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End of life care pathways: ethical and legal principles

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Summary

Myths have developed surrounding the law and ethical principles in end of life care, which can make care provision at the end of life complex and fraught with potential dilemmas. This article examines three of the most common myths related to the provision of palliative care and highlights their inadequacy when set against the ethical and legal principles on which end of life care pathways are based.

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NURSES MAY FEEL they are walking a legal and ethical tightrope when caring for a dying patient; it seems all too easy to slip from good care to serious wrongdoing. This article demonstrates that this is not so, particularly when end of life care pathways are adhered to. These pathways are examined, alongside commonly held beliefs of healthcare professionals and associated ethical and legal principles.

Myths related to end of life care

Some of the most difficult ethical and legal problems encountered by nurses arise because of the following end of life decisions (Quill *et al* 1997, Taylor 2003, Veterans' Health Association National Ethics Committee 2007):

- Withdrawing or withholding life-prolonging treatment. For example, the care team might decide not to start a patient on ventilation, dialysis, artificial nutrition or hydration, or antibiotics. Alternatively, having started a particular treatment, the team might then decide to withdraw it. In these cases, patients might die earlier than otherwise.
- Starting palliative treatment, which may also be life-shortening. This might include the use of strong analgesia and sedation. Terminal sedation, where a patient with uncontrollable symptoms at the end of life is sedated to a level of unconsciousness, is frequently discussed in this context.

However, it seems unlikely that many of these decisions contribute to patient deaths. For example, a decision not to attempt to resuscitate a dying patient will often merely save the patient and carers from what would most probably be a futile intervention. It is also clear that some decisions, such as switching off life support or withdrawing artificial nutrition, will almost certainly shorten patients' lives. The question is: why is it legal to end someone's life by, for example, switching off a ventilator or withdrawing artificial nutrition, but not by giving a lethal injection of potassium? A number of myths and half-truths impede clear thinking here. Three common myths are:

- There is a crucial difference between passive and active euthanasia. In other words, it is permissible to let patients die, but not to kill them. For example, it might be acceptable to decide not to ventilate a patient who has had

a severe stroke, but it would never be acceptable to give the individual a lethal injection.

- There is an important difference between withdrawing and withholding treatment. For example, it is permissible not to start a patient on dialysis, but it is much more difficult legally and ethically to stop the treatment once it has been started.
- Intention is key, but also highly subjective. The nurse is allowed to give care that might shorten a patient's life, but not to intend that end. For example, a nurse who thinks: 'I hope this helps my patient to a peaceful death' when giving sedation or withdrawing nutrition is seriously mistaken, but not if he or she thinks: 'I hope this palliates my patient's symptoms, but regret that it might bring forward his or her death.'

A belief in the first myth could result in the health professional's unwillingness to start a patient on life-saving treatment, and overall caution when giving treatments to palliate symptoms that result from that decision. A practitioner that believes the second myth might think it unacceptable to commence a particular treatment because once started it will be difficult to withdraw it. A belief in the third myth might result in the practitioner continuing with treatment that keeps a patient alive, but with a poor quality of life. All three myths could make nurses wary of providing good end of life care.

End of life care pathways

The use of end of life care pathways is approved by the Department of Health's *End of Life Care Strategy* (DH 2008) and guidance on palliative care from the National Institute for Clinical Excellence (NICE 2004). Approval by these bodies does not mean that end of life care pathways are accepted legally as being good practice, but it strongly suggests that the pathways are perceived as being compatible with current law. The Liverpool integrated care pathway is a widely used example (Ellershaw and Wilkinson 2003). The pathway advises that patients who meet certain criteria should be diagnosed as dying. Once the diagnosis is made, clinicians are instructed to stop non-essential treatments and to commence those essential only for symptom relief, particularly to control pain, agitation and pulmonary secretions (Ellershaw and Wilkinson 2003).

The three myths mentioned earlier reflect the view of death as being regrettable and a failure of health care; in that, once all has been done to save a patient, nature must take its course and the nurse should palliate symptoms, if possible. The end of life care pathways advocate the array of interventions that can be undertaken to ensure that the dying patient is comfortable and that any unpleasant symptoms are treated effectively. So, on the one hand, there is the view that death is inevitable and health professionals and carers have little to do but avoid hastening the patient's death; and on the other hand, the view that death is inevitable but that health professionals and carers have an active role to play in ensuring it is a good death.

Ethical and legal principles

Best interest All actions in health care should be driven by the desire to promote the patient's best interest, taking into account ethical and legal principles (Nursing and Midwifery Council (NMC) 2008). In legal cases, whenever decisions have been made on behalf of patients, the principle of best interest has been foremost (Mason *et al* 2006). This includes decisions that have been made on behalf of patients who lack the capacity to decide for themselves. The treatment of such patients is covered by the Mental Capacity Act 2005. Underpinning this act is the principle that 'An act done, or decision made, under this act for or on behalf of a person who lacks capacity must be done, or made, in his best interests' (Department for Constitutional Affairs and Department of Health 2005).
In terms of ethics, practitioners are seen to have an obligation to do the best they can for patients in their care. This might, for example, be expressed as beneficence (to do good) (Gillon 1994).
Consent As well as acting in the patient's best interest, the nurse should ensure that he or she obtains informed consent, whenever possible (NMC 2008). In law, the idea that people with capacity should only be treated after informed consent has been obtained is well established. This is underlined by the Mental Capacity Act 2005, which states that all adults should be assumed to be able to make their own decisions (unless there are good grounds to think otherwise), all practicable steps must be used to help patients make their own decisions and patients with capacity are free to make unwise decisions, which must be respected.

In ethics, discussion of consent is usually framed in terms of autonomy (Dworkin 1988, Allmark 2008). Autonomy describes a person's ability to make and act on decisions. Nurses need to respect patients' autonomy. This can be

achieved by ensuring that patients are able to decide what happens to them and then to respect those choices. In addition, the Mental Capacity Act makes clear that people's advance decisions should be taken into account in decision making; in particular, people's advance refusal of treatment should be respected.

Duty of care Nurses have a legal duty to avoid foreseeable harm to others. This is the duty of care, which covers omissions as well as actions. A patient who is harmed when a nurse negligently omits the right action, such as giving drugs on time, has as good a case to sue as one who is harmed when a nurse negligently performs a wrong action, such as giving the wrong drugs.

Homicide Where someone has a duty of care, homicide could occur through an act, such as giving a lethal injection, or an omission, such as failing to give life-saving treatment. There are different types of homicide, including murder, infanticide, and voluntary and involuntary manslaughter. The notion of intention plays an important part in deciding the category of homicide. Murder and voluntary manslaughter require an intention to kill or harm. Involuntary manslaughter requires recklessness or criminal negligence (Law Commission 2005).

Three myths revisited

In light of the ethical and legal principles on which end of life care pathways are based, the three myths can be revisited and their inadequacy highlighted.

Passive and active euthanasia The thought behind this myth is that where a patient is dying it is futile to intervene, but that practitioners must be careful not to do anything that hastens death. The use of care pathways allows this situation to be viewed differently. When a patient is dying it is the nurse's duty to intervene in the patient's best interest. What constitutes best interest will vary. For almost all patients it will include the palliation of symptoms such as pain, nausea, agitation and lung secretions, and for many it will include the removal of treatments that have become a burden, doing the patient more harm than good. For example, the nurse might stop carrying out regular observations and monitoring, and withdraw dialysis or artificial nutrition. This is not carried out to ensure that the patient dies, but to ensure that the dying patient dies well. Conversely, euthanasia involves a decision to hasten the death of a patient, passively or actively. No such decision is made when following the guidance provided in end of life care pathways.

Withdrawing and withholding treatment The second myth is that there is a crucial difference between withholding and withdrawing treatment. Decisions to withhold or withdraw particular interventions are driven by the principles of best interest and consent (British Medical Association (BMA) 2007). Any decisions, either to withhold or withdraw life-prolonging treatment, will be acceptable insofar as they are in line with these principles. The end of life care pathway is a pathway, not a slide. Patients might travel up and down the pathway. Their condition might take an unexpected turn; or they might change their mind about a treatment; or a treatment might have disappointing effects. In these and similar cases, withdrawal of a treatment after trying it will be acceptable legally and ethically. If the team believes that a treatment could do some good, it would be unacceptable not to commence it on the basis of a false fear that it would not be possible to stop the treatment. Special legal procedures are associated with decisions relating to patients in a persistent vegetative state (BMA 2007).

Intention Charges of murder and voluntary manslaughter require an intention to kill or harm on the part of the accused. It could be argued that a nurse has such an intention if he or she is responsible for certain actions, for example switching off a ventilator, or omissions, such as not attempting to resuscitate a patient. One way the law is sometimes said to address this problem is by invoking the doctrine of double effect (Cavanaugh 2006). The idea behind this doctrine is that some decisions made have both good and bad consequences. One might be said to intend the good consequences, but only to foresee the bad. Not intending the bad consequence might provide the basis for a defence in law. There is a substantial body of opinion that believes this to be the law when, for example, a nurse gives a large dose of opiates and sedation to have a patient at the end of life (Price 1997, Gillon 1999, Mason *et al* 2006).

This, then, is the origin of the third myth. It could be said that sometimes, when a nurse switches off a ventilator or gives a large dose of opiates, he or she intends to end the patient's life; perhaps, in the back of his or her mind, there is the hope that this will help the patient to have a peaceful death.

However, in the first instance, there are serious doubts about whether some of the acts typically described as life-shortening are indeed so. In particular, there is little, if any, evidence that opiates and sedation given in doses to palliate symptoms would shorten life (Thorns 2002, Sykes and Thorns 2003a, 2003b, Good *et al* 2005). It is impossible to carry out the type of controlled trials that would deliver a definitive answer. However, a lawyer would face a hard, perhaps impossible, task in showing 'beyond

reasonable doubt' that palliative doses of such drugs shortened a patient's life.

Furthermore, from a legal perspective, intention is not simply what happens to be in a person's mind when he or she performs an act; the courts could never know what this is. Legally, intention is what can be inferred to have been in a person's mind from the nature of the act performed. This is clear from the Woollin judgement (R v Woollin [1998]). In this case, a man (Mr Woollin) lost his temper and threw his three-month-old son onto a hard surface. The baby died. The defendant said he did not intend to kill the baby; and in the everyday sense of the term 'intend' this might well be true. However, the jury was told that they might find (or infer) the necessary legal intention of the defendant if they believed death was a virtual certainty and that he appreciated this.

Hence, a nurse will not be found to have intended a patient's death if he or she has followed standard palliative care as prescribed and set out in end of life care pathways, even if he or she entertained a vague hope that the patient's and relatives' suffering would soon be over. Legally, an intention to kill could only be found if the nurse had stepped well beyond the boundaries of standard care by, for example, giving 100 times the standard dose of morphine. Therefore, intention is crucial in relation to the law on homicide, but it is not highly subjective.

The Woollin problem

An important area of difficulty arises from the Woollin judgement (R v Woollin [1998]). This judgement states that a jury is entitled to find intention to kill if the act was almost certain to kill and the defendant was aware of this. This has serious implications for the doctrine of double effect, which allows that a nurse might foresee, but not intend, a bad effect such as the patient's death. Some have argued that this contradicts the Woollin judgement; as such, the double effect doctrine is not accepted in criminal law (Kennedy and Grubb 2000, Tur 2002). If this is so, it could be argued that the nurse who removes a feeding tube or halts dialysis meets the Woollin criteria for intending death (because death is inevitable and the nurse knows it).

However, this is not the case, provided he or she is following reasonable practice, such as an end of life care pathway. There are different accounts as to why this is so. Perhaps the most common account states that double effect is still a defence in UK law despite the Woollin judgement. The key point is that the Woollin judgement only entitles the jury to find intention, it does not compel them to (Williams 2001). Faced with the violent Mr Woollin, the jury is likely to find intention to kill; it is very unlikely to find intention when faced with a nurse who ceased dialysis as part of an agreed plan of care. So, despite the Woollin judgement, perhaps in cases such as where the nurse discontinues dialysis, the law allows him or her to foresee, but not intend, adverse effects.

An alternative account makes use of the legal principles of the duty of care and of best interest. Essentially, this states that in pursuance of the nurse's duty of care and the patient's best interest, health professionals are entitled to perform some acts that would be illegal if they were performed by non-professionals (Tur 2002). For example, a health professional is entitled to switch off a ventilator in a patient's best interest, but a relative is not allowed to do the same. So, whether or not double effect still holds following the Woollin judgement (and similar judgements), the nurse is not at risk of serious legal wrongdoing when he or she gives good end of life care.

Criticism of end of life care pathways

End of life care pathways have been subjected to criticism recently. Some of the criticism is part of a larger body of criticism of pathways and guidelines in general. Some critics believe that pathways undermine individualised care and remove the ability of clinicians to make small changes in patient care (Palmer 2008, Rycroft-Malone *et al* 2008). For more information on this debate, refer to the discussion in Kennedy *et al* (2009).

Some of the criticism of end of life care pathways relates to law and ethics. In particular, critics state that diagnosing death and putting people on end of life care pathways is a form of euthanasia – one newspaper story featured the headline 'Sentenced to death on the NHS' (Devlin 2009). This type of criticism is founded on the myths outlined above, particularly those relating to passive and active euthanasia and to withdrawal of treatment.

It is worth restating that care pathways allow healthcare professionals to try out treatments and withdraw them if they are not effective, and to reintroduce treatments if patients respond in unexpected ways. A clearer understanding of the ethics and law in this area should help nurses to address these criticisms and reassure themselves that the guidance set out in care pathways is legally and ethically sound.

Conclusion

Care of the dying patient should be driven by the general principles of respect for autonomy (informed consent) and beneficence (best interest) as set out in numerous ethical documents and in the Mental Capacity Act 2005. At no point in a patient's life does good care involve withdrawing from the patient or giving up on him or her. However, implementation of good end of life care can be impeded by false beliefs concerning ethics and the law.

The authors have critiqued three myths, which might act as an impediment to good end of life care, to reassure nurses that following the guidance set out in such pathways is ethically and legally sound **NS**

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