

Quality of Life by Proxy: A Risky Business

Can One Person Truly Assess Another's Quality of Life?

Quality of life determinations made on behalf of others have the potential to be unjust in light of well documented discrepancies between quality of life ratings of patients and caregivers. In addition, the emphasis on quality as a basis for medical decision making departs from reliance on sanctity of life to justify claims to equal medical care for all.

As the nation confronts the mammoth task of health care reform, a chief aim will be to control health care costs. One method employed by other national health care systems is the use of "quality-adjusted life years."¹ This model attempts to direct resources toward those practices which yield a greater number of healthy years at lower cost, as well as toward those that result in higher "quality of life." Although it is possible to predict how well a particular intervention might serve to prolong life, measurements of the quality of those additional years (or months) are much more subjective. This subjectivity has the potential to be particularly unjust when quality of life estimations made by proxy are used to withhold life-prolonging treatment. Numerous studies show that both caregivers and health care professionals typically underestimate a patient's quality of life.² This problem is especially acute in the context of cognitive impairment.

As a medical director of a long-term care facility, my interest in this question revolves particularly around patients with advanced dementia, who are wholly dependent on proxies for all decision making, including a valuation of their life's quality.

In one of the earliest attempts to address this issue, bioethicist Paul Ramsey highlighted the immorality inherent in using quality of life determinations to limit treatment in non-dying patients.³ Medical decisions, in these cases,

should simply be based on a "medical-indications" policy: If a medical condition will likely improve as a result of medical intervention, then that medical intervention is to be initiated in non-dying patients, regardless of their perceived quality of life. Ramsey noted the practice of some physicians in taking social and economic factors into account in determining whether to treat compromised infants. In Ramsey's view, "to deliberately make medical care a function of inequities that exist at birth is evidently to add injustice to injury and fate."⁴ He criticized efforts to produce quality of life indexes of both "positive" and "negative human criteria," noting that from his perspective of Jewish and Christian traditions, personhood is granted by God, not achieved by fulfilling a set of criteria. If these religious traditions assert that all humans are equal regardless of achievement, social situation or cognitive function, then to warrant care only if one achieves a certain quality of life rating is to violate a patient's God-granted personhood. In Ramsey's view, allocating care based on a life's "quality" stands in opposition to care decisions based on life's "sanctity."

Ethicist Paul Wolpe raises another important issue. To him, it seems arbitrary to base quality of life on the sum total of various criteria, doubting that human lives are "made up of discrete, identifiable components of quality of life."⁵ Wolpe contends that when we rate the quality of life of others, we are imposing a standard generally created by the healthy and able-bodied. Is it realistic to act as if these standards can be applicable to all people? Why do these standards matter more than the patient's own valuation? Wolpe reminds us that able-bodied people frequently underestimate the quality of life experienced by those with even severe disabilities. A study of patients with Duchenne Muscular Dystrophy showed surprisingly low levels of dissatisfaction with life, for example.⁶ Wolpe feels that the only valid measurement of quality of life is one given by the



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patient and suggests that in order to determine quality we begin by asking “How do you feel about yourself and your life?”⁷

Peter Singer agrees that secular and religious approaches to health care decisions differ in their appeal to either life’s “quality” or life’s “sanctity.”⁸ He is convinced that views such as Ramsey’s, assuming that life is sacred and humans are a “special form of creation, made in the image of God,” have no practical application in modern health care systems. Singer recommends doing away with this “religious mumbo jumbo,” so that decisions can be based not on the concept that life is a sacred gift, but rather on the assertion that life has value only as defined by the “quality of life each human has or can achieve.” He points out that once freed of religious constraints, one is able to assign quality based on “morally significant” criteria such as rationality, ability to communicate — criteria, he points out, that can invest

a dog or a pig with a value superior to that of a severely defective human infant.

Singer’s argument is important in the sense that it clarifies just what is at stake when we use proxy quality of life ratings to withhold treatment. Is personhood achieved through fulfilling certain activities and functions, or is personhood imparted to one as a gift quite independent of personal achievement, cognitive function or ability to communicate?

Two examples help to focus our thoughts: severely cognitively impaired newborns and persons with late-stage dementia. Regarding cognitively impaired newborns, neonatologist Ian Holzman reminds us that “mental disability, *per se*, does not equate with a poor quality of life.”⁹ Again, quality of life estimates made by proxy typically underestimate the quality of life enjoyed by those who are cognitively challenged. Numerous studies have reviewed discrepancies between quality of life ratings by patients and their proxies in this setting. A review by Zwicker and Harris detailed the improvement of quality of life measures in very low birth weight infants as they grew to adulthood.¹⁰ Once these infants enter their teen years, quality of life measurements become equivalent to their normal peers. Not surprisingly, this improvement in quality of life coincides with the ability of the patients themselves to rate their life’s quality. When quality of life is determined by patient instead of proxy, quality assessments improve.

On the other end of the spectrum is Alzheimer’s dementia. Over 5 million people in the United States suffer from this disease and depend in part, or fully, on proxies for their health care decisions. When we ask persons with mild to moderate Alzheimer’s to rate their quality of life, scores are consistently higher than that estimated by the caregiver. The lower scores assigned by caregivers seem to depend more on caregiver stress than on the health status of the person with Alzheimer’s.¹¹ In later stages of dementia, when self-rating of quality of life becomes more difficult or impossible, one should assume that these discrepancies between quality of life ratings by proxy and patient continue.

In the past, I have used proxy quality of life determinations to justify withholding medical treatment.¹² The potential injustice in using these ratings, however, has given me pause, and my practice has changed as a result. If proxy quality

of life decisions generally underestimate a life's quality, and, by implication, the desire of the patient to continue living that life, then I stand on morally shaky ground when I withhold treatment based on these miscalculations. In advanced dementia, the major question that now informs my treatment decisions is: "Is this person with Alzheimer's dementia actively dying?"

Although it can be difficult to determine when exactly a person with Alzheimer's is actively dying, it is not impossible. For example, if Alzheimer's disease has destroyed that part of the brain responsible for hunger and thirst, the process of dying has begun. Inserting a feeding tube would only prolong the dying process and could distract from efforts to provide comfort to both patient and family. Those of us who are guided by life's sanctity must also take responsibility to acknowledge its finitude and prepare for its ending.

There may be instances when one can use proxy quality of life estimates in a moral manner; I have certainly thought so in the past. Upon reflection, though, I must agree with Ramsey. There are no instances, at least in the care of the elderly, where proxy quality of life measurements should be used to withhold treatment in non-dying patients. In allocating medical resources, therefore, I propose that we approach proxy quality of life ratings with extreme prejudice, recognizing that this model is a break from a long-standing emphasis on "sanctity of life" in Jewish and Christian ethics.

Singer is correct to question whether the "religious mumbo jumbo" behind the "sanctity of life" concept has any meaningful place in the health care system of an increasingly secular society. Some 3,500 combined years of Jewish and Christian emphasis on sanctity, however, would tend to lend credence to the utility of such an approach. It is also important to recall that poor quality of life has been invoked in practices we now find abhorrent — in the exposure to the elements of defective newborns by the ancient Greeks, allowing these infants to die, to the compulsory sterilization programs of the United States, to the euthanasia of the mentally ill in Nazi Germany.

Using "quality" instead of "sanctity" to guide

medical decision-making represents a new path for us, a departure from a tradition that has served to protect the outcast, the weak, the mentally challenged and the physically disabled. If we choose this new path, we will be reminded that controlling costs can sometimes come at the expense of justice. ■



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NOTES

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