DEVELOPING INSTITUTIONAL POLICIES TO OBViate AGONIZING OVER COMPLEX ETHICAL DILEMNAS

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On can hardly pick up a newspaper or magazine without seeing something starting off like “one of the most complex and wrenching problems we face... or technology has created problems which will become increasingly complex and force difficult and agonizing decisions to be made in the future”. Ethical dilemmas cause us to scrutinize and test our own values, our moral stances, our senses of professionalism, our sense of duty, our fear of exposure to liability and may shape the way in which we care for our patients in a dramatic way. When you put all these concerns together, no wonder it appears so difficult and even mystifying to address these ethical issues.

Most of these dilemmas or often associated with prolonged and ongoing chronic disease or those which involve the ongoing diminishing of competence and ability to retain lucidity so characteristic of Alzheimer’s disease. Yet, often family members are told that therapeutic modalities must be continued despite what the patient has indicated. A distinctive characteristic of the Alzheimer’s patient is that while the prognosis may be hopeless in terms of one suffering an ongoing deterioration with no chance of remission, death is often not imminent. Most of the controlling case law over the past ten years has provided guidance when both death is imminent and the prognosis is hopeless. This, to some extent, still remains a concern. While some states and many institutions have redressed this to some extent through agents appointed through a durable power of attorney (while the patient is still competent), there are still problems where people appear to be prolonged against their earlier stated wishes or those of their families. Rather than perceiving pneumonia as “the old man’s friend,” pneumonia is now perceived as the basis for further interventions which may often compromise the patients wishes. I in no way mean to suggest that everyone would not want to have antibiotics or artificial feeding to prolong his or her life, only that we assure the same self-determination for Alzheimer’s patients as we do for other citizens in this nation rather than having them frustrate our sense of anticipating grief and their ability to better integrate loss into life. The result would, therefore, foster the prevention of disenfranchisement and the realization of greater autonomy and self-determination.

A critical component in this area which is often misunderstood is the importance and significance of patient self-determination and consent. We
frequently speak of "getting or obtaining" consents as if consent were a piece of paper we get which we then attach to the chart, and it's over and done with. Consent is often perceived as a legal transaction almost as if it were a form of contract. However, since clinical care is an ongoing and dynamic process, then consent itself must be dynamic and thus better attuned to the ongoing process of care when the patient and family are integrated into the decision-making process with continually renewed options for participation.

Interestingly, most of the more troublesome issues we face are extensions of informed consent. These often arise when one, when informed of the consequences, may choose a course we either disagree with or one with which we might agree but may perceive to be much more complicated than it actually is. This may occur because of misconceptions about what we must do and legal liability, questions and policies surrounding the removal of respirators, whether we are required to initiate feeding supports to one who is unable to swallow or whether we must give antibiotics to the severely impaired Alzheimer's patient against his earlier stated wishes or his family's currently stated wishes.

Consent allows for the performance of certain procedures in accordance with patients' wishes. This important ingredient is often misunderstood, particularly within the context of terminal illness or severely debilitating and progressively degenerative diseases. This is exacerbated or complicated when the competence of the patient is questionable or when the patient has been determined to be incompetent. At times, patients and family members feel their ability to make choices is jeopardized and clinicians feel uncomfortable making decisions in this area particularly when those decisions may involve the discontinuance of medically-supportive measures.

While making difficult decisions may be a necessary ingredient in the clinical forum, I have found that most of the ethical dilemmas of which we speak are indeed often avoidable when we gain appropriate understanding to develop administrative policies to diminish the incidence and breadth of these dilemmas through development of institutional policies so as to avert excessive fear. By having guiding policies which integrate national standards and guidelines with the distinctiveness of a given institution and institutional setting, we allow clinicians to get back to the practice of clinical medicine while better assuring the wishes of the patient and better insulating the institution against legal liability.

While removal of respirators and other life supports have been topics of major concern in tertiary care, historically, less attention has been paid to addressing these topics in long-term care settings. Recent legal decisions, however, have revived discussions surrounding removal of life supports with dramatic implications for nursing homes. Two very recent major court decisions in New Jersey and California have equated removal of feeding supports with removal of respirators. These decisions indicate that removal of feeding supports to hasten or assure death may be perceived as "appropriate care." These new decisions require a better understanding of surrogate decision-making and proper documentation which is now more critical than in the past.

Over the past ten years, certain guidelines for the discontinuance of life supports have been consistently used as precedents. Without belaboring the legal legacy, it is important to understand some of the other controlling considerations that are involved in removal of life supports of incompetent patients. Besides highlighting the key elements of these rulings, this article will discuss such vehicles for decision-making as living wills and durable powers of attorney as well as some discussion of proper documentations.