

ETHICS AND PALLIATIVE CARE

It is helpful to have a good understanding of the application of bioethical principles when caring for patients with life-threatening illness.

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Medical decision-making is guided by the four bioethical principles of respect for autonomy, beneficence, non-maleficence and justice.¹ In caring for patients with life-threatening illness, there are often complex decisions to be made and it is helpful to have a good understanding of the application of bioethical principles to assist decision-making.² The South African Health Professions Council has clear general ethical guidelines for the health care professions to assist this understanding.³

There are concerns regarding the application of bioethical principles in that while these principles provide a guide to decision-making, they may fail to take into account the individual and family members, personal preferences and context.⁴ In palliative care it is always important to consider each patient individually and to develop a care plan relevant to the individual, the stage of the illness, the person's preferences and the family's wishes. Shared decisions discussed in an understanding and compassionate way allow for appropriate patient care with the patient and family involvement in this care.

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This article describes the four principles of autonomy, beneficence, non-maleficence, justice briefly and uses a case scenario to explore the application of these principles in a practical way, recognising the 'importance of concrete lived experience of health care professionals and of their patients.'³

Bioethical principles

Autonomy

Autonomy – from the Greek meaning self-rule – describes the ability to make decisions for oneself based on deliberation. This presumes a decision maker who has the required information, capacity and circumstances to make rational decisions. Respect for autonomy requires the doctor to provide full information in language and wording that promote patient understanding. The ethic of respect for autonomy contrasts with the ethic of paternalism, which sees the patient as a passive recipient of care.

Respect for autonomy underpins the concepts of informed consent, confidentiality and truth-telling about prognosis, treatment options and side-effects. The Hospice Palliative Care Association Code of Ethics⁵ recognises that the fundamental principle underlying all care practices is respect for the worth, dignity and human rights of every individual, and that respect for human dignity requires the recognition of patient rights, particularly the right to self-determination.

Capacity to make decisions depends on a person's mental competence which may be compromised as illness progresses. If a patient lacks the capacity to make decisions, a proxy decision-maker should be consulted. A person may have written his wishes for future care in



a Living Will⁶ or Advance Directive. If there is no proxy, decisions should be made in the patient's best interests, taking into account his known values and in accordance with society's norms and values.⁷

Decisions in the palliative care setting are often made in an environment of emotional distress. The doctor should be sensitive to the 'human vulnerability, dependency and fragility'³ of the patient who is critically ill and to the family member acting as proxy.

Beneficence

Beneficence provides benefit to the patient and balances the benefits against risks and costs.¹ An imperative in acting within the ethic of beneficence is to keep abreast of modern medical knowledge, which includes knowledge and understanding of palliative care. If the doctor is not able to manage severe or refractory symptoms, it is important to refer the patient to a qualified palliative care specialist or hospice.

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Any treatment embarked upon should be with the intent to benefit the patient, taking into consideration the intended benefit and the burden or discomfort of the treatment. If the treatment will not benefit the patient at this stage of the illness it is a sound clinical decision to withhold

or withdraw treatment in discussion with the patient and family members and other members of the care team.⁸ Such decision making would be considered both legal and ethically acceptable.^{9,10}

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The withholding or withdrawing of futile treatment is sometimes described as 'passive euthanasia'. It is time that this term is dropped from the language debating end-of-life issues. To elucidate the understanding of terms, the EAPC Ethics task force make the statement that euthanasia is active by definition: Euthanasia is killing on request and is defined as a doctor intentionally killing a person by the administration of drugs, at that person's voluntary and competent request. 'Passive' euthanasia is a contradiction in terms – there is no such thing.¹¹

The task force also states that none of the following should be seen as euthanasia:

- withholding futile treatment
- withdrawing futile treatment
- palliative sedation,

and that 'palliative sedation in those imminently dying must be distinguished from euthanasia'.

In palliative sedation the intention is to relieve severely distressing and refractory symptoms, 'the procedure is to use a sedating drug for symptom control and the successful outcome is the alleviation of distress. In euthanasia the intention is to kill the patient, the procedure is to administer a lethal drug and the successful outcome is immediate death'.

Experienced palliative care clinicians may use mild to moderate sedation to relieve distress or refractory symptoms. The degree of sedation is titrated to achieve comfort and some patients may still be able to communicate with their loved ones.

The intellectual debate about euthanasia does not prevent requests for euthanasia, however infrequent. These requests often derive from a fear of the dying process, from fear of experiencing severe unrelieved pain, from fear of loss of control or loss of dignity. A request for euthanasia should be seen as a cry for help² and the reasons for the request explored so that the person's concerns can be understood, unrealistic fears explained

and realistic fears discussed. In addition, interventions available to reduce the impact of possible complications of the illness should also be explained. Often the request for euthanasia is not for active dying right now but for some control over the time of dying and as the patient experiences good care and control of distressing symptoms the request becomes less urgent or no longer an issue.

Here again is a situation where a Living Will⁵ or Advance Directive enhances the autonomy of the patient by involving him in advance care planning.

Non-maleficence

Non-maleficence describes the bioethical principle of 'do no harm' and is closely related to beneficence and the balancing of risk and benefit. For example, one should not embark on futile treatment that is unlikely to benefit the patient such as when 'treatment results in preserving permanent unconsciousness'.⁹ A more common situation is the initiation of CPR in a dying patient. This can be addressed by advance care planning that may include a 'Do Not Attempt Resuscitation' order so that the treatment offered is appropriate to the individual situation.¹²

Justice

Justice can be described as 'fairness' and can be further considered as distributive justice (fair allocation of resources), rights-based justice (similar to autonomy), fair access for the individual to health care and legal justice according to the laws of the country.

Ethical decision making

In applying bioethics to a practical situation, it is necessary to identify the ethical dilemma, to engage in discussion with the patient, family and care team, to explore assumptions and present factual information. The bioethical principles provide a foundation for the discussion and assist in reaching a decision for the immediate care plan. There is also opportunity for further discussion and review of the care plan as the illness progresses (or improves).

Case study

Mr James Petersen is 68 years old with pancreatic carcinoma and liver metastases. Treatment options were discussed with him and his wife at the oncology clinic and he opted for palliative measures, stating that he wished for treatment to enable him to live as comfortable as possible without 'useless' medication interventions. He requires opioid analgesia, laxatives and anti-emetics and over the course of the illness loses weight and becomes weaker and bedfast. He is nursed at home by his wife, Susan, and in the later stages of his illness, his daughter, Rachel a palliative care nurse, comes home to assist with his care and is determined to carry out her father's wishes to remain at home throughout his illness. Following a period

of nausea and vomiting, his medication is administered subcutaneously via a syringe driver, morphine sulphate 30 mg and haloperidol 2.5 mg over 24 hours, which achieves good symptom control. His oral intake declines markedly.

You are called to see him as he has developed myoclonus and confusion over the last 2 days. His son, Mike, an intensive care physician, has returned home from the USA and is very concerned that his father is severely dehydrated and requests hospital admission for rehydration.

The ethical dilemma revolves around the fact that Mr Petersen's wife and daughter have been caring for him during this illness and have experienced the progression of his illness to this advanced stage and are determined to respect his wishes to remain at home and to die at home. His son believes his condition is reversible and he insists on hospital admission to reverse the dehydration and improve his father's condition. This is a very emotional time and an emotional situation with heated disagreements possible.

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The son may also harbour feelings of guilt at not being present to advise on his father's care. His assumption is that his father's condition can be improved and that he is dying of 'neglect'. The wife, daughter and palliative care team recognise that Mr Petersen is in the final stage of a terminal illness. The palliative care team recognise that the myoclonus and confusion experienced by Mr Petersen are probably due to build-up of morphine metabolites as his renal function declines in the last stages of his illness.

Autonomy

Mr Petersen no longer has the capacity to express his wishes but these were discussed in detail with his wife and his GP. It would be helpful to have a Living Will or Advance Directive although these are documents to guide decision-making and not legally binding documents under South African law. His wife would be seen as his proxy decision maker but may be swayed by her son with his clinical knowledge expertise and authority. Her daughter supports her father's wishes.

Benevolence

Is there treatment that at this stage of the illness could benefit Mr Petersen? As it is likely that morphine metabolites are causing the myoclonus and possibly the confusion (see David Cameron's article on p. 292) it is recommended that analgesic medication is changed from morphine sulphate in the syringe driver to transdermal fentanyl. It may be that additional fluid would assist in eliminating the morphine metabolites. Does this require IV rehydration or can it be achieved through subcutaneous infusion of normal saline – hypodermoclysis? This procedure can be instituted at home. Will it improve his comfort? There is no certainty about this but we could do a trial

of hypodermoclysis and assess Mr Petersen's response to this intervention. Current evidence suggests that artificial hydration is futile treatment at this stage of advanced cancer. His son may not feel this is enough and we would need to explain to him the physiological processes that occur at the end of life.¹³

Many patients with advanced cancer lose weight due to the anorexia-cachexia syndrome and 'reduced food intake causes reduced gastric contractions and leads to reduced hypothalamic stimulation and anorexia. With the lack of glucose and protein from the diet, the body will turn to the metabolism of fat stores. The resulting ketone levels further suppress hunger and thirst ... greater water production and a reduced need for fluid intake.'

Benevolence also extends to the family to support Mrs Petersen and her daughter in following his wishes and in assisting the family to agree on Mr Petersen's care will improve bereavement outcomes following his death. Empathetic counselling of the son may assist him in coming to terms with his father's irreversible condition and impending death.

Non-malevolence

'Harm' would be caused if we admitted Mr Petersen to hospital, going against his wishes and those of his wife and daughter to provide care at home, in a familiar loving environment. There are also a number of disadvantages to IV hydration: an IV cannula is uncomfortable and a barrier to contact with the family, there may be incontinence due to increased urine output, a urinary catheter may be required, fluid overload may result in pulmonary oedema.

Justice

If we consider the fair allocation of resources, it is clear that Mr Petersen should not be in hospital if there is no hospital treatment that will improve his condition and would deprive another patient of the hospital resources. Right-based justice indicates that Mr Petersen has the right to choose his place of care and to refuse treatment he has described as 'useless medical interventions'.

Conclusion

The four principles of bioethics are a valuable foundation for clinical decision-making and must be combined with compassionate support of family members including clear explanations and sharing of information.

References available at www.cmej.org.za

IN A NUTSHELL

- The four principles of bioethics are respect for autonomy, benevolence, non-malevolence and justice.
- A person requires clear information to make autonomous decisions.
- Benevolence intends best possible treatment for the individual.
- Benevolence infers a balancing of possible benefits and possible risks or harms.
- Benevolence requires clinicians to keep up to date with current knowledge.
- Withholding or withdrawing treatment is ethically and legally acceptable if the treatment is futile.
- A Living Will or Advance Directive provides guidance on a person's preferences for care.

SINGLE SUTURE

From A to B

There's a double dose of good news in the battle against meningitis this week. It has taken just six months for a cheap new vaccine against meningitis A to work its magic, reducing the number of new cases in West African trial zones to almost zero. And a new vaccine against meningitis B is showing promising results in Europe.

Meningitis A causes epidemics in the notorious 'meningitis belt' from Senegal to Sudan, but none of the people who received the new vaccine six months ago in Burkina Faso, Mali and Niger has developed the illness. People in Chad, Cameroon and Nigeria will receive shots this year as part of a 5-year programme to extend the treatment to all 25 countries affected, provided enough money can be raised.

Meanwhile in Europe, pharmaceutical firm Novartis has reported encouraging results in 1 800 infants with what could be the first vaccine against meningitis B. The company recently revealed that recipients of '4CmenB' produced antibodies against strains that cause 80% of meningitis B cases.

New Scientist, 18 June 2011, p. 7.