Measuring quality of life

Is there such a thing as a life not worth living?

Bobbie Farsides, Robert J Dunlop

Measuring quality of life has an important place in health care, but what about when life has no quality? Or worse? From an ethical perspective there are two areas in which these issues have been extensively explored: termination of pregnancy and end of life decision making for competent and non-competent adults. One way in which quality of life is sometimes introduced to decision making is through the concept of "a life not worth living." The seemingly logical conclusion is that lives not worth living may not be worth creating or saving. This final paper in the series debates the problems—both the practical difficulties of measurement and ethical issues—associated with measuring quality of life in situations in which lives have been judged to have no quality.

The beginning and the end

If a pregnancy is terminated because the fetus has an abnormality we will never know for sure whether the life in question would have been worth living. However, we allow lives to be terminated if they are predicted to be of low (or maybe only slightly diminished) quality. We base these decisions not only, or maybe even not primarily, on the judgment of quality but rather on the morally tenuous status of a biological life (that is, the cluster of cells in the developing embryo) as opposed to a potentially lived life (that is, the view that the cluster of cells represents a human being with a right to life) and the attendant idea that a fetus's interests can be trumped by those of others. We may also rely on ideas of replaceability (the possibility of creating another biological life) that are unavailable to us once a person has been born.

A similar problem arises in assessing non-competent adults; the problem of accessing the patient's judgment and wishes is not as limiting, and when we feel that we understand the patient's wishes we are allowed to rely on this information to decide not to treat the patient. However, the fact that someone is living their life means that we are not entitled to end it in the interests of others. Their moral status remains undiminished by the deterioration in the quality of their life, and even a confident assumption that they would not want to carry on living is not taken to justify the direct and intentional termination of their life. In a sense we commit them to living their biological life in respect for the life they may never regain, but we acknowledge that the quality of the life that they are living may make it unworthy of prolonging or saving.

When treating competent adults we can ascertain whether they believe their life to be worth living, but patients cannot use the claim of competence to demand that we should end their life. Once again the interests of the person are trumped, this time by societal concerns about deliberate killing or by an individual's moral reluctance to end a life. We are not permitted to end a person's life in the interests of others, but we are permitted to deny patients the means to the death they might prefer given their evaluation of the quality of their life.

Summary points

There are no quality of life measures that reliably identify patients who feel that life is not worth living

Basing management decisions on such measures requires extreme caution because of the fluctuating nature of patients' valuations of life and their desire for death

Patients who are dying may find some quality in life, even when their quality of life as assessed by current measures is abysmal

The use of proxies to determine whether a life is worth living is problematic because of the possible disparity between an observer's assessment and the patient's own valuation

Both patients and their proxies have identified health states that they consider to be worse than death

This is the last in a series of five articles

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Who can say that a life is not worth living?

The moral concept of "a life not worth living" raises important issues for measuring quality of life. There are formidable problems in using any quality of life instruments in competent, terminally ill adults: many of the people who are most likely to feel that their own life is not worth living are too ill to complete an assessment. Furthermore, few instruments specifically address this issue.

The effect of depression

Depression scales often assess suicidal ideation—for example, the Beck depression inventory includes the specific items "I feel I would be better off dead," "I feel my family would be better off if I were dead," and "I would kill myself if I could."[1] This emphasises the key part that depression plays in triggering a sense of worthlessness. The implication is that appropriate treatment will reverse this feeling, although some argue that the beneficial effect of antidepressant treatments on quality of life has yet to be quantified.[2]

Although depression, which is a common feature of terminal illness, may cause a person to feel that life is not worth while, it cannot be assumed that patients' requests for death are a proxy for a life not worth living. Chochinov et al found that fleeting or occasional thoughts of a desire for death were common in their study of people who were terminally ill, but few patients expressed a genuine desire for death.[3] They subsequently found that the will to live fluctuates substantially in dying patients, particularly in relation to depression, anxiety, shortness of breath, and their sense of wellbeing.[4] If the will to live is inversely related to a sense that life is not worth living, it could be expected that this sense would also fluctuate over time. Although such a relation is speculative, there is enough doubt to conclude that any study of a life not worth living must take this into account.

Euthanasia and assisted suicide

Evidence suggests that some patients who think that life is not worth living are not depressed, and it is important to acknowledge such a possibility. Ganzini et al found that patients with motor neurone disease who were willing to consider assisted suicide had higher scores on scales measuring hopelessness and lower scores on quality of life.[5] Significantly, hopelessness and depression were not synonymous in these patients. However, only one patient expressed a wish for assistance with suicide within the next month. It is as if the remaining patients were saying that they could foresee a time when life may not be worth living. Clinical experience would suggest that even the one patient's request should be interpreted with caution. Sometimes patients use a request for euthanasia as a cry for help, implying that life is not worth living now but if they could manage symptom x, problem y, or fear of z, then life would still be worth living. However, a patient's evaluation might remain unchanged, even in the face of better care that results in the alleviation of painful or traumatic symptoms.

Some patients do persist in requesting euthanasia and decide to follow through with assisted suicide. Prospective studies of quality of life have not been carried out on these patients. Chin et al found retrospective evidence from physicians which suggested that patients who actually follow through with assisted suicide were more likely to be concerned about a loss of autonomy and a loss of control of bodily functions.[6] The assumption that depression was not a contributory factor for these patients cannot be sustained from this study,[7] but the message is none the less important. In a recent study conducted in the Netherlands, physicians reported that "avoiding loss of dignity" and "unbearable or hopeless suffering" were the two most common reasons given by patients for requesting euthanasia.[8]


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Who can decide that a life is not worth living?

- A fetus cannot decide that its life is not worth living nor can a proxy. Therefore terminating a pregnancy because of fetal abnormality must be justified in other terms
- A non-competent adult is similarly unable to evaluate whether life is worth living, and proxies confront many problems in using the measures available to them. In the absence of additional evidence, such as an advance directive, decisions about whether to withhold or withdraw treatment cannot rely solely on the proxy's view that "the patient would not consider their life worth living"
- Competent adults may claim that their life is not worth living and that they wish their life to end. Such claims must be investigated sympathetically. If the claims persist despite optimum care and in the absence of depression healthcare professionals must find ways to compensate such patients for the fact that society has denied them the means to exercise their autonomy. How patients could or should be compensated has not been determined

Limitations of current measures

The use of proxies

No objective way of clearly distinguishing patients who feel that life is not worth living has been identified. Patients may find quality in life when death is imminent and when their quality of life as assessed by current measures is abysmal.[9] This calls into question any notion that observers can reliably judge if and when non-competent adults might consider life not to be worth living. Proxy measures of quality of life, completed by relatives or healthcare professionals, for example, frequently underestimate patients' quality of life.[10] Emanuel and Emanuel also found that family members and proxies often do not have an accurate idea of what a patient's values or preferences might be, casting doubt on their ability to make decisions for non-competent patients.[11] The use of proxies to measure quality of life was discussed in detail in the fourth paper in this series.[12]

Boyle et al have explored the impact on the child, parents, and society of living an "abnormal" life in the context of termination of pregnancy.[13] In doing so they did not assess the effects of fetal abnormalities, however, they evaluated the medium term impact of very low birth weight in a cohort of survivors from a regional neonatal intensive care programme. The study used the health utilities index, a variant of the quality adjusted life years (QALY) method. Quality adjusted life years attempt to aggregate data on both quality and duration of life into a single outcome measure that can then be used to describe the benefit of a particular healthcare programme or technology.[14] The benefit measure is then divided by the cost of the programme, resulting in a ratio that can be used to allocate resources.[15]

Health states worse than death

Boyle et al created a classification of health states using quality of life domains: physical function, role function, social and emotional function, and health problems.[13] Each domain was subdivided into different levels, giving rise to 960 possible combinations. Each combination represented a distinct possible health state. A random sample of parents then created a ranking of these health states by comparing the desirability or undesirability of each state with other states and with the reference states “healthy” and “dead.” By assigning 1 to healthy and 0 to the state of being dead with a continuum in between, each health state could theoretically be assigned a value between 0 and 1. In practice, the investigators found that parents ranked some chronic dysfunctional states in children as worse than death.

In response to concerns about healthy proxies judging the quality of life of patients, Rosser and Kind involved psychiatric patients and medical patients as well as healthy volunteers and healthcare professionals in ranking health states.[16] They found that patients also ranked some health states as worse than death, notably the states of being confined to bed in severe distress and being unconscious and in no distress. However, the use of death as an anchor point can make some participants reluctant to answer and thereby produce arbitrary results.[15] The European quality of life questionnaire (EuroQol) avoids this problem by using the “worst imaginable health state” as the negative anchor point.[17] It is not clear how this concept relates to a life not worth living.

Quality adjusted life years

Quality adjusted life years are the best known but not the only approach that can be taken to analysing economic data on quality of life and survival.[14] The use of different methods can produce distinct and profound interpretations of a life not worth living—namely, that particular lives may have a negative economic worth. Moral as well as technical concerns inevitably surround this area of study,[14 15 18] not least because the methods used to assess quality of life do not reflect the use to which the information will be put—for example, making decisions whether to continue treatment on economic grounds.[15] However, it is clear that these methods will have an increasing role in the assessment of health technology and the allocation of resources.

Implications for the future

Ultimately the concept of a life not worth living is not very useful, as the cases of both competent and non-competent adults and the termination of pregnancy illustrate. In a termination this is because it is unclear how the claim could be established. Additionally, this concept is unnecessary in these circumstances given society’s view of the healthy fetus as having limited moral status.

In competent and non-competent adults the moral status of people who are still alive rules out the possibility of trumping their interest in being alive so we could not kill them in the interest of others; however, our wish to endorse the importance of the moral prohibition against killing them means that we will trump their own interests when they claim that they want to die. Thus the idea that a life is not worth living has little power other than to support a decision not to treat a patient and so will prevent a life from being prolonged or saved. Although the moral, social, and political reasons for wanting to maintain a prohibition on ending someone’s life are powerful, it is important to acknowledge that these deny individuals the right to make the full range of choices that logically follow from a decision that life is not worth living.

Future research and education

Research into quality of life should focus on

- Developing measures that permit people to make evaluations of conditions that are considered “worse than death”
- Educating healthcare professionals to enable them to care for patients who make such evaluations despite not being depressed and receiving optimum care
- Evaluating the reliability of proxy decision making for both fetuses and non-competent adults
- Involving patients who persistently claim that life is not worth living in research to understand the cost to them of not being assisted to die

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1 Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. *Arch Gen Psychiatry* 1961;4:561-71.
2 Orley J, Saxena S, Herrman H. Quality of life and mental illness: reflections from the perspective of the WHOQOL. *Br J Psychiatry* 1998;172:291-3.
3 Chochinov HM, Wilson KG, Enns M, Mowchun N, Lander S, Levitt M, et al. Desire for death in the terminally ill. *Am J Psychiatry* 1995;152:1185-91.
4 Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D. Will to live in the terminally ill. *Lancet* 1999;354:816-9.
5 Ganzini L, Johnston WS, McFarland BH, Tolle SW, Lee MA. Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *N Engl J Med* 1998;339:967-73.
6 Chin AE, Hedberg K, Higginson GK, Fleming DW. Legalized physician-assisted suicide in Oregon—the first year’s experience. *N Engl J Med* 1999;340:577-83.
7 Enck RE. Recent issues in physician-assisted suicide. *Am J Hosp Palliat Care* 1999;16:500-1.
8 Haverkate I, Onwuteaka-Philipsen BD, van der Heide A, Kostense PJ, van der Wal G, van der Maas PJ. Refused and granted requests for euthanasia and assisted suicide in the Netherlands: interview study with structured questionnaire. *BMJ* 2000;321:865-6.
9 Mount BM, Scott JS. Whither hospice evaluation. *J Chronic Dis* 1983;36:731-6.
10 Sprangers MAG, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: a review. *J Clin Epidemiol* 1992;45:743-60.
11 Emanuel EJ, Emanuel LL. Proxy decision-making for incompetent patients: an ethical and empirical analysis. *JAMA* 1992;267:2067-71.
12 Addington-Hall J, Kalra L. Who should measure quality of life? *BMJ* 2001;322:1417-20.
13 Boyle MH, Torrance GW, Sinclair JC, Horwood SP. Economic evaluation of neonatal intensive care of very-low-birth-weight infants. *N Engl J Med* 1983;308:1330-7.
14 Billingham LJ, Abrams KR, Jones DR. Methods of analysis of quality-of-life and survival data in health technology assessment. *Health Technol Assess* 1999;3:55-63.
15 Spiegelhalter DJ, Gore SM, Fitzpatrick R, Fletcher AE, Jones DR, Cox DR. Quality of life measures in health care. III: resource allocation. *BMJ* 1992;305:1205-9.
16 Rosser R, Kind P. A scale of valuations of states of illness: is there a social consensus? *Int J Epidemiol* 1978;7:347-58.
17 Van Agt HME, Essink-Bot ML, Krabbe PFM, Bonsel GJ. Test-retest reliability of health state valuations collected with the EuroQol questionnaire. *Soc Sci Med* 1994;39:1537-44.
18 Kaplan RM. Profile versus utility based measures of outcome for clinical trials. In: Staquet MJ, Hays RD, Fayers PM, eds. *Quality of life assessment in clinical trials: methods and practice.* Oxford: Oxford University Press, 1998:69-92.

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