

THE DANGERS OF QUALIFYING LIFE

Those of us old enough to remember the television series "Lost in Space" might recall the kindly robot who, whenever it perceived a threat or danger, would flail its robotic arms in all directions and announce, "Danger! Danger!" Such ought to be our reaction should the day come when we are standing in a hospital corridor, nursing home, or doctor's office, and hear a doctor, nurse, or (God help us) hospital chaplain invoke the criterion of "quality of life" as a factor in deciding who should live and who should die.

There is a certain mind-set that has surfaced in the last thirty or so years in medical practice that has become the prevailing way of thinking about medical care and medical decisions. This way of thinking was never voted on and never consciously adopted by the populace, and yet it has an almost total consensus. It incorporates a criterion for medical decision making that is known in the medical literature as "quality of life."

Defining Our Terms

Quality of life is easier to describe than it is to define. This is ironic, because it is invoked as a scientific concept and term by a field that prides itself in precise definitions. Yet there is no agreed-upon definition in the medical or bioethical literature for it—which at the very least is a threat to its validity. We therefore offer our own definition of quality of life as a criterion or even an ideology that governs many actions, especially medical decisions:

Quality of life refers to a subjective estimation of the value of human life based on extrinsic factors. Extrinsic as used here means "not essential or inherent; being outside of a thing; outward or external, on the surface."

People who have physical or mental impairments, who may have experienced a diminishment of abilities, who have become dependent, and so on, are invariably viewed as possessing lowered, little, or no quality of life. The very same factors used to determine quality of life have also been used to determine whether or not a person's life is worth living, worth preserving, or worth saving. In a "quick-fix" culture, if a person is not "reparable," or is chronically "broken," then his or her life lacks "quality."

The phrase "quality of life" was originally a research term that referred to a combination of conditions in a geographical area, such as quality of air, water, population density, availability of health care, and so forth. In other words, "quality of life" was, and still is, useful as an index to describe and compare the living conditions of populations. Why argue against its use in medicine? After all, we should care about the circumstances that affect our lives, so why not refer to those circumstances as affecting our quality of life? Because something is lost in moving from describing living conditions of a population to describing

circumstances of an individual person's life. In medicine, when quality of life is applied to a person, it tends to be interpreted as meaning the quality of the particular life (not the surrounding conditions), and is therefore misunderstood as meaning the value of a life. Quality of life used in this way loses its utility for Catholic Christians who believe that every human life is inherently sacred. The intrinsic worth of an individual life can never be diminished or enhanced by any measure of life's "quality."

Quality of life in medicine is often used as a factor in determining whether or not a medical treatment should be employed. Our eschewal of the term does not mean that we ignore the predictable effects of a medical treatment when making treatment decisions. But even in such instances, the phrase has little utility. Quality of life has become a catch-all term for conveying almost any meaning—and therefore no meaning. Doctors who may be reluctant to give specific negative predictions as to what effects a treatment might entail, may instead refer to a lessened "quality of life." Rather than say, "This fifth course of chemotherapy is likely to cause diarrhea, vomiting, muscle and bone pain, and extreme fatigue and has only a 5 percent chance of causing any improvement," a doctor might short-circuit the discussion by saying, "This treatment will not enhance your quality of life." The former explanation, while harder to discuss, conveys more information than an imprecise and value-laden use of the phrase "quality of life."

Given that "quality of life" conveys no real, precise, or useful information, and given that the term is likely to be misinterpreted as referring to the value of a life, we recommend that it be abandoned. When weighing whether a treatment is to be employed, the predictable effects of a specific treatment should be discussed in more concrete terms.

We often hear phrases invoking "quality of life" from people who would hasten death (by inappropriately withholding or withdrawing treatment). We know of one person who had Huntington's chorea (a disorder involving progressive degeneration of nerve cells in the brain) and was living in a nursing home. "Jane" was susceptible to respiratory infections, and on one occasion, when Jane had pneumonia, the nurse on duty asked Jane's advocate what he wanted them to do: Send her to the hospital, or "make her comfortable"? In other words, treat or not treat? If she was not treated, Jane would surely die. Treatment was requested, but at the hospital emergency room, the physician on duty asked the same thing: "What do you want us to do, given Jane's poor quality of life?" The decision to treat or not treat was to be based on the presumed (low) "quality" of Jane's life, and not on the benefit or the burden of the treatment measure. Jane got the treatment she needed, and lived for several more years.

Some Examples

Estimating the value of human life from a quality of life perspective is largely influenced by (a) the degree to which one makes autonomous choices, and (b) the development of communicative faculties—which would affect relationships, personal enjoyment, satisfaction, and personal



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fulfillment. There is a strong focus on the value of what the individual self wants. We are living in a society that argues, sometimes in court, often in hospital hallways, whether or not someone's life is worth living based on these factors.

Quality of life assumptions have serious implications for everyone, but especially for certain devalued people in our culture, because they are so commonly viewed as having a low quality of life. Such people—the poor, the handicapped, the “lower classes”—are usually perceived as obstacles to promoting the good of others, because they are thought to prevent others from achieving pleasure or enjoyment in life. Even normal human conditions, such as aging and pregnancy, or other common conditions such as mental retardation and dementia, have become viewed as “illnesses” that interfere with the attainment of pleasure or human fulfillment.

“Quality of life” reflects a mind-set about life's value that may be at work whether or not the term is said aloud. Another patient (whom we shall call “John”) had become septic from a staphylococcus infection of unknown origin. He was also mentally retarded. John was not terminally ill; rather, he had a serious, acute illness. John had only been in the intensive care unit for four days, and the conclusive test results were not in yet. The family and John's caregivers said they did not want to “see him suffer,” yet with the proper treatment, he might have recovered. John died following a decision by his family and his caregivers to withdraw a breathing tube and administer morphine. The decision to remove the ventilator was not based on the efficacy of treatment, but upon how John's life was valued—or rather devalued—because of his mental retardation. In his case, the quality of life mind-set—measuring life according to extrinsic factors—had deadly consequences.

People who value their autonomy tend to view dependency as an unbearable burden—that is why we fear getting old. The young and vigorous are assumed to have a better quality of life than the old and frail. A good quality of life means to most people freedom from illness and disability.

These are factors that may or may not improve one's circumstances. But the term “quality of life” has come to be used to characterize “life” itself, even so far as to describe a life judged to be not worth living because of its poor quality.

Ideas have consequences. Often, when a medical professional says that a patient has low (or no) quality of life, what he really means is that he believes the patient may be better off dead. Of course, most people who espouse quality of life concepts deny this, even to themselves, because wishing someone dead is an unpleasant thought that is typically below the surface of conscious thought. Often what triggers this idea is real or perceived suffering the person is enduring or is likely to endure in the future. The notion that no future is better than a future filled with or encumbered by suffering might be crossing the caregiver's mind. Or the thought might be that a person who relies on others to live, and perhaps extensively so, is a burden to others, and a burden that others should not have to bear. In this case, it may not be so much that the person cared for would be better off dead, but that those who will have to make sacrifices and provide care would be better off if the person were dead.

Whether the message is intended, the term “quality of life” implies that life's value can be measured according to extrinsic factors. This is simply untrue. Human life is sacred, and its intrinsic worth cannot be qualified.

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