Ethical Issues: Futility Policies and Politics

In Texas Legislators are having second thoughts about a controversial futile care law that allows hospitals to unilaterally terminate life support in patients with end stage illness. Under the terms of the state's "futile-care law," if a hospital review committee feels that further treatment of a patient is futile they can ultimately withdraw treatment after giving a patient's family 10 days to find another facility who will accept them. If no accepting hospital can be found the treating hospital can then end treatment, even if the family objects. As a result several high-profile cases have turned Texas into a right to life battleground. Recently, legal action kept Memorial Hermann Hospital in Houston from withdrawing life support from a severely brain-damaged 29 year old woman, Kalilah Roberson-Reese. She now has regained some consciousness, responds to familiar voices and can sit upright in a chair, bringing into question the accuracy of diagnosing "irreversible brain damage" and the right of providers to unilaterally decide about the fate of patients.1 The Texas law has been on the books since 1999 but it's only in recent months that families of some patients with terminal disease have begun waging public battles against it. More than a dozen cases like Roberson-Reese's have surfaced, which prompted Texas lawmakers to reconsider and hold hearings this summer on possible amendments.

Flaming the debate is news coverage echoing the right to life debates of the 1970s (Quinlan), 80s (Cruzan), and 90s (Schiavo). The earlier debates set historical precedent and pressed for the right of those with irreversible illness and debility to refuse unwanted and burdensome treatment. But now that hospitals have been empowered to unilaterally withdraw treatment in such cases, sometimes against the wishes of the family, the autonomy debate seems to have swung back toward the question of patients’ “positive rights” of being protected from harmful and unwanted withdrawal of treatment, rather than the “negative rights” of refusing unwanted and life sustaining treatment.

Some have argued that these decisions may be financially motivated. According to the director of Texas Right to Life, Elizabeth Graham, quoted in the Chicago Tribune, "... it does seem that the majority of patients or families calling us for help are either uninsured, underinsured, or they have Medicaid." The article also identifies disability groups who have opposed the futility law fearing that people who don't see the value of living with disability may determine that because life is too burdensome and thus not worth living, further treatment would be futile for some patients.
This public controversy is one that is unavoidable when decisions about the welfare of patients are extracted from those directly involved at the bedside and thrust into the abstract realm of institutional policy. Considerations of futility are a clinical calculus with medical and moral implications that provide physicians and other members of the health care team, along with the patient or their families, a means by which to explore the moral permissiveness of withholding or withdrawing treatment. i Futility must take into consideration the medical effectiveness of treatment, prognosis, the moral beliefs and preferences of the patients, caregivers and other family members, as well as the moral beliefs and professional influences of health care providers--but to be ethically applicable it must remain at the bedside as a personal and unique moral consideration of the physician-patient-caregiver unit of care.

Futility policies created in institutions to address decisions about withholding or withdrawing treatment on the grounds of futility should be crafted and utilized cautiously, recognizing that good clinical outcomes equate to more than biomedical success or economic savings. Futility policies should function as guidelines that will support and encourage the relationships between patients and their providers, avoiding wording that may institutionalize or regiment decisions in such a way that will remove critical and individualized decision-making from the hands of the physician – patient unit. Organizational policies and guidelines that dictate the determination of futility would do well to incorporate an understanding of charity, not utility, as the final principle and ultimate virtue of care for the dying.

i Witt H. Who gets to make decision on end of life? Chicago Tribune. September 17, 2006