

Reasoning through the rationing of end-oflife care

January 19 2010

Acknowledging that the idea of rationing health care, particularly at the end of life, may incite too much vitriol to get much rational consideration, a Johns Hopkins emeritus professor of neurology called for the start of a discussion anyway, with an opinion piece featured in this month's issue of the *Journal of Medical Ethics*.

In the January article, John Freeman, M.D., Lederer Professor Emeritus of Pediatric Neurology and a faculty member of the Johns Hopkins Berman Institute of Bioethics, asks the Obama administration to consider rationing end-of-life care as an initial step towards healthcare reform.

The piece, "Rights, Respect For Dignity And End-Of-Life Care: Time For A Change In The Concept Of Informed Consent," starts with the premise that futile and expensive care at the end of life is widespread, that it has been a major contributor to the increasingly unaffordable cost of healthcare and that the nation is unable to provide it equitably to all.

He goes on to say that while administering such care—as ordered through a living will, next of kin or parent—should be respected, he advocates that the ethical imperatives of "patient autonomy" and "surrogate autonomy" (passing responsibility for decision-making to next of kin when a patient no longer is competent to make his own decisions) should be weighed against the societal impact and costs of such care in futile circumstances.



"Perhaps when surrogate autonomy and the ethical principles of beneficence"—the duty to do more good than harm—"compete with the utilitarian principle of doing the greatest good for society, the family be given a 'nudge' towards comfort care only," Freeman suggests in the piece.

"There must be few situations more undignified, more dehumanizing or more humiliating than lying in bed, incontinent, tube fed, with or without a respirator, unable to speak or to relate to individuals or the environment," Freeman says, factors that more surrogates may want to give more weight.

Rationing and providing only comfort care should be considered not just at the end of life for adults, Freeman maintains, but also in instances of extremely premature births. He cites studies showing that intensive care for infants born at 22-23 weeks resulted in more than 1,700 extra days in intensive care, with less than 20 percent surviving. Of those 20 percent, less than 3 percent survived without profound impairment that required expensive interventions.

Provided by Johns Hopkins Medical Institutions

Citation: Reasoning through the rationing of end-of-life care (2010, January 19) retrieved 19 April 2024 from https://medicalxpress.com/news/2010-01-rationing-end-of-life.html

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