Ethical dilemmas in the care of cancer patients near the end of life

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ABSTRACT By definition, an ethical dilemma involves the need to choose from among two or more morally acceptable options or between equally unacceptable courses of action, when one choice prevents selection of the other. Advances in medicine, increasing economic stress, rise of patient self-determination and differing values between healthcare workers and patients are among the many factors contributing to the frequency and complexity of ethical issues in healthcare. In the cancer patient near the end of life, common ethical dilemmas include those dealing with artificial nutrition and hydration, truth-telling and disagreements over management plans. It would stand the clinician in good stead to be aware of these issues and have an approach toward dealing with such problems. In addition, organisations have a responsibility to ensure that systems are in place to minimise its occurrence and ensure that staff are supported through the process of resolving dilemmas and conflicts that may arise.

Keywords: cancer, conflicts, end-of-life care, ethical dilemmas Singapore Med J 2012; 53(1): 11–16

INTRODUCTION

The case of the troubled social worker

"The amount requested can pay for the medication of so many of my diabetic patients," a senior social worker confided her dilemma to a physician colleague (non-oncologist). A new cancer drug had just arrived on the scene and this was soon followed by requests for Medifund (endowment fund set up to help the needy in Singapore to defray medical costs) support of patients deemed eligible. "They (oncologists) say that it can improve survival by a few months with fewer side effects."

"Should I support the request?"

The case of the concerned son

"Please do not say it is cancer." The computed tomography of the abdomen had revealed a pancreatic tumour, explaining the obstructive jaundice. Nodules in the peritoneum also looked ominous. An endoscopic retrograde cholangiopancreaticography was scheduled the following day.

"Just tell her it is a procedure for gallstones."

The case of the doctor under duress

With carcinoma of lung and brain metastases, Mdm Y has had numerous bouts of chest infection. Held in check by courses of antibiotic treatment previously, she nevertheless continued to decline. Imaging showed progression of cerebral as well as lung metastases. As she became bed-bound, another bout of pneumonia ensued. Her family insisted that the patient be sent to the intensive care unit, as not to do so was tantamount to 'euthanasia'. "I don't expect you to pounce on her chest if she dies, but we believe in the sanctity of life. When God had given man the ability, He would expect man to use it."

"Are you saying that my mother is old and no longer of economical value to society and hence, you can just bump her off?"

The above scenarios, in its different forms and degrees of complexities, are but some of the ethical dilemmas played out not too infrequently in the care of the advanced cancer patient. In a study carried out in a Taiwanese hospital, issues concerning the place of care (33.3% of patients), truth-telling (32.1%), hydration and nutrition (25.2%) and disagreements over management strategy (24.8%) were the most common ethical dilemmas encountered in the care of advanced cancer patients.⁽¹⁾

ETHICAL DILEMMAS - THE INGREDIENTS Increased options and limited resources

Dilemma (dil-em- \check{a}) noun: a perplexing situation, in which a choice has to be made between alternatives that are equally undesirable.⁽²⁾

Dilemmas necessarily only arise when there are options. In the absence of alternatives, there would not be dilemmas. The rapid advance on many fronts in medicine over the last century ensured that more options are now available, even as the effectiveness of one wanes.

When the inability to feed orally meant certain starvation before the twentieth century, the development of nasogastric tubes made from superior plastics in the early 1900s with its improved tolerability⁽³⁾ meant that patients could be fed directly

¹Dover Park Hospice, Singapore, ²Department of Palliative Medicine, Tan Tock Seng Hospital, Singapore **Correspondence**: Dr Angel Lee, Medical Director, Dover Park Hospice, Jalan Tan Tock Seng, Singapore 308436. Angel_Lee@ttsh.com.sg via a tube placed into the stomach, improving the survival of many patients with acute illnesses. Further progress in parenteral nutrition offered new options of care when the concept of feeding patients mainly or entirely by injecting nutrients and fluids intravenously came into practical consideration in the last few decades.⁽⁴⁾ With these advances came the dilemmas related to artificial nutrition and hydration near the end of life.

Sir William Osler (1849–1919) had famously said, *"Pneumonia is an old man's best friend."* However, the discovery by Alexander Fleming that a substance produced by a mould could kill bacteria in 1928,⁽⁵⁾ 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 with its ventilatory support was not developed till the latter half of the last century,⁽⁶⁾ offering hope to those with respiratory failure on the one hand and decision-making conundrum to those facing a terminally ill patient.

Up till the middle of this century, the diagnosis of advanced cancer invariably meant a death sentence. With advances in cancer chemotherapy, treatment can be curative 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.⁽⁷⁾ 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.⁽⁸⁾ Illustrating their recommendation, the authors pointed out that 18 weeks of cetuximab treatment for nonsmall 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.

Changing norms and conflicting values

Ethics, from the Greek word "ethos" meaning "well-developed habits".

To kill when offended may be acceptable in the world of the mafia and may even be expected, but not in the universe of the law-abiding citizens. Whether a given behaviour is acceptable or the norm depends on the culture the individual exists within and the values he holds. Whether these behaviours become 'habits' requires cultivation.

Healthcare is no exception. Collusion, when families request for the truth to be kept from the patients, is common in oncological practice,^(9,10) 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.^(11,12,13) Before then, there was general consensus among healthcare workers and the lay public that bad news should be kept from patients. Hippocrates⁽¹⁴⁾ encouraged physicians to "conceal most things from the patient while attending to him. Give necessary orders with cheerfulness and serenity, turning his attention away from what is being done to him; sometimes reprove sharply and emphatically, and sometimes comfort with solicitude and attention, revealing nothing of the patient's future or present condition". 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⁽¹⁵⁾ of the past.

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,⁽¹⁶⁾ 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. Many attribute the rise in patient autonomy in the doctor-patient relationship to the atrocities carried out in World War II. A judgement at the Helsinki trials gave central importance to the principle of patient autonomy and made it an ideal that governs the doctor-patient relationship.⁽¹⁷⁾ 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.⁽¹⁸⁾ With this, the onus also rests on the patients to assume responsibility for decisions. 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?⁽¹⁹⁾ 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 minimised. 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.

ETHICAL DILEMMAS – THE EFFECTS

Stress related to dealing with ethical dilemmas is usually referred to as 'moral distress'. First described by Andrew Jameton in 1984,⁽²⁰⁾ it refers to the inability of a moral agent to act according to his own core values and perceived obligations due to internal and external constraints.

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.⁽²¹⁾ 15% of nurses in one study and 26% of nurses in another study admitted to leaving the profession as a result of moral distress.^(22,23) 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.⁽²⁴⁾ Moral distress has been found to lead to feelings of frustration, anger and guilt.⁽²⁵⁾

Psychological distress as a result of moral distress has also manifested as loss of self-worth, depression, anxiety, helplessness, compromised integrity, dread and anguish.⁽²⁶⁾There is a direct and significant relationship between emotional exhaustion leading to burnout and frequency of encountering morally distressing futility cases.⁽²⁷⁾ Half of the nurses and social workers surveyed felt frustrated and fatigued when they could not resolve ethical questions.⁽²⁸⁾ 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 DILEMMAS - AN APPROACH

We cannot avoid having to make difficult decisions when faced with ethical dilemmas. Having a systematic approach⁽²⁹⁾ may help to mitigate against the often stressful encounter.

Step 1: Identify ethical issues and define guiding principles

Ethical questions often evoke emotional responses. While gut reactions such as anger and indignation provide important cues 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 (Table I).

Generally accepted principles of biomedical ethics include:

- Respect for 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.
- Fidelity: To honour commitments.
- Confidentiality: Not to disclose information shared in an intimate and trusted manner.
- Privacy: Respect for limited access to a person.

Step 2: 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.^(30,31) 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.

Table I. Ethical dilemmas in the care of cancer patients near the end of life.

Ethical Issue	Conflicting	imperatives	Considerations
Nutrition and Hydration near the end of life (AHN)	• Respect for autonomy (usually at the request of caregivers in the incompetent patient)	• Nonmaleficence (AHN not proven to prolong life of stroke patients. For terminally ill cancer patients, concern has been mainly over increase in secretions, oedema and 'terminal rattling' and prolongation of the dying process rather than sustenance of life ⁽³²⁾)	 The law and medical codes of practice define the provision of food and water by mouth as basic acts and artificial forms as treatment. However, Roman Catholic religious thinking is based on the presumption of providing food and water by whatever means unless the burden outweighs benefits.^(19,33) Advance care planning helps to decrease the burden of decision-making in the incompetent patient.⁽³⁴⁾
Request for 'futile' treatment ⁽³⁵⁾	 Respect for autonomy Beneficence (sufficient time for patients and families to come to terms with deterioration) 	 Justice (when resources are limited) Nonmaleficence (false hopes may be detrimental and 'futile' treatment increases the risk for adverse events) 	 Doctors have no obligation to provide treatment that they deem futile. Providing futile management is more contentious if resources are limited. Psychosocial support is a crucial element in maintenance of hope in the context of deteriorating condition. Cultivating good doctor-patient relationship and communication training have been shown to minimise conflicts in this area.
Withholding/ withdrawing of treatment (e.g. ventilator support) ⁽³⁶⁾	 Beneficence (not providing/ prolonging futile care) Justice (when resources are limited) 	 Nonmaleficence (psychological trauma of treatment withdrawal seems to weigh more heavily than withholding) 	 Withdrawal of treatment should not equate to withdrawal of care. On ethical grounds, withdrawal of therapy is equivalent to withholding of treatment. As opposed to PAS and euthanasia, death is the unintended foreseeable result in the withholding and withdrawal of therapy. Similar to some other issues, advance care planning may help to decrease the burden of decision.
Collusion and truth-telling	 Veracity Confidentiality and right of the patient to information Respect for autonomy (patient's right to make own healthcare decisions) Beneficence (potential benefits with open disclosure)⁽³⁷⁾ 	• Nonmaleficence (psychological trauma of truth-telling as perceived by families, burden on the unprepared family with truth- telling. Negative psychological impact on patients ⁽³⁸⁾)	 Need for empathic communication; otherwise, harm indeed may be caused by insensitive discussions. Delegation of decision-making authority may be implicit in some cultures. Most patients want doctors to be realistic when discussing prognosis and be given the opportunity to ask questions.⁽³⁹⁾ Use of communication strategies can reduce collusion and empower healthcare workers to engage families.⁽⁴⁰⁾
Request for euthanasia/ Physician- Assisted Suicide (PAS)	 Respect for autonomy (the right to die at one's appointed time) Beneficence (provide relief from suffering) 	• Nonmaleficence (act of killing)	 Usually, alternatives exist in the relief of suffering for the majority of patients, making palliative care an essential component of the healthcare system. As opposed to the withdrawal and withholding of treatment, death is the intended outcome of the act and hence, often taken to be contrary to the practice of medicine. Concern is also raised of the 'slippery slope' as it may become difficult to limit the act to the terminally ill and to the reasons of 'intolerable' suffering, as these in themselves are not easily defined.⁽⁴¹⁾ As of this year, euthanasia is legal only in Netherlands, Belgium and Luxembourg. Assisted suicide is legal in the American states of Washington, Oregon and Montana.
Costly or burdensome treatment	• Beneficence (improved survival and quality of life)	 Justice (requirement for financial assistance when resources are limited) 	• Dependence on affluence and generosity of society.
Participation in research	• Beneficence (contribution of patient to advancing scientific knowledge)	• Nonmaleficence (burden of trials, adverse effects in a vulnerable group)	 Evidence-based practice is needed to provide quality palliative care. Terminally ill patients represent a vulnerable group for whom research raises both heightened and distinct ethical objections.⁽⁴²⁾ Some challenges include difficulty in obtaining informed consent and assessment of risks and benefits of palliative research. Investigators are often healthcare providers who must balance their competing responsibilities to patient care and scientific rigour.⁽⁴³⁾
Palliative sedation	Beneficence (relieve suffering)	 Nonmaleficence (possible hastening of death) 	 Often a 'last gasp' measure to alleviate distress in a patient near the end of life but may be a 'double-edged sword'. Should be guided by principles of proportionality (what is necessary to relieve suffering) and intent (to relieve and not to kill).⁽⁴⁴⁾

Step 3: 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 II).

Step 4: 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.

Step 5: Evaluate and assess

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 DILEMMAS - 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.^(45,46) In this regard, having 'Do Not Resuscitate', 'Advance Care Planning' and communication policies and

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

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."⁽⁴⁷⁾ However, discernment of what is right in the murky waters of ethical dilemmas could be challenging. In these 'perplexing' situations, some clarity and guidance could be obtained through a systematic approach.

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