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Chapter 1

Death and dying: decisions at the end of life

Section 1: Values and goals at the end of life

> Rather than reaching a more finely honed consensus about the values and practices that undergird end of life care, conflict has come to dominate the discussion. The consequences are serious for patients, health care providers, family members, and society.
> (Dubler, 2005, p. 19)

Death is an unavoidable fact of life. However, the manner in which we each will die is a matter of great concern and conjecture, not least given the considerable advances presented to us by modern medicine. It is nowadays possible for us to delay death and, in many cases, to enable those who would previously have died prematurely to recover and to live full and healthy lives. Such techniques also allow us to exert a greater degree of control over the processes of dying, even when full recovery is not possible. This means that there are people who can now be kept alive by medical interventions but who will never recover sufficiently to live an independent, or in some cases even a conscious, life as a result. There are also patients for whom medical interventions make no (or no appreciable) difference to their suffering – and, sometimes, these patients insist that they would rather die than endure their current existence.

The occurrence of such requests, along with the opportunities and challenges that modern medical techniques simultaneously present, raise a host of important ethical questions. In this chapter we will explore various dilemmas that arise in end-of-life care. In doing so we will consider two fundamental questions:

(1) What is the value of human life?
(2) What are the goals of medicine?

This will prompt us to ask such questions as: does life possess an intrinsic value or is it only valuable for as long as it is a happy life, of a good quality? Or, instead, is the value to be determined by the individual, such that it is for him or her to decide when life is – or is not – worthwhile? And what is medical expertise supposed to achieve, particularly when the patient is nearing the end of his or her life? In other words, if we cannot heal the patient, then what should be the goal of medicine and of the healthcare professional?

These questions undoubtedly have great relevance in the context of end-of-life decision-making – and, we suggest, they also underpin many of the other ethical issues that we will explore throughout this book. As such, your reading of this chapter should give you some of the philosophical tools that will help you to think through the other areas of medical practice you will encounter.

In order to explore these questions we will introduce a range of real clinical cases. Some of these cases have proven so difficult that they have ended up before a court of law. However, even those that have not been passed to a judge can involve intense ethical dilemmas, as our first case poignantly demonstrates. This case was referred to us by the bioethicist Alastair Campbell and, unlike many of the cases we will discuss, the patient, Anna, was happy to be named – indeed, she was keen for the issues to be debated as widely as possible, as Campbell explains (Campbell, 1998, p. 83).

The case of Anna

Six and a half years ago I met a woman called Anna for the last time. Anna asked me to tell her story whenever I could, and I often have since that time. She was a woman in her thirties who was tetraplegic as the result of a road traffic accident some years previously. She also suffered diffuse phantom pain, which required constant administration of high doses of analgesic to make it bearable.

Anna was married and had three young children. She had previously been a very active person – she had loved hiking and was an amateur singer of considerable talent. She also enjoyed amateur dramatics. By profession she was a schoolteacher. Now she felt she no longer had a life to live, that she was no longer the person she had been, and she wished to die.

ACTIVITY: Imagine that you are one of the doctors caring for Anna. How would you respond to her statement? Do you share (or at least sympathize with) the conclusion she has reached about the value of her life? Or do you think that there is still value in Anna's life, perhaps even enough to say that Anna is wrong to feel this way?

As you work through this book, you will be introduced to various articles about the topics under consideration. In the first reading, below, Richard Huxtable describes some of the different views that have been taken on the value of human life, which you may yourself have considered when thinking about Anna's case.

Calculating the value of life?

Richard Huxtable

Modern medicine is capable of securing great victories for a diverse range of patients, whose afflictions may range from the minor to the major, from the transient to the chronic, to the incurable and even to the terminal. Indeed, in much of the developed world at least, experts trained in palliative care have the knowledge and means to offer the dying patient a death that is, so far as possible, free from painful and distressing symptoms. Yet, such victories may be hard fought and incomplete, and they may even be more apparent than real. Some patients will continue to suffer; some will reject the medicines and machines on offer; and some will insist that what they really want is positive help in dying.

Given the differences in outlook and opinion that exist, it is perhaps inevitable – but still regrettable – that conflict is rarely far from the practices and policies adopted at the end of life. Sometimes the conflict is all too real: the judges in England have had occasion to consider a case in which a physical struggle developed between medical staff and the relatives of a seriously unwell boy on a paediatric intensive care ward (Huxtable and Forbes, 2004). The physical struggle emerged from an ethical dispute, involving a fundamental difference in opinion about the ways in which the boy, who the doctors believed was dying, ought to be treated. That was, of course, an extreme case. Nevertheless, the ethical tensions on which it rested are rather more common, since even our everyday practices and policies often require us to take a stand on what it is that makes life valuable – and this is something about which many of us will disagree, and often reasonably so.

So, which (and whose) values should guide us in our actions at the end of life and in shaping the rules that govern those actions? The ethical terrain has been comprehensively mapped over decades, if not centuries, and three themes emerge as particularly dominant: the duty to respect life; the obligation to alleviate suffering; and the need to respect patient autonomy, essential to such concepts as informed consent. It should come as no surprise to learn that each of these options will, in turn, shape death and dying in quite distinctive ways.

The first theme, the duty to respect life, has the longest history, as it has long featured in (for example) Judaeo-Christian teaching. The basic idea here is that life has a special worth, such that it should never intentionally be brought to an end. This is often formulated as the principle of the sanctity of life, but it can also be phrased in less theistic terms as the principle of the inviolability of life, or in terms of the right to life (Keown, 2002). Whichever formulation is preferred, its supporters emphasize that life is a basic good, and that it possesses an intrinsic value.

Adherence to this concept of the value of human life will give rise to a set of policies on terminal care which emphasize our commitment to valuing the patient regardless of any disability or inability. Viewed from this perspective, all of society, including the terminally ill themselves, should see every life as worthy of respect and protection. Proponents emphasize that this does not commit us to doing everything in all circumstances; rather, futile or overly burdensome treatments can still be avoided, and potentially risky symptom relief can also be undertaken – provided that there is never any intention to shorten life.

Opposition to this viewpoint comes from the argument that life is only instrumentally valuable: life essentially derives its value from the uses to which it can be put. A useful or happy life is one that we can describe as having a good quality; conversely, a life of disability, inability and suffering might sometimes be described as a poor quality life. Obviously, proponents of this viewpoint believe that we are morally obliged to tackle suffering, through treatment and ongoing research. But some defenders of this position go further and argue that it is not necessarily wrong for us to think that some patients' lives are of such desperately poor quality that they would be better off dead (e.g. Singer, 1993, pp. 191–2).

An appeal to the instrumental value of life is therefore a key feature of arguments in favour of euthanasia. Yet, it is seldom the only feature; it is more common to encounter such a claim alongside an appeal to self-determination or autonomy, which derives from the Greek *auto* (self) and *nomos* (governance). The duty to respect patient autonomy thus grounds a third perspective on what it is that makes life valuable, which maintains that we should leave the assessment to the patient.

Respect for people's choices has a central place in modern healthcare ethics and, indeed, in modern healthcare. However, it is not just *anyone's* choices that we ought to honour; instead, it is the choices of *autonomous* individuals that deserve the most respect. At a minimum, an autonomous individual is one who is mentally 'competent' (that is, capable of taking the particular decision), appropriately well informed about the choice to be made, and able to make their choice freely. Provided that the patient satisfies the relevant criteria, the value of life is entirely a question for her – indeed, it would be unjustly *paternalistic* of anyone to interfere with her view, such as by imposing treatment on her against her will or denying her the right to commit suicide, even with assistance (e.g. Harris, 2003).

There would appear to be something of value in each of the three perspectives just outlined: we should aim to protect and preserve life; we should also want to eradicate or at least minimize suffering; and we should also strive to heed and respect people's views on how they would like (or not like) to be treated. But, we might have very different views about which of these obligations is to take priority, and this will undoubtedly give rise to dilemmas in practice. Sometimes we can devise practical (and principled) methods for dealing with disputes: one example involves affording recognition to a professional's conscience, and thus protecting their autonomous right to refrain from involvement in a policy with which they personally disagree. On other occasions, however, it will be less easy to discern a way of dealing with the competing injunctions that emerge from these various perspectives on the value of life.

No doubt the values conflict will persist. Nevertheless, some bioethicists are looking for new ways of answering the fundamental questions associated with life and death. There will, as a result, be important creative contributions (for example, recent writing on the meaning and scope of human dignity; Beyleveld and Brownsword, 2001; Biggs, 2001), and there will also be value in seeking consensus wherever possible. There will also be merit in seeking to combine the different insights on offer, along the lines of a compromise approach (Huxtable, 2007). Whichever option is favoured, the quest for values is an important one and it is one in which we all have a stake; as such, the very least we might legitimately expect is an open dialogue on the various issues arising in end-of-life care, so that we may all help to shape the resultant practices and policies.

ACTIVITY: According to Huxtable, there are three prominent views on the value of life, which can be summarized as: life is *intrinsically* valuable; life is *instrumentally* valuable; and life has a *self-determined* value. Which of these do you find most persuasive and how do you think it applies in Anna's case?

As Huxtable explains, our responses to Anna might differ according to which account of the value of life we find most persuasive. An adherent to the intrinsic value of life would most likely seek to remind Anna that her life is something she should continue to value. However, this would not require her to submit to every form of medical treatment that would prolong her life: Anna is entitled to say 'enough is enough' if any such treatment is proving futile or otherwise overly burdensome for her.

Alternatively, a supporter of the instrumental value of life could probably be persuaded that Anna's perspective on the quality of her life is entirely understandable. A quality of life assessment is, in essence, a relative one: the patient is judged to be worse off than he or she had previously been, or worse off than other people who are not so afflicted. As Campbell describes her story, Anna herself seems to judge her present existence, in which she is confined to a hospital bed, as significantly worse than her previously active life.

Anna's judgement on the worth (or worthlessness) of her life is undoubtedly important, and it comes to the fore if we believe that life has a self-determined value. Of course, our first task here would be to ensure that Anna is exercising an autonomous choice to die. This could require us to ask various questions of Anna. Is there anything interfering with her ability to reason? For example, is she depressed and, if so and we treat her depression, will she change her mind? Is there

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anything or anyone exerting pressure on Anna, such that the decision is not really *hers*? And is she sufficiently informed about how she could best cope (and even thrive) with life in her condition? Meeting other patients in her condition might help her to see the value in such an existence.

However, even if we are tempted to ask these sorts of questions, we might still reach the conclusion that Anna *is* making an autonomous decision about the value of her life. And doesn't that mean that we should therefore leave it to her to determine the timing and manner of her death?

Of course, true respect for autonomy undoubtedly hinges on appropriate *communication* between the patient and the healthcare professional. The healthcare professional will need to ensure that they have informed the patient of their options, so that the patient can truly exercise a choice. The patient, in turn, will need to communicate their decision to the healthcare professional. We think that good communication skills and good ethics tend to go hand-in-hand. Indeed, and here we return to Anna's story, you might have been tempted to think that Anna was asking the doctors to help her to die. In fact, this was not quite the case, as Alastair Campbell explains.

> Although she had made it clear that she wished no resuscitation, she had suffered a respiratory arrest while away from her usual carers, had been resuscitated, and was now respirator dependent. After some months of discussion and the seeking of legal and ethical opinion, it had been agreed that her request to disconnect the respirator could be agreed to. A device was fixed up that enabled her to switch off the machine, and three days after our conversation, at a pre-arranged time and with all her family present, she flipped the switch. Drugs were administered to alleviate any respiratory distress and she lapsed into unconsciousness. However, a short time later she woke up and asked angrily, 'Why am I still here?' More medication was given and she relapsed once more into an unconscious state. It was some hours later before eventually her breathing ceased entirely and she died.
>
> (Campbell, 1998, pp. 83–4)

ACTIVITY: What are your reactions to this series of events? Which, if any, aspects do you agree with, and which do you oppose?

The fact that Anna was resuscitated against her wishes is a highly regrettable feature of her story, which raises questions about the effectiveness of the communication between Anna's different carers. Again, then, we see the importance of good communication, not only between patients and carers but also between members of the care team.

For her part, Anna made certain to communicate not only with her professional carers but also with her loved ones: she had clearly made her wishes known to her family, and they were there with her when the respirator was turned off. This suggests that Anna knew that her choice did not exist in a vacuum, in which the only salient concern was what she, as an autonomous person, wanted. Anna knew that her decision would impact upon her family, and she had evidently gained their understanding and perhaps even their support – in other words, she seemed to know that ethics means not only considering our *rights* but also our *duties* to others.

Anna finally got what she wanted all along – but, in the end, did her doctors act ethically? This is another point at which there is sincere and serious disagreement amongst the ethicists, which again rests on competing philosophies of the value of life. Some might say that this was euthanasia, that is, an action intended to end Anna's unwanted life of suffering.

> The administration of drugs at this stage seems clearly to be a response to her request to die, through ensuring that her still active respiration was further compromised. At this stage, in my view, the doctor killed the patient at her request, clearly an act of voluntary euthanasia . . . and therefore a criminal act, since there was no law to authorize it. No action was taken against the doctor in this case, nor was it likely to be given the circumstances of respiratory and emotional distress in which the sedatives were administered.
>
> (Campbell, 1998, p. 89)

If, like Campbell, you believe that this was a case of euthanasia, then do you think there is anything wrong in this? Here, it is helpful to consider the extent to which a practice like this can be said to fit with the *goals* of medicine, particularly when the patient is nearing the end of his or her life.

ACTIVITY: What do you consider to be the goals of medicine in general (i.e. not simply at the end of life)? What would you consider to constitute an absolute violation of these goals? Which of these goals are no longer appropriate at the end of life? Which goals would you modify or remove, and what new activities and attitudes would you add?

You are likely to have thought that 'healing' will be a vital part of the healthcare endeavour. However, you are also likely to recognize that, for Anna, healing is no longer possible in any meaningful sense. Perhaps, instead, the central goal of medicine ought to be the *alleviation of suffering*. But we might go further and claim that the duty to end suffering means that we should also be prepared to end lives. Of course, not everyone will share this view: some will object that this involves violating goals intrinsic to medicine, such as the duty to protect and preserve life.

ACTIVITY: Now read the following article and, as you do so, consider the extent to which the goals of medicine (in the broadest sense) are in tension with and perhaps even conflict with what we would consider ethical treatment or care at the end of life. Are the ethical dimensions different when questions of life and death are at issue?

Physician-assisted death, violation of the moral integrity of medicine and the slippery slope

Ron Berghmans[1]

Those who take the view that physician-assisted death involves a violation of the moral integrity of medicine argue that doctors must never be a party to intentional killing, because that would go against the very essence of the medical profession (Singer and Siegler, 1990; Pellegrino, 1992; Momeyer, 1995). The essence of medicine from this perspective is considered to be healing and the protection of life. This view is opposed to the possibility of physician-assisted death in all circumstances. Those who defend this view refer to categorical claims such as the inalienability of the right to life, the sanctity of life, the absolute prohibition against killing other human beings, and to healing as the single and ultimate goal of medicine. I want to focus on this last claim.

On this view, the essence of medicine is to be found in the *telos* of benefiting the sick by the action of healing. It is worth asking however just what is the status of this claim. It should be recognized that the practice of medicine and the ends it serves are of human invention, and not 'naturally given' activities deriving from the structure of natural order. The practice of medicine is shaped by human beings in order to serve human purposes. It involves human choice with regard to value systems, and choosing such a value system requires moral argument and justification, not an appeal to the "nature of things". Whatever the goals of medicine are, or should be, is thus a matter which is open to rational debate, and cannot be decided without reference to value considerations.

But even if, for the sake of argument, we agree that the *telos* of medicine is healing – and not, for instance, the relief of human suffering or the promotion of the benefit of patients – then we still are left with the question of exactly what moral force such an end or goal of medicine has. If we look at the actual practice of medicine, it is clear that healing is more an ideal than an unconditional goal of medical endeavour. Take for instance the case of refusal of treatment by the patient. A well-considered refusal of treatment ought to be respected, even if the physician takes the view that treatment would be beneficial to the patient. The reasons for respecting competent refusals of treatment are twofold. The first reason is that non-consensual intervention where a person has decision-making capacity invades the integrity of the person involved. The second is that competent persons ought to be considered the best judges of their own interests. Only the competent person himself can assess the benefits, burdens and harms of treatment in view of his or her wishes, goals and values. So if a person refuses treatment because he or she does not value treatment in his or her personal life, then such a refusal ought to be respected, even if this might result in an earlier death. Thus, as this example shows, healing as an ideal in medical practice implies that other goals and values can and do operate as constraints upon medical actions serving this ideal.

More directly related to the issue of physician-assisted death is the consideration that the ideal of healing can become illusory, for instance in cases of severe and unbearable suffering in which no prospect of alleviation exists. The goal of relieving the suffering of the patient then becomes the primary goal of the physician, rather than healing.

Part of the moral integrity argument is the claim that if physicians assist in suicide or euthanasia, then the public will begin to distrust the medical profession, and as a result the profession itself will suffer irreparable harm (Pellegrino, 1992; Thomasma, 1996). Against this objection it can be argued that if physician-assisted death is categorically rejected the result may also be a loss of trust in the medical profession. The public may experience this as a lack of compassion and personal engagement on the part of physicians in those cases where no adequate means of relieving the suffering of the patient are available and the patient wants some control over how to die, but is left alone by the doctor.

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My conclusion is that in principle as well as in practice euthanasia and physician-assisted suicide do not *necessarily* go against the goal or goals of medicine, or the moral integrity of the medical profession. The Hippocratic vow of 'helping the sick' and of exercising medical skills for the benefit of patients does not prohibit the co-operation of physicians with requests for euthanasia and assisted suicide, so long as they are convinced that this is what is in a patient's best interests and to the degree that the physician is committed to respecting a patient's own values.

The involvement of doctors in the dying of patients is inescapable. In many cases, a decision of a doctor leads to a hastening of death, although that decision may not always be considered the direct cause of the death of the patient (i.e. the decision to respect the treatment refusal of a patient). In euthanasia and assisted suicide, the causal role of the actions of the doctor is more clear-cut, and the practice of physician-assisted death raises a number of issues regarding the proper role of the physician and the self-understanding of the medical profession. Although the primary task of the physician is to preserve the life of the patient, preservation of life is not an absolute goal. This would demand an unconditional obligation to preserve life by all possible means and under all circumstances. If the relief of suffering is also a proper goal of medicine, then in particular circumstances a weighing or balancing of the goal to preserve life and the goal of relieving suffering becomes inescapable.

Euthanasia and assisted suicide do not necessarily violate the moral integrity of medicine.

ACTIVITY: What do you make of Berghmans' arguments about the *telos* or goal of medicine? Can you think of any counter-arguments?

Berghmans proposes that the goal of terminal care ought to be the alleviation of suffering, even if this sometimes goes against our sense that, in general, medicine ought to be concerned with healing. You may wish to continue to reflect on his arguments as you work through the remainder of this chapter. You should also bear in mind the three views that tend to be taken on the value of human life, which Huxtable described. In the remainder of this chapter we shall be going on to explore the ethical implications of these arguments in a variety of different ways. We will start with one of the key issues arising in Anna's story: the ethical dimensions of decisions about whether (or not) to attempt resuscitation.

Section 2: Deciding not to attempt resuscitation

In the previous section, Huxtable and Berghmans demonstrated how deciding whether or not to treat a patient will give rise to important questions about the value of life and the goals of medical treatment, particularly where the patient is suffering greatly. These questions arise again in the following case, known for reasons of confidentiality as the case of 'Mr R' (*Re R* [1996] 2 FLR 99).

The case of Mr R

Mr R was born with a serious malformation of the brain and cerebral palsy. At eight months of age he developed severe epilepsy. At the age of 23 he had spastic diplegia (paralysis) and was incontinent, as well as apparently deaf and blind (with possible vestigial response to a buzzer and to light). He was unable to walk, to sit upright or to chew; so that food had to be syringed to the back of his mouth. His bowels had to be evacuated manually because his limited diet resulted in serious constipation. He suffered from thrush and had ulcers 'all the way through his guts', according to testimony. When cuddled he did indicate pleasure, and he also appeared to respond to pain by grimacing. Although he was not comatose, nor in a persistent vegetative state, his awareness on a scale of 1 to 10 was rated somewhere between 1 and 2 in an assessment by Dr Keith Andrews of the Royal Hospital for Neurodisability at Putney, London, who said:

> It is my opinion that he has very little, if any, real cognitive awareness at a level where he can interpret what is going on in his environment. He reacts at the most basic level by responding to comfort, warmth and a safe environment by being relaxed and producing the occasional smile. He responds to discomfort, pain and threatening situations by becoming distressed and crying. These are very basic level responses and do not imply any thought processes.

Until he was 17 Mr R lived at home, where he was totally dependent on his devoted parents. He then moved to a residential home, but continued to return home at weekends. Now his condition was beginning to deteriorate: his weight had dropped to just over 30 kg, and he was extremely frail, suffering from recurrent chest infections, bleeding from ulceration of the oesophagus, and continued epileptic

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fits. In 1995 he was admitted to hospital on five occasions, each time for a life-threatening crisis. After the last crisis Dr S, the consultant psychiatrist for learning difficulties who was responsible for his care, wrote:

> To hospitalize Mr R if he had another life-threatening crisis would, in my clinical judgement, be nothing more than striving officiously to keep him alive for no gain to him. In my opinion, this is tantamount to a failing against a basic duty of humanity. Indeed, at the last few admissions to hospital, I have had real concern as to whether it was ethical to treat him actively. That said, I would never withhold treatment against the wishes of his parents. In summary, taking R's best interests into account and whilst taking into account the basic premise of the sanctity of human life, it is in my judgement unquestionably in R's best interests to allow nature to take its course next time he has a life-threatening crisis and to allow him to die with some comfort and dignity. That would relieve him of physical, mental and emotional suffering.

ACTIVITY: Read through Dr S's opinion and make a list of the ethically charged terms and concepts that are being used to construct an argument. After each term, write down the consultant's apparent interpretation of it. Do you agree with this interpretation? If not, write down your own.

It strikes us that there are at least 10 ethically charged terms and concepts contained within Dr S's opinion:

(1) Best interests of the patient
(2) Gain or benefit to the patient
(3) Sanctity of life
(4) Duty of humanity
(5) Death with dignity
(6) Relief of suffering
(7) Wishes of the parents
(8) Withholding treatment
(9) Treating actively
(10) Medical futility.

This is quite a full list for one paragraph, and the exercise illustrates how tightly packed with ethical concepts an apparently clinical judgement can be.

You will be aware from your reading of the papers by Huxtable and Berghmans that there are various ways in which these terms and concepts can be interpreted. You might, for example, think that serving the best interests of the patient involves the eradication of suffering, perhaps even by ending their life; alternatively, you might think that the third point, the sanctity of life, must be central to our thinking about a case like Mr R's, such that we must always recognize the worth of his life, notwithstanding his disabilities.

For her part, Dr S was clearly concerned to avoid 'striving officiously' to keep Mr R alive; as she elsewhere put it, she felt it better 'to allow nature to take its course'. This idea is open to interpretation. Dr S appears to mean that it might be better not to attempt to resuscitate Mr R; in other words, that we should *withhold* treatment from him. A similar issue arose in the case of Anna – but for her the issue then became whether or not treatment should be *withdrawn*. Is there any difference between the two? The General Medical Council (GMC) has noted that:

> Although it may be emotionally more difficult for the health care team, and those close to the patient, to withdraw a treatment from a patient rather than to decide not to provide a treatment in the first place, this should not be used as a reason for failing to initiate a treatment which may be of some benefit to the patient. Where it has been decided that a treatment is not in the best interests of the patient, there is no ethical or legal obligation to provide it and therefore no need to make a distinction between not starting the treatment and withdrawing it.
>
> (GMC, 2002, para. 18)

The GMC is here addressing – and denying – the alleged distinction between withholding and withdrawing treatment; i.e. the GMC believes that there is no difference between the two. The distinction often invites a variety of ethical questions. Does a doctor incur additional obligations to his or her patient (or even to their family) once treatment has been started? Or is there no substantial difference between the two, particularly if their consequences are identical? And does the physical behaviour associated with withdrawing, as opposed to withholding, have any moral relevance? This latter question draws us into another contested distinction, between *acts* and *omissions*. The GMC, for its part, holds that the 'actions' of withholding and withdrawing treatment are actually both to count as 'omissions'.

The distinction between acts and omissions originated in Catholic moral theology and for its

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supporters intentionally ending life by (negative) omission can be just as wrong as doing so by (positive) action. The wording in the Anglican creed, for example, asks God to pardon believers for two separate matters: that 'we have done those things we ought not to have done' (wrongful acts), and that we have 'left undone those things we ought to have done' (wrongful omissions).

However, it is not the case that *every* omission that might shorten life would be condemned. In the sanctity of life tradition, a doctor is not obliged to give a 'disproportionate' or, some would say, 'extraordinary' treatment – but he or she *is* obliged to provide 'proportionate' (or 'ordinary') treatments. Notice, though, that it is only when treatment is disproportionate that it can be withdrawn or withheld: neither the patient nor the doctor is entitled to omit treatment for some other reason, say, because the patient wants to die or because the doctor thinks that the patient's quality of life is poor. And, the argument continues, the active, intentional ending of life can never be permitted.

Some critics of the principle of the sanctity of human life think that it is wrong to draw these various distinctions, because they simply do not stand up to scrutiny. Indeed, their objections show how some of the conflicts that exist at the level of applied healthcare ethics can rest on deeper conflicts about what it is that makes an action or an omission ethical in the first place.

According to one school of thought we should do that which it is our duty to do. This is a *deontological* position, one which is famously associated with Immanuel Kant. You might detect this sort of thinking in the sanctity of life approach, under which we are duty-bound to protect life and, by extension, to recognize that everyone has a right to life – although we should also recognize that the position also features in the autonomy approach, where a doctor may be duty-bound to respect the patient's autonomous choice, even if the patient has chosen to bring an early end to his life.

Alternatively we might think it more appropriate to do that which has the best consequences. This is a *consequentialist* stance, popularly adopted by *utilitarians*, who ask us to achieve the greatest good for the greatest number. The philosophers who advance these sorts of ideas tend to be persuaded by arguments first outlined by Jeremy Bentham and John Stuart Mill.

Utilitarians will claim that the distinction between acts and omissions makes no moral sense. For one thing, it is difficult to distinguish between them in practice. For example, is turning off a ventilator a positive act, or merely omitting to perform the treatment any longer? More radically, these philosophers argue that there is no significant moral difference between killing and letting die (Rachels, 1986). Jonathan Glover uses the following example to illustrate the objection:

> A man who will inherit a fortune when his father dies, and, with this in mind, omits to give him medicine necessary for keeping him alive, is very culpable. His culpability is such that many people would want to say that this is not a mere omission, but a positive act of withholding the medicine. Supporters of the acts and omissions doctrine who also take this view are faced with the problem of explaining where they draw the line between acts and omissions. Is consciously failing to send money to [charity] also a positive act of withholding?
>
> (Glover, 1977, p. 96)

Supporters of the distinction might first answer Glover's challenge by saying that the point at which to draw the line is the duty to care. It is because the son has a duty to care for the father that failing to give the medicine is wrong. (It might also be wrong to fail to give it to anyone who needed it, if we think we have a generalized 'Good Samaritan' duty to others.) In the context of a doctor's duty to care, both acts and omissions may indeed be wrongful: treating without consent would be a wrongful act, whilst failing to treat someone who had consented and who needed treatment might be a wrongful omission.

This may explain why doctors are sometimes reluctant to rely on the distinction between acts and omissions, why they feel a duty to treat at all costs – sometimes against the wishes of the patient or their relatives. However, some healthcare professionals, like Karen Forbes (a consultant in palliative medicine), are not so wary of the distinction that Glover attacks:

> I do not agree with those authors who argue that it is only the outcome of medical action or inaction that is morally relevant, so that to kill and to allow to die are one and the same thing . . . There seems a certain arrogance in the underlying assumption that with medical action, i.e. treatment, people will live, and without treatment people will die, and that therefore to deny medical action is to kill. It is

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> salutary to remember that usually it is the timing of the outcome, rather than the outcome itself, that is altered by medical action or inaction.
>
> (Forbes, 1998, pp. 100–101)

ACTIVITY: What do you make of the alleged distinction between acts and omissions? Do you think that it makes moral sense? Can you see a role for the distinction in working out what should be done in the case of Mr R?

Now please continue with your reading of the case.

> The immediate question now was whether to resuscitate Mr R in the event of another acute admission resulting in cardiac arrest. He was so frail that it was feared CPR (cardio-pulmonary resuscitation) might crush his ribcage. In addition, there was a risk of further brain damage from resuscitation. A subsidiary question was whether to administer antibiotics if he developed pneumonia. After Mr R's fifth hospital admission, in September 1995, the consultant, Dr S, discussed the position with Mr R's parents. They agreed that Mr R would not be subjected to CPR if he suffered a cardiac arrest in future. Accordingly, Dr S signed a DNR (do not resuscitate) direction, signed by Mr R's mother under the heading 'next of kin'.
>
> This decision was opposed by staff at the day care centre which Mr R had been attending; they felt that he did in fact have some 'quality of life'. In addition they interpreted Dr S's decision as a 'no treatment' policy, which Dr S denied: the only treatment which she was withholding, she argued, was cardio-pulmonary resuscitation. Agreement could not be reached, and a member of the day care centre staff applied for review of the decision by a court, on the basis of information provided by social workers involved in Mr R's day care.
>
> The basis of the application was that the DNR decision was irrational and unlawful in permitting medical treatment to be withheld on the basis of an assessment of the patient's quality of life. The hospital sought a court judgement that, despite Mr R's inability to give a valid refusal of treatment, it would be lawful and in his best interests to withhold cardio-pulmonary resuscitation and the administration of antibiotics. However, a proposed gastrostomy would be performed, underlining that there was no question of a comprehensive refusal to treat Mr R. Likewise, the hospital decided that it would ventilate Mr R and provide artificial nutrition and hydration if applicable, although initially it had indicated it would not. The application made it clear that the hospital intended 'to furnish such treatment and nursing care as may from time to time be appropriate to ensure that [R] suffers the least distress and retains the greatest dignity until such time as his life comes to an end.'

In the High Court hearing, where Mr R was represented by the Official Solicitor (who acts on behalf of incompetent patients), discussion centred on guidelines for resuscitation issued by the British Medical Association (BMA) in 1993 in a joint statement with the Royal College of Nursing (RCN). It has been argued that resuscitation, originally devised to be used in a small minority of cases, is sometimes overused (Hilberman *et al.*, 1997). Although the technique can be very successful in the right context, in some US states it has become the default response to cardiac arrest, that is, it is required unless it is explicitly refused or clearly 'futile'. Yet cardiac arrest is part of death. But was Mr R dying?

It is also wrong to think that CPR necessarily will work for every patient. Because it might not do so, we nowadays prefer to talk of 'DNAR' orders; in instructing 'do not *attempt* resuscitation', we make it clearer to patients, their families and even the healthcare professionals that CPR can sometimes be *tried*, but there is no guarantee that it will revive every patient (British Medical Association *et al.*, 2007).

The 1993 BMA/RCN guidelines, as used in relation to Mr R, did not actually say that resuscitation must always be attempted unless the patient is clearly in a terminal condition. Instead, they suggested three types of case in which it is appropriate to consider a DN(A)R decision:

(a) Where the patient's condition indicates that effective cardio-pulmonary resuscitation (CPR) is unlikely to be successful
(b) Where CPR is not in accord with the recorded sustained wishes of the patient who is mentally competent
(c) Where successful CPR is likely to be followed by a length and quality of life which would not be acceptable to the patient.

ACTIVITY: Which, if any, of these conditions might apply to Mr R? Note down the reasons for your answer.

Condition (a) is the most obviously 'clinical' of the three. It seems to focus solely on the medical facts of

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the matter. Certainly Mr R is gravely ill, but he has come through five acute admissions in the past year, so it is difficult to say that he is definitely unlikely to survive CPR. Condition (b) cannot be met, because Mr R is not mentally competent to record a wish. Finally, we have condition (c), focusing on unacceptable quality of life – but again, the guidance talks of this being acceptable or unacceptable *to the patient*. It is very hard to know whether Mr R gets any enjoyment out of life: he seems to respond to being cuddled, and to react to pain, but that is really all we can say. The BMA guidelines did note that 'If the patient cannot express a view, the opinion of others close to the patient may be sought regarding the patient's best interests.' But, although the situation is nowadays different in England, the 1993 guidelines do not say that opinion has anything more than advisory value as to what the patient would regard as reasonable quality of life. (We will consider the views of his family again in a moment.) The guidelines also appear to envision a different kind of situation – where a previously competent patient, who (unlike Mr R) had expressed definite views about good and bad quality of life, is no longer able to enunciate his or her wishes, but where the family will remember his or her preferences.

So, strictly speaking, it is possible to make a case for arguing that none of these conditions applies to Mr R. But that was not the opinion of the court. Prompted by guidance from Keith Andrews as an expert witness, the court agreed that conditions (b) and (c) were not applicable – ruling out the quality of life arguments both for and against. Only condition (a) was to be considered, that is, the likelihood rather than the desirability of successful CPR. Even in hospital settings only about 13% of patients receiving CPR survive to discharge, Dr Andrews testified; in a residential home such as the one Mr R lived in, the chances would be virtually nil. Accordingly, the case turned on the alleged *futility* of treatment, rather than on the quality of Mr R's life. On the basis of medical futility, the Court accepted the DNAR order, but not a global policy against other interventions by the consultant when and if a potentially life-threatening infection arose.

ACTIVITY: Do you think there are any valid counter-arguments to this view? What might be the pitfalls of using medical futility to decide whether or not to resuscitate?

The British guidelines have been updated since Mr R's case, but they continue to reflect the ethical issues that his doctors encountered. The latest guidance contains the following statement:

> In some cases, the decision not to attempt CPR is a straightforward clinical decision. If the clinical team believes that CPR will not re-start the heart and maintain breathing, it should not be offered or attempted. CPR (which can cause harm in some situations) should not be attempted if it will not be successful. However, the patient's individual circumstances and the most up-to-date guidance must be considered carefully before such a decision is made.
>
> (British Medical Association *et al.*, 2007, p. 8)

Notice that this statement avoids using the word 'futile'. Indeed, although the concept is one that features prominently in the sanctity of life principle, it is also subject to widespread distrust (e.g. Gillon, 1997). Critics of futility have made the following points:

(1) It is never possible to say that, in any particular case, a treatment will be completely futile; rather, it is a question of what levels of probability are acceptable. What if this particular patient happens to be in the 0.01% of patients who can benefit from a seemingly 'futile' intervention? Surely that means that the intervention is far from futile for *them*?
(2) If we think something is futile then we basically mean that it will not achieve its purpose. In order for us then to say that a *treatment* is futile, we need to have some idea about the very purpose of medicine – and this returns us to familiar questions about the *telos* of medicine (what about offering hope to patients and families?) and the value of life (Halliday, 1997).
(3) Given the background assumptions that must inform the decision to label something 'futile', it is wrong to conclude that this is a purely 'clinical' criterion that can be determined wholly by the doctors. In other words, the label might be used to conceal value judgements, which might themselves be *paternalistic* and unrepresentative of the values of the patient and his or her loved ones.

However, you might think that the label is sometimes appropriate and, indeed, unavoidable. Unless we want to say that treatment should always be provided to a competent patient at their request or to an incompetent patient whatever the circumstances, then someone