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Prognosis Terminal

Truth-Telling in the Context of End-of-Life Care

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Abstract: Recent contributions to the medical literature have raised yet again the issue of whether the term "terminal" is an intelligible one and whether there is a consensus view of its meaning that is sufficient to justify or even require its use in discussing end-of-life care and treatment options with patients. Following a review of the history and development of informed consent, persistent problems with the communication of prognosis and the breaking of bad news are analyzed. The author argues that candid but compassionate communication between physicians and patients about prognosis is essential to informed decisions about both disease-directed (curative) and palliative therapies.

Keywords: terminal; informed consent; prognosis; bad news; truth-telling

> Informed consent is a foundational concept of medical ethics. Since its enunciation almost 4 decades ago, it has engendered, and continues to engender, a great deal of debate and opposition from practicing physicians.
>
> A. Meisel and M. Kuczewski, "Legal and Ethical Myths about Informed Consent"[1]

Introduction

The passage above appears to pose a conundrum. How can a concept that is deemed foundational to a profession at the same time be a source of serious and sustained opposition within that very profession? Reason would seem to dictate that both propositions cannot be true. Either informed consent is not, in fact, a foundational concept of medical ethics or the appearance of opposition is an artifact of divergent views on how a patient's right to informed consent can be respected in the context of individual cases. In the relatively brief history of informed consent (barely more than 60 years), the sources of contention have varied. Originally the focus was primarily on the risks that must be disclosed. Later the debate moved to the standards for disclosure of information—was it what a reasonable physician would choose to disclose, what a reasonable patient would want to know, or what *this* particular patient wants to know? More recently still, the dispute is one of whether the standards of disclosure of prognosis should be different from those for diagnosis or treatment options. The question of whether a

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patient's prognosis is always an essential element of an informed consent to undergo or decline treatment will be answered in different ways by different practitioners. Moreover, as we shall consider further, on the rare occasions when this issue has arisen in the context of litigation, the message from the courts has been mixed.[2]

In a recent piece in the *BMJ*, Leslie Blackhall, a palliative medicine specialist at the University of Virginia School of Medicine, states without qualification or equivocation: "Patients do not need to be told that they are terminally ill." Apparently she does not consider this assertion to be inconsistent with her subsequent statements that "patients have the right to the best prognostic information available," and she upholds that not telling patients that they are terminally ill does not, by implication, constitute "an argument for deceiving patients, or for reverting to a paternalistic mode of care."[3] Blackhall insists that her critique of a purported duty to disclose a terminal prognosis is more than merely a semantic quibble over the meaning of "terminal." Nevertheless, she begins by maintaining that an important reason why disclosing a terminal prognosis is impossible is because we have no clear and consensus-driven definition of the term. But she goes on to raise a more subtle and substantive critique of the failure of the medical profession and larger society to address the question of how human mortality should inform the practice of medicine. It is to this larger question that more attention should be paid, though it will not necessarily support Blackhall's wholesale dismissal of terminality from physician-patient discourse.

Moving beyond the Semantics of Dying and Death

As a palliative medicine specialist, Dr. Blackhall surely is aware of the requirement in the United States that in order to qualify for the Medicare hospice benefit, beneficiaries must be certified by their personal physician, and by a hospice physician, to be terminally ill, that is, they have six months or fewer to live if the illness runs its normal or reasonably anticipated course.[4] In conjunction with the Oregon Death with Dignity Act, which requires that a patient be determined by two physicians to have a terminal disease, the Oregon legislature defined "terminal disease" as "an incurable and irreversible disease that has been medically confirmed and will, with reasonable medical judgment, produce death within six months."[5] What physicians in such situations are being called on to do in making such a certification is to engage in the clinical endeavor of prognostication. About the vagaries of this process, and remarkable attitudes toward it that have been found to be pervasive among medical practitioners, there will be much more to say in due course. What is most important for our purposes at this point is that it is not semantics but the exercise of sound clinical judgment about the trajectory of the patient's illness in which physicians are engaged. Indeed, this is precisely the point made by the coauthors of a counterpoint commentary appearing in the same issue of the journal.[6] In their view, the characterization of a condition as terminal simply indicates that it is incurable and life limiting. It in no way dictates how the patient might or should take that into account in making decisions about treatment.

Lack of a clear and strong consensus definition is not limited to the term "terminal illness." The same can be said about "dying," or "end of life." One of the primary

lessons of the extensive research protocol of intensive care unit patient management practices in the mid-1990s known as SUPPORT—Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment—is that it is extremely difficult to overcome the pervasive disinclination of physicians to discuss prognosis and patient preferences with gravely ill patients and/or their families.[7] One reason for this disinclination is that physicians realize how little training they have received, and hence how inadequate is their knowledge base and skill set, in the science and art of prognostication. As the SUPPORT project demonstrated, in the hospital setting the consequence of these deficiencies is that much terminal care in the United States is unwanted and inappropriate.[8] But other research has identified an even deeper and profound basis for the disinclination to confront gravely ill patients with the best available information about and assessment of their prognosis. But before delving into that, a brief review of the history of informed consent and the place of prognostication in it is in order.

In the Crucible of the Courts: From Brute to Informed Consent

The footprints of attorneys and judges are all over the history of informed consent doctrine in the United States. The ostensible duty of healthcare professionals in general and physicians in particular to engage patients in a discussion of important aspects of their condition was not the product of some presidential commission on bioethics or ethics committee of an influential professional organization such as the Council on Ethical and Judicial Affairs of the American Medical Association. The belated recognition by such organizations of the ethical responsibility of physicians to obtain the informed consent of their patients to any proposed treatment (or nontreatment) of a condition was a lagging indicator of what began as a legal duty forged in the crucible of the courts. No one has written more extensively or more eloquently on the categorical resistance of the medical profession to the principle of informed consent and the autonomous decisionmaking by patients than the late physician and longtime law professor Jay Katz, who wrote: "Disclosure and consent, except in the most rudimentary fashion, are obligations alien to medical thinking and practice. Disclosure in medicine has served the function of getting patients to 'consent' to what physicians wanted them to agree to in the first place."[9] This is the paternalistic use of information that Blackhall ostensibly rejects. As Katz points out elsewhere, the term "informed consent" initially appeared in the Nuremberg Code as the first principle of a set of duties owed by those conducting research on human subjects. He notes, however, that the authors of the code appeared to believe, erroneously, that they were merely articulating what was already a well-accepted principle of such research that had been flagrantly violated by the "Nazi doctors," when in fact such a principle of full disclosure was no more part of the ethos of clinical research than it was of clinical practice in that era or for some time thereafter.[10] The extent to which this was true was not fully documented and disseminated until the seminal article by Henry Beecher appeared in 1966 describing a host of research studies by prominent American academics in which the consent of the subjects was either inadequate or absent altogether, and in the worst of cases, in which material misrepresentations of fact were made in order to induce consent to participation.[11]

The first case involving patient care in which the term "informed consent" was used followed the Nuremberg Code by ten years and involved what was at the

time a novel procedure (administration of sodium acetrizoate) offered by physicians at Stanford University to definitively diagnose a suspected block of the abdominal aorta. Following the procedure the patient suffered permanent paralysis of both legs. In finding that the physicians had failed to adequately warn the patient that the procedure was not yet standard care and carried substantial risks, the California Court of Appeals wrote: "In discussing the element of risk, a certain amount of discretion must be employed consistent with the full disclosure of facts necessary to an informed consent."[12] Prior to this decision, legal cases recognized the general duty of physicians to secure the consent of the patient before performing any procedure that carried material risks, but there was never any clear articulation of what information, if any, a physician must impart to the patient for such consent to be valid.

Delineating the Parameters of the Informed Consent Doctrine

The most clearly articulated and often-cited informed consent decision is *Canterbury v. Spence*.[13] A detailed discussion of the facts of the case is both unnecessary and beyond the scope of this article. What is most illuminating about the opinion, written by the distinguished federal judge Spottswood W. Robinson III, is the analysis of the history and implications of the very silent world of doctor and patient alluded to by Jay Katz. Critiquing prior decisions that looked to the custom and practice of physicians as the benchmark for the standard of disclosure, Robinson wrote:

> There are, in our view, formidable obstacles to acceptance of the notion that the physician's obligation to disclose is either germinated or limited by medical practice. To begin with, the reality of any discernible custom reflecting a professional concensus [sic] on communication of option and risk information to patients is open to serious doubt. We sense the danger that what in fact is no custom at all may be taken as an affirmative custom to maintain silence. . . .
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> Nor can we ignore the fact that to bind the disclosure obligation to medical usage is to arrogate the decision on revelation to the physician alone. Respect for the patient's right of self-determination on particular therapy demands a standard set by law for physicians rather than one which physicians may or may not impose upon themselves.[14]

This portion of the decision is not only a definitive pronouncement of a patient's legal right to pertinent information, but also one of a number of important court decisions standing for the proposition that no industry, occupation, or profession (even one as revered as the medical profession) can be allowed to set its own standards of safety and performance such that it is beyond the authority of law to review as to its adequacy.[15]

Having established a physician's duty to disclose and the absence of any prior custom and practice of doing so, the standard of disclosure set by the *Canterbury* court (also adopted by a substantial minority of other U.S. jurisdictions) is what a reasonable person in the patient's situation would wish to know. Despite the persuasive language in *Canterbury*, a slight majority of jurisdictions adopted the reasonable physician standard of disclosure. The focus in *Canterbury* was on risks of the procedure, because that was the thrust of the complaint. However, in its

entirety, the duty to disclose encompasses much more than potential risks and anticipated benefits of the procedure or therapy in question. Other well-recognized elements of the informed consent doctrine include the nature and purpose of the procedure, alternative approaches and their relative risks and benefits (including doing nothing, sometimes referred to as "active surveillance"), and the prognosis with and without treatment, as well as the qualifications and experience of the clinician(s) providing the treatment.

Of particular relevance to this discussion, the *Canterbury* court was also careful to note certain exceptions to the duty to disclose. The first was the so-called emergency exception, in situations in which the patient is unconscious or otherwise without the ability to provide an informed consent, no acceptable proxies are readily available, and delay in initiating treatment poses material risks of morbidity or mortality. A reasonable patient is presumed to want timely and appropriate treatment under such circumstances, so the patient's consent is presumed. Another exception, which the court does not address but which is implicit in the bioethical principle of respect for individual patient autonomy that the informed consent doctrine seeks to preserve and protect, is when the patient voluntarily declines to receive information that would otherwise be essential to an informed consent. It is axiomatic that a patient can decline to receive any information that she has a right to receive. In other words, the right to receive such information cannot legitimately be transmogrified into a duty to receive it. The final exception, discussed at some length in *Canterbury*, is critical to our current consideration.

"You Can't Handle the Truth": The Rise and Fall of the Therapeutic Privilege

In a classic trial scene from the motion picture *A Few Good Men*, the young judge advocate general (played by Tom Cruise) shouts at the seasoned officer whom he is cross-examining (played by Jack Nicholson): "I want the truth!" In response, Nicholson shouts back at him: "You can't handle the truth!" This assertion, in a nutshell, constitutes the foundation for the exception to the disclosure duty recognized (with strong reservations) in *Canterbury*; this exception has come to be known as the "therapeutic privilege." In theory and practice, it may be invoked if and only if the physician, in the exercise of sound clinical judgment and discretion, determines that a patient's physical and/or psychological state is such that disclosure of certain information otherwise required for a fully informed decision poses an unreasonable and significant risk of harm. As judge Robinson noted: "The physician's privilege to withhold information for therapeutic reasons must be carefully circumscribed, however, for otherwise it might devour the disclosure rule itself. The privilege does not accept the paternalistic notion that the physician may remain silent simply because divulgence might prompt the patient to forgo therapy the physician feels the patient really needs."[16] Given the significant changes in medical practice in the decades since the privilege was initially recognized, including the depersonalization of many physician-patient encounters, it will rarely be the case today that a physician can maintain with conviction and credibility that she knows her patient's psyche well enough to determine that she can't handle the truth about her condition. So it is that a report by the American Medical Association Council on Ethical and Judicial Affairs concluded, without qualification or exception, "Withholding medical information from patients without their knowledge or consent is ethically unacceptable."[17]

Not only should patients be presumed to be able to handle the truth, but they should be presumed to want the truth unless they provide a clear indication to the contrary. In a 1982 national survey conducted by the Louis Harris agency at the behest of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 96 percent of Americans wanted to be told if they had cancer (or presumably another potentially life-threatening condition) and 85 percent wanted a realistic estimate of how long they had to live if the nature of their disease usually leads to death in less than one year.[18] It would be paternalistic in the extreme to suggest that such results are simply the surmises of generally healthy people who really have no idea what they would wish or what would be in their best interests at such time as they were to develop a serious illness.

What We Have Here Is a Failure to Communicate: Clinical Antipathy to Breaking Bad News

The mid-1990s was a period in which major national medical organizations engaged in a careful and thorough reexamination of end-of-life care in response to a collective sense (based on data such as SUPPORT) that as a result of an overemphasis on delivering high-tech, disease-directed therapy, too many patients with no realistic prospects for recovery were being cruelly flogged with interventions that merely prolonged and in many instances even exacerbated their suffering. Organizations such as the American Board of Internal Medicine[19] and the Institute of Medicine[20] published reports setting forth the hallmarks or essential elements of good care for the dying. Both emphasized the importance of a sensitive but truthful discussion of information concerning prognosis and of showing respect for patient wishes. In roughly the same period, studies were being published that confirmed that an accurate (as possible) discussion about prognosis actually matters in the choices patients make. For example, Murphy and colleagues found that similar groups of patients over the age of 60 with major chronic conditions came to significantly different conclusions about cardiopulmonary resuscitation (CPR) depending on what they understood to be their likelihood of survival to discharge after resuscitation. Once they understood that the likelihood was quite low, the percentage of patients wishing CPR dropped by 50 percent.[21] Similarly, Weeks and colleagues found with regard to cancer patients that those who understood that their prognosis was six months or more were 50 percent more likely to favor disease-directed (life-extending) therapy over palliative measures than those whose prognosis was believed to be less than six months.[22] In that study, unlike in SUPPORT, physician prognostic accuracy was quite high, whereas patients who did not receive prognostic information from their physician frequently overestimated their chances of survival for at least six months, thereby demonstrating the importance of prognostic disclosure to patients at the end of life.

No one has studied contemporary physician attitudes and practices in the domain of prognosis more extensively than the Harvard internist and medical sociologist Nicholas Christakis, who, in his seminal work on the subject, observed: "Physicians regard prognosis with anxiety and disdain, and they avoid it if possible."[23] Christakis reached this conclusion after conducting numerous qualitative studies that consistently revealed that a substantial percentage of physicians expressed negative attitudes toward prognostication, some going so far as to acknowledge a

belief that by the very act of rendering a grim prognosis one could, through some mysterious and inexplicable process, directly influence the trajectory of the patient's illness—a form of self-fulfilling prophecy. Even clinicians who do not go this far consistently express concerns about causing patients to lose hope if they fully inform them about the statistical likelihood that their disease will result in their death in the foreseeable future regardless of what therapeutic measures are undertaken.[24]

The legal case that most directly confronts the duty of physicians to disclose prognosis as part of the informed consent process is a decision by the California Supreme Court in *Arato v. Avedon*.[25] In discussing *Arato*, it is important to understand that the precedential value of any case is limited by its factual context. The clinical facts at issue arose in the early 1980s, when Mr. Arato, age 42, underwent surgery for the removal of a kidney. In the course of that operation, the surgeon noted a tumor on the tail of the patient's pancreas. After obtaining the consent of Mr. Arato's wife, the surgeon resected the tumor along with the spleen and diseased kidney. He indicated to the Aratos in a follow-up discussion that the biopsy revealed that the tumor was malignant and that he was referring Mr. Arato to an oncologist for consideration of further treatment. There was no discussion at that time of the patient's prognosis.

At the time of the initial meeting between the Aratos and the oncologist, Mr. Arato was asked to complete a 150-item questionnaire, which included a question as to whether he wished to be told "the truth" about his condition or whether he preferred for the physician to "bear the burden." Mr. Arato checked the disclosure option. The court's discussion of the treatment recommended to the Aratos by the oncologist focuses more on the reasons why further treatment was recommended than on precisely how much of that was disclosed in the process of securing the consent. The aspects of Mr. Arato's situation that made his prognosis somewhat more favorable than the typical pancreatic cancer patient included the following: (1) the tumor was discovered before it became symptomatic, (2) the resection achieved clean margins, and (3) tumors in the distal (tail) portion of the pancreas tended to have a somewhat lower mortality rate. In combination, these factors were believed to warrant an aggressive approach in the hope of reducing the likelihood of recurrence or metastases. A further complicating factor, not directly addressed by the court, was the quasi-experimental nature of the therapy offered, which included a strong combination of chemo and radiation therapy.

The undisputed aspects of the disclosures made to the Aratos were that most patients with pancreatic cancer die from the disease, and if he did experience a recurrence, it would not be treatable. Mr. Arato consented to the proposed treatment but nevertheless experienced a recurrence of the cancer less than a year after the initial diagnosis and died several months later. The critical issue in the litigation that Mrs. Arato initiated against the oncologist and the surgeon was whether or not the failure to provide Mr. Arato with the statistical life-expectancy data for patients with pancreatic cancer rendered his consent to treatment uninformed and thereby fell below the standard of care. Mrs. Arato's complaint maintained that in the absence of all of the available information about the grimness of his prognosis, Mr. Arato consented to painful and debilitating therapy he would have otherwise refused, and he failed to get the family's financial affairs in order.

In justification of the decision not to provide such data as part of the informed consent process, the surgeon offered intimations of the therapeutic privilege,

asserting that, given the level of anxiety he observed in Mr. Arato, it would have been medically inappropriate to disclose specific mortality rates. The oncologist argued both that disclosure of the extremely high mortality rates for pancreatic cancer would deprive these patients of hope and also that such data had little predictive value for individual patients.[26] The jury found in favor of the defendants, specifically finding that they had "disclosed to Mr. Arato all relevant information that would have allowed him to make an informed decision regarding the proposed treatment."[27] The court of appeals reversed the judgment on several grounds, including that, in the absence of statistical life-expectancy data, a patient in Mr. Arato's situation would be unable to adequately assess the reasonableness of undertaking the rigors of the therapy that was being recommended to him. The California Supreme Court, however, reversed the decision of the court of appeals and reinstated the jury verdict on the grounds that the jury instructions had been adequate and, in applying them to the facts of the case, the jury had reasonably determined that the information provided to the Aratos by their physicians was sufficient for a reasonable person to assess the risks and benefits of proffered treatment. The California Supreme Court particularly noted that as a matter of law and policy it considered it unwise to require that "a particular species of information be disclosed."[28]

Shortly after it was rendered, the decision prompted two divergent commentaries in the medical literature. George Annas critiqued the decision as much too narrowly focused, thereby failing to sufficiently emphasize how robust was the law of informed consent in California. Invoking the deception inflicted on Ivan Ilyich and drawing on the writing of Jay Katz, Annas argued for the strongest of presumptions (rebuttable only by clear and convincing evidence) that patients in circumstances similar to Arato would wish for a full and candid disclosure of their prospects.[29] The other commentary, by Kodish and Post, argued that, particularly in the care of cancer patients, physicians have a dual duty—to meet the patient's informational needs while at the same time fostering hope that is reasonable given the patient's circumstances. They seek to draw a distinction between the moral duty to disclose a cancer diagnosis, about which there is rarely uncertainty, and a duty to disclose prognosis, which may be subject to much greater uncertainty.[30] Interestingly, recent developments within the oncology community suggest that the relative certainty of cancer diagnosis may be subjected to further scrutiny. Presently there is a movement afoot to redefine what constitutes a legitimate cancer diagnosis so as to remove from that designation premalignant conditions that, in the view of some clinicians, have led to a disturbing trend of overdiagnosis and overtreatment.[31] The medicolegal implications and potential ramifications of this project are complex and significant but also well beyond the scope of this article.

Informed Consent and the Moral Duty to Prognosticate

The overwhelming weight of the evidence is that prognosis is as an essential element of informed consent as diagnosis, treatment options, and the risks and benefits of those options. In the words of Christakis, "there is not only a moral duty *in* prognostication, but a moral duty *to* prognosticate. Thus the avoidance of prognosis that is prevalent in medical care represents the shirking not only of a clinical but also a moral responsibility by physicians."[32] The question raised by Blackhall is whether truth in prognostication, and respect for the patient's right to

make informed decisions about treatment in the context of grave or life-threatening illness, entails at least in some circumstances the use of the term "terminal." As noted previously, for some purposes medical certification of at least the medical probability that the patient is terminal according to prevailing clinical criteria for the use of that term is required if patients wish to qualify for the Medicare hospice benefit or secure a lethal prescription in Oregon, Washington, or Vermont. Whether or not Blackhall agrees, the studies and public opinion surveys noted previously strongly suggest that knowing as much as can reasonably be known about the likelihood that they will survive for more or less than six months (the parameters of terminality) is important to a majority of Americans. In some sense, perhaps for a variety of reasons, it has meaning to them, and consequently physicians need to engage with patients accordingly to meet those needs and expectations.

Recognizing how poorly trained and profoundly uncomfortable many physicians are when it comes to sensitively discussing prognosis and answering patients questions such as "how long do I have to live?" some outstanding specialists in this field have developed educational opportunities for their fellow clinicians. One of these is Education in Palliative and End-of-Life Care (EPEC®).[33] Another valuable resource is Oncotalk®.[34] Both of these contain modules on breaking bad news. These communications strategies encompass a range of situations, from the initial diagnosis of cancer or some other potentially life-threatening condition to situations in which disease-directed therapy has failed to prevent the progression of the disease and the prognosis has become poor. Hospice and palliative care then become an integral part of the discussion.

We See through a Glass, Darkly

The duty to engage in prognostication, an essential feature of which is communication of the best prognostic evidence to the patient in a cogent yet compassionate manner, does not presuppose a level of certainty that current prognostic science will not support.[35] Among the skills that physicians who care for patients with serious conditions from which they will likely die in the short term must cultivate is the sharing of clinical uncertainty. The following is an apt articulation of the case for conveying clinical uncertainty to patients.

> Although the anxiety associated with uncertainty is real, it is not a sufficient argument for failing to disclose uncertainty. The evidence that patients want information is overwhelming, and the mere fact that the receipt of information causes distress does not mean that patients would prefer not to know. . . . The mere fact that a patient exhibits anxiety and even some reticence about discussion is not sufficient evidence that discussion should not proceed.[36]

This admonition effectively undermines the rationales for nondisclosure of statistical life-expectancy data by the physicians caring for Mr. Arato. As Jay Katz so eloquently argued, patients have a dignitary interest in the most accurate information about their medical condition that can be provided. Consequently, we do them a profound injustice when we revert to abstract speculations as to what a reasonable physician would disclose or a reasonable (hypothetical) patient would wish to know. The patient is present to the clinician in most instances and

is available for direct engagement on that question. Gauging the patient's informational needs is an essential feature of the communication process.[37] The profession of medicine and the patients that it exists to serve are both diminished when silence, false hope, and the cultivation of ignorance predominate.

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