

Oncology and Hope

By Eric Kodish and Stephen G. Post

WHAT SHOULD cancer patients be told? Progress in the diagnosis and treatment of cancer, and fundamental changes in the ethical basis of the practice of medicine, have dramatically altered the answer to this not-so-simple question. In this report, we suggest that oncologists must balance the obligation to be honest with an equally important duty to cultivate hope, and we recommend practical measures to achieve this balance. We analyze a recent and important case, *Arato v Avedon*, which forced California courts to address this complex problem.

After review of the facts and implications of *Arato v Avedon*, we summarize the contributions of both classic and modern writers on the role of hope in medicine and ethics. We then consider the moral dynamics of hope, specifically examining the role of hope in the care of patients with cancer. We argue that hope remains an existential aspect of the patient that merits respect and sensitivity. We distinguish between diagnostic and prognostic disclosure, and use the principle of respect for hope as a heuristic key into the question of prognostic disclosure. Finally, we provide practical recommendations, based on *Arato v Avedon*, to help clinicians balance the important moral values of honesty and hope.

ARATO v AVEDON

Miklos Arato was a 43-year-old man diagnosed with pancreatic cancer during a nephrectomy. The surgeon who incidentally discovered and resected the tumor and the oncologist who administered chemotherapy were not asked for and did not volunteer a specific statistical estimate of prognosis. On a questionnaire at his first oncology visit, Mr Arato answered "yes" to the question, "If you are seriously ill now or in the future, do you want to be told the truth about it?" Testimony of his physicians suggests that Mr Arato was told that most victims of pancreatic cancer die of the disease, and that he was at great risk of recurrence and death.

Dr Avedon, the primary oncologist, testified that during more than 70 subsequent visits, Mr Arato "studiously avoided confronting these ultimate issues" and "never asked for information concerning his life expectancy."¹ The tumor recurred, and Mr Arato died 1 year after diagnosis. His family sued the surgeon and oncologists, claiming that they had violated California's informed consent

doctrine because Mr Arato was not told that 95% of people with pancreatic cancer die within 5 years.

The surgeon stated in trial that Mr Arato displayed such great anxiety about his cancer that disclosure of prognosis was "medically inappropriate." The chief oncologist stated that reporting such high mortality rates might "deprive a patient of any hope of a cure." He further testified that because Mr Arato never asked about life expectancy, in his (Dr Avedon's) judgment this patient did not want specific prognostic information. Mrs Arato claimed that had her husband been informed of the probabilities of mortality, he would have had the opportunity to make final arrangements and he would have chosen to die "at peace," without experimental treatment, and surrounded by his family.²

The saga of *Arato v Avedon* in the judicial process bespeaks the degree of controversy that surrounds prognostic disclosure in oncology. At the level of the trial court, a jury verdict and Superior Court judge ruled for the defendants, that physicians had no obligation under informed consent to disclose statistical life expectancy. This decision was reversed by the Court of Appeals, which ruled for the plaintiffs,³ only to be reversed again by the Supreme Court of California, which ruled in favor of the physicians.¹

The Supreme Court ruling recognized:

The contexts and clinical settings in which physician and patient interact and exchange information material to therapeutic decisions are so multifarious, the informational needs and degree of dependency of individual patients so various, and the professional relationship itself such an intimate and irreducibly judgment-laden one, that we believe it is unwise to require as a matter of law that a particular species of information be disclosed.

Later in the ruling, the Court alludes to the importance

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of hope to cancer patients when summarizing the testimony of physician witnesses at the trial with regard to the value of statistical life-expectancy data:

“. . . to assume that such data are conclusive in themselves smacks of a refusal to explore treatment alternatives and the medical abdication of the patient's well-being.”

Contrary to Annas,⁴ who calls for the nearly mandatory disclosure of a terminal prognosis, we argue that oncologists should respond to the individualized needs of each patient and have no obligation to extinguish hope in dying patients. Many patients are like Mr Arato, who, according to his oncologist Dr Avedon, “wanted to be told the truth, but did not want a cold shower.” *Arato v Avedon* is important because the questions it raises are tragically common. Our purpose here is to address the ethical, rather than legal, questions generated by this case, providing an analysis of the moral dynamics of hope and oncology.

HOPE: FOR AND AGAINST

Contemporary medical ethics and law have achieved much for patient self-determination. Physicians routinely disclose information to patients based on respect for individual autonomy, a clear, profound, and recent change in medical practice. Hope is castigated as having provided justification for paternalistic lies and half truths. At worst, serious harms were carried out in the name of hope. In a report that many consider the starting point of modern medical ethics, Beecher⁵ described a case in which melanoma was transplanted from a daughter to her informed mother “in the hope of gaining a little better understanding of cancer immunity and in the hope that the production of tumor antibodies might be helpful in the treatment of the cancer patient.” The daughter was dead a day after the transplant; her mother died from metastatic melanoma 451 days later.⁵

In reaction to a history of deception in order to preserve hope, many now think that hope has no role in our thinking about clinical medical ethics. Yet hope should not be entirely dismissed, for it is one major mode by which people anticipate the future. By their words and actions, physicians can be powerful modulators of patients' hope.

Thoughtful scholars have long considered and written about human hope. Plato wrote that we are all filled with hope all of our lives (*Philebus* 39e). Hope is such a central element of the human experience that it is creatively ensclosed in mythologies and symbols from all civilizations. Without condoning the deceptions and harms perpetrated in the name of hope, Thomas Percival's⁶ image of the physician as “minister of hope and comfort to the

sick” remains authentic. Percival cited the Enlightenment philosopher Francis Hutcheson, “No man censures a Physician for deceiving a patient too much dejected, by expressing good hopes for him . . .” These writers support a “weak paternalism” that would, for example, suggest that physicians withhold information from a depressed patient deemed likely to harm himself or herself were the facts disclosed. By contrast, the physician who lies because he or she thinks that patients want to be “protected” from the truth, practices “strong paternalism,” and does deserve censure.

That hope has traditionally been a value in medical ethics suggests that its general absence from current ethics literature is unacceptable, even if understandable as a reaction against strong paternalism. One notable exception, James Drane,⁷ has written more recently that “Because despair is so painful and so frequently part of the dying process, it is not too much to say that it (hope) falls within the scope of a doctor's ministrations.”

For some cultural groups, a physician who suggests that there is no hope is always wrong. For example, among Arab Muslims, “Hope helps a patient mobilize his own resources to cope with the illness, even if such hope is false by Western standards. As long as the patient has faith in Allah and His power, hope is never false.”⁸ Because God and hope are intertwined, promoting hope does not entail deception. Understanding the Islamic perspective can help us to recognize the importance of hope in the medical care of patients from many cultural backgrounds.

More than most other medical specialties, oncologists understand the real import of hope. But how and when to introduce facts in given cases is a matter of significant ethical concern, and here the principle of respect for hope must always remain relevant. Oncologists need the freedom to negotiate this sensitive moral terrain, and ethical norms must recognize the clinical importance of hope.

ONCOLOGY AND HOPE

In American medicine, attitudes and practices have changed to diminish emphasis on hope. In a landmark report published in 1961, Oken⁹ demonstrated that 90% of 219 physicians he studied did not tell patients about a diagnosis of cancer. Based on personal interviews with respondents, Oken observed that “variations in approach converge to a single major goal: maintenance of hope . . . Every single physician interviewed spontaneously emphasized this point and indicated his resolute and determined purpose is to sustain and bolster the patient's hope.”

A repeat of this study was performed 18 years later, and documented a dramatic change. By 1979, 97% of physicians "indicated a preference for telling a cancer patient of his diagnosis—a complete reversal of attitude."¹⁰ The irony of this reversal is considerable. When physicians overwhelmingly emphasized protecting the hope of their patients, the clinical reality was such that little hope actually existed. Now, when emphasis on hope has given way to the obligation of honest disclosure—there is more rational basis for hope. Progress made in the treatment of cancer between 1961 and 1979 may have paradoxically contributed to this reversal in physician attitude and practice. As therapeutic modalities like radiation, chemotherapy, and surgery made survival a possibility for many patients, physicians had more to offer when discussing a diagnosis with patients. They could foster hope while at the same time remaining honest with the cancer patient.

However, physicians were not the only ones to change. Patients' expectations of their doctors were fundamentally altered by the consumer movement in this country, bolstered by a new willingness to question established authority. To some extent, then, physicians' newfound honesty with cancer patients was a direct response to pressure from patients themselves, and must be understood in the context of the new doctor-patient relationship.

In this country at the present time, the honest disclosure of a cancer diagnosis has become routine. The moral issue of whether to tell the truth has now shifted from disclosure of diagnosis to disclosure of prognosis. Important distinctions between diagnosis and prognosis must not be overlooked. Although rare cases present the pathologist and clinician with diagnostic uncertainty, most cancer diagnoses are quite clear. By contrast, prognostic uncertainty is ubiquitous.

Physician reluctance to disclose a grim prognosis may be related to discomfort with putting odds on longevity, recurrence, and cure. Treatments may be recommended with few details as to probabilities of success, and definitions of what a "successful" outcome might be are often left vague. While this reluctance to communicate prognosis may be based on the desire to foster hope in the patient, there may be three important additional factors.

First, caution regarding specific prognostic disclosure may be based in the difference between prognosis and prediction. Since the medical literature itself reflects significant variation in outcome, oncologists think in terms of prognostic ranges rather than precise survival estimates. For example, two recent reports on pancreatic can-

cer demonstrated 1-year survival rates of 75% in patients with resectable tumors,¹¹ but only 39% in unresectable cases,¹² with variations in adjuvant therapy. Second, data suggest that oncologists themselves may have inconsistent perceptions of therapeutic benefits, generally overestimating the proven benefits of chemotherapy.¹³ This would introduce another element of variability in prognostic disclosure, and provides more support for a cautious approach. Finally, doctors may allow their own hope for a good outcome for the patient to influence the dialogue, which may be appropriate.

A recent study of 51 oncologists indicates that concern with hope is still significant among oncologists, whose "discourse on hope" has been examined in open-ended interviews using the methods of anthropology.¹⁴ Del Vecchio et al¹⁴ emphasize how dominant the "message of hope" is in the "war on cancer" waged by American oncology, embedded in a popular and professional culture that places emphasis on "will." This emphasis reflects "fundamental American notions about personhood, individual autonomy, and the power of thought (good and bad) to shape life course and bodily functioning" (p 61). All physicians said that they view instilling hope in their patients as essential. This study contends that oncologists manage patient demand for probabilities of success and failure, because "controlling information is essential to maintain or instill an optimistic attitude in their patients . . ."

In an important book that interprets issues in clinical ethics against the background of hope and despair, Nuland¹⁵ includes a chapter entitled "Hope and the Cancer Patient." He presents cases of cancer patients in which physicians "misunderstand the ingredients of hope, thinking it refers only to cure or remission" (p 223). Nuland claims that misguided hope leads to futile treatments. Physicians and patients need to find their hope in ways other than prolonging dying or beating death. Patients might find hope in the existence of God and an afterlife, or in the accomplishment of some goal, such as seeing a child graduate (p 256). But this redirecting of hope is difficult to achieve: "In this high-tech biomedical era, when the tantalizing possibility of miraculous new cures is daily dangled before our eyes, the temptation to see therapeutic hope is great, even in those situations when common sense would demand otherwise. To hold out this kind of hope is too frequently a deception, which in the long run proves far more often to be a disservice than the promised victory it seems at first" (p 233). Nuland contrasts our era with previous centuries in which the only approach to death was to let it happen "artfully."

He believes that we must recover the "art of dying" to balance the art of curing.

Oncologists who foster hope are responding to patient expectations. For example, a study of parents' expectations for physician communication of medical bad news indicates a desire for a caring attitude, empathy, and a sensitivity to the importance of hope.¹⁶ This work showed that parents who had experienced the communication of bad news about their child wanted doctors to make them feel better about the news. One mother said that "physicians can remain objective and professional and still impart to others some very basic human elements, . . . above all, never, never try to take away faith or hope." Physicians must communicate with patients and families in a way that integrates the moral obligations of honest disclosure with the legitimate needs and desires of the patient and family.

BALANCING HOPE WITH HONEST DISCLOSURE

How much hope should the oncologist foster when talking with patients and families? The answer to this question will vary with the type of cancer, the patient's age, underlying medical conditions, and the point in time at which the discussion occurs. However, honest disclosure of diagnosis and prognosis must be distinguished from the mandatory communication of survival statistics.

The discussion between oncologist and patient at the time of a new diagnosis is only the beginning of an evolving doctor-patient relationship. In this section, we will use the Arato case at various points to illustrate strategies for managing hope that may be useful to practicing oncologists. The degree of hope the physician should promote is influenced by both objective data and subjective information, which he or she must constantly integrate to determine what information to share with patients and how the discussion should proceed. Although each case will unfold in its own unique way, we will examine the ethics of hope at four important points in the typical pattern of oncology care.

Diagnosis

Mr Arato's pancreatic cancer was discovered accidentally by a surgeon who was performing a nephrectomy. This important fact distinguishes this case from most cancer diagnoses, which present because of a medical sign or symptom. This may be the first important point in the ethics of hope and oncology: expectations play a key role in patients' reactions. Physicians must consider the patient's state of mind when discussing diagnosis and prognosis. Patients with long-standing or severe symp-

toms may be less surprised and more prepared than patients like Mr Arato, whose cancer diagnosis was an incidental finding.

Although pancreatic cancer has a terrible prognosis, disclosure of the statistical likelihood of death despite treatment must be balanced with the following two important factors: (1) The oncologist cannot predict at the time of diagnosis which patients will respond to therapy, and which will not; (2) the psychologic and spiritual resources of the patient and family must be nurtured during this particularly difficult period. While this does not justify outright deception, it may allow for ambiguity or, more commonly, withholding of information that is not specifically sought by a patient or family member. This may explain the judgment of Mr Arato's physicians at diagnosis.

A key point in our understanding of hope must be the distinction between physician-initiated disclosure and response to specific questions put forth by patient or family. Doctors have a clear obligation to initiate discussions to inform patients about the diagnosis, specifics of treatment options and their side effects, and of the prognosis in general terms. They must also actively encourage patients and family members to ask any question of importance to them, provide multiple opportunities for such discussion, and give forthright, honest answers to all questions asked.

But doctors must also respect patients' prerogative to decline further information, and should guard against exhaustive disclosure for the moral comfort of the physician, rather than the actual needs of the individual patient. If a patient does not wish to know the exact statistical prognosis for his or her condition, physicians must not force the patient to accept this disclosure. By encouraging patients to ask questions to which they would like answers, physicians can promote an individualized approach, allowing patients to maintain hope on their own terms.

Initiation of Therapy

The delivery of cancer treatment may have meaning for patients that is quite different from the understanding of physicians. The administration of chemotherapy or radiation, or the undertaking of a therapeutic surgical procedure, carries with it an implication of hope. Physicians must recognize that any treatment prescribed, even if unlikely to be effective, will often engender significant hope. The very act of treating Mr Arato with chemotherapy conveyed hope to this patient and his family, and the moral impact of this act should be understood.

Discussion between doctors and cancer patients at the

outset of therapy will frequently focus on the specifics of a treatment, its mechanism of action, and potential side effects. Because of the implicit hope that accompanies any treatment, this juncture is a natural time for optimism in many patients. Doctors should be aware of this tendency and can effectively balance honesty with hope by focusing discussions on the goals of therapy. While specific details of treatment issues are of obvious importance, clinicians should be careful to emphasize the overall therapeutic strategy. Doctors could have told Mr Arato that although chemotherapy was unlikely to be effective, some patients do benefit. They could dampen any unrealistic expectations by discussing the infrequency of response and eliciting the patient's views toward hospice care in the case of recurrence. This would lay the groundwork for future discussions, which are likely to be necessary, and would signal to the patient the physician's willingness to talk about these difficult issues.

Remission/Off-Therapy

The completion of cancer therapy is a time of mixed emotions. Anxiety about return of disease may be heightened by the fact that no active treatment is currently being used. At the same time, patients may be elated to have completed often rigorous treatment programs, and their anxiety frequently coexists with tremendous hope. Physicians caring for off-therapy cancer patients must guide them through the psychologic middle ground between hope and fear of relapse.

Questions about the usefulness of statistics may come up at any point in the oncologist-patient dialogue, but these issues are especially prominent when patients are in remission. "Now that I am in remission, what are the chances of relapse?" and "When will I be considered cured?", are questions frequently voiced at this point. Should the oncologist have told Mr Arato the relevant statistics?

Many patients may not have a full understanding of statistics. Even those with complete mastery of statistical concepts recognize their limitations when applied to specific cases. For this reason, many oncologists will not voluntarily disclose the chances for cure to individual patients. When specifically asked for numeric estimates of chance for cure, it may be appropriate to provide a range derived from the literature or institutional experience. However, it is crucial to ensure that patients understand that statistical information includes only patients whose outcome has already been determined and that their own illness may or may not follow a similar course. Doctors and patients must be reminded that survival is

an all-or-none phenomenon, the ultimate limitation of statistics to any given case.

Relapse/Recurrence

A fourth important juncture to consider in the case of Mr Arato is the discovery of tumor recurrence. The ethics of hope and oncology are transformed with a cancer that is clearly incurable and expected to be rapidly fatal. In this situation, actively fostering hope for survival would be deceptive and cannot be condoned.

With regard to the ethics of hope after tumor recurrence, the question to be considered is "Hope for what?" Even those patients who can have no expectation of cure or long-term survival can hope for good pain relief, spiritual peace, and a good death. Doctors must go beyond simply responding to patients' hope and be active participants in shaping realistic hopes when cancer recurs. For Mr Arato, physicians might have emphasized the altruistic value of participating in a clinical trial or focused on palliation of specific symptoms Arato experienced. The maintenance of any obtainable goal, mutually agreed upon by doctor and patient, can provide valuable hope to patients with tumor recurrence or relapse.

CONCLUSION

In one sense, complete and total disclosure of all medical information would be the easiest course for oncologists to follow. Because patients are not physicians, this strategy would be an abdication of the physician's responsibility. Patients rightfully expect their doctors to interpret and filter medical information before they disclose that information. Doctors must be honest with their patients, but must also use common sense and understand human nature.

In addition to the positive obligation to be honest with patients, there exists an obligation to promote reasonable hope for patients with cancer. This obligation is based on respect for the remarkable healing powers of the human spirit, responsibility for promoting the psychologic and physical health of patients, and humility in understanding the limitations of a clinician's ability to predict the future with certainty.

The principle of respect for hope should be more prominent and explicit in medicine and bioethics. Patients do not want a callous disclosure of grim diagnosis or prognosis, but wish for a style of disclosure that allows for them to preserve hope. Beyond the simple rationale of giving patients what they want and need, the promotion of hope holds a valued place in the traditional art of medical practice.¹⁷

Physicians should be encouraged to disclose prognosis, even in tragic cases like that of Mr Arato. But interpretations of *Arato v Avedon* that mandate statistical disclosure¹⁴ may have the unfortunate result of removing from physicians the latitude necessary to

disclose prognosis sensitively at the right time and without unnecessary bluntness. Individual physicians at the bedside must be free to determine the best mixture of hope and honesty at a particular clinical moment.

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