The Question of Duty in Refusing Life-Sustaining Care

E. Christian Brugger

Abstract. Critics sometimes claim that Catholic moral principles unreasonably oblige patients to adopt life-preserving medical treatments "at all costs," even when the treatments are excessively burdensome or futile and when their adoption may badly disadvantage patients' family members or caregivers. The author argues that this is a mischaracterization. Because of obligations arising from our relationships, not only is it sometimes licit to refuse life-sustaining medical care, but we sometimes have a duty to refuse it. This is the case when the treatments are morally extraordinary and when adopting them would unfairly disadvantage someone for whom we have responsibility. The author argues that this conclusion is not inconsistent with the duty we have to properly care for our own lives or with moral principles prohibiting self-killing. National Catholic Bioethics Quarterly 12.4 (Winter 2012): 621–630.

Do we ever have a *duty* to refuse life-sustaining medical treatments? The question is important because traditional norms governing end-of-life decision making are sometimes characterized as unreasonably "preservationist"—tending to preserve life at all costs. Critics of those norms put them forward in an overly simplified way, attack the overly simplified version as obviously false, and then advance their own extreme accounts as reasonable alternatives. For example, an influential essay published in 1997 in the prestigious bioethics journal the *Hastings Center Report* asked in its title, "Is There a Duty to Die?" ¹ The author, University of Tennessee

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¹ John Hardwig, "Is There a Duty to Die?," *Hastings Center Report* 27.2 (March–April 1997): 34–42. The essay is skillfully written, as it sets forth what the author believes would be required of *him* at the end of life. So it reads like a personal resolution on death and dying

philosopher John Hardwig, argues that opponents of euthanasia (or at least of his account of it) impose unreasonable burdens on patients with respect to their duties toward life-sustaining medical treatments. He represents his opponents as advocates of a view that considers only the selfish desires of patients—a preserve-life-at-all-costs view—that is blind to the possibly crushing burdens that one's decisions may have on one's caregivers and loved ones. He argues that this is unreasonable because such decisions can unfairly burden others, and puts forward his own extreme alternative, his "duty to die" (in other words, to kill oneself when the time is right), as a legitimate way of freeing caregivers and loved ones from serious burdens.²

I do not intend to address Hardwig's defense of euthanasia in this essay. I rather use his caricature of traditional values to raise a question that Catholic health care institutions need to address in order to reply adequately to critics who believe that the norms the Church defends in the area of end-of-life decision making are unreasonable.

The Problem: The Use of Futile Care and Its Psychological, Physical, Social, and Economic Costs

Hardwig draws attention to certain very real burdens that caregivers of seriously disabled loved ones can suffer: a caregiver's health can be "destroyed" by the responsibilities of round-the-clock and long-term care, adequate attention to the needs of other family members can fall by the wayside, and friendships and social life can "evaporate." Costs can also be devastating. Hardwig describes one study of families who were caring for terminally ill members, which notes that in "20% of cases a family member had to quit work or make some other major lifestyle change, almost one third of these families lost all their savings, and just under 30% lost a major source of income."

from a man keenly interested in protecting others from burdens. By eliciting sympathy for the problems raised by end-of-life decisions today (and the problems are very real), and by not alienating readers by saying what they should do but only by saying what *he* would do, Hardwig is able to put forward arguments for the conclusions that he clearly thinks are normative for everyone.

² Ibid. "This point does not depend on a utilitarian calculus. Even if death were the greatest burden ..., serious questions would remain about the moral justifiability of choosing to impose crushing burdens on loved ones in order to avoid having to bear this burden oneself. The fact that I suffer greater burdens than others in my family does not license me to simply choose what I want for myself, nor does it necessarily release me from a responsibility to try to protect the quality of their lives. ... We must admit that we have been promulgating an ethic that advocates imposing greater burdens on some people in order to provide smaller benefits for others just because they are ill and thus gain our professional attention and advocacy" (38). "Surely there is something deeply insulting in a medicine and a bioethics that would ask only what I want (or would have wanted) when I become ill. To treat me as if I had no moral responsibilities when I am ill or debilitated implies that my condition has rendered me morally incompetent. Only small children, the demented or insane, and those totally lacking in the capacity to act are free from moral duties. There is dignity, then, and a kind of meaning in moral agency, even as it forces extremely difficult decisions upon us" (40–41).

³ Ibid., 36.

⁴ Ibid.

In addition, some patients demand that every possible means of sustaining their lives should be used, even when treatments do not promise a reasonable hope of benefit. To illustrate this, Hardwig appeals to a case study:

An 87-year-old woman was dying of congestive heart failure. Her APACHE score predicted that she had less than a 50% chance to live for another six months. She was lucid, assertive and terrified of death. She very much wanted to live and kept opting for rehospitalization and the most aggressive life-prolonging treatment possible. That treatment successfully prolonged her life (though with increasing debility) for nearly two years. Her 55-year-old daughter was her only remaining family, her caregiver, and the main source of her financial support. The daughter duly cared for her mother. But before her mother died, her illness had cost the daughter all of her savings, her home, her job and her career.⁵

Hardwig believes that most reasonable people would conclude that the daughter's burden of losing savings, home, and career at age fifty-five outweighs the mother's 50 percent chance of living six more months at age eighty-seven.

Although Hardwig is principally interested in defending a duty to kill ourselves when (or preferably before) our lives become too burdensome to others,⁶ his article raises the interesting question of whether, on the basis of an analysis of the kinds of burdens he describes, we can ever have a duty to refuse treatment.

The Norm of Fairness

The chief norm used to assess the question of a duty to refuse treatment is fairness. Sometimes expressed as the Golden Rule, fairness requires us to place ourselves in the position of others and to consider from their perspectives what types of behavior it would be reasonable to expect from those in our position. It would be unreasonable, and hence wrong, to render or fail to render to others what we would judge unreasonable for them to render or fail to render to us ("Do unto others ...").⁷

⁵ Ibid., 37. Hardwig notes that APACHE stands for "Acute Physiology and Chronic Health Evaluation." APACHE is a scoring system used to classify the severity of a disease for patients who are admitted to intensive care units. They receive a score from 0 to 71 computed on the basis of several measurements. The higher the score, the more severe the disease and the higher the risk of death.

⁶ He thinks this "duty to die" entails for some a duty to kill themselves even when they are not terminally ill and would prefer to live: "Even those who want to live can face a duty to die. ... I believe that my obligation may be to die while I am still competent, *before* I become unable to make and carry out that decision for myself." (Ibid., 35, 39, original emphasis). In "Going to Meet Death: The Art of Dying in the Early Part of the Twenty-First Century," Hardwig writes, "Suicide is sometimes perfectly fitting and morally acceptable—sometimes even morally praiseworthy." *Hastings Center Report* 39.4 (July–August 2009): 42.

⁷ The most famous formulation of the principle is by Jesus in his Sermon on the Mount (Matt. 7). But the principle is formulated in almost every ethical code in human history, as well as in the prominent works of political philosophy of the last forty years. See John Rawls, *A Theory of Justice* (Cambridge, MA: Belknap Press, 1971), 111–114; Robert Nozick, *Anarchy, State and Utopia* (New York: Basic Books, 1974), 90–95; Ronald Dworkin, *Law's*

Hardwig implicitly appeals to fairness when he argues that our end-of-life decisions should not arbitrarily or needlessly impose burdens on others. He formulates the principle in the language of "other-centeredness" versus "self-centeredness": we have "a duty not to make selfish or self-centered decisions about our lives ... to protect the lives of loved ones from serious threats or greatly impoverished quality ... not to make choices that will jeopardize or seriously compromise their futures" and so on. But beneath this is the moral imperative that benefits and burdens should be distributed with a view to what is rightfully due to each person.

Hardwig wrongly believes that death is sometimes due to patients by virtue of the chronic or severe nature of their medical conditions. And so his application of fairness is flawed. But his belief that we should make advance planning decisions in light of the welfare of all those whom we reasonably foresee will be affected by those decisions, and not only our own good, is correct.

Fairness requires that I make all my consequential decisions, including end-of-life decisions, in light of my prior duties to family members, caregivers, the community, and God (not necessarily in that order). Relationships of family and friendship generate an interdependent sharing of goods. My children, for example, depend on me for their healthy development. Their need for food, shelter, nurture, religious education, and discipline all presuppose that I am being responsible at work, attentive and empathetic at home, generous with my time, and prudential in my financial planning decisions. Spousal interdependence, neighborhood interdependence, and citizen interdependence all generate different degrees of duties to which I should attend in my decision making.

Turning back to the issue at hand, the question of refusing or accepting lifesustaining measures should be made in light of the many goods at stake in such a decision. Assessing the relevance of each of those goods to my choices can be complex. The most proximate good, of course, is the good of my life. Because of life's intrinsic value, the effort to preserve my life ordinarily holds a presumption over letting myself die.

But other goods are also at stake. Opting for a certain type of costly care, for example, may deplete my and my wife's retirement savings. If she is still healthy and our savings are consumed by the cost of my medical care, her future economic stability may be badly threatened. If the costly treatment promises to restore me to a semblance of normal health, then the reasons in favor of adopting it are much stronger. If it offers me, as in the example of the 87-year-old above, little chance of regaining functionality at a crippling financial cost, then the reasons in favor of

Empire (Cambridge, MA: Belknap Press, 1986), 164–165; and John Finnis, *Natural Law and Natural Rights* (New York: Oxford University Press, 1980), 106–109. An analysis of fairness criteria does not replace what we already know about morality. In putting myself in another's place, I take along my capacity to make sound moral judgments, as well as all my known moral truths, my duties, my ability to reason, and my normal feelings with regard to the matters at issue.

⁸ Hardwig, "Duty to Die," 36.

adopting it are weaker. (There is, of course, always a decisive reason *not* to adopt euthanasia, namely, because it is always gravely wrong to intentionally kill ourselves or approve of our intentional killing.)

It seems to me that I *should* forgo a treatment if, after comparing the strength of the reasons for and against it (in other words, after a responsible moral assessment), I judge first that, in the language of Catholic bioethics, it is an extraordinary or disproportionate means of sustaining life and that the reasons in favor of adopting it anyway are manifestly weaker than the reasons against it. Saying I "should" here means I have a duty to forgo it.

This may seem to go further than the conclusion set forth in the *Ethical and Religious Directives for Catholic Healthcare Services* (ERDs). ¹⁰ Directive 57 states that a person may forgo extraordinary or disproportionate means, not that they have a duty to forgo them, and defines extraordinary or disproportionate means as treatments "that in the patient's judgment do not offer a reasonable hope of benefit [in other words, are futile] or entail an excessive burden, or impose excessive expense on the family or the community." So it seems to teach no more than that it is not illicit to refuse extraordinary means.

I agree that directive 57 does not explicitly teach that we can have a duty to forgo treatment. But I do not think the text excludes this conclusion either. I have already argued that moral reasoning supports it. Papal teaching seems also to support it. Pope Pius XII, in his important address to a congress of anesthesiologists in 1957, sets forth basic principles governing the refusal of life support. After addressing the duty of patients to accept ordinary means of medical care (which he defines as "means that

⁹ Allow me to set forward a more balanced approach for dealing with the difficult situation of the eighty-seven-year-old woman. The intrinsic value of the grandmother's life is not diminished because she is sick. Human bodily life, no matter its condition, is never merely an instrumental good of persons, but always constitutes part of the person's intrinsic good. Therefore, the prospect of sustaining the grandmother's life provides a reason to act, that is, it is not pointless. This does not imply it is a decisive reason, since life is one (indeed a substantive one) among many goods that constitute a person's fulfillment. But it is a reason. However, since measures to sustain the grandmother's life do not promise remediation of her condition—and since the condition (let's presume) deprives her of the possibility of participating in many kinds of human goods—many reasons for acting on behalf of sustaining her life have dropped away, except as we said, the good of bodily life. Moreover, providing certain kinds of treatments may impose grave burdens on the grandmother and her loved ones; they may be exorbitantly expensive and may involve the time of loved ones that could be used for other good purposes. One is therefore not obligated to do everything possible to sustain the grandmother's life (for example, spend all one's savings). One should do what reasonably can be done without doing everything that can be done: caring for the grandmother at home; accepting the help of friends, parishioners, neighbors, and others in providing loving care; not exhausting one's savings, but not abandoning one's loved ones. Also see Germain Grisez, Difficult Moral Questions (Quincy, IL: Franciscan Press, 1997), 220-223.

¹⁰ US Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 5th ed. (Washington, DC: USCCB, 2009).

do not involve any grave burden for oneself or another"), he asserts, "On the other hand, one is not forbidden to take more than the strictly necessary steps to preserve life and health, as long as he does not fail in some more serious duty." ¹¹ The Pope is specifically addressing the question of the refusal of "artificial respiration." But there is nothing in his text that excludes his principles of rightful refusal being applied more generally. Pius XII clearly teaches here that taking more than strictly necessary steps to preserve life (the term "necessary steps" here corresponds to ordinary means) can be "a failure in some more serious duty." The specific context indicates that the Pope may be referring to duties arising from "spiritual ends." 12 But since the Pope has just specified the wider concept of duty in end-of-life decision making in relation to both rightly ordered self-love and our relationships toward God, the community, and particular persons—and given that the consistent teaching of the New Testament shows the integral relationship between the duties arising from love of God and neighbor (see 1 John 4:7, 11-12, 20-21; Matt. 22: 37-39)—even if Pius XII is referring here to spiritual ends, we can rightly subsume under that umbrella the binding duties we have toward other persons.

Then what are we to make of the fact that the US bishops do not explicitly teach in the ERDs that we sometimes have a duty to refuse extraordinary treatments? In the present climate, in which the refusal of life support by elderly patients is increasingly expected, the norm specifying the duty to refuse could easily be taken to bind more strictly than it does to include the refusal of forms of medical care that are rightly judged to be ordinary. In 2009, the ERDs were revised to include a directive teaching the obligation in principle to administer food and water to all, including those in a vegetative state. This indicates that the greater pastoral problem has arisen from the wrongful refusal of life-sustaining treatments, not from their wrongful acceptance.

¹¹ Pius XII, "The Prolongation of Life," Address to an International Congress of Anesthesiologists (November 24, 1957), reprinted in *National Catholic Bioethics Quarterly* 9.2 (Summer 2009): 329, emphasis added.

¹² Ibid., 329: "But normally one is held to use only ordinary means—according to circumstances of persons, places, times, and culture—that is to say, means that do not involve any grave burden for oneself or another. A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult. Life, health, all temporal activities, are in fact subordinated to spiritual ends."

¹³ USCCB, *Ethical and Religious Directives*, n. 58: "In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the 'persistent vegetative state') who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be 'excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed.' For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort."

But it seems perfectly sound to say that if reasons rooted in human goods do not justify me in adopting some procedure, I should not adopt it. In the language of fairness, if the reasons for not adopting a procedure are precisely to avoid the kinds of serious harms that would arise if I adopted it, and if the reasons for not adopting it, because of my duties, are stronger than the reasons for adopting it (for instance, if it offers little hope of physical benefit and poses a significant threat of financial harm to my family), then to adopt the procedure and bring about those harms, even unintentionally, could be unfair to the people who will suffer them.

If, however, the reasons in favor of one alternative are not clearly stronger than those in favor of another, then either alternative—refusal or acceptance of treatment—may be chosen without unfairly disadvantaging the patient or caregivers. Christians should then undertake a process of discernment, which is to say, they should seek God's will in order to discover which of the morally licit alternatives God wills them to choose, and they should take the outcome of the discernment as normative.

In defending the possibility of a duty to refuse extraordinary life-sustaining treatments, I do not mean to lend credence unwittingly to the refusal mentality I am criticizing in this essay. Quite the opposite. Unless we set forth clearly the implications of a Catholic theory of action and human good, we open ourselves to mischaracterization by those opponents of Catholic values who gain the high ground by criticizing views we do not hold (and that most reasonable people take to be false), and by putting forward their own more extreme positions as "balanced" alternatives.

We know that there can be a *duty to accept* life-sustaining medical treatment when the treatment is neither futile nor excessively burdensome (see directives 56 and 57). This duty is grounded in the love we should have for our own bodily lives, our responsibility to God to exercise good stewardship over the gift of bodily life he has given us, and our commitments to justice toward those for whom we care. He duty always prohibits us from acting with the intent of bringing about our own death. But rightful self-love does not prohibit actions that we foresee will hasten our deaths. A soldier may have a duty to fight in a battle in which he knows he will probably be killed, like the soldiers who stormed Omaha Beach at the Battle of Normandy. Choosing to fight in such a battle is not equivalent to suicide. The soldier's duty stems from the commitments he has arising from his enlistment, as well as from his relationships to fellow soldiers and to the country he serves. The duty is a normative requirement of justice even when it entails foreseeable though non-intentional death.

¹⁴ Aquinas, writing on the norm against suicide, argues that self-killing is wrong because it is "contrary to charity [*caritatem*] by which every man ought to love himself." Belonging to this proper self-love, he says, is the fact "that everything naturally preserves itself in being, and resists corruption as much as it can." *Summa theologiae* II–II, q. 64, a. 5c. Speaking on the duty to "take necessary treatment for the preservation of life and health," Pius XII adds to charity the duties we have "toward God" and "the human community": "This duty ... derives from well-ordered charity, from submission to the Creator, from social justice and even from strict justice, as well as from devotion toward one's family." Pius XII, "Prolongation of Life," 329.

Similarly, patients have duties arising from their marriage vows, their paternity or maternity, and from other relationships. There may be times where the refusal of life-support, like going into battle, is prescribed by the normative requisites of justice (fairness) even though it promises to hasten death. The ERDs, however, make it clear that the decision of what is or is not a rightful condition for refusal is for the *patient* to make, not his family, physicians, or bureaucrats in Washington. ¹⁵ Pastoral workers and family members should have frank discussions with patients about the harms and benefits arising from various end-of-life alternatives.

Five Principles

I formulate here five principles to assist us in making end-of-life decisions without opening ourselves up either to a charge that we are unreasonably preservationist in our view of end-of-life duties, or to the charge that we are not adequately taking into consideration the intrinsic value of our lives.

- 1. We should accept the prospect of our own death serenely when we are able to foresee it coming and when there is nothing we can or should do to forestall it.
- 2. If we can forestall death, then we should ask if we have a duty to do so. That duty can arise from rightful self-love or from our committed relationships. ¹⁶ For example, a dying parent who is unreconciled with one of his children should make every reasonable effort to forestall death long enough for his child to be able, if possible, to visit his bedside and engage in a conversation aimed at reconciliation. (Obviously the circumstances of the relationship and the proximity of the child may affect this possibility.) Similarly, a mother with small children who is suffering from metastatic breast cancer may have the duty to attempt another round of chemotherapy, even though it promises to forestall her death for only a limited time. In addition, all Catholics ordinarily should direct that their lives be preserved until they have the opportunity to receive the last rites of the Church, in particular, if they are still conscious, the sacraments of Penance, Anointing of the Sick, and Viaticum. ¹⁷

¹⁵ Directive 57 of the *ERDs* states, "Disproportionate means are those that *in the patient's judgment* do not offer a reasonable hope of benefit" (emphasis added). William E. May sets forth some characteristic reasons that could ground a judgment that some treatment is excessively burdensome: the treatment is experimental or risky; it is painful or brings about other conditions that are undesirable or that one wishes to avoid during the time of life remaining; it is objectionable on the basis of some ethical or religious principle; one finds it psychologically repugnant; or it imposes severe demands upon others, including grave financial burdens. *Catholic Bioethics and the Gift of Human Life* (Huntington, IN: Our Sunday Visitor Press, 2008), 283, quoting Germain Grisez and Joseph Boyle, *Life and Death with Liberty and Justice* (Notre Dame, IN: University of Notre Dame Press, 1978), 268–269.

¹⁶ Recall that Pius XII states that "devotion toward one's family" may give rise to the duty to accept treatment for the preservation of one's life (see note 14 above).

¹⁷ Addressing the duties of physicians, Pius XII teaches, "If Extreme Unction has not yet been administered, one must seek to prolong respiration until this has been done." Earlier he stated, "When it is not known whether a person fulfills the necessary conditions for valid reception of the sacraments, an effort must be made to solve the doubt. If this effort fails, the

- 3. We never have a duty to hasten our deaths. If we did, then it would be morally licit to act for the sake of that end. But acting for the sake of our own deaths is suicide or attempted suicide. And suicide is always incompatible with the duty we have to love our lives. ¹⁸ Therefore we never have such a duty.
- 4. We *may* forgo life-sustaining treatments if they are either medically futile (in other words, if they promise no reasonable hope of benefit) *or* if, in the patient's judgment, they are excessively burdensome.¹⁹ I add to this, as a necessary condition, that we have no prior duty to forestall death by accepting treatment.

"Excessive burden" as a justifying condition does *not* refer to the patient's life (for example, "Life is so burdensome that I think I will refuse treatment.") If the life is the burden, then eliminating the burden would entail ending the life, which would be suicide (or assisted suicide). "Excessive burden" is our judgment on the foreseeable harms or sufferings threatened by undertaking some treatment; it is the *treatment* that creates the burdens, and we wish to be free of those burdens. Intending to avoid the burdens, we forgo the treatment and accept as an unintended side effect that our refusal may hasten death.

5. We may have a duty to forgo extraordinary life-sustaining treatments—but never a duty to die—if accepting those treatments promises to impose very grave burdens on others and if the benefits promised are minimal.

For example, an elderly spouse is confined to the hospital with end-stage renal disease. He has no medical insurance and no other sources of income. He is on dialysis and facing care expenses of up to a thousand dollars a day or one hundred thousand dollars for a kidney transplant. In these circumstances, he may conclude that it is not only legitimate for him to cease his daily care but that, in light of the punishing costs of the (extraordinary) treatments²⁰ and the threats they pose to his wife's financial security in old age, he ought to stop them. He chooses to do what reasonably can be done without doing everything that can be done.

If adopting extraordinary means of care would not unfairly disadvantage anyone (say, for example, an infirm elderly person has ample financial resources and

sacrament will be conferred under at least a tacit condition (with the phrase "Si capax est," "If you are capable"—which is the broadest condition)." Pius XII, "Prolongation of Life," 330.

¹⁸ Summa thelogoiae II–II, q. 64, a. 5c.

¹⁹ Said in another way, an "ordinary" or "proportionate" treatment, which we are obliged to accept, is one that is not excessively burdensome *and* offers hope of improvement; and an "extraordinary" or "disproportionate" treatment is one that *is futile or excessively burdensome*. (See USCCB, *Ethical and Religious Directives*, nn. 56 and 57.) The terms "ordinary" and "proportionate" became prominent in Catholic moral theology after Pius XII used them to distinguish between obligatory and non-obligatory treatments. See Pius XII, "The Prolongation of Life"; and Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (May 5, 1980), IV.

²⁰ I am presuming for the sake of this argument that the treatments in question here are rightly judged to be extraordinary.

no other strong reason not to adopt them), then I do not think we ordinarily have an obligation to refuse life-sustaining treatments.²¹

Fairness and Duty

My basic argument has been this: advocates of revisionist morality capitalize on end-of-life fears by arguing that Catholic values unreasonably oblige patients to adopt life-preserving medical treatments even when the treatments are excessively burdensome or futile; such advocates then put forward their own extreme alternatives as more moderate and reasonable. This mischaracterizes Catholic values regarding the dignity of human life, self-determination, and licit end-of-life decision making. Fairness obliges persons to consider not only their own welfare but also the welfare of others in their end-of-life decisions.

²¹ It is of course possible that the person suffers from a morbid fear of death such that the decision to adopt further treatments is motivated, at least in part, by disorderly emotions and not the intelligible good of remaining alive. In order for this person to be more fully reasonable in choosing, medical caregivers and pastoral workers probably should help the person come to terms with the reality he faces. Having said this, because life is intrinsically good even when a person suffers from serious privations, the decision to sustain life, though not always morally required, is never pointless. The intelligible good grounding the decision to sustain the life of a badly disabled person is precisely the good of that person's life (in other words, of being alive, rather than dead).