

Occasional essay

The elephant in the living room. Ethics as a screen for covering one's butt

As an anthropologist studying end of life issues in an American surgical ICU, I observed the following case:

"He's going downhill" said the intensivist on morning rounds, making a diving motion with his hand, adding "We're treating the family. If we treat all the way, we could keep him alive for months".

Mr. James, aged 63, was obese, diabetic, in acute renal failure, with vancomycin-resistant enterococcus, and had a perirectal abscess with necrotising fasciitis extending to the scapula. The nurses reported that they needed lined baskets when cleaning the wound, because the transporters who held him open would vomit. Intensivists, fellows, residents and nurses all agreed that Mr. James was being kept alive "mainly by electricity", as one nurse disapprovingly observed.

Each intensivist, who came on service for a week, agreed there was no hope of survival. Nevertheless, the two grandchildren, with whom the patient lived, refused to consider discontinuing aggressive treatment. His daughter, who came from her home in another state, had agreed to shift the patient to "comfort care", but the grandchildren, aged 18 and 21, insisted that there would be a miracle and their grandfather would recover. Their mother deferred to their opinion (the nurses suspected their persistence was influenced by Mr. James' veteran's pension). After six weeks in the unit - at a base rate of \$1500 a day, covered by public assistance - the patient died. The grandchildren wanted him "shocked" and were upset when they were told this would not revive him.

The nurses were upset about continuing heroic measures for a patient whom everyone agreed would not leave the unit. "It's the doctors who supposedly make the decisions", said one, "but here, it's the family". When I asked the doctors who made decisions in a case like this, they equivocated. One, whom I overheard saying to a colleague: "I'm about ready to throw my hands up", did not discontinue treatment. When asked about the issues involved, another responded "What issues?" and hurried off. "Well, all the doctors have to agree", explained several others, but when I pointed out that they did agree about Mr. James' prognosis, they changed the subject. One of the ICU co-directors, whom I questioned about the unit's policy in such cases,

responded "That's an interesting issue", and promised to schedule a conference on decision-making at the end of life. No conference was held at that time. When cornered, another doctor finally admitted that in today's climate doctors and hospitals are deathly afraid of being sued, and of family members going to the newspapers saying "they killed my grandfather!"

This is the only time, during more than 18 months studying this unit, that a doctor mentioned fear of lawsuits and unfavorable publicity. And he did so only when cornered. A cynical resident told me that poor neighborhoods are filled with lawyers 'trolling' for clients to sue hospitals when a family member dies. Perhaps the doctors discussed such fears with one another but they were not about to allow an outsider to penetrate "backstage". Instead, there was much talk of ethics and "autonomy", as though permitting family members to keep a patient going as long as possible was exercising that person's autonomy.

I observed similar cases during my 18 months studying this unit, where even one recalcitrant family member had the power to subject dying patients to prolonged treatment. Ethics was used as a screen to cover fear of legal and public relations repercussions and dying patients were "punted" from one intensivist to another on call the following week.

Similar mechanisms have been described by Institutional Review Boards, where the notion of "ethical review" is used to cover liability and legal issues, as well as individual and institutional risk management.^{1,2} "Ethics" becomes a screen for covering one's butt. This is the elephant in the living room: everyone knows it is present, but it is rarely discussed openly. As one observer comments: "The regulations that were intended to increase accountability have been transformed into routines that decrease culpability".³

Such fears are, of course, justified in the United States of America, where every state has different laws, and it is impossible to predict how judges will rule, and politicians weigh in, delivering media "sound bites" when an obdurate family member goes to court to demand that a hospital continue care.^{4,5}

American bioethics stresses the values highlighted in American culture; the emphasis is on individualism, autonomy, activism, and self-determination as opposed to connectedness, community, caring, and interdependence. *Individual rights* are accentuated and *social responsibilities* downplayed.^{6,7} American medicine subscribes to the same value-complex. One observer describes American doctors' "imperative to intervene", noting that British physicians pay more attention than their American colleagues to the comfort and well-being of patients. Attitudes toward death differ as well. A British physician describes why hospices for the dying

grew up first in Britain rather than America: "To accept the idea of hospice, one must accept the fact that people die" and "in the UK we strive less officiously to keep alive".⁸ American surgeons provide the quintessential example of the aggressive American "can-do" approach; when a treatment fails, the solution is to be more aggressive.⁹

American families share these values. Encouraged by media descriptions of medical "miracles", family members have been known to ask for a "brain transplant" when told that a patient is brain dead.¹⁰ When technology has the capacity to keep a patient going for weeks, even months, some family members are going to insist on "doing everything". Death becomes a medical error, to be redressed in the courts.

Ethicists have noted that "autonomy", originally a response to extreme paternalism, has shifted from a moral good to a "moral obsession".^{11,12} Moreover, "autonomy" has been defined by American legislators as a moral good that can be *transferred*, delegated to surrogates.¹³ Family members are asked to make decisions that, because of the incommensurability of medical and lay knowledge, they are too often ill-equipped to comprehend.¹⁴ "End of life decisions require detailed knowledge of physiology and disease processes, as well as an understanding of medical knowledge". A choice about assumption of risk for the possibility of statistical benefit is translated by family members into the choice of doing something so that the patient will live versus the option of giving up and "pulling the plug".¹⁵ Small wonder, then, that many surrogates opt for "miracles".

The situation is very different in New Zealand, where I studied a medical-surgical ICU. National and medical values differ: community, social responsibility, egalitarianism, and consensus are stressed, as opposed to the American individualistic ethic. Moreover, the New Zealand intensivists I studied had gone to court to obtain a decision, in the case of a patient who had lingered in the unit for almost a year, that permitted them to discontinue treatment with no fear of legal repercussions.¹⁶⁻¹⁸ End of life decisions were made by the doctors, as a group, and were then presented to the family, with intensivists emphasizing that it was not they nor the family, but the disease, that was killing the patient. The intensivists spoke in terms of "not prolonging the dying" rather than asking whether or not to allow the patient to die. When necessary, successive meetings were held until a recalcitrant family did, indeed, agree to shift from aggressive treatment to comfort care. The doctors appeared concerned with the ethical ramifications of their work, and would discuss thorny questions to determine the best course of action.

Rather than employing ethical *terms*, they discussed ethical *issues*.

Although I visited Australia more than 20 years ago and talked with doctors, I do not know how end-of-life decisions are arrived at in ICUs there. I wonder: is there an elephant in the Australian medical living room?

My thanks to Dr. Stephen Streat and Dr. Timothy G. Buchman for help with legal and medical details. However, I bear complete responsibility for the opinions expressed.

J. CASSELL

Department of Anthropology, Washington University, St Louis, UNITED STATES of AMERICA

REFERENCES

1. Gunsales CK. Human subject regulations: Whom are we protecting from what, and why? Working to align incentives with ethical goals. *Prof Ethics Rep* 2003;XVI:1-3.
2. Fitzgerald M. Big basket or mission creep? *Prof Ethics Rep* 2004;XVII:1-3.
3. Staffen L. Heroic medicine, physician autonomy, and patient rights. *Law Soc Inq* 1994;19:757.
4. http://www.miami.edu/ethics/schiavo_project.htm
5. Helga Waglie's ventilator. *Hastings Cent Rep* 1991;21:23-24.
6. Fox R. The evolution of American bioethics: A sociological perspective. In: Weisz, G, editor. *Social Science Perspectives on Medical Ethics*. Philadelphia, U. of Pennsylvania Press, 1991, pp. 201-217.
7. Callahan D. Minimalist ethics. *Hastings Cent Rep* 1981;11:19-25.
8. Payer L. *Medicine and Culture: Varieties of Treatment in the United States, England, West Germany, and France*. New York, Henry Holt and Co. 1996, pp. 121-129.
9. Cassell J. *Life and Death in Intensive Care*. Philadelphia, Temple U Press, 2005, pp. 73-79.
10. A request by a patient's spouse in the ICU I studied.
11. Veatch R. Autonomy's temporary triumph. *Hastings Cent Rep* 1984;10:38-40.
12. Callahan D. Autonomy: A moral good not a moral obsession. *Hastings Cent Rep* 1984;10:42.
13. Meisel, A. *The Right to Die*. New York, John Wiley and Sons, 1989.
14. Kaufman SR. *And a Time to Die: How American Hospitals Shape the End of Life*. New York, Scribner, 2005, pp. 34-7.
15. Drought TS and Koenig BA. 'Choice' in end-of-life decision making: Researching fact or fiction? *Gerontologist* 2002;42:115-120.
16. *Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235.
17. *Shortland v Northland Health Ltd* [1998] 1 NZLR 433.
18. *Auckland Healthcare Services Ltd. v L & L* [1998].