Individual Versus Community: Ethical Issues in Quality of Life

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What is quality of life? It has been variously defined as happiness (Beckman & Ditlev, 1987), satisfaction, contentment and fulfillment (Calman, 1987), sense of well-being (Dalkey & Rourke, 1973), "privately known and privately evaluated aspects of life" (Andrews & Withey, 1976, p. 12). In the Spring 1994 issue of *Nursing Science Quarterly*, a number of articles discussed quality of life from various points of view utilizing nursing conceptual models. In a recent city newpaper story describing quality of life, criteria cited included reported AIDS cases in the community, bus ridership, type of garbage being sent to the landfills, crime and death-by-vehicle rates, among others. Clearly, quality of life means many things and may even be in the eye of the beholder. The focus here is to address quality of life from a resource allocation perspective, especially when interests of the individual and the community diverge, presenting an ethical dilemma for health care providers, and indeed, for the society at large. The situations presenting the dilemma are not when quality of life is on the positive end of the spectrum but, rather, when there is profoundly diminished life, which can be characterized as the negative end of the spectrum. In addition, conflicts can arise when quality of life is assessed to be at various points along the positive/negative continuum.

Various reports have shown that health care in the last year of life is extremely expensive (accounting for up to 1 in 7 of all health care dollars spent); similarly, trends in Medicare payments suggest increased expenditures (about 1% of the gross national product) for the elderly in the last year of life. Despite evidence that care of the very ill or the elderly is very costly, it cannot necessarily be concluded from such data that these expenditures are inappropriate or comprise misallocation of resources. Ethical problems arise when expensive treatments are provided with unknown or marginal utility, or when quality of life following a given treatment is diminished without the promise of improvement.

A debate is ongoing with regard to care of the elderly. For example, Callahan (1988) argues that in caring for the aged the goal should be improving quality of life rather than seeking ways to extend life. He proposes that we examine our notion of a natural life span, providing care and comfort to the elderly who are above age 75, instead of providing expensive and extraordinary care to prolong their natural life; he proposes that neither the elderly nor the young will be well-served if we allow continued escalation of costs and disproportionate allocation of health care funds to extend the life of the elderly (Callahan, 1988). Etzioni (1988), on the other hand, raises the specter of intergenerational conflicts that might result from Callahan's proosals and cites the "slippery slope" argument: once we abandon the precept of doing all that is possible to avert death, it becomes feasible to think about circumstances in which we might stop trying or might lower the age at which extraordinary measures cease to be taken. Also, Etzioni further proposes ways in which funds could be raised to provide care for the elderly to the ultimate extent possible.

Morreim (1994) discusses two groups which he thinks have profoundly diminished life: (a) permanently unconscious or demented patients who are not terminal and can survive for a long time with nursing care and nutrition, and (b) those who are terminally ill who will die with or without care. He views the quality of life for both groups as poor. He posits the arguments of futility (quantitative or qualitative), cruelty (invasive care that will not serve the goal of recovery), and wastefulness (with millions of citizens who do not have access to care, it is irresponsible for care providers to use costly resources in ways that do not promise to be fruitful).

Undoubtedly, some will argue that the elderly or individuals with diminished life have the right to receive vigorous health care and that respect for their autonomy requires this. Others might counter: that such individuals have a duty to die; that rights without responsibilities are detrimental to the larger good; that

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in our emphasis on individuality, personal choice and autonomy, we have failed to pursue an understanding of community; that individuals, in the exercise of their autonomy, need to place self-restraint on their behavior for the common good. Still others might say that in an ethic of care, people want to care for their loved ones, and that caregivers need moral and other support to do so. This means at the policy level that the focus is on providing what is needed to enable the caregivers to do the caring (Noddings, 1994).

Much emphasis has been placed on the need for individual practitioners to address and resolve ethical issues such as these. However, the scope of these ethical issues is too broad; since they concern society as a whole, they need to be addressed at another level. For example, in dealing with thorny issues, the professions can play a critical role beyond that of individual professionals engaged in public service. Rather, there is a collective professional responsibility to promote the common good. The professions can promote and enhance civic discourse about society's goals and can contribute to the process of democratic deliberation and moral debate; they can play an important role in guiding the terms of the dialogue for addressing and resolving compelling social issues. This is not a call for ideological advocacy but, rather, a cooperative search for a reasonable deliberative process that is respectful of a diversity of moral perspectives (Jennings, Callahan & Wolf, 1987). In this manner we may be able to evolve a communitarian vision of what is right.

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