

REVIEW ARTICLE

End of Life Ethics in Cancer Patients: Conflicts and Dilemmas

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ABSTRACT

Ethical issues near the end of life arise because of concerns about how much and what kind of care makes sense for patients with a limited life expectancy. There is often physician-family conflict about what constitutes appropriate care. Understanding ethical framework in which such decisions are made can also transform what appear to be problematic questions into straightforward answers. Rapid medical advance over the last century ensured that more options are now available, even as the effectiveness of one wanes. In cancer patient near end of life, common ethical dilemmas include dealing with artificial nutrition/hydration, truth-telling and disagreements over management plans. It would stand clinician in good stead to be aware of these issues and have an approach toward dealing with such conflicts. In addition, organizations have a responsibility to minimize its occurrence and ensure that staffs are supported through the process of resolving dilemmas and conflicts that may arise.

INTRODUCTION

Oncologists deal almost exclusively with patients with serious and life-threatening diseases, many who are terminally ill. While best supportive end of life care remains an ideal model of care for cancer patients with life-ending disease, many obstacles are present in the clinical setting that either impede or prevent the otherwise appropriate type of end-of-life care. These obstacles are best viewed as ethical dilemmas for oncology clinicians, as they often challenge or obscure a clinician's perceptions about what is in the best interests of their advanced cancer patients.(1) These dilemmas include: Issues surrounding prognosis determination and communication, Concerns about effectively communicating a terminal prognosis while still allowing patients and families to maintain hope, Conflicts of interests for involved clinicians and For oncologists caring for advanced cancer patients.(1,2)

it is essential that they have a working knowledge regarding these ethical issues, and overt dilemmas, present in end-of-life cancer care in order that they might better appreciate how, and when, to initiate palliative care for as many of their patients as possible(3)

Ethical dilemmas and conflicts, why?

Despite principles of patients' rights to self-determination of treatment, studies of end of life care tend to focus on factors that put patients at risk of receiving life-prolonging care(2), indicating a general perception that this is an undesirable outcome for patients with poor prognoses (3). Inaccurate expectations about prognosis may explain some patients' desire for life-prolonging care(4); however, goals for care may vary even when patients recognize that they are terminally ill. Younger patients and patients with dependent children, for example, are more likely to choose

therapies directed at life-prolongation,(5) perhaps reflecting a desire to live or be available to their children as long as possible. Attainment of one's goals for end of life care may therefore be an important outcome of end of life care, whether goals involve life-prolonging or symptom-directed care. Kinzbrunner reported that the most frequently encountered ethical dilemmas in the US concerned predicting the survival of the terminally ill (as documented by the Medicare Hospice Benefit limitation of six months); truth-telling; hesitancy to use morphine for fear of causing respiratory failure; issues related to parenteral nutrition, and difficulty in meeting the needs of delirious patients.(6) Finlay described difficult clinical decisions in hospice treatment in the UK such as the treatment of hypercalcaemia, uraemia, abnormal serum sugar level, abnormal liver function; the principle of hydration and nutritional support; the use of antibiotics, steroids and analgesics; the place of care; strategies employed in medical emergencies, and the withholding or withdrawal of life-sustaining procedures. Despite cultural differences, it seems widely agreed that appropriate hospice and palliative care be given within the framework of the principles of medical ethics.(7,8)

ETHICAL CONFLICTS – THE INGREDIENTS

1. Increased options and limited resources

When the inability to feed orally meant certain starvation before the twentieth century, the development of nasogastric tubes in the early 1900s (9) with further progress in parenteral nutrition offered new options of care when the concept of feeding patients came into practical consideration in the last few decades. (10) With these advances came the dilemmas related to artificial nutrition and hydration near the end of life. The discovery of penicillin by Alexander Fleming in 1928, (11) and the revolution in management of infections with the development of more and more potent antibiotics meant that the course of terminal care in patients with advanced illnesses has changed. The modern intensive care unit and ventilatory support was not developed till the latter half of the last century, (12) offering hope to those with respiratory failure on the one hand and decision-making conundrum to those facing a terminally ill patient. Recent rapid advances in cancer chemotherapy, allowed curative treatment in subsets of Hodgkin's and non-Hodgkin's lymphoma, acute lymphoblastic and acute myelogenous leukaemia, small cell lung cancer, ovarian cancer and choriocarcinoma. For cancers that are not curative, the increasing array of new chemotherapeutic agents and the transition to 'targeted treatment' with novel agents directed against molecular targets, improved surgical techniques as well as advances in radiotherapeutic strategies have led to increased overall survival for many.

The above are but some advances in the field related to cancer care, which offer ever-increasing options. Thus, treatment decisions could become more challenging as uncertainties in survival outcomes and quality of life are weighed against the side effects of treatment offered. (13) A point often comes in the treatment cycle when the question of 'when does further treatment become futile?' arises. Doctors are loathe to put a value on a life, but conflicts over perceived futile treatment take on added significance when scarce resources are at stake. Arguments about providing something that does not cost much, such as amoxicillin/clavulanate, for a patient in the terminal stages of carcinoma of the lung with fever, are interesting but not compelling. There would be greater angst in recommending Sunitinib to someone with advanced renal cell carcinoma if the family is contemplating the sale of their family home to finance the cost. For many working in the public sector, a chord is struck at the sight of patients transferred from private care after their savings have been exhausted. The bludgeoning cost of cancer therapies, many of whom typically produce a relatively short extension of survival led Fojo and Grady to recommend that studies powered to detect a survival advantage of two months or less should test only interventions that can be marketed at a cost of less than US\$20,000 (a figure that most in the world still find unaffordable) for a course of treatment. (14) Illustrating their recommendation, the authors pointed out that 18 weeks of Cetuximab treatment for non-small cell carcinoma of the lung, which was found to extend life by 1.2 months, costs an average of US\$80,000, which translates into an expenditure of US\$800,000 to prolong the life of one patient for one year and US\$440 billion annually to extend the lives of the half a million Americans who die of cancer annually. This amount is astronomical by any standard.

2. Changing norms and conflicting values

Collusion, when families request for the truth to be kept from the patients, is common in oncological practice, (15,16) challenging as it is in the current context, it was the norm to not disclose bad news to a patient until the last half a century.(17,18,19) Before then, there was general consensus among healthcare workers and the lay public that bad news should be kept from patients. However, through the ages, with the rise of patient autonomy, a better-educated public and studies that showed the benefits of disclosure, this practice has changed such that it is the norm in 'Western' cultures for open disclosures to patient. In many places, including locally, the approach is still rather cautious and it is still not uncommon for family members to be informed before patients are. Even then, in these cultures, it is envisaged that with better education and greater acculturation with the 'West', more people will want to be in control of their own healthcare decisions, and hence, withholding a

diagnosis of cancer from patients may become a thing of the past(20). Respect for patient autonomy and self-determination as key components in a patient-doctor relationship is also of recent heritage. Meant to safeguard patients' interest, it can, paradoxically, be a source of stress and create potential for conflict in ethical dilemmas. This is illustrated in a study carried out in Canada, (21) which ranked disagreements between patients/families and healthcare professionals about treatment decisions as the most challenging ethical issue encountered in healthcare. With diminishing paternalism on the part of healthcare workers and an associated rise in patient self-determination, no longer are doctors expected to be able to make decisions regarding patient care without questions from patients. Similarly, patients are no longer expected to accept care with quiet passivity. A judgment at the Helsinki trials gave central importance to the principle of patient autonomy and made it an ideal that governs the doctor-patient relationship. (22) Dissatisfaction over unilateral decision-making with resultant patient harm had also started surfacing prior to that. As a result, the need to obtain 'informed consent' as a key cornerstone in patient care became a standard for all interventions on patients. (23) This shift away from paternalistic decisions by doctors opens the way for disagreements with the patients when opinions differ. The root cause of these differences in opinions on 'what is best' often rests on the different values placed on the very principles that were supposed to guide decision-making. Collusion is a case in point. 'Not to tell' would seemingly contradict the principle of patient confidentiality and respect for his autonomy. However, to collude, in the family's eyes, is consistent with the principle of nonmaleficence, with fears of adverse psychological impact on the patient and the challenges the family would face in confronting emotions of grief and loss following open disclosure. Does one place a higher value on that which leads to the greater societal good than the individual (the utilitarian approach)? If so, where resources are limited, that which would lead to the greater good of all should prevail. When patients are in states of unconsciousness, do we believe that artificial nutrition and hydration is a form of medical treatment or an obligatory act? (24) If we believe in the latter, there may be conflict if the other party believes in the former. Hence, when similar values guide decision making, the potential for differences between different parties is minimized. Since not everyone subscribes to the same moral authority or shares the same values, the potential for disagreements would always remain with us as long as moral imperatives conflict with each other.

MORAL DISTRESS

Stress related to dealing with ethical dilemmas is usually called 'moral distress'. It is referred to the inability of a moral agent to act according to his

own core values and perceived obligations due to internal and external constraints (25). In a study carried out among nurses caring for the elderly, nurses identified situations involving unjustifiable life support and unnecessary tests and treatments as causing the most moral distress. The moral distress score was significantly higher in nurses with intentional or actual job-leave. (26) 15% of nurses in one study and 26% of nurses in another study admitted to leaving the profession as a result of moral distress.(27,28) Almost half of the 760 nurses in a 1993 study reported acting against their conscience in providing care to the terminally ill, which then led them to experience emotional suffering and compromised integrity. (29) Moral distress has been found to lead to feelings of frustration, anger and guilt. (30) Psychological distress as a result of moral distress has also manifested as loss of self-worth, depression, anxiety, helplessness, compromised integrity, dread and anguish. (31) There is a direct and significant relationship between emotional exhaustion leading to burnout and frequency of encountering morally distressing futility cases. (32) Half of the nurses and social workers surveyed felt frustrated and fatigued when they could not resolve ethical questions. (33) Even though these findings were not specific to the cancer population, the burden of dealing with ethical dilemmas in this population is unlikely to be dissimilar.

ETHICAL CONFLICTS – RESOLUTION CYCLE

We cannot avoid having to make difficult decisions when faced with ethical conflicts. Having a systematic approach (34) may help to mitigate against the often stressful encounter. (Figure 1)

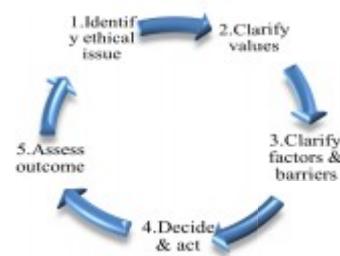


Figure 1. Resolution Cycle

Identify ethical issues and define guiding principles

Generally accepted principles of biomedical ethics include:

- Autonomy: Respect for individual liberty, values, beliefs and choices.
- Nonmaleficence: Not to inflict harm or evil.
- Beneficence: To do good and prevent or remove harm.

- Justice: To treat equals equally and those who are unequal by their needs.
- Veracity: To tell the truth and not to deceive others.
- Confidentiality: Not to disclose information shared in an intimate and trusted manner.
- Privacy: Respect for limited access to a person.

Ethical questions often evoke emotional responses. While gut reactions such as anger and indignation provide important clues about personal values, objective observations provide a stronger foundation for logical reasoning. So, the first step in approaching any morally problematic situation is to separate the emotional response from the objective issue and to clearly define the ethical issues involved and the guiding principles that help to direct decision-making.

Clarify personal and professional values

It is important for a doctor to be aware of his own values and the values that drive others and their behaviour. Values are pivotal to the art of medicine, and practice based on unexamined values often leads to confusion, indecision and inconsistency. (35,36) Even if one believes that to lose the ability to move about independently is a state of unbearable existence, this does not entitle a doctor to insist that patients who cannot do so should be deprived of a craniotomy for brain metastases and subsequent radiotherapy for a chance at extension of life

Clarify influencing factors and barriers

Gather and review additional information from the practice setting and professional literature. Discussions with patients over options would be meaningless without adequate knowledge of the medical facts (e.g. discussion on benefits of whole brain radiotherapy cannot take place unless one is cognizant of the benefits and risks in a patient with brain metastases), study of the possible barriers (e.g. if intensive care support is not available, it makes no sense to offer it to a patient who is terminally ill) and understanding of individual characteristics of the patients (e.g. if the patient's religion dictates that artificial nutrition is an obligatory act, insertion of a feeding tube would probably be non-negotiable) (Table 1).

Table 1. Influencing factors and barriers for action in dealing with ethical dilemmas

Medical facts	Patient history, diagnostic results, risks, complications, previous interventions
Barriers	Operational/logistical, competing interests, inter-professional perspectives
Individual characteristics	Values, culture, religion, relationships, previous experiences
Medical facts	Patient history, diagnostic results, risks, complications, previous interventions

Barriers	Operational/logistical, competing interests, inter-professional perspectives
Individual characteristics	Values, culture, religion, relationships, previous experiences

Decide and act

Ultimately, resolving any ethical dilemma requires decision and action. Ideally, one's personal ethical values would be consistent with those of other team members and consistent with the guiding legal and professional standards of practice. Given the nature of ethical decision-making, however, one is more likely to find himself facing internal and/or external conflicts. However, if the problems have been systematically evaluated, one should be able to select the course of action that is best supported by the analysis and be able to articulate a concrete foundation from which to defend the decision made. Be mindful that ethical dilemmas can lead to disputes. Strategies for conflict resolution may include:

- Collaboration (optimal approach): Build consensus through the mutual evaluation of information and active identification of each party's interests.
- Compromise: If all parties are morally certain about their position, but also committed to preserving the relationship, each may be able to find acceptable trade-offs.
- Accommodation: One party may simply agree to another's position. Sometimes used as a concession to imply reciprocal action.

Assess outcome

Post-event reflections are useful exercises to evaluate the process and assess the outcomes of decision-making, paying attention to solutions (among the alternatives presented), unanticipated consequences, if any, and overall satisfaction with the results of the plan of action by all the parties involved. This evaluation process would help to minimise or avert future dilemmas and improve approaches to them.

ETHICAL CONFLICTS and ORGANISATIONAL RESPONSIBILITY

Healthcare organisations are responsible for using strategies to promote an organisational ethical climate. There is evidence that ethics protocol, guidelines and programmes may help reduce ethical conflicts. (37,38) In this regard, having 'Do Not Resuscitate', 'Advance Care Planning' and communication policies and processes are important in end-of-life care. Evidence-based guidelines on transfer of patient to the intensive care unit and use of welfare funds also take the burden of decision-making off staff and decrease the stress associated. Multidisciplinary meetings provide a forum for the airing and discussion of such dilemmas, and allow for collective wisdom and mutual support to take place. Where the complexities of the case exceed those of the managing teams, there should be access

to clinical ethics consultation and staff support schemes. Considering the investment in time often required to handle these situations compassionately, there is also a responsibility to ensure that the organisation is adequately resourced.

CONCLUSION

“To see what is right, and not to do it is want of courage.” However, discernment of what is right in the murky waters of ethical dilemmas could be challenging. In these ‘perplexing of situations, some clarity and guidance could be obtained through a systematic approach.

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