptoms and, therefore, eliminate one hindrance to hope. Similarly, non-abandonment and respect are important features of good palliative care, which completely rejects the mind-set of "there is nothing more I can do," an attitude frequently adopted by contemporary physicians.

In terms of active hope enhancing measures, I have already mentioned the suggestion of realistic, attainable goals. Clinicians can also use the therapeutic relationship to affirm personal worth, foster a sense of connectedness with others, encourage uplifting memories, and, where appropriate, facilitate lightheartedness. One example of a therapeutic regimen that employs these components in a systematic way to enhance patients' hope and sense of dignity is that described by Chochinov and his colleagues [67, 68]. This includes structured clinician-patient interactions that encourage patients to speak about their personhood, values, relationships, accomplishments, and the meaning and purpose of their lives. Beyond specific "dignity-conserving therapy," hope-enhancing care features kindness, humanity, and respect, which, after all, are, or should be, basic components of all medical care [69]. These factors, in the aggregate, make it clear that fostering deep hope is a realistic therapeutic goal in palliative medicine.

Deep hope is often associated with religious belief. Certainly, several of the identified hope-enhancing factors (spiritual practices, finding meaning in life, and affirmation of personal worth) may stem from a core trust or faith in the goodness of being. Likewise, the sense of interpersonal oneness or connectedness may be another way of speaking about love. These values are traditionally articulated in all institutional religions, albeit reflected through the prism of differing beliefs and practices. The deep personal experiences of meaning, affirmation, connectedness—and hope—seem more reflective of a mystical tradition that underlies and cuts across specific institutional religions [70].[5] For this reason deep hope at the end of life may in part be related to generic mystical experience, accessible to believers and nonbelievers alike, rather than to religious belief as such.

[5] This is not a claim that all mystical traditions are the same but merely that mystical experience appears to share many characteristics across religions.

Summary and conclusion

Hope is a universal balm that serves to alleviate the suffering of illness and injury. In the case of terminal illness, physicians have traditionally considered it their duty to maintain their patients' hope by withholding or manipulating information, on the belief that hope is fragile, and complete disclosure could be disastrous for the patient. Experience in palliative medicine has taught us that, in fact, hope is durable and often thrives even in the face of imminent death. Palliative medicine has developed new therapeutic strategies, like (a) setting concrete, achievable hope-goals for the patient, and (b) helping the patient make practical preparations for her imminent death while, at the same time, encouraging a deeper, more generalized form of hope.

Deep hope has long been recognized by poets, clinicians, philosophers, and theologians. This quality is the agency by virtue of which we discover or rediscover meaning in our lives, even in the face of radical loss. It is experienced as a durable inner power that enriches our being and motivates us into the future. Psychologists debate whether hope is primarily cognitive or affective in nature, but there is wide agreement that hope is a natural human trait, the individual profile of which is determined by genetic and environmental factors. Hope differs from, although it may be related to, optimism and expectation. Expectation, in particular, may suggest the beginnings of a neurophysiologic model for hope, since expectation plays a major role in the placebo effect, the biology of which has been extensively studied.

Studies of terminally ill patients have demonstrated clusters of personal and situational factors associated with enhancement or suppression of hope at the end of life. Enhancing factors included interpersonal connectedness, attainable goals, spiritual beliefs and practices, personal attributes of determination, courage, and serenity, lightheartedness, uplifting memories, and affirmation of personal worth. Suppressive factors included uncontrollable pain and discomfort, abandonment and isolation, and devaluation of personhood. Most of these factors can be modulated by good palliative care, utilizing basic interpersonal techniques that demonstrate kindness, humanity, and respect.

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