Ethical aspects of withdrawing and withholding treatment


Summary

Decisions about withdrawing and withholding treatment are common in health care. During almost every encounter between health professionals and patients a decision needs to be made about treatment options. In most cases these choices do not pose any difficulty, for example, starting antibiotics when a patient has an infection. However, decisions not to treat, or to stop treating, raise fundamental questions about the nature and purpose of nursing and the ethics of end-of-life care. This article argues that nurses need to be proactive in deciding what is nursing care and what is treatment. An ethical distinction is drawn between acts and omissions. How this distinction relates to withdrawing and withholding treatment will be considered. Further ethical issues discussed relate to judgements about the futility of treatment, patient autonomy and nurses’ duty of care to patients at the end of life.

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ACCORDING TO WARNOCK (2006):

‘Considering that all men are mortal, we are curiously unwilling to acknowledge that death, our inevitable fate, should not always be postponed.’ One of the main aims of healthcare professionals is to provide curative treatment. Many people enter the healthcare professions because they want to make a contribution to society by helping those in distress and relieving suffering. As the British Medical Association (BMA 2005) states: ‘The primary goal of medicine is still seen as being to benefit the patient by restoring or maintaining the patient’s health as far as possible.’ While it is accepted that this is not always possible, the overriding purpose of health care is to try to make people better.

Over the past 20 years, the emphasis in UK health policy has been on what is termed ‘health gain’. Effectiveness of health care is measured in terms of reduction in disease and extension of life. Economists evaluate cost-effectiveness of treatments with reference to how well a treatment relieves a condition and for how long (Malek 2003). Medicine’s fixation on curing is often contrasted with the nursing role of caring. However, in reality, the division is not so clear-cut.

Before discussing the ethical aspects of withdrawing and withholding treatment, this article explores the relationship between care, viewed as the primary preoccupation of nurses, and treatment, arguably the main focus of a cure-oriented medical profession.

Care and treatment

Tony Bland was a football fan who was injured in the Hillsborough stadium disaster on April 15 1989. He suffered brain damage as a result of oxygen deprivation and was left in a persistent vegetative state (PVS). His family requested that his feeding tubes be removed. Airedale NHS Trust, fearing criminal proceedings if the patient was allowed to die in such a way, sought a ruling from the courts. Given the seriousness of the decision the case was taken to the House of Lords.

On February 4 1993, the Law Lords ruled, three years after insertion, that Tony Bland’s feeding tubes could lawfully be removed (BBC News 2007). The ruling was as follows: ‘Although it is unlawful for a doctor to do a positive act to bring about a patient’s death, the discontinuance of life-support treatment is an omission which is lawful when such treatment is futile because the patient is unconscious and there is no prospect of any improvement and discontinuance is in accordance with responsible body of medical opinion’ (Airedale NHS Trust v Bland [1993]).

This ruling has ethical significance for three reasons:
The provision of nutrition and hydration was categorised as a medical treatment that could be withdrawn, rather than as nursing care that must be provided.

It was concluded that it is not necessary to continue with treatment considered ‘futile’.

A distinction was made between acts and omissions.

The second and third issues will be discussed later in the article. First it is necessary to consider the difference between ‘treatment’ and ‘care’ and why it is of ethical importance.

Differences between treatment and care

The BMA guidelines on withholding and withdrawing treatment (BMA 2005) describe the objective of medicine as being to benefit the patient and to act in the patient’s best interests. Thus, the medical justification for using a treatment is that it is of benefit. If a treatment will not be beneficial and therefore is not in a patient’s best interests, it should not be used or it should be withdrawn.

There is a clear ethical defence for this stance. Treatments are costly and resources should not be wasted (a utilitarian defence based on the principle of non-maleficence, that is, do no harm (Beauchamp and Childress 2001)). Also, some treatments have side effects which can be serious and unpleasant. Patients should not be exposed to risk or extra suffering unless there is a reasonable expectation of a proportionate benefit (this defence is based on the principle of beneficence, meaning doing good and promoting benefit (Beauchamp and Childress 2001)). Suffering should not be caused without good reason (a defence based on the principle of non-maleficence, that is, do no harm (Beauchamp and Childress 2001)).

Care is considered to be the raison d’être of nursing. It is what nurses do, a view reinforced by the frequency with which we use phrases such as ‘nursing care’ and ‘quality of care’. However, it is a complex concept and over the decades a large amount of literature has grappled with it.

As van Hooft (2006) states: ‘A great deal of writing about the professional life of nurses stresses the concept of caring. It has become almost traditional to distinguish the role of the medical practitioner from that of the nurse by saying that the former seeks to cure the patient while the latter cares for him or her. Even though warnings have been sounded that this distinction between caring and curing may be an ideological cover for the historically contingent nurse-doctor distinction and that it is improperly based on gender distinctions, it seems clear that there is a role for caring in therapy even if the question as to who exercises that role might receive different answers at different times.’

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There tends to be agreement about what counts as caring activities, for example, assisting someone to wash or dress, but less agreement about activities at the boundaries of care and treatment. The provision of nourishment is generally considered to be a caring activity, for example, from a parent to a child. However, in the Tony Bland case, the giving of food and fluids was deemed to be a treatment that could be withdrawn. A distinction was made between nutrition and hydration taken orally and that given by other means, for example, via a nasogastric or gastrostomy tube.

Reluctance to withdraw oral nutrition and hydration is reflected in guidance concerning so-called ‘living wills’, more accurately referred to as advance statements or advance refusals (BMA 1995). The BMA (1995), in its Code of Practice on advance statements, states: ‘Advance statements refusing basic care and maintenance of an incompetent person’s comfort should not, as a matter of public policy, be binding on care providers. Although the law on this matter is not free from doubt, this code provides that people should not be able to refuse basic care in advance or instruct others to refuse it on their behalf. Personal autonomy, which refers to a person’s ability to be self-governing and to make decisions (Beauchamp and Childress 2001), although important, cannot always be an overriding ethical principle. In most situations, the individual’s right to refuse treatment outweighs any competing interests, including the wishes of other people. In exceptional circumstances, the individual’s choice has unacceptable consequences, such as potentially serious harm for others which is sufficient to outweigh the patient’s right of refusal. Others may be harmed if refusal of basic care leads, for example, to the spread of infection.’

Similarly, the Alzheimer’s Society (2002) states that advance statements cannot be used by people to:

- Refuse basic nursing care that is essential for comfort, such as washing, bathing and mouth care.

- Refuse measures solely designed to maintain comfort, for example, analgesia.

- Refuse the offer of food or drink by mouth.

- Demand care that the healthcare team considers inappropriate.

- Ask for anything that is against the law such as euthanasia and assistance in committing suicide.

The British courts, in developing the argument that nutrition and hydration should be defined as a treatment and thus can be withdrawn, coined the
phrase ‘artificial nutrition and hydration’ with regard to the Bland case. This rather clumsy term (there is nothing ‘artificial’ about nutrients or fluids) was, it is presumed, intended to distinguish between the more natural oral route and other methods. In Tony Bland’s case, Lord Keith stated that: ‘feeding and hydration are achieved artificially by means of a nasogastric tube’ (Airedale NHS Trust v Bland [1993]).

Another distinction that could have been used is by ‘ordinary’ and ‘extraordinary’ means. According to Calman (2004): ‘This concept, in summary, states that in life-saving decisions at the end of life only ordinary means or techniques should be used, that is, techniques which would be considered routine and not out of the ordinary. It is clear that over the years the definition as to what is ordinary and what is not ordinary has changed considerably and thus the decisions to be taken, and knowing how far one can go to prolong life, have become more difficult.’

In the case of patients in a PVS, two questions need to be considered: whether tube feeding counts as extraordinary and whether the decision relates to the end of life. Given the ease with which tube feeding can be accomplished, the number of patients fed by this route and the length of time that tube feeding can keep a patient well nourished, it hardly counts as extraordinary. It is also debateable whether Tony Bland was at the end of his life as he had been maintained with relatively simple (although heavy and demanding) care and treatment for almost four years.

Whatever disagreement there may be about what counts as treatment and what counts as care, it is important for nurses to understand that they have a professional duty to provide competent and ethical care in all circumstances (Nursing and Midwifery Council 2004).

**Acts, omissions and ethics**

Three case scenarios are outlined in Boxes 1, 2 and 3. These scenarios raise a wide range of ethical issues about withdrawing and withholding treatment. The doctrine of ‘acts and omissions’ is sometimes used to help make an ethical distinction between what people do and what they omit to do, for example, in the case of active and passive euthanasia. According to Glover (1977): ‘In certain circumstances, failure to perform an act, with certain foreseen bad consequences of that failure, is morally less bad than to perform a different act which has the identical foreseen bad consequences.’

Philosophers offer a range of examples that both support and challenge the doctrine. Gibson (1998) provides two examples in justification of acts and omissions:

- ‘Although it might be morally permissible to leave one injured person to die by the roadside when hurrying to the rescue of several, it would be outrageous to drive over a recumbent person to reach the others in time.’
- ‘If a man who will inherit a fortune when his father dies omits to give him the medicine necessary for keeping him alive, this is as bad as actively killing him.’

The Tony Bland ruling makes a legal distinction between acts and omissions. Gibson’s examples, however, do not provide a clear ethical distinction between them or help us to understand the complex issues involved in decisions about the withdrawal and withholding of treatment.

Much appears to depend on the intention, or culpability, of the person responsible for the act or omission. You may fail to do something that it is in your power to do—for example, help an injured person—not through malice or desire to cause harm, but for some other reason: for example, because you want to rescue several other people.

Driving over an injured person is a deliberate act that appears malicious. If the person dies there will be a direct link between your action and the death and you would rightly be held culpable (deserving of blame).

The example of the man who deprives his father of medicine raises other issues. We may feel that because it concerns his father, rather than a stranger, this has a bearing on the matter as we have certain obligations to our parents.

Not giving medication, for example, insulin for a patient who has diabetes, results in rising blood sugar, ketoacidosis, unconsciousness and death.

If the son’s father was on insulin and if the son were to replace the contents of the insulin bottle with water, he is clearly acting with intent.

If he had gone out in the morning and had forgotten to give his father the insulin, the son would be filled with remorse and might be criticised and even accused of negligence or neglect. However, the blame attached to him would not be the same as if he had acted deliberately.

In the first scenario (Box 1), the registrar has taken a unilateral decision to withhold (an omission) from Devi what has been described by Johnstone’s definition as an aggressive treatment, that is, cardiopulmonary resuscitation. Whether an omission in care is better or worse than ending Devi’s life by a particular action does not capture all of the relevant ethical issues, for example, the likely clinical outcome, Devi’s wishes...
Futility and hope

The aim of health care is to extend or prolong life. Therefore, clinicians prefer to provide active treatment rather than doing nothing. Once treatment has been started it is difficult to stop and admit defeat. The families and friends of a patient want him or her to get better and may find it hard to accept that the situation is hopeless. This is not a new phenomenon. Florence Nightingale once commented: ‘I really believe there is scarcely a greater worry which invalids have to endure than the incurable hopes of their friends’. I would appeal most seriously to all friends, visitors, and attendants of the sick to leave off this practice of attempting to cheer the sick by making light of their danger and by exaggerating their probabilities of recovery’ (Nightingale 1969).

Nightingale refers to ‘the incurable hopes of their friends’; in this context health professionals could be considered ‘hopeful friends’.

Psychologically and ethically, health professionals and the public are not well equipped for failure and death is, typically, seen as failure. While people may campaign for euthanasia or assisted suicide, many also fight to ensure that they, or their loved ones, receive every possible treatment, as demonstrated by a succession of high-profile court cases. Even when medical professionals and the family agree that a patient should be allowed to die, permission may have to be obtained from the courts to withdraw life-sustaining care, such as nutrition and hydration.

In the third scenario (Box 3), reference was made to the term ‘futile’. Johnstone (2004) notes that the word comes from futilis, the Latin for ‘worthless’. The concept of ‘medical futility’ is generally taken to refer to treatment that ‘fails to achieve the goals of medicine’ and which does not benefit the patient. Johnstone (2004) points out that ‘medical futility’ was first debated in the 1980s and was primarily an attempt to engage the public in a debate about policy – relating a doctor’s clinical judgement and skill to determining the usefulness or futility of certain treatments.

Given the uncertainties that surround everyday healthcare practice, assessments or judgements of medical futility are not as straightforward as they may first appear. Questions of prognosis and predictions of survival and eventual quality of life are difficult and frequently turn out to be inaccurate. Judgements about the futility of treatments are made by patients, families, professionals and, in the case of Tony Bland, lawyers. Such judgements cannot be made about nursing care.

The definition and purpose of nursing, as expressed by the Royal College of Nursing (2003), are as follows:

Definition: ‘The use of clinical judgement in the provision of care to enable people to...’

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Scenario 1

Devi is a 75-year-old and has been admitted to a medical ward following an episode of chest pain and difficulty in breathing. She is a smoker and has long-standing hypertension. Following an initial assessment by the ward registrar nurses are informed that Devi is not for resuscitation.

Scenario 2

Marie has emphysema and has been connected to a ventilator for eight years. She asks nursing staff to turn off her ventilator saying that she feels that she has a ‘poor quality of life’ and does not want to continue in such a way. One of the nurses, following what she says are the instructions of a consultant, turns off Marie’s ventilator alarm. Marie disconnects her ventilator when the nurse leaves and dies soon afterwards. Her partner had not been involved in the decision.

Scenario 3

Denis was involved in a car accident and has been on a ventilator in the intensive care unit for the past 11 months. He has sustained multiple trauma and has severe head injuries. He has not regained consciousness. The ward team concludes that continuing with ventilation, nutrition and hydration is ‘futile’. They discuss the situation with Denis’s family and it is agreed that treatment should be withdrawn.

Definition: ‘The use of clinical judgement in the provision of care to enable people to...’
ethical decision-making: 2

improve, maintain, or recover health, to cope with health problems, and to achieve the best possible quality of life, whatever their disease or disability, until death.'

- **Purpose:** ‘...to promote health, healing, growth and development, and to prevent disease, illness, injury and disability. When people become ill or disabled, the purpose of nursing is, in addition, to minimise distress and suffering, and to enable people to understand and cope with their disease or disability, its treatment and its consequences. ‘When death is inevitable, the purpose of nursing is to maintain the best possible quality of life until its end.’

Nursing care extends beyond curative treatment and contributes to the patient’s quality of life, whether the prognosis is good or poor, and whether treatment is provided, withheld or withdrawn. It might also be argued that accepting the rationale for the withdrawal or withholding of treatment does not mean that all hope is lost. Rather, as Tombs (2002) writes: ‘The possibility and necessity for choice is an integral part of the dynamics of hope. For those with incurable illness the choice between hope and despair is a choice that must be made not once but every day. Hope cannot primarily be related to cure of disease. Nevertheless, to be seriously and incurably ill is not to be hopeless. Hope relates, rather, to the ability to face forthrightly and with courage whatever comes one’s way. Hope is tempered with flexibility, a willingness to remain open to the possibilities of different ways of being in the world.’

Nurses play a significant role in helping patients to have hope and to confront the challenges that come with incurable illness by providing support and skilled companionship (Campbell 1984).

**Conclusion**

Nurses have a key role in decisions about the withholding and withdrawal of treatment. Their duty of care extends to their omissions as well as their actions. There are circumstances when treatment will be considered futile. However, it is never the case that nursing care is futile. Nursing care extends beyond treatment contributing to enhancing the patient’s comfort and quality of life, whatever the prognosis. This is not always easy and sometimes requires courage, resilience, discernment and a commitment to consider all points of view and the goals of nursing.

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