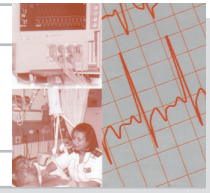


# End-of-life care in intensive care units



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Ethical theories have been posited since the dawn of civilisation. We all approach moral decisions informed by our historical, family and cultural backgrounds, augmented in turn by our personal and professional experience. Theories and practice reflect the beliefs, values and knowledge of the ages, refined, modified and reinstated to address present ethical concerns. Platonic and Aristotelean ethics were modified in the ensuing centuries: theorists constructed models based on natural law, seeing humankind as a link in the chain of being – stretching from God Himself to the smallest of inanimate beings.

In the following centuries, particularly from the time of the Enlightenment, in response to scientific, socio-political and economic changes, universal and particular theories emphasising variously reason, autonomy and duty, the consequences of actions, emotion and hedonism, and ethics of the situation were posed, criticised, revised, tested and refined. Human rights theories were ratified after World War II and the Holocaust. Aristotle's virtue ethics, expanded in the Middle Ages, have been revisited in this age, focusing on the moral character and intent of the person performing the action. The virtues of compassion, fortitude and perseverance are considered to be important for clinical practitioners.<sup>1</sup>

Modern civilisation, with dramatic advances in science, technology, communications, industrialisation, population growth and migration, has posed particular challenges, exceeding those experienced in the Enlightenment. Secularisation and multi-cultural societies with competing and seemingly incommensurable values and beliefs initially cast ethics into a state of semi-paralysis. Toulmin<sup>2</sup> has described the amazing contribution medicine made to ethics: by deriving principles from the examination of specific cases, medical ethicists were able to agree on ethical principles despite the fact that they came from different and incommensurable theoretical backgrounds.

Because of the remarkable advances in pharmaceuticals and technology, the ability to extend life beyond the bounds of ordinary human biology has resulted in death being seen as an enemy and a failure.<sup>3</sup> At the same time, consumers, aware of their autonomy and rights, are requesting that they be given the opportunity

to decide when and how they will die and issuing advanced directives or requesting assistance to die with dignity and without pain.

Countering this is medicine's traditional 20th-century role of managing health, life and death, based on science and technology. This has led to ethical dilemmas being played out in all areas of medicine but most particularly in the intensive care unit. As the central role players, society, professional organisations, ethicists and theologians grapple with ethical issues and the tensions existing in medicine; no doubt the subjects of moral theology and applied ethics, debated and revised, will in turn inform and direct practitioners, as did Toulmin's protagonists.

Because the intensive care unit is a very different environment, we will first discuss this area. Thereafter, we will discuss the persons who play out central roles in this area in end-of-life care. They are not the only characters in the drama; social workers, psychologists, managers, pastoral counsellors, laboratory and technical staff are also involved. However, at the end of life, patient, family, doctors and nurses are the primary persons involved in the actual ethical decision-making process and they are the human face of care. Decision-making is frequently a fraught and contested process with potential to markedly disadvantage patient care.<sup>4,5</sup> As a response, we advocate the formation of an ethical committee to be a central part of the decision making and support resources that should also be central in the ICU.

## The ICU as an ethical arena

ICUs are special places. They are staffed by experts in intensive care, who are also able to care intensively. Health care professionals are called to bring their professional and ethical knowledge, experience and expertise to bear in order to make ethical and humane decisions and, in doing so, add to the theory of ethics and the excellence of health care interventions. Despite medical advances, mortality rates have remained constant at around 20% in ICUs, and for certain large subgroups remain at more than 40%.<sup>6</sup> Ninety per cent of patients who die in ICUs now do so after a decision to limit therapy.<sup>7</sup>

Death and discussion about end-of-life care are common in ICU settings, yet these conversations are often difficult. The ICU ethos is orientated to saving lives, and acknowledging that death is approaching may be difficult.<sup>8</sup> Unfortunately, clinicians may fail to appreciate how their personal emotions and values can influence their clinical responses in issues of life and death. Good communication is a matter of insight and self-awareness, not just language skills. In many cases, clinicians are forced to confront their own limitations, their memories of personal loss or their own mortality. Withdrawal and avoidance with unilateral decision-making may also be a response to counter-transference.<sup>9</sup>

Inconsistent practices have been noted with regard to decisions to withdraw or withhold treatment. Differences have been found in judgements about the appropriate level of care for critically ill patients and diversity in the process of withdrawal as well as who is charged with withdrawing treatment.<sup>6</sup> These differences have been attributed to professional, personal, social and attitudinal attributes of the caregivers, including specialty status or whether the patient has a unit or private attending physician. Asch's<sup>10</sup> survey of critical care nurses in the USA revealed that almost 20% of more than 1 000 respondents reported engaging in what they considered euthanasia or assisted suicide, or in hastening death in response to a perceived overuse of technology or over-aggressive treatment, to relieve suffering or counter the perception of physician unresponsiveness to the patient's suffering.

To care for the patient who is approaching death, ICU clinicians need to remember that death is part of life, not an enemy to be defeated; that palliative care is part of intensive care and requires a physical, moral, psychological and interpersonal intensity surpassing most other clinical procedures. The physical, psychosocial and spiritual needs of the acutely ill individual need to be addressed, and this requires extraordinary expertise in communication and information giving, comfort care, and pharmacological management.

## The current situation in intensive care units

Science and technology have progressed beyond belief, particularly in the area of pharmacology and medicine. This has had a huge impact on end-of-life decisions, and decision making is becoming increasingly complex. Other factors impinge on ethical decision making in critical care practice: the cost of health care due to shrinking financial and personnel resources and managed health care, the increasing emphasis on patient rights and autonomy, the requirement that more information and decision making be shared with patients or their surrogates, and the increase in

litigation have severely impacted on the ability to offer care.

High levels of chronicity and co-morbidity (HIV/AIDS-related diseases, tuberculosis, renal, endocrine and cardiac disease) in populations require multiple interventions and present practitioners with complex and difficult decisions. Open units, those staffed by different specialists, also present particular problems. Different regimens and protocols favoured by different specialists place burdens on nursing staff.

In South Africa, the government policy privileging primary health care and budgetary constraints imposed on tertiary care present management with a conundrum as to how to ensure adequate services for primary, secondary and specialist services within one institution.<sup>11</sup>

The continued exodus of trained and experienced nurses is affecting all levels of health care. Trained ICU nurses are in particular demand, however, and due to poor salaries and working conditions they are leaving the country at an alarming rate. Currently only 25% of nurses staffing ICUs are registered as critical care nurses.<sup>12</sup> Staffing ratios and the staff ratio mix are matters of concern, and moves are afoot to increase the staff complement by including sub-professional categories of nurses in units to address the paucity of registered ICU nurses.

Severity of the patient's illness is a cause for concern, dealing as we are with both First- and Third-World circumstances. HIV/AIDS affects a significant proportion of the population, posing the threat of sepsis in immune-compromised individuals. Multiple trauma resulting from high levels of violence, motor vehicle accidents and patient intentionality – the suicide rate in all populations is rising – also impact on the acuity of patients in ICUs. All these factors increase the likelihood that palliative care will be necessary, and decisions as to when and how to withhold or withdraw treatment are becoming increasingly important in ICUs.

## Applied ethics

Applied ethics relies on the common morality. The widely shared values and conventions of society, national and international codes of research and professional ethics, governmental and institutional policies and various ethical theories as well as the character of the person or ethical agent inform decision making in medical ethics. Beauchamp and Childress<sup>13</sup> acknowledge the complexity of ethical decision making. They advocate a principle-orientated approach: respect for autonomy, non-maleficence, beneficence and justice, and considerations of risk/benefit from which rules and particular judgements can be weighed and selected. However, they emphasise that, in moral reasoning, appeals to principles, rules, rights, virtues, passions, analogies and paradigms are

mutually supportive and frequently need to be blended. The more general and the more particular should be linked together in moral thinking.<sup>13</sup> The principle of justice informs the clinician's decisions of resource allocation.

Christian moral decision making relies on these sources but also considers scripture, experience, moral tradition and personal virtue. Basic convictions in Christian morality include that life is a sacred gift from God and persons are required to be stewards of life and consider all life a basic good;<sup>14</sup> that, as Christians, we are called to be compassionate and choices cannot be made that undermine the worth of the person; that while sacred, life is not the overriding value in every set of circumstances and we are not required to use extraordinary means to prolong life; that personal autonomy is important and the patient is the most important person in the ICU; that adequate, compassionate care is needed to ensure that the dying person is comfortable and free from pain and that anxiety is alleviated; that intensive care means intensively caring; and that intentionally assisting a person to die is not a private moral decision but has professional, institutional and societal implications. All care rendered should must address these broader concerns.<sup>15</sup>

A growing body of evidence has exposed the problems of postponing palliative care for intensive care patients until death is obviously imminent. Integration of palliative care in comprehensive intensive care units is seen as appropriate for all critically ill patients.<sup>6</sup> Detailed guidelines for end-of-life care have been published and provide help for the multi-disciplinary team to assist patients and families negotiate the process of dying in the ICU.<sup>16,17</sup>

## The role players in the ICU

### The patient

By definition, patients in an ICU are critically ill which implies failure of one or more vital organ systems.<sup>18</sup> Patients are generally admitted after calculating an acute physiology and chronic health evaluation score and other evaluative measurements to determine whether they are likely to benefit from admission and the probable outcome. Patients who are unlikely to survive should not be admitted to specialist ICUs; this practice is common, however, in private health care.

Pain is frequently underestimated; half of the patients in the large SUPPORT study<sup>19</sup> reported either directly or through surrogates that they experienced pain. Among patients who died, clinically important levels of pain were found in all disease categories studied.<sup>6</sup> The fear of uncontrollable and unbearable pain is one shared by all human beings. It is perhaps the fear most regularly cited by persons seeking physician-assisted

suicide or euthanasia. It must be remembered that sedation is not analogous to analgesia. Morphine, in doses calibrated to alleviate suffering, is recommended by all medical and ethical experts, even if this serves to shorten life – 'the double effect'.<sup>20,21</sup> The official Catholic teaching has supported the use of advanced directives; nonetheless, the Catholic Church and Western medicine have consistently drawn a line between assisting the person to die peacefully and intentionally causing death; Pope John Paul II noted that a request for euthanasia is rather a request for companionship, sympathy and support.<sup>15</sup> In recent years, some Christian ethicists have suggested that assisted suicide might be moral in certain cases. McCormick and Connors<sup>15</sup> cite Maguire, Curran, Cahill and Nelson, suggesting that the duty to respect the sanctity and dignity of life might not mean an absolute prohibition on intentionally assisting a person to die.

The presence of family members with the patient is ideal; it is comforting for the patient to know that someone known and trusted is beside them, will touch and speak to them, pray with and for them, and won't leave them alone. However, a known and trusted nursing practitioner who can alleviate their fear, explain what is being done and enhance their sense of control is just as important both for the patient and the family. The family and patient should be asked whether spiritual reassurance would be appreciated, and if so a minister of religion should be called to counsel the patient and family, administer the Eucharist, hear confession or anoint the person as wished.

Other members of the team are also needed at the bedside. One ICU nurse who wrote of her experience in caring for dying patients mentioned how very lonely *she* felt – doctors and nurses would pass by the cubicle leaving her alone with the dying person (personal communication, 2005). How distressing for the family noticing this, and how much more terrifying for the patient should he or she be aware of it.

A good death inevitably means dying with dignity. Intrusive and painful interventions should be avoided. Extraneous and invasive lines should be removed if possible, and attention to basic hygiene (skin, hair and mouth care) and comfort requires that the patient be positioned comfortably without unnecessary technical and medical instrumentation hindering movement or access to him or her by the family. Modesty should be preserved – the patient should be dressed and covered. Sedation and analgesia can alleviate pain, fear and distress, and should be calibrated upward as necessary to ensure this. Care cannot be limited to medical interventions; it must include compassion, spiritual and emotional care in order to humanise suffering.<sup>14</sup>

The decision whether to continue with hydration and nutrition remains controversial. In the USA, conflicting opinions are held by the Bishops interpreting the

Vatican's Charter for Health Care Workers, some maintaining that nutrition and hydration are normal care and demonstrate love. Others, including John Finnis and William May, insist that if burdensome, feeding tubes should be removed. Ford maintains that it is inhuman to allow a competent patient to starve to death, and consequently mentally impaired patients should not be deprived of hydration and nutrition, provided this is not too burdensome for them.<sup>21</sup> Treatment should not be determined by how the clinicians feel but by the benefit afforded to the patient. Generally, if the nasogastric tube causes distress it should be removed and the patient's mouth kept moist with ice (if conscious) and good mouth care.

When the decision has been made to withdraw treatment, this should be explained to the patient and the family and reassurance given that this will not result in suffering. Sedation rather than physical restraints must be used if the patient is distressed.<sup>22</sup> Oxygen and positioning can alleviate dyspnoea.

The autonomous identity of the person (and the family) goes beyond merely requesting consent for procedures or interventions. The principle of autonomy incorporates the rules for respect, truth-telling, disclosure and informed consent.

If the patient is conscious and able to make decisions, he or she has the right to refuse any recommended life-sustaining treatment. These situations demand empathy and the exploration of all possibilities. If there is no evidence that specific interventions will provide any benefit, the clinician is not obliged to provide such treatment. Both withdrawing and withholding treatment pose difficulties; withholding often appears less difficult, and withdrawing can be seen as 'giving up'.<sup>23</sup> However, treatments should not be withheld for fear of having to be withdrawn; time-limited trials of therapy may be useful to establish a patient's prognosis.

The competent patient or surrogate has a right to decide when medical treatment is too burdensome.<sup>21</sup> If an intervention offers a small prospect of benefit but will result in an unacceptable burden of suffering or cost and the patient or his family elects to pursue this, a difficulty arises. In most cases, an impasse can be avoided if the patient and his family has received information from the outset. Ongoing, regular communication from the time of admission is paramount. The patient's diagnosis and progress should be regularly communicated – to the patient, if possible, with all members of the team and with the family. It is conceded that accurate prognosis is extraordinarily difficult,<sup>24</sup> but communicating the patient's status to those who have the right to know not only includes them in the care of their loved one but also helps to prepare them for likely changes.

## The family members

As with any traumatic experience, fear, disbelief and denial of reality exist. The family also experiences confusion, hope, guilt and anxiety; conflicting responsibilities and distrust, primitive guilt and assumption of responsibility are present. There is also fear of the outcome – whether death, permanent disability, or their own envisaged responses to the outcome. Because the ICU is perceived as a unit where active extraordinary care is given, the family continues to hope for 'a miracle', even though there might be no grounds for this.

Confusion exists about the roles and authority of the various caregivers as well as which person from the family should assume responsibility for decision making on behalf of the family and the patient. The ICU milieu, with its high-technology, movements and sounds and the seeming abrupt changes between active and palliative care also causes confusion and distrust. Concern includes anxiety about what the patient is feeling, why he or she is being subjected to certain procedures, whether these are necessary, how much pain is being experienced, and whether enough or too much is being done. Pressing and conflicting responsibilities exist towards the patient, family, home and work. Financial concerns also intervene – whether medical insurance will cover the expense of treatment, and loss of earnings should the patient be the breadwinner.

Immediate and ongoing information, communication and support, not only from the clinician in charge of caring for the family member but also from all members of the team, need careful attention.<sup>25</sup> Azoulay *et al.*<sup>26</sup> found that over half the families of intensive care patients failed to comprehend the diagnosis, prognosis or treatment explained to them. Although critically ill patients and their families rank communication as a pre-eminent concern, evidence suggests that it needs improvement in many ICUs.<sup>6,24</sup> Explaining equipment, interventions, the patient's current status and envisaged progress (even if guarded), as well as asking about the patient's needs, preferences and life, will ensure that family members feel that they are valued and part of the process of caring for their loved one. Research to date indicates that many ICU practitioners struggle with communication.<sup>24</sup> This is complicated by the facts that admission to units is frequently sudden and traumatic and that families are distressed and anxious. Consequently, when communication is abruptly instituted family members often react with distrust.<sup>9</sup>

As far as is possible, visiting should be open to all family members. The ability to be with their loved one and, if possible, to assist with care not only helps to assuage their anxiety and distress but will, should the person die, be of comfort to them. They can go away

knowing that they did all they could to help. Families do, however, need to accept that the patient is in the unit to receive medical and nursing care. This requires that they may need to be absent during periods when care activities are being carried out. These facts need to be empathically but firmly enforced.

Families need to be reassured that everything possible is being done to ensure the comfort of the patient. Even when active treatment is stopped, they need to know that the person isn't being abandoned and that the best treatment is being offered for his or her current condition. A trusted spiritual advisor can help support the family, instil hope, unite them and the patient in prayer and the sacraments, help the family and patient to deal with unresolved issues, guilt and reconciliation, and assist the clinicians in explaining options.

### The medical and nursing practitioners

The emotional intensity, technical and problem-solving skills and physical effort required in caring for the patient means that clinicians are subject to emotional stress. The pain, distress and high mortality rates ensure that they are continually aware of the ethical issues surrounding caring for the critically or terminally ill. The practice of triage – refusing certain people care because of their perceived poor prognosis – leaves people feeling frustrated and angry. Babies who die because they are deemed too immature to survive, innocent persons and the young dying because of needless violence and accidents, patients succumbing to overwhelming sepsis after relatively benign surgery – all reinforce their helplessness in the face of death.

The current shortage of trained and experienced staff in all South African hospitals means that units are frequently staffed by agency nurses or inadequately experienced and even unqualified staff.<sup>12</sup> This places a burden on the experienced and specialist practitioners.

One of the challenges facing health professionals is working in a multi-disciplinary team. Blurring of roles, the need for continuous dialogue, and moving from a hierarchical to a collegial model method requires shared decision making and can result in a clash of cultural, religious and professional values.<sup>25</sup> Medical specialists, schooled in a previous model, are apt to make decisions on their own and leave the nursing practitioners to effect the action and to explain the decision to the family.

The intense environment, the severity of the patient's illness, conflicting prescriptions, ethical conundrums, unremitting responsibility and disparate expectations lead to dissent and frustration, which impact negatively on the clinical staff and lead to burnout.

## Difficult decisions regarding care at the end of life

It is never obligatory to use medical measures which are morally 'extraordinary' to preserve life; concepts such as ordinary and extraordinary treatment have evolved into the concept of proportionate and disproportionate means.<sup>14</sup> These include all those means which are experimental, involve excessive physical pain, subject the person to extreme distress, discomfort or expense, or merely serve to prolong life.<sup>27</sup> This distinction requires clarification, as means that are thought of as medically ordinary may be morally extraordinary. Owing to the rapid advances of medical treatment, the language of ordinary and extraordinary may not be appropriate. Theologians usually designate ordinary means as those that can be obtained and used without great difficulty. Ordinary means may become extraordinary depending on the circumstances. The immediate and long-term benefits and risks to the patient must be assessed; a reasonable hope of recovery, the ability to interact in familiar surroundings and the bearable amount of discomfort entailed in providing life support must be considered, as well as the patient's long-term quality of life.<sup>14</sup> For example, a person in an irreversible coma, with terminal cancer or who has Cheyne-Stokes respiration should not be subjected to artificial means of maintaining life. The appropriate means of caring for this person is palliative care. Schotsmans<sup>27</sup> quotes Janssens and McCormick in stating that proportionality is a question of the relationship between end and good. There must not be an intrinsic contradiction between the basic good that we hope to preserve and the means used to obtain the end.

According to the principle of double effect, a difference exists between the intention and what can be envisaged as a possible side-effect of an action. Some acts may be considered wrong in themselves (for example, willfully killing the innocent or a patient who is likely to survive). But, if the morality of the case is to be assessed, the agent must be deemed less responsible for the foreseen or indirect consequences of an action.

The conundrum lies in distinguishing between active killing, letting die, and hastening death by an action. It is therefore not the active treatment that is under question, but the agent withholding or withdrawing treatment.<sup>26</sup> Is omitting treatment rather than sustaining life morally the same? Giving increasing doses of analgesia and thus (inadvertently) hastening death is acknowledged to be moral.<sup>14</sup> However, intravenous inotropes are regularly withdrawn (far more frequently than turning off respirators), leading to the patient being unable to sustain a blood pressure

and dying as a direct consequence of the action. This can be construed as acting to cause the death of the patient. Would this be considered moral, considering that the patient's blood pressure is being maintained by a relatively inexpensive, easily accessible and minimally distressing procedure (i.e. ordinary means)? By the same token, withdrawing inotropes is far less distressing for patients, family and staff than the dramatic removal of a ventilator.

Another dilemma is illustrated by the case, experienced first hand, of a patient diagnosed with Guillain-Barré syndrome. Despite being fully conscious, he was unable to breathe on his own. Medical insurance had been exhausted and he was transferred to a government hospital where ventilation was continued for a further 6 months with continuous attempts to wean him off the respirator and with no change in the paralysis of the muscles. There is pressure to admit other patients who would benefit from treatment in the unit. Reluctantly, he was taken off artificial respiration and allowed to die. This caused extreme distress among the clinical staff. Dilemmas like this require more than the normal negotiations that are the daily experience of clinical practitioners. Consequently, we would advocate for a dedicated sub-committee to enhance the care afforded to patients and families and support and educate the clinical staff.

## The dedicated ethics committee

The presence of a sub-committee comprising clinicians, ethicists and pastoral counsellors would be of inestimable value.

Patients who are conscious and contemplating terminating or continuing further treatment could be counselled as to the ethical and legal implications of their decisions. As the family and clinical team need to be appraised of the patient's wishes, the counsellor could assist the patient and family to consider and discuss options available and the likely consequences of each action.

Family members could be assisted to evaluate and negotiate care options by a member of the ethics committee explaining the options available. Referral resources could be suggested to family members for counselling, social support or pastoral care before or after the patient has died. Written material explaining medical terms, treatments and the aims and methods of active and palliative care could be developed to aid family understanding and acceptance of proposed options.

The group could assist clinicians in addressing ethical dilemmas and reinforce sound values within the unit. Identification and discussion of personal and group beliefs, values and aims would contribute to interpersonal respect, collaboration and multi-disciplinary cohesion and encourage the development

of personal virtues. Policies and protocols for the guidance of clinicians could be compiled to help in the difficult tasks of communicating and negotiating with the patient and family and arriving at a plan of care. In-service education could be offered to the staff to promote ethical knowledge and skill in decision making. This core group could also join support staff such as social workers in offering supportive counselling and debriefing to staff to prevent burnout.

Research into current and best practice in palliative and end-of-life care could assist clinicians and management of health institutions to institute care plans acceptable to all concerned. In this manner, empirical evidence and clinical experience could inform theory to the benefit of moral theology theorists and, once again, the circle of theory and practice would be enriched.

## Conclusion

In conclusion, the ICU milieu and the experiences therein are dramatic, fraught with emotion and distress as well as miracles. Palliative care is increasingly being advocated as necessary in the unit, and though dying in an ICU is not ideal, patients frequently do so. Care offered must be compassionate, ethical and focused on the patient, as the central and most important person, as well as the patient's family. Apart from cultivating the necessary skills and virtues, clinicians must be practised in exercising ethical principles in the treatment of their patients. A committed sub-committee comprising members of the multi-disciplinary team and ethicists would enhance ethical care as well as afford the patient and family improved palliative and end-of-life care.

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