Clinical review

Recent advances
Medical ethics

Peter A Singer

University of
Toronto Joint
Centre for
Bioethics,
88 College Street,
Toronto ON,
Canada M5G-1L4
Peter A Singer
*Sun Life chair and
director*

Recent advances in medical ethics? This may sound odd if your vision of medical ethics is the application to medicine of the Hippocratic oath. If, however, you believe that the goal of medical ethics is to improve the quality of patient care by identifying, analysing, and attempting to resolve the ethical problems that arise in the practice of clinical medicine,[1] the concept of "recent advances" won't come as such a shock. In this article I review advances in medical ethics in five areas—end of life care, medical error, priority setting, biotechnology, and medical ethics education—and anticipate two future issues, "eHealth" and global bioethics.

Methods

Any selection of "recent advances" in medical ethics will be somewhat arbitrary, but I took two steps to diminish this. Firstly, I selected topics featured in theme issues of major journals within the past two years. Of course, journals are inevitably "journalistic" about covering hot topics—especially where views are passionate and polarised. Secondly, to identify key articles, I searched the Science Citation Index, consulted with key informants, and attended international meetings. Although citation counts reflect influence on other publications, they may not reflect the clinical application of an idea.

I have included both advances in medical ethics and advances in medicine and science with enormous ethical ramifications. The topics span clinical medicine (end of life care and medical error), healthcare management (priority setting), science (biotechnology), and education (of medical ethics).

A discussion of common medical ethics topics for clinical readers can be found in the *Canadian Medical Association Journal*'s series on bioethics for clinicians.[2] Web pages on specific bioethics topics with links to online resources are available through the website of the University of Toronto Joint Centre for Bioethics.[3]

End of life care

The most important recent advance has been the emerging focus on the quality of end of life care and how to improve it. Although four of the five most widely cited studies on end of life care published since 1998 dealt with euthanasia and assisted suicide,[4–8] the concerns of dying patients relate to quality of end of

---

Recent advances

The emerging focus on the quality of end of life care and how to improve it

Development of the Tavistock principles, which serve as an ethical foundation for those working to improve medical error

Development of an ethics framework—accountability for reasonableness—for legitimate and fair decisions on setting priorities

Emerging consensus on the acceptability of stem cell research

The General Medical Council's requirement that medical ethics be a core subject in the medical curriculum and the development of a medical ethics curriculum

Emerging ethical issues include "eHealth" and global bioethics

---

life care—receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones.[7] Improvements in end of life care can occur at the clinical, organisational, and health system levels.

Clinical advances—The "education for physicians on end of life care" (EPEC) project is an ambitious effort to provide continuing education to US physicians. The innovation here is to shift the emphasis from training palliative care specialists (which itself is an important undertaking) to developing the clinical skills of all physicians who commonly care for dying patients. I have found the project materials useful in the care of my own patients.[9]

Organisational advances—Methods in quality improvement have been applied to end of life care. Probably the best examples are the Institute for Healthcare Improvement's collaborative on "Improving care at the end of life"[10] and the toolkit of instruments to measure end of life care.[11] Exciting future possibilities include report cards for hospitals and community agencies on quality of end of life care.

Health system advances—Quality of end of life care as an issue in the accountability of health systems (including indicators of quality of end of life care in national health information systems) is a vision for the future.

Medical error

The main recent advance is the development of the Tavistock principles, which serve as an ethical foundation for those working to improve medical error.

In November 1999, the US Institute of Medicine released a report on medical error, *To Err is Human.*[12] This prompted a vigorous response from President Clinton, including proposals for systems for reporting error and a centre for quality improvement and patient safety.

Ethical analyses have focused on the obligation to disclose and report error when it occurs.[13] However, disclosure, though important, does not provide a solid ethical basis for the development of a culture of safety in medicine envisaged by leading commentators on error.[14] The Tavistock Group's draft statement of "Shared ethical principles for everybody in health care" provides a solid foundation.[15] All the Tavistock principles are relevant to the problem of medical error, but the most important are:

● Cooperation with each other and those served is the imperative for those working within the healthcare delivery system

● All individuals and groups involved in health care, whether providing access or services, have the continuing responsibility to help improve its quality.

● In developing a culture of safety, clinicians will need to act as role models for their students by applying these principles themselves the next time they encounter a medical error. Healthcare leaders will need to "feel personally responsible for error" and "declare error reduction to be an explicit organisational goal, and [devote] a significant proportion of the board and management agenda … to achieving this goal."[16]

Setting priorities

The most important recent advance has been the development of an ethics framework—accountability for reasonableness—for legitimate and fair decisions on setting priorities.

Clinicians often find themselves in the role of manager—being required to set priorities—or affected by the decisions of others about priorities. Priority setting was called "rationing" 20 years ago, and "resource allocation" 10 years ago—and will be called "sustainability" 10 years from now, as our language about this problem becomes progressively sanitised.

In October 1998, the *BMJ* (with the King's Fund and others) sponsored an international meeting and published a special issue on "Priority setting: the second phase." The first phase had been based on "simple solutions," such as cost effectiveness analysis, on the assumption that it was "possible to devise a rational priority setting system that will produce legitimate decisions." The second phase "has followed the realisation that the idea of devising a simple set of rules

> ### The four conditions of accountability for reasonableness
>
> **Publicity**
> Decisions regarding coverage for new technologies (and other limit setting decisions) and their rationales must be publicly accessible
>
> **Relevance**
> These rationales must rest on evidence, reasons, and principles that fair minded parties (managers, clinicians, patients, and consumers in general) can agree are relevant to deciding how to meet the diverse needs of a covered population under necessary resource constraints
>
> **Appeals**
> There must be a mechanism for challenge and dispute resolution regarding limit setting decisions, including the opportunity for revising decisions in light of further evidence or arguments
>
> **Enforcement**
> There must be either voluntary or public regulation of the process to ensure that the first three conditions are met

is flawed" and focuses on the priority setting process itself.[17]

Daniels and Sabin have developed a framework—accountability for reasonableness—for this second phase of priority setting.[18] [19] To make legitimate and fair decisions on priorities, organisations must meet four conditions (see box).

Evidence that accountability for reasonableness has been influential includes 23 citations of the original article in the Science Citation Index (more than the most cited articles from 1998 found using a search for "rationing"[20] or "priority setting"[21]) and the frequency with which other authors refer to this work in the recent book based on the 1998 international conference on priorities in health care (an excellent summary of recent research in priority setting).[22]

Accountability for reasonableness provides guidance on how priority setting decisions should be made. This will need to be harmonised with careful empirical studies of how such decisions are made in different contexts. A fine example of this type of research is the case study of priority setting in the Oxfordshire Regional Health Authority, conducted by Hope and colleagues.[23] In his analysis of the case of "child B" Ham has shown how accountability for reasonableness can be effectively applied to the analysis of an actual clinical case.[24]

Biotechnology

A major recent advance is the emerging consensus on the acceptability of stem cell research. Several groups, including the US National Bioethics Advisory Commission[25] and the UK Nuffield Council on Bioethics,[26] have issued reports supporting stem cell research. These are only the latest in a series of important consensus documents on biotechnology such as the World Health Organization's guiding principles on medical genetics and biotechnology[27] and the Human Genome Organization's statement on benefit sharing.[28]

ARTHUR TRESS/PHOTONICA

Stem cells are "cells with the capacity for unlimited or prolonged self-renewal that can produce at least one type of highly differentiated descendant."[29] The clinical potential of stem cells is enormous, including neuronal repair, haematological reconstitution, and organ transplantation.[30]

From an ethical point of view, the problem with embryonic stem cells is that they are derived from human embryos. Opponents of embryonic stem cell research are concerned with the moral and legal status of the embryo and advocate a moratorium.[31] Proponents, however, focus on the potential benefits to patients.[32]

Recent reports suggest that adult stem cells can differentiate into developmentally unrelated cell types. This would mitigate the ethical tensions related to embryonic stem cells. Whether adult stem cells possess the same therapeutic possibilities as embryonic stem cells, however, remains to be determined.

Medical ethics education

The main recent advance has been the General Medical Council's requirement that medical ethics be a core subject in the medical curriculum and the development of a medical ethics curriculum.[33]

Although the undergraduate medical curriculum is a good time to introduce medical ethics, students may learn best when faced with ethical dilemmas in clinical practice. The best time to teach medical ethics may thus be during postgraduate education or continuing professional development. The Royal College of Physicians and Surgeons of Canada requires medical ethics to be taught as a condition of accreditation of a postgraduate programme and has developed model curriculums in various specialties.[34]

Many medical students and physicians resent the unbalanced, highly theoretical approach taken in some traditional teaching programmes in medical ethics (this is not necessarily characteristic of the UK curriculum). Performance based approaches are increasingly seen as crucial for the advancement of medical education, and this is no less true for teaching medical ethics. A particular challenge is to develop reliable and valid measures for evaluating performance, such as evaluation reports for medical ethics during training.

In all these efforts, educators should pay particular attention to how medical ethics is "taught" in the informal, "hidden" curriculum—arguably the most effective and least understood aspect of medical ethics education.[35]

Future issues

"eHealth"

The revolution in information technology will dramatically change medical practice. This subject raises many ethical issues, including confidentiality of electronic medical records, and the relation of clinical records to research and management of health systems. There will also be a dramatic change in the way physicians learn and access the medical literature. To address these issues, a code of ethics for "eHealth" has been developed.[36]

Global bioethics

In this era of advanced globalisation the problems of medical ethics can no longer be viewed only from the perspective of wealthy countries. Global bioethics[37] seeks to identify key ethical problems faced by the world's six billion inhabitants and envisages solutions that transcend national borders and cultures. An International Association of Bioethics has been formed,[38] and a discussion board on global bioethics has been launched,[39] and I invite readers to join the conversation.

Hans Kung has developed a conceptual framework for global bioethics that may serve as a useful starting point.[40] Amartya Sen's work on inequality provides a valuable foundation for initiatives in setting global priorities for health care.[41]

The relevance of global bioethics is obvious with respect to international research ethics (as evidenced by the controversy over changes to the declaration of Helsinki), global vaccine initiatives, or global health equity.[42] Global bioethics is also highly relevant in some less obvious areas such as end of life care—46 million of the 54 million deaths annually occur in low and middle income countries. Almost any debate in medical ethics today must give consideration to global implications.

1 Siegler M, Pellegrino ED, Singer PA. Clinical medical ethics. *J Clin Ethics* 1990;1:5-9.
2 Bioethics for clinicians. *Can Med Assoc J* www.cma.ca/cmaj/series/bioethic.htm (accessed 26 Jun 2000).
3 University of Toronto Joint Centre for Bioethics. Bioethics resources. www.utoronto.ca/jcb/ (accessed 26 Jun 2000).
4 Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med* 1998;338:1193-201.
5 Chin AE, Hedberg K, Higginson GK, Fleming DW. Legalized physician-assisted suicide in Oregon—the first year's experience. *N Engl J Med* 1999;340:577-83.
6 Emanuel EJ, Daniels ER, Fairclough DL, Clarridge BR. The practice of euthanasia and physician-assisted suicide in the United States—

adherence to proposed safeguards and effects on physicians. *N Engl J Med* 1998;280:507-13.

7   Singer PA, Martin DK, Kelner M. Quality end of life care: patients' perspectives. *JAMA* 1999;281:163-8.

8   Ganzini L, Johnston WS, McFarland BH, Tolle SW, Lee MA. Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *N Engl J Med* 1998;339:967-73.

9   American Medical Association: Ethics. EPEC participant's handbook. www.ama-assn.org/ethic/epec/handbook.htm (accessed 26 Jun 2000).

10   Institute for Healthcare Improvement. Collaboratives. www.ihi.org/collaboratives/completed/bts-endoflife.asp (accessed 26 Jun 2000).

11   Center for Gerontology and Health Care Research, Brown University. Toolkit of instruments to measure end of life care (TIME). www.chcr.brown.edu/pcoc/toolkit.htm (accessed 26 Jun 2000).

12   Kohn LT, Corrigan JM, Donaldson MS, eds. *To err is human. Building a safer health system.* Washington, DC: National Academy Press, 1999.

13   Wu A. Medical error: the second victim. *BMJ* 2000;320:726-7.

14   Leape LL, Berwick DM. Safe health care: are we up to it? *BMJ* 2000;320:725-6.

15   Smith R, Hiatt H, Berwick D. Shared ethical principles for everybody in health care: a working draft from the Tavistock Group. *BMJ* 1999;318:248-51.

16   Reinertsen JL. Let's talk about error. *BMJ* 2000;320:730.

17   Holm S. Goodbye to the simple solutions: the second phase of priority setting in health care. *BMJ* 1998;317:1000-7.

18   Daniels N, Sabin J. Limits to health care: fair procedures, democratic deliberation, and the legitimacy problem for insurers. *Philos Public Aff* 1997;26:303-50.

19   Daniels N, Sabin J. The ethics of accountability in managed care reform. *Health Aff* 1998;17:50-64.

20   Klein R. Puzzling out priorities—why we must acknowledge that rationing is a political process. *BMJ* 1998;317:959-60.

21   Olsen JA, Donaldson C. Helicopters, hearts and hips: using willingness to pay to set priorities for public sector health care programmes. *Soc Sci Med* 1998;46:1-12.

22   Coulter AS, Ham C, eds. *The global challenge of health care rationing.* Buckingham: Open University Press, 2000.

23   Hope T, Hicks N, Reynolds DJM, Crisp R, Griffiths S. Rationing and the health authority. *BMJ* 1998;317:1067-9.

24   Ham C. Tragic choices in health care: lessons from the Child B case. *BMJ* 1999;319:1258-61.

25   Shapiro HT. Ethical dilemmas and stem cell research. *Science* 1999;285:2065.

26   Nuffield Council on Bioethics. Stem cell therapy: the ethical issues. www.nuffieldfoundation.org/bioethics/publication/stemcell/p_0022221.html (accessed 26 Jun 2000).

27   World conference on science. WHO steps closer to its responsibilities. *Nature* 1999;398:175. (helix.nature.com/wcs/d04.html, accessed 26 Jun 2000).

28   HUGO Ethics Committee. Statement on benefit sharing. *Eubios J Asian Int Bioethics* 2000;10:70-2. (www.biol.tsukuba.ac.jp/~macer/benshare.html, accessed 26 Jun 2000).

29   Watt FM, Hogan BLM. Out of Eden: stem cells and their niches. *Science* 2000;287:1427-30.

30   Vogel G. Can old cells learn new tricks? *Science* 2000;287:1418.

31   Young FE. A time for restraint. *Science* 2000;287:1424.

32   Perry D. Patients' voices: the powerful sound in the stem cell debate. *Science* 2000;287:1423.

33   Teaching medical ethics. *BMJ* 1998;316. www.bmj.com/content/vol316/issue7145/fulltext/supplemental/1623/index.shtml (accessed 26 Jun 2000).

34   Royal College of Physicians and Surgeons of Canada. Bioethics curricula. rcpsc.medical.org/english/public/bioethics/bioeth.html (accessed 26 Jun 2000).

35   Hafferty FW, Franks R. The hidden curriculum: ethics teaching and the structure of medical education. *Acad Med* 1994;69:861-71.

36   Internet Healthcare Coalition. e-Health ethics initiative. www.ihealthcoalition.org/community/ethics.html (accessed 26 Jun 2000).

37   Potter VR. *Global bioethics.* East Lansing, MI: Michigan State University Press, 1988.

38   International Association of Bioethics. www.uclan.ac.uk/facs/ethics/iab.htm (accessed 26 Jun 2000).

39   University of Toronto Joint Centre for Bioethics. Discussion board on global bioethics. ots.utoronto.ca/cgi/utotsadmin/users/jcb/bb.cgi (accessed 26 Jun 2000).

40   Kung H. *A global ethic for global politics and economics.* Oxford: Oxford University Press, 1998.

41   Sen A. *Inequality reexamined.* Boston: Harvard University Press, 1995.

42   Feachem RGA. Poverty and inequity: a proper focus for the new century. *Bull World Health Org* 2000;78:1-2.

Great Aunt Rose

"You know Betty, they should have just taken my leg off. I was a young woman then, I would have coped with it but not now."Great Aunt Rose, my grandfather's oldest sister, was talking to my mother while I was eating my sticky iced gingerbread. I was 4 years old and just about the right size to be sitting at eye level with my great aunt's offending leg. I was incredulous. Perhaps it was because grown ups chopping off their legs seemed so bizarre to me that I remembered it for so long.

Her leg seemed enormous, tightly bound in a thick orange stocking, as it sat propped up on a leather poof. I have no clear recollection of what she looked like, but I fancy I can remember the leg.

My great aunt was 40 when she was pulled out of a bombed air raid shelter during the Clydebank blitz in March 1941. She was one of only two survivors. She sustained a severe crush injury to her lower leg and extensive soft tissue loss. She recovered and brought up her children and got on with her life. Over the years she had multiple operations and skin grafts to her damaged leg, and my mother remembered my aunt saying that the pain from the skin grafts was often worse than the leg pain. She became housebound when she could no longer bear weight on her damaged leg. She always seemed to have leg ulcers on her damaged shin and the district nurse was a frequent visitor.

I am working outside Britain now and, perhaps with homesickness for my old home town, I remembered her when I was researching the topic of quality of life measurements in children.[1]

I read that researchers in Ohio in 1993 who followed up patients with open tibial fractures and severe soft tissue loss found that those who had a below knee amputation had better quality of life measures than those with limb conservation surgery. The two groups were similar in terms of their mobility and function, but significantly more patients who had had limb salvage considered themselves severely disabled (P < 0.05). They also had more problems in performing occupational and recreational activities (P < 0.05).[2]

There are undoubtedly other papers which show that limb conservation surgery results in a better quality of life for the patient compared with an amputation, but I believe that difficult treatment decisions where there is no right answer have to be made with individual patients. When we have enough evidence of long term outcomes they can decide for themselves. Long term outcomes must include the day to day morbidity of pain, hospital visits, operations, possible complications, and outcome as an elderly person.

In 1970 Great Aunt Rose believed that she would have had a better quality of life if she had had her leg chopped off. Multiple operations, with immobilisation and chronic pain, had had a profound effect on her life. She believed that if the leg had been amputated it would have healed and she would have been mobile and pain free. Thirty years later and after a medical education, I can at least appreciate what she was talking about.

Elizabeth Clarke   *paediatric registrar, Singapore*

1   Clarke E, Sulaiman S, Chew FT, Shek LPC, Lee BW. Pediatric asthma quality of life questionnaire: validation in children from Singapore. *Asian Pac J Allergy Immunol* 1999;17:155-61.

2   Georgiadis GM, Behrens FF, Joyce MJ, Earle AS, Simmons AL. Open tibial fractures with severe soft-tissue loss. Limb salvage compared with below-the-knee amputation. *J Bone Joint Surg Am* 1993;75:1431-41.