NATIONAL BIOETHICS CONFERENCE 2007

Conference report

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The recently concluded *Indian Journal of Medical Ethics* Second National Bioethics Conference brought together over 500 delegates, speakers and other participants from a wide range of disciplines. The participants were a blend of healthcare professionals, academicians, researchers, media professionals and, interestingly, many retired professionals and laypersons. Though doctors and researchers represented the majority, the blend clearly reflected the growing interest in bioethics amongst people of all walks of life and an increase in the strength and momentum of the bioethics movement in India.

As the conference was held in Bangalore, my hometown, I expected to see many familiar faces. I was pleasantly surprised to also meet many old friends who are extremely busy clinicians. Quite a few of them had come there to stay for a few hours and ultimately stayed on for the entire duration of the conference. Needless to say, the sessions were absorbing and very interesting.

The conference offered a good blend of plenary sessions, workshops, paper presentations and panel discussions. While the theme of the conference was "moral and ethical imperatives of healthcare technologies", a number of sessions also dealt with topics like research ethics, bioethics education and ethics of public health, not necessarily connected to healthcare technologies. The keynote speakers, too, represented disciplines ranging from primary care, intensive care and traditional medicine, to health economics, public health, health administration and health policy.

There were five plenaries during the conference. During the inaugural plenary, Dr Abhay Bang called for a shift of "knowledge power" to the community by proposing that research initiatives be conceived and implemented by the community and not by researchers alone. Dr Padmini Swaminathan called for more holistic and comprehensive healthcare technologies and for more interfacing between economists and medical professionals in responding to changes in environment and disease profiles. Dr MS Valiathan, scientific advisor to the prime minister of India, gave a moving keynote address on the rich legacy of medical ethics of traditional medical systems within the treatises of Caraka and Sushrutha. He pointed out that the conference programme did not sufficiently dwell on the contributions of traditional medicine to the discourse on medical ethics. Dr Vasantha Muthuswamy added that ethical issues and their nuances must be debated not merely by doctors but all of civil society. She stressed that supportive health policies were needed to ensure that healthcare technologies reached those who need them, and also called for more attention to regulation of research in medical devices and healthcare technologies.

Each of the next three plenaries was on the three sub-themes of the conference. During the plenary on use and misuse of technologies in clinical practice, my own concerns as a pathologist were echoed when Dr Arjun Rajagopalan observed that many a time, too many tests are ordered, too often, and for unproven indications. I concur with his suggestion that diagnostic practices must be audited and there must be transparency in tariffs. The plenary on research on healthcare technologies dwelt on the lack of adequate regulation of research related to medical devices and genetic and stem cell technology. Concerns were also expressed about related dilemmas such as disclosure of results in gene testing, gene therapy, DNA finger printing and even determination of the moral status of the embryo. He cautioned that the social consequences of such technologies would be far-reaching. The penultimate plenary on public health and policy dimensions of technologies contained an interesting talk by Dr Anant Phadke. Dr Pushpa Bhargava spoke on the ethics of vaccine programmes using two case studies from India, of the polio eradication programme and of the anti-rabies vaccine. The issues raised by him may have been challenged by some but demonstrated the subtle ways in which the community's interests can be compromised by the decisions of policy makers.

The conference provided a platform for sharing views, research findings and expertise on a wide variety of ethical issues inherent in clinical care, public health, research in healthcare as well as health policy.

Healthcare technologies today enable clinicians to prolong life to unexpected lengths. The dilemmas that clinicians face in the care of terminally ill patients were discussed. In the session on neonatal intensive care it was noted that, in the absence of proper guidelines on the criteria for triaging babies for intensive care, access to intensive care facilities seems to depend more on the person's buying power than on the patient's medical needs. Interesting debates were also initiated during the conference about philosophical appraisal of healthcare technologies, euthanasia and end-of-life care.

Sessions referred to the emerging and predicted implications,

for patients' access to medications, of the amended Patent Act in India and the Trade Related Intellectual Property Rights agreement These discussions were particularly enlightening for participants like me who are not directly involved in such matters. The amendments will have far reaching social implications and it will be useful to have more public debates on the subject. Beyond the affected patient groups, civil society must also be closely involved in such debates and in monitoring the implications on accessibility to essential drugs.

Research in healthcare has been an area in bioethics that has always garnered enormous interest and debate. Given the thin line that sometimes divides clinical care and research, this area is coming under close scrutiny. In this conference too, ethics of clinical trials, international therapeutic research, vaccine research and stem cell research attracted a lot of attention. Participants discussed and debated the ethical dilemmas they face in conducting research with vulnerable groups, in recruiting participants, in implementing the informed consent protocol and in establishing standards of care. While most of the issues raised were already well-known and familiar to those in the field, some speakers presented evidence that western models for ethical conduct of research may not be completely relevant to the Indian scenario. These papers also lent support to Prathap Tharyan's call for more "evidence-based ethics" to guide research in developing countries.

Increasing collaborative research with international partners has ensured that ethics review boards (ERBs) are gaining acceptance amongst researchers in India. Besides workshops on setting up ERBs, the conference also provided guidance on preparing proposals to meet the ethical requirements of review boards. Such sessions were very useful for young and up-coming researchers. Also relevant to the Indian scenario was the workshop on running ERBs in resource-poor settings.

Besides international collaborative research, HIV/AIDS has been another important factor strengthening the ethics movement in India. At the Second NBC, too, a good share of the proceedings went to discussions on the ethical ramifications of HIV/AIDS that extend to every aspect of preventive and clinical care of this disease. This was evident at the conference in the sessions related to mass prevention programmes, screening, access to second-line drugs, and vaccine trials.

The first and second days of the conference ended with media sessions marked by screening of thought-provoking films on issues such as public health strategies, medical disasters and women's health. The films succeeded in stimulating thought about many contemporary trends in healthcare. To sensitise medical professionals and journalists to their respective roles in responsible communication of medical issues to the public, a workshop for media and medical students was held during one of the media sessions. In addition, papers from the LV Prasad Eye Institute in Hyderabad discussed the ethics of reporting on scientific research, the role of the media in framing ethical issues and the supportive responses of public, patients and media to the first clinical trial of cell therapy.

Education in ethics is the key to sensitise and train professionals to integrate ethical perspectives into their work. An important contribution of the conference was the dialogue initiated on bioethics education. A pre-conference workshop reviewed and discussed the curriculum for a public health ethics course to be integrated into a masters programme in public health. An international panel discussion provided a forum for international participants to share experiences of bioethics education programmes in their countries. Most of ethics education programmes in India are short-term training courses on research ethics. Research ethics are but a small component of the many ethical issues that confront health professionals today. Save a couple of medical schools, there is no forum to provide ethics training in medical education in India. The deliberations at the conference also identified the inadequacy of expertise in India to impart this education.

One of the more lively sessions was a pre-conference event called 'SOCH' ('Think' in Hindi) directed at students from various medical and allied disciplines. Through student-friendly cultural events and competitions, it was organised to provoke students to reflect, debate and understand the issues of ethics in healthcare which they would be encountering in their future professional lives.

The valedictory address during the concluding plenary was rendered by Dr Madhava Menon, member of the central government's Commission on Centre-State Relations. Speaking on the topic of medicine, law and ethics, he pointed out that in science and medicine, if ethics are followed, law becomes unnecessary. It is the instances of negligence and wilful misconduct that have given rise to the need for ethical and legal regulatory standards.

Overall, the deliberations at the conference successfully sensitised participants to the spectrum of ethical issues inherent in different medical situations and policies. The sessions also enabled them in acquiring skills to recognise dilemmas and constructively deal with them. The discussions were greatly enriched by the variety of disciplines represented. However, I perceived a distinct disadvantage in this multi-disciplinary gathering. Time for questions was used up by many participants to merely voice opinions or relate anecdotes. Consequently, very rarely could issues be settled by factual knowledge about the relevant policy or legal status. There were very few participants with in-depth knowledge in emerging fields like genetic and stem cell research, vaccine research and patents. So most of the discussions and queries remained on a general level.

The lack of regulation of many medical practices was a common refrain during the conference, particularly related to the fields of reproductive technology, genetic testing, clinical trials, organ transplantation, vaccine strategies, media reporting, research, patenting and marketing of devices/drugs and e-medicine. Guidelines for regulation are best evolved by the participation of the clinical experts in that field. Due to the vast variety of disciplines at the conference, expertise in specific fields was spread too thin. Beyond exposing the

lacunae in regulation, the conference could not provide a platform to evolve guidelines that can influence future policy and law. Perhaps IJME must make inroads into the individual medical societies and initiate processes (through workshops and debates) for medical specialties to evolve guidelines to address the dilemmas specific to their field. Evolving guidelines can be brought to more public discussion, debate or review in future NBCs.

Most of the ethical debates in the conference related to regulation (or lack of regulation) of healthcare technologies. Most of the arguments were articulated in legal jargon. "Illegal" was freely replaced by "unethical". Conceptual issues regarding the direction of scientific progress, its impact on individual aspirations and the matching of ethical norms to a cultural and societal ethos largely remained unaddressed. It is a fact that ethical discourses in India are heavily influenced by western thought. While it is good to emulate good models and systems from the West, norms must evolve from local contexts and cultures. Religion has not figured prominently in evolving ethical norms in India. On an individual level, religion has an important influence on life decisions and there is a need to provide space for religious dialogue in the public arena of ethical discourses. This gap must be bridged so that people are empowered to take ethical decisions in alignment with their values and beliefs. As a participant pointed out, ethics is more than guidelines and regulations.

Rapporteurs: Anant Bhan, Pranoti Chirmuley, Teju Daman, Daphne Furtado, Baneen Karachiwala, Nora Kropp, Surabhi Kukke, Deepak Kumaraswamy, Vasudha Mohanka, Nabeel M K, Catherine Pagett, Vijaya Pawar, Lakshmi Prasad, Mala Ramanathan, Sadath Ali Sayeed, Sridevi Seetharam, Suja Shunmugavelu, Murgesan Subramanian, Sukanya R, V Vinay.