

Ethical Issues

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Introduction

A doctor has neither the duty nor the right to prescribe a lingering death.

—Prof. Robert Twycross

Bio-ethics, also known as medical ethics, is the study and employment of moral principles, duties and rights in the broad fields of medical conduct, applications and research. The term ‘ethics’ is used in three different but related ways, signifying (1) a general pattern or ‘way of life,’ (2) a set of rules of conduct or ‘moral code,’ and (3) inquiry *about* ways of life and rules of conduct.

Individuals working in the field of medicine are faced daily with moral dilemmas and difficult decision-making, such as when life begins and when life ends; the withholding or withdrawal of treatment; the allocation of scarce medical resources; and the accessibility of resources. Practical decision-making is often influenced by family and community (including other health care professionals’) beliefs about what is right and wrong.

In the case study below, some of the many ethical questions raised are: Was their right to refuse treatment as their child’s proxy more valid than the child’s right to live? Should we consider quality of life when making decisions to treat or not? Who should the decision-makers be?

The case outraged many, and officials in the administration of President Ronald Reagan rushed to pass legislation preventing future similar scenarios. The American Paediatric Association and other organisations went to court and overturned the legislation. The US Department of Health and Human Services then drafted guidelines which said that it was not necessary to give futile treatment to terminally ill infants.

Many of the contemporary debates in bio-ethics are the direct result of advancement in scientific and medical knowledge and technology. With these new advances the human race is not only morally challenged as to the basic nature of life and death but also about the power the social structure can assert over those in need who do not have

CASE STUDY: AN ETHICAL CONUNDRUM

An ethical conundrum for example is the decision of when, and if, it is ethically permissible to withhold treatment from a child. This issue came into public focus with the case of ‘Baby Doe’ in the USA in 1982. The newborn infant was diagnosed with Down’s Syndrome, a chromosomal disorder that causes moderate to severe developmental disabilities. The baby also had oesophageal atresia, the separation of the oesophagus from the stomach. The obstetrician who delivered the baby told the parents that their child would have only a 50 percent chance to survive surgery for his atresia of the oesophagus, and that even if surgery were successful, their child would remain severely retarded and would face a lifetime of medical treatment, disability, and dependency. The parents consequently refused to consent to the surgery and the baby died after six days.

Terms you will read in this chapter:

Alleviation: to make something such as pain or hardship more bearable or less severe

Conundrum: something that is puzzling or confusing

Duress or Coercion: the use of force or threats to make somebody do something

Euthanasia: the active killing of someone in a painless manner

Fraudulent (Will): not honest, true or fair and intended to deceive people

Ineluctable obligation: inescapable obligation – it must be done

Maximal (comfort): the best or greatest possible (comfort)

Not fundamentally immoral: not essentially, completely wrong, right down at the very root of the matter

Paternalistic approach: an approach where the authority figure makes decisions on behalf of others supposedly in the other’s best interest but depriving the others of their choice

Prevail: to prove to be stronger and more effective

Proxy: somebody authorised to act for another person

Vegetative state: a wakeful but unconscious/unaware state usually due to brain damage

the means to pay for it. There is often no clear-cut right or wrong answer, particularly when we also consider diversity in cultural traditions in South Africa.

Clinical decision-making in hospices and palliative care has relied on bio-ethical principles as a guide. These principles – beneficence, non-maleficence, autonomy and justice – assist the palliative care practitioner to assess issues that are often very emotive and to use a framework to guide the patient, family members and care team to a practical decision which is open to review as the patient's condition or wishes change.

These principles were initially described by two US authors Beauchamp and Childress¹ to assist clinical decision-making in medicine. We recognise the US emphasis on the individual (autonomy) compared to an African emphasis on community so that principles of beneficence and distributive justice may have more weight in the South African setting.

Patient autonomy

Autonomy is the ability to make decisions for oneself on the basis of deliberation.² No-one has the right to infringe upon another person's autonomy or coerce them into making decisions. The basis for this is the established right of privacy and the right to refuse treatment. Personal autonomy is a minimum self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding that prevent meaningful choices.

Informed consent

The autonomous person is well informed about the risks and benefits of each technique or treatment and can make an unbiased, informed decision, without being pressured in decision-making. It is the duty of the medical practitioner or researcher to disclose all available information to the individual – whether adverse or not.

The right to information is enshrined in both the South African Constitution and international and regional human rights conventions. Under the South Africa Constitution, 'Everyone has the right of access to- (a) any information held by the state; and (b) any information that is held by another person and that is required for the exercise of protection of any rights.'³

This right to information plays a central role in health care. Only when an individual is properly informed by having received all information available on the subject matter, can he or she give informed consent to start or continue with the treatment he or she is receiving on a voluntary basis. The decision to receive treatment or not to receive treatment can be changed at any time as the individual reviews his/her decision.

The right to information entails both a right of access to health information from the state so that citizens can play an active role in the formulation of health policy and a right to information from health services concerning treatment.

In many settings, medical care has been implemented through a paternalistic approach where the doctor decided the treatment without providing adequate information and without discussion with the patient. Legally and ethically, the patient may even make decisions contrary to the advice of a medical practitioner, with possible detrimental effects,

CASE STUDY: INFORMED CONSENT

Peter has AIDS and has been taking antiretrovirals for two months. He has bad side effects from the drugs. Peter is now depressed and wants to stop all treatment. He says that he doesn't care if he dies. He becomes very ill and is admitted to a hospice. The doctor there explains to him that there are a number of different antiretrovirals and that there are some with fewer side effects than the drugs that he is taking. Peter did not know that he had other options. After hearing about the different antiretroviral regimens, Peter decides to try a different set of drugs. He is now improving and no longer experiences side effects from the new medication.

as long as that patient has been informed properly beforehand. It is clear that the information given to the patient should be accurate and understandable to that patient. When patients lack the capacity to make a decision, a designated proxy decision-maker should be consulted. The proxy assists in the decision-making process based upon the patient's previously expressed wishes and known values (also referred to as the Living Will or Advance Directive). A proxy might be guided by these documents but is under no legal obligation to follow it to the letter if he or she thinks the requested action is not to the benefit of the person). If there is no recognised person to act as proxy, decisions should be made in the best interests of the patient, considering the patient's personal values to the extent that they are known and in accordance with societal norms and values. Medical personnel should always support patient self-determination by discussions with proxies, providing guidance and referral to other resources such as the Living Will or Advance Directive and identifying and addressing problems in the decision-making process. Within our African context it is important to remember that support of autonomy also includes recognition that some cultures place less weight on individualism and choose to defer to family or community values in decision-making.

The fact that social norms assign primary responsibility for care to women and decision-making to men, means that gender affects decision-making as women may not have autonomy in decision making. In particular in the circumstances of communal decision-making, women's opinions may be discounted, over-ruled or not even asked for.

Respect for human dignity, described in the HPCA of South Africa's Code of Ethics⁴, requires the recognition of patient rights. Patients have the moral and legal right to determine what will be done with their own person; to be given accurate, complete, and understandable information in a manner that facilitates an informed decision; to be assisted with weighing the benefits, burdens, and available options in their treatment, including the choice of no treatment; to accept, refuse, or terminate treatment without undue influence, duress, coercion, deceit, or penalty; and to be given necessary support throughout the decision-making and treatment process. This includes the opportunity to discuss and make decisions with family, significant others, knowledgeable personnel and other health professionals.

Confidentiality

All medical personnel have a duty to maintain confidentiality of all patient information. Trust between patient and medical personnel can be destroyed by unnecessary access to patient information or by the inappropriate disclosure of

patient information. The rights, well-being, and safety of patients should be the primary factors in arriving at professional judgments concerning the sharing of confidential information received from or about patients, whether oral, written or electronic. Relevant data should be shared only with those members of the medical team who have a need to know. Information pertinent to patients' treatment and welfare is disclosed only to those directly involved with their care. However, duties of confidentiality are not absolute and may need to be modified to protect the patient and other innocent parties. The right to privacy is enshrined in the South African Constitution: 'Everyone has the right to privacy, which includes the right not to have-(d) the privacy of their communications infringed.'⁵

Beneficence and non-maleficence: Balance the benefits and risks

The principles of beneficence providing benefit to the patient, and non-maleficence ('first do no harm') are often considered together. According to the guidelines presented by the MRC⁶, beneficence refers to the practise where individuals are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their wellbeing.

The moral obligation of beneficence is paramount to ethics where actions are weighed for their possible good against the costs and possible harms. The MRC⁵ points out that a difficult ethical problem remains when applying the principle of beneficence. Some treatment presents more than minimal risk without immediate prospect of direct benefit to the individual. Therefore all risks and benefits should be carefully assessed by analysing all relevant information, a practical balance of the principles of beneficence and non-maleficence.

The SA Medical Research Council (MRC) has issued a position statement regarding detention of XDR-TB patients. It includes the statement that:

Prevention of XDR-TB through improved TB control must be the first priority. Nevertheless, the Department of Health is also legally required to address XDR-TB appropriately in the interest of protecting public health, while operating within the context of the Bill of Rights enshrined in the Constitution, thereby promoting, respecting and protecting individual rights.

Enforced hospitalisation/quarantine of patients with XDR-TB is only justifiable as a last resort; after all reasonable voluntary measures to isolate individual patients have failed.

This situation highlights the dilemma of protecting the individual patient's rights (beneficence for patient) and protecting people who may become infected by the untreated XDR-TB patient⁷ (non-maleficence with regard to the community).

Futile Treatment

If a patient's condition continues to deteriorate and treatment is ineffective, it may be that life-prolonging treatment is no longer appropriate⁴. This requires careful assessment and evaluation and a review of the goals of care in discussion with the care team including patient and family members. Futile treatments are those that are assessed as bound to fail, those that may not restore a patient to independence or at least to an acceptable quality of life, or treatments that may simply be prolonging the dying phase. It is unethical to subject patients to futile treatments. The challenge comes when clinicians are uncertain or disagree whether the treatment is effective or futile.

Living Wills

Some people draw up a document stating who may make decisions about their treatment on their behalf if they become unconscious, and when treatment should be stopped. Some insert this information into their will. An example of the wording in a Living Will:

If I am in a coma or persistent vegetative state or in the opinion of my physician and two consultants, have no hope of regaining awareness or higher mental functions, then my wishes would be for all treatment and artificial feeding to stop. I direct that only medication directed at relieving pain should be provided.

Living Wills have been the subject of ongoing debate in South Africa for many years. Health workers were unsure

of the legality of these documents. The National Health Act at s.7 (1)(e) clears up the debate by stating that a health service may not be provided to a patient without informed consent unless a delay in treatment might result in the patient's death and the patient has not 'expressly, impliedly, or by conduct refused that service.' The Living Will, which sets out a refusal of certain procedures in writing, is a clear example of a patient's express refusal of treatment which may save his life but not restore the quality of life which he considers necessary for a meaningful existence. Some people object to Living Wills because of a concern that the patient may have changed his mind, but not changed the Will. There are also concerns raised that family members could draw up a fraudulent Living Will. The response to these objections is that if the doctor does not believe that the patient is terminally ill or in a persistent vegetative state, for example, the Living Will shall not be relevant. The decision whether to use a Living Will always follow a medical diagnosis, which minimizes the two concerns above.

Withholding and withdrawing treatment

Consideration of withholding or withdrawing treatment as a sound clinical decision developed as a consequence of the availability of advanced medical technology and the resultant ability to prolong life that in some cases leads to prolonging the dying process. This prolongation of life may occur without allowing for patient perspectives such as quality of life, being close to family members at a critical stage of life, and the implications of provision of end-of-life care in the alien environment of the hospital or intensive care unit⁸.

The key is to be able to identify when active treatment will improve quality of life and prolong life, in contrast to when active care and medical technology will not positively influence the course of the illness but merely prolong the

CASE STUDY: CLARKE VS HURST 1992(4) SA 630 D

Dr Clarke suffered a heart attack, and while resuscitation eventually restored his heartbeat, he had severe brain damage. After he had been in a persistent vegetative state for four years, his wife applied to the court for permission to take treatment decisions on his behalf, in order to halt the artificial feeding which was keeping him alive. Dr Clarke had made a Living Will before he had the heart attack.

The court said that the doctors should 'give effect to his wishes as expressed when he was in good health', but should also look at his quality of life. The court found that Dr Clarke experienced no quality of life after the brain damage. Furthermore, the court also took into consideration that Dr Clarke expressly stated in his Living Will, before he became ill, that he would not want to be kept alive in a persistent vegetative state. Taken together, these two factors led to the judgment allowing his wife to refuse artificial feeding on his behalf.

dying process. Twycross makes the statement that a doctor has neither the right nor the duty to prescribe a lingering death.⁹ Benatar et al. of the University of Cape Town Bioethics Centre wrote a comprehensive and considered statement on withholding and withdrawal of life-sustaining therapy, providing clear guidelines and recommendations and making the unequivocal statement that withholding or withdrawing treatment 'is regarded as distinct from participating in assisted suicide or active euthanasia neither of which is supported by this statement'¹⁰.

It is important to consider the rights and needs of the patient, who may, for example, decide to discontinue treatment for a life-threatening illness, preferring to die with dignity while still mentally competent to make that choice. The clinician should ensure that the patient has the information required to make an informed choice and should support the patient in his/her decision.

Double Effect

The doctrine of double effect originated in the thirteenth century philosophy of St. Thomas Aquinas. St. Thomas Aquinas observes that 'nothing hinders one act from having two effects, only one of which is intended, while the other is beside the intention.'

Beauchamp and Childress¹ identify four conditions which usually apply to the principle of double effect:

1. The act itself must not be fundamentally immoral, but must be a good or neutral act;
2. Only the good effect (patient comfort) must be anticipated, not the bad effect, even though it is foreseen;
3. The negative effect must not be the means of the good effect; and

4. The good effect must prevail over the bad that is permitted. In modern palliative care practice, trained clinicians balance the good effect and minimise the unwanted effect of treatment to maximise comfort for the patient and minimise the risk to the patient.

Justice

Justice is described as fairness. Essentially justice is about treating people equally in relation to criteria acknowledged to be morally relevant – such as treating people equally in relation to their needs, rights, ability to benefit, or autonomous desire.¹¹

Justice may be further described as distributive justice (fair distribution of resources), right-based justice (equal access to health care), and legal justice according to the laws of the land.

Discrimination in access to health care and in health insurance, combined with dramatic increases in the costs of health care and the allocation of scarce resources, have fuelled debates about what social justice requires.¹ Problems of distributive justice arise in resource-poor settings and this highlights the concern about an unfair distribution of burdens, which includes inequitable access to therapies (due to geographical, financial or even political reasons) and the prioritizing of allocation scarce resources (**see case study below**).

In South Africa, there is a dual health care system where private health care is provided to those who have the ability to pay either directly or indirectly through insurance. However, should one not have the means to pay one is

CASE STUDY: TAC VS MINISTER OF HEALTH (NEVIRAPINE)

The case brought by Treatment Action Campaign which dealt with the provision of drugs for the prevention of mother-to-child transmission of HIV/AIDS came before the Constitutional Court. TAC launched legal action to demand broader access to Nevirapine in 2001. In December 2001 Judge Botha of the Transvaal High Court *declared that 'a countrywide PMTCT programme is an ineluctable obligation of the state.'* The High Court's order instructed the government to allow Nevirapine to be prescribed where it was 'medically indicated' and where, in the opinion of the doctors acting in consultation with the medical superintendent, there was capacity to do so. The High Court also ordered the government to develop 'an effective comprehensive national programme to prevent or reduce MTCT' and to return to the court with this programme for further scrutiny before 31 March 2002. The Minister of Health appealed this ruling directly to the Constitutional Court. Unanimously, the Constitutional Court decided that the government's policy had not met its constitutional obligations to provide people with access to health care services in a manner that was reasonable and took account of pressing social needs. The Court said that the government was wrong to restrict access to the antiretroviral medicine, nevirapine, that is effective in reducing the risk of mother-to-child HIV transmission. It ordered the government to make the medicine available to pregnant women living with HIV.

forced to go without and might even become part of a 'vulnerable' community. This merits the inclusion of the debate surrounding the existence or absence of a moral responsibility to protect the vulnerable of society – and to give them access to the benefits of therapies even though they cannot afford to pay for it. This is further covered in the access to care chapter.

In a society where justice prevails the aim is therefore for all citizens to have access to health care. In such a society the benefits of medicine would be for all and not a selected few.

Legal and Palliative Care aspects of the Euthanasia debate

Death is usually considered a tragedy but there are circumstances where patients, family members, the health worker and/or society regard death as something desirable for the patient.

Society may identify death as a desirable outcome when the patient has no hope of recovery and is experiencing terrible pain, or because the patient has a terminal illness and although the pain is under control, the patient feels that their continued existence is undignified or meaningless. Palliative care developed as a response to the experience of suffering in the widest sense of the term – physical, psychosocial and existential suffering. Whereas palliative care may not be able to alleviate all suffering completely, pain control can be achieved through accurate assessment and management of a patient's pain.

In South Africa, euthanasia, or the deliberate, direct act of killing a patient is illegal. The act of euthanasia is not the same as withholding or withdrawing treatment following due consideration of the patient's condition, the likely benefit and effectiveness of treatment in the face of the progressive illness. In these cases, the underlying disease or trauma takes its course and leads to the patient's death, not a direct act by the health worker.

Concerns are raised in society that continuing futile treatment may result in the dying process being extended over a longer period of time. Palliative care ensures that care is not withdrawn although a particular treatment may be considered futile and therefore withdrawn. The patient still receives care and medication to optimise comfort.

In the cases which have come before our courts, the courts have found that acts which have the express intention of hastening a patient's death, even when the patient was dying, fall within the criminal law definition of murder.

An additional concern from the lay public and some health workers is that strong pain medication may depress respiration and hasten death. Clinicians trained in pain management recognise that this is, in fact, not a valid perception as pain medication used appropriately does not depress respiration and will not hasten death. Without this insight, the courts nevertheless stipulate that this medication can be prescribed, as the direct intention is not to kill the patient, but to relieve pain.

Assisted suicide takes place when the health worker or family member helps the patient to end his/her life. This is not euthanasia because the patient carries out the act which leads to death himself. This is illegal in South Africa, but allowed in certain other countries such as the Netherlands and the state of Oregon in the USA. South African courts have regarded the act of suicide assistance as setting in motion the train of events leading to death and fulfilling the definition of murder in our law, i.e. the intentional killing of another human being.

Palliative care workers recognise a request for euthanasia as a cry for help that demonstrates a sense of hopelessness and results in part from a gap in care. It is important to discuss issues that may have led to this request with sensitivity, to acknowledge the person's concerns, to explain unrealistic fears, discuss realistic fears and what can be done to manage these issues. It is also important to explore the patient's perception regarding when s/he would choose to die. Frequently the patient doesn't want euthanasia immediately but at a time in the future. The issue is more one of having control or autonomy over dying than a wish to end life today. If the doctor or nurse can have an open, compassionate discussion with the patient regarding the care available and goals of care, the patient is may be reassured. The euthanasia discussion is complex with both the pro and anti camps convinced of their convictions and since there is no simplistic response, we anticipate that this debate will continue for many years to come.

Conclusion

The aim of palliative treatment is to obtain symptom control and a high quality of life even if life expectancy may be relatively short and the patient's health may be poor. In essence, palliative care is an affirmation of life, even in the face of impending death. There is thus a shift of goals from the cure and prolongation of life to the alleviation of psychological and spiritual suffering, the relief of pain and other symptoms, and the enhancement of the meaning and quality of the patient's remaining life.¹² Palliative care therefore utilises every relevant component of modern

medicine to achieve maximal comfort, to alleviate fear and anxiety, to establish security and trust, and to encourage patient autonomy.¹³

terminally ill patients and their families and to make every effort to explore, understand, and address suffering that persists despite their best efforts.

Physicians and hospice health care workers have the responsibility to give comprehensive palliative care to

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