Talking About Clinical Practice Guidelines: How Much Should Patients Be Told?

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Clinical guidelines are 1 of the tools available to help physicians and patients make decisions about appropriate health care. When clinicians are asked to follow guidelines, however, the potential for ethical dilemmas arises. The central ethical dilemma faced by today’s clinicians is the difficult task of balancing traditional obligations to the patient with new and less well-understood obligations to conserve resources [1]. When clinicians are asked to both advocate for their patients’ well-being and to be responsible stewards of health care resources, they must fulfill dual and sometimes incompatible roles [2,3]. This article will discuss the ethical issues surrounding the task of balancing obligations and the standards to which physicians should be held accountable.

Some Ethical Questions Raised by a Breast Cancer Screening Guideline

Case Presentation

Mrs. Jones, a 40-year-old married librarian with 3 children, presents to her new primary care physician, Dr. Smith, for routine health maintenance. She has no complaints. During the visit, the physician learns that she has not had a screening mammogram. No one in her family has had breast cancer and she has no other factors that increase her risk for developing breast cancer. The physician is aware that some organizations, such as the American Cancer Society, recommend screening with mammography beginning at age 40 [4]. Other organizations, including the staff-model HMO to which he belongs, recommend mammography screening beginning at age 50 for women who are at average risk for breast cancer. Radiology will not schedule mammograms for patients under age 50 unless they meet the high-risk criteria.

In this case, the physician is being asked both to fulfill his fiduciary responsibility to the patient and to participate in quality improvement initiatives within his organization. Should he discuss the conflicting guidelines with his patient? Should he inform her about the lack of consensus regarding breast cancer screening?

The Physician’s Dual Obligations

These difficult questions arise from the central ethical dilemma of the clinician’s duty to the patient versus another, less well-defined duty to future patients and to society. The physician’s obligation to the patient is never absolute, and this dual role is not a unique ethical problem. Physicians have always had some obligation to society, and they have always been asked to balance this obligation against an obligation to the patient. For example, there is general agreement that physicians have a duty to protect patient confidentiality. However, society also requires physicians to break that obligation if a patient shows evidence of violence or has a sexually transmitted disease. Therefore, Dr. Smith’s choice between following a guideline that will best serve society and acting in what he perceives to be Mrs. Jones’s best interest is not a new dilemma. However, the recent focus on using guidelines to deliver the best care for the greatest number of people does create new challenges for physicians.

What the Physician is Obligated to Discuss

In cases involving proven treatments or tests, the law and norms of physician responsibility mandate that physicians seek a patient’s consent before performing them [5]. If Dr. Smith decides to order a mammogram, he should first provide Mrs. Jones with the information necessary for her to make a choice that is free of influence and coercion [6–8]. Mrs. Jones would then have the right to refuse the procedure. However, because the HMO’s guidelines do not recommend a screening mammogram for Mrs. Jones, the issue is more complicated. If Dr. Smith is obligated to obtain Mrs. Jones’s consent before ordering a mammogram, is he also obligated to obtain her consent not to order it?

Dr. Smith has an obligation to discuss all proven diagnostic and treatment options. If a mammogram would clearly produce effective results in Mrs. Jones’s case, Dr. Smith would be obligated to discuss it. However, he need not discuss a
Discussing Interventions of Uncertain Benefit

Dr. Smith’s choice would be straightforward if screening mammography were proven to be either clearly effective or clearly ineffective for women in Mrs. Jones’s age-group. The problem Dr. Smith faces, however, is that in Mrs. Jones’s case a mammogram is neither. Although a mammogram may benefit Mrs. Jones, a false-positive result would require further tests and possibly a biopsy, with their attendant costs. Therefore, because the benefits of ordering a mammogram for Mrs. Jones are disputable, and because her health plan will not pay for the procedure, Dr. Smith must decide whether or not to discuss the guideline with Mrs. Jones and whether or not to discuss his uncertainty about it.

Discussing Guidelines: When and How Much Should You Tell Your Patients?

Although there is no easy solution to the dilemma of balancing obligations, we recommend 3 general criteria for deciding how much information physicians are obligated to share with their patients: the reasonable person standard, the subjective standard, and what we will call “the equipoise standard.” Although we discuss each criterion individually, in actual clinical practice they are not discrete categories for evaluating a physician’s responsibility to disclose information to her patients. Physicians should discuss the diagnostic or treatment option in question if any of the criteria apply.

The Reasonable Person Standard

Given the increasingly rapid rate of advances in health care technology, many patients may not be aware of newly approved treatments or diagnostic tests. Although information is becoming readily available to patients, physicians should assume that their patients do not know about a new test or treatment option unless a health care provider discusses it with them. According to the reasonable person standard, a physician should discuss a test or treatment with her patients if she believes that a reasonable person would expect to be informed that it is an option.

Because a duty to tell the truth is implied in the physician-patient relationship, physicians must tell patients the truth whether or not patients expect them to. This duty to tell the truth, in turn, is mandated by the broader duty of the physician to respect her patients [9,10]. Because disclosing information to patients can therefore be seen as a mark of respect for them as people, physicians may also be obligated to discuss treatment and testing options with patients if failing to do so would constitute conscious deception on the part of the physician.

Consciously withholding information about a test or treatment may significantly damage the public’s trust in the medical profession [11]. More importantly, a lack of trust could weaken the foundation of the physician-patient relationship and reduce the efficacy of the therapeutic alliance. Therefore, to the extent that physicians have a duty to preserve the public’s trust in the profession [12], they may also have a duty to discuss even futile treatments if failure to do so might weaken that trust. If a patient believes that her physician would have discussed an intervention if there were even a marginal chance of its efficacy, failure to do so would violate the reasonable person standard. In the case of Mrs. Jones, Dr. Smith should discuss the disputed mammography guidelines if he believes that a reasonable person would expect to be informed that the procedure is an option, despite it not being covered by her health plan. Failure to discuss the mammogram guidelines may cause Mrs. Jones to believe that early screening for breast cancer is of no benefit to her.

The Subjective Standard

Although the reasonable person standard requires that a physician discuss a procedure or treatment if a reasonable person would want to know about it, the subjective standard requires that she discuss it if she believes that the patient in question would desire that information. This criterion is more stringent and requires not only that physicians disclose the options that most patients would want to know about, but also those options that each individual patient would believe important. Dr. Smith should discuss the mammogram with Mrs. Jones if he has reason to believe that she would want information about it. This might be the case if she had indicated that she was particularly worried about developing breast cancer.

The Equipoise Standard

In some cases, the health care community may be uncertain about the effectiveness of a test or treatment. Benjamin Freedman’s concept of “equipoise” provides an eloquent description of such situations. Freedman originally used the term in the very different setting of clinical research to capture the uncertainty about efficacy that pervades much of modern medical practice [13]. Reasonable, well-informed people often disagree about the merits of a medication, test, or procedure. Under these circumstances, care providers identify as accurately as possible the best treatment by relying on research and consensus. This uncertainty is not an exception or aberration; rather, it is the usual state of the evolving practice of medicine.

Dr. Smith first must assess whether or not equipoise truly exists in Mrs. Jones’s case. He must decide, for example,
whether the HMO’s guideline is derived from sound data and reviewed by experts, or whether it is motivated by financial concerns [14]. Dr. Smith might also consult with physician colleagues whose judgment he respects to assess whether or not equipoise exists. Finally, Dr. Smith should have a working understanding of the guidelines of national organizations.

After careful review, Dr. Smith may decide that a state of uncertainty, or equipoise, exists. To apply Freedman’s term to this case, we might say that because the medical community is divided by uncertainty about the use of mammography, Dr. Smith must assess Mrs. Jones’s preferences in order to decide, with her, if the procedure offers what she believes to be a significant benefit. That is, because science has been unable to establish a definitive answer about the efficacy of mammography in Mrs. Jones’s case, it is especially important for Dr. Smith to elicit her opinions. Mrs. Jones’s concerns, fears, and priorities should drive decisions when no clear scientific consensus exists.

Conclusion
The physician-patient relationship is built on trust and the expectation that physicians will conduct themselves honestly and with respect for their patients. Unfortunately, managed care may threaten the trust that patients have in their physicians. It is not clear how and why the advent of managed care has eroded patient trust, but this danger appears to be real [15]. Therefore, it is more important than ever for physicians to communicate as clearly as possible about options and potential tests and treatments.

Physicians can best accomplish this difficult goal by considering what Howard Brody has described as the ideal of “transparency” [16]. The informed consent process, he argues, should ideally be one of open and honest discussion between physician and patient. Brody urges physicians to make their thinking, particularly their doubts and uncertainties, as clear to their patients as they possibly can.

Thus, Dr. Smith should be prepared to discuss the mammography guidelines openly and honestly with Mrs. Jones and to share any doubts he has about them with her. As we have suggested, a physician might withhold discussion only if she believes that most patients would not expect to be informed about a noncovered intervention or that an individual patient would not expect to be informed about a test or treatment, or if there is general agreement in the medical community that the noncovered intervention does not offer significant benefits to the patient. In all other circumstances, physicians should adhere to Brody’s ideal of transparency. Not only do such discussions offer respect for patients as persons, but they also maintain trust in the medical profession and allow physicians to continue their participation in quality improvement efforts.

References
5. Salgo v Leland Stanford University, 317 F2d 150 (CA 1957).

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