

FORTHCOMING CONFERENCE

Moral and ethical imperatives of health care technologies: scientific, legal and socio-economic perspectives

CONFERENCE COORDINATORS, THE SECOND NATIONAL BIOETHICS CONFERENCE: *INDIAN JOURNAL OF MEDICAL ETHICS*

The *Indian Journal of Medical Ethics* organised the First National Bioethics Conference (NBC 2005) in November 2005 as a platform for sharing and exchanging views on bioethics amongst groups and individuals from various fields. The broad theme of the first conference was "Ethical challenges in health care: global context, Indian reality" and it was attended by over 400 participants. Encouraged by the enthusiasm of the participants and the support of a wide range of institutions and groups, *IJME* has decided to hold the Second National Bioethics Conference (NBC 2007) on December 6, 7 and 8 2007 in Bangalore. We expect active participation from those involved in clinical medicine, bioethics, medical and social science research, community and public health, women's rights, theology, biotechnology, law, governance, and public policy.



Health care technologies: social and moral dimensions

Developments in technology have been crucial in shaping health care all over the world. Today, physicians utilise and depend on a wide range of tools to guide and support their healing practices, and new relationships between health care professionals, patients and industry have emerged. In the field of public health, the impact of technology has been dramatic. Measures such as immunisation, antenatal screening and purification of water have contributed significantly to lowering mortality and transforming the demographic profile of entire regions. Advances in health care technologies include the development of an array of diagnostics such as the ultrasound scan, magnetic resonance imaging, DNA-based laboratory tests, and treatments using genes and stem cells

Although many of these diagnostic and treatment modalities have improved standards of care, their abuse has simultaneously led to an adverse impact on clinical practice and outcomes. Market forces have influenced the development and use of technology and at times led to inappropriate treatment. Further, as a result of these forces, the cost of these technologies is often so prohibitive that the gap in access to health care technology between socio-economically privileged and disadvantaged individuals and communities has been widened. The costs of

innovation and the pressure to stay technologically advanced have often prompted health care professionals and institutions to adopt strategies such as increases in the cost of care, advertising, and outsourcing of various services to maintain their profit margins.

Today in India, the State and State-run institutions are no longer the focal point of health care development and provision. In fact, corporations and private providers, who are primarily unregulated, increasingly control the development of health care technology and its use. The increasing application of health care technologies may also be related to expansions in foreign investment in health care and medical tourism. These developments give rise to ethical questions such as those related to the appropriateness and equitable distribution of technologies; the need for setting priorities in research; the role of governments and/or independent agencies in regulating research and the use of health care technologies; and the control of intellectual property.

In view of the importance of health care technologies and the social, economic, legal and moral dimensions that shape their development, use and misuse, *IJME* has decided to focus its second National Bioethics Conference on health care technologies. The conference aims to facilitate comprehensive debates and dialogues on health care technologies in the contexts of clinical practice, research, and public health and policy.

Ethical issues in clinical practice

Medical technologies dominate present day clinical practice. However, advances in technological know-how have not necessarily been accompanied by the systemic changes in public policy that are required to make these benefits accessible and affordable. Thus, health care providers who work in resource-poor settings confront a range of challenges related to the distribution of technological advances. They are compelled to ration or, often, do without the latest technological aids that can serve their patients better. Further, in a largely market-based health care system, there is a heavy burden on the poor to pay for services; this creates a dichotomy between those who have the means to pay and therefore have access to technology-based care and those who cannot afford to pay, and do not have access. This dichotomy is particularly apparent in the treatment of chronic diseases, including cases in which organ transplantation may be necessary. Another challenge that has

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emerged is linked to the fact that hi-tech treatment-oriented solutions are given more attention, leading to the neglect of simpler prevention-focused responses.

Particular ethical issues have arisen in the use of technological means to prolong life. The possibility of prolonging human life by artificial means has radically transformed our understanding of life, death, and the acceptable quality of life. Several cases, now historic, have brought to the fore the moral conflict between the health care system and civil society in the context of life prolongation. Families have gone to court demanding the right to withdraw life support and allow their loved ones to die a "natural" death. These documented cases represent just the tip of the iceberg. Providers and families are compelled to make these choices routinely in the course of their work, often despite the lack of institutional understanding or support.

Another area where the use of technology has become particularly controversial is in the field of artificial reproduction and reproductive health. The possibility of using technological means to predict or even influence the characteristics of the foetus has created a whole range of ethical debates. Most noteworthy in the Indian context is the widespread use of diagnostics to determine or select the sex of the foetus, a practice that has distorted sex ratios in several states. This provides a classic example of the manner in which the deployment of a technological innovation in a market-driven health care system adapts to suit dominant interests. Debates on the ethics of assisted reproductive technologies have brought to the fore the intersections between gender, society, national policy and regulation, and ethical practice.

The above has, in some sense, overshadowed an equally long and important debate on eugenics. Increasingly sophisticated tools are now available due to technological advances in diagnosis of foetal abnormalities and "undesired" genetic traits. The impacts of these tools include eugenic abortions, reduced access to health care (through restrictions on health insurance, for example), and stigmatisation.

Other ethical issues related to the use of technology in health care are in the arena of professional education. Providers face the challenge of having to continually update their knowledge and skills. Moreover, there has been sustained pressure from various quarters to expand the cadre of health professionals who can deploy health care technologies. One example is the training of paraprofessional health workers to conduct medical abortions. A key challenge is the expansion of access to the benefits of health care technologies at the same time as ensuring their safe and scientific use. Although trained professionals are liable to make mistakes, there are virtually no institutional mechanisms to monitor the use of technology by the broad array of health workers (registered and unregistered) practising in countries like India.

Ethical issues in research

Research on health care technologies has been a hotly debated subject in bioethics. This is particularly so in fields such as vaccine and drug development, genomics, artificial reproduction and

stem cell research. Concerns related to justice have been at the crux of these debates. Although there has been a rapid increase in research in the developing world, the extent to which the people of these countries share in the benefits of this research has been questioned. Some have argued that it is the global market that determines the relevance and access to the products of research, particularly in the case of developing countries.

The explosion of research activity has led to completely new arrangements for conducting health research in different parts of the world. The growth of contract research organisations and the outsourcing of trials have raised several questions about research oversight and mechanisms for demanding accountability from dispersed and often unrelated stakeholders.

Research on emerging health care technologies such as genomics and stem cells raise fundamental questions about the meaning of life and personhood. The possibility of mapping the genetic makeup of entire populations has implications for the human rights of individuals and communities who are found to possess genetic traits that make them either susceptible or resistant to particular diseases. Further, the patenting of life forms (including cell functions and pathways) has raised important questions regarding what may be patented and under what terms. The burgeoning number of lawsuits in the western world is evidence of the contentiousness of these issues.

Other issues that are relevant in discussions of the ethics of research on health care technologies include the participation (or exclusion) of vulnerable groups as well as the quality of informed consent. There is often a very fine line between treatment/care and research because both are undertaken in the same setting and by the same professional. Thus, the conditions of consent, including the motivations for participation in research, must be critically examined.

Setting priorities in research on health care technologies also poses several ethical dilemmas. Not only is there a need for attention to the ethical dimensions of medical research that is being undertaken, but the ethical implications of neglected areas of research also need to be considered. Communicable diseases, nutritional deficiencies and occupational hazards are major causes of morbidity and mortality in developing countries. Nonetheless, there is a very little investment in research on these issues. Technological advances in the prevention and control of these adverse health outcomes have been less than satisfactory. Developing affordable technologies and scaling up available affordable technologies have also not received adequate attention.

Ethical issues in public health and policy

Any technology, when used on a wide scale, has important consequences for society. This is particularly evident in the case of food and agricultural technology. Large numbers of people all over the world still suffer from malnutrition. Developing nations have limited political clout when it comes to issues such as gene modification, intellectual property rights, biodiversity, conservation, and the erosion of traditional farming practices. Despite nearly a decade of discussions on labelling, marketing

restrictions and banning genetically modified foods, many constituencies continue to view current regulations as extremely weak. Further, some argue that developing nations have become laboratories for research on food technologies, agriculture, and biotechnology. Others contend that these developments will make significant contributions to end world hunger, poverty, and malnutrition.

Another example of the profound impact of technology on human society is in the development and deployment of vaccines. Ensuring appropriate coverage, a necessary condition for the effective use of vaccines, brings into focus the State's roles and responsibilities in health care delivery. Firstly, the State has to enlist community support and participation, and, secondly, it has to make resources available to ensure coverage. Both these aspects raise several ethical dilemmas related to individual freedom, the use of State power as well as the welfare function of the State. Vaccine research is driven by large conglomerations involving both private and public (State) entities. Thus, private interests have the potential to exert considerable influence on governments and international organisations in the making of vaccine-related policies. Questions remain about the future availability of these vaccines and their costs.

While technology has vastly expanded the range of health care options, it has led to a massive increase in the cost of health care. Prohibitive costs have meant that health care has become out of reach for a significant proportion of the population, and this has led to indebtedness and further exacerbation of poverty. Paradoxically, the growth of medical technology has levelled international barriers. Medical tourism has become a popular policy option for developing countries that have a large trained professional workforce and access to technology. While it is conjectured that the revenues from medical tourism will benefit the local population, there is little documented evidence to support this contention. On the contrary, the development of hi-tech infrastructure necessary to promote medical tourism has led to human, financial and material resources being diverted

away from institutions accessible and available to the local population. The superimposition of a highly modernised health care system on societies where primary care remains a pressing need is fraught with ethical dilemmas.

Ethical issues also emerge at the intersections of policies on trade and health. For example, intellectual property rights, compulsory licensing, and international trade agreements have had important implications for drug pricing and access in developing countries. The balancing of economic and health concerns merits close attention.

Conference programme

In the current era, the task lies before medical professionals, public health researchers, social scientists, engineers, policy makers, elected representatives, governments, and other interested individuals to examine the moral and ethical imperatives of health care technologies at both the individual and societal level.

Through NBC 2007 the *Indian Journal of Medical Ethics* hopes to provide a neutral platform for individuals and institutions holding a range of opinions and perspectives on health care technologies to engage in constructive debate and dialogue. The conference will include plenary sessions, paper presentation sessions, workshop and panel discussion sessions, and film-viewing sessions, as well as pre-conference satellite workshops and meetings.

We encourage interested individuals to submit abstracts of papers they would like to present at the parallel scientific sessions of the conference (reflecting the above three themes); concept notes for workshops, panel discussions, and debates for the parallel workshop sessions; proposals for the organisation of pre-conference satellite meetings and workshops.

The deadline for submissions is May 15, 2007. Please send submissions by email to nbc@ijme.in or nbc.ijme@gmail.com

The Second National Bioethics Conference of the Indian Journal of Medical Ethics will take place on December 6, 7 and 8, 2007, at the Convention Centre, National Institute of Mental Health and Neuro Sciences, Bangalore 560029, Karnataka, INDIA.

BODHI

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