The value of life: who decides and how?

Questions about the value of life involve some of the most important considerations made in the fields of medicine and medical ethics, including treatment and management decisions in all areas of life and death. Placing a value on a given life is significant in antenatal care, infant care, childhood, adulthood and into old age. It is relevant to congenital birth defects and genetic conditions, as well as to mid-life accidents and senile dementia. How we make decisions regarding the value of a given life, and who ought to make these decisions, is difficult to discern (Fig. 6.1). Perhaps most importantly of all, why are we even interested in assessing the value of a life?

Consider the following case.

**Case 23**

**The value of life**

Katherine Lewis is an intelligent, unmarried, 40-year-old woman suffering from Guillain–Barré’s syndrome, a painful neurological illness that leaves its sufferers paralysed for unpredictable lengths of time. Many people recover from the syndrome more or less completely and live long, relatively healthy lives. However, Katherine has been paralysed for 3 years and, 10 months ago, it was recognized that she was unlikely to be able to move or breathe on her own again because of the extent of damage to her nerves and muscles; she now needs a ventilator to help her breathe.

You explained this to Katherine in a gentle but clear manner. Last week Katherine asked to speak with you privately. She told you that she had considered her options and decided that she no longer wanted to live. She said her life held no value for her if it meant being in constant pain and without the freedom to move or even breathe on her own. She told you that she has discussed this with her family and that they have accepted her wishes to have the ventilator removed.

The case illustrates the relevance of questioning the value of a life, if for no other reason than that some people come face-to-face with the reality of asking this question about their own lives. The key consideration in end of life challenges is how that life is valued. In the case of James Brady (see p. 91), it became clear that Brady placed little value on his life as his health began to fail. On balance, he preferred to die rather than continue to live with the quality to which his life had deteriorated. The courts made the same decision for Janet Johnstone after recommendations from her...
family and doctors (see p. 96). Similarly, Katherine Lewis, in the case above, made a long-considered decision about the value of her own life. So the issue is relevant. Nevertheless, how the value of a life is determined is so far unanswerable, although there are some useful ideas and principles to consider.

In this section we will consider first how decisions about the value of life are made and, second, who is, and ought to be, involved in these decisions. The first question will be resolved by exploring concepts of quality, quantity and sanctity of life. We will also examine the differences involved when making decisions about individual lives as distinct from making general decisions about the value of types of lives (in other words, we will distinguish decisions made at the micro and macro levels). The second aspect will explore the differences between stakeholders and decision makers, and ask who has a legitimate stake in the decisions about value of life and who ought to be permitted to make those decisions. We will ask:

- how do we place value on life?
- who are the relevant stakeholders and decision-makers?

How do we place value on life?

There are essentially three elements to consider when determining the value of life:

- quality
- quantity
- sanctity.

Quality

The first criterion that springs to mind regarding the value of life is usually the quality of the life or lives in question:

The quality of life ethic puts the emphasis on the type of life being lived, not upon the fact of life. Lives are not all of one kind; some lives are of great value to the person himself and to others while others are not. What the life means to someone is what is important. Keeping this in mind it is not inappropriate to say that some lives are of greater value than others, that the condition or meaning of life does have much to do with the justification for terminating that life.1

Those who choose to reason on this basis hope that if the quality of a life can be measured then the answer to whether that life has value to the individual can be determined easily. This raises special problems, however, because the idea of quality involves a value judgement, and value judgements are, by their essence, subject to indeterminate relative factors such as preferences and dislikes. Hence, quality of life is difficult to measure and will vary according to individual tastes, preferences and aspirations. As a result, no general rules or principles can be asserted that would simplify decisions about the value of a life based on its quality. Nevertheless, quality is still an essential criterion in making such decisions because it gives legitimacy to the possibility that rational, autonomous persons can decide for themselves that their own lives either are worth, or are no longer worth, living. To disregard this possibility would be to imply that no individuals can legitimately make such value judgements about their own lives and, if nothing else, that would be counterintuitive.2 In our case, Katherine Lewis had spent 10 months considering her decision before concluding that her life was no longer of a tolerable quality. She put a great deal of effort into the decision and she was competent when she made it. Who would be better placed to make this judgement for her than Katherine herself? And yet, a doctor faced with her request would most likely be uncertain about whether Katherine’s choice is truly in her best interest, and feel trepidation about assisting her. We need to know which
considerations can be used to protect the patient’s interests.

Write a list of three things that make your life worth living and ask someone else to do the same.

Compare your lists.
Are they identical? Why?
Are they not identical? Why not?

The quality of life criterion asserts that there is a difference between the type of life and the fact of life. This is the primary difference between it and the sanctity criterion discussed on page 115. Among quality of life considerations rest three assertions:

1. there is relative value to life
2. the value of a life is determined subjectively
3. not all lives are of equal value.

Relative value
The first assertion, that life is of relative value, could be taken in two ways. In one sense, it could mean that the value of a given life can be placed on a scale and measured against other lives. The scale could be a social scale, for example, where the contributions or potential for contribution of individuals are measured against those of fellow citizens. Critics of quality of life criteria frequently name this as a potential slippery slope where lives would be deemed worthy of saving, or even not saving, based on the relative social value of the individual concerned. So, for example, a mother of four children who is a practising doctor could be regarded of greater value to the community than an unmarried accountant. The concern is that the potential for discrimination is too high.

Because of the possibility of prejudice and injustice, supporters of the quality of life criterion reject this interpersonal construction in favour of a second, more personalized, option. According to this interpretation, the notion of relative value is relevant not between individuals but within the context of one person’s life and is measured against that person’s needs and aspirations. So Katherine would base her decision on a comparison between her life before and after her illness. The value placed on the quality of a life would be determined by the individual depending on whether he or she believes the current state to be relatively preferable to previous or future states and whether he or she can foresee controlling the circumstances that make it that way. Thus, the life of an athlete who aspires to participate in the Olympics can be changed in relative value by an accident that leaves that person a quadriplegic. The athlete might decide that the relative value of her life is diminished after the accident, because she perceives her desires and aspirations to be reduced or beyond her capacity to control. However, if she receives treatment and counselling her aspirations could change and, with the adjustment, she could learn to value her life as a quadriplegic as much or more than her previous life. This illustrates how it is possible for a person to adjust the values by which they appraise their lives. For Katherine Lewis, the decision went the opposite way and she decided that a life of incapacity and constant pain was of relatively low value to her.

It is not surprising that the most vociferous protesters against permitting people in Katherine’s position to be assisted in terminating their lives are people who themselves are disabled. Organizations run by, and that represent, persons with disabilities make two assertions in this light. First, they claim that accepting that Katherine Lewis has a right to die based on her determination that her life is of relatively little value is demeaning to all disabled people, and implies that any life with a severe disability is not worth
living. Their second assertion is that with proper help, over time Katherine would be able to transform her personal outlook and find satisfaction in her life that would increase its relative value for her.

The first assertion can be addressed by clarifying that the case of Katherine Lewis must not be taken as a general rule. Deontologists, who are interested in knowing general principles and duties that can be applied across all cases would not be very satisfied with this; they would prefer to be able to look to duties that would apply in all cases. Here, a case-based, context-sensitive approach is better suited. Contextualizing would permit freedom to act within a particular context, without the implication that the decision must hold in general. So, in this case, Katherine might decide that her life is relatively valueless. In another case, for example that of actor Christopher Reeve, the decision to seek other ways of valuing this major life change led to him perceiving his life as highly valuable, even if different in value from before the accident that made him a paraplegic. This invokes the second assertion, that Katherine could change her view over time. Although we recognize this is possible in some cases, it is not clear how it applies to Katherine. Here we have a case in which a rational and competent person has had time to consider her options and has chosen to end her life of suffering beyond what she believes she can endure. Ten months is a long time and it will have given her plenty of opportunity to consult with family and professionals about the possibilities open to her in the future. Given all this, it is reasonable to assume that Katherine has made a well-reasoned decision. It might not be a decision that everyone can agree with but if her reasoning process can be called into question then at what point can we say that a decision is sound? She meets all the criteria for competence and she is aware of the consequences of her decision. It would be very difficult to determine what arguments could truly justify interfering with her choice.

Subjective determination
The second assertion made by supporters of the quality of life as a criterion for decision-making is closely related to the first, but with an added dimension. This assertion suggests that the determination of the value of the quality of a given life is a subjective determination to be made by the person experiencing that life. The important addition here is that the decision is a personal one that, ideally, ought not to be made externally by another person but internally by the individual involved. Katherine Lewis made this decision for herself based on a comparison between two stages of her life. So did James Brady. Without this element, decisions based on quality of life criteria lack salient information and the patients concerned cannot give informed consent. Patients must be given the opportunity to decide for themselves whether they think their lives are worth living or not. To ignore or overlook patients’ judgement in this matter is to violate their autonomy and their freedom to decide for themselves on the basis of relevant information about their future, and comparative consideration of their past. As the deontological position puts it so well, to do so is to violate the imperative that we must treat persons as rational and as ends in themselves.

It is important to remember the subjectivity assertion in this context, so as to emphasize that the judgement made about the value of a life ought to be made only by the person concerned and not by others. Of course, this assumes that the person deciding is conscious and competent to make the decision at all, which is especially complicated in cases when the patient is unconscious, immature or suffering from a mental illness, such as depression, that could distort their decision-making abilities. Thus, seeking patient choice is not always a viable option. Not all patients are capable of choosing for themselves. In Janet Johnstone’s case, and in the similar case
of Tony Bland, the decision was made externally, by people involved in their care. In such situations, family or practitioners have been known to make the decision on behalf of the incompetent patient, usually because they claim to know what the patient in question would have wanted. Relatives and doctors of Janet Johnstone argued that her condition lacked the dignity and control she valued, and that her situation would not improve. Under the circumstances, the judge decided the quality of her life was so diminished that her life was no longer worth living and that Ms Johnstone herself would have reached the same conclusion.

The same sort of proxy decision making occurs when a woman, or couple, decide to terminate a pregnancy based on antenatal screening and testing. Here, parents make the decision on behalf of a fetus or a child.

Case 24
Screening/testing for Down syndrome

A 42-year-old woman presented at an antenatal clinic with her husband to discuss the results of her recent amniocentesis. In addition to Down syndrome, echocardiography of the fetus showed cardiac abnormalities, including atrioventricular septal defect. After extensive discussion between the parents and the obstetrician, the parents decided that the fetus had too many problems and that it would be unfair to the unborn child and to their other four children to continue with the pregnancy.

In such cases the parents must decide if, on balance, their child’s life is worth living given the possibility of pain and suffering or such inhibited interaction with the world that it would be of no value to the person living it. Needless to say, this is a difficult and trying dilemma for anyone to face. It also introduces a concern that underlies all prenatal screening programmes, in that these are supported by the social values implied by screening, which direct women towards termination of positive tested pregnancies. In the past, women were barred from screening and testing for similar conditions if they had previously decided that they would not terminate a pregnancy if the fetus carried the genetic condition. Hence screening was meant to be followed by testing, and positive results were meant to be followed by termination of pregnancy. The conclusion this yields, like it or not, is that our screening programmes carry with them an implication that the lives of those who are affected with certain conditions ought to be terminated because they are of comparatively less value than the lives of those who are not. This is supported in law by Wrongful Life suits in which parents of people born with screenable genetic conditions, such as spina bifida, have successfully sued doctors for the burden involved in caring for those born with such conditions. The problems associated with screening will be discussed elsewhere in Chapter 8 (p. 146–147). They are significant here because they elucidate the third assertion made by supporters of quality of life considerations in the medical context.

Equal or unequal value?
The third assertion is that, as a result of subjective and relative determinations about the quality of a life, lives can be seen to be of unequal value. At the extreme, it follows that it is possible to describe a life as valueless, especially when it is compared with the value of a life that has greater quality. In the case of the unborn fetus affected by a debilitating inherited condition, the welfare of the parents and their other children can be invested with greater value than the potential good of a potential child born with a severe disability. This allows us to make relative judgements among or between lives of individuals or groups. This is especially useful in healthcare economics, where decisions about distribution of resources rely on comparative information of the effectiveness of treatments. In this way it can be determined that resources will be made available for treatments that are more effective at improving quality of life in
particular conditions and not where the quality of life is not improved or so diminished that improvements are too small to justify.

This point will be developed more fully in the section on quality-adjusted life-years (QALYs) and rationing in Chapter 9 (p. 163). Here, it is important to point to the possibility of making comparative judgements based on assessments of the quality of life and to emphasize that such judgements can be used to inform decisions about distributing and rationalizing scarce resources. As a result, there is a concern about quality of life decisions being made for others without their participation, and about decisions imposed without their consent. Both these concerns are tempered by the second assertion of the quality of life ethic. This states that value must be personally assessed by the individual concerned, and imposed externally only in extreme circumstances where patients are unable to decide on their own behalf and their wishes can be reasonably determined. An advance directive can be highly useful in the latter case. If a balance is made between both subjective determination and comparative decisions, we can avoid classifying a life as of comparatively low value where the person possessing it does not agree.

Basing value of life decisions on quality of life has strong advantages. It:

- **Is subjective:** takes seriously personal assessments made by individuals about the quality of their own lives
- **Is flexible:** recognizes the possibility that the subjectively determined value of one’s life can change
- **Is comparative:** recognizes that the way one life is valued need not impose the identical value on a similar life condition
- **Permits rational suicide:** recognizes that one can legitimately assert the relatively low value of one’s own life.

No one denies the importance of a good quality of life, or one that is acceptable to the person who has to live it. However, some argue that it is not the sole criterion upon which to base value of life decisions. These people include considerations of quantity and sanctity in their determination.

**Quantity**

The value of the quantity of a life should not be underestimated. In the past, so much emphasis was placed on the quality of life lived that quantity was virtually forgotten. More recently, attitudes have changed and consideration is given to the possibility that a long life of diminished quality could be as highly valued as a short life of high quality. In some senses the comparison seems absurd, unless we consider cases in which patients have refused complicated or agonising treatments that they perceived would exacerbate their suffering rather than extend their lives. Other patients prefer to extend their lives at any cost or risk to them because they value their existence so much that they will sacrifice quality in favour of quantity. This indicates that quantity ought not to be mistaken for quality and that prolonging a patient’s life might be nothing more than a burdensome and painful extension of suffering for them and their loved ones. However tempting it is for doctors to provide whatever care they are capable of providing, there is a responsibility to ensure that the treatments are actually useful to the patient and not unnecessarily burdensome. This means that a cost–benefit analysis can be usefully applied to a care management plan for an individual patient. The aim is to determine the extent to which treatment will be helpful and where the healing stops and the burden begins.

Quantity might not be identical with quality but, often, increased quantity in medicine can be equal to cure or control of disease and hence does enhance quality of life. The Compression of Morbidity principle cited by Downie and Calman is useful for guiding these decisions:
Compression of morbidity principle: the objective of increasing life-span should be associated at the same time with an increasing quality of life or reduction of disability.5

So, provided quality of life is maintained or enhanced, quantity is a positive factor in healthcare.

There is a sense in which quality of life judgements are made in a wider context and not just as they pertain to particular patients. Health economists have long tried to determine the appropriateness of costly treatments on the basis of their burdensomeness and effectiveness. The most famous of these is a system known as QALYs. QALYs stand for quality-adjusted life-years, and are a means of making comparisons between health states. Equally concerned with quantity and quality, QALYs can be applied to a ‘relative health states’ scale. The problem is that these scales are themselves value-laden. Such issues will be covered in Chapter 9, where the idea of QALYs will be discussed as they relate to rationing and distribution of resources. They are introduced here because they show how a model for decision making can include the notions of quality and quantity discussed in this chapter. QALYs help decide which healthcare needs will be met by identifying which yield:

- the greatest amount of good for
- the greatest amount of time for
- the greatest number of people.

However, this utilitarian approach also involves a degree of casuistry: patients’ QALYs are assessed and decisions are made on the basis of how well a treatment worked for them. The treatment with the most acceptance can then be applied exclusively. But all patients are unique, so what works for many will not work for all individuals. This is the classic problem with inductive arguments where particulars are used to imply generals.

Sanctity

Supporters of the sanctity of life ethic dismiss considerations about quality and quantity because, they assert:

- all life is worth living under any condition because of
- the inherent value of life.

The upshot of the theory is that quality of life, although desirable, is irrelevant to assessing the value of a life because all life is inherently valuable. Many supporters of the sanctity of life criterion say this is true only of human life, but there are religious groups who claim sanctity extends to all life. Either way, the sanctity of life principle states that all human life is worthy of preservation and hence eliminates the justifiability of abortion, euthanasia and rational suicide and, at extremes, withdrawal of futile treatment:

The sanctity of life ethic holds that every human life is intrinsically good, that no life is more valuable than another, that lives not fully developed (embryonic and fetal stages) and lives with no great potential (the suffering lives of the terminally ill or the pathetic lives of the severely handicapped) are still sacred. The condition of a life does not reduce its value or justify its termination.6

So, whereas to determine the value of a life on its quality asserts that there is a relevant difference between the type of life and the fact of life, this distinction is rejected by sanctity arguments as irrelevant.

The sanctity criterion tends to be associated with religious beliefs. The Judeo-Christian rationale is usually that lives are inherently valuable because they are gifts from God and not ours to end as we wish. In a sense, our lives are on loan to us and, as such, must be treated with respect. In Islam, the suffering associated with reduced quality of life is also considered a divine endowment and therefore ought to
be borne without assistance, as the suffering is said to lead to enlightenment and divine reward.

However, religious arguments are not required to defend sanctity beliefs. It is enough simply to say that all human lives are deserving of equal respect not because of what they have to offer or have offered or potentially will offer, but because they exist. The notion of inalienable human rights attributes force to the value of human life with the assertion that it needs no justification. This is the primary merit of the sanctity of life ethic – that a life requires no justification – but justification is required for the premature termination of that life. In this sense, the principle acts as a forceful bulwark against devaluing human life. Article 3 of the United Nations Declaration of Human rights asserts simply that:

Everyone has the right to life, liberty and security of person.7

No argument is made to justify this claim because no argument is necessary. However, it will be necessary to justify any violation of this right.

The sanctity of life criterion is appealing because it appears to resolve a number of ethical quandaries. To accept it would entail rejection of so many of the problematic issues faced by practitioners and ethicists. For instance, it will mean rejecting abortion at any stage of pregnancy because of the inherent value of the life of the fetus. This seems like an easy solution to the problem of abortion, except in cases where a pregnancy might be terminated to save the life of the mother. In such cases, sanctity of life cannot inform the decision of which life should be saved. On the one hand, we might choose to save the mother’s life because she is already viable and independent and she might have responsibilities that give her life added value. On the other hand, we could save the fetus which, although only a potential life, has not had the opportunity to live that the mother has had, and so deserves a chance. The list of reasons can be given on behalf of either life, but this is no solution. In fact, all it does is present us with reasons to use quality and quantity criteria for resolving the dilemma. This is a serious practical shortcoming of the sanctity criterion. Other problems will be discussed below.

Problems faced by the quality, quantity and sanctity criteria

Quality of life problems

There are two major concerns about the quality of life criterion for assessing the value of life. The first is that it is a value-laden and judgement-relative alternative. The second problem is that it relies on subjective rather than objective decision-making, so it is difficult to know when we are getting it right.

Quantity of life problems

There is really only one problem with this position and that is that it cannot work in isolation. Length of life is not identical with a good or valuable life, so quality of life questions emerge.

Sanctity of life problems

Judgements on the basis that life is sanctified leave no room for personal judgement about the value of one’s own life, let alone the lives of others. It cannot account for the fact that some of us do feel we have reached the point of suffering beyond endurance or that our lives have so diminished in dignity that only death can restore its value. Disturbing though it is, some people will reach this point. The assumption that all life is sanctified would remove the right of the suffering individual to choose how and when it should end:
Different people, of different religious and ethical beliefs, embrace very different convictions about which way of dying confirms and which contradicts the value of their lives. Some fight against death with every weapon their doctors can devise. Others will do nothing to hasten death even if they pray it will come soon. Still others...want to end their lives when they think that living on, in the only way they can, would disfigure rather than enhance the lives they had created. Some people make the latter choice not just to escape pain. Even if it were possible to eliminate all pain for a dying patient – and frequently that is not possible – that would not end or even much alleviate the anguish some would feel at remaining alive, but intubated, helpless, and often sedated near oblivion.8

The stakeholders - who ought to decide?

Where individuals are capable of estimating the value of their own lives we encounter problems of whether they are competent enough to do so and of ensuring that depression or fear is not interfering with their evaluation. The subject is further complicated when decisions are made for people who are not competent to judge for themselves the value of their own lives. In either case the question becomes who ought to decide?

External arbiter

An external arbiter is usually believed to be objective and capable of having a clear picture of the person and the context of his or her life. However, the arbiter might not be objective, to the extent that all judgements are based on values and external arbiters will be affected by their own values in making the determination. In addition, given that this person is not the same person whose life is under consideration, he or she might not be able to truly know what is best for the patient. Generally speaking, it feels like a counterintuitive imposition to assume that any one person can make a decision about the value of another person’s life.

The main concern is that decisions about the value of another person’s life would deteriorate into general assertions about the devaluation of similar lives, as expressed by the concerns in this quote about the value of life of a disabled child:

I cannot accept [the parent’s] view that Stephen would be better off dead. If it is to be decided that ‘it is in the best interests of Stephen Dawson that his existence cease’, then it must be decided that, for him, non-existence is the better alternative. This would mean regarding the life of a handicapped child as not only less valuable than the life of a normal child, but so much less valuable that it is not worth preserving. I tremble at contemplating the consequences if the lives of disabled persons are dependent upon such judgements.9

The example of parenthood reveals that it might be impossible to escape the need for an external arbiter when individuals are not competent to decide for themselves. Neonates, severely disabled or demented persons and people in a persistent vegetative state will not be able to make this choice for themselves.10 Parents and loved ones are frequently left with the burden of deciding what to do in these tragic situations. In certain cases these decisions clash with established expectations, as they did in the following case.

Case 25
Who decides? Samuel Linares11

Five-month-old Samuel Linares aspirated a blue balloon at a birthday party on 2 August, 1988. Paramedics removed the balloon with forceps.
The problem of who decides is made poignantly clear by the seemingly somewhat exaggerated case of the Linares family, but the events described are true. It is not the first time that the best interests of the patient were not obvious, or where agreement could not easily be found.

Samuel Linares was going to be moved to a nursing home, despite his family’s protests. On 25 April 1988, the night before Samuel was to be moved the distraught father went to the hospital. Mr Linares removed his son from the ventilator, revealing a .357 Magnum when nurses attempted to intervene. Saying, ‘I’m not here to hurt anybody’, he allowed staff to remove three children from the ICU. His son died in his arms 10 minutes later. Mr Linares confirmed the death with a stethoscope that a doctor slid across the floor. The weeping father surrendered the baby and the gun. Later he said, ‘I did it because I love my son and my wife.’

The problem of who decides is made poignantly clear by the seemingly somewhat exaggerated case of the Linares family, but the events described are true. It is not the first time that the best interests of the patient were not obvious, or where agreement could not easily be found.

Consider how a deontologist and a consequentialist would have responded under similar circumstances.

Internal
Permitting individuals to determine the value of their own lives preserves autonomy and reduces the likelihood of coercion. However, it could be too subjective, especially when the person is hindered from making a rational decision by fear and illness. Nevertheless, it is the best choice because no one can decide for another person what is the best quality of life.

Perhaps the ideal is to let people make their own decisions about the way the quality of their lives affects what quantity they have left. If they perceive their own lives to be sanctified despite any diminishment in quality then that is their own decision. If they prefer to see their lives of such low quality that they seek to reduce or eliminate it altogether, then they ought to be given the assistance they require to ensure that it improves or at least meets the values and hopes they desire. Related reflections are made in Chapter 5 on end of life issues.

Conclusion
We have considered the ideas of quality, quantity and sanctity as they relate to the value of life. These were revealed to have advantages and disadvantages in their application.

Consideration was also given to who ought to determine the value of a given life. External and internal arbiters were considered with the conclusion that it is always safest to permit people to judge for themselves what value to give to their own life.

Notes and references