

Euthanasia and Quality of Life

Critique of a Subjective Standard

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Abstract. Euthanasia advocates argue that end-of-life decisions should be based on patients' autonomous evaluations of their own quality of life. The question is whether a patient's quality of life has deteriorated so far as to make death a benefit. Criteria for evaluating quality of life are, however, unavoidably arbitrary and unjust. The concept is difficult to define, and human autonomy has limits. This essay discusses the moral issues raised by quality-of-life judgments at the end of life: who makes them, what criteria they use, and what clinical actions the conclusions justify. It then looks at ways in which quality of life can be considered legitimately, in relation not to euthanasia, which is always illicit, but to specific proposed treatments. If a patient decides to forgo treatment, the decision should be based on the judgment that the treatment, its side effects, or its long-term consequences would be excessively burdensome or useless. *National Catholic Bioethics Quarterly* 17.3 (Autumn 2017): 417–424.

Is there such a thing as a life not worth living, a life that lacks dignity because of illness, handicap, or despair? The *Declaration on Euthanasia*, promulgated by the Congregation for the Doctrine of the Faith, defines *euthanasia* as “an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated.”¹ Euthanasia can be active, as when someone intentionally chooses to kill a person by an act of commission, or it can be passive, as when someone brings about the death of a person by an act of omission. Each form can

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1. Congregation for the Doctrine of Faith, *Declaration on Euthanasia* (May 5, 1980), II.

be either voluntary (performed on persons who give free and informed consent to the act), nonvoluntary (performed on persons who are incapable of giving free and informed consent), or involuntary (performed on persons who refuse to give free and informed consent). In all forms of euthanasia, the killing occurs because the victim's life is judged to be either useless or excessively burdensome—he or she is considered better off dead than alive.

The major arguments used to justify voluntary euthanasia focus on respect for a person's bodily integrity and autonomy, or right to self-determination. Carrying out a "merciful death" is considered an act of beneficence, or kindness. Consequently, it is considered incumbent on others, including health care professionals, to give people this option, while its prohibition is considered cruel, as it prolongs suffering and infringes personal liberty.²

But how can we determine when it is appropriate for someone to consider euthanasia? And how are we to reconcile conflicts between individual autonomy and the duty of beneficence? Although issues involving euthanasia usually concern patients who are terminally ill, advocates of both voluntary and nonvoluntary forms of euthanasia are increasingly using a more complex and existential quality-of-life standard with patients who have nonlethal disorders or disabilities, to judge whether to allow their lives to end or actively end them.³

Defenders of euthanasia state that if its complexities were reduced to the opposing arguments of "'intrinsic value of life' versus 'quality of life,' the latter should prevail."⁴ In voluntary euthanasia, an individual typically perceives his or her quality of life as being so poor that continued living is burdensome and no longer beneficial. In nonvoluntary euthanasia, an observer or surrogate judges an incompetent person's life to be of no value to him or her; thus, killing the person is a benefit and not a harm.

The concept of "quality of life" is, however, difficult to define. It implies a value judgment in which the worthiness of living—altogether or in part—is deemed to be good or bad, better or worse. The criteria for assessing it are also difficult to establish, and advocates of euthanasia have been unable to agree on what they should be.

Can the Quality of a Life Be Objectively Defined?

Some, who focus on the ethic of personal autonomy, consider quality of life a state that expresses that degree of satisfaction that a person takes in life as a whole, and experiences in its particular aspects, such as physical or mental health or social situation.⁵ The American Medical Association suggests that quality of life should be

2. Christian Barnard, "The Need for Euthanasia," in *Voluntary Euthanasia: Experts Debate the Right to Die*, 2nd ed., ed. A. B. Downing and Barbara Smoker (London: Peter Owen, 1987), 173–177.

3. Paula McCormack, "Quality of Life and the Right to Die: An Ethical Dilemma," *Journal of Advances in Nursing* 28.1 (July 1998): 63–69, doi: 10.1046/j.1365-2648.1998.00762.x.

4. Benjamin Brady, "Euthanasia, a Quality of Life Choice," *BENHEIS* (blog), accessed September 5, 2017, <https://benheis.wordpress.com/>.

5. Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 6th ed. (Oxford: Oxford University Press, 2009), 336–343.

defined by the patient's interests and values and should be considered "in determining what is best for the individual."⁶

Basing clinical decisions—end-of-life decisions in particular—solely on a person's subjective judgment of worth is prone to error. As a consequence, considerable efforts have been made to provide an objective or empirical basis for quality-of-life value judgments.

Quality-of-Life Measures

Over the last several decades, quality-of-life measures have been increasingly applied in clinical medicine to evaluate responses to interventions. A variety of instruments have been designed to measure the multidimensional attributes of quality of life in relation to general health or specific diseases, like inflammatory bowel disease or scleroderma. These attributes typically include a variety of physical and mental functions, such as mobility, the ability to perform the activities of daily living, physical symptoms, social interaction, mental acuity, and overall satisfaction and general well-being.⁷ Scales are then devised to rate the quality of life either in relation to certain aspects of what is measured or its entirety (for example, composite score), and the scales are validated in certain populations. These scales are meant to provide an objective assessment of what would otherwise be a highly subjective and personal evaluation.

These measures of quality of life have been developed primarily to evaluate responses to therapeutic interventions in research settings, usually clinical trials. In clinical (non-research) settings, however, it is far more common to base treatment decisions on quality-of-life judgments that are not derived from rigorously developed and validated instruments, such as a patient's personal satisfaction, social function, symptoms, prognosis, and values. Far more problematic is the extrapolation of these quality-of-life judgments to end-of-life decisions.⁸

Distinctions at the End of Life

In an increasingly patient-centered health care system, more patients demand autonomy when deciding their fate. While the euthanasia debate generally revolves around patients who are terminally ill or suffering from intractable pain, in recent years there have been calls to liberalize the indications to include less-incapacitating

6. American Medical Association, "The AMA Code of Medical Ethics' Opinions on End-of-Life Decision Making," *AMA Journal of Ethics* 16.5 (May 2014): 325–415. See also AMA, *Code of Medical Ethics*, opinion 2.17, "Quality of Life," updated 2001. Opinion 2.17 was withdrawn from the 2016 code.

7. Ingela Wiklund, "Measuring Quality of Life in Medicine," *Scandinavian Journal of Primary Health Care Suppl* 1 (1990): 11–14; and Gordon H. Guyatt, David H. Feeny and Donald L. Patrick, "Measuring Health-Related Quality of Life," *Annals of Internal Medicine* 118.8 (April 15, 1993): 622–629, doi: 10.7326/0003-4819-118-8-199304150-00009.

8. Submission to the Court of Appeal by the Archbishop of Westminster, Cormac Murphy-O'Connor, regarding *Central Manchester Healthcare Trust vs. Mr. and Mrs. A*, reprinted as "The Conjoined Twins I," in *Catholic Medical Quarterly* 50.4 (November 2000), http://www.cmq.org.uk/CMQ/2000/conjoined_twinsI.htm.

disorders, including psychiatric disorders and even nonlethal disabilities in both adults and children. Some people have suggested that end-of-life decisions should be based solely on the ethic of personal autonomy as determined by the patient's evaluation.

Human autonomy and freedom of choice are not unlimited, however. Autonomy cannot justify choices that are inconsistent with the basic worth and dignity of every human being. Legitimate autonomy must be guided by the truth in a way that is conducive to human fulfillment and rooted in God's eternal natural law.⁹ The intentional killing of oneself or others, regardless of the reason, sets us against the intrinsic value of human life over which God has made us stewards.¹⁰ In this light, we can see that it is disingenuous to claim that opponents of euthanasia lack beneficence, dignity, and compassion. True compassion recognizes the intrinsic value of life and is willing to suffer with those who are in pain. Indeed, as stated in *Evangelium vitae*, euthanasia must be called a false mercy, even a perversion of mercy, because true compassion leads to sharing another's pain. True compassion does not kill the person whose suffering we cannot bear.¹¹

Three Areas of Moral Concern

The use of quality of life in making life-and-death clinical decisions draws our attention to three principal areas of moral concern. The first involves the person making the judgment, either the patient or a surrogate. Because quality of life means different things to different people, its use in end-of-life decision making is fraught with potential problems and confusion. These are particularly significant in cases where a surrogate makes decisions for an incapacitated or incompetent patient. Burdens that appear unbearable to an observer might be satisfactory to a person living with them. Extreme caution should be used when applying one's own values to quality-of-life judgments, and whenever possible, surrogates should not presume to judge without seeking the patient's personal evaluation.¹² Biases affecting the decision maker may also prejudice these judgments. In particular, the surrogate's assessment may be affected by prejudice relating to lifestyle, disability, race and ethnicity, social status, sexual preference, gender, and age.

The second area of concern is the criteria used in the evaluation. As Glenys Williams notes, philosopher John Keown has referred to quality of life as an assessment "of the worthwhileness of a person's life. . . . If it falls below a certain threshold, it becomes a life not worth living."¹³ There is no consensus about what qualities give

9. John Paul II, *Veritatis splendor* (August 6, 1993), nn. 38–45.

10. Linacre Centre "Euthanasia and Clinical Practice: Trends, Principles, and Alternatives," in *Euthanasia, Clinical Practice and the Law*, ed. Luke Gormally (London: Linacre Centre for Health Care Ethics, 1994), 53–54.

11. John Paul II, *Evangelium vitae* (March 25, 1995), n. 85.

12. See *ibid.*, n. 66.

13. Glenys Williams, *Intention and Causation in Medical Non-Killing: The Impact of Criminal Law* (New York: Routledge-Cavendish, 2007), 75, citing John Keown, "Restoring Moral and Intellectual Shape to the Law after *Bland*," *Law Quarterly Review* 113 (July 1997): 487.

meaning to life. The qualities that allegedly make life worthwhile—for example, intelligence, physical ability, appearance, ability to respond to stimuli, and awareness of others—have differences in degree such that any cut-off value for “meaningfulness” becomes arbitrary; different people assign different weights to the degrees within chosen criteria. It follows that making end-of-life decisions on the basis of such criteria is ultimately unjust.

This ill-conceived idea that the worthwhileness of life can be defined by specific criteria suggests a dualistic approach to human existence: when an individual’s life becomes burdensome or useless, he or she is free to end it. In a sense, this approach implies that since an individual belongs to himself, he can set conditions for his consent to go on living.¹⁴ This ignores the fact that our bodily lives are more than simply useful goods for ourselves; they are integral to our status as human beings. When seen in this light, an attack on one’s life is also an attack on one’s being.

The third area of concern involves the type of clinical decision that is justified using quality-of-life judgments. The consequences of these decisions can be far-reaching and may entail death, as when questions arise about forgoing or withdrawing life-sustaining treatments. As a person is affected by various events in life, many short-lived, the quality of his life also changes. But these changes are often transient, and point to the need for additional caution in using quality-of-life judgments to make major health decisions. Disappointment about a turn in health, loss of hope about a particular treatment, or discouragement about circumstances over which one has limited control, such as family disputes, can all affect judgment. As we can see, human autonomy, given its subjective and changing nature, is not in itself unlimited and is incapable of fully guiding our choices.

Confusion between Quality of Life, Social Worth, and Best Interests

Quality of life can be confused with the value of a person’s contribution to society, or social worth. Such confusion generally assigns greater value to persons who exhibit certain socioeconomic characteristics, such as productivity, prominence, and creativity, than to those who lack these characteristics. These sorts of judgments have no place in clinical decision making; however, the confusion seems to be creeping more and more often into discussions about treatments that are scarce (transplantation) or expensive (cancer therapy). A person’s social status or productivity does not affect his or her quality of life, and social worth should not be a factor when considering whether to provide, decline, or withdraw medical care.

It is difficult to apply the concept of best interests, which is commonly invoked in child-custody cases, to clinical medicine. It is most commonly encountered when surrogates must make decisions about seriously ill persons with a poor prognosis. Best interests can be understood as the set of elements that make up quality of life; however, each element must be considered on an individual basis and, as much as possible, from the viewpoint of the person for whom the judgment is being made

14. Gormally, *Euthanasia, Clinical Practice and the Law*, 42.

and with respect to the particular clinical condition present. Instances when these viewpoints conflict require close ethical evaluation.

The *Declaration on Euthanasia* equates suicide to murder, because “such an action on the part of the person is to be considered as a rejection of God’s sovereignty and loving plan.”¹⁵ Euthanasia is a violation of the divine law, an offense against the dignity of the human person, a crime against life, and an attack on humanity. On this line of reasoning, it is always gravely immoral to allow persons to be killed on the basis of someone’s judgment that the quality of their lives is so poor that they would be better off dead. Frequently, this position is inaccurately characterized as implying that human life should be protected at all costs because it is sacred and has intrinsic value.¹⁶ In fact, Catholic tradition does not suggest that a person’s life must be prolonged at all costs, but it does reject any decision to deny medical care simply on the basis of a perceived poor quality of life.

Catholic teaching allows decision makers to evaluate quality of life as it relates to the means used to prolong life. Refusing treatment is not equivalent to committing suicide or performing passive euthanasia, although they are sometimes conflated by euthanasia advocates. Instead, it is an “acceptance of the human condition, or a wish to avoid the application of a medical procedure disproportionate to the results that can be expected.”¹⁷ Therefore, it is legitimate to consider quality of life in relation to specific treatments so long as these focus on the burdensomeness and usefulness of the treatments rather than the value of a person’s life.

Differentiating Person and Treatment

When a patient is considering forgoing treatment, specific criteria are available to assist in the determination of whether withholding or withdrawing treatment is morally licit. Importantly, the person’s intent must be non-suicidal, as this differentiates a potentially licit action from passive euthanasia.

In an address to anesthesiologists, Pope Pius XII described an approach for determining whether it can be morally appropriate to withhold or withdraw treatment on the basis of the distinction between ordinary (obligatory) and extraordinary (not obligatory) treatment, although he did not specify criteria for distinguishing them.¹⁸ The terms *ordinary* and *extraordinary*, however, are imprecise, leading to ambiguity. As a result, the terms *proportionate* and *disproportionate* are preferred for describing treatments that are or are not morally obligatory, respectively. The *Declaration on Euthanasia* states that it is possible to differentiate between the two on the basis of the treatment, its complexity and short- or long-term side effects, and its costs, and then comparing these aspects with the result that can be expected, “taking into account the state of the person involved and their physical and moral resources.”¹⁹

15. CDF, *Declaration on Euthanasia*, I.3.

16. Benjamin Brady, “Euthanasia, a Quality of Life Choice.”

17. CDF, *Declaration on Euthanasia*, IV.

18. Pius XII, “The Prolongation of Life” (November 24, 1957), reprinted in *National Catholic Bioethics Quarterly* 9.2 (Summer 2009): 327–332.

19. CDF, *Declaration on Euthanasia*, IV.

This last remark is important, as it makes clear that although it is always immoral to kill a person “mercifully” because of his or her perceived poor quality of life, it is legitimate to consider the quality of someone’s life in relation to the usefulness or burdensomeness of specific treatments.²⁰

Criteria for Distinguishing Proportionate and Disproportionate Treatments

In a commentary on *Bouvia v. Superior Court*, Brian Liang and Laura Lin argue that quality of life should be the overriding concern for health care providers, because it is an “expression of patient advocacy and respect for patient autonomy.”²¹ Elizabeth Bouvia, a young quadriplegic woman with cerebral palsy and a history of suicide attempts by self-starvation, requested that medical personnel remove her nasogastric feeding tube during a hospitalization for a life-threatening but readily treatable condition. Importantly, Liang and Lin ignore any differentiation between suicidal and non-suicidal intent, between the treatment and the patient, and between the proportionality and disproportionality of the patient’s proposal.

Germain Grisez and Joseph Boyle have helped clarify legitimate criteria for distinguishing proportionality and disproportionality when considering reasons for withdrawing or withholding treatment. In the following situations, for example, the burdens imposed by a treatment may exceed the benefits likely to result from its use:

- The treatment is experimental or risky.
- The treatment is painful or brings about other undesirable effects or conditions.
- The treatment would interfere with desired activities and experiences during the patient’s remaining life.
- The treatment is morally objectionable to the patient.
- The treatment is psychologically repugnant to the patient.
- The treatment imposes severe demands on others.²²

Excessive expense may also be considered when determining whether a treatment is unduly burdensome.²³ Additional criteria have been suggested by others:

- The burdens of treatment are more than the patient can cope with.
- The burdens of treatment exceed any promised benefit.
- The dying patient has reason to think that he or she no longer has an obligation to prolong life.
- The treatment is obviously futile and therefore inappropriate.²⁴

20. Grisez and Boyle, *Life and Death with Liberty and Justice*, 260–269.

21. Brian A. Liang and Laura Lin, “*Bouvia v. Superior Court*: Quality of Life Matters,” *AMA Virtual Mentor* 7.2 (February 2005), doi: 10.1001/virtualmentor.2005.7.2.hlwa1-0502.

22. Grisez and Boyle, *Life and Death with Liberty and Justice*, 268–269.

23. William May, *Catholic Bioethics and the Gift of Human Life*, 3rd ed. (Huntington, IN: Our Sunday Visitor, 2013), 273.

24. Gormally, *Euthanasia, Clinical Practice and the Law*, 66.

It is worth emphasizing that these considerations draw attention to the two principal criteria for determining whether a treatment can be withheld or withdrawn, namely, the burdens it imposes on the patient and its utility as a means of preserving life. Again, judging a specific treatment, not the patient's life, as excessively burdensome does not constitute euthanasia.²⁵

The Licit Consideration of Quality of Life

It is wrong to use a quality-of-life standard to justify euthanasia, because euthanasia is an act of injustice against the patient. Human life is intrinsically valuable, and it is always wrong to take innocent human life intentionally. The judgment that a person's life no longer has value is incompatible with the justice due to human persons, who, regardless of their state of health, have value and dignity. Furthermore, judgments about whether someone's quality of life is so bad that death is a benefit differ from person to person and are necessarily arbitrary and unjust. Nevertheless, the condition of a person's life can be used when assessing whether a particular medical treatment is proportionate or disproportionate. Therefore, decisions made on the basis of quality of life should focus on the burdens and utility of specific treatments rather than the perceived value of a person's life.

25. Arthur J. Dyck, "An Alternative to the Ethic of Euthanasia," in *To Live and Let Die: When, Why and How?*, ed. R. H. Williams (New York: Springer, 1973), 110–111.