Ethical decisions in end-of-life care

Palliative medicine is the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life.

DEBBIE NORVAL
MB BCh, D PallMed

Director of Education
Centre for Palliative Learning
Hospice of the Witwatersrand
Johannesburg

Debbie Norval qualified at the University of the Witwatersrand in 1991, and has a diploma in palliative medicine through the University of Wales. She has recently completed research for her master's degree in palliative medicine through the University of Cape Town. She is also studying towards the City and Guilds International Diploma in Teaching and Training. Dr Norval is a board member of the IAHPC (International Association of Hospice and Palliative Care), a member of the HPCA (Hospice and Palliative Care Association of South Africa) Patient Care and Education Subcommittee, and a course tutor and examiner for the University of Cape Town Masters/Diploma in Palliative Medicine. Over the past 7 years, Dr Norval has been actively involved in patient care at Hospice of the Witwatersrand, and has more recently dedicated her time to education and training in palliative care in South Africa.

ELIZABETH GWYTHER
MB ChB, MFGP, DipPalMed

CEO
St Luke's Hospice
Cape Town

Liz Gwyther graduated from UCT in 1979 with MB ChB. She worked as a GP in Zimbabwe and Somerset West and studied for MFGP in 1993. She has been involved in hospice care on a voluntary basis from 1993 and obtained the Diploma in Palliative Medicine from University of Wales, College of Medicine (UWCM) in 1998 and the MSc in Palliative Medicine (UWCM) in 2002. She has been active in palliative care training and education and in hospice development programmes. She is a member of the education subcommittee of Hospice Palliative Care Association of South Africa (HPCA) and member of the HPCA Board. She is convenor for the postgraduate programmes in palliative medicine at the University of Cape Town.

Patients with far-advanced disease are often vulnerable and anxious and the doctor, care team, patient and family may face difficult decisions regarding care. It is important that the doctor bases his/her practice on sound ethical principles, based on the four prima facie principles of autonomy, beneficence, non-maleficence and justice. Prima facie means that the principle is binding unless it conflicts with another moral principle, in which case we have to choose between them.[1]

Application of these principles varies in different parts of the world and different cultures so that, for example in the USA, autonomy is an overriding consideration whereas in the UK and South Africa, the principle of distributive justice is more pressing.

AUTONOMY

Autonomy literally means 'self rule'. Respect for autonomy promotes the idea of the individual making his own decisions. This places a responsibility on the doctor to ensure that his/her patient is fully informed. Information sharing is based on good communication and assessment of the patient's understanding and includes assessment of how much the patient wants to know. In the context of South African medical practice, this means moving from a paternalistic medical model to a partnership between doctor and patient which allows for mutual decision making.

Thus respect for autonomy includes concepts such as informed consent, confidentiality, truth telling and promotes the development of a trusting relationship between doctor and patient. This also results in the patient becoming an active member of the management team and restores a sense of control in the face of an illness that has removed control from the patient.

BENEFICENCE AND NON-MALEFICENCE

Beneficence (to benefit the patient) and non-maleficence (to do no harm) are closely related. In medical treatment, we need to recognise that any intervention carries a risk of harm, e.g. side-effects of medication, risk of surgery. This is even more marked when managing a patient with life-threatening illness, e.g. risks of chemotherapy which may equally offer cure or control of cancer, the side-effects of antiretrovirals. As medical practitioners we are very aware of the concept of risk versus benefit.

One contributing factor to beneficence is the responsibility for rigorous and effective professional education[1] which is followed through by the requirement for continuous professional development (CPD).

Effective and relevant medical research contributes to the body of knowledge recognised as evidence-based medicine.This is disseminated in our journals and collected in a database such as the Cochrane database.

JUSTICE

The principle of justice is that by which competing claims may be decided upon in fairness. This can further be considered according to distributive justice (fair distribution of resources), rights-based justice (e.g. all people have the right to equal health care) and legal justice (according to the country's laws). There are a number of competing claims, particularly in the SA setting, where patients in a medical aid or private health care setting have access to health care that is not afforded to patients in the public health care setting.

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In considering ethical decisions one also has to decide who makes the decision — is it the doctor, the patient, the health care team? Who comprises the team?

In practice in palliative care we consider the facts, the assumptions and ethical principles, debate the issue, come to a working decision and reassess the decision if appropriate (Fig. 1).

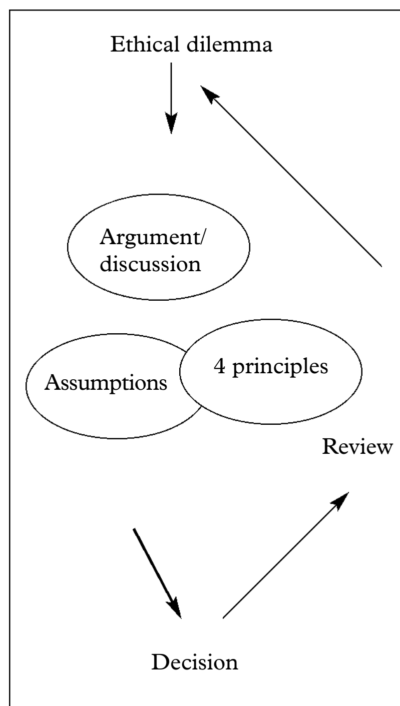

Fig. 1. Decision-making process in palliative care.

FUTILE TREATMENT

Advances in medical technology have resulted in patients' lives being extended by interventions now available to us. However, the availability of technology and advanced intervention does not mean that the intervention is appropriate to all patients.[2] The practitioner should ensure that the patient and family are informed regarding the treatment, benefit and burden and likely improvement in quality of life, and should support the patient's decision. If the patient chooses not to have further treatment, the withholding or withdrawal of treatment is a sound medical decision based on ethical principles.[19]

Patients may choose to sign an Advance Directive or Living Will which may include the following: '*If the time comes when I can no longer take part in decisions for my own future,let this declaration stand as the testament to my wishes. If there is no reasonable prospect of my recovery from physical illness or impairment,expected to cause me severe stress or to render me incapable of rational existence, I request that I be allowed to die and not to be kept alive by artificial means and that I receive whatever quantity of drugs that may be required to keep me from pain or distress even if the moment of death is hastened.*' (SAVES Living Will)

Whereas this document may not be legally binding, it does give the practitioner and palliative care team guidance as to the patient's wishes. The drawback with the Advance Directive or Living Will is that patients may change their mind but may be unable to communicate this.[2] There is also an anomaly in South African law in that the directives of incompetent persons, expressed when competent, are not regarded as valid.

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THE DOCTRINE OF DOUBLE EFFECT

The doctrine of double effect asserts that a bad effect (such as the patient's death) may be permissible if it is not intended and

occurs as a side-effect of a beneficial action.[3]

It is important that the primary aim is to relieve distressing symptoms and that the death of the patient (should that occur) is unintentional.

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Whenever doctors try to help a patient, they inevitably risk harming them, but the principle of beneficence should always outweigh maleficence. Fear of double effect should not be a reason for withholding treatment that would bring relief.[4]

British law states that the Doctrine of Double Effect may only be cited if the patient is terminally ill, if the treatment is right and proper and recognised by a responsible body of medical opinion and, lastly, if the motivation was to relieve suffering.[3]

The practitioner should be aware of the effective palliative care techniques that can relieve distressing symptoms without shortening life. Considered decision-making including consultation with palliative care practitioners and discussion with patient and family will assist in forming a management plan that will benefit the patient and protect against risk of abuse of the doctrine of double effect.

EUTHANASIA

The possibility of legalising euthanasia has been a topic of much debate in many countries and doctors need to maintain their knowledge surrounding a debate that would undoubtedly impact on clinical practice.

The word euthanasia comes from the Greek word for 'a good death, a gentle, easy death'.[5] This differs from current definitions of euthanasia which include the direct, intentional killing of a person at his/her request as part of the medical care being offered,[6] or deliberate intervention with the express intention of ending life to relieve intractable suffering at the patient's request.

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Physician-assisted suicide differs from euthanasia in that a physician complies with the request for a prescription of a lethal dose of medication from a competent patient.[7] It is then the responsibility of the patient to take the medication.

A study done in the Netherlands on the reasons patients request euthanasia showed that out of a group of 200 patients, 80% requested euthanasia out of fear of unbearable suffering, 14% of patients requesting an end to life had profound depression, 4% cited general tiredness of life as being the reason for requesting euthanasia. Only 1% wanted to end their lives because of loss of independence and control or because of extreme pain.[8]

These figures reflect that most patients requesting euthanasia are not, in actual fact, suffering but fear possible future suffering.This reveals lack of knowledge that almost all pain, physical suffering and existential distress can be adequately controlled with good palliative care.

'It is dying, not death,that I fear.' — Montaigne

Arguments in favour of euthanasia

- Compassion and mercy are fundamental moral values of society and no patient should be allowed to suffer unbearably.[5] The ethical principle of beneficence could be applied to euthanasia as death could be considered good for the patient if it is a release from intractable suffering.
- The basic ethical principles of autonomy and self determination support the view that patients have the right to make choices about their own life.[9]

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- Palliative care is not universally effective or available.[5] Meticulous symptom and pain control cannot heal deep emotional and spiritual anguish. Diane Pretty said:'While palliative care makes a great difference to many people it is not the solution to all.'[10] In South Africa palliative care has not, as yet, been introduced into most hospitals but is available in hospices and NGOs. Many remote areas have no health care

personnel trained in palliative care.

- The option of euthanasia provides an escape route when health insurance is exhausted and patients are faced with inadequate and scarce health care resources.[12]

Arguments against euthanasia

- The ethical principle of non-maleficence protects a patient from the greatest harm that could be done by a physician — taking a patient's life.[2]
- Although proponents of euthanasia claim compassion and mercy as arguments in favour of euthanasia, others believe that the truly compassionate and merciful way to manage a request for euthanasia is to explore the reason behind the request. Research shows that 80% of requests for euthanasia are due to fear of suffering. Health care professionals, instead of ending a patient's life, should rather spend time communicating, exploring and listening to their patients.[15]
- Requests for euthanasia are rarely sustained after good palliative care is established.[2] In countries where palliative care services are well developed, such as the UK, there is a vastly reduced call for euthanasia.[14] In 1998 in the Netherlands there were two palliative care units in the country.[8]
- The last few weeks and days of a patient's life do not have to be negative and depressing. There is a great deal of value to the final days and weeks of life. Many emotional wounds are healed, spiritual growth occurs and strained relationships are reconciled. Failure to recognise this results in paternalistic medical care that aims to minimise suffering by hastening death.[16]
- The 'slippery slope' argument states that voluntary euthanasia may lead to non-voluntary euthanasia or that physician-assisted suicide may lead to technician- or family-assisted suicide.[11]
- Bereavement in carers and loved ones after euthanasia has taken place is often complicated. Those left behind are often fraught with guilt and regret.[2]
- Legalising euthanasia places pressure (whether real or imagined) on the vulnerable and the terminally ill.[17] Those who are old, poor, demented, mentally retarded or marginalised by society, might feel that they are a burden on society and consent to euthanasia.[4]

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'Ageing and death are inevitable aspects of life that should be handled with grace and dignity.' — Solly Benatar[18]

Society has a compelling responsibility to care adequately for the elderly, the dying and the disabled.[17]

- There is a potential for psychological repercussions among physicians who assist in suicides and euthanasia.[7]
- There is very low incidence of suicide in terminally ill patients in spite of easy access to potent drugs. This suggests that most terminally ill patients cling to life and value life. It supports the view that requests for euthanasia are more a cry for help and are due to fear of possible suffering and not to suffering itself.
- Legalisation of euthanasia could lead to distrust and fear of the power of doctors and nurses, fear of admission to hospitals, hospices and frail care centres.
- Lastly the religious argument against euthanasia is that no human being has dominion over the life of another, that life is sacred and has value and meaning right up until death.[5]

Palliative care practitioners believe that there should be no move to legalise euthanasia until we have mounted a credible and sustained effort to train doctors in the skills required for the care of the dying.[5] This is of particular importance in South Africa, where palliative medicine has not been a part of the undergraduate curricula.

HOW TO RESPOND TO A REQUEST FOR EUTHANASIA

How should a medical practitioner respond to euthanasia requests? This is a difficult and challenging aspect of care and the experienced practitioner will realise that there is no easy answer. However, we need to recognise that the request for euthanasia is a cry for help which demonstrates a sense of hopelessness and despair. It is also essential to recognise that the request also reflects a gap in perceived care. An appropriate response includes explanation of the source of the request, to acknowledge the patient's anxieties, concerns and fears, to explain unrealistic fears and discuss realistic fears and what interventions are available. Most importantly, the practitioner must recommit to care of the patient and family throughout the illness.

There is currently a trend away from the ethic of prolonging life at all costs to an ethic of emphasising

the quality of life and quality of dying over duration of life.

Saving lives will always remain a primary goal of clinical practice and the passion to prolong life is responsible for the exceptional advances in medicine over the past century.[20] But when it does not take into account the fact that at some point life cannot and should not be prolonged, it creates rather than alleviates suffering. In medicine, we need to accept that dying is a natural part of living.

'The challenge is — to try to preserve the values we have traditionally considered to be central to medicine and to our lives as humans.' — Solly Benatar[18]

References available on request.

IN A NUTSHELL

- It is important that doctors base their practice on sound ethical principles of autonomy, beneficence, non-maleficence and justice.
- Respect for autonomy promotes the development of a trusting relationship between doctor and patient.
- The practitioner should ensure that the patient and family are informed regarding the treatment, benefit and burden and likely improvement in quality of life, and support the patient's decision.
- Effective palliative care techniques can relieve distressing symptoms without shortening life.

A matter of timing

EVERY INVESTOR wants to buy at the bottom of the market and sell at the top. Unfortunately, that's easier said than done. Successfully timing the market requires analysing hundreds of variables as diverse as interest rates, consumer confidence, company fundamentals, commodities prices, bond yields and the weather. Not surprisingly, even the top professionals cannot get it right all the time. For individual investors, it is more difficult still. So, while buying at the bottom remains a tempting prospect, most investors are better off adopting a more practical long-term investment strategy.

Barclays' offices in Illovo, Johannesburg

With recent stock-market falls fresh in their minds though, it can be hard for investors to stand by their rational investment objectives - the reasons they invested in the first place. But, just as every investor wants to buy low and sell high, it is also important to avoid the reverse - buying high and selling low. Steph Bester: Head of Sales, Barclays Private Clients says "The problem is that, psychologically, it is easier to invest at the top of a bubble, after several years of comforting gains, than it is to invest near the subsequent low point, when the news inevitably looks bleak - even though it is clearly better to buy near the bottom of the market than at the top."

Steph Bester: Head of Sales, Barclays Privat Clients

So, for investors who do not need to cash in their investments, now may not be a good time to sell, especially as the rebounds that follow prolonged bear markets have in the past tended to be both strong and rapid. And remember that, historically, markets have risen much more of the time than they have fallen. This suggests that it is more important to be in the market than to time the market correctly.

For prospective investors, meanwhile, it is tempting to wait for further falls before buying. But the only way to be sure the market has bottomed is to wait until news has improved beyond any doubt. By then, much of the upside may already have occurred. So the question investors ask themselves should not be "Is this the lowest markets are going to go?", but "Are markets likely to be higher than this by the end of my investment period?" If the answer is "Yes", now should be a good time to invest.

As with all investments much depends on the amount of risk the investor is prepared to take. Generally, the higher the risk of an investment, the greater the returns on offer. Shares tend to produce better returns than bonds or cash in the long term. But, as the recent past has amply demonstrated, stock markets are more volatile and can decline for months or years at a stretch.

So it is crucial for investors to decide which investments are appropriate for their financial circumstances before considering which unit trust, individual stock or bond to buy.

For investors who are not prepared to risk losing any of their capital but would like to share in the gains if markets go up, other choices - such as limited issue bonds - may be more appropriate.

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