Withholding and Withdrawing Medical Treatment

MF files

By James Haslam

Death is a certainty ¹ for all of us and yet in recent times there is an obsession with living longer, and discussing death and dying has become increasingly off-limits. Most patients wish to die at home with their families, but now more die in hospital under the care of their doctors. Death is becoming increasingly over-medicalised, with an ever greater reliance on modern medical technologies, particularly in Intensive Care Units (ICUs). This creates the illusion that death can somehow be evaded. Patients seldom consider what kinds of treatment they are prepared to undergo prior to becoming ill and fewer still communicate their wishes to their family or their doctor in the event of their loss of capacity to make decisions.

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End of life decision-making, particularly around the withholding and withdrawal of medical treatments, is by no means easy; many clinicians find it the most difficult part of their job. However, the provision of quality end of life care to patients and their families, helping them negotiate the dilemmas faced as death approaches, can be extremely rewarding.

This *File* will include legal and ethical principles, key concepts and controversies (including two case examples) and a biblical perspective around the withholding and withdrawal of medical treatment.

Key legal and ethical principles

Intention versus foresight

Under UK law, largely thanks to the historical influence of the Judeo-Christian and Hippocratic traditions, human life is sacrosanct. Following established ethical and legal (including human rights) principles, decisions concerning lifeprolonging treatments must not be motivated by a desire to bring about the patient's death, and there is a presumption in favour of prolonging life.^{2,3}

A crucial exercise when approaching end of life decisions is to consider our intentions when recommending the initiation of a treatment or course of action. What is our goal? And what are the patient's expectations of treatment? There is an important distinction between intention and foresight, also known as the principle of 'double effect'. It is ethically legitimate to suggest or administer a certain treatment to our patient, or perhaps withhold or withdraw a treatment, with the intention to relieve suffering despite foreseeing that it may entail unpleasant side effects or perhaps even a shortening of our patient's life. Yet, it is always wrong to intend a patient's death, whether actively or passively (by act or omission, directly or indirectly). It is not necessarily wrong, however, to accept death as a foreseen consequence of a disease process or side effect of non-intervention.

Capacity and end of life decision-making

If a patient has capacity to decide, following discussion with their doctor, the patient makes decisions about their own treatment. They have the right to accept or refuse treatment options (even if their decision seems irrational), but they cannot insist a doctor provides a treatment he or she deems inappropriate.

If the patient lacks capacity to decide, the doctor must first consult any legal proxy,

such as those with a health and welfare lasting power of attorney, who can make decisions on behalf of the patient bearing in mind the overall benefit to the patient. If no legal proxy exists, then the doctor in charge of the patient's care takes responsibility for deciding which treatment will provide overall benefit to the patient, though they must consult relatives or those close to the patient who are able to represent their wishes.

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If there is no one close to the patient, then an Independent Mental Capacity Advocate (IMCA) can be appointed to contribute to any decision-making, but they cannot make a decision on behalf of the patient. The General Medical Council (GMC) emphasises the patient's best interests – which encompass medical, emotional, cultural and religious factors relevant to a patient's welfare – when doctors assess which treatments will provide overall benefit.

This all seems straightforward, but the reality is somewhat more complex.

Key concepts and controversies

In exploring the nuances of when it is appropriate to withhold or withdraw medical treatments to patients approaching the end of their lives, we need to consider some key concepts and controversies.

End of life?

According to GMC guidance, ⁴ patients are approaching the end of life when they are likely to die within the next twelve months, including those whose deaths are imminent and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within twelve months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events

Example 1

An 84-year-old man with a background of moderate chronic obstructive pulmonary disease, type 2 diabetes mellitus and ischaemic heart disease (unable to climb one flight of stairs) presents to the Emergency Department with severe abdominal pain and vomiting. He is confused and unable to communicate coherently and deemed to lack capacity. A CT scan reveals a bowel perforation. If he is to survive, he will require an operation emergency laparotomy - and subsequent treatment in ICU. A surgical risk calculator predicts a mortality risk of >60% and a morbidity risk >80%. What recommendation should the Consultant Surgeon and Anaesthetist make in their discussions with the family? If the family are adamant they want 'everything possible to be done', but the medical team disagree and take the view that such an invasive course of action is not in the patient's best interests with little prospect of a good outcome, what approach should they take?

Reversibility

The challenge comes when deciding whether to withdraw or not start a treatment that may prolong a patient's life. A helpful concept to consider is whether the patient is suffering from a reversible condition; might the disease process potentially respond to treatment, or is the process irreversible? Does the patient have an acute deterioration that may still respond to treatment to enable them to return to their baseline or is their condition 'end-stage'?

Technology has progressed to such an extent that we are now able to care for patients and potentially save lives in ways that would have been inconceivable only a few decades ago, or at all in some resourcelimited developing countries. But with these advances in technology come ethical questions about where to draw the line and the appropriateness of certain interventions. In some circumstances, might technology be prolonging death rather than life?

Levels of care

It is also helpful to consider and discuss with our patients the different levels of care available and their appropriateness. Providing oral food and fluids is fundamental to nurture and care and should always be offered to patients, provided they are conscious, willing and can safely swallow. However, clinically-assisted or artificial tube feeding and hydration by intravenous or subcutaneous infusions is more controversial, often considered a medical act (though, once artificial tube nutrition is *in situ*, it may be considered provision of basic care), yet may not provide overall benefit.⁵

Broadly speaking, medical treatments can be categorised into more basic, ward-level interventions such as fluids, supplemental oxygen and antibiotics versus more advanced interventions such as the kinds of organ support (blood pressure-supporting drugs, kidney machines, invasive ventilation etc) you will find on ICUs (Intensive Care Units). Additionally, it is important to assess the appropriateness of attempting cardiopulmonary resuscitation (CPR) in the event of a patient's cardiac arrest; might a Do Not Attempt CPR (DNACPR) order be indicated? This is a decision that needs to be made in light of the individual's circumstances and incorporate the wishes of the patient and how likely they are to benefit.

Burdens versus benefits

When assessing the pros and cons of a potential diagnostic or therapeutic intervention it is helpful to weigh the burdens versus the benefits, the risks versus the rewards; a reminder of those pillars of medical ethics: beneficence and nonmaleficence. Will this potential treatment provide overall benefit to the patient?

For example, advanced technologies can support the failing organs of critically ill patients in ICU, but these invasive treatments do not come risk-free. Blood pressure-supporting drugs, though they may sustain a failing circulation, can initiate abnormal heart rhythms and even starve peripheral areas of their blood supply in order to preserve the vital organs centrally. Renal replacement therapies, such as haemofiltration and dialysis, can support failing kidneys but require anticoagulation, which might cause the patient to bleed. Mechanical ventilation may support patients with respiratory failure, but can leave them susceptible to ventilator-associated pneumonias (VAPs) and the sedation required promotes hallucinations and ICUdelirium, with the potential for cognitive decline in those susceptible. Critical Care is an environment fraught with potentially traumatic experiences and many survivors go on to suffer from Post-Traumatic Stress Disorder (PTSD).

It is important to remember that though these technologies are supporting failing organs, they are not necessarily treatments for the underlying condition itself. We must

Example 2

A 69-year-old woman is diagnosed with advanced ovarian cancer that has spread to multiple organs. She has a discussion with her Consultant Oncologist about the pros and cons of a course of chemotherapy; the potential benefits (perhaps an additional four months of life) and burdens (unpleasant side effects, complications and risks, with perhaps a significant proportion of her remaining life spent in hospital). She weighs up which course of action is best for her, given her priorities at the end of her life.

diagnose, treat and assess the potential for recovery of the underlying disease process when considering whether to initiate these potentially burdensome, aggressive, even cruel, therapies. Are we over-medicalising the care of those patients who are clearly dying?

Another factor that can help assess a patient's likeliness to benefit from a treatment is their physiological reserve. Has the patient been fit until recently, or are they in a state of functional decline? Patients who have been well are more likely to overcome the ordeal of a life-threatening illness than those with multiple comorbidities or frailty. Even a previously young and fit survivor can take many weeks or months to recover from a prolonged critical illness, and sometimes they are never the same again.

The British Medical Association (BMA) defines the primary goal of medical treatment 'is to benefit the patient by restoring or maintaining the patient's health as far as possible, maximising benefit and minimising harm'.⁶ In other words, goals might include cure, palliation of symptoms, prevention of further disease or complications, and improvement in functional status. If it is not possible to achieve these aims, then perhaps the wisest course is to allow a natural death to occur.

Good communication here is key, plus a healthy dose of realism. Using my knowledge, experience and clinical judgment, what can I realistically offer as a prognosis? Can I help my patients to understand that attempts to prolong their lives when there is no realistic prospect of recovery is unwise and unkind? We must collaborate with our patients and normalise conversations around the subject of death and dying, though this clearly requires great sensitivity.

Regular ongoing conversations between patients, their family members and their

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clinicians about hopes and expectations around the process of ageing, the transition from independence to dependence and the approach of death can help all concerned reflect and anticipate what kinds of treatment are most appropriate ahead of time. Treatment Escalation Plans (TEPs) are being introduced in many NHS Trusts and Community Services to aid in formalising this process.

Justice

The cost of hospital care, as opposed to hospice care or palliative care at home, at the end of life is substantial. ⁷ Is it right or just that significant sums of money are spent on hospital treatment in the last weeks of life that may be anticipated and avoided, not in the patient's best interest (patients often live longer if treated less) or against their expressed wishes? Perhaps these resources could be better spent elsewhere, especially when some areas have inadequate provision of palliative care services.

Futility

When contemplating the withholding or withdrawing of treatments that have ceased in their utility, we are encountering the concept of futility. Futility can be defined as 'pointlessness' or 'uselessness'. The subject of medical futility is a controversial one and there have been advocates of an approach whereby all life-sustaining measures should always be attempted, that futility is a value-laden concept arising from medical paternalism.8 A counter argument is that offering treatment that is not going to work is deceitful and thus violates our patients' trust, further undermining the practice of medicine. Perhaps we should take an alternative, more balanced, approach:

'It is surely better to locate these decisions about medical treatment abatement (or limitation) in a gentle, compassionate but clear understanding of the reality of death and the process of dying. It is our natural destiny to die, and obstruction of the dying process, when it is manifestly underway, is indeed both futile and unkind. This can be done by an honest and transparent evaluation of realistic goals of care: curative /restorative, palliative or terminal'.⁹

Certainty

Can we be sure that treatments will or won't be of benefit to patients reaching the

end of their lives? How can we be *certain*? Decisions should, of course, be evidencebased – technology and scoring systems can be of help in prognostication, though even when they determine our patient has a 99% risk of mortality, we can't know if they might be in that 1% of survivors. Physicians, even dedicated and experienced ones, are not omniscient, they make mistakes.

Patients surprise us and even those we are 'certain' will die within hours can sometimes confound our predictions. There is an opportunity here for humility. Patients appreciate truthfulness and sincerity about the limits of our expertise and prognostication, we should have an open dialogue concerning our projections. The GMC advises that when in doubt, give the benefit of the doubt: 'If there is a reasonable degree of uncertainty... the treatment should be started in order to allow a clearer assessment to be made'.¹⁰

Conflict

Instances of conflict between the judgment of clinicians and their patients or surrogates will arise, how do we deal with them? The GMC gives a solid framework for resolving disagreements such as the use of independent advocates, advice from senior colleagues, second opinions, case conferences, mediation services and ultimately recourse to legal rulings.

Treatment versus care

Throughout all our encounters with treatment limitation in end of life care it is important to remind ourselves and our patients that in withholding or withdrawing a treatment we are not withholding or withdrawing our *care*. Our diligent care of our patients continues, even when we decide certain treatments, such as CPR, are not in their best interests. When the focus of care switches from restoration to palliation, we must be alert to our patients' symptoms – managing any pain, breathlessness, agitation or other kinds of distress.

A biblical perspective

Christians believe life is a gift from God and that human life, made in the image of God, has absolute (not relative) value:

'Then the Lord God formed a man from the dust of the ground and breathed into his nostrils the breath of life, and the man became a living being.'¹¹ 'So God created mankind in his own image, in the image of God he created them; male and female he created them.'¹² 'The God who made the world and

everything in it is the Lord of heaven and earth... He himself gives everyone life and breath and everything else.'¹³

We have confidence that God is ultimately in control of our lives and our deaths:

'Your eyes saw my unformed body; all the days ordained for me were written in your book before one of them came to be.' ¹⁴

'The Lord brings death and makes alive; he brings down to the grave and raises up.'¹⁵ 'There is a time for everything, and a

season for every activity under the heavens: a time to be born and a time to die.' ¹⁶

'A person's days are determined; you have decreed the number of his months and have set limits he cannot exceed.'¹⁷

'So, whether we live or die, we belong to the Lord.' $^{\rm 18}\,$

Amongst Christians there is a spectrum of opinion concerning what kinds of treatment they anticipate accepting towards the end of their life, from minimal intervention to having everything possible done. There may be a perception in some Christian communities that to accept all kinds of invasive treatments is to express a lack of faith or, on the contrary, that to reject lifeprolonging treatments is tantamount to euthanasia. Interestingly, one research project found that religious believers, rather than accepting death as inevitable and under God's control, are more likely to request futile life-sustaining treatment continuing to the point of death than non-believers. 19

When we approach treatment limitation we must exercise godly wisdom and weigh whether 'the burden to the individual of invasive and unpleasant Intensive Care outweighs the possible benefit that such treatment can bring. Provided there is a consensus... it seems appropriate to withdraw intensive treatment with the realisation that death is very likely to follow. The intention is not to end life, however, but to withdraw futile treatment, although doctors... can foresee that death may occur as a result of this action. ...We cannot withdraw life support because a life is not worth living, but we must decide if

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treatment is not worth giving.²⁰ There is a profound moral difference between allowing a person to die, on the one hand, and actively ending life on the other.²¹

It would seem Scripture may give us a clue as to when to 'pull out all the stops' and when to 'let nature take its course'. Individuals in both the Old and New Testaments who are raised from the dead seem to involve invariably children and younger people (see accounts of miracles performed by Elijah, Elisha, Jesus, Peter and Paul). Perhaps this provides a guide for discerning those whose lives are being cut short prematurely and those who 'shall come to [their] grave in ripe old age, like a sheaf gathered up in its season'.²²

The CMF resource *Facing serious illness: Guidance for Christians towards the end of life*²³ offers practical and biblical guidance to Christians who are facing a life-threatening illness.

In summary, it is morally, medically and biblically appropriate to withdraw life-sustaining treatments that are an inappropriate extension of the dying process, so long as basic, compassionate care is not interrupted. As Christians, our hope after death is secure, we are confident that to be away from the body is to be at home with the Lord.²⁴

Conclusion

Modern medical technologies provide us with powerful tools to aid us in helping and healing our patients, but they can also present us with significant ethical challenges. Is it right that we continue to sustain biological existence at any cost? Intensive medical treatments can, rather than prolonging life, end up prolonging death. Effective communication with our patients and their loved ones is crucial when facing end of life discussions and decisions. We must treat our patients with the dignity they deserve and, God-willing, help them wisely choose the treatments appropriate to their individual circumstances. On occasions that may mean withholding or withdrawing treatments that no longer provide a benefit, and allowing a natural death to occur.

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11.

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