At the end of life, who gets the last word, doctor or family?

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If you're a competent adult and if you *don't* want life-sustaining treatment, there's no doubt about who decides when enough is enough. The final word is yours. No one is entitled to intermeddle with your body against your wishes. On this issue, the principle of patient autonomy trumps all. Others may think your decision to refuse treatment unwise or even foolish; but it's your call.

So much is established in Canadian law: see the famous case of Nancy B., decided by the Superior Court of Quebec, in 1992. Moreover, if you have a living will ("an advance directive") or appoint a surrogate decision maker ("give durable power of attorney"), then your treatment refusal must be respected even after you've ceased to be competent.

What hasn't yet been clearly established is whether you or your family also have a right to compel doctors to provide you with life sustaining treatment when the doctors believe that such treatment would be futile or even harmful.

Professional standards of medical practice are set by the College of Physicians and Surgeons in each province. Interestingly, the Manitoba College is the first to tackle the challenge of setting ethical guidelines for withholding and withdrawing life-sustaining treatment. These guidelines apply only to Manitoba; but they could become a template for doctors across Canada. Here, in essence, is what they say.

When a patient is so brain damaged that he cannot achieve either self-awareness or awareness of his environment then it is ethical for a doctor to take him/her off life support and provide, instead, comfort care. "A physician cannot be compelled by a patient …or member of a patient's family to provide treatment that is not in accordance with the current standard of care."

Quite rightly, the Manitoba guidelines require that doctors communicate openly and honestly with the family of an incompetent patient. Where possible, a second medical opinion should be sought. Discussions will often include not only doctor and family but also nurse, social worker, chaplain and hospital ethicist. The aim or goal is to achieve consensus. In the great majority of cases this is achievable.

But, in those exceptional cases where no agreement can be reached, the doctor is entitled to withhold or withdraw life-sustaining treatment – whether it's CPR, kidney dialysis, respirator or ventilator. This does not mean, however, that the doctors have the last word. If the family disagrees with the doctors' decision then they have the option of going to court, as is happening currently in the Winnipeg case of Mr. Samuel Golobchuk.

Key to understanding the guidelines is the following distinction: "A patient is not just a physical being, but a person with a body, mind and spirit expressed in a human personality of unique worth". The implicit value judgement here is that aggressive lifeprolongation is not always beneficial. When extensive brain damage has destroyed personhood, leaving mere biological life, then life-prolonging treatment is futile and may even be harmful to the patient. In my view, this value judgement offers a sensible and humane basis for physician ethics.

Doctors are inevitably the gatekeepers for patient access to medical resources. You can't obtain restricted medicines unless a doctor is willing to write a prescription; you can't gain admission to hospital, unless a doctor decides that you will benefit thereby. There is a scarcity of intensive care beds; so, to admit or keep patients in the ICU who cannot benefit is to rob others who could benefit. Put simply, one person's provision is another person's deprivation. It's unethical to waste scarce life-saving resources.

If a patient will never again know who or where he is, as appears to be the case for Mr. Golobchuk, then artificially to prolong his breathing seems at best a waste of precious ICU resources and at worst a cruel ordeal for the patient.

Doctors and nurses are not simply technicians providing marketplace services to customers. They are health care professionals who are bound by the ethical obligation "first of all, do no harm". When a patient has irreversibly lost self-awareness then employing medical high technology in a vain attempt to resist death is often experienced by doctors and nurses as both unprofessional and deeply demoralizing. Physician integrity includes the right, even the duty, to say "no" when treatments offer no genuine benefit to the patient.

Before concluding this brief discussion, I should consider a few of the more unusual arguments being advanced in court by the lawyer for the Golobchuk family.

The family, it's claimed, wants a "natural" death for Mr. Golobchuk rather than an artificial death. Apparently the family believes that it's natural to die in an ICU, intubated from every orifice, surrounded by rotating teams of anonymous strangers.

The family also argues that if ICU doctors "pull the plug" on Mr. Golobchuk and death results then the doctors will be guilty of "murder". If the court agrees with this claim then thousands of Canadian doctors should prepare to stand trial for murder. Now, it's true that most often when doctors discontinue life support they do so with the consent of the patient and/or the family. But consent is no defence to a murder charge.

Finally, Mr. Golobchuk's children, who are orthodox Jews, are relying upon the guarantee of religious freedom contained in the Canadian Charter of Rights and Freedoms. According to their understanding of Judaism, every moment of every life is infinitely precious, regardless of its quality. Thus, every life should be maximally prolonged by whatever means are necessary. The implications of this view for our health care system would be dramatic, not to say potentially bankrupting. Heart transplants for 90 year old patients with metastatic cancer? Intensive care wards filled with patients who can never regain consciousness because their cerebral cortex has turned to mush? One may be forgiven for doubting the proposition that religious freedom includes either the right to make unreasonable demands upon our health care system or the right to compel doctors to act against their professional conscience.

At the end of the day we may all be forced to accept some fundamental truths: death is inevitable; health care resources are limited; health care professionals have an obligation to steward those resources; and patients and their families must try to understand what a modern health care system can realistically offer.

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