

Chapter XXI

BIO-MEDICAL DEVELOPMENTS, ETHICS AND EQUITY

Bioethical issues at the turn of the millennium – a brief overview

1. Bioethical issues have become topics of increasing political, economic and social concern and have moved to the centre of global attention in recent years. Bioethical concerns encompass a wide array of issues related to medicine and the biological sciences. In relation to the human lifespan, they involve issues of contraception, abortion, research on embryos, treatment of genetically or congenitally disabled newborns and infants, the care of terminally ill patients, dying, and definitions and determination of death.
2. Questions that bioethics address at all human ages include the need and locus of responsibility for ethical constraints on medical research; the basis for patient-doctor relations; possible ethical tensions between health care for individuals and health care for populations; the conditions for consent to treatment in young children, mentally ill persons and persons who are distressed and frightened in emergencies; living wills and physician-assisted suicide; the family pressures surrounding the gravely ill; laws and regulations for organ harvesting; rights to health care; and the role of human rights in bioethics.
3. At the same time, bioethical issues address considerations of resources and distribution, including the distribution of scarce resources. This engages criteria of justice that take account of health needs, likelihood of maximizing benefit, patients' preferences, distributive preferences and the requirements of payers, and reject others, such as racially based preferences. In an international context, national practices to open or close health care to non-national groups is of particular relevance.
4. These issues are currently subjects of debate in the field of bioethics, among others. In recent years they have seized the attention of the public, the media, politicians, as well as scholars globally. Scholarship in bioethics is characterized by a broad academic perspective, including medicine, nursing, health-care professionals, philosophy, theology, law, economics, sociology, anthropology, psychology and history.

Bioethical issues of particular contemporary concern

5. Of especial relevance at this time are the uses of diagnostic, therapeutic and other new developments in genetics, including applications of the human genome project, the availability of a growing number of assisted reproductive technology procedures, human and xenotransplants, developments in alternative organs, technology for prolonging life and the regulation, both national and international, of biomedical advances.
6. Economic considerations arise in connection with progress in biomedical technology as well as the role of commercialization. Dilemmas arise when need is greatest in groups that, for resource reasons, either cannot lobby for a particular biomedical advance to be supported or pay for it once it is developed. The current status of the treatment and vaccines for the HIV/AIDS virus may be a case in point.
7. In view of the very high cost of medical developments, the need for them and for their financing may especially challenge national and international health-care budgets. Competition for health-care resources in the face of limited budgets may pit the demand for simple and inexpensive preventive and curative treatments for people living in poverty against the strong and growing demand for sophisticated technology.

Cultural responses to bioethical issues

8. Just as moral dilemmas in the field of bioethics are challenging to delineate and specify, their resolution continues to be problematic and contentious. In some cultures, it is the practice for physicians to withhold distressing information from patients with fatal diseases, but this practice can be interpreted as deception or prevarication in other cultures. Cultures vary in the priority they accord to the saving – or prolongation – of life. Cultures also vary in their degree of moral obligation to pay for the health care of those people who need but cannot afford to pay for treatment. Similarly, the formulation of health in a human rights context is culturally widely variable.
9. In view of cultural diversity, it is relevant to

consider whether there is a prospect of shared, common or universal approaches to bioethical issues. Some theorists in bioethics and proponents of pluralist societies question whether the search for universal ethics is not a form of moral imperialism, whereby one cultural approach prevails over others on the basis of a belief that its ethical standards and norms embody a universal moral wisdom and truth. Others, who favour moral relativism, contend that all moral positions are valid and that there are no simple ways to make moral choices between claims originating from different moral standpoints and cultures.

10. As the activities of medicine and related sciences become themselves increasingly universal, bioethical discourse has been called upon to seek clarification of the interrelationships of these various approaches with a view to identifying their complementary strengths and the potential for some common internationally and interculturably acceptable approaches to bioethics.

Four common moral commitments

11. A number of health-care practitioners have begun to accept four major general moral commitments common to a variety of cultures as a useful basis for considering bioethics in pluralist societies. Applications and acceptance of these four general moral commitments need to be both cautious and qualified, as all cultures do not apply them systematically. Some critics see such variation in judgments as a fatal flaw in the approach; proponents see it as advantageous because it can reflect the essential, contestable nature of moral judgments arising from conflicting moral values, and because it balances justified cultural variations with the need for some level of common moral commitments.

12. The commitments, formally termed “prima facie moral principles”, include **beneficence** (a commitment to benefit others); **non-maleficence** (a commitment to avoid harming others); respect for **individual autonomy** that is compatible with the larger group; and a commitment to **justice as fairness**.

13. This approach is not universally accepted in bioethics; however, there is growing acceptance of the importance of these moral commitments in the field of health care. Moreover, theorists who prefer alternative approaches to bioethics may accept these prima facie principles as a component of their own approach.

Consistency with other approaches: virtue ethics, feminist ethics, narrative ethics, casuistry and religious ethics

14. At the same time, proponents of the four commitments generally welcome alternative approaches, such as virtue ethics (that focus on good people); feminist ethics (that generally emerge from and support personal and emotional relationships); casuistry (that focuses on the application of general principles to particular cases on the basis of “paradigm” cases); narrative ethics (in which the cultural and historical context is the basis for ethical analysis); and religious ethics, which comprise the major approach in many cultures. Proponents of the four commitments consider these alternative approaches as compatible and complementary.

15. It is not unreasonable to hope that an approach that combines appropriate insights from each of the current systems mentioned could serve to form the basis for a core that addresses universal issues. A thumbnail sketch of elements from such an approach follows, using the examples of the bioethical issues outlined earlier.

New developments in genetics

16. New genetic discoveries may revolutionize the practice of medicine and humankind's perception of itself, of other forms of life and its interrelations with other forms of life. The identification and diagnosis of genetic contribution to many diseases is anticipated in the near future. Genetic therapies to correct and replace faulty genes are under development. Ethical issues are underscored by genetic manipulation, for which the four ethical principles or commitments may provide a sturdy foundation. These moral commitments may succeed in being honoured internationally, although their interpretation and the priority attributed to each may vary from culture to culture, and society to society. The aim of their proponents is to achieve some general universal moral commitment while preserving a respect for cultural variation, thereby avoiding the danger both of moral imperialism and of moral relativism.

Developments in genetics, beneficence and non-maleficence

17. To determine how much benefit can be expected and at what risk of harm cannot be provided by a computer programme or algorithm producing an uncontested moral

outcome, as harm and benefit are value variables about which individual, cultural and societal views will vary. Some societies are risk-tolerant and enthusiastically back research and development to pursue potential benefits; other societies are risk averse, preferring to forego the prospects of new benefits to avoid the risk of possible harms. The "precautionary principle", cited in favour of caution in the development of new genetics, may represent another interpretation of the principle or commitment to non-maleficence or not harming others. The principle is important to counterbalance and temper the enthusiasm of innovators. At the same time, excessive emphasis on the obligation not to harm can threaten innovation and the possibility of action to benefit others. It is likely that every action to benefit others carries a degree of risk of harm to some.

Developments in genetics and individual autonomy

18. It could be argued that the new genetics need also take account of the principle of respect for a person's autonomy. It is already widely agreed that such interventions must be voluntary. Respect for autonomy may, however, conflict with other moral commitments. For example, genetic testing of one person may reveal results that can avert harm to other members of that person's family, which conflicts with the patient's entitlement to confidentiality. Traditional medical ethics that provide for patient confidentiality and ascribe to it a very strong moral obligation also provide for exceptions when danger to others can be averted by breaking confidentiality. As genetic testing becomes more widespread, one possibility is to obtain prior agreement as a precondition from patients as to the release of genetic information to avert harm to their relatives in the case of specific findings. Such an approach would maintain respect for autonomy of the tested patients (they will know the conditions for testing before exercising choice) and acknowledge an associated obligation to benefit others with the results of medical interventions.

Developments in new genetics and justice

19. There may also come about a consensus that the new genetics should be subject to the criteria of justice, as well as concerns for distributive justice (fair distribution of scarce resources), rights-based justice (justice based on rights, including human rights) and legal justice (respect for morally acceptable laws) that are likely to be acknowledged by one culture or another as relevant moral systems of evaluation.

Assisted reproductive technology and the potential contributions of bioethics

20. Among a number of ethical issues raised by developments in the field of assisted reproduction technology (ART), the most pressing issues are likely to include disposition of embryos, views about ART as non-natural or immoral, and potential harm to women, mothers, donors and children born as a result of ART.

21. Once again, the four commitments provide a means to analyze such issues, although additional complexities may arise. With respect to embryo research and the concomitant disposition of embryos, the issue of "scope" may be more important than the substantive moral commitments, as there is controversy regarding the status of a human embryo and whether there are any rights to life attendant to that status.

22. If this issue is perceived as essentially a complex religious issue rather than a fundamentally moral one, clarification of such a complex religious dispute as this one may prove to be an area where bioethics can make a significant contribution to international debate by providing a simple moral framework while preserving respect for other world views.

23. Bioethics may also help to address differing views of ART as "unnatural", by guiding such considerations through a more formal analysis of the meaning of unnatural, whether it is understood to mean "against nature in a morally undesirable way", and what is and is not morally undesirable.

24. Assisted reproductive technology also introduces feminist approaches to bioethics, because women are primarily concerned by the process and also because many issues raised by ART concern relationships and their moral implications. For example, people may perceive a difference between a woman bearing a baby for a sister or a friend unable to bear the child herself, and a woman who does so in order to earn a living. The difference may be explained in terms of the special relationships and moral commitments of sisters and friends, with the relationships they engender, and by the reluctance to allow monetary payment to be seen to impair the mother-child relationship. Proponents of paid surrogacy argue that such perceptions are mistaken and that payment is compensation for a surrogate mother's time, disturbance and particular abilities, and not for the child itself; in these ways, it is more similar to the payment made to a nurse for the nurse's time and skill in caring for a baby.

Moral commitments and transplantation

25. The above-mentioned four moral principles or commitments may also serve to clarify and assess issues related to transplantation of human, animal and artificial organs and tissues. Disagreement with respect to transplantation is likely to arise in two areas, principally the role and definition of "brain death" and the issue of animal rights. Debate may centre on what moral obligations are maintained after brain death and whether they are similar to the moral obligations to gravely ill patients who are under medical care or to those accorded to the deceased, thereby allowing respectful organ removal and their transplantation into living patients to save lives.

26. With respect to animal rights and the transplantation of animal organs, some have raised the question of whether animals should be accorded the same moral rights as people. Such a question touches on the attributes that are necessary and sufficient to be classed as a human and to be accorded the moral status and rights of a person. The debate over animal rights and the moral status of animals can be anticipated to grow in the coming years, and there is already a movement that has gained support from the legislature of New Zealand to accord higher primates, such as orangutans, the same moral status as people, and thereby prohibit their use for animal experimentation, *inter alia*. This has relevance in view of the importance of ongoing attempts to genetically alter animals to diminish the risk of transplant rejection when their organs are utilized. It is likely that in the case of animal transplants, neither reckless and unregulated experimentation nor an absolute "precautionary" prohibition of all experimentation is likely to prevail.

27. Another important concern with respect to transplanted organs or tissues from animal sources is the question of anticipated harm and benefits. Currently, there is a publically voiced concern regarding risk of causing harm to human populations by transferring infections from animal populations to the human population while transplanting organs. One theory regarding the origination of HIV/AIDS is that it arose from a monkey virus that transferred to human beings in a yet undetermined way. Bovine spongiform encephalopathy (BSE; also known as mad cow disease) has crossed the barrier to human beings, causing a similar infection in people, the new variant Jacob-Creutzfeld disease. Such cases cause concern about the possible risks of transplanting animal organs.

Prolongation of life

28. In recent years, medicine has developed techniques to prolong life and has come to utilize them routinely. At the same time, the question whether prolongation of peoples' lives is a proper goal of medicine,

regardless of the quality of those lives, has increasingly been raised. Some believe that physicians have an obligation to keep people alive when there is a reasonable prospect for them to live in a manner they would consider worth living. The question raises many issues and engages further reflections on the differences between hastening death and withholding treatment. Some argue that to disconnect a respirator or a feeding tube is deliberately to hasten death, and thereby purposefully to inflict harm. Others argue that when life-prolonging interventions cannot or no longer provide any health benefit to a patient there is no moral obligation to prolong his or her life. They stress that a patient who is unlikely to recover consciousness, for example, is unlikely to achieve a life that she or he would consider worth living, with some degree of physical, mental and social well-being, and therefore cannot benefit from an extended life. A decision to cease non-beneficial interference in the face of a fatal outcome is, according to this viewpoint, different to the decision deliberately to end a patient's life.

29. Even if prolongation of life concerns the healthy and not the terminally ill, there remains a question of justice and especially of distributive justice or fair distribution of scarce resources. Some would argue that when millions of children still do not reach their fifth birthdays and millions of others die prematurely, it is unjust to spend scarce resources on increasing the lifespans of relatively few wealthy people who can afford and take advantage of life-extending advances, having already achieved a reasonable lifespan.

Bioethics, justice and human rights

30. A number of academic scholars in the field of bioethics have begun to shift their focus from issues of individual ethical concern to issues that focus on the commitment or principle of social justice. In so doing, they have moved toward two fields of thought previously seen as distinct from ethics: human rights and politics. The attitude that bioethics adopts in the matter of social justice is different, however, from the attitudes adopted from the perspectives of the other two fields of activity. In the coming years, the addition of a bioethical perspective may be perceived as helpful and complementary to the other two approaches.

31. An important first task may be to clarify the term "justice", especially in relation to health and health care. There may be a consensus regarding the pursuit of justice, although there may also be disagreement of its precise definition and attributes. For example, a simple claim that justice means to treat people as equals can be countered by the evidence that in some circumstances it is unjust to treat people as equals, the distribution of health-care resources providing an obvious example. If all people were to be

treated equally with regard to health care, this would imply an equal portion of available health-care resources given to everybody by simple allocation. Such an approach is unjust because it ignores people's different health-care needs. A person who is very ill *needs* more health-care resources than a well person. It is likely that an adequate theory of justice in health care would require an objective of distributing health care resources *unequally*, to deliver *more resources* to the ill than to the well. Aristotle stipulated that justice requires us to treat equals equally and unequals unequally, in proportion to the relevant inequalities. Philosophers continue to debate about the proper criteria for those "relevant inequalities".

32. Need, however, cannot be the only criterion for determining the just distribution of scarce resources. Maximizing the benefit obtained from expending a unit of health resources may be another plausible candidate. For example, a government with scarce resources for health care may seek to produce as much benefit as possible from those limited resources. Benefit maximization may, however, conflict with the goal of providing the most resources to those most in need of health care and whose lives may depend on it. From the point of view of the benefits obtained per unit of resource expended, it makes more sense to treat people suffering from minor diseases or illnesses, since they are more likely to be cured (high benefit) through minor expenditures (few resources), than to treat the very ill, for whom expenditure of greater resources may not even guarantee a return to health.

33. A further criterion applied to achieve an adequate theory of distributive justice in health care is the patient's own preferences: a patient might well need health care that the patient simply rejects. Another criterion to be considered could be the outcome of democratic processes undertaken to settle priorities. A further priority to consider may be the provider of health care, whether the care is paid for by taxpayers, insurance premium payers or private payers. The role that the market plays in determining distribution of scarce health-care resources and whether it can deliver justice is an important issue in this context and will determine whether market forces, including such special interests as the pharmaceutical industry and the medical equipment industry, have a role to play.

34. Application of ethics of justice would also require the elimination of unjust criteria of distribution that may already be in place. A difficult issue, nevertheless, is the extent to which special relationships can play a part in determining distributive justice, recalling that individuals and communities in real life naturally give more of their resources to those closest to them, including families, friends and fellow nationals. The issue of personal responsibility is likely to be more contentious; specifically, an approach from justice and fairness may take account of a person's responsibility for becoming ill due to a lifestyle choice, for example by smoking, overeating, abusing alcohol, engaging in unprotected, "unsafe" sexual intercourse, driving unsafely, or taking risks in physical activities or sports that are considered dangerous. Such an approach would need to consider whether lifestyle choices play a role in an acceptable theory of health care justice.

35. To some political and philosophical theorists, justice is primarily about rights, in particular human rights. These theorists consider issues that may be highly complex, such as the nature of human rights, whether there are rights to health, the source of such rights, how to resolve rights conflicts and the locus of obligation for such rights. The role of rights and of both national and international law in determining health-care justice, as well as their relationship to bioethics, involves proponents of all these fields.

36. Considerations of justice entail practical concerns regarding regulation and enforcement. This raises the question of how to set up appropriate controls that are also ethical, and how to define the responsibilities of the legal, social and professional domain to establish and enforce regulatory mechanisms.

37. At this time, the newly emerging and multidisciplinary field of bioethics has not yet developed answers to the complex questions that have been briefly outlined here. There is an ongoing search for consensus on real ethical issues, which also strives to have a firm foundation in ethical reasoning and to find approaches that are based on common and universal moral commitments, while respecting the varying diverse ways that different cultures apply common commitments to practical moral problems.