CONFERENCE REPORT

Indo-German -multidisciplinary symposium:. Medical ethics today

Introduction

The Max Mueller Bhavan, New Delhi, along with the All India Institute of Medical Sciences **(AIIMS)** and the International Centre for Genetic Engineering & Biotechnology, New Delhi organised this very rewarding symposium at the Board Room, AIIMS. 27-28 October 1995

Genetic research

Professor Sharat Chandra (Indian Institute of Science, Bangalore), chairperson at the first session, set the ball rolling by pointing out that the first hundred patients seeking fetal sonography at AIIMS were women with female offspring. They requested prenatal diagnosis of fetal sex despite the absence of genetic abnormalities in their families. Recent advances in genetics are and will be used for their' non-medical applications for emotional and cultural reasons. The yearning for baby boys is an example. Is it ethically wrong to help families to have children of the desired sex?

He also touched upon the vexed question, 'Who owns information?' Should a carrier of disease, detected during a scientific study, be informed? Can individuals demand that all data on themselves be deleted from all databases? Can data obtained during a study be used in a court of law?. Since it is now possible to amplify genetic material supplied for a test or study thanks to techniques such as polymerase chain reaction, a huge of amount of material will soon be collected by laboratories. Who owns this? Who owns cell lines? Can they be sold? Is informed consent of the donor necessary? Can life forms be patented.

As the distinction between academia and commerce gets ever more nebulous and as workers become increasingly secretive and concentrate on the commercial consequences of research, we need to confront a whole range of questions.

Dr. Hans-Martin Sass (Professor of Philosophy, Ruhr-Universitat, Germany and Kennedy Institute of Ethics, Washington). pleaded for differentiation between patents (of which he disapproved) and 'breeder's privileges' (which are justified). Recognition by society and. appropriate rewards to the discoverer are necessary to ensure discoveries that further medical care, enlarge the supply of food, help improve standards of quality control and efficacy, especially of new life forms and, in general, make life worth living, especially for the sick and poor.

He voiced a theme that he was to return to again and again during the symposium. In dealing with the new challenges thrown up by biotechnology as with all complex situations in biomedicine, we must also involve lawyers, priests, teachers and the public at large so as to empower the people and enable them to make appropriate choices.

Dr. Ishwar C. Verma (AIIMS) noted that non-directive counseling (where the patient is provided information but is not led towards one or the other decision) often fails in India as the family keeps asking the therapist to decide. Families often do not understand what is said to them either because the explanation is too technical or was in a language not familiar to the patient (e.g. explanation offered in Hindi to a Nepali).

Dr. Anton Leist (Professor of Philosophy, University of Zurich) felt that as a scientist, the doctor must present all relevant data to the patient and family after establishing personal rapport with them. He must then also offer his own recommendation making it clear that this is his personal view. The final decision can then be made by the patient.

Mr. R. Srinivasan (retired Secretary, Ministry of Health, Government of India) pointed out that in India we have a wide variation'bf backgrounds of those seeking health care in India from that of those providing it, making all medical consultations encounters between two widely differing cultures. The anthropological distance traveled by the patient when he comes to a doctor is, at times, interpreted by the latter as evidence of disease. This diversity of cultures makes it_ imperative that we learn to carry on meaningful dialogues with cultural strangers. We must also ensure fairness of access and sufficiency of service.. Distributive justice is still far from being a reality, the chief obstacle being hubris in those provi

health care.

Dr. Rita Kielstein (Professor of Internal Medicine, University of Magdeburg, Germany) emphasised that the mother must remain the key person in making decisions on the life of the fetus with inherited disease. **Mr. Srinivasan** was quick to point out that the reality in India does not permit a mother to be a moral agent who can influence decision on whether her fetus with hereditary disease should be killed. The decision is usually made by her husband and in-laws and enforced on her.

Assisted reproductive technology

Dr. P. C. Anand Kumar (Hope Infertility Clinic, Bangalore) quoted Richard McCormick's statement (1981) that the morally good is in danger of being equated with what is technologically feasible, He spoke of the national guidelines on various aspects of reproductive technology including quality control, ensuring absence of bacteria in sperm stored in banks, ensuring uninterrupted supply of electricity and true informed consent. His concluding statement was thought-provoking: 'If discipline is not enforced; mediocre; unimaginative professionals will emerge from substandard private medical institutions.'

The law in Switzerland, as enunciated by **Dr. Leist,** showed how far we need to travel to reach an international standard. Switzerland requires all semen banks to maintain records on all donations of semen. This helps them match donor to the family in physical characteristics so that the child does not stand out as an anomaly. It also enables the resultant offspring, when 16 years or older, to obtain details on the biological father and, if so desired,' meet him. The law also restricts the supply of semen to couples where the social father is alive and the marriage is intact.

Dr. Indira Hinduja (Jaslok Hospital, Bombay) commented on the fact that in India, even when the defect causing infertility lies in the husband, the social stigma is borne by the wife who cannot or will not proclaim her normalcy. Artificial insemination is therefore carried out in great secrecy. On the other hand, donation of the egg is publicly proclaimed as the husbands manhood is under a cloud. She also commented on **the high cost of the donated** egg - Rs. 25,000 or **more. The** cost for **in vitro fertilisation of eggs is Rs. 100,000 per cycle** with **a 30% chance of success.**

Dr. **Punit Bedi** (consultant obstetrician, New Delhi) felt that infertility necessitating assisted reproduction, is an economic disease. informed consent for such therapy must include **a detailed explanation of all costs and the chances of failure. Dishonest directive counselling has made families** sell whatever little they possess in the hope of begetting **a child.** He **was not optimistic about any form of audit by any agency** in’ the current situation **where case records** are hardly ever maintained by any practitioner. **There** is thus a total lack of accountability. This is likely to persist as **assisted** pregnancy **involves a lot** of money and the need to **generate** large profits must, inevitably, lead to **unethical** practices.

Professor D. Banerjea (**Lal** Bahadur **Shastri** National Academy of Administration) **cautioned** against relying on the law and **legal** processes. The law is what is does and not what it says. It is a subset of the social system and with the general erosion of character, is likely to prove ineffective until standards are raised. It makes good sense to strengthen autoregulation by the profession with senior members taking the lead. The law should be reserved only for the recalcitrant minority. Unfortunately, at present, the ethical are in a minority. **Dr. Hans-Martin Sass** agreed. Whilst the law is a powerful agency, in matters medical, especially when they concern making love and babies, empowering the people - through the media, schools, colleges, philosophers, religious leaders - is more likely to prove effective.

Ethics of dealing with death

Dr. Ajit Banerji (VIMHANS, New Delhi) recalled Yudisthir’s observation that it is most astonishing how man, aware of his mortality, continues to feel that he can cheat death **and** does all he can to attain this goal.

Dr. Chaturvedi Badrinath (philosopher, **New** Delhi) recalled the Hindu philosophical view that death is merely a step in the continuum or birth, life, death and rebirth. To one who understands this unity between life and death, the latter holds no terror. He **counseled** physicians against playing God.

Speaking on the medical **duty** to save life, **Sunil Pandya (K.** E. M. Hospital, Bombay) felt that it must be tempered by respecting the autonomy of the will of the patient and doing all one can to **ensure** a meaningful life. The law in India **does** not permit the **doctor to** respect **a** living will or do-not-resuscitate order by the patient. **In** doing so, the law lags behind ethics.

He **also** pointed to the need for nationally acceptable criteria for certification of intensive care units and admission **to them. One criterion for admission could be ‘correctable abnormality that threatens life, with high expectation of a meaningful** life after treatment’. We also need a consensus on practical matters within the intensive care unit. When the **intensive** care unit is already full of seriously ill patients and yet another such patient is brought in, what should be the criteria for deciding that his **need** for a bed is **greater** than that of patients already within and how should we **choose** the person to be sent out? What should be the criteria for stopping life support systems? One such criterion could be **irreversible** failure of vital organs and systems.

We must differentiate between the **preservation** and saving of life and its unnatural prolongation. The latter is irrational in an individual permanently deprived of his senses because it prolongs the agony of family and friends, consumes scarce **resources** and, in its **extreme** forms leads to such attempts as cryogenic preservation of the brain and an attitude that commands death to wait.

Dr. P. M. Bakshi (former Director, Indian Law Institute, New Delhi) discussed the legal aspects of a doctor’s act of stopping life support systems in patients who are brain dead. The law, at present, uses the definition of brain death exclusively for the purpose of organ transplants. He felt, however, that if a **case** was brought before the judges against such a doctor, they are **likely** to use the definition in the Organ Transplant Act in making their judgment. Whilst unlawful causation of death is murder, the bona fide act of a doctor in shutting off life support systems in a brain dead person following the family’s **directive** or the patient’s living will is unlikely to attract any **punishment.**

Dr. Chicot Vas (FIAMC, Bombay), speaking on euthanasia, pointed out that the right to die does not permit the seeking of death as one pleases. It **refers** to the right of the individual to **determine** the quality and manner of death, peacefully and with dignity.

Dr. Leist referred to the right to suicide in the Netherlands. If the individual is incapable of committing suicide, he has **the** right to seek **the help** of a doctor **for the purpose. This stand is** based on the principle of autonomy of the individual. This is, **however,** a slippery **slope** and **needs** legal controls and **protocols in place/Speaking on the living will, Dr. Saas pointed out that it must be individualised according to values, wishes and visions of the patient irrespective of machines or the ability to pay.** When devising **a model living will it is necessary to ensure that the patient** is in the driving seat. **(Dr. Leist:** ‘What if the patient **doesn’t** want to drive?’ **Dr. Saas: The default** position based on what is sanctioned by **society then** comes into. play.) **Dr. Saas** discussed the various **models** of the living will - **directive,** proxy and **value profile** (which provides a checklist and **offers several narrative examples** which **help** the patient form his own **directive)** and showed the advantages of the latter.

Discussing organ donations, **Dr. R. R. Kishore** (Ministry of Health, **Government** of India) **recommended** a tightly knit definition of death to be applied under any circumstance and not just with reference to donation of organs. **(Professor D. Banerjea:** The moment you define something, you also **confine.** It is better to find functional solutions.) Dr. Kishore also spoke of the need for **guidelines** on when life support **systems** can be turned off. **(Dr. Saas:** Such guidelines should deal not only with brain **death** but also with the **persistent** vegetative state where the living will is **often** of crucial **importance.)** We also **need** a public debate on **euthanasia** in India. Finally, the public needs to be educated on the living will. Once public **awareness** has **been** created, draft forms can distributed in hospitals and the manner in which **they** are **received** and understood can be studied.

Political and social issues

Wide ranging discussion was permitted in the final session. The chairperson, **Dr. M. G. K. Menon,** pointed out that if the professions do not **regulate themselves** or address **themselves** to the task of organising themselves as a community with values and ethics they will, perforce, be subjected to external **regulation.** The Consumer **Protection** Act is an example of such **external** regulation. Instead of fighting negative **aspects,** medical and scientific professions should **concentrate** on putting out positive information.

Conclusion

Dr. Tilmann Waldraf (Director, Max Mueller Bhavan, **New** Delhi) and his team - of whom **special** mention must be made of Ms. **Petra** Matusche - deserve kudos for organising this excellent multidisciplinary meeting. In the closing session he requested guidance on how succeeding meetings should be organised. In particular he asked for suggestions on topics to be discussed (with special emphasis on topics relevant to India). Should such meetings be between Indian workers or should foreign experts be invited? Can there be international collaboration on medical ethics? Which are the specific areas where the Max Mueller Bhavan can help?

Interested readers should get in touch with him.

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INHHRO conference of Health, human rights, ethics

The Johannes Wier Foundation for Health and Human Rights hosted a conference of the International Network of Health and Human Rights Organisations (INHHRO) from November 3 to 5, 1995 in the Netherlands. Its objective was to share details of the work done by the organisations associated with the network and to discuss a document titled "Making standards work: an international handbook on good prison practices"[1] issued by Penal Reform International, The Hague. Representatives from seventeen health and human rights organisations and other invitees participated in this conference. Due to constraints of space, only two issues pertinent for our readers are discussed in this report.

(1) While 'Making standards work' is a well researched and useful book for prison authorities, health and human rights activists interested in implementing the international standards in prisons, the standard of health care inside and outside the prison generated debate and raised ethical issues. The document says that the level of health care and medication in prison should be at least equivalent to that in the community outside it. An obvious question raised by the document as well as the participants, particularly those from underdeveloped countries, where the level of health care actually available to a vast majority of poor is abysmally low, was, 'Should medical care in the prison be better than that available or would be available to that prisoner, outside it?' The document answers the question in the affirmative as while a person outside is at liberty to seek better treatment, a prisoner is deprived of such an option. This position runs parallel to the situation in USA where a better standard of health care is legally granted to prisoners and psychiatric patients undergoing involuntary hospital treatment, but not to those uninsured and the underprivileged.

(2) The second issue related to interaction between human rights and health organisations. While the human rights organisations have largely concentrated on the violation of liberty of individuals or groups by the state, progressive health organisations have given priority to people's right to health care.

The first level of interaction between these two sets of organisation has resulted in the health organisations taking active interest' in opposing the violation of human rights by health workers and their participation in coverups. They have also provided treatment to victims of torture. However, we have yet to see human rights organisations broadening the scope of their work by incorporating the right to basic health care as'a major human rights issue. Mutual broadening of perspectives will play a crucial role in consolidating the shared work of human rights and health organisations. Indeed, adequate attention to people's right to health care by human rights movements and similar active interest in prisoners' right to health care by the health movement would reduce the apparent dichotomy between the demand for good health care for prisoners when underprivileged people outside prisons are not getting even low level primary health care as a basic right.

As regards India, Danish doctors discussed the health of displaced Kashmiri people who were tortured by security forces. A study of police custody deaths (1981-90) in Maharashtra by CEHAT, Bombay was also presented. The representation by the Forum for Medical Ethics Society to the Supreme Court of India on its January 1995 judgement directing the prison doctor to participate in the death penalty' in violation of medical ethics, was discussed. Individuals and organisations participating at the Netherlands conference decided to appeal the Chief Justice of Supreme Court of India for a review of the judgement.

References:

1. Penal Reform International:' ***Making standards work: an international handbook on good prison practice.*** The Hague: Penal Reform International. 1995. 176 pages.
2. Jesani Amar: Supreme Court judgement violates medical ethics (Editorial). ***Medical Ethics*** 1995;38.

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Determining fetal sex

Prenatal sex determination with a view to aborting female foetuses is ethically and morally abhorrent. Prohibiting sex determination by law will not, in itself, eradicate this practice but it does send a strong signal that society condemns such abortions. It is ridiculous to argue that because a law does not immediately achieve what it seeks to do, it is useless. One may as well say that since the law prohibiting murder does not prevent murder, why have it?

Does the law prohibiting sex determination make things worse for women? Here Ruth Macklin treads on the quicksands of determining nuances of oppression. Her arguments that unwanted female children may be murdered; or that they may be given less food and health care; and that women who fail to bear male children will be forced to have more children than they want; or face desertion are all based on calculation of