Ethical Challenges in Oncology, Explored Through a Series of Vignettes

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In this article, we have chosen to focus on three ethical challenges that we believe practicing oncologists might commonly encounter with their patients. The ethical dilemmas are presented in a case-based approach in the hope of better joining the ethical theory to clinical practice.

Introduction

Ethics plays a large role in the practice of medical oncology. Because the study of oncology deals so heavily with life or death decisions, physicians are often asked to make ethically difficult choices with their patients. Oncologists may be better equipped to deal with these challenges by being made aware of the related ethical questions in their practice and of the current literature surrounding those questions. We have chosen to focus on three ethical challenges that we believe practicing oncologists might commonly encounter with their patients. The ethical dilemmas are presented in a case-based approach in the hope of better joining the ethical theory to clinical practice.

1. Cost of Therapy

A 50-year-old male patient presents to your clinic with new-onset headaches, fatigue, weight loss, and left extremity weakness. Magnetic resonance imaging (MRI) of the brain shows a large heterogeneous infiltrating right hemispheric mass. Further workup reveals a glioblastoma multiforme. After surgical resection, the patient is sent to you to start treatment with temozolomide (Temodar). He is self-employed, has no health insurance, and has a gross income of about $45,000/year. You want to begin therapy but are mindful of the financial implications of continuing with treatment and all its associated costs. What are your obligations to provide this patient with temozolomide if he cannot afford it?

At the core of every healthcare system is the challenge of treating populations with finite resources. This universal fact makes decisions concerning distribution of resources a significant concern. The rising cost of healthcare in the United States, coupled with underperformance in many outcome measures compared with similar developed nations, raises questions about whether we are distributing resources effectively and fairly. Sulmasy comments that “decisions to distribute resources will always be moral decisions, informed by concepts of justice.”[1] This concept is usually termed distributive justice. Beauchamp and Childress point out that distributive justice applies to the “distribution of all rights and responsibilities in a society, including civil and political rights.”[2] Although allocation of resources is a controversial topic, it is useful to examine how the means of making allocation decisions may already be at work in our healthcare system. Beauchamp and Childress describe six principles of distributive justice that underpin allocation of resources in a healthcare system. Resources might be allocated to each person according to these principles: (1) equal share, (2) need, (3) effort, (4) contribution, (5) merit, and (6) free-market exchanges.[2] Historically, the United States has worked under the principle of “to each person according to free-market exchanges,” meaning that resources are rationed according to whether a patient can afford to pay for them, either through his or her own means or by virtue of having access to health insurance. Free-market exchanges as a basis for determining healthcare allocation decisions have proven difficult because, unlike in other circumstances in which consumers purchase goods, “the consumer patient is not generally in control of purchasing decisions.”[3] The Lancet Oncology Commission, which developed a report on delivering affordable cancer care in high-income countries, found that healthcare does not conform to the principles of an ideal market. The Lancet Commission argued that there is an inherent inequality in information and power relationships between buyers and sellers.[3] Analyzing our case above, if the decision is to be made according to free-market exchange principles, the patient should not receive temozolomide because he cannot...
The healthcare provider is thus in the difficult, but increasingly common, position of being asked to consider directly the cost of therapy, including the cost of the drug itself and the cost to the patient, when discussing therapy options. Generally, physicians are uncomfortable with engaging in such allocation decisions at the bedside. A 2006 survey by Nadler found that as many as 81% of physicians consider their patient’s out-of-pocket expenses when determining therapy,[4] although it is unclear to what extent allocation decisions are made in real practice by individual physicians about individual patients. Sulmasy comments that “many health care policy analysts and ethicists have argued that...the only point in the system at which one could effectively ration health care would be through the individual practitioner.”[1] Some analysts and ethicists believe physicians should play an instrumental role in balancing the needs of their patients and those of society.[1,5]

One reason that physicians are generally uncomfortable being placed directly in the position of making allocation decisions about individual patients at the bedside is that their strongest obligations to advocate on behalf of patients are then brought into conflict with obligations to the greater societal good.

Under these circumstances, physicians often feel that they are bound by an oath to act in the patient’s best interest and so perceive that they must provide beneficial therapies that have been shown to significantly prolong overall survival. We would suggest reframing this obligation, however, since physicians cannot in reality be ethically obligated to provide the temozolomide. Rather, we would argue that physicians must (1) provide information about the relative risks (including financial risks) and potential benefits of the therapy in question, including the alternatives and their risks and benefits; and (2) attempt to use all reasonable means to help the patient obtain the medication if he or she makes an informed decision to take it. This might include seeking charity sources, patient assistance programs, or even, in some cases, providing the treatments at cost if they can be reasonably balanced against other sources of revenue. That physicians must provide a beneficial treatment at all costs, even personal costs, is clearly not an ethical obligation under any framework of professional ethical practice.

It is also useful to recognize that physicians may have particular views of the cost-effectiveness of the therapies they offer, and that patients’ views may in fact differ from those of physicians, although patients’ attitudes in this area remain largely unexplored. For example, when asked about cost-effectiveness, the median implied cost-effectiveness threshold among oncologists was $280,000 per quality-adjusted life-year (QALY), which is well above the standard $50,000/QALY used by health policy experts.[4] Indeed, in this same study, at least one oncologist replied that the addition of 1 day of life would justify a $70,000/year cost, which was the equivalent to $25 million/QALY. The challenge in this particular patient’s case begins with a discussion of the true risks, benefits, and costs of the therapy in question; an exploration of whether charitable and other resources can be brought to bear on the patient’s access to the drug; and a careful understanding of the patient’s goals of treatment and his views of cost-effectiveness, given that his own personal finances may be at risk.

2. Communicating Prognosis

A 60-year-old male recently diagnosed with small-cell lung cancer with metastasis to the brain comes to you for further care following whole-brain radiation. He is accompanied by several family members. You explain his diagnosis and discuss further treatment options. As you come to the conclusion of the conversation and ask for further questions, a family member asks, “So, doc, what are we looking at time-wise? Can you tell us how much longer Dad has?” The patient looks down, and you notice tears welling up in his eyes. How do you proceed?

Occasionally situations arise in which the information needs of family members differ from the needs of the patient.[6] Physicians typically find themselves torn between meeting those two needs. Common situations include when family members do not want the patient to know information concerning prognosis or, conversely, when family members want to know, but the patient does not want to have detailed information. Efforts have been made to study the ethical issues surrounding communicating prognosis to help physicians navigate this sometimes difficult terrain. The studies are often small, however, and excluding bias from the experimental design is often difficult.[7]

Because of the challenges in communicating prognosis, multiple studies have concluded that prognosis is infrequently discussed with patients, and when it does occur, the conversation is frequently between the physician and someone other than the patient.[7,8] Furthermore, studies have found that physicians have consciously optimistic biases about prognosis,[9] and tend to avoid
prognostic conversations with patients by focusing on treatment plans.[7] A few studies in the United States have examined patient preferences concerning prognostic communication. In a 2003 study by Fried et al, 205 out of 214 patients reported that they did not have any prognostic conversations with their physicians, although 55% of patients said they would have wanted it.[10] Interestingly, caregivers wanted to know the patient’s prognosis more often than the patient did. A study by Marwit in 2002 showed that the majority of Americans preferred full disclosure of prognostic information.[11] Not a single study participant preferred nondisclosure, though there was some variation in the amount of information that the patients wanted disclosed. Only 32% of patients wanted to be given the information alone, and more than 64% of patients preferred to have a loved one present. In a study in 2002 by Kaplowitz, 80% of patients were found to prefer a qualitative prognosis over a quantitative one. Furthermore, elderly patients were significantly less likely to request prognostic information.[12] The interpretation of these studies is complicated by the fact that not all of them distinguished between the information preferences of patients with poor prognoses and those with better prognoses. In several studies, patients with poor prognoses have been found to desire less-specific information about their prognosis.[7]

Evidence also suggests that individual patient and family preferences vary within and across studies. Although there have been roadmaps designed for physicians to use when communicating prognosis, the physician must be flexible enough to tailor the conversation to the patient's preferences and level of understanding. Indeed, it is sometimes a challenge to know how to assess information preferences. Appropriate questions to ask in the above situation would include inquiring about the patient’s preference for knowing his prognosis, assessing and attempting to understand his fears or concerns surrounding prognosis, determining in what form he would like to have prognostic information (qualitative or quantitative), and asking whether the patient is agreeable to your discussing the information with the family separately from himself, so that differing desires for information might be managed. Although these conversations are difficult and often time-consuming, effectively communicating prognosis has been shown to lower anxiety and decrease depression levels.[13] It has also been shown in many studies to affect decision making regarding intensity of treatment.[14] Continuing to study more effective strategies and further educating physicians in prognostic communication is important for a higher level of quality of care for cancer patients.

3. End-of-Life Care

A 45-year-old male patient with metastatic pancreatic adenocarcinoma who has progressive disease during first-line chemotherapy comes into the emergency department (ED) with altered mental status and is found to have an acute saddle pulmonary embolism requiring high levels of oxygen. The patient’s wife accompanies him to the ED and is his healthcare power of attorney. You know the patient well, and his health has been declining over the past month. He had an Eastern Cooperative Oncology Group (ECOG) performance status of 3 at his last visit. You were to see him again in clinic next week to discuss hospice. The ED physician calls you to help direct treatment and goal assessment discussions with the patient’s wife. She is adamant that the patient should be intubated and placed in the intensive care unit (ICU) for further care. She has read on the Internet about FOLFIRINOX (oxaliplatin [Eloxatin], irinotecan, fluorouracil [5-FU], and leucovorin) and wants her husband to be given this chemotherapy regimen once he has been admitted to the ICU. She says her husband would have wanted to keep fighting for their daughters, who are 7 and 9 years of age. She wants everything possible to be done for him.

Over the last 20 years, the US healthcare system has seen a trend toward increasing intensity of treatment towards the end of life in patients with advanced cancer.[15] In a 2004 study, Earle et al found that an increasing number of patients were receiving chemotherapy within 14 days of death and that, over a 4-year span, there was an increasing proportion of cancer patients admitted to the ICU within the last month of life. This same study also found an increasing enrollment of cancer patients into hospice programs, but those patients were enrolled later in their disease course.[15] Prior studies have shown that 30% of Medicare expenditures are spent on patients in their last year of life, and one-third of that money is spent within the last month of life.[16,17] Furthermore, studies have also shown that 78% of the costs incurred in the final year are spent on life-sustaining treatments, such as ventilator support and resuscitation efforts.[18] In 2009, Zhang et al looked at the correlation between end-of-life discussions occurring between physicians and patients and the effect on outcomes and cost. In patients with advanced cancer, they

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reported no survival difference between those who received more intensive care with higher costs at the end of life and those who received less intensive care with lower costs.[14] They also found that those undergoing more intensive treatments at higher costs had a worse quality of life in their final weeks of life. The results of this study also suggest that patients who could recall having an end-of-life discussion with their physicians underwent less intensive treatment and had lower medical costs and better quality of life in the weeks prior to death, indicating that having end-of-life discussions has a true impact on treatment choices at the end of life.

Although it seems clear that discussing prognosis may have a major impact on end-of-life decisions, we should ask ourselves what the major barriers are to having these discussions. Prior studies indicate that these end-of-life discussions are often overlooked or only occur during an emergency.[19,20] A science reporter for the *Annals of Internal Medicine*, Jennifer Fisher Wilson, commented in an article in 2009 that this problem is multifactorial. Wilson reports that “some patients don’t want to know their prognosis or expect to beat the odds.” Furthermore, Wilson claims that physicians often do not want to discuss realistic prognosis because of their emotional need to help the patient and fix the problem.[21] Finally, she notes that “anticipating the trajectory of the patient’s decline” is often difficult for the physician, and prognostic and end-of-life discussions come too late, as was the case in our vignette above. Though we want to support our patients and their families in their fight against cancer, often the best support we can give them is to educate them on when it is time to focus on comfort care. The set of skills necessary to engage in such compassionate, emotional, but useful discussions should not be underestimated. However, in the case above, it is clear that further chemotherapy would not benefit the patient at all, and so should not be presented as an option. The reasons that such treatments will not benefit the patient (which may be hard for family members to accept) should be communicated with as much care and compassion as possible. Systematic efforts to facilitate earlier transitions from disease-directed care to palliative treatments should remain a focus of our efforts in caring for patients with advanced cancer.

**Conclusion**

The three vignettes presented show various ethical dilemmas that medical oncologists encounter in their everyday practice. Our hope is that oncologists may be better equipped to deal with these challenges by being made aware of the current literature, and that they will continue to participate in discussions about how we might better overcome these obstacles to quality healthcare.

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**References:**

**REFERENCES**


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