

Withholding and withdrawing treatment: Practical applications of ethical principles in end-of-life care

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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 is in fact unwanted prolongation of 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 unit.

Many people fear the process of dying rather than the fact of dying. This fear is often associated with interventions that may be undertaken at the end of life as well as with the knowledge that suffering may be a part of dying and that both may be associated with loss of dignity of the individual.

The paper discusses the statement that withholding or withdrawing treatment can be considered a sound clinical decision when reached in discussion with the patient (if competent), the family and the clinical care team. This decision is not taken lightly and it may not be easy to reach consensus on the decision. It is therefore important that the discussion and decision making are based on established bioethical principles.

In the practical setting of care for patients at the end of life the four principles of ethics articulated by Beauchamp and Childress¹ are a useful guide for the clinical team.

It is important to determine the goals of care and to enter into the discussion with these goals in mind. Treatment should then be focused on achieving realistic goals of care within an ethical framework.

Beauchamp and Childress articulated four principles of bioethics: respect for autonomy, beneficence, non-maleficence and justice.

Respect for autonomy addresses the concept of 'self-rule' and in particular deliberated self-rule.² This emphasises the importance of patient choice and the recognition that patients require clear factual information in order to be able to deliberate on their choices. It is the responsibility of the clinician to ensure that s/he has the communication skills to present the information to the patient (and family members) in a way that allows for patient understanding. This is the basis of the concept of informed consent. Once the information has been presented and the patient has been encouraged to ask questions, it is still important to check the patient's understanding, not simply by asking 'Do you understand?' but by asking 'How would you explain this to ...?' This allows for identification of gaps in the patient's understanding and further discussion of the issues.

End-of-life discussions often revolve around matters where there are no clear-cut answers and require the clinician to be comfortable in dealing with uncertainties and with compassionate truth-telling. We are often then confronted with the patient's question of 'What would you do, doctor?' and need to recog-

nise that while we may have the clinical knowledge, we do not have the knowledge of the patient's life, family and priorities and should hesitate before giving directive advice. It may, however, be appropriate to lead the discussion, balancing benefits and burdens. It is important that patients are encouraged to take an active part in clinical decision making throughout their life and in every clinical encounter, as this facilitates their active involvement in care decisions at the end of life. It is difficult to devolve this responsibility to patients who have always experienced autocratic medical care in previous medical encounters. The concept of empowerment combines autonomy and beneficence and results in the patient becoming an active member of the management team, restoring a sense of control for the patient in the face of an illness that appears to have removed any sense of control from the patient.³

End-of-life discussions become more complex when the patient is no longer competent to take an active part in the discussion. A Living Will or Advance Directive is useful in guiding the discussion but may not be comprehensively relevant to the circumstances under discussion. The patient may have identified a proxy decision maker who is now in a position of considerable responsibility at a time when he/she is emotionally fragile. The proximity principle that those who are closest to the patient have the best knowledge of the patient's wishes may only be true if the patient and family members have discussed these issues. Often families have delayed or avoided these discussions as too painful and may be uncertain or not in agreement as to what would be the patient's wishes. We also need to recognise that people may change their minds and attitudes between writing the advance directive and the time for its implementation.⁴ Regular review of the advance directive is to be encouraged.

Beneficence refers to the ethical imperative to ensure that treatment benefits the patient and non-maleficence to the Hippocratic ideal⁵ of 'first do no harm'. Taken together, the intent is that treatment can only be justified if there is net benefit to the patient and that decisions about treatment balance benefit and risk to the patient with a requirement for net benefit. In end-of-life care this may be a fine balance; for example, multi-organ failure may affect metabolism and elimination of medication so that it may be difficult to predict a patient's response to a particular treatment.

It is recognised that rigorous and effective professional education² based on evidence developed through research improves benefit to our patients. In end-of-life care, this includes education and research in palliative care.

The World Health Organization defines palliative care⁶ as 'an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.

Within the definition are the statements that 'Palliative care affirms life and regards dying as a normal process; intends neither to hasten nor postpone death'.

The WHO definition also states that palliative care 'will enhance the quality of life, and will also positively influence the course of illness'.

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 dying process. Twycross makes the statement that a doctor has neither the right nor the duty to prescribe a lingering death.⁷

The fourth principle articulated by Beauchamp and Childress is that of justice. This includes distributive justice – the allocation of scarce resources; rights-based justice – closely linked to patient choice and autonomy; and legal justice – acting within the laws of the country. The South African Law Commission submitted a report to the Minister of Health in 1998 which includes a recommendation to legalise withholding or withdrawal of life-prolonging treatment while fulfilling specific requirements in coming to this decision. However, this report has not yet received attention as yet.⁸ However, the Health Professions Council of South Africa provides advice to clinicians in the booklet *Guidelines for the Withdrawing and Withholding of Treatment*.⁹ Within this booklet is the statement (7.1.2) that 'Health care practitioners should bear in mind that the decisions of competent adult patients to refuse a particular medical intervention must be respected, even where this would result in serious harm to them or in their own death.'

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

In the practical setting of end-of-life care, decisions are influenced by the response to treatment of the individual patient, and the timeline or trajectory of his illness. It is difficult to make decisions for patients the doctor is seeing for the first time so that the consideration of the trajectory of the patient's illness depends on clinical notes, the patient's and family's narrative of the illness. It may be decided to embark on a course of treatment with a view to evaluating the patient's response to treatment and recognising that this treatment may be withdrawn if it does not appear to be of benefit to the patient. The essential commitment is to continuity of care and non-abandonment of the patient during the final illness.

As discussed earlier, goals of care need to be agreed upon by the patient, family members and the care team and reviewed regularly. As an illness progresses we may find that the goals of care change from a goal of cure to a goal of active good quality of life to a goal of comfort care to a goal of dignified death and support for bereaved family members. The complexity of end-of-life decisions demands that comprehensive attention be given to the particular patient and his life circumstances including the patient's unique biology, the pathology of the illness, and the patient's clinical condition, physical needs, desires, life plans, relationships, hopes, sufferings, strengths and limitations, perceptions and understanding of the illness.¹¹

Bioethical principles provide a framework within which to view the patient's circumstances and to decide on an appropriate course of treatment. This course of treatment may change as the clinical condition and goals of treatment change.

Refusal of treatment

If a fully informed, competent patient refuses treatment, what should be our response? Are we guided by the will of the patient or the clinical condition of the patient? If we are agreed that the patient is competent, fully informed and not suffering from depression and that this is his own decision not pressurised by others, we should respect our patient's wishes even if this goes against our personal feelings and judgement. The patient requires our understanding and support of his decision. Family members may also require compassionate support, especially if the patient's decision is contrary to family members' wishes. In this situation, beneficence is not simply seen as clinical benefit to the patient but also respecting the patient as an individual with benefit to the psychologically intact persona.

Futile treatment

It requires clear assessment of a patient's condition and recognition that a treatment may be therapeutically ineffective to identify a point when life-prolonging treatment is no longer appropriate. If medical interventions are assessed as bound to fail, if they will not restore a patient to independence or at least to an acceptable quality of life, or if they are likely to prolong the dying phase they may be described as futile treatments. There may not be agreement as to the futility or effectiveness of a particular treatment, and it helps to be able to distinguish the difference between physiological effect and benefit to the patient⁴ and again to review the goals of care for the patient at this new point in the disease trajectory. Uncertainties regarding effectiveness of treatment arise because treatment effects are often expressed as percentages and it may be difficult to predict individual patient response.¹⁰ It may be that a treatment is initiated with the intent to assess the benefit for a particular patient and to withdraw the treatment if there is no net benefit. The critical discussion and decision rests on an analysis of the burden-benefit proportion and whether the likely benefit contributes to the patient's treatment goals.

Advance directives and 'do not attempt resuscitation' (DNAR) orders

Advance care planning attempts to ensure that the intent of patient consent is respected when the patient is no longer able to discuss treatment options and to articulate his wishes. Advance directives should be discussed sensitively with patient and family members to specify what kind of treatment the patient would want in particular disease states. However, advance directives can only be a guide and cannot cover all eventualities.

DNAR orders have been developed to guide health care workers where cardiopulmonary resuscitation is inappropriate. The purpose of resuscitation is to benefit patients whose condition is treatable.¹² In patients with incurable and terminal illness, resuscitation is inappropriate. The DNAR should be discussed with the competent patient or his proxy/close family members, if he is not competent. The patient's wishes are paramount and a Living Will or Advance Directive is helpful on deciding DNAR orders.

Conclusion

When we consider the palliative care imperative to improve quality of life at a time when the individual is experiencing declining physical function and distressing physical symptoms with associated psychosocial and spiritual angst, the clinician should have a clear understanding of bioethical principles and their application in the practical setting. Ten Have and Janssens contend that bioethics and palliative care have similar objectives: 'to maintain or reinstitute a humane medicine, ... to commit first and foremost to the patient and their particular interests'.¹¹ Decisions to withdraw or withhold treatment, when reached in discussion with patient, family members and the clinical team, uphold this essential commitment to the patient.

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