

## Medical Futility and the Death of a Child

Nancy S. Jecker

Received: 18 November 2010 / Accepted: 7 February 2011 / Published online: 8 March 2011  
© Springer Science+Business Media B.V. 2011

**Abstract** Our response to death may differ depending on the patient's age. We may feel that death is a sad, but acceptable event in an elderly patient, yet feel that death in a very young patient is somehow unfair. This paper explores whether there is any ethical basis for our different responses. It examines in particular whether a patient's age should be relevant to the determination that an intervention is medically futile. It also considers the responsibilities of health professionals and the rights of family members in situations where an intervention is clearly futile.

**Keywords** Medical futility · Withholding and withdrawing treatment · Ethics · Goals of medicine · Quality of life · Beneficence · Non-maleficence · Patient's age

### Medical Futility and the Death of a Child

A three-year-old boy named Jeffrey wandered into the backyard while his mother was answering the door

and fell into the family swimming pool. It took about 5 min for his mom to finish with the visitor at the door, and another 2 to 3 min for her to notice that her son was missing. She searched the house frantically before discovering her three-year-old lying motionless at the bottom of the pool. She panicked at first, then swung into action, retrieving Jeffrey from the water, initiating mouth-to-mouth breathing, and dialing 911. When Emergency Medical Technicians (EMTs) arrived, Jeffrey was pulseless and blue in the face due to poor oxygenation from having spent between 5 and 15 min in the water. EMTs performed CPR and intubated the child. En route to the hospital, epinephrine and atropine were administered, and a needle was placed in the boy's left tibia. At the hospital, Jeffrey was stabilized and transported to the pediatric Intensive Care Unit (ICU), where he was placed on a ventilator. After 24 hours, the boy's pupils remained fixed and dilated and his peripheral muscle tone flaccid. He began to exhibit repetitive twitching, which progressed to a generalized seizure. Phenobarbital was administered and the seizure stopped. A consulting neurologist requested an EEG, which showed very low voltage neural activity throughout the brain, with occasional spike and wave activity consistent with suppressed seizure activity. CT showed severe edema of the brain. At a conference with family the following day, the attending physician explained that Jeffrey had suffered a severe brain injury, with subsequent swelling of brain tissue, resulting in severe and permanent injury. Parents

---

A version of this paper was presented to the Trueman Katz Center for Pediatric Bioethics in Seattle, Washington on June 4, 2009.

---

N. S. Jecker (✉)  
School of Medicine Department of Bioethics and  
Humanities, University of Washington,  
Seattle, WA 98195, USA  
e-mail: nsjecker@uw.edu

were told that their child's prognosis was extremely poor, that the brain had been profoundly and globally damaged, and that survival was unlikely, even with intensive medical support. The physician recommended withdrawing support, and emphasized that the miniscule chance of prolonged survival would only lead to permanent disability, permanent coma, and dependence on medical care for all aspects of life. Jeffrey's parents adamantly rejected the physician's recommendation, insisting that everything be done to keep Jeffrey alive as long as there was a chance, however remote, that he might survive (Mathers 2005).

It is hard to imagine anything worse for parents than a devastating brain injury to their child. When a perfectly healthy child, like Jeffrey, is suddenly and irrevocably injured, families face particularly challenging decisions, and there may be a variety of reasons why they wish to continue life support (Whitney 2005). They may be concerned that the medical staff is giving up too soon, making an error of judgment, or cannot be trusted. Or perhaps they have had an experience where a physician predicted that a family member would die and was wrong. Perhaps the family simply feels they are just not ready to face such a momentous decision and need time.

In addition to these concerns, there is the fact that this is a child. Would Jeffrey's parents have felt different if the victim of near-drowning was not their three-year-old son, but their 83- or 93-year-old grandparent? Would even sudden death be easier to accept if the dying person were elderly? For many, the answer is emphatically, Yes! We feel worse about the death of a three-year-old than an 83- or 93-year-old. While death may always be an occasion for sadness, the intensity of these feelings is often very different depending on the dying person's age. Very young people can trigger protective impulses, which can lead parents and providers to feel more vigilant about advocating on their behalf. With respect to the frail and vulnerable elderly, we may feel that it is "just a matter of time" before death occurs and that death is a natural, inevitable outcome in old age.

Yet the fact that death's timing triggers such feelings does not itself show that death is objectively worse or that our feelings about death's timing are justified. Is there any ethical basis for such feelings? If there is, are we also justified in recognizing a greater duty to avert such a death? Should health professionals exert more effort to defeat the odds and

apply futile treatments when the patient is very young, while avoiding "heroics" on behalf of older patients? This paper considers these questions and looks specifically at whether there is any ethical basis for making age-based distinctions within the concept of medical futility.

### Reasons Why Dying Young Could be Worse

It will be helpful to begin by considering the *reasons* why dying young might be worse (Jecker and Schneiderman 1994). Perhaps the most obvious reason is that a very young person has not yet had the opportunity to live a life. Dying in infancy means that a patient will never experience such things as learning to walk and talk, bonding with a parent, growing up, going through adolescence, falling in love, setting goals, completing projects, raising children, facing middle age, growing old, and seeing the next generation come into its own. In short, the goods that living a life offers, whatever they are, will be missed by someone who dies so young. Callahan argues that it is for this reason that we find it more difficult to recall, anticipate, or witness the death of a young child than the death of an elderly person (Callahan 1993, 1987). We deem death in an elderly person "peaceful," meaning "free from strife or commotion," or "undisturbed, untroubled, calm, tranquil, quiet"; by contrast, the death of an infant or small child we consider "senseless," which indicates "without sense or meaning" and "purposeless" (Oxford English Dictionary 1971). These ideas suggest one possible basis for our divergent attitudes about death's timing: the death of a young person is unfair, whereas the death of an elderly person is not. When death occurs in old age, it is considered acceptable, although sad, because the person who dies had his or her full share of life. By contrast, when death occurs very early in life, we feel that someone was wrongly deprived of the opportunity for life he or she should have had.

Further developing this idea, Nagel asks us to compare the death of Tolstoy, who lived from 1828 to 1910, and died at the age 82, with that of Keats, who lived from 1795 to 1821, and died at 24 (Nagel 1979). He argues that we regard Keats' death as worse than Tolstoy's, because it is worse to die at 24 than 82. After all, Tolstoy had "more than his share" of a life, while Keats, because he died at a young age, missed

out on many of the opportunities life affords. Although we would acknowledge that the death of both men was a great loss, we would nonetheless say that Keats' death was worse.

Yet in response it could be argued that life itself is properly understood not as something we are "owed" a fair share of, but as a "gift" or benefit we are fortunate to have. In secular terms, this suggests we should aspire to be grateful for the time we have, however little or much we get. Toward patients and loved ones, our goal would be similar. Rather than believing that a dying child did not get what she deserved, or had a right to, we would instead feel lucky to have shared what we did with this child.

A second reason why an early death might be worse is that it is not normal for the species. Whereas death in old age is a normal, expected event for members of our species, death at a young age is not a normal, expected event. Nagel invites us to consider the following analogy (Nagel 1979):

1. Blindness or near-blindness for a mole is not a misfortune or evil for the mole because it is the natural condition of a mole.
2. Generally speaking, we do not regard a limitation that is normal for a species as a misfortune or evil.
3. Tolstoy's death at 82 (in contrast to Keats' death at 24) is normal for the human species.
4. Therefore, we do not regard Tolstoy's death as a misfortune or evil for Tolstoy.

Other reasons that lend support to the belief that it is worse to die young are that young persons as a group have more future years ahead to lose than older persons do. When there is more to gain and at least some possibility of a win, the costs of a gamble may seem "worth it." In other words, whatever the burdens associated with using futile interventions in children, these burdens may seem offset by the benefit, both to the individual and the society, of a longer life expectancy. Likewise it might be argued not only that the young have more potential years ahead to lose, but that if they die they also lose entire life stages. Thus, a five-month-old will miss all of childhood, adolescence, adulthood, and old age. By contrast an 85-year-old not only has fewer years ahead to live, but has enjoyed the opportunity of living out each stage of life. Such reasoning lends support to favoring the young over the old, even if the odds of success are admittedly slim.

Yet in response it must be noted that, although children in general have a longer life expectancy than elderly persons, the quality as well as length of their future life must be considered. The concern here is not just that outcome measures must be adjusted for the quality, as well as the number, of life years saved. Instead a larger question is at stake: What does it mean for an individual to live a *human* life, i.e., to live with freedom and dignity? If Jeffrey were to survive against the odds, what would that life be like? Would he be capable of any of the activities we consider central to living a human life? According to Nussbaum, a "truly human" life requires certain basic capabilities, including the following (Nussbaum, 1999, 2000):

- (1) Life—being able to live to the end of a human life of normal length.
- (2) Bodily health—being able to have good health, being adequately nourished, being able to have adequate shelter.
- (3) Bodily integrity—being able to move freely from place to place.
- (4) Senses, imagination, thought—being able to use the senses; being able to imagine, think, reason, and to use the senses; being able to imagine, think, reason; being able to do these things in a way informed and cultivated by an adequate education.
- (5) Emotions—being able to have attachments to things and persons outside ourselves; being able to love those who love and care for us.
- (6) Practical reason—being able to form a conception of the good and to engage in critical reflection about the planning of one's life.
- (7) Affiliation—being able to live for and in relation to others, to recognize and show concern for other human beings, to engage in various forms of social interaction.
- (8) Other species—being able to live with concern for and in relation to animals and the world of nature.
- (9) Play—being able to laugh, to play, to enjoy recreational activities.
- (10) Control over one's environment—having control over one's political and material environment, such as having the rights of free speech and freedom of association and being able to hold property; having the right to seek employment on an equal basis with others.

Most infants have capabilities for practical reason and imagination, even though they require more development and education to use them fully. By contrast, were Jeffrey to miraculously beat the odds and survive, his life would lack such basic capabilities. He would not have the freedom to move himself about or the functional ability to play, form attachments, create a life plan, or control his environment. Nor would education cultivate more developed capabilities. By contrast, Nussbaum points out that healthy children have basic capabilities in all ten areas. Jeffrey's brain injury has not only reduced his quality of life; it has left him without the most basic human capabilities.

If my reasoning is persuasive, we should reject the proposal that the use of futile interventions in children is a gamble worth taking. The larger "pay off" that might be gained is hardly an unqualified "win." Instead, it represents a profound loss. Regardless of his biological survival, Jeffrey has irrevocably lost the human life he might have lived.

To return to the example mentioned previously, if Keats had nearly drowned, as Jeffrey did, then even if he were saved from the brink of death and lived for many decades he would not produce more poetry. Instead, he would be left to languish in bed, requiring constant caregiving for all activities of daily living, such as toileting, bathing, dressing, eating. It is obvious that having such basic capabilities is integral to living a human life, and that the absence of these not only reduces a person's quality of life but robs that person of the human life they might have lived.

A final argument that could be offered in support of favoring the young arises on a more personal level. For a parent, the death of a child may convey what psychiatrist Irvin Yalom calls "project loss" (Yalom 1989). "Project loss" refers to the loss of "[w]hat one lives for, how one projects oneself into the future, how one may hope to transcend death" (Yalom 1989, 132). By contrast, the death of an aging parent is not the loss of a life project, but of an "object" or figure that played an instrumental role in the constitution of one's personal past. Thus, with the loss of a parent, one's personal future remains viable, even enlivened.

Lifton and Olson convey a similar thought, noting that offspring can represent a kind of "symbolic immortality" for parents (Lifton and Olson 1974). They describe "symbolic immortality" as a psychological process of creating meaningful concepts, imagery, and symbols that fulfill the human need for a sense

of historical connection beyond an individual life. Offspring afford parents symbolic immortality not only through continuing their physical/genetic material, as sociobiologists emphasize (Wilson 1978), but also by virtue of showing the imprint of parents' values and attitudes in the way they lead their lives. Parents may feel that their influence on children connects them to humankind as it enters "into a general human flow beyond the self" (Lifton and Olson, 1974, 77).

Neither of these arguments purports to show that the value of child's life is inherently greater than the value of an older person's life. Instead, each suggests that losing a child has a different meaning and different consequences. If these reasons are persuasive, and the death of a child truly is worse in this sense described here, what does this imply for health care professionals? Does it follow, for example, that physicians have a greater obligation to try to prevent the death of a child? In the case of Jeffrey, are his parents warranted in asking for aggressive interventions even if the odds of success are slim?

In response it is important to point out that the obligations of health care professionals hold for all patients: for *all* patients, we should try to do good, to help the patient, and refrain from whatever is injurious or burdensome. If an intervention will not benefit the patient, there is no duty to use it. Moreover, since interventions are often burdensome for patients, families, and society, the requirement to avoid harm suggests more strongly that there is a duty to refrain from futile interventions unless there is a reasonable prospect of helping the patient.

It could be argued, however, that the concept of medical futility itself incorporates age-based distinctions. Yet this suggestion is quite misleading. Futility refers to interventions where the likelihood or quality of benefit is exceedingly poor and falls well below a threshold considered minimal (Schneiderman, Jecker, and Jonsen 1990). In Jeffrey's case, the chance of averting death is virtually nil; thus, interventions aimed at saving his life are futile in a quantitative sense. What I call "quantitative futility" refers to interventions where the *likelihood* of achieving an intended outcome is extremely poor and falls well below a threshold considered minimal (Schneiderman, Jecker, and Jonsen 1990). Elsewhere I have argued (together with colleagues Lawrence Schneiderman and Albert Jonsen) that if there is less than one chance in 100

that an intervention will achieve its intended goal, it qualifies as futile in a quantitative sense. The poor odds of success in Jeffrey's case are not based on his young age, but on the near drowning and loss of oxygen to the brain. Even if Jeffrey were miraculously to survive, the quality of outcome he would experience would be extremely poor and would approach what I have elsewhere called "qualitative futility" (Schneiderman, Jecker, and Jonsen 1990). A medical intervention is futile in the qualitative sense if the *quality* of outcome is exceedingly poor and falls well below a threshold considered minimal. For example, qualitative futility is associated with outcomes where a patient will never regain consciousness or where the patient will require constant monitoring, ventilator support, and medical and nursing care that is available only within an intensive care unit. The qualitative aspect of medical futility draws a distinction between an effect and a benefit. Even where medical interventions can produce an effect on Jeffrey's body, such as keeping his lungs expanding and contracting with oxygen, interventions do not necessarily produce a benefit that helps the patient. The goal of medical care for Jeffrey, and for any patient, is to benefit the patient, not just to produce physiological effects on body parts or organ systems. Expressed differently, the goal of any medical intervention is not simply to produce a physiological change, but rather to make changes that help the patient. This account of medical futility is widely accepted and has been discussed at length in the literature. Elsewhere, I have responded (with Schneiderman and Jonsen) to critiques of this position (Schneiderman, Jecker, and Jonsen 1996).

Does Jeffrey's age make a difference in assessing qualitative futility? Clearly not: there is nothing in the definition of qualitative medical futility stated above that regards the life of a young person as inherently of higher value than the life of an elderly person. Age per se is not relevant to determining either the likelihood or quality of medical benefit. Even when patients of a certain age are in general more likely to experience poor outcomes, age functions as a marker for medical outcomes, not as something we regard as important in its own right. In the case of Jeffrey, there may be greater uncertainty in predicting the outcome of brain injury due to his young age, and so age is a marker of greater medical uncertainty, but is not itself a relevant factor. In these cases, what matters is the chance of a poor outcome or the degree of uncertainty,

not the fact that a patient is a certain chronological age. It is not "more futile" to use futile interventions in the elderly. Nor is it "less futile" to use such interventions in the young. Instead, when we are reasonably confident that an intervention will not help the patient, physicians should not offer it regardless of the patient's age (Schneiderman and Jecker 2011).

So far I have argued that the physician's duty is to benefit the patient. If interventions do not help, there is no obligation to use them. The fact that a patient is very young does not provide a special justification, or give us grounds for going to extra lengths, to try to save the patient. If my reasoning is correct, health care professionals have no duty to offer interventions that are clearly futile. It follows that there is no corresponding right, on the part of patients or their surrogates, to receive futile interventions. For to say that a patient or family member is entitled to a particular treatment implies that someone—for example, health care workers or hospitals—has an obligation to offer it.

Yet even if we accept the claim that physicians are not *obligated* to offer futile treatment, it might be argued that as long as some health professionals and hospitals are willing to offer futile interventions, it is ethically *permissible* to grant patients' and families' requests for futile interventions. This is the reasoning that lies behind the 1999 Texas Advance Directives Act. The Texas law holds that even though health professionals cannot be forced to continue with interventions that are clearly futile, they must participate in a fair conflict resolution process, which includes giving notice before an intervention is withdrawn, involving a third party ethics consultation service, and referring patients and families to another institution or provider willing to accommodate their preferences if one is available. The Texas law grants health care professionals immunity from civil or criminal prosecution if futile treatments are withheld or withdrawn against the patient's or family's wishes, provided the steps required for fair conflict resolution are followed.

From an ethical standpoint, the approach taken by Texas will meet the ethical requirements I have set out in many cases. To its credit, the law allows for respectful treatment of dissenting views in situations where there is a challenge to, or an attempt to modify, existing professional standards. Yet to its detriment, it can compel health professionals and hospitals to help patients and families secure futile interventions in

situations where such treatments are exorbitantly expensive or scarce, or are unacceptably burdensome to an incompetent patient or minor child, but demanded by family members or surrogates. In the final analysis, the ethical permissibility of referring patients and families to providers willing to use futile interventions as part of a conflict resolution process depends upon whether and to what extent doing so harms patients or society. When interventions may be unable to produce benefit, but also unable or unlikely to produce harm, it might be ethically permissible to refer patients and thereby assist them in obtaining futile treatments. However, this approach has its limits. Specifically, it is not ethically acceptable to proceed with assisting patients and families to obtain futile interventions from another provider or facility when there are clear burdens to individual patients, or to the wider society. When significant positive harms occur, the principles of nonmaleficence and justice apply and establish a positive duty to refrain from futile interventions. It is important to note that, to the extent that the futility of an intervention is unclear and no professional consensus exists, the obligations of health professionals, and the corresponding rights of patients and surrogates, will look quite different. In such situations, there is simply not sufficient evidence to make a determination of medical futility. Thus it is important to distinguish between futile interventions—where empirical studies demonstrate an exceedingly poor likelihood or quality of benefit—and experimental or innovative interventions—where the outcome is not known and the evidence is not yet in (Schneiderman and Jecker 1996). Although I have argued that health professionals should not offer futile interventions, experimental methods—especially when they are part of a larger clinical study—advance medical knowledge and benefit society, even if they do not benefit individual patients.

To summarize, when a treatment is clearly futile, both old and young patients may be harmed by age-based bias. When age-based bias influences futility judgments, this can result in either under-treating elderly patients or over-treating younger patients. Thus, if we regard the death of a small child as a greater evil, health professionals and families may be inclined to go to greater lengths to try to prevent death, using life-saving measures that are futile and not in the patient's best interest. These interventions harm patients when they

cause pain and discomfort, or are an affront to dignity. Yet even when futile interventions do not increase the patient's discomfort, they often produce other tangible harms: wasting society's resources, distracting the health care team from more appropriate palliative and comfort measures, and feeding false hopes that discourage families from coming to terms with the reality of a patient's situation. Alternatively, if we regard the death of an older person as relatively acceptable, members of the health care team may err in the opposite direction. They may decline to use treatments that would in fact benefit the patient. Both of these age-based responses should be avoided. For all patients, the obligation of health professionals is to help the patient, regardless of age, and to avoid treatments that do not confer any benefit.

### Medical Futility and Patient Age

Regardless of whether we believe that dying young is really worse, we may continue to feel as if it were a more bitter fate. Yet when it comes to deciding what to do, we must act on the basis of ethically defensible values. If medicine can do nothing to save a patient's life, then the issue is not whether the patient will live or die, but how the patient will live until she dies. (This point is from Stu J. Farber, M.D.) The goal for health professionals in such situations should be to help patients and families live the richest life possible with the time that remains. While futile treatments may seem to symbolize love or caring, there are other, better ways of expressing this, such as being present, listening, and using supportive palliative and comfort measures to the best of one's ability (Schneiderman, Faber-Langendoen, and Jecker 1994). Acknowledging the futility of life-prolonging interventions can create a possibility for patients and families to dismiss false hopes, and begin the process of coming to grips with an impending death by expressing grief, acknowledging loss, and letting go. Patients, whether young or old, deserve nothing less.

### References

- Callahan, D. 1987. *Setting limits: medical goals in an aging society*. New York: Simon and Schuster.
- Callahan, D. 1993. *The troubled dream of life: living with mortality*. New York: Simon and Schuster.

- Jecker, N.S., and L.J. Schneiderman. 1994. Is dying young worse than dying old? *The Gerontologist* 34(1): 66–72.
- Lifton, R.J., and E. Olson. 1974. *Living and dying*. New York: Praeger Publishers.
- Mathers, L.H. 2005. Letting go: A study in pediatric life-and-death decision making. In *Ethical dilemmas in pediatrics: Cases and commentaries*, ed. L.R. Frankel, A. Goldworth, M.V. Rorty, and W.A. Silverman, 89–94. New York: Cambridge University Press.
- Nagel, T. 1979. Death. In *Mortal questions*, ed. T. Nagel, 1–10. New York: Cambridge University Press.
- Nussbaum, M.C. 1999. *Sex and social justice*. New York: Oxford University Press.
- Nussbaum, M.C. 2000. *Women and human development: the capabilities approach*. New York: Oxford University Press.
- Oxford University Press. 1971. *The Compact Edition of the Oxford English Dictionary*.
- Schneiderman, L.J., K. Faber-Langendoen, and N.S. Jecker. 1994. Beyond futility to an ethic of care. *The American Journal of Medicine* 96: 110–114.
- Schneiderman, L.J., and N.S. Jecker. 1996. Is the treatment beneficial, experimental, or futile? *Cambridge Quarterly of Healthcare Ethics* 5: 248–256.
- Schneiderman, L.J., and N.S. Jecker. 2011. *Wrong medicine*, 2nd ed. Baltimore: Johns Hopkins University Press.
- Schneiderman, L.J., N.S. Jecker, and A.R. Jonsen. 1990. Medical futility: its meaning and ethical implications. *Annals of Internal Medicine* 112: 949–954.
- Schneiderman, L.J., N.S. Jecker, and A.R. Jonsen. 1996. Medical futility: response to critiques. *Annals of Internal Medicine* 125: 669–674.
- Wilson, E.O. 1978. *On human nature*. Cambridge: Harvard University Press.
- Whitney, S.N. 2005. Near-drowning, futility, and the limits of shared decision making. In *Ethical dilemmas in pediatrics: Cases and commentaries*, ed. L.R. Frankel, A. Goldworth, M.V. Rorty, and W.A. Silverman, 95–107. New York: Cambridge University Press.
- Yalom, I. 1989. *Love's executioner and other tales of psychotherapy*. New York: Harper Collins.