

Ethics at the end of life

John Idris Baker

Abstract

End-of-life care has always been prominent in discussions of clinical ethics. Almost 30% of hospital inpatients are in their last year of life. Doctors frequently encounter people with end-of-life care needs and should be equipped to respond. However, what has been written about it leaves many doctors, other healthcare workers and the public uncertain and confused. What key things should doctors know and understand? The principles are the same as in any area of medicine, but they have to be applied in a different context. Some goals (e.g. long-term survival) can no longer be achieved, but new ones (e.g. new ways to improve quality of life) become available. By clearly understanding the ethics, we can learn how to do good end-of-life care. This article addresses key areas including why ethics matters in end-of-life care, how to apply familiar principles, how we can overcome barriers to respect for autonomy, applying the doctrine of double effect and understanding the application of ethics in the last days of life. It also gives pointers to further detailed reading.

Keywords Advance care planning; assisted dying; autonomy; double effect; end of life; ethics; last days of life; living well; palliative care; substituted judgement

Introduction

The principles of ethics are the same in adult end-of-life care as in any field of medicine. How they are applied in healthcare as a whole has a direct effect on the care of the dying. This article applies those general principles to some specific areas in end-of-life care. It does not cover assisted suicide and euthanasia, which are distinct in that they entail an intentional decision to end life.

Patients come to harm when the term 'end of life' is used vaguely, for instance something being omitted from the care of a patient in the last year of life simply because it would not be needed by a patient in the last days of life. It is important (clinically and ethically) to be clear about what is meant. In this chapter, end-of-life care is the care of people who are likely to die in the next year,¹ and not only care in the last days of life.²

The case for end-of-life care

Rage, rage against the dying of the light.

Dylan Thomas, *Do Not Go Gentle into that Good Night*

It is not only possible but morally significant that dying patients can live healthy lives until death. If this sounds oxymoronic, then we must develop a stronger understanding of what is meant by 'living healthily'.

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Key points

- End-of-life care is about living, not just about dying: its ethical principles apply as in other fields
- Words must be clear, for example distinguishing the last *year* of life and the last *days* of life
- Good end-of-life care is a duty, applying sound principles to changing contexts, needs and the patient's goals. Listen and discern patient preferences even when they cannot be expressed
- Look out for changes in condition, priorities and needs, and respond to them
- Understand the distinction between end-of-life care and 'assisted dying', and the doctrine of double effect

David Hester, *End of Life Care and Pragmatic Decision Making* (2010)

There comes a time when you are ready to lay it down.

Lily, a patient quoted by Cicely Saunders, *Watch with Me* (2003)

Doctors sometimes protest that the uncertainty in prognostication means we should shy away from seeing a patient as needing end-of-life care. Uncertainty is one of the few certainties, but we can embrace the uncertainty rather than being put off by it. Even when the outcome is not known, we can usually be clear about the probability of a particular course of action changing that outcome (Table 1). Moreover, it is possible to reduce the uncertainty, for instance by using disease-specific criteria such as those published by the Gold Standards Framework Centre in the UK, and most importantly by good communication within a team. This can reveal unnoticed signs of deterioration or (importantly) of potential reversibility.

As a patient nears the end of life, goals change. The emphasis can shift from maximum survival to optimum quality of life. Even for someone whose goal (as yet) remains long-term survival, if there are no treatments capable of achieving it, decisions should reflect that reality. Many patients are interested in both survival and quality of life, and that complexity is compounded by how options and preferences change over time. The application of ethical principles in end-of-life care means considering the following:

- We should recognize the changing benefits and harms of the available options. Some benefits (recovery, extended survival) may not be available. The meaning of others may change; quality of life, for example, is (according to Kenneth Calman) 'reflective of the congruence between hopes and expectations and the reality of their achievement'. As those hopes change, so will our approach to quality of life. Some harms may matter less to someone nearing the end of life; others may matter more.
- Autonomy must be promoted by offering information and explanation, and fostering shared decision-making.

Examples of treatment questions in end-of-life care when outcomes are unknown. In each case, the outcome is uncertain, but there is certainty to inform a treatment decision

| Treatment question | Uncertainty | Certainty |
|--|---|---|
| Whether to continue CAH in a patient thought to be in the last few weeks of life who has been deteriorating on a drip with no identifiable reversible cause and has widespread peripheral oedema | Whether there is any potential to recover | Continuing CAH will not improve the chances of recovery but will compound the oedema |
| Whether to start antibiotics in a patient with advanced cancer and a sudden deterioration with signs of pneumonia and sepsis | Whether antibiotics will work | The probability of antibiotics working is enough to justify a trial if the patient accepts it or (in incapacity) the treatment does not violate any prior preference or refusal |

CAH, clinically assisted hydration.

Table 1

Figure 1 is an illustration of how following both positive and negative obligations of autonomy (in this case giving information and explaining the options, and then giving the patient a free choice) can enrich a decision. Note that it shows a wide range of influences rather than being based solely on a medical judgement of benefit and harm. It also gets us past the position, uncomfortable for doctor and patient alike, of the patient simply being given huge quantities of information and told to make a choice. Patients nearing the end of life are, once they know what goals are possible, experts in what they would choose but not in the means that can help achieve those goals. In order to use that expertise, they need doctors who appreciate their knowledge of what goals are possible and inform their understanding.

- Think carefully about fairness and the requirement to respond in proportion to a person’s needs. Such needs can be equal to or more or less important than those of other

patients. At the end of life, patients have the same claim as others to the resources required. End-of-life care is urgent: whatever we are going to do must be done quickly. For someone with a month to live (and likely to be alert for diminishing periods), a week waiting for pain control or discharge home to die forms a high proportion of the remaining useful time. A decision to let a dying person wait is a decision not to act because the patient will have died before the action is taken. Table 2 gives an individual illustration of this.

Some problems with autonomy in end-of-life care

Treatment decisions in end-of-life care are often complex and the stakes are high (because decisions often seem to be matters of life and death). Factors that can compromise capacity (exhaustion, delirium, distress, drugs) become more prevalent. As a result, incapacity for a particular decision is common. In addition, some

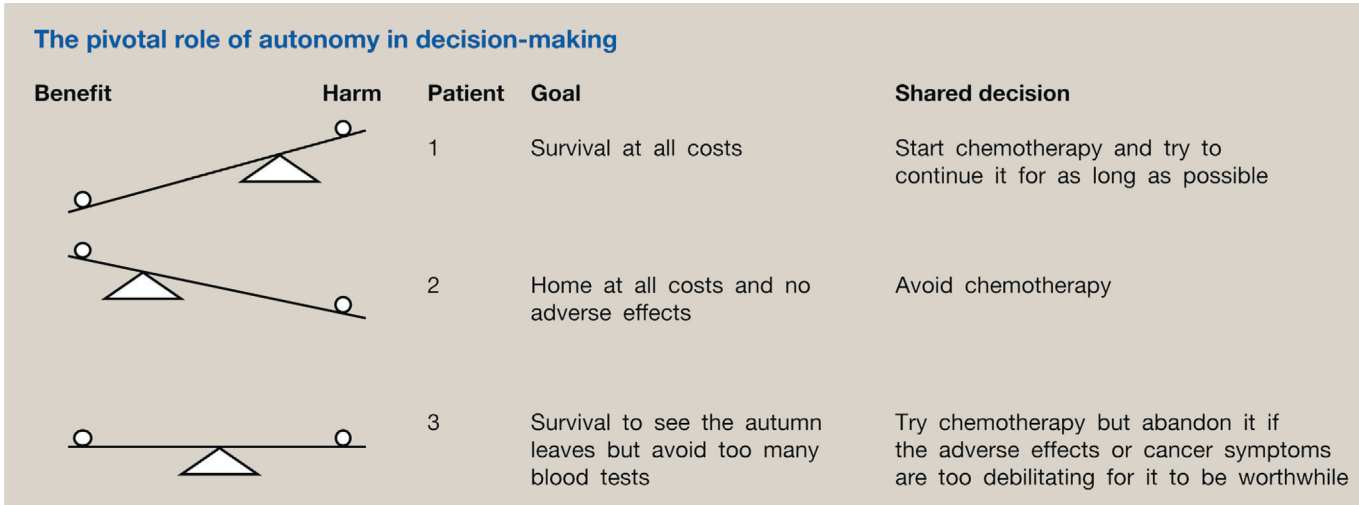


Figure 1 The pivotal role of autonomy in decision-making: when the benefits and harms of treatment are finely balanced, different people can judge them differently. Three biophysically identical patients with the same incurable cancer who were offered palliative chemotherapy, aiming to prolong life but with a substantial burden of adverse effects and hospital appointments, surprised their oncologist by reaching different decisions. The differences arise rationally from their different goals, which in turn might be driven by factors including social circumstances, aims, values, beliefs and life experiences. Note that the size of the benefit and harm is the same in each case but balancing them in light of the goal, represented here by the pivot or fulcrum, leads to different balance points. Each balance point fits; each patient has made the ‘right’ decision.

Text from an email from Jane, aged 32, living with end-stage motor neurone disease

4 months after DX I started finding things at home difficult, turning taps on and off, ... 4 months after applying I received the long awaited lever taps. 4 months too late I think? downstairs shower room, was told had to wait 18 months? I don't think I need to explain my problem there!!!
Now I apply for aids before I need them. But if I don't know what aids I will need, how can I apply?

Table 2

patients have capacity but prefer to delegate some decisions to others, including professionals or family members.

Advance care planning (ACP) and substituted judgements in end-of-life care

Some people with life-shortening illnesses like to lay out their preferences for future circumstances in an advance care plan. Doing ACP well requires close knowledge of future possibilities and treatment options. A positive obligation to respect autonomy should encourage doctors to help patients do this if they wish.

In this area, however, the 'inverse care law' described by Julian Tudor-Hart in 1971 can apply. Helping with ACP only when asked favours individuals who are informed, confident and articulate; doctors should consider offering the opportunity to people who do not request it. Helping to facilitate ACP can help to reassure patients and families that their views are known. Some patients find it less intimidating to do this in the form of an advance care plan, which gives an indication of preferences as a guide to decision-making, as opposed to a legally binding formal advance decision to refuse treatment or to arrange lasting power of attorney.

The aim is to help make a patient's own goals pivotal even when they have lost capacity or their expression is limited by exhaustion. Some patients find they do not know clearly enough what they might want in future circumstances, and some change their minds. Preferences for care in unpredictable future circumstances are dynamic and complex. If a patient cannot voice their preferences and these are not specifically known, it may nonetheless be possible to use what is known (from the patient previously, or from those close to them) to form a substituted judgement – an attempt to make the decision the patient would make if they could. This is imperfect but is probably a lot closer to respect for autonomy than deciding simply according to what others think would be best.

Double effect

Achieving a good effect sometimes requires that a doctor does something where they foresee bad effects, such as death. This is seen as justified provided¹ the act is not wrong in itself,² the *intention* is only to achieve the good effect and not to hasten death,³ the death is not the means to the good effect, and⁴ there is proportionality between the effects.

Textbook accounts of this 'rule', 'principle'³ or 'doctrine' of double effect often cite symptom control in end-of-life care as the area where it applies, perhaps because this was the context of *R v. Adams*, the case that first saw the rule applied in English common law. In reality, competent symptom control near to death does not generally shorten life, and the rule is

required less often in end-of-life care than in other high-risk treatments.

Last days of life

In the UK, the National Institute for Health and Care Excellence has published guidance on the care of people thought to be in the last days of life.² Among their detailed clinical recommendations are several with particular ethical relevance. The emphasis is on sound clinical assessment and review, careful attention to both the patient's preferences and the patient's and family's communication needs, and making decisions that are appropriate to that person ('individualization'), rather than on standardized responses.

One facet of this is continuing to consider clinically assisted hydration. The withdrawal of food and fluid, not only by artificial means but altogether, has in recent years been a persistent theme in concerns about the practice of care in the last days of life. For most people who are dying, clinically assisted hydration does not help, but doctors should resist the temptation to turn this into a universal approach that does not make fluids available. Sometimes they have a role.

The ethics of end-of-life care matters to hospital physicians because many hospital patients are in their last year of life – 28.8% in one Scottish multicentre study.⁴ The proportion is probably higher among acute medical admissions. Failure to recognize this, and not to think clearly about the ethics of end-of-life care, means ignoring the needs of too many of our patients. Above all, doctors should get past a tendency (in Julia Neuberger's words in a 2003 *Br Med J* commentary) to 'regard death as failure' and move on to offer good end-of-life care. ♦

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FURTHER READING

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