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# Rights, respect for dignity and end-of-life care: time for a change in the concept of informed consent

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## ABSTRACT

The current concepts of autonomy, surrogate autonomy and informed consent often lead to futile and expensive care at the ends of life. They may impinge on the dignity of the patient as well as subject society to unwarranted expense. In order to provide affordable healthcare for all, these concepts are in need of modification.

...[T]he purpose of informed consent is to ensure that no one is coerced or deceived. —O'Neill<sup>1</sup>

The most serious threat to Americans' access to care [is] rapid growth in healthcare costs... Most observers think that only by rationing beneficial care or making draconian price cuts can we slow the costs. —Fischer<sup>2</sup>

...[E]verything we do in a budget prevents us from doing something else we also care about. —Lamm<sup>3</sup>

As President Obama's team develops a new healthcare plan that will be fair, equitable and affordable, it is time to realise that our current care is increasingly unaffordable and providing healthcare equitably to all will break the bank. We cannot continue to have all our demands met; thus rationing of care will become a necessity.

I would propose that an initial step might be to apply rationing to end-of-life care.

## END-OF-LIFE CARE

End-of-life care accounts for a disproportionate share of medical costs. One article noted that from 2001 to 2005, a national average of US\$46 412 per patient was spent on chronic illness in the last two years of life.<sup>4</sup> They noted the large discrepancy in cost between caregivers: New York University Medical Center averaged US\$105 000 per patient in the last two years of life; UCLA US\$94 000, Mayo Clinic US\$53 000. Most of this money was spent in acute inpatient settings, the amounts varying with the volume of services provided: length of time in intensive care, number of specialists consulted, and the number of tests performed—all without impact on mortality rates. Similar results have been reported by others. Although some of these tests may be done because of fear about malpractice and others to enrich the physician, a portion of this expense is due to misperceptions about autonomy and surrogate autonomy regarding informed consent.

A patient's right to autonomy and surrogate autonomy are clearly established in the field of medical ethics, but there are disagreements about the origins and meanings of these rights<sup>5</sup> Does a person have the right to die with dignity? Clearly,

but what constitutes a dignified death? David Luban, in his Isaac Franck Memorial Lecture titled *Human dignity, humiliation and torture*<sup>6</sup> discusses the problems with 'rights' and citing the Helsinki Charter notes that rights "derive from the inherent dignity of the human person...", dignity is a property of relations between human beings, "respecting human dignity means not humiliating people". Although his lecture and its preamble are about the morality of torture, his thinking may equally be applied to end-of-life issues, to individuals in coma or a persistent vegetative state when treatment would be futile or virtually futile. There must be few situations more undignified, more dehumanising 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?

Ethical teachings in medicine emphasise autonomy and allow the patient, when in a competent mental state, to write a living will determining his or her preferences for future care. This decision-making power termed surrogate autonomy, may be shifted to another individual through a power of attorney or when the patient is no longer competent to the next of kin.

Should we modify the concept of the primacy of surrogate autonomy? Perhaps the concept of autonomy itself should be modified when applied to end-of-life decisions when beneficence, the duty to do more good than harm, suggests that further treatment may be futile?<sup>7</sup>

Rationing and decisions about providing only comfort care should not be limited to the elderly. Studies document that providing intensive care to infants born at 22–23 weeks resulted in more than 1700 extra days in intensive care with less than 20% of the infants surviving. Of those 20%, less than 3% survived without profound impairment. Costs per day were approximately US\$3400. The authors conclude that, "extending intensive care to all the most immature infants would entail considerable suffering, resource use and cost in order to benefit only a small proportion of infants".<sup>8,9</sup> They did not add the huge lifetime costs of caring for and educating the handicapped survivors.

In another article, a paediatric intern caring for a devastated, very premature infant writes of her moral distress and asks, "Why do we continue to keep this child alive...? Has our technology outpaced our ability to make ethical decisions about life and death...? What are the best interests of the child? Of the family...? Should a family with unrealistic expectations for survival and recovery be allowed to make medical decisions?"<sup>10</sup>

## Teaching and learning ethics

Decisions about end-of-life care, whether for the incompetent, the comatose, or the newborn should not be bound by autonomy of surrogate autonomy. Often such decisions are dependent on how the questions of informed consent are framed.<sup>11 12</sup> O'Neill<sup>1</sup> states, "...the purpose of informed consent is to ensure that no one is coerced or deceived, and not to ensure that autonomous choices are respected". Perhaps when surrogate autonomy and the ethical principles of beneficence compete with the utilitarian principle of doing the greatest good for society, the family be given a 'nudge' towards comfort care only?<sup>13</sup>

In 1999, Richard Lamm,<sup>3</sup> the former governor of Colorado, eloquently stated the ethical dilemmas and fiscal problems of our current healthcare system: "Individual-centered ethics," he maintains, "are incompatible with maximisation of the social good,...[We]...cannot have unlimited healthcare with limited premiums and limited taxes... As a society we must begin to re-think our priorities in healthcare". As the administration begins to expand healthcare for all, perhaps the time has come for that redrawing.

**Competing interests:** None.

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