

## Bioethics? A grand idea

When Mahatma Gandhi was asked about American democracy, he said he thought it a grand idea and hoped, someday, Americans might try it. A devastating critique, gently delivered, it is how I think of bioethics, a good idea we await rather than one we have instituted.

Beginning in the 1960s, a group of medical amateurs skilled in moral philosophy hijacked medical ethics, creating a “bio-ethic” based on simplistic readings of enlightenment philosophers. The result is more often a liability than a boon to patients and medical personnel alike. We see the ethic’s outline in the endless tomes of the discipline, and the dissertations of the students indoctrinated through them. The limits of bioethics are evident in the policies its professionals assert in hospitals and clinics, and research facilities, today.

In a career that now spans 2 decades of work with the fragile and their families, I can state categorically that I’ve never found the standard principles of bioethics useful in my work. More often, I find they serve as an excuse for behavior contrary to the client’s long-term health and interest. Simply put, 19th-century philosophy does not translate easily into practice at the 21st-century medical centre or patient bedside.

Consider: As its guiding principles, bioethics asserts first the autonomy of the individual and secondly a right to self-determination. Here the trouble begins. Autonomy is a fiction. We are not feral creatures, but, by nature and evolution, members of a communal and interrelated species. Medical ethics is never about the individual, but instead concerns the often conflicted, confused congress of familial, institutional and medical persons involved in a person’s care.

Similarly misguided is the ideal of self-determination that assumes a person’s ability to choose between complex procedures and possible outcomes. To be meaningful, self-determination assumes

an understanding of medicine and choices that few patients can claim. At the extreme, we ask patients to choose between states requiring long-term medical care — life in a wheelchair, with a colostomy bag, etc. — and no life at all. How do they make this choice without a detailed understanding of what the resulting life might be?

With no experience, and regret over the loss of a lifestyle they have lived, many choose to die. And yet, every study I have read of persons who have transitioned from thoughtless normalcy to conscious disability asserts that, in time, the majority find their newly constituted lives more than worth living. Some academics call this the “disability paradox.” There is no self-determination without knowledge and no knowledge without experience. An ethics asserting self-determination in such conditions is no ethic at all.

Similarly, bioethicists assert beneficence (doing good) as a principal virtue. I’m all for “good,” but the question is: Whose good are we talking about? Is it “good” that we terminate 90% of all fetuses with Trisomy 21? As a principal, beneficence is typically employed less about the patient or person’s good than society’s. It is a means of arguing patients should give blood and DNA samples, and participate in drug trials that will help others, but not the patient him or herself. In application these days, bioethics is mostly a rationale for institutional objectives rather than patient desires and needs.

If bankrupt at the level of principled thought, bioethicists become positively dangerous in action. In cases from Toronto, Ontario, to Vancouver, British Columbia, in Honolulu, Hawaii, and elsewhere in the United States where I have consulted, bioethicists have served more often as apologists for questionable medical decisions than as advocates of patient (or surrogate) interests.

The problem is we have an advancing, 21st century medicine wrapped in a 19th century economic vision,



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encapsulated in the simplistic application of 18th and 19th century philosophers. We need a robust medical ethic that matches the science we strive for and the care we are capable of as a society, one that acknowledges diversity rather than asserts normalcy as an ideal. Ethics, like medicine, must promote the care and best interests of the patient rather than those of industry and institutions. To paraphrase Ghandiji: I’m all for a robust bioethics and look forward to its development.

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