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An Intimate Collaboration: Prognostic Communication with Advanced Cancer Patients

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INTRODUCTION

As a young oncologist, I find myself wrestling with many of the most difficult issues in the practice of oncology: helping patients to make difficult trade-offs between the risks and benefits of arduous treatments, finding sources of strength to deal emotionally with the devastating realities of patients' situations, and communicating important information to patients in ways that give them honest and useful information, but still allow them to preserve some hope for the future. It is this last issue on which I offer my thoughts here.

I have noticed that, although common wisdom about the communication of prognosis with advanced cancer patients holds that we should give accurate and honest prognostic information to patients at all times, in practice this is hard to do. So, I find myself engaging in a process of communication about prognosis with patients which, in a sense, allows the cold, hard facts to come out over time, as opposed to presenting them all at once. I have found other oncologists who seem to use a similar strategy. I do this because it is a style of communication that, I think, "works" for me and my patients: patients come to deal with the painful knowledge of their ultimate outcomes over time in ways that I think allow them to cope and maintain hope along the way. But I have continuously asked myself whether this is the "right" way to communicate. Is it ethically acceptable to support some patients' desires to avoid the cold, hard facts about their prognosis? If so, how can one do this and avoid the harms that could come from complete denial and avoidance? What purpose could the provision of less than "all of the information" serve?

I will argue in this article that artful communication of prognosis with advanced cancer patients often involves a kind of "intimate collaboration," with both the prognostic communicator (in this case, the oncologist) and the prognosis receiver (that is, the patient) contributing to a collaborative process that controls the flow of devastating prognostic information in a way that allows patients to come to an understanding of their prognosis on their own terms.

DEFINITIONS

For the purposes of this discussion, it is helpful to distinguish between two periods in the disease course of advanced cancer patients. After diagnosis, most advanced cancer patients enter a period that I will call the "ambulatory period." The ambulatory period may be brief for some patients (for example, advanced pancreatic cancer patients), and long for others (for example, colon cancer, ovarian cancer patients). It is the period in which, arguably, most prognostic communication between oncologists and cancer patients actually occurs. It is often much longer than the terminal phase of disease, and is, in many respects, paradoxical. The paradox is that many patients with advanced cancer in the period between diagnosis and the terminal phase are ambulatory and otherwise fairly *well*. This extraordinary set of circumstances — possessing a life-ending disease and yet being functional and alive — is one of the defining features of the ambulatory period and inevitably shapes the perceptions of patients about their disease, their prognosis, and their own views of their ultimate outcomes.

However, all advanced cancer patients eventually enter what I would call a "terminal phase." This later period is generally recognized by those familiar with advanced cancer patients, and begins around the time when it becomes clear rapid clinical decline is imminent, further anticancer therapy is not advisable, and a shift to a purely palliative mode of care is warranted. Obviously, having specific knowledge of numerical time frames takes on more urgency during the terminal phase, as time grows short, and many patients must attend to practical details surrounding their imminent death during this time.

In this article, I will also distinguish two modes of prognostic communication. When I refer to *prognostication* in advanced cancer patients, I mean communication of specific numerical estimates of life expectancy. This may take several forms in practice: "I believe you have about four months to live" would be a typical way to deliver such information. Others might offer other formulations: "Average patients live around four months," or "I would estimate that you have three to five months to live." In my view, there is little practical or emotional difference for patients between hearing a specific numerical estimate ("four months") and a narrow range estimate ("three to five months"). Obviously, some communicated numerical estimates of life span would not meet this definition. Examples include the communication of broad ranges (for example, "Patients can live anywhere from three months to more than two years with your condition") or the communication of chances of survival beyond a given time frame (for example, "10 percent of patients live beyond five years"). I will distinguish such specific, numerical estimates of life span from a process-based method of prognostic disclosure, for which I will borrow the term "forecasting." The "collaboration" to which I will refer encompasses the spoken or tacit agreement we sometimes enter into with patients to avoid, or delay, discussing a specific, numerical estimate of life expectancy. I will attempt to argue later that when patients desire such a style of communication — or appear to desire it — oncologists are ethically bound to honor this.

ACCEPTANCE AND AWARENESS OF PROGNOSIS

Much of the literature about prognostic communication with advanced cancer patients suggests that the majority of patients want accurate estimates of their prognosis and that accurate estimates benefit them by allowing them to make end-of-life plans consistent with their values, and that open awareness and acceptance of a terminal prognosis is a normative ideal for patients facing life-ending diagnoses.¹ On this view, such awareness may be achieved through a careful, thoughtful, realistic, and empathetic conversation about prognosis.² This conversation allows patients to reach an open understanding and acceptance of the inevitability of their ultimate outcomes, that, it is argued, helps them to make better decisions about their care by allowing them to prioritize certain activities according to their own values.³

It is probably more realistic to presume, however, that for most advanced cancer patients, acceptance and open awareness of the ultimate outcomes of their disease evolve and change over time. For example, many patients initially react against their diagnosis and the prognosis it entails through hope, denial, avoid-

ance, and other psychological coping mechanisms. As a consequence, they fall back to a much lower level of outward awareness. Their level of open awareness generally increases over time, however, reinforced by the inevitable periods of setback in the illness: disease progression, complications requiring hospitalization, or delay and denial of further therapy. In my experience, most patients eventually reach a level of acceptance that end-of-life experts would consider appropriate, but the process rarely occurs early or all at once.

It is my view that the normative goal of open awareness throughout the disease course, and particularly during the ambulatory period, is both unrealistic and ethically problematic. Although it is easy to see why this model of prognostic acceptance might ethically apply to patients during the terminal phase of their disease (when decisions regarding momentous issues of hospice enrollment, do-not-resuscitate orders, and intensity of therapy take on special significance), ethically, this model does not take account of ambulatory advanced cancer patients' need to "fight," to "beat the odds," and not to accept what those around them — and often their own hearts — tell them is inevitable.⁴ Their need (at times) to deny their prognosis stems from their need to maintain hope. Hope, I will try to argue, is so vital a part of patients' psychological experience of advanced cancer that it must be balanced carefully and valued as much as realism.

COLLUSION IN DOCTOR-PATIENT COMMUNICATION ABOUT PROGNOSIS

Ann-Mei The and colleagues attempted to evaluate what they called "false optimism about recovery" among patients with small cell lung cancer by following 35 patients intensively through the course of their illness.⁵ The authors report that, in discussing clinical care, including prognosis, doctors and patients communicated in ways which the investigators characterized as "collusive." This was done, according to them, so that optimism could be retained through much of the treatment course until patients began to deteriorate physically themselves or saw other patients around them do so. The collusion they describe usually centered on shifts in the conversations between oncologists and patients from the bad news of diagnosis and prognosis to the "good news" of treatment planning. Because much of the course of illness was defined by the treatment calendar, patients infrequently asked about prognosis, and doctors rarely offered such information, assuming that when patients did not ask, they did not want to know. The authors of this study portray collusion as a strategy by which oncologists and patients avoid the truth about prognosis. The truth about prognosis is seen in this study as being "swept under the rug" — just beneath the surface, but not overtly acknowledged.⁶ Other studies have noted similar collusive tendencies in doctor-patient communication in oncology.⁷ Although the authors of this study clearly portray such collusive communication on the part of patients and their oncologists negatively, I believe it is helpful to examine the roots of this kind of collusion and to consider why it might be ethically justified. First, however, I must clarify the term "collusion," which the authors of this study identify, and which I think is a real phenomenon in clinical oncology.

This very real phenomenon, which The and colleagues identify in their study, refers to the efforts that oncologists and their patients consciously or unconsciously make to avoid specific, numerical estimates about expected life span. In some cases, such collusion follows from a specific conversation in which, after being asked how much information a patient would like to know about his or her prognosis, the patient responds that he or she does not want to hear a specific estimate. In my own experience, this exchange is often followed by a comment such as, "Only God knows anyway; you are only human," or, "I just can't take any more bad news right now; maybe we can talk about it later." These sorts of comments set up the expectation that the patient will dictate the timing of a return to the subject of their expected life span.

Again in my own experience, such collusive communication may also follow from a *tacit* understanding about the limits of specificity for prognostic information that an individual patient wants or can tolerate. For example, newly diagnosed cancer patients often do not ask about their prognosis during their initial meetings with their oncologist, although their family members more commonly do. If a family member asks on behalf of the patient or if prognostic information comes up naturally in the course of the discussion of treatment or treatment goals, I will commonly ask the patient if he or she wants to know about his or her prognosis and,

if so, how much information he or she wants. Some patients tell me that they want a straight answer, a realistic time frame to help them make decisions about their remaining lives. I try to honor such requests by including in my answer a prognostic estimate involving a realistic time frame for persons in their condition. Other patients state explicitly that they are not ready to hear anything at that time, and I usually respond that I would be happy to talk more about the subject at a later time when they feel more ready. Finally, some patients seem to hesitate at this question, never actually answering it. Reflection on that hesitation or ambiguity in response has often given me the sense that the patient is not ready to tackle "the whole, naked truth" all at once during that meeting. When patients tell me explicitly that they are not ready to hear specific prognostic information or when I sense such hesitation, I often adopt a strategy of progressive disclosure of prognosis over time. This "dance" that the patient and I do together around numerical prognostic estimates — sometimes skirting the issue, sometimes brushing up against it, sometimes backing away from it entirely — continues until there are clearer indications that the patient is ready to hear more specific information.

Just to clarify: although in these early conversations with patients I am willing to avoid providing a specific, numerical estimate of prognosis, I personally do not ever avoid specifying the goals of patients' therapy: unless there is a realistic chance that a patient can be cured of her or his disease, then I always specify that the goals of therapy are palliative (to prolong life and improve cancer-related symptoms). I often use a phrase such as, "This therapy is not meant to cure the cancer, but rather to slow it down as much as possible, and thus to buy time." Helping patients to accept that their disease is incurable is the first step in guiding them toward acceptance of their ultimate prognosis.

Just as was noted in the study mentioned above, I and other oncologists at times avoid direct discussion of specific estimates of life expectancy when the estimates are uncertain and when patients appear unready to tackle such information. Some might argue that this kind of collusion is not honest, and thus not ethical. Others would say that in maneuvering around specific, numerical estimates of life span we are "abandoning our patients prognostically."⁸ I believe, however, that this kind of collusive communication can be justified ethically. This justification stems from two empirical assertions: (1) it is consistent with many patients' stated and unstated wishes, and, (2) it preserves hope by acknowledging the initial uncertainty surrounding prognosis in advanced cancer patients, allowing prognostic information to emerge over time. This progressive disclosure takes advantage both of the progressive degree of prognostic certainty that emerges over time, and of the increasing receptiveness to prognostic information that patients experience as their physical situation worsens. I will examine both of these assertions in turn.

COLLUSION IS CONSISTENT WITH SOME PATIENTS' WISHES

Many published studies suggest that the overwhelming majority of cancer patients want to know everything about their disease, including prognosis.⁹ These studies have been used to justify the belief that advanced cancer patients all want accurate prognostic information all of the time. However, there are a number of problems with the interpretation of the studies that examine patients' desires for information, the most important of which is that many of the studies that are used to support these assertions included both curable and incurable cancer patients. The conceptual flaw in this study design is that curable patients receive and perceive prognostic information (including the chances that they will be cured) in totally different ways from those who have incurable disease. The conclusions about information preferences among cancer patients drawn from such studies must therefore be interpreted with caution.

Two classic studies about information-seeking in cancer patients from the early 1980s found that the overwhelming majority of cancer patients wanted maximum amounts of information, but these studies included both curable and incurable patients.¹⁰ Other studies suffer from the same flaw. Meredith and colleagues' study of cancer patients in West Scotland found that 91 percent of patients wanted to know their prognosis, but this study also included both curable and incurable patients.¹¹ Judith R. Davidson and colleagues found that patients have a high desire for all of the information in their study of lung cancer patients, but their sample included mostly curable patients.¹²

In other published studies in which only terminally ill cancer patients were included, a different picture emerges. Such studies suggest that patients' individualized needs for information in terminal illness should be the guiding ethical rule, and that blanket rules about providing prognostic information may not be appropriate at all times for all patients. Leslie Fallowfield and colleagues found that most people want "all the information," but that older patients and patients with poorer prognoses wanted less information.¹³ Andrew Steptoe and colleagues found in a mixed population of cancer patients that some patients avoided stress by avoiding information.¹⁴ In a study of information needs in terminal illness (60 percent of the study subjects had cancer), Jean S. Kutner and colleagues found that 100 percent of interviewed patients wanted their doctors to be honest, and 91 percent wanted them to be optimistic.¹⁵ Only 60 percent of patients in this study wanted to know their life expectancy, fewer than the proportion of patients who wanted to know if they would be able to eat.¹⁶ The authors conclude that the information needs of the terminally ill are extremely diverse. As Ami Schattner points out in a 2002 editorial, a considerable number of patients express significant reservations about their doctors being completely frank with them regarding their prognosis.¹⁷ Patients have a right not to know or to delay knowing difficult information, and complete respect for patients' ability to make their own decisions dictates that an assessment of patients' actual and current desires (which may change over time) be attempted. Benjamin Freedman even suggested that an ethical approach to prognostic disclosure, when the wishes of a patient are not known, is to "offer truth," and then to respect the answer the patient gives.¹⁸

COLLUSION PRESERVES HOPE BY ACKNOWLEDGING UNCERTAINTY

I think everyone would agree that the preservation of hope is a vital goal for advanced cancer patients. Many studies confirm the importance of the concept of hope for cancer patients,¹⁹ and several studies present evidence that the ability to maintain hope, specifically through avoidance of prognostic information, may be important. In a qualitative study of patients' need for information among mixed cancer patients (most of whom had theoretically curable cancers) conducted by Geraldine Leydon and colleagues, the authors found that information needs varied considerably over time, that patients described hope for the future as essential, and that hope could be maintained by denial and by avoiding information.²⁰ Phyllis Butow and colleagues found that 15 percent of 80 mostly curable cancer patients (67 percent of whom had a prognosis of years or of a normal life expectancy) desired to have minimal detail about their illness.²¹ In one study of terminally ill patients that included cancer patients, maintaining hope was universally important to patients, and among the cancer patients in this study, hope and a positive attitude were the most frequently raised emotional support topic.²²

But one question is, How can oncologists communicate in a way that is honest and yet preserves hope? Honest answers require that we take the extreme variability of cancer biology and of individual cancer patients into account. For example, providing information about the median survival for a given cancer in response to a question about life expectancy is an honest answer, but it only communicates part of the story. Median estimates say nothing about the variability around the median or about outlying cases on either end of the spectrum. Thus, a truly honest answer must include as much information about the uncertainty of prognostic estimates (especially at the outset of disease after diagnosis) as about medians, averages, and one-year rates of survival.

It follows from this inherent uncertainty that when patients either do not ask or request *not* to be told a specific, numerical estimate of life expectancy, it is permissible to avoid devastating (and often inaccurate) estimates until there are clear indications that a patient is ready to hear them *and* a more specific estimate may be honestly provided. Although it may sound as if I am advocating a controlled withholding of information from patients, I am really arguing for allowing the honest uncertainty that surrounds disease outcome and prognosis to be marshaled into the service of patients' sense of hope and open-endedness.²³ Allowing patients to come to terms with their terminal prognosis over time respects both the variable biology of cancer *and* the tremendous emotional pain that accompanies the knowledge of a terminal prognosis.

HOPE

It seems important at this point to discuss what I mean by *hope* in advanced cancer patients since, inevitably, some will raise objections that we should encourage true hope but not false hope, and hope for some goals, but not other, unattainable goals, such as cure. Traditionally, hope in cancer patients has meant hope for cure. However, advanced cancer patients clearly hope for many other goals. There is evidence that persistent hope to go on living for advanced cancer patients is often cultivated in the context of understanding the incurability of their situation.²⁴ In my experience, patients generally switch fairly early on in their course from naïve hopes for definitive cure of their disease to hope for as long a life as possible. When patients say (as they commonly do), "Doc, I will be the one to beat it!" I do not understand them literally, believing that they do not understand their situation. I take them to mean that they will be the ones that outlive everyone's expectations.

Some have argued that such attempts to preserve patients' ability to maintain hope through avoidance of specific prognostic estimates about life span are dishonest, and that we can preserve hope in other ways, for example, by helping patients to shift their hopes from surviving their cancer to hopes for a "good death." Take Nicholas Christakis' argument:

[P]atients might . . . be harmed if erroneous predictions of imminent death resulted in the withholding of interventions that would otherwise save a life. But my study has convinced me that, most of the time, the problem is the other way around. Rare are the cases where making or offering a carefully considered and framed prognosis results in choices that are harmful to a patient. If seriously ill patients had better information about their chances of survival and about the likely success and implications of proposed treatments, and if they were supported by their physicians in how they chose to use this information, they might make different choices at the end of their lives. . . . With it, they might be empowered to plan for, and achieve, the kind of good death most Americans say they want: free of pain, at home, with loved ones, having said good-byes and put their affairs in order.²⁵

I believe that such arguments in favor of shifting advanced cancer patients' hopes for more life to hopes for a "good death" are misguided. While it is a virtuous and admirable goal to assure comfort, dignity, and the pleasures of social interaction for dying patients of all kinds, in my experience the hopes of advanced cancer patients can only be redirected toward "a good death" in the terminal phase of disease, when patients actually feel they are dying. Such hopes rarely cross the minds of patients with terminal cancer during the often much-longer ambulatory period. I have never had a patient say to me, even when I have asked about the patient's hopes for the future, "Doc, what I really hope for is a good death." I have had many patients tell me their hope is to live as long as they can; it is interesting that they rarely add, "and as well as I can."

COLLUSION ALLOWS PATIENTS TO DIGEST DIFFICULT INFORMATION OVER TIME

I have argued previously that patients nearly always reach a point in their illness when "open awareness" is possible. In my experience, this comes very late in the course of cancer for some patients. Although some advanced cancer patients are able to ask about and handle specific prognostic information almost from the time of their diagnosis, in many cases it is possible to discuss time frames in completely naked terms only when patients have come to see the inevitability of their own deaths on their own, when their disease has made their bodies weak, and when increasing signs and symptoms of progressive disease become a constant reminder of their approaching death. A strategy of progressive prognostic disclosure fits well with this increasing receptiveness to the prognostic information many patients experience over time.

The strategy of communication I am advocating can obviously serve to bolster patients' avoidance and denial, and clearly has the potential to contribute to maladaptive end-of-life decisions for some patients.

However, given the empirical evidence that denial may be a means of supporting hopefulness²⁶ and that the ability to maintain hope for survival is critical to quality of life during terminal illness,²⁷ careful and reflective "collaboration" in denial may be permissible.

I recognize that denial is a powerful coping mechanism for some patients, in others, denial may have negative consequences. Rare patients may deny until the very end the internal signs of their illness, and ignore the external reminders those around them — both the medical team and, often, their family members — attempt to provide them. This "terminal denial" causes them to postpone the important life tasks that dying patients must often face: preparing a will, writing letters to children, attempting to heal relationships.

I can think of several patients over the years like this: the young mother of three with advanced colon cancer who put off telling her children about her rapidly approaching death and never had time to say the many things to them she surely wanted to say; another young mother who, because she did not want to face her imminently terminal esophageal cancer, traveled to an East Coast medical center under the illusion that she would receive life-prolonging cancer therapy there, and died within 24 hours of arrival, leaving her husband and two young children back home, never having said good-bye.

These are painful examples of the harm that can come from excessive denial, and one can see how, without careful consideration of the risks and benefits of various strategies of prognostic communication, one might actually contribute to such potentially harmful denial. However, I think that such "terminal deniers," while illustrating real, potential harms that could be exacerbated by collusive avoidance of prognostic discussions, are rare. They represent the edge of the spectrum of challenge that prognostic communication represents: how to lead patients through and into an understanding of their prognosis in a way that is consistent with their desires, that respects the emotional pain of their situations, that provides them with useful information with which to make decisions, and that allows them to sustain some hopes for the future.

Although we would like to protect such patients from themselves and their seemingly harmful denial, it is not clear to me that such patients with "terminal denial" will ever hear and accept their prognosis, no matter how often we repeat our expectations to them. In such cases, I usually attempt to help the loved ones around such patients to prepare in a more adaptive way for the patients' eventual deaths. Examples such as those I have provided above are used to illustrate the harms of denial and to justify the provision of prognostic information, even against a patient's wishes. I am cautious of such facile justifications, however, under the complicated circumstance of terminal cancer. While complete denial of the difficult issues that an approaching death raises is not the way most of us would want to lead our lives (or deaths), rare individuals simply cannot face devastating prognostic information in an open way. They use denial as a means of coping with what is for them untenable emotional pain, even though the negative outcomes illustrated in the cases I mentioned above are sometimes the real consequence. So, as a clinician who frequently deals with dying patients, I must find a way to confront, in a respectful way, these individuals' psychological makeup and the pain that leads them to behave in this way. In "terminal deniers," I have rarely found that repeated reminders of an approaching death are heard, understood, and acted upon; sometimes, such verbal reminders cause patients to run away to find an oncologist who will not "pound them over the head" with their prognosis. In both cases mentioned above, the patients had been repeatedly warned by me and others of the gravity of their situations, but did not or could not act on the information.

Hence, I have concluded that working in a cooperative way with patients, and within the psychological confines and limits that they draw, is the most productive way to communicate about prognosis over time. Given the complex considerations I have attempted to outline, I have found that one strategy for balancing hope, useful information, and patients' desires is to "forecast" the future at multiple points along the way.

FORECASTING IN INCURABLE CANCER PATIENTS

I borrow the term "forecasting" from the sociologist Douglas Maynard, who has written about this concept in the context of delivery of bad news. This concept, which derives from empirical qualitative studies of social interactions involving the delivery of bad news, might be summarized as follows.

Forecasting is a strategy for delivering bad news and is compared to two other strategies, stalling and being blunt. Forecasting involves the provision of "some warning that bad news is forthcoming without keeping the recipient in a state of indefinite suspense (stalling) or conveying the bad news abruptly (being blunt). Forecasting appears to be more effective than stalling or being blunt in helping a recipient to "realize" the bad news because it involves the deliverer and recipient in a social relation: the deliverer of bad news initiates the telling by giving an advance indication of the bad news to come; this allows the recipient to calculate the news in advance of its final presentation, when the deliverer confirms what the recipient has been led to anticipate. Thus, *realization of bad news emerges from intimate collaboration*, whereas stalling and being blunt requires recipients to apprehend the news in a social vacuum.²⁸ [Emphasis added.]

Maynard's work focuses on relatively isolated instances of the delivery of bad news in which specific verbal and nonverbal cues (for example, pre-announcements or a somber demeanor) are used by the deliverer to presage the bad news in some way, often leading the recipient to reach the conclusion ahead of the receipt. But the principle underlying this strategy — that the act of forecasting allows difficult information to emerge from a kind of collaboration between the deliverer and recipient — may be applied more broadly to the process of prognostic communication with advanced cancer patients. As Maynard explains, the "collaboration" that develops through forecasting between the deliverer and the receiver leads to a "deeply collaborative, orderly achievement" that makes the bad news event more tolerable to the receiver, while at the same time promoting and strengthening the underlying relationship.

Whereas prognostication emphasizes numerical estimates of a patients' life expectancy, a process that includes uncertainty of estimate, but no uncertainty of outcome, forecasting is a strategy in which the future is predicted, although without absolute certainty, leaving room for the uncertainty that surrounds every patient's eventual outcome after diagnosis. As successive events are realized ("The chemo will eventually stop working" or "A cancer's response to a second or third line of treatment is usually shorter than to the first line"), patients are in Maynard's sense *led to* their own understanding of their prognosis, anticipating negative events in advance. Forecasting allows both the oncologist and the patient to face and prepare for likely outcomes, and to maintain hope about unlikely ones, and does so in a way that involves them in a social relation (again, in Maynard's sense), and so is implicitly supportive of the patient and the doctor-patient relationship.

OPEN-ENDEDNESS

One of the strengths of using forecasting over a more narrow view of prognostication for those patients who do not want a precise, numerical estimate of life expectancy is that it preserves a sense of open-endedness about time frames. For example, a patient may understand that his or her disease is incurable, but may still be able to hope that treatment will prolong his or her life for as long as possible, something that the communication of a numerical estimate of life expectancy ("You have three to five months to live") does not allow. Some will argue that leaving such uncertainty about eventual outcomes can lead to false hopes about the possibility of being cured. However, as Nicholas Slevin and colleagues have argued, the hope that patients with terminal cancer experience is often not related to false hopes of cure, but rather the need to feel that life still retains some open-endedness, something that he argues is necessary for people to have meaning in life.²⁹ Empirical evidence supports (and personal experience confirms) that patients are able simultaneously to understand that their disease is life-ending and to maintain hope that, even against all odds, they may be the statistical anomaly who survives.³⁰

Fulfilling the physician's obligations to tell the truth under such circumstances seems impossible on the surface. How does one simultaneously leave patients with a sense of open-endedness about their terminal cancer and inform them about their life-ending disease in a way that is useful for deciding how best to spend their time? One solution lies in presenting a clear-eyed view of what is likely, unlikely, and possible. Be-

cause of the inherent uncertainty and biological variability of cancer and of individual cancer patients, we can honestly tell our patients that a disease is curable or incurable, provide a range of prognoses, including outlying examples, and make certain that patients understand what the goals of therapy are. This kind of hope, hope that recognizes the obstacles and odds, but that still allows room for unlikely outcomes, is what Jerome Groopman calls "true hope," which he distinguishes from false hope. In his view, false hope is the pervasive belief that everything will turn out all right.³¹

CONCLUSION

I have tried to argue that prognostic communication with advanced cancer patients may ethically be collaborative, that is, it may ethically privilege open-endedness and uncertainty about specific time frames over certainty in prognosis, especially during the ambulatory period of disease, because of the inherent variability of cancer patients and the crucial role that hope plays in their lives. I have contrasted this with an approach to prognostic communication that attempts to provide an accurate, numerical estimate of life span, aimed at bringing about open awareness of prognosis that, it is hoped, will contribute to excellent decision making about cancer treatment and end-of-life goals. The "collaborative" strategy ultimately relies on a series of conversations, during which the technique of forecasting is used to bring about incremental awareness of the ultimate course and outcomes of the disease, and on careful and honest maintenance of hope through the preservation of open-endedness.

While I believe that the strategy of prognostic forecasting I am advocating here works well for many patients as a means of balancing useful information and hopefulness over time, it is dependent in many ways upon the sensitivities of the oncologist to the verbal, nonverbal, and other cues that patients give us about their needs and desires for information. We inevitably get these cues wrong from time to time, and, in doing so, risk leaving some of a patients' needs unmet. Certainly, humility toward our ability to "read" patients and account for their needs (in the absence of specific, verbal direction) is warranted.

Faced with such a situation, can we ethically enter either a tacit or an explicit agreement with patients (which I have called "an intimate collaboration") to avoid dire and specific numerical prognostic estimates about life span, until patients ask for them or appear ready to hear them? Recognizing that the natural history of any individual's cancer is extremely variable, I think we can justifiably and honestly outline a range of prognostic estimates and include descriptions of outcomes that are unlikely — even highly unlikely — as long as such outcomes are within the range of clinical possibility. This honest prognostic picture, which forecasts the future in probabilistic terms while including some honest open-endedness about time frames, is the means by which hope may be maintained for patients. Over time, we should refine these prognostic estimates, delivering information through a measured series of "forecasts" about the future. As each successive forecast is realized, patients gain confidence in their oncologist, and the inevitable outcome of their disease is revealed to them. Through the course of this, patients become engaged in a beneficial, healing relationship that our efforts to preserve hope engender in them.

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NOTES

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