

Quality of Life

By John Wyatt

In the last few decades the term 'Quality of Life' (QoL) has slipped into medical decision-making, and at first sight it seems to make sense. A more careful assessment, however, shows that some of the thinking behind the term is flawed, and that the way it is sometimes used runs potentially counter to Christian philosophy.

The idea that physicians should be responsible for assessing or measuring a patient's quality of life (QoL) has obvious attractions. It seems right that doctors should not just strive to prolong life (*quantity* of life), but should ensure that the life that is prolonged meets certain criteria (*its quality*). The two ideas are then sometimes presented as if there is a conflict between them; which should doctors be concerned about, the quantity of life, or the quality of life?

Some clinicians and ethicists have suggested that assessments of QoL should be employed in clinical decision-making in many areas of medicine—from prenatal screening to do-not-resuscitate (DNR) decisions at the end of life. This file discusses the concept of QoL as currently used in healthcare and looks at it from a Christian perspective. It illustrates some of the problems as well as the positive aspects of this approach. Issues raised by the use of quality adjusted life years (QALYs) and the cost-effectiveness of health interventions will be the subject of future files.

QoL scales

Before it can be discussed, QoL must be defined. And this is where the problems start. A recent definition of QoL is, *'the combination of objectively*

*and subjectively indicated well-being in multiple domains of life considered salient in one's culture and time, while adhering to universal standards of human rights.'*¹

A new growth industry is devoted to developing and administering questionnaires and assessment tools to measure QoL in different patient groups, countries and cultures. All the scales measure a variety of dimensions in an attempt to capture many aspects of an individual's subjective experience. Some scales focus on impairment and other negative aspects of life, whereas others aim to capture more positive aspects of health and well-being.

Patients are usually asked to assess and rate their experiences. Individual readings from different dimensions are then compared with population norms, and frequently summated into a single test score. When caring for individuals before they are born, for infants, or those with severe illness who cannot assess their own conditions, the physician does it for them.

Some of the features considered in different assessments of QoL include:

- Somatic sensation / pain
- Physical function
- Cognitive function
- Psychological well-being
- Social interaction
- Economic productivity

Setting the tests up is not simple, and different questionnaires tend to produce different results. In addition, QoL measures tend to focus on pathology and impairments that are easy to detect and quantify, while paying less attention to functions and capacities that are more difficult, if not impossible, to quantify, such as personal and relational strengths.

Nonetheless these assessment tools have improved the medical care provided to some patient groups. By formally assessing a patient's subjective well-being before and after a particular surgical procedure, it is possible to obtain extremely valuable information.² For example, in terminal illness invasive surgical procedures may prolong life but substantially worsen the patient's QoL scores. In patients with chronic disabling conditions, such as rheumatoid arthritis or chronic pulmonary disease, QoL scores can help by providing quantitative feedback on the effect of various treatments, leading to more effective and individualised care.

Used well, QoL scores enable clinicians to focus more on the subjective experience of their patients than on crude survival statistics.

The concept of QoL has also been taken one step further by some health economists who have developed the idea of the Quality Adjusted Life Year

(QALY). This enables the outcomes (or technically speaking, the *cost-utility ratios*) of different treatments to be quantitatively compared. To do this the QoL is assigned a value between zero (a life that has no quality) and 1.0 (a life of ‘perfect’ quality).

If a medical intervention is successful the assumption is that the person’s QoL will increase. The QALY for a given intervention is then the QoL experienced after the intervention, multiplied by the number of years that this benefit lasts, which is often the person’s remaining lifespan.

History

Although QoL scales may be beneficial and valuable in clinical practice, their use can be misleading and potentially dangerous in the context of contemporary social and financial pressures. In traditional Hippocratic medical ethics, doctors have always been concerned to maximise the welfare and well-being of their patients. But the idea that each human life can be

‘It is the quality rather than the quantity that matters’

*Lucius Annaeus Seneca
(5 BC – 65 AD)*

assigned a ‘quality’ is a surprisingly recent innovation, and the concept did not start to enter medical practice until the 1970s.

The quote from Seneca, although referring to a shortage of books, was a comment on the importance of striving for quality in human activities. It shows that the terms ‘quality’ and ‘quantity’ have been juxtaposed from ancient times. But there is an interesting ambiguity in English, in that the word

‘quality’ has two distinct meanings. According to the new Oxford English Dictionary it can mean:

1. ‘The standard of something as measured against other things of a similar kind’ (eg This is a quality car, but that one is rubbish).

or,

2. ‘A distinctive attribute or characteristic possessed by someone or something’.

Thus chemists might talk about both the ‘quantity’ of an element such as lead and its ‘qualities’, meaning its attributes or characteristics. So in English the word ‘quality’ can be used either to have an *evaluative* meaning (meaning 1) or a *descriptive* meaning (meaning 2).

In the past, the evaluative meaning was applied almost exclusively to objects, particularly manufactured artefacts, rather than to people. In contrast when applied to people, the word was used almost always in its descriptive meaning, for example ‘... *she has obvious leadership qualities*’ (meaning 2).

But now the evaluative meaning of the word ‘quality’ is being applied to individual human life. The implication is that having quantified the unique experience of an individual we can go on to compare him or her against an agreed common standard.

Incommensurable categories

One key weakness in the concept of QoL is that it creates a single quantitative score by bundling together assessments from a series of domains that span material, physical, social, emotional, and productive well-being. Summing the various scores not only mixes very different classes of characteristics, but gives a curious notion of values. Can you, for instance, really create a useful score by combining into a single number an assessment of a person’s ability to walk more than 10

metres, with a number indicating their involvement in an emotionally close and intimate relationship?

It is particularly absurd to attempt to rank the ‘goods’, attributes or functions, of human life in some kind of hierarchy. Is physical well-being *of greater intrinsic value* or importance than emotional well-being? Is creativity more valuable than perfect sensory functioning? Is mobility more valuable than short-term memory capacity? It is clearly impossible to have any consensus within our own society on these issues, and many would argue that the questions themselves are logically incoherent and meaningless.

On top of this, many philosophers have emphasised that, within any one life, each of us has competing values, desires and goals that cannot be ranked against each other—they are incommensurable, to use a piece of philosophical jargon.³

Comparing QoL scores between different groups of patients is further complicated by the changing emphasis given to different domains through life. In adolescence, body image and peer group acceptance may dominate one’s priorities. To an elderly person, social isolation may be seen as a greater loss than physical impairment. Trying to rank life experiences of individuals from different cultures quantitatively becomes even more futile.

QoL is not a biological variable that can be measured like plasma sodium or even the Apgar score. Each person’s experience of life is unique, profoundly complex, constantly evolving, and continually modified by relational, social and spiritual factors. It is therefore logically incoherent to evaluate this experience in a single score.

Life not worth living

Another profound consequence of the use of QoL, is that it leads logically to the concept of the individual whose life has a QoL score of zero. In other words there are individuals whose lives have no net positive value or significance – they are literally lives that are not worth living. Some ethicists have gone further

and suggested that some individuals affected by disease or chronic disability have a QoL score that is negative. For them, death is preferable to continued life and terminating that life would be a beneficial act.

The concept of the ‘life that is not worth living’ can be traced in modern history to 1920 in Germany, when Alfred Hoche, a professor of medicine, and Rudolf Binding, a professor of law, published their book *Release and Destruction of Lives Not Worth Living*. They argued that the principle of ‘allowable killing’ could be applied to the incurably sick and severely disabled. The right to live, they asserted, must be earned and justified, not dogmatically assumed. Those who are not capable of human feelings – ‘those *ballast lives* and *empty human husks* that fill our psychiatric institutions - can have no sense of the value of life’.

In 1949, after the end of the Second World War, an American psychiatrist Leo Alexander, who had attended the Nuremberg War Trials, wrote a paper entitled ‘Medical Science under Dictatorship’.⁴ In it he traced the historical roots of the Nazi euthanasia movement. How was it that respected doctors could have participated in such horrendous acts?

Alexander concluded that; ‘It started with the acceptance by doctors of the idea, basic in the euthanasia movement, that there is such a thing as a life not worthy to be lived. This attitude in the beginning referred to the severely and chronically sick. Gradually the sphere of those to be included was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted... But it is important to realise that the infinitely small lever from which this entire trend of mind received its impetus was the attitude towards the incurably sick.’

Once we accept that it is possible to *evaluate* people’s life experiences then it seems we must be prepared to accept that some individuals may have a life of zero value.

It’s an idea promoted by some ethicists, philosophers and health economists. Those with a sense of history may well feel uneasy.

Misleading

The use of QoL in clinical practice can be unhelpful, and may even be misleading. For instance a paediatrician may say, ‘If this baby survives, she will develop cerebral palsy and therefore will have a low quality of life.’ A number of things could be implied by this:

Firstly, this use of the concept of QoL assumes that a biological impairment such as impaired motor function translates automatically into a loss of well-being or life-satisfaction. This does not necessarily follow at all.

Secondly, in focussing attention on the individual’s biological impairments, QoL can inadvertently divert attention from the social, political and economic policies that are centrally important to the life-experience of individuals who have disabilities.

Many disabled adults argue that dissatisfaction comes not from their functional impairment, such as the fact that they use a wheelchair, but social attitudes and political responses to their disability.⁵ The question, ‘Are you able to use your local transport system?’ could be rephrased, ‘Has the local transport system been adapted to meet your requirements?’

Thirdly, using QoL this way implies that there is something called ‘normal’. It assumes that functioning within the normal range of abilities on a series of dimensions is in every way preferable and more desirable than unusual, or impaired forms of functioning. Do we really believe that physically impaired individuals such as Ludwig van Beethoven or Stephen Hawking have lives that are of less value compared with the average member of society?

Furthermore, in a world obsessed by the pursuit of perfection, where do we set our ideas of ‘normal’? To many disabled people the use of QoL is just one more way in which the ‘normal’ majority can express their prejudices, assumptions and fears about the lives and experiences of the disabled minority.

Fourthly, any evaluation of QoL can never be objective. It will inevitably be influenced by the assumptions, prejudices and life-experiences of the observer. For example, there is empirical

evidence that health professionals and parents of adolescents who were born very premature consistently undervalue their QoL compared with the individuals themselves.

Although QoL appears to be a value-free idea, in reality it can never be separated from an underlying and highly questionable philosophical value-system. The assessment of an individual’s QoL, however undertaken, conceals value-judgements about the goals, purposes and ‘goods’ of human life. In particular it gives privileged status to a utilitarian perspective, in which the value of one individual life can be directly weighed and compared with others. A form of ‘ethical calculus’ is performed in which the positive value of one life can outweigh the negative value of another’s.

Fifthly, it is sometimes implied that clinicians can decide whether it is appropriate to provide life-sustaining treatment for a particular baby by estimating his or her future QoL. But no clinician can predict with certainty how a patient will progress. All involved need to remember that QoL assessments are based on probabilistic or statistical elements. The situation becomes even more extreme when QoL is used in neonatal care, because the physician is making predictions about the infant’s life as an adult in 20, 40 or 60 years’ time. That kind of prediction is fraught with assumptions and incalculable factors, and yet these huge uncertainties are obscured in the apparent quantitative precision of QoL measures.

Finally, unthinking use of the concept of QoL is dangerous because of its potential for abuse within the political and economic structures of our society. It is all too easy for a low QoL to perpetuate negative prejudices about the lives of disabled people. It can also be used to encourage a eugenic desire to eliminate people with biological impairments. In an economic environment where the costs of health care are soaring there is explicit or implicit pressure on health professionals to find any approach that can reduce on-going health expenditure. The danger is that QoL could be used to lessen the political and economic obligation for improving

resources for disabled people. Instead it puts on clinicians and parents a responsibility to ensure that people who are likely to be disabled are not brought into the world, or that their lives are not prolonged by medical intervention.

Christian responses

It is surely preferable for clinicians to resist any use of medicine that hints at eugenics. Clinicians are called to act with wisdom, care, transparency, and humane judgement, but we must resist the concept that medicine is a form of social engineering. If QoL is a flawed and potentially misleading concept, what alternative approaches are more consistent with a Christian perspective?

Christian thinking recognises that, as human beings, we are all special. This is not because of our function, '*What I can do*', or because of our subjective experience, '*What I feel*'. Instead, we are special because of who we are; unique beings made in God's image, reflecting his character and being. The value of human life resides in the stuff of our humanity.

The concept of QoL tends to rank human beings into a hierarchy with those with perfect QoL at the top, and those with lives not worth living at the bottom. In contrast, Christian thinking leads to a radical equality. We are all the same in the stuff of our humanity, fallen and flawed, but of unique and incommensurable value in God's eyes. Comparing the value of two human lives

is rather like comparing the value of a masterpiece by Rembrandt with that of a symphony by Beethoven. The comparison is nonsensical. Each is a unique masterpiece.

This does not negate all attempts to assess the experience of patients. Indeed we should support and encourage the development of sophisticated scales and tools to assess the subjective experience and well-being of patients. It is vital that clinicians are concerned not just about survival but about the subjective experiences of their patients. Similarly the formal assessment of physical and cognitive functioning, psychological well-being and social interactions of patients may be extremely helpful in assessing the value of particular medical interventions, and in improving the quality of medical care.

These scales should be seen as *descriptive* and not *evaluative*. In other words we are attempting to record the *qualities* or properties of an individual's life not evaluate its *quality*. Perhaps it would be more accurate to call these scales 'health status assessment' rather than 'quality of life assessment'.

We must resist the misleading suggestion that subjective well-being or functional assessment can be translated into any form of evaluation of the *worth* or *significance* of an individual human life. We may be able to judge whether a *treatment* is worth giving, but we can never judge whether a *life* is worth living. As Christians, we should support the development of techniques that compare the cost-effectiveness of different treatments in

an open and transparent way. The Christian concept of stewardship indicates that we must use health resources wisely and effectively. But we need to guard against letting QoL assessments lead to misleading, discriminatory and potentially dangerous outcomes in the context of social and political pressures. Here is an area where further work, research and debate is urgently required.

Above all, as clinicians we are called to demonstrate the compassion of Christ to each of our patients, whatever their degree of disability, however restricted their experience. We need to re-learn the attitude of care that was summed up so elegantly by the twentieth century, German philosopher Joseph Pieper; 'Love is a way of saying to another, "It's good that you exist. It's good that you are in the world"'.⁶

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John Wyatt is Professor of Neonatal Paediatrics at University College, London, and chairman of the CMF study group.