Ethics of Ongoing Cancer Care for Patients Making Risky Decisions

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Vignette

A 31-year-old woman in excellent health presents to her gynecologist with a right breast mass. Mammography and ultrasound confirm a 3-cm suspicious lesion, and biopsy demonstrates high-grade endocrine receptor and human epidermal growth factor receptor 2–negative invasive ductal carcinoma. After discussion of standard therapeutic options with a multidisciplinary oncology team, the patient agrees to neoadjuvant chemotherapy with a plan for subsequent breast-conserving surgery if possible.

The patient is treated with neoadjuvant dose-dense doxorubicin and cyclophosphamide followed by paclitaxel. She tolerates chemotherapy well, and the mass shrinks to the point that it is undetectable on physical examination. After therapy, there is no evidence of the mass by breast magnetic resonance imaging, indicating a clinical complete response. As planned, she is then referred back to surgery.

Although the importance of surgery was explained at initial consultation and subsequent visits, the patient now expresses her intent to forgo surgery and use natural methods to prevent the return of cancer. The potential for residual tumor, limitations of imaging and examination to detect microscopic disease, and the potential life-threatening consequences of incomplete therapy are carefully explained. The patient seems to understand the recommendations and concerns of her physicians. However, she explains that she has found an alternative through the Internet and has met with an herbalist who advertises a more holistic approach. She provides her physicians with correspondence indicating that surgery is viewed as one option, but an alternative involving herbs and supplements can restore balance to the body and prevent recurrence of her cancer. Furthermore, the herbalist has recommended that the patient undergo a battery of laboratory tests, claiming they will help monitor her neuroendocrine terrain and optimize her herbal therapy. The herbalist also recommends indefinite breast imaging studies, including an ultrasound once every 3 months and magnetic resonance imaging once every 6 months to promote early detection of any recurrence. Despite further discussion, the patient continues to refuse surgery and requests that the medical oncologist order the tests recommended by the herbalist and correspond with the herbalist regularly regarding her care and test results.

The oncologist wants to help the young woman and is highly worried that she is placing her life unnecessarily at risk through

this course of action. Her physicians are unsure of how they should proceed.

Discussion

In cancer care, we believe in a model of shared decision making.¹ This is particularly true in the management of early-stage breast cancer, which can involve difficult decisions regarding surgical approach and adjuvant therapy. Patient preferences weigh heavily in determining the ultimate course of care. Oncologists understand that a patient may decline therapy or a component of therapy regardless of the physician's recommendation. However, although there has been considerable attention in the literature to shared decision making, there has been relatively little attention to what happens when patients and physicians disagree. What are the oncologist's obligations in the ongoing care of that patient?

This article evaluates the ethical challenges that arise when an oncologist not only disagrees with a patient's choices but finds them inappropriate or dangerous and presents considerations for ongoing care that can honor the physician's obligations to the patient and society.

The oncologist's obligations. A physician's primary obligation is to the interests and well being of his or her patients. This includes not only the impetus to promote a patient's health, termed beneficence, but also an obligation to respect the patient's individual goals and preferences for his or her care, termed respect for autonomy. In addition, the physician has an obligation to avoid actions that may harm the patient, termed nonmaleficence, as embodied in the Hippocratic charge to do no harm. Finally, the physician is expected to provide care consistent with the broader interests of society and other patients, described as the ethical principle of justice.

The model of shared decision making stems directly from our desire to respect patient autonomy. The fact that medical decisions are not viewed as simply clinical calculations of the course of greatest benefit and lowest toxicity or harm reflects the preeminent position of autonomy in the hierarchy of obligations. However, there are limits to autonomy and the degree to which a patient's choices can compel others to act against their medical judgment or conscience. Conflicts between the obligations noted here must be recognized and evaluated on a case-by-case basis. When a patient's preferences lead to decisions that the physician believes will cause the patient to forgo an opportunity for benefit, there may be an unavoidable conflict

between the obligations to respect autonomy and promote beneficence. If the patient requests the physician to act in a way that may directly or indirectly bring harm, respect for autonomy comes into conflict with the principle of nonmaleficence. If the patient's wishes also require nonevidence-based care or inappropriate use of resources, the principle of justice comes into conflict as well. Negotiating these conflicting obligations requires consideration of the rights of the patient and limits of autonomy.

Patients have a well-defined right to refuse care based on the principle of autonomy and legally grounded in the due process clause of the 14th Amendment, as established in the 1990 *Cruzan* case.² The 2011 American Medical Association Code of Ethics states that physicians have an obligation to discuss benefits, risks, and costs of appropriate interventions, and patients then have the right to accept or refuse any recommended medical treatment.³ If an informed patient refuses care and declines further follow-up, the oncologist's role is limited. The oncologist should offer the patient an opportunity to reestablish care should the patient change his or her mind. The situation becomes more complex if the patient selects alternative therapy and wishes to continue follow-up with the oncologist.

Patients with cancer frequently consider alternative or complementary therapy while also seeking the care of a traditional allopathic oncology specialist.^{4,5} Patients may explicitly wish to retain the option to return to standard therapy, or they may desire access to conventional aspects of Western medicine such as narcotics and radiographic and laboratory studies. Some may want ongoing oncology advice, whereas others may want to use their oncologists' authority to order tests and procedures that will facilitate alternative plans of care.

Potential risks and benefits of ongoing care. Are there ways to ethically continue to provide care and counseling to a patient while not supporting an alternative treatment plan? The optimal course of action may be driven in part by the nature of the patient's condition, the interventions in question, and the patient's rationale for decision making. In some cases, the general prognosis, good or bad, is not markedly changed. A patient forgoing adjuvant tamoxifen for ductal carcinoma in situ still has a good prognosis, and a patient forgoing disease-directed therapy for advanced breast cancer still faces incurable illness with or without therapy. There are multiple factors, including comorbidity, age, risk tolerance, and personal goals and preferences that might lead a patient to decline intervention despite an oncologist's recommendation in either setting.

In contrast, the situation described in this article is challenging on several levels. First, the stakes are high. The medical condition in question is life threatening but curable, and it occurs in the context of a young patient with no other medical issues who achieved an excellent response to neoadjuvant chemotherapy. Decades of life and presumably good health are at risk. Second, the patient and oncologist do not share a common understanding of the evidence supporting her actions. In choosing to undergo alternative therapy, the patient is indicating that she remains concerned by the risk of recurrence and wishes to

take action. She believes the herbal therapy is an acceptable alternative to surgery. The oncologist disagrees and feels that she is acting on misinformation. Third, the oncologist is asked to play an ongoing role that supports the alternative care plan. The oncologist is asked to use his or her medical authority to order laboratory and imaging tests that would otherwise be unattainable or prohibitively expensive for the patient. Complicating the situation further, the patient does have clear ongoing needs. Several potential components of ongoing care must be considered.

Communication. Patients may refuse care. They also may change their minds. The oncologist has the obligation at the time of initial consultation to educate the patient regarding the prognosis, options, and potential consequences of declining therapy. Patients should be informed whether the decision to forgo a therapy will limit their future options. For example, the benefits of adjuvant chemotherapy for breast cancer begin to decline by 3 months after surgery, and the risk-benefit ratio of treatment months beyond that point are unknown.⁶ Endocrine therapy, in contrast, may provide benefit even if initiated years after initial consideration.⁷

We do not know if any patient can forgo surgery after neoadjuvant therapy without higher risk of recurrence and death. Still, even under optimal conditions, patients treated with breast-conserving therapy may experience local recurrence. Salvage surgery is believed to provide some benefit and is considered standard unless there is evidence of distant disease.⁸ Thus, ongoing communication and follow-up may facilitate appropriate care in the future, even if there is disagreement regarding the current course of care.

Pain medications. Treatment of cancer-related pain is clearly within the scope of standard oncology practice. For patients with advanced disease, treatment of pain and other symptoms is considered standard regardless of whether the patient pursues disease-directed therapy.^{9,10}

A patient pursuing alternative therapy for cancer may seek follow-up with a medical oncologist specifically for pain management, given that many alternative practitioners are not licensed to prescribe narcotics. Ongoing pain management need not imply agreement with the alternative treatment regimen. A physician prescribing pain medication should monitor its safety and evaluate the source of pain as needed. It might be expected that a patient regularly returning to the medical oncology clinic for pain management would periodically be reminded of disease-directed options to help control the pain, but acceptance of these options should not determine the patient's access to care or pain relief.

Pain management can be performed in the primary or palliative care setting or by a pain specialist. If the patient clearly has no interest in disease-directed therapy, he or she may be appropriately referred to a colleague in one of these fields.

Tests and procedures. As is the case with pain medication, a physician's medical license provides authority to order tests and procedures that cannot be ordered by some alternative practi-

tioners. The physician's order implies medical necessity and is often required for insurance coverage. In some cases, an alternative practitioner may even request a procedure such as central intravenous catheter placement that might facilitate alternative therapy administration.

If the primary purpose of a test or procedure is to facilitate a nonstandard plan of care that the physician feels is potentially harmful, the physician has not only the right to refuse but also an obligation to do so. The analogy is imperfect, but in the case of the *Abigail Alliance v Von Eschenbach*, the courts found that the right to refuse care established in *Cruzan*² and similar cases does not imply a corresponding right to demand care that may be harmful.¹¹ There is no right to unproven care.¹²

Complementary therapy. Although complementary and alternative medicine are often considered together, there is a need to distinguish between use of a nontraditional therapy instead of conventional cancer therapy versus in addition to such therapy. Forty percent to 66% of patients with breast cancer report that they use at least some form of complementary therapy in addition to conventional therapy.⁴ In most settings, the potential risks and benefits of adding such therapy to conventional treatment are unknown. Oncologists should discuss use of complementary therapy with their patients and be aware of what they are taking. In many circumstances, explaining the potential for harm as well as benefit and allowing patients to make their own decisions in the face of uncertainty is reasonable.

An oncologist may be asked to verify the safety or value of a complementary medicine with which he or she is not familiar. The oncologist is expected to have expertise in evidence-based options for a patient's condition. A patient considering a complementary medication that lacks an adequate evidence base should be informed and advised to consult those supplying the intervention. Patients and oncologists wishing to learn more about complementary medicine can find information from the

American Society of Clinical Oncology at <http://www.cancer.net> and from the American Cancer Society at <http://www.cancer.org>. If there is a known risk to the complementary therapy or a reasonable chance that it will make conventional therapy either more toxic or less effective, discontinuation of standard therapy might be considered. As stated, respect for patient autonomy does not convey an obligation to put the patient at risk against the clinician's medical judgment.

Summary

Patients who decline conventional cancer therapy yet seek to continue follow-up while pursuing alternative therapy can pose an ethical challenge. The potential benefits and harms of an ongoing clinical relationship need be assessed on a case-by-case basis. Ongoing efforts at communicating, understanding the patient's basis for decision making, and seeking to negotiate evidence-based care that is respectful of the patient's preferences may improve outcomes.¹³ However, respect for the patient's autonomy does not require support for inappropriate care and should not require that the oncologist check his or her professional judgment at the door.

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