

Hope and the Prospects of Healing at the End of Life

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ABSTRACT

Is healing possible at the end of life? Answering “yes,” this paper argues that the achievement of holistically conceived health-related goals that patients value is an important dimension of the phenomena of healing and that such achievements are possible at the end of life, especially if hope is adroitly managed. Conceiving of hope: (1) as a set of goal-directed cognitive processes that influence and are influenced by emotion, (2) as a potent cognitive/affective heuristic that influences how individuals consider and select goals, and (3) as an individual experience that occurs in a hierarchical social and cultural ecology of hope, this paper considers possible interventions and how they might be evaluated, seeking to improve the prospects of healing at the end of life.

INTRODUCTION

Three (3) PM Thursday. In a private conference room adjacent to the pediatric hospital ward, we are assembling. Everyone seems separate from everyone else, with only furtive glances and terse phrases exchanged as we sit down around a table. Across from me sit the parents of a 4-month-old infant, who after 2 months in the hospital with worsening failure to thrive, was finally diagnosed just a week ago with a rare lethal metabolic disorder. Around the parents are gathered the grandparents and other family members, the primary nurse, and the primary attending and resident physicians. As the palliative care consultant physician, I am to lead the meeting along with the palliative care nurse who accompanies me. The mood in the room is gloomy, irritable, depressed. The primary medical team had requested our palliative care service’s help because they felt “stuck”; none of their efforts to improve the child’s state of health were working; all forward progress had stalled. Likewise, the parents had no idea of what to do next; the terrible news of the diagnosis had destroyed the future.

After soliciting introductions from all the participants, I briefly review my understanding of the sad predicament and

confirm it with those gathered: that their beautiful baby has a medical condition that will cause him to die in the coming weeks, that no therapy exists that would slow down his inexorable deterioration, and that despite the grief in our hearts we had to figure out what to do next, seeking what was best for him. Looking around, everyone concurs. Then, addressing the parents, I ask: *In order to figure out how to help you to help your son, I need to know—given the bad news of his diagnosis—what are you hoping for now?*

Softly came the first reply from the mother: *We hope for a miracle, of course.* Then a long pause, the atmosphere of the room full with desire and suppressed tears, as other hopes condense and start to precipitate. *But we are realistic,* the mom continues, *and it doesn’t look like any miracle is going to happen. So we want to go home. We want our son to not suffer through any more medical tests. We want him to be as comfortable as possible. That’s what we’re hoping for.*

The father nods in agreement, as do others. The medical team says, essentially, we can help some of these things happen. A plan is devised to leave the hospital the next day. The meeting ends. Although one would never describe the mood as cheerful, an energy and purposefulness has

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emerged as everyone moves in an upbeat manner toward the attainment of these newly articulated hopes.

A mystery in need of a theory

What happened? How can we understand the occurrence of such clinical events, wherein a certain transformation seems to occur? Many explanations can be offered—and many should be considered carefully, given the import of such occurrences. Let us, on the basis of clinical experience and the synthesis of various lines of research into how people make decisions, propose the following thesis:

The explicit and skillful management of hope in the process of medical decision making can facilitate a transformation in how individuals think and feel about their situation, which consequently has a direct impact on the decisions that they make and their subsequent experiences, including the experience of healing at the end of life.

Before proceeding to develop this thesis, we need to define the seemingly well-worn concepts of end of life, healing, and hope, specifically in terms of goal-directed thinking and behavior.

The *end of life* is a period of life when a person's health status imposes marked constraints on the set of feasible goals. These constraints may be temporal (due to limited time left to accomplish goals) or functional (due to diminished capacity to perform tasks or have certain kinds of experiences). Because of the restrictions imposed by these constraints, the end of life is a period when human beings often must define or confront their ultimate goals of living—literally, the “ends” of life become paramount at the end of life. When confronting a grave health problem (see Fig. 1), an individual must prioritize their goals, with a general distinction between goals that seek to maximize the quantity of one's life versus those goals that aim to maximize the

quality of one's life. To understand how people approach this decision—namely, which goals to prioritize—is precisely a core task of the theory we are developing.

Healing has been defined as “those physical, mental, social, and spiritual processes of recovery, repair, renewal, and transformation that increase wholeness and often (though not invariably) order and coherence.”¹ Viewed from within the context of the end of life and the paramount importance of goals, though, we might want our definition to emphasize a cardinal characteristics of healing—namely, the “conscious development of intention, awareness, expectation, and belief in improvement and well-being.”² This focus suggests that we offer this alternative definition that *human healing represents the attainment of a holistically conceived health-related goal*. This goal may target one of the general notions of wholeness, order, and coherence cited in the first definition, or more likely may approach these notions through goals that are far more particular, individualized, and even idiosyncratic. In this way, viewing healing as the attainment of a holistically conceived, health-related goal—be it the diminishment of physical or psychic pain, the acquisition of a sense of peace, or the repair of a cherished relationship—enables the prospect of healing to move quite confidently into the realm of end-of-life care.

The last of our key terms, *hope*, is coated with a rich patina of associations and connotations, ensconced deep within the mythos of Western culture from the Greek fable of Pandora's jar though to the present allure of the City of Hope medical center and other signs that hope is valorized through our society. Consequently, no single definition can suffice to convey the plethora of meanings of hope.

One psychologically grounded definition of hope, though, seems particularly useful in the end-of-life care setting. As proposed by Snyder,^{3,4} *individuals experience hope when they have an expectation that a desired goal can be achieved*. His definition of hope focuses on three key components, namely: (1) goals, which provide the mental and motivational targets that people aim to achieve, conceived

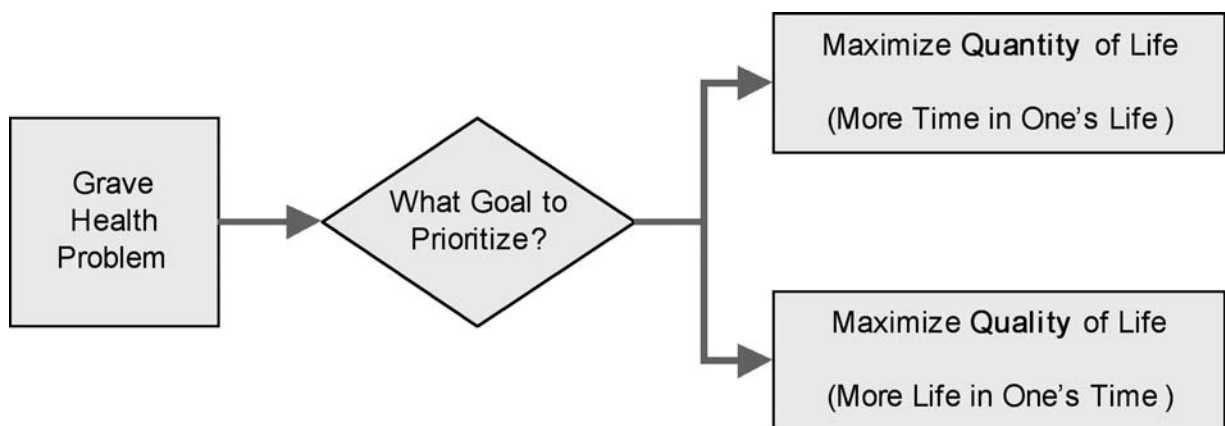


FIG. 1. Key decisions in end-of-life care.

either as the attainment of an outcome (e.g., “my goal is to be peaceful”) or the prevention of an outcome (e.g., “my goal is to not suffer pain”); (2) a person’s strategic or tactical thoughts about what actions need to be done in order to achieve the goal (so-called “pathway thoughts”), and (3) that person’s energizing thoughts about whether she or he can actually perform those actions successfully (“agency thoughts”).

Snyder’s conceptualization of hope (Fig. 2) is dynamic. When confronting a new decision, individuals do so outfitted with the pathway and agency thoughts they have acquired from childhood onward. This base set of pathway and agency thoughts for a given individual interact with that individual’s emotional base state; people who have high levels of pathway and agency thoughts tend to feel happier, friendlier, and more confident than people with low levels of these thoughts; and in reverse, these feelings promote and potentiate the generation of more robust pathway and agency thoughts. Thus equipped when facing a decision, individuals first consider what outcome or goal they value enough to pursue. Once they have selected a goal (or set of goals), they then start a sequence of thinking-feeling-doing, assessing by a series of feedback loops how well a particular decision and its goal-directed behavior is proceeding both in terms of the necessary actions (pathway) and in terms of

the requisite sense that one can complete the job (agency). This model of hope—with the three phases noted above (prior learning, deciding what goal to pursue, and assessment of how things are going), the concepts of pathway and agency thoughts, and the reciprocal relationship between thoughts and feelings—provides several potential points of intervention to enhance hope, as we will see later.

Theoretical model relating hope to healing via decisions

How might hope (as we have defined it) influence healing? We can postulate that modulations of hope can affect healing through *both direct and indirect mechanisms*. Directly, hope is *ipso facto* a state desired by most individuals: We want to be hopeful. To the degree that any intervention increases a patient’s experience of hope, that intervention has accomplished one potential act of healing. An increase in hope or hopefulness may also directly decrease stress or cause other salubrious side-effects that are themselves either signs of healing or that directly facilitate healing. More indirectly, the content and quality of one’s hope may influence healing by markedly affecting decisionmaking: Specifically, let us hypothesize that more robust hope may improve the timing and quality of medical

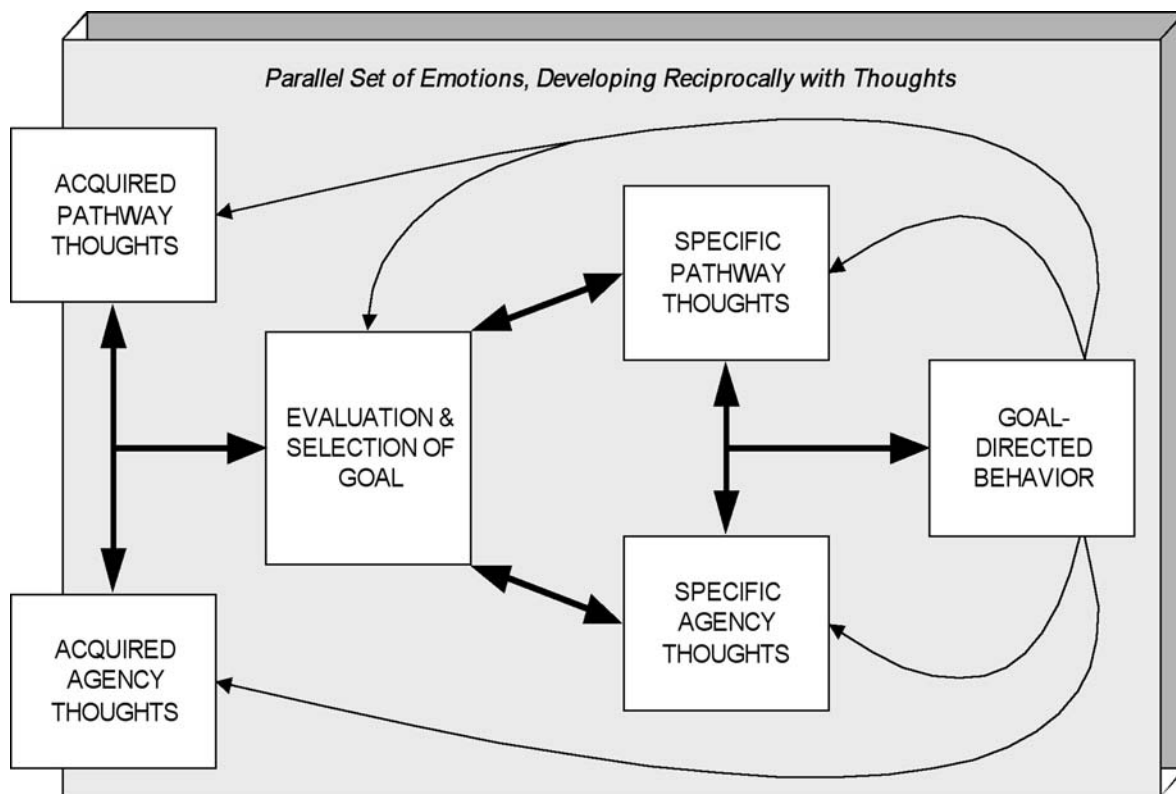


FIG. 2. A psychologically grounded dynamic model of hope. Adapted from Snyder CR, refs 3 and 4. Compared to Snyder’s specification in his model of thoughts in large part shaping emotion, this model views the development of cognitive and affective responses as more nearly equal and reciprocal throughout.

decisions and the effectiveness of subsequent actions based on those decisions.

This theory is built from a basic set of premises about how thoughts and feelings influence the manner in which we formulate goals, consider different options, make a decision, and then enact the decision as a sequence of actions (Fig. 3). The *first* premise is that both thoughts and feelings influence our decision-making processes, for better or for worse, through both explicit awareness and also the far more implicit operation of cognitive and affective decision making heuristics or shortcuts.^{5,6} The *second* premise is that the typical analysis of decision making focuses too exclusively on the role of thoughts, and so consequently standard approaches to decision making (such as informed consent) provide inadequate guidance regarding how to manage the affective aspects of decision making, and, in particular, the influence of affective heuristics (which cause us, often unwittingly, to be attracted to certain goals or options, and repulsed by others). The *third* premise is that phenomena such as hope (but also including states such as guilt and some forms of anger) combine thoughts and feelings together in an inexorable package of experience that serve as *cognitive/affective heuristics*, powerfully influencing what goals are deemed acceptable (or, in the negative direction, repugnant, anathema, or taboo), what options can be tolerably examined, and thus what decisions can be constructed based on the goals and options that passed the screening of the cognitive/affective heuristic of hope. The *fourth* and final premise is that a person's behavior subsequent to having made the decision (such as adherence to a treatment plan) is vitally influenced by the ongoing legacy of how thoughts and feelings were (or were not) wisely integrated into the decision.

The ecology of hope

Hope does not occur in social isolation or in a cultural vacuum. Pediatric patients in particular are typically located

in a *social network of relationships* that is extremely relevant to how goals are formulated and hope is cast (Fig. 4). A child and the parental adults constitute the most intimate level of this network, but the hope of these individuals will be influenced substantially by the conduct of physicians, nurses, pastoral care workers, and other members of the family, community, or health care staff. Even the policies and decisions of third-party payers, the precedents of legal decisions, or the belief and values of a culture and its ethics will influence, via this social network, the hope of patients and families.

This network of social influences on hope, concatenating outward from an intimate to a macro level, suggests that the individual experience of hope can be situated—and perhaps best understood—within an encompassing *ecology of hope* (Fig. 5). This ecology exists in a hierarchy of levels. Let us here consider six possible layers. Patients and family members, who exist as individuals at *level 1*, exert a strong influence on each other, specifically the cognitive and affective mechanics of how they hope, at *level 2* of the family unit. At *level 3* in this ecology, the family unit is influenced by a physician (or nurse, child life specialists, social worker, or pastoral care worker), who thus links families together by encouraging that hope in the context of illness be addressed in a particular way. In the setting of hospital care, these multifamily/health-care-provider units aggregate into *level 4* of the ecology, cohabitating on particular wards of the hospital. At this level, shared features of the physical environment—how cheerful or gloomy it is, how much it is dominated by technology versus having a more domestic feeling, how much privacy it affords, and how much respect for patients' personhood it conveys—will potentially influence all individuals operating within this niche of the ecology of hope. Furthermore, shared features of how decisions tend to be made in this context—how to process information and handle its effect—will likewise influence an individual's experience of hope (and promote adaptive or maladaptive decision making⁷). These hospital wards (or, with a different scheme of

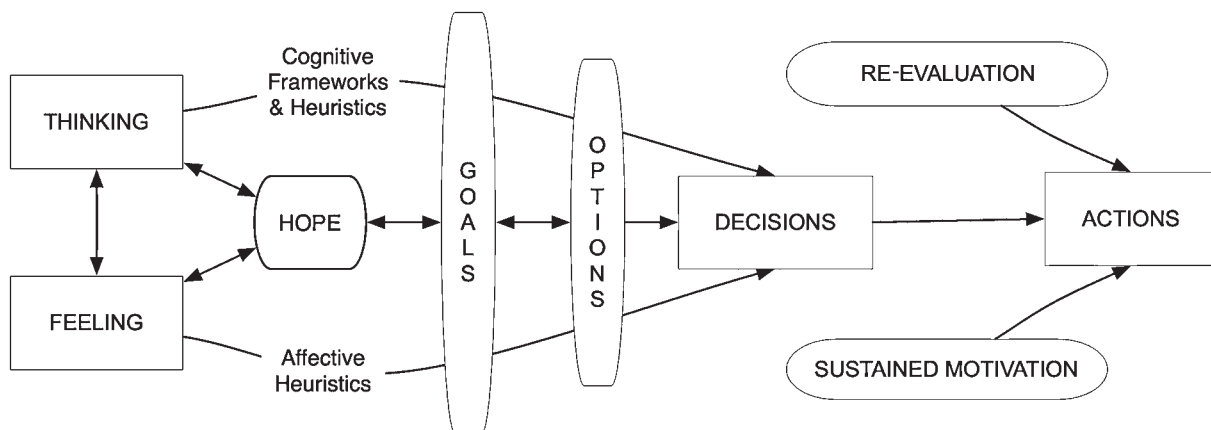


FIG. 3. A model relating hope as a cognitive/affective heuristic to decisions and behavior.

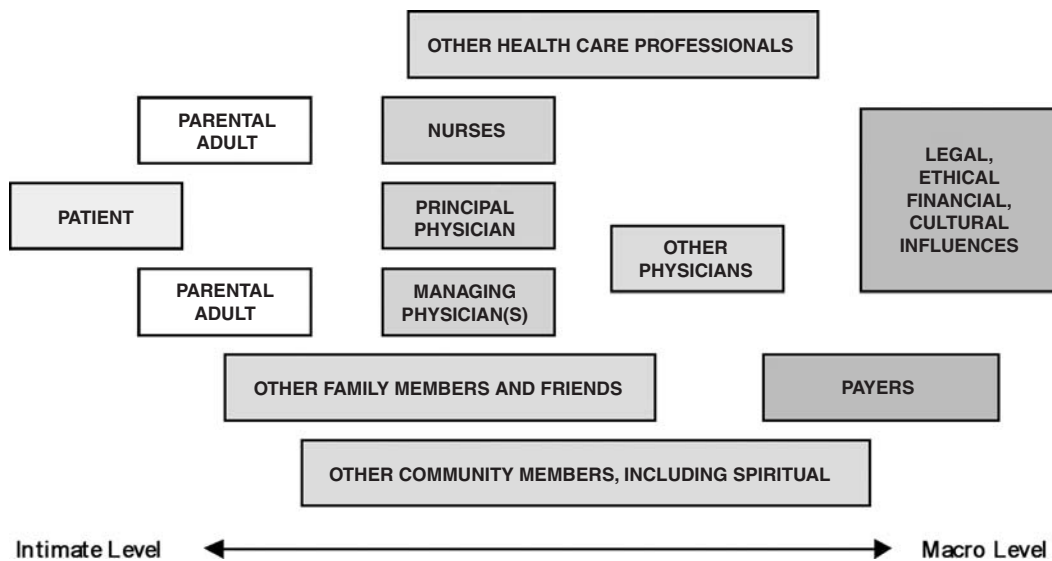


FIG. 4. Social network of relationships relevant to goal formulations and hope.

aggregation, specialty services, such as medicine, surgery, or any of the subspecialties) compose *level 5*—namely, the hospital or health care institution, which, through its history, charitable origins, religious affiliations, research commitments, economic realities, managerial priorities, administrative techniques, or leadership style influences how health care professionals and other members of the staff conceive of themselves and behave in each of the wards or specialty services. Finally, these hospitals—and all the levels contained therein, including the individual patients and family members—exist in the broadest *level 6* of the ecology of hope—namely, our society and its culture.

This concept of an ecology of hope, when joined with our prior development of hope as a cognitive/affective heuristic, produces the second major thesis of this article:

The prospects for healing—defined as the attainment of a holistically conceived, health-related goal—when gravely ill or at the end of life depend upon the perspicacity of choice of goals made by that individual or a designated surrogate decision maker. Yet, decisions in such emotional and often uncertain circumstances are prone to strong biases of thought and feeling that lessen the quality of decisions, erode hope, and thus diminish the possibility of achieving healing outcomes. To the degree that an environment—comprising the patient, family, care providers, and other physical, social, and cultural elements—can prevent, correct, or counteract these cognitive and affective biases, that environment moves closer to being an optimal healing environment.

Which is to say: If a clinic, hospital, or other institute can do a better job of nurturing a salubrious ecology of hope,

by helping individuals to perform with greater skill and alacrity the cognitive and affective processes that constitute the mechanics of hope, this thesis proposes that healing will be enhanced.

Potential interventions

There are as yet no specific hope-promoting interventions that have been rigorously evaluated to determine whether they benefit patients at the end of life or their families. What follows then are some untested thoughts about potential interventions, drawing on the insights gained from the elaborated theory of hope outlined above.

Firstly, and most simply, there may be value in simply addressing hope explicitly in clinical practice (this, as suggested by the opening vignette, has been my experience). Asking patients or family members, “What are you hoping for?”, followed by attentive, patient listening and then the follow-up question, “How are these hopes faring?” cannot only generate a wealth of important information, but also bring some clarity to a chaotic and confusing situation, address emotional realities in a more open manner,⁸ and provide a point of empathic entry into the life situations of these individuals.⁹

These simple questions may represent a broader set of *cognitive/affective management strategies* that could be developed and tested to determine whether they make a person’s hope more vibrant and robust, and, in turn, whether they increase the likelihood of achieving desired outcomes. Some cognitive/affective management techniques would *enter into the process of goal evaluation and selection*. To this end, the questions posed above regarding what people are hoping for (that is, a statement regarding their current goals, such as to “beat this cancer, to be comfortable and not in

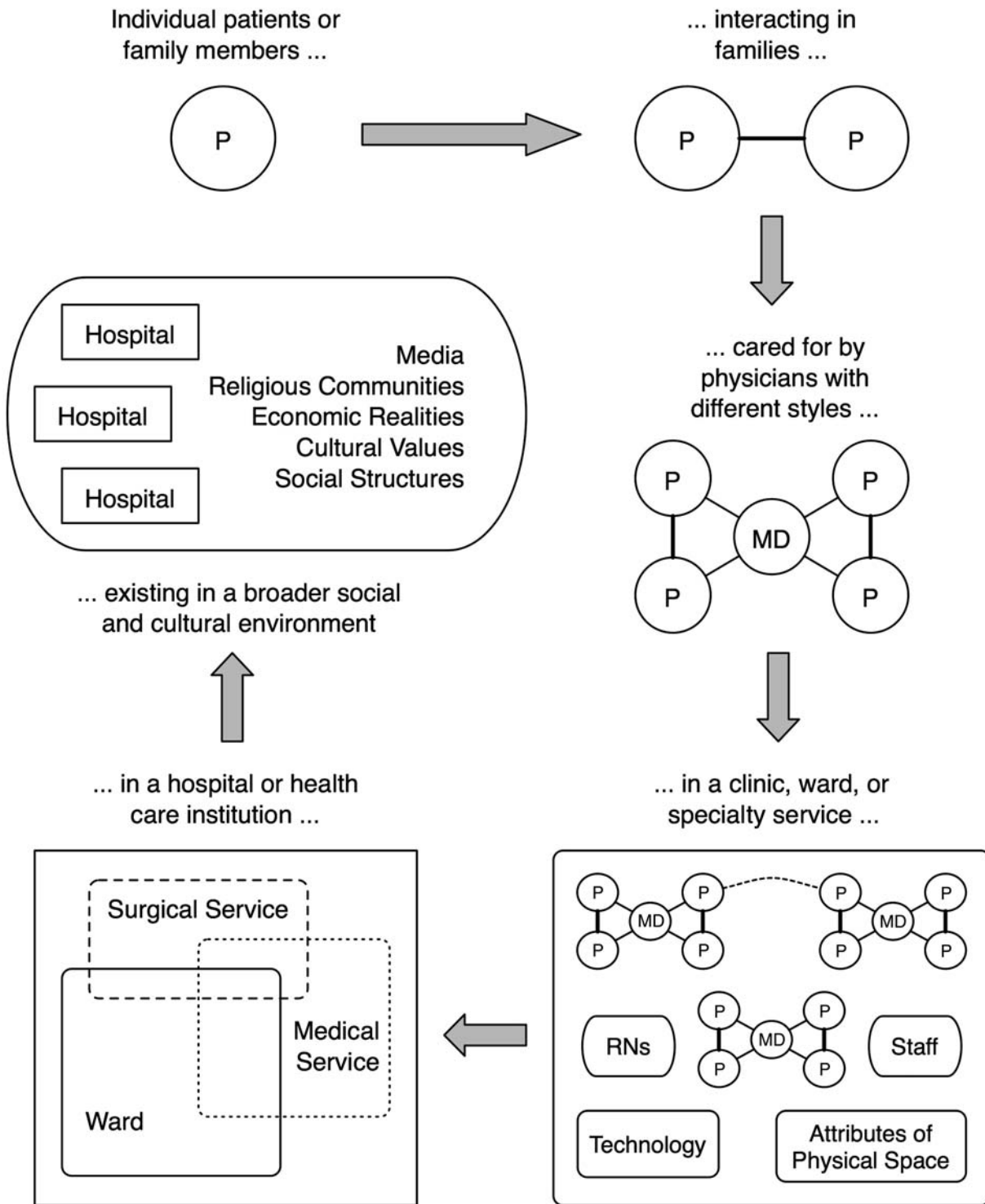


FIG. 5. Multilevel model of an ecology of hope.

pain, and to be at home”), and how these hopes are faring (their assessment of the likely effectiveness of current goal-directed behavior, such as “well, the cancer has come back real bad despite the chemo, and I’m stuck here in this hospital where they mean well but keep poking me for blood”),

set the stage for the next question: “Do we think it might be time to consider emphasizing different goals? Perhaps it is time to really go all out to helping you be comfortable and enable you to go home with help in the home?” The ensuing dialogue will be pivotal in determining not only the goals

but consequently the necessary pathway and agency thoughts, and ultimately have a fundamental impact on a patient's degree of hopefulness and thus on the prospects of healing at the end of life.

Other cognitive/affective management strategies would seek to *elaborate pathway thoughts*, helping individuals see how various goals could be achieved through a series of feasible actions. Presenting action scenarios would be one way to do this: For example, if a patient has identified freedom from physical pain to be a cardinal goal, a clinician might briefly sketch how "we can start with mild painkiller medicine that you can take by mouth; if that isn't enough to keep your pain under control, we will then change to a stronger painkiller; and if that stops working well, then we will be able to give you even stronger medicine through your veins, in larger doses so that you are not suffering from physical pain. However much your pain increases, we have ways to provide more pain relief. Okay?"

Complementing these goal-valuation-selection and pathway-thought-elaboration strategies would be techniques to *enhance agency thoughts*. In the context of grievous illness, many patients and family members report feelings of senseless and a profound threat to one's self-identity, which, in turn, can radically diminish individuals' self-perceptions of agency: the belief that they can do things is shaken; the energy to do things, sapped. In response, one possible intervention would be for clinicians—physicians, nurses, child life specialists, and social or pastoral care workers—to engage patients and families in the work of creating life story narratives that start to make some sense of, or derive meaning from, the illness experience.¹⁰ There may be no formula that can specify how to perform such engagement well, being as it is more like an art than a science. Still, artistic endeavors can be guided and improved by certain useful tenets: in this instance, simply broaching the topic and then grappling with the challenge of making sense or meaning may have positive results. The search for sense or meaning may be thwarted by anger and grief; acknowledging the legitimacy of these feelings, while gently examining the meaning of relationships and of caring in the past, present, and future, may prove helpful in constructing life narratives that revive a person's sense of agency.

Study design considerations

Rigorous studies of the relationship of hope to healing in the end of life care setting will encounter the usual bugbears of palliative care research: limited time to enroll subjects, perform the intervention, and assess the outcome; limited consensus regarding what constitutes a "good" outcome; small number of eligible patients, often with great heterogeneity of underlying conditions or other features among the subjects; and the problematic ethics of studying such a vulnerable population. These are all present, and with forethought and care, surmountable.

Accurate measurements of various outcomes and exposures will be both imperative and somewhat elusive. Many of the constructs under consideration in this article, such as hope^{11,12} or perceptions,¹³ have validated instruments measuring core aspects of these phenomena. However, the constructs themselves are sufficiently complex and multidimensional that measurement will always be incomplete. Investigators will be wise to consider carefully, given their guiding theory of cause and effect, whether they hypothesize that a particular hope-modulating intervention would result in a response that a specific instrument is likely to measure and in a manner responsive to change.

For the various hope-modulating interventions proposed above, using various cognitive/affective management strategies, we can anticipate several other issues that will require accommodation in study design. Firstly, the administration of the intervention is likely to vary across providers. In an effectiveness trial (i.e., how the interventions would perform in the "real world"), such variation is to be expected; and if it dilutes a treatment effect to the point of no benefit, then the intervention would not be a benefit in the "real world." For efficacy studies (i.e., under ideal circumstances, does this intervention work), though, investigators should collect data regarding how the intervention is being delivered, so that the analysis can account for differences in treatment effect on the basis of variation in the delivery of the intervention. Secondly, we should expect provider-specific effect modification. This is related to the variation in how providers deliver the intervention, but posits that some providers—by nature of their personality and interpersonal style—will augment the impact of an intervention, while others will diminish the impact, even if the interventions per se are delivered in virtually the same manner. Again, to understand the efficacy of these interventions, investigators should collect data about the providers to examine this possible interaction between providers and interventions. This would also have practical implications, if it were determined that some providers with particular traits are especially salubrious when administering these interventions, while other providers are the opposite, so that the work of providing such care can be steered toward providers with greater aptitude.

The concept of an ecology of hope argues that a patient's (or family member's) experience of hope in health care settings may well be a multilevel phenomena. Research studies will have to contend with this hierarchical clustering and the potential nonindependence of observations. Not only will analytic procedures of statistical inference have to account for clustering, but also the design of studies should consider whether it is unwise to assess only one level (e.g., patient-doctor interactions), since positive or negative study results could ensue from effects emanating from a level (e.g., ward-level or hospital-level) other than the one of the intervention.

Finally, there is a larger ethical question that the kind of “hope work” that we have been discussing raises: What role do physicians have—or should have—in challenging cultural tropes (such as the fight against cancer) that can so powerfully influence goals and life story identity? Said differently: What are the ethics of engaging in “collaboration” or “coauthorship” with a patient regarding the selection of goals or elaboration of a life story narrative? Given that there are a host of external influences already leaning on how people construct their life story narrative and select their goals, does the engagement of the physician (or other health care provider) in any compelling way diminish the autonomy of patients or family members? Or does such engagement enhance autonomy and dignity? One can assert, on the basis of experiential observation, that clinicians do “hope work” all the time—they just do so implicitly, and often (sorry to say) very poorly. This needs to change. Discomfort on the part of health care providers regarding these issues of appropriate collaboration and coauthorship may be one of the important barriers limiting explicit development of more beneficial and effective hope work techniques in clinical medicine.

CONCLUSIONS

Hope is a powerful influence in our lives. Hope is potentially everywhere, including the bedside of someone who is dying. When mobilized effectively, robust hope is precious; when left untended, effete hope can send us in perilous directions. Patients and patient family members care intensely about hope,^{14,15} so we as providers of health care, aspiring to be healers, should be equally fervent in our pursuit of hope. But to do so effectively, we need to develop and test techniques to manage—or more aptly, marshal—hope.

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