

Education and debate

Planning for a good death: responding to unexpected events

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When a terminally ill patient develops an acute problem, risky emergency treatment may seem futile to medical staff. But sometimes patients are not ready to die. What is a good death in such circumstances and how do we achieve it?

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In palliative care we aim to provide good symptom control and ultimately a good death. Patients and their families need time to prepare for death. Sometimes acute situations arise that can interfere with this process, leading to a distressing and undignified end. Decision making in emergency situations is difficult. We use a case history to illustrate the problems surrounding such decisions.

Case history

A 19 year old man was diagnosed with rhabdomyosarcoma of the prostate with lung metastases and bone marrow disease. He was treated with four chemotherapeutic regimens. Although the pulmonary metastases completely resolved, the disease progressed at the primary site and regional lymph nodes. He had multiple complications from the chemotherapy, which resulted in lengthy hospital admissions. Controlling his pain, particularly neuropathic pain in his left leg, was difficult.

He had many plans for the future and promising career prospects ahead of him. Despite several attempts, we were unable to open a discussion with him

about his prognosis or end of life issues in the days preceding the emergency event.

While he was an inpatient on the palliative care ward at the tertiary referral unit he developed intermittent melaena sufficient to require blood transfusion. Gastroscopy showed no abnormality. Angiography was arranged for the following day at a nearby hospital to locate the bleeding point. That evening, however, the rate of bleeding became catastrophic, and an immediate decision had to be made about his management. He was transfused with large volumes of blood products. By midnight, it was clear that he would die without further intervention. At this point he was fully alert and oriented, aware of what was happening and of the consequences of continued blood loss.

Staff from different disciplines were present—an oncology registrar and senior house officer, a haematology registrar, a surgical registrar, a palliative care consultant, and ward nursing staff. In addition the oncology, surgical, and anaesthetic consultants were contacted at home for advice. Both the patient's parents were present.

The nearby hospital was unable to perform angiography and embolisation that night because it had no critical care beds available. By 3 am we had found another hospital with facilities to perform the procedure, but it was several miles away. Our patient was faced with a traumatic and frightening death. The dilemma was whether to sedate him on the ward or take the risks of transferring him to another unit for a potentially life saving procedure, despite the terminal phase of his illness.

What is a good death?

In terminally ill patients it is not only quality of life that is important but the concept of a good death.¹ Steinhauser et al evaluated factors considered important at the end of life from the perspective of various stakeholders (box).² The factors are similar to those described by others, but there is an added emphasis surrounding the need for patients to retain control of their environment and destiny.¹

The patient's judgment in this case was overwhelmed by his desire to stay alive at all costs. The concept of dying was not within his decision making



A Bench in Paris by Osmond Caine, 1960

Factors important for a good death²

Control of symptoms
 Preparation for death
 Opportunity for closure or “sense of completion” of the life
 Good relationship with healthcare professionals

framework because he had not come to terms with the terminal nature of his disease.

What is futile treatment?

There has been much debate concerning what constitutes a futile action or intervention³ and who is qualified to make such a judgment.⁴ Whether an outcome is considered beneficent depends on the criteria used to define what constitutes doing good. Clearly physiological quantitative measures, such as survival to discharge after cardiopulmonary resuscitation, can only be a part of these definitions. Other spheres such as the psychological, social, economic, religious, familial, and legal outcome are also important.⁵

An individual's assessment of whether an act is futile depends, firstly, on the goal he or she is trying to achieve and, secondly, the probability of success he or she deems acceptable. The goal may vary from complete cure of an illness to simply avoiding death. Such a value laden decision can lead to unrealistic demands for treatment.⁶ Patients with cancer are more likely to choose radical treatment with minimal chance of benefit than people who do not have cancer or healthcare professionals.⁷ This situation is not confined to young people—for example, personal goals such as seeing the birth of grandchildren or special anniversaries may influence decision making.

Considering the family and carers

In making decisions about treatment, doctors have to consider what is best emotionally and psychologically for the family and carers involved, in particular how and where should the patient die? There is often the feeling that people have been “put through enough.” Doctors also have to consider the use of costly interventions for short term gain and the cost of transferring the patient to make this possible. It is extremely difficult, however, to apply a cost analysis to the personal gain of the patient and family in such a situation.

To “do nothing” requires enormous restraint by a doctor, and he or she needs to be sure that they are informed of all relevant information. It is difficult to withhold medical treatment in an emergency. Doctors are usually expected to intervene, not only by the patient and family but also by nurses and other doctors. Unlike withholding treatment in non-emergency settings, where there is more time available and the patient can be better prepared, withholding emergency treatment is obvious and cannot be done in a controlled way.⁸ This is different from withdrawal of care, which is often done in more managed surroundings with adequate information and surrogate decision makers.

The decision

Without intervention, our patient would require sedation. The parents would inevitably be involved in

this decision and would have to live with it afterwards. Their son wanted to live, whatever the cost. If they chose sedation, would they have feelings of regret or guilt afterwards or wonder what the outcome would have been if they had opted for intervention?

However, transferring a critically ill patient to another hospital has risks, and these had to be weighed against any potential benefits.⁹ Very sick patients are more likely to suffer adverse events during transfer.¹⁰ Although adequate equipment, monitoring of the patient, and experienced staff all decrease mortality and morbidity associated with transfer,^{11 12} there was a real risk that he might not survive the journey. Suppose he died an “awful” death (as perceived by healthcare professionals) in the ambulance? He might consider this a good death because he would have died fighting for his life. How would such a death be perceived by his family and the staff involved?

Stakeholders' views

The patient was awake, frightened, aware of the implications of continued bleeding, and asking his mother and the doctors to do something to help. We explained that he would have to be transferred to another hospital for treatment and that the journey and subsequent procedure would involve certain risks. His reply was, “Well I don't have any choice do I?” and he asked to go.

Both parents were aware of the terminal nature of his disease but were at different stages in accepting and processing this information. One felt he had been through too much in the past year with very few gains. During this time he had reached several critical points in his treatment when death had seemed imminent. As a result, the family was emotionally drained and aware of the suffering that might result from further active treatment. The immediate situation was explained to them: one parent was keen for everything to be done and the other was undecided; above all, however, they wanted their son's wishes to be respected and therefore agreed to support his desire for active intervention.

The nursing staff had mixed views. They thought that the number of doctors involved increased confusion and led to delay in finalising management decisions, including a change in the resuscitation status of the patient.

The doctors wanted to transfer the patient for embolisation. They were reluctant to allow something



French physician Francois J V Broussais on his death bed, 1838 (etching by A Gourlier)

Summary points

Terminally ill patients should be properly prepared for death

Emergencies sometimes occur before preparation is completed

Life saving treatment may be appropriate in such circumstances

The emotional and psychological needs of the patient, the family, and carers have to be considered alongside medical issues

The definition of a good death will vary for each patient

potentially reversible to lead to the patient's immediate death. They therefore changed the resuscitation status of the patient for transfer. Because of the terminal nature of his illness, with an estimated prognosis of two weeks, his status was initially for fluid resuscitation only. However, since a cardiopulmonary arrest at this stage would have been precipitated by the massive bleeding and was therefore probably reversible, full active resuscitation was agreed. There are circumstances when it is appropriate either to reverse a do not resuscitate order or to introduce a limited aggressive therapy order.¹³

Outcome

The patient was transferred in the early hours of the morning. Embolisation was successful despite being technically difficult. The patient remained confined to bed on the palliative care ward, requiring increasing amounts of nursing care over the ensuing days. He became drowsy because of resistant hypercalcaemia, and communication with the family became limited. The terminal phase was peaceful and controlled, and he died 18 days after the procedure with his mother and father present. During this time the staff reported a change in the attitudes of the family, and they felt that this extra time had been valuable as it allowed the family to come to terms with the patient's death.

Discussion

Patients must be treated as individuals, but everyone has to accept that outcomes may not be as planned. In this case, the fact that the patient did not survive to discharge does not mean that the action taken was necessarily futile. In the end, he had what we would describe as a good death, but he could easily have had what we

would perceive as a bad death if events had taken a different course.

The options available to this patient, who was in a tertiary referral unit, were clearly different from those of patients in a hospice or at home. Patients' expectations are also influenced by place of management and vice versa. Management of severe bleeding in terminally ill patients, particularly when tumours are known to be locally invading blood vessels, is a well recognised problem. Standard management in the palliative setting is to limit the bleeding as much as possible and to give adequate doses of sedation—for example midazolam—to relieve the acute distress.¹⁴

If possible, patients should be prepared for the end of life, but sometimes they cannot process the information fast enough to keep pace with events or remain in denial. Conservative treatment of acute events is usually appropriate for patients who have accepted death. However, active treatment may be the right choice for patients who have not accepted death, even if the intervention seems futile. Both may result in a good death from the patient's perspective.

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Commentary: mother's response

Lynn Boland supported by Diane Laverty

My husband and I had been estranged for about six years when our son became ill. Despite our separation, we always communicated about decisions relating to our son's care.

The night when he began bleeding is etched in my memory. The most poignant thing is my recollection of my son's face. He looked absolutely terrified. After his condition stabilised, we (the family) left the room to

discuss the situation with the doctors. They explained that if the procedure was not performed immediately he would not live through the night. My husband and I spoke about it and he was keen for us to proceed, but I pointed out that it needed to be our son's decision. I recall discussing what would happen if they couldn't find a bed anywhere for him. The whole incident felt like torture for all of us.

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I don't think I thought about the futility of the situation until later. It was not until the next day that I was told that it wouldn't be appropriate for him to have a procedure like that again. I realised then that there had been an element of doubt about the value of such an intervention, but it was difficult for me to comprehend because the procedure had left my son feeling so much better. I do not know how I would have felt if the procedure had not gone well.

After the procedure, we were able to spend a happy weekend with him. He then became very drowsy but he was also settled. After several months of seeing him constantly in pain, it was such a relief to see him peaceful. We all agreed that he was so much more comfort-

able. Although he was unable to communicate, he did give us indications that he was aware that we were present. I do not know what my husband's innermost thoughts were during the course of the illness as we talked about only factual issues, but in the end I feel sure that he had come to terms with the imminent death.

Those last two weeks allowed us the opportunity to accept the situation and prepare ourselves as much as possible for his death. If he had died on that night, it would have been much more traumatic for us and his death would not have been so easy to come to terms with.

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A healthy view of dying

Julia Neuberger

Death is the one great certainty in life, yet Western society, and Western medicine in particular, seem unable to come to terms with this. Rabbi Julia Neuberger discusses how attitudes need to change

In his president's lecture for the King's Fund in June this year Richard Chartres, the bishop of London, drew attention to our society's inability to see life and health holistically (lecture available on the King's Fund website, www.kingsfund.org). He took us back to ancient Pergamon and its Temple of the Divine Healer, Aesculapius, and gave us an insight into that hospital: "In the Greek medical tradition, the fundamental recipe for healthy living was 'know thyself and be moderate in all things,' and this outlook was expressed in the regime followed in the hospital ... the temple must have been a tranquil and beautiful environment in which to recover, in an atmosphere that was a cross between Champneys and an Oxbridge college ... It was in the ruins of this place that I can remember contemplating the theme of healthy living and healthy dying."

The whole person was considered: mind, body, and spirit were as one. In the discussion that followed his lecture, a groundswell of feeling grew that, as a society, we are somehow not paying attention to the whole person in the care of dying patients and bereaved people, because of our strong Western medical model. Part by part, specialty by specialty, no integrated view can develop of the person and the culture from which he or she comes.

At the King's Fund, we had already been aware of a growing concern about this, from applications for grants from a variety of organisations. Some wanted to do work on "natural burials" and different kinds of funerals. Others wanted specialist palliative care services for people from various ethnic and religious minorities. Some wanted a well trained group of "sitters" for dying people, so that relatives could have some respite. Others wanted to explore palliative care for conditions other than cancer, motor neurone disease, and AIDS. Time and again, we were being asked for help. As part of our response, we published a short paper on psychosocial support for dying people last year, which received an enormous amount of attention.¹

Shortcomings in palliative care services

The degree of concern we have noted and the large number of grant applications we have received, plus the start of a campaign after Richard Chartres' lecture, suggest there is widespread unease with the Western medical approach to dying. Despite the huge advances made by the hospice movement and general advances in palliative care, in which Britain has undoubtedly taken a lead, the care available for terminally ill people is far from adequate, and far from satisfactory for a range of groups in our society—elderly people who do not have cancer, people with end stage renal failure, those with heart disease, those with Alzheimer's disease, black people, Muslims, Jews, Buddhists, Chinese, and so on. Meanwhile hospices worry increasingly about funding for the excellent work that they already do. Despite several national attempts to encourage primary care and hospital services to provide better care at the end of life,

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Seppuku—honourable Samurai death