Human values in health care: trying to get it right

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n most medical specialties discoveries and advances are made every year. Bioethics is a field that evolves more slowly. After all, it is mainly concerned with how we treat one another, with standards, or norms, of

"right" and "wrong" behaviour, and with our relationships with patients and colleagues. The age-old questions at this "micro-level" of ethics

do, nevertheless, change slowly over time. No longer is paternalism or a "doctor knows best" attitude an acceptable expression of the duty of beneficence. No longer can we justify not telling our terminally ill patients their prognosis on the grounds that it is not in their best interest to know. No longer do physicians believe that getting close to a patient's vulnerability is unprofessional and to be avoided. The conceptualization of health care delivery as team work is gaining acceptance, and brings with it increased respect for the contibution of each person involved in the patient's care. Even the name of bioethics is changing: many now prefer the term "health and health care ethics."

Other evolving trends in bioethics can be discerned.

Contemporary health care ethics was founded on the principles of beneficence, nonmaleficence, patient autonomy and distributive justice, articulated in the classic work of Beauchamp and Childress.¹ Careful exploration of these principles in a Canadian context has led to the development of important new consensus statements in this country. Two are worthy of special mention. The 1984 *Joint Statement on Terminal Illness*, now renamed the *Joint Statement on Resuscitative Interventions (Update 1995)*,

embodies new ethical positions with respect to cardiopulmonary resuscitation.² The *Code of Ethical Conduct for Research Involving Humans*³ of the Medical Research Council, the Natural Sciences and Engineering Research Council of Canada and the Social Sciences and Humanities Research Council of Canada, now in the final stages of development, will stand as an authoritative guide for

Wired into bioethics

Here are a few of the many bioethics Web sites now available.

Canadian Bioethics Society www.bioethics.ca

Ethics Committee Core Curriculum (University of Buffalo Center for Clinical Ethics and Humanities in Health Care) wings.buffalo.edu /faculty/research/bioethics/CC.html

Ethics Updates http://ethics.acusd.edu/index.html

Provincial Health Ethics Network (Alberta) www.phen.ab.ca

University of British Columbia Centre of Applied Ethics www.ethics.ubc.ca

University of Pennsylvania Center for Bioethics www.med.upenn.edu/~bioethic

University of Toronto Joint Centre for Bioethics www.utoronto.ca/jcb the ethical conduct of research in this country for decades to come. One hopes that it will be followed by the development of a formal process for the evaluation and accreditation of research ethics boards. As yet undefined, however, are ethics review guidelines for research proposals in alternative or complementary medicine.

The dominance of principles in ethics — principleism — is now being questioned, not because such principles are now less relevant but because they may fail to take contextual features or the meaning of relationships adequately into account. For example, a principlesbased analysis might lead to the conclusion that a given intervention for a dying person is inappropriate because it is essentially nonbeneficial. However, other considerations - such as the impending arrival of loved family members from afar ---

might provide a context in which the intervention seems appropriate. Thus, in addition to applying ethical *principles*, there is need to recognize the importance of virtues (e.g., compassion, patience, making time for listening) and the ethical importance of relationships or, in other words, the sharing of experience, as epitomized by the injunction "Don't just do something, stand there!" Indeed, *relational ethics* may be seen to be in balance, and sometimes in tension, with *principleism*. Some years ago,

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Duff described this as the difference between "close-up" and "distant" ethics.4

A comparable tension in health care ethics comes from the desire to balance duty-based Kantian deontologic ethics (by which each person is of equal moral value to every other person, and each person's life is beyond value or price) with outcome-based utilitarian ethics. For example, one may have a desire to respect a person's autonomous wish to have dialysis when, say, untreatable cancer is causing urinary obstruction: this is a duty-based response. Yet the realities of longer term outcomes may suggest that a lack of real benefit — or utility — should preclude such a use of limited resources. Both approaches are important: each is needed to interpret the other, and the physician's actions should be guided by a sensitive balancing of issues in the search for optimal understanding of a complex situation.

As the focal point of health care delivery moves to the community and away from acute care institutions, and toward a greater emphasis on health promotion and illness prevention, interest in applied ethics is moving toward the problems that arise in the provision of long-term and palliative care and care in the community. Ethics committees designed to serve the needs of institutions are less suitable for addressing issues in the home or community, and new ways of addressing these new and complex contexts are being developed. How does one cope with the ethical stresses in a home where different providers are acting independently - some for profit and some in the public sector? Where is the concept of the "health care team" in such situations? Who is best able to promote the best interest of the person needing care?

At the level of personal decision-making, the concept of patient autonomy must accommodate itself to the increasingly multicultural character of Canadian society. In some cultural contexts individuals may waive their personal autonomy in favour of the values, needs and concerns of the family group.

New methods for handling health care information are also engendering new ethical dilemmas. There is clearly much to be gained by new systems for studying health care outcomes using large amounts of aggregated, nonidentifiable data. There is also much to be gained by having one's own identifiable medical history available in an emergency to health care providers whom one has not encountered previously. New systems are being constructed in Manitoba and Alberta and can be anticipated across all provinces in Canada. But how do we cope with issues of privacy and confidentiality as this stream of information - presently no more than a trickle, given the inefficient systems on which it is currently recorded swells to a torrent? In ethical terms, how does one transmit full awareness of the fiduciary obligation of a trust relationship (such as between patient and physician) to third parties who have never met the individual whose identifiable data they are using? There are also unsolved technical problems that will have ethical implications.

The world of health ethics is evolving, and this article has not even touched on the broader issues of resource allocation at the institutional ("meso") or regional and governmental ("macro") level. As the Canadian health care system prepares itself for the future and governments make macro-allocative decisions every week, we may hope that Canada remains committed to the ethically defensible principles of the Canada Health Act, which provides for a single-insurer system, with no monetary obstacles at the point of entry and full coverage for all essential services. This would seem to be a bastion for the defense of what it means to be Canadian.

References

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Concours de dissertation

La Société canadienne du cancer Prix de dissertation sur l'oncologie ou la lutte contre le cancer

La Société canadienne du cancer (Bureau national) accordera un prix de 1000 \$ à la meilleure dissertation portant sur un sujet lié à l'oncologie ou à la lutte contre le cancer et rédigée par un étudiant inscrit à un programme de médecine de premier cycle au Canada. Les dissertations devraient avoir au plus 3000 mots et seront jugées en fonction de leur pertinence, de leur originalité et de leur mérite scientifique. On envisagera de publier les textes primés dans le JAMC.



Les textes doivent être présentés au plus tard le 30 janvier 1998.

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