

ABSTRACTS DAY 1

Ethical dilemmas in conducting research on reproductive and sexual health in rural Bangladesh

Ilias Mahmud

The James P Grant School of Public Health is conducting research to map local understanding and concerns about sexual and reproductive health and the role of providers in a rural area of Bangladesh. The study employed a mixed method approach using semi-structured surveys and in-depth interviews. This paper will present the ethical challenges during data collection.

The ethical challenges that emerged were: keeping confidentiality, obtaining informed consent, compensating respondents' time, deciding on what to do with people suspected of having RTIs/ STIs and, finally, evaluating the benefits to community.

Biomedical research participation: concerns of HIV-infected women regarding participating in a cervical cancer screening study

Shirin Shikalgar, Mahesh Kharat, Sucheta Kadam, Latika Karve, Sanjay Mehendale, Seema Sahay, Vikrant Sahasrabudhe, Sten Vermund

It is important to understand and overcome challenges and obstacles in recruiting HIV-infected women into clinical trials. We studied their concerns in the context of a biomedical research study aimed at screening for early diagnosis of cervical cancer.

The biomedical research study compared the accuracy of screening tests for cervical cancer detection in 300 HIV-infected women. Pre-screening data on textual responses about concerns and barriers for participation were available from 151 HIV-infected women who were recruited through a community involvement programme. Content analysis was done to understand their concerns regarding participation.

18.5% participants expressed a fear of breach of confidentiality of their HIV-positive status. They were afraid that participation might lead to disclosure of their HIV status either to their family (15.2%) or in their workplace (15.8%). In the Indian context, societal restrictions on movement of women (12.5%) and stigmatisation by in-laws and families (14.5%) were factors that limited their participation. Self-perception of the dual burden (12.5%) of HIV infection and participation in biomedical research and financial problems (39.7%) also affected the willingness of women to participate in biomedical research.

Women's unique social and familial responsibilities make it difficult for them to participate in trials. Recruitment strategies should consider the basic social, economical and familial needs of HIV infected women by counselling them and educating their families before offering recruitment in biomedical research. Provision of HIV-related care as part of a comprehensive

reproductive health package should be considered and evaluated for facilitating participation of HIV-infected women in biomedical research.

Menstrual suppression as a lifestyle choice: autonomy to control body functions or medicalisation of women's bodies?

Ritu Mathur, Anant Bhan

Menstruation is a monthly occurrence for most women. However, many find it an uncomfortable experience. Long-term menstrual suppression, without the customary withdrawal monthly bleeding as seen with oral contraceptive pills, is used as a remedy for medical conditions such as endometriosis. Long-term menstrual suppression is now being developed and marketed as a lifestyle choice for women who are not comfortable with menstruation or who want to avoid it for the sake of convenience. For example, the oral contraceptive 'Seasonale', approved by the US Food and Drug Administration, combines 84 days of active pills with seven days of placebo, reducing the number of pill-induced periods from 13 to four annually. Such drugs could soon be marketed in India as well.

Some of the questions that need to be asked are: Is menstrual suppression safe and a reasonable lifestyle choice? What is the risk-benefit ratio when it is taken as a lifestyle choice? Is there evidence that such medication is safe and effective? What uncertainty exists on its future benefits and harms? Who should use such medication? Do women have enough knowledge to make informed choices?

Disruption of a normal physiological process for non-medical reasons may be acceptable as part of the autonomy women should enjoy over their own bodies. However, no long-term studies have been conducted on the impact that menstrual suppression may have on the fertility or health of women.

The paper will help illuminate an important aspect of the medicalisation of women's bodies and body functions; and the implications on their reproductive, sexual and general health.

New Reproductive Technologies and questions of choice

Supriya Bijlwan

This paper discusses the issues relating to "reproductive health and questions of choice." New reproductive technologies, the newfound assistants in conception, are heralded as a major step in scientific progress and development in the area of medical science. The amniocentesis test provides an opportunity to detect the genetic "normality" and sex of the foetus. A range of assisted reproductive technologies claim to give women "test-tube" babies without actually treating infertility. Pre-selection

techniques enable a "choice" regarding the sex of the foetus and, perhaps in the near future, other favourable traits such as colour and looks.

These techniques have been criticised because they capitalise on the social stigma attached to infertility. Further, their safety remains an area of concern. Those who use these technologies are ignorant about such ill effects.

I focus on issues of policy in relation to the introduction and implementation of these new reproductive technologies. I propose that such technologies violate women's bodies and are an invasion of their personhood. When science does not study the causes of infertility and its treatment, and when it ignores women's experiences, it only succeeds in providing "technological fixes" without solving the problem.

Mass public health interventions in India: some ethical issues

Angus Dawson

This paper explores some of the ethical issues that arise during the implementation of mass public health interventions sponsored by external international organisations but delivered in the developing world. The problems that arose in Assam in 2001 as part of the Vitamin A supplementation programme are used as a particular example to illustrate the argument. The focus of discussion is upon the use of arguments appealing to the idea of preventing harm. This idea is intuitively appealing as it is often felt to be better to seek to prevent harm from occurring than to treat it once it emerges. However, preventive interventions can also be ethically contentious, mainly because they are introduced into asymptomatic populations. Even if the risk of harm from the intervention is very low, significant harm can result from a mass programme because of the numbers of people involved. Issues to be discussed in this talk will include both theoretical issues lying at the heart of public health ethics as well as particular ethical issues (eg consent, trust and the balance of harms and benefits). Whilst many such programmes might, all things considered, turn out to be justified, there are many ethical and policy problems that require careful exploration and consideration.

Use of coercion in public health interventions

Leni Chaudhuri

This paper focuses on the government's use of coercion towards its population control programme, in the provision of reproductive health services. It reviews the history of coercive measures by state agencies and current policies favouring the use of coercion and analyses the human rights violations that these entail. It also looks at the consensus building that the government machinery indulges in to get support for its actions. The paper explores the nature of the exclusion that the community faces because of this coercion. Finally it examines the impact of coercions on the community's health. The paper suggests that not only does the use of coercion violate the rights of the community, it does not fulfil the objectives with

which the services were initiated. The bottom line is that people should have the choice to decide for themselves, and the state should be the facilitator.

Ageing women and health care technologies, public health and policies

Anjani Jani, Swatija Manorama

There is a need to look at the ethical issues related to health care technologies and public health and policies related to the health of ageing women.

This paper reviews health care technologies such as hormone replacement therapy (HRT) in the context of its ban after years of its promotion and use as the only technology for healthy ageing. An issue in bioethics is the health costs of HRT. Another issue directly concerned with bioethics is the abuse and misuse of long-acting contraceptives and surgical or medical interventions during women's reproductive years, and the effect on their ageing. Public health policies on women's health are restricted to maternal and child health. Current policies related to ageing are essentially gender neutral. Given the proportion of older women in the population it is necessary to have a gender sensitive policy on ageing.

This paper comments on the question of physical and psychological violence against women by denying their health related concerns related to ageing. It discusses limitations in the research methodologies used for reproductive health technologies and proposes ethical trials of long-acting reproductive technologies as well as surgical and medicinal devices used for sterilisation and contraception.

Newer reproductive technologies and the law: the case for equality

Jayna Kothari

Genetic technology affects family law in many ways. The influence of new genetic knowledge and reproductive rights can be seen in questions relating to parental rights, custody of children and consent. The availability of newer reproductive technologies such as in vitro fertilisation, tissue transplant, pre-implantation genetic diagnosis, freezing of embryos etc is exciting as it means new reproductive choices for women. However, these new technologies also create legal controversies. Some areas of family law that are affected by such newer reproductive options are paternity, the meaning of parental responsibility, the use of genetic knowledge, sex selection and adult choice. Some technologies also necessitate discussions on questions of morality and welfare. The emergence of these controversies needs to be understood so as to inform legal debates in India.

One recent relevant development in India has been the amendment, in 2002, of the Pre-Natal Diagnostics Techniques (Regulation and Prevention of Misuse) Act 1994 to ban pre-conceptual sex selection. The amendment was made as newer reproductive technologies allow for sex selection even before conception. The PNDT Act has thus radically altered the legal

landscape in the field of reproductive rights. This paper will explore these issues using the themes of gender, equality, autonomy and human dignity.

Evidence-based ethics and clinical research in India

Prathap Tharyan

Ethical decisions are often made using a deontological or a teleological perspective. This paper highlights the need to consider an evidence-based ethical framework when deciding whether research conducted in India is ethical and uses the controversies raised by the trial on risperidone versus placebo in mania to illustrate this need.

An industry-funded, placebo-controlled clinical trial conducted in India of risperidone in the treatment of acute mania invited considerable criticism and debate regarding the ethics of using placebos in clinical research when effective treatments exist; the methods of evaluating the effects of interventions in health care research; the validity of informed consent, particularly in supposedly vulnerable populations and societies; the interpretation of ethical guidelines; and the role of ethics committees, regulatory agencies, sponsors and medical journal editors in international collaborative clinical research. A search for the evidence of the consequences of participation in placebo-controlled trials, particularly in mental health, was undertaken.

Data from systematic reviews reveal that methods that improve the internal validity of clinical trials often involve placebos, and placebo-controlled trials are not automatically ethically dubious, even in vulnerable populations.

A productive interpretation of this debate should appreciate the culturally and economically grounded preferences in setting priorities in research. It should include questions about the evidence that informs ethical opinions in order to prevent harm to participants and subsequent recipients of health care and to restore confidence in the methods and the results of research in health care.

Protecting the rights and interests of trial participants, users and communities: an advocacy project of the Global Campaign for Microbicides

Anandi Yuvaraj, Paramita Kundu, Ananthi Thambinayagam

HIV prevention research poses a variety of ethical and scientific challenges best addressed through broad-based participatory dialogue and meaningful partnerships between communities and researchers. The purpose of this paper is to talk about the work of the Global Campaign for Microbicides (GCM) on ethics and community involvement regarding HIV prevention trials in India and globally.

Several microbicides -- female-initiated methods of HIV/STI prevention -- are currently in clinical trials. These trials often take place in resource-poor settings and enrol particularly vulnerable populations. A core goal of the GCM is to ensure that, as science proceeds, the public interest is protected and the rights and perspectives of trial participants, users and communities are

fully represented and respected. One way to achieve this is to build the capacity of communities to advocate for their rights as trial participants.

Through its community involvement and research ethics initiatives, GCM seeks to engage stakeholders in a dialogue on community involvement, build capacity among community-based and civil society organisations to engage in ethical debates, and catalyse dialogue to inform key decisions on trial design and implementation. GCM-India organises meetings between researchers, policy makers and civil society, facilitating discussions of clinical trial ethics to create shared understanding and build consensus around this issue.

Civil society has an important role to play in the design and conduct of clinical trials, and should be involved at each and every step of the development and testing of novel health technologies like microbicides.

Analysis of legal remedies available to subjects of clinical trials

Adarsh Gangadhar

Nearly all studies relating to clinical trials have examined issues such as the pros and cons of relaxing norms to facilitate clinical trials in India; the conduct of illegal clinical trials; flaws in existing legislation; the plight of individuals who volunteer to undergo testing in the process of drug development; and changes to be accommodated through legislative prescriptions. There seems to be little literature on the legal recourses that a subject can avail of against the government and other stakeholders involved in the drug development process.

This paper proposes to examine the options available to trial subjects within the existing legal framework. It will examine the following options:

1. As the revised Schedule Y requires compliance with the GCP and Ethical Guidelines, sponsors and investigators are obliged to provide a far-reaching victim compensation package as expected under the guidelines;
2. The informed consent form can be treated as a contract, defining the rights and liabilities of the parties involved. Arbitration clauses can be incorporated to ensure that claims regarding compensation can be resolved expeditiously;
3. A claim can be made against the government for its inability to safeguard the health concerns of the public, thereby breaching its positive obligations under Article 21 of the Constitution;
4. Disciplinary proceedings can be instituted against physicians who fail to comply with guidelines while conducting clinical trials [Chapter VII of Code of Ethics];
5. Remedy can be sought under the tort law, on the basis of negligence; and
6. Criminal liability can be under section 336 of the Indian Penal Code for any rash or negligent act which endangers human life or personal safety.

Ethical issues in biomedical e-publishing

M G Sreekumar, Nabeel M K

Governments the world over are spending millions of dollars to fuel biomedical research. Scientific journals are the source of information on the latest research. Unfortunately, the costs involved in gaining access to scientific journals have often been forbidding, especially in developing countries. At the same time, the proliferation of information has reached exponential proportions with the Internet. The information explosion has been even more marked in the biomedical domain, providing better access to scholarly communication and also enhancing research activities. The time from submission to publication has come down, making the path from the labs to the media shorter and smoother, boosted by the Open Access movement. The lay public also has better access to such information.

However, the same qualities that have improved access to information can raise questions about its quality and reliability. The emergence of newer publishing models as when the author bears the cost of the publishing process, issues of intellectual property rights and the activities of commercial establishments promoting their products and services have their impact as well. This paper addresses such issues from an ethical point of view.

Privacy and confidentiality of health information: an emerging issue in implementing health information technology

Rajesh Kumar Sinha

The quality of health care today depends on the physician's ability to obtain complete, accurate, and adequate health information on the patient in a timely fashion.

The application of health information technology includes electronic health records, computer-based patient records, physician digital assistants and decision support systems.

Such applications make it possible to provide information on all users of a health care facility and also help physicians make quality decisions on medical care, research and public health surveillance and intervention. Information security in this area ensures the privacy, confidentiality and integrity of data, making them available only to authorised personnel.

Such applications can also pose a threat to patients' privacy and confidentiality and raise various legal and ethical issues. However, technologies such as audit trail and encryption / decryption biometrics can be used to protect information from unauthorised disclosure and use.

Health information technology must be used in ways that do not pose an unacceptable risk to patient privacy and confidentiality. It must maintain data security and accuracy; prevent its inadvertent release; deter access to unauthorised users; and discourage, detect and punish the inappropriate use of health information.

Patient, doctor and telemedicine: ethical concerns

G K Karanth

The use of telemedicine consultations, especially in remote areas, with specialists in medical metropolises, has been gaining in popularity. Its use in India is perceived as a welcome step forward in forging a private-public participation in health care delivery. While the evolution of guidelines governing ethical issues in telemedicine is in its infancy in India, there has been little debate on the issues in the field. This paper proposes to highlight issues that have defied ethical prescriptions and some which have escaped attention. What is the agency of patients or attendants who seek or get a tele-consultation? Who signs a prescription, and who owns it: the consulting doctor or the prescribing specialist? Should the patient be asked to pay for a telemedicine consultation even if it had been sought without his or her knowledge or consent? Should consent be taken? If a fee is involved, how is it to be shared? Several questions that are apparently administrative in nature do, in fact, contain many ethical concerns.

This paper based on data collected among users and providers of telemedicine focuses on some of these problems and their ethical implications. It argues that that not only should technological innovation be accompanied by a change in mindset, the profession also needs to reflect on its ethical standards.

Reporting the ethics of science: how the media frame ethical issues in scientific research

Usha Raman

Over the past few decades, while there is more information available in the public domain on how science is done, there remains a considerable gap between the cultures of doing and consuming science. The mass media play an important role in shaping public attitudes toward science and technology and therefore are an important interface between these two cultures. Through a textual analysis of coverage in two national newspapers, *The Hindu* and *The Times of India*, over a three-month period, from January 2007 to March 2007, this paper examines how the media frame coverage of ethical issues in biomedical research.

Response of the people, patients and media to the first clinical trial of cell therapy

Geeta Vemuganti, Virender Sangwan, Balasubramanian Dorairaja, Nageshwar Rao Gullapalli

This report on the public response to the first clinical trial of cell therapy summarises the different kinds of verbal and written responses from the public, patients, and the media to the use of cultivated limbal epithelial transplantation for ocular surface reconstruction, conducted at LV Prasad Eye Institute and supported by the department of biotechnology and the Hyderabad Eye Research Foundation. The period reviewed is from August 2001 till November 2007.

In the initial phase, the media, public and patients did not know the difference between embryonic stem cell and adult stem cells and assumed that this cell therapy involved foetal or embryonic tissues. This placed considerable stress and strain on the team. In the second phase of the project, there came a series of enquiries if this could be extrapolated to other kinds of eye diseases, especially retinal diseases which constitute an irreversible form of blindness. Later enquiries were made about the allogenic use of limbal tissue, and bone marrow derived cells for patients with other diseases, and about guidelines and regulations in India.

Various forms of presentations, publications, guest lectures on these issues led to the acceptance of this trial followed by a spurt of requests from people within and outside the country for holding courses and sharing knowledge.

Scientists and clinicians should anticipate the response of the general public and be prepared to address them at different intervals, particularly when they involve ethical decision making and regulatory authorities. Public forums and efforts at public education can help ease the situation.

ABSTRACTS DAY TWO

“There is such a thing as too many daughters, but not too many sons”: the intersection of medical technology, son preference and sex selection among south Asian immigrants in the United States

Sunita Puri

Prenatal and pre-conception methods of sex selection are illegal in India but legal in the US, where they are used by a number of immigrant families. This study examines social and cultural reasons underlying sex selection in the Indian immigrant community, its impact on women, and the attitudes of American physicians offering sex selection to South Asian immigrants.

Semi-structured interviews were conducted with immigrant South Asian women and men aged 19-65 who utilised sex selection clinic services; second-generation South Asian youth who grew up in families where sex selection was practiced; physician-providers of sex selection; and primary care physicians who had encountered requests for sex selection among their South Asian patients.

Most couples interviewed already had an average of two female children and wanted to ensure the birth of a boy. Physicians offering sex selection argued that patient autonomy and the concept of “choice” in reproductive rights made their practices ethical. Primary care physicians for South Asian families argued that these services were unethical.

This research illustrates the importance of interrogating the bioethical principles of autonomy, beneficence, and the idea of ‘cultural competence,’ as these three major principles have been applied by different physicians to both defend and criticise the development, marketing and use of sex selection technologies. It is my hope that this presentation will contribute both to a discussion of the social and cultural underpinnings of sex selection in the migrant South Asian community, and a discussion of physicians’ and legislators’ responsibilities to recognise and respond to these trends in an ethical manner.

Everyday ethics: ultrasound and sex determination in Australia

Victoria Loblay

This paper details ethnographic research undertaken in the ultrasound department of a public hospital in Sydney, Australia. In this particular clinical setting, ultrasound is not performed for the sole purpose of sex determination. However there is no regulation of the practice of sex-determination during routine scans for “medical” purposes. Thus, the negotiation of ethical issues surrounding sex determination and ultrasound often takes place during the process of the ultrasound scan, between individual sonographers, pregnant women, accompanying family members, and the foetal images. Based on data gathered through participant observation and qualitative interviews, I examine how sonographers and patients engage in meaning-making processes during the ultrasound scans, and how these meanings inflect parental decision-making and their desire to know the foetus’ sex. In the absence of formal ethics of sex determination, I discuss how sonographers grapple with their own moral stance on sex determination and its place as part of the clinical management of pregnancy. Based on my analysis, I argue that the practice of sex determination highlights the pivotal role of sonographers as they negotiate the moral territory that inhabits the space between the ethical guidelines that govern their practice.

Technology, quality and rights: an exploration

Abhijit Das

Large public health programmes like the Family Planning Programme or the Global Polio Eradication Initiative or the DOTS in the case of tuberculosis depend upon certain technologies for the fulfilment of their objectives. Successful, controlled pilot phases are up-scaled and these become part of national and, often, global public health initiatives. Many of the features that are present in the smaller pilots are often ignored

in the up-scaling process, leading to poorer quality and/or lower success. In India the bureaucratic response to such situations has been intensification of the programme, which is known to lead to violations and abuses of human rights. The author has been part of an advocacy effort to improve the quality of care of family planning operations using an adverse outcome accounting framework. This advocacy effort has been successful in combining a scientific and legal approach to introduce far-reaching changes in the design and delivery of family planning and reproductive health services in India - namely, the introduction of quality assurance committees at the district level and the family planning insurance scheme.

In this paper the author explores the potential of using this adverse outcome accounting process in examining alternative technologies for the same public health purpose. The first section outlines the framework, the second section describes the use of this framework in ongoing advocacy work on family planning operations and the third section applies this framework to the Pulse Polio Programme and Revised National Tuberculosis Control Programme as they are being implemented in India.

Ethical issues in the conduct of HPV vaccine trials in the developing world

Anant Bhan

Human Papilloma Virus (HPV) infection is a leading causal factor for cervical cancer, a major killer of women in the developing world. Prophylactic vaccines have been introduced in the West by pharmaceutical companies. In some parts of the West HPV vaccination has been made mandatory, which has been a controversial step because of opposition from conservative policy makers and religious heads. The vaccine is prohibitively expensive for use in the developing world, including India. Scientists are exploring low cost HPV vaccines for in the developing world and clinical trials of these low cost vaccine candidates are being planned in the developing world.

HPV vaccine research can be controversial given its links with sexuality, a taboo subject in many societies. The prophylactic vaccine needs to be given before the first sexual exposure, hence to adolescent girls. Research and provision of vaccines to adolescent girls have proved to be controversial in the West, and would probably be so in developing countries as well. Parents are often uncomfortable with letting their adolescent daughters participate in research linked to their sexuality and sexual exposure. The issues of privacy, confidentiality, affordability and ensuring post trial obligations would also be relevant.

This paper will deliberate on crucial issues in the introduction of HPV vaccines in the developing world. It will attempt to analyse existing bioethics theories and principles as they apply to this situation.

Consent issues in genetics of late onset and behavioural disorders

Sanjeev Jain, Meera Purushottam, Shobana Kubendran

Advances in molecular biology and genetics will accelerate our

knowledge about the basic biology of several diseases, including cancer, diabetes, schizophrenia, and late onset disorders. This knowledge may help predict the risk of developing these diseases, and also include access to genome-specific medication or interventions. Novel therapeutics derived from modified human genetic material may become a possibility. Thus consensual participation in genomics research and equitable access to genomics technologies will need to be ensured. The application of these technologies has been fraught with debate and their use in a less scientifically literate or cognisant society such as India raises important questions. Issues regarding privacy of genetic information may be a particular problem in extended communities as it may stigmatise entire families. Health care providers would need to be aware of the tests and interventions but at the same time, treatment for those known to be at risk would need to be ensured. Public health issues and access to these technologies would need to be addressed to ensure that there is no creation of a "genetic underclass" that are denied these treatments purely on account of affordability. We have compared practice guidelines and specific laws governing research and counselling between the European Community, the USA and India, and the WHO guidelines. Though there are broad agreements there are significant deviations in critical areas (such as sharing information between family members). We need to address these issues to inform and guide the practice of genomics based medicine in the coming years.

The procedure of informed consent in Indian clinical research: directions towards improving the quality of provision of information

Simble Susan Thomas, Rajendiran Duraisamy, Baiju Julian

Obtaining informed consent is based on a process of exchange of information between investigators and potential trial subjects. Such a process guarantees that subjects receive sufficient information to make free and informed choices about their involvement in research.

However, most patients consider the physician-patient relationship to be the same as the investigator-participant relationship. Many subjects enrolled into research programmes are inadequately informed of the study and of the consequent risk/benefits ratio. Poor and illiterate patients face difficulties in asserting an equal relationship with the physician. Even if informed consent meets all given standards, there is a major gap between the information presented and the capacity of the patient to fully understand the risks and benefits of being a subject in a research study.

This paper proposes to examine the informed consent process. It will make suggestions on how an informed consent should be presented to patients and how to ensure that patients are truly fully informed. A simplified format for informed consent will be proposed. It is not sufficient to follow international formats; consent must be contextually adapted to the Indian culture and worldview. The patient's comprehension must be ensured. Finally, the possibility that poor patients give their consent in order to receive treatment without payment will be discussed.

The reluctance of patients to take autonomous decisions: what is the relevance of the informed consent process in new medical technological interventions?

Sridevi Seetharam, Renzo Zanotti

New medical technologies are often promoted with scarce information about actual benefits and potential risks, exposing patients to the undesirable use of such technology. In order to understand how patients perceive their role in decisions related to their health care, a study was conducted to assess how rural patients make decisions to undergo surgical interventions. The results are interpreted in the context of the increased demands on the informed consent process posed by the new interventions and reduced intimacy of doctor patient relationship.

A qualitative study was conducted, using semi-structured interviews, on 25 adult patients advised surgery in a rural hospital in South India. The results were analysed using the Grounded Theory approach.

Awareness of social position and power hierarchy emerged as the core variables governing the process of decision-making of the patients. A majority of patients made decisions based on faith or trust in the doctor rather than by an objective evaluation of risks and benefits. They also expressed inhibitions in seeking information or taking an active role in the decision.

While the standard consent process stresses the individual's role in decision making, a majority of rural patients were reluctant to assume such a role. The new interventions also impact personal values and beliefs. Unanticipated risks, insufficient evidence of benefits and the trust-based approach of rural patients place greater responsibility on the medical professionals to help patients feel empowered to make autonomous decisions in line with personal values.

Comprehension and recall of informed consent among participating families in a birth cohort study on diarrhoeal disease

Rajiv Sarkar, Edward Wilson Grandin, Beryl Primrose Gladstone, Gangadeep Kang, Jayaprakash Mulyil

In research, informed consent provides participants with information to enable them to make an "educated" decision. This study assessed the comprehension of informed consent among participants of a cohort study.

Parents or guardians of children who, after giving consent, participated in three years of twice-weekly follow-up for a diarrhoeal surveillance study, were asked about the study objectives, their reasons for joining and their feelings or concerns about the study process.

Of 368 respondents, 329 (89.4%) recalled that the study was explained during enrolment, but only 159 (43.2%) knew that it was on diarrhoea. Only 50 (13.6%) respondents stated that they knew that they could leave the study at any time. The primary reason for 223 (60.6%) respondents agreeing to participate was

free medical treatment. The majority, 339 (92.1%) respondents, expressed their desire to join similar studies. Approval of the spouse was the most important factor (305, 82.9% of respondents) in the decision to participate. Belonging to the Muslim religion (OR=1.79, p=0.009) and maternal illiteracy (OR=1.69, p=0.035) were factors associated with lack of knowledge about the illness being studied.

Despite informed consent and a high compliance with the study protocol, retention of understanding about a research study was low over a long period of time. This study was conducted in a setting where the government provides free and accessible health care, but the study participants cited free health care as an important reason for participation, highlighting the need for health equity before true informed consent can be obtained.

Issues in patient use of Indian systems of medicine

Helen E Sheehan

The Indian Systems of Medicine (Ayurveda, Unani, and Siddha) and Homeopathy are supported by Indian's central government, as well as by many state governments, to train medical professionals, provide health services, and perform research on traditional pharmacy and treatments. Policy statements and funding resources sustain the ISM as health providers and as symbols of Indian culture and tradition. Social science and health economics research on health services' access for the poor in India (and elsewhere in South Asia) show that ISM may often be the only or one of many types of health care available. Faced with either limited choice on the one hand or a bewildering array of health provider choices on the other, low income patients are often inadequately served. They may not be able to ascertain the legitimacy and qualifications of the health provider. They may receive a misdiagnosis, incorrect medicines and treatment, which in turn may result in prolonged ill health, indebtedness because of high medical costs, and/or death.

This paper will discuss the status of the ISM system's services as provided by qualified, credential practitioners, and will review the complex array of unqualified practitioners, indicating the problematic intersection of multiple providers for patients in seeking care. The role of the state in providing guidance in regulation of health practitioners, in patient protection, and in assuring access to qualified health services will be raised as a basic, but often overlooked, ethical issue.

Practice of traditional medicine for hepatitis cure in Atchampathu village: a case study of adherence to bioethical principles

M A Jothi Rajan, Arockiam Thaddeus

Invariably in medical practice, the learned and the affluent think of "English" or Allopathic medicines for health care and cure. In India the literacy rate is poor and the per capita income of the socio-economically downtrodden is low. Health care has become an expensive affair and the poor cannot afford to buy medicines privately. Traditional medical practices offer treatment at an affordable cost with minimum waiting time for consultation

and with satisfaction for the patient and practitioner -- but with no scientific proof that they work. The state's and the medical community's refusal to recognise the services of traditional medicine practitioners is in a way a human rights violation and therefore unethical.

For over a century, in a village known as Atchampathu in the north of Madurai city in Tamil Nadu, a traditional medical practice is used to treat all types of hepatitis. Nearly 125 families render their services to those affected, irrespective of their caste, creed or religion. The fees collected depend on the patient's economic condition and never exceed 50 rupees. About 300 patients who had been cured by this method were interviewed. They attributed the cure to the good and godly nature of the traditional practitioner. Though the practitioners are Hindus by religion the patients who come there are from different faiths.

Though the practice seems to be unscientific without proof of cure, both patients and practitioners follow certain bioethical principles. When the prices of Allopathic medicines go up, the poor in particular may prefer traditional medicines. This could be a public health solution based on bioethical principles.

Medical innovations in orthopaedics : addressing issues of cost and benefit in relation to ethical resource allocation

Ajay Radhakrishnan, Nabeel M K, Abdul Jameel Shareef, Naveen C Balan

Principles of economic analysis and the issue of ethical resource allocation are not new in medical research but they may not have been given their due. In this paper we aim to address this issue by using the subset of orthopaedic research articles from indexed medical journals. A literature review shows that there has been an increase in orthopaedic research over the years but not proportionate to the phenomenal growth of medical literature overall. The dearth is felt in areas where it is needed the most as in the case of innovative modalities such as computer assisted orthopaedic surgery.

There are also concerns about the quality of such analysis. A search in orthopaedic literature using the keywords "cost effectiveness" obtained a large number of results but only because of the extensive misuse of that term. But even among those published papers containing some cost effectiveness and cost-benefit analysis it was found that many did not use basic analytic principles. This paper outlines the basic concepts in this area and some common analytical methodologies involved such as cost-effectiveness, cost-benefit, cost utility and cost-minimisation. The basic tasks of any economic evaluation are to identify, measure, value and compare the costs and consequences of the alternatives under consideration. This paper urges researchers to take economic analysis more seriously. We should not spend on new procedures without scientific proof of their worth; this would deny resources to another, perhaps more important matter.

Some ethical issues in primary care

B C Rao

This paper will highlight ethical dilemmas faced by general practitioners in their day-to-day practice. They work in a context of worsening ethics with the advent of private players in health care. Most providers are practising unethical methods in health care delivery. The implications are: delivery of services that are below par; unlawful gains, unethical practices and rising costs of health care

When "enough is enough" Withdrawal of technological life-support: a case of euthanasia or disproportionate means?

Daphne Viveka Furtado

The decision to withhold or withdraw mechanical ventilation is a highly controversial issue in these days of advanced medical technology. Having once decided to start artificial support, it becomes increasingly difficult to determine at which point it is ethically acceptable to withdraw it. This paper discusses the ethical aspects of withholding or withdrawing life-support in the light of the internal morality of medicine, the principlist bioethical approach and the understanding of euthanasia.

The ethical issues are related to end-of-life dilemmas, discussed in the context of two recent and similar cases (persons suffering from Duchenne's Muscular Dystrophy) that raised similar questions (respect for autonomy, quality of life, euthanasia) in two different parts of the world (India and Italy). While the media in both countries focused on the need for legalising euthanasia, very little appeared in the press about how euthanasia is defined or understood. This paper falls into the category of "retrospective reflection and analysis" with the dual role of being educative and proactive.

There is a widespread confusion between the notions of "letting die" and "euthanasia". Though both have the same physical result, namely, the death of the patient, they have a radically different moral significance.

In determining withdrawal of life support, the type of treatment, its complexity, cost and possibilities of use must be compared with the expected outcomes and excessive burden in terms of the patient's physical and moral resources. Professionals have an important role in educating the public to the semantics of euthanasia and an ethical assessment of health care technology.

Health care technologies as counter-death technologies: a philosophical appraisal

Sreekumar N

This paper will examine the underlying philosophical assumptions of the very idea of health care, as understood in modern medical science and its supporting institutions. With corporate interests increasingly influencing the practices of health care professions, the general belief is that the world is witnessing an alarming

transformation in the way the science of medicine is practised. I argue that the major culprit is the philosophy of life that prevails in our times, on the basis of which the notion of health care is defined. This notion is intrinsically related to an idea of welfare. I argue that the paradigm of welfare has lost its direction as it has ceased to be life-oriented. It now operates with a set of technologies which have the potential to be employed for providing genuine care to the human self but fail to do that as they now function merely as "counter-death" technologies. This will enable us to see the futility of such an approach as no one can counter death. Instead of being life-promoting, they become death-preventive. Our general understanding is to conceive life and death as dichotomies, which is not actually the case. This paper will argue that the fundamental philosophical outlook of the medical sciences provides us insights to understand the value of human life. This allows us to use technical knowhow to promote a welfare based on a philosophy of life that views peace and quality of life as defining features of welfare.

Selection criteria in the NICU: who should get effective critical care?

Zulfiker Ali

There are few tertiary level neonatal intensive care units (NICUs) in India and even government medical colleges do not always have a full fledged NICU. Thus there is a need for a protocol for selection and referral to an NICU. Any selection process raises a number of social and ethical issues.

This paper will discuss the reasoning behind the following criteria for selection to an NICU:

Babies deserving access to prenatal and neonatal specialty care on medical grounds; the critical condition of the baby, co-morbid

conditions, period of viability and gestational age; the financial condition of the parents and the affordability of the treatment; and, finally, the availability of resources in the Centre.

The complex promise of newborn screening

Fiona Miller

Population screening of newborns for relatively rare, primarily genetic, diseases (such as phenylketonuria) offers the promise of reduced infant morbidity and mortality. In most developed countries, newborn screening (NBS) has been standard practice since the 1960s. In India and other developing countries (such as the Philippines, Ethiopia and Iran), the emergence of newborn screening is more recent, becoming available to families with the financial means through private laboratories and clinics, and to wider populations through state- or NGO-subsidised pilot studies or programmes in several hospitals or cities in India.

The promise of NBS is complex, raising difficult policy questions about the priority to be placed on these public health initiatives, and the ethics of these multi-faceted interventions. In this paper, we report on a study of NBS in Ontario, Canada, using this data as a platform to consider the implications of the introduction of NBS in India. Our mixed methods study suggests that consumers and providers are ill-equipped to understand and manage some of the information that is generated. The interpretation of test results is not simply clinical, but biosocial. Further, gendered and racialised meanings of motherhood and fatherhood are relevant to understanding the reproductive risks that arise, with particular consequences for women. Southern Ontario, where we conducted our research, is ethnically diverse. But the health system is universally accessible and of high quality, and extreme poverty is rare. Outside these privileged contexts, the implications of NBS are less certain, and warrant careful consideration.

ABSTRACTS DAY THREE

Ethical issues in community study of severe mental disorders in India: the Thirthahalli experience

Jagadisha Thirthalli, Kudumallige Suresh, K V Suma, Basappa Venkatesh, Magadi Naveen, Ganesan Venkatasubramanian, Udupi Arunachala, Kengeri Kishorekumar, Bangalore Gangadhar

The study of patients with severe mental disorders living in the community is an important area of research. However, ethical issues involved in conducting such research have not sufficiently been documented. This paper highlights the ethical dilemmas that the research team faced while conducting such a study in a rural Indian setting.

The community intervention in psychotic disorders (CoInPsyD) project entails the identification, treatment and follow-up of schizophrenia patients living in Thirthahalli Taluk, Karnataka. The primary aim of the project is to examine the effect of duration of untreated psychosis on the outcome of schizophrenia. Personnel from the existing public health care system were trained in the

identification and referral of patients. Mass media and public fora were used to publicise the project. Ethical dilemmas observed during the identification and treatment of patients were recorded anecdotally.

A number of ethical issues were noted: (1) difficulties in ensuring confidentiality in a rural community setting; (2) responsibilities of the research team regarding schizophrenia patients without caretakers; (3) the deliberate avoidance of treatment by family members; (4) the role of private psychiatrists practising in the region; and (5) the fate of the patients after the termination of the project.

Understanding of the socio-cultural background of the community is of utmost importance in understanding the ethical issues of community-based research in psychiatry. There are any unanswered questions that require systematic research in this area.

Ethical issues in treating pregnant women with severe mental illness

Geetha Desai, Prabha Chandra

With advances in psychiatric treatment, more and more women with severe mental illness are considering pregnancy and are often at risk for unplanned pregnancies. The stage and severity of illnesses can variably affect the woman's decision-making capacity about management of pregnancy. While untreated illness may have adverse consequences on the pregnant woman as well the foetus, adverse consequences have also been reported with some psychopharmacological agents. This poses great ethical challenges for the treating psychiatrist who has to strike a balance between the woman's autonomy for wanting a child versus beneficence-based obligations. In addition, there is responsibility to protect the rights of the viable foetus.

The initial decision in the treatment process that the woman must make is whether to become pregnant and subsequently, if there is foetal exposure to psychotropics, whether to continue the pregnancy. The psychiatrist has to evaluate whether the illness has altered the woman's decision-making capacity and whether she can participate in the informed consent process. The next step is discussing treatment options, the impact on pregnancy outcomes, the effects of non-treatment on the pregnancy, the foetus and herself, and available support systems.

Involving the woman and her family as partners in decision making is important. The perinatal psychiatry clinic at NIMHANS has been involved in pre-pregnancy counseling and care of pregnant women with mental illness for the last two years. The paper will describe the ethical dilemmas it has faced in the form of case studies from the clinic and discuss a possible ethical approach to several of these challenging situations.

Should mental health assessments be integral to domestic violence research?

Veena A S, Prabha Chandra

Research on sensitive issues such as abuse and violence in vulnerable populations poses several ethical dilemmas. An important aspect is the impact of such enquiries on one's mental health. The paper discusses specific ethical issues related to mental health, based on violence research conducted and reviewed by the authors.

Research on violence among women includes the possibility that some revelations are occurring for the first time and are likely to be emotionally charged. Further, the very act of disclosure may involve emotional risks for the respondent. Hence assessing mental health parameters becomes essential and integral to research of this nature. Several issues in methodology are also important in mitigating the level of distress. Obtaining informed consent in violence research should be a process rather than a one-time formality. Reports of adverse events are likely in violence research, hence such studies cannot be bereft of mental health intervention, ongoing follow up, documentation

and appropriate referral services. Some women may also report positive mental health consequences which should be documented. Finally, since the researcher and the researched are both affected in a study of this nature, adequate sensitisation, ongoing training and supervision of research staff are equally essential.

Based on findings from ongoing research on violence and from review of other studies done in India, the paper will focus on best practices in addressing mental health issues in domestic violence research.

Down's screening guideline: roles, values and the problematic ethical issue of autonomy

Evelyn Lacson

The new American College of Obstetrics and Gynecology guideline for universal antenatal Down's screening has increased the number of women recruited into the screening network. This network brings people and technology together in a common language and practice. Embedded into the practice of screening are meanings, values and priorities which women may not be aware of. This paper brings into the ethical discourse three issues: the role of the guideline in the screening network, the values in the practice of screening and the problematic issue of autonomy when screening is made to appear routine.

An electronic and hand search was conducted of relevant literature written in English from 1990 to 2007 using keywords. It employed the explorative-descriptive method for the discussion and reflection of the research.

The research found that evidence based guidelines make screening appear as a routine standard of prenatal care. Under such circumstances more women are offered screening and possibly invasive diagnostic tests and intervention. Based on information they receive, women fail to carefully consider and understand the rationale of screening, the implications of its result and its embedded values. Therefore, they make uninformed decisions and consent for screening. When women understand information on risks for Down's, they decline screening.

Impact of bioethics on patents

Vishwas Devaiah

Patents have played a vital role in encouraging innovations on new medicines. But this is often embroiled in controversies regarding access to new drugs and further research on improving drugs. In the past decade biotechnology has made significant advancements in developing new medicines. But issues of the morality and ethics of patenting new biotechnology-based medicines derived from human biological material has created uncertainty in various parts of the world. European countries have increasingly discouraged patents on medicines derived from biological materials. More recently, Germany has rejected patents on stem cells derived from embryos on similar grounds. While research involving the derivation of stem cells was conducted under strict protocols of bioethics, the patent claim was rejected. It is of significance that ethical practices in

research are increasingly invoked to reject claims on patents involving the use of biological material.

This paper looks at research ethics and their possible impact on patent claims. It explores the relation between morality, bioethics and patents in the context of stem cell research in India as it is an emerging technology which has assumed great importance in recent years. The paper will illustrate the importance of ethical research in securing patent protection for new technology. While links between bioethics and patents have never occurred in the Indian context, developments in this area in the European Union can influence patent laws in India.

Post TRIPS world: what next in public health and policies?

Nalin Bharti

In the post TRIPS era public health is one of the most pressing issues for developing and least developed countries. Due to a collective approach by developing economies, the Doha and post Doha round talks considered the issue of public health seriously. But the matter does not end here because the trade concessions given to these countries are temporary. This paper argues that public health faces a crisis in the long run. It will present a summary of public health in the pre TRIPS era and then discuss the post TRIPS era in which, due to the product patent regime populations in developing and least developed economies face a "drug famine". The discussion calls for a mass awareness and an intervention in government policy.

Biotechnology and intellectual property rights: ethical aspects for biomedical and theological scientists in Iran

Mansoorah Saniei, Ladan Naz Zahedi, Saeed Shahraz, Elnaz Jafari Mehr, Saye Sayar, Ala Melati Rad, Roya Sherafat, Mohammad Reza Zali

Genetic engineering and biotechnology is considered to be amongst the most powerful and economically promising technologies in this millennium with potential economic and social benefits to all sections of society. Since the first steps were taken towards commercial exploitation of biotechnological inventions, tensions have been growing over intellectual property rights (IPRs) of the information contained in genetic material and biotechnological results. This study reports on what Iranian scholars in the field of medicine, genetics and theology think about the most important ethical issues on IPRs and biotechnology according to the four principles approach.

To investigate the attitude of Iranian scholars on this issue, a Likert scale questionnaire was developed that included a series of the most important ethical dilemmas about IPRs, human genetic material and biotechnological results. The research was conducted through face-to-face in-depth interviews

Thirty four geneticists, 136 physicians and 65 theologians responded to the survey. Forty three per cent of physicians and geneticists and 62% of theologians believed that genetic innovations should not belong to a particular person. Most theologians (58.1%) said that IPRs belong to the people. Most

biomedical participants disagreed. About 40% of participants believed that the right to use genetic innovations belonged to the researcher or company that supports the research project.

Participants showed a weak positive attitude towards IPRs of genetic material and biotechnological results. Most agreed that the benefit of society prevailed over the autonomy of researchers or companies.

E-medicine: an ethical evaluation

Sanghamitra Pati

Information and communication technology have engendered many changes in our lives. Among the recent developments of information technology is cyber medicine. Seeking medical information, advice or even procuring drugs via the internet is gaining momentum among the urban population in India. Numerous websites claim to provide medical assistance to patients. There is no doubt that cyber medicine has the potential to transform medical practice in the Indian context. However, knowledge and capabilities, particularly of a new technology, tend to develop faster than the guidelines needed for ethical practice in the new arena. This is particularly true in e-medicine. The blending of medicine and health care with e-commerce and the internet raises many questions. What sort of ethical conduct should be expected by practitioners and developers of the medical internet? This research attempts to analyse the ethical issues surrounding the arena of cyber medicine and stimulate more discussion in the medical internet community towards a morally acceptable cyber medicine. Several key challenges were identified, the first being to determine the boundaries of "medical/healthcare internet ethics" in the Indian context. Care should be taken to make the best use of this emerging internet technology in medicine and health care without compromising the fundamentals of medical ethics.

Ethical dilemmas in the recruitment of volunteers in the first HIV vaccine trial in Pune, India

Seema Sahay, Sanjay Mehendale

Protecting autonomy of volunteers and ensuring their informed participation in clinical research are basic ethical expectations from investigators. During the process of fair selection of volunteers in the first HIV vaccine trial in Pune, India, the trial team experienced ethical dilemmas and were made aware of the vulnerability of some potential participants.

Potential volunteers had to participate in a multi-level contact and education approach and then were critically assessed for ethical issues. In-depth analyses of issue based cases are presented.

Participation of unmarried young individuals posed the dilemma of legal maturity and protection of autonomy versus social dependency and family support in decision-making. The trial team involved family members, respected cultural norms and lost some eligible volunteers.

The trial team ruled out participation of an eligible female

participant after realising on probing that she wanted to win confidence of her husband with high-risk behaviour and her eagerness to participate was driven by a sense of security likely to be offered by the trial vaccine.

The enrolment of a volunteer with a lower socioeconomic background was carefully scrutinised to rule out participation for monetary benefit while also ensuring equitable opportunity. With a proven history of several altruistic tasks the volunteer was enrolled, respecting his autonomy.

The trial investigators succeeded in reaching the volunteers' enrolment target by strictly adhering to ethical norms. We applied a viable form of moral pluralism described as "negotiated universalism" by adapting a set of values most appropriate for the given socio-cultural context that would be close to wider expectations.

Standards of care in microbicide efficacy trials: a mapping exercise

Katharine Shapiro, Katie West, Lori Heise, Sean Philpott

In 2006 the Global Campaign for Microbicides embarked on an exercise to map standards of care (SOC) and prevention in seven different Phase 2B and 3 international multi-site clinical trials being conducted to evaluate the effectiveness of vaginal microbicides or the diaphragm for prevention of HIV acquisition in women. The goal was to provide empirical evidence of progress made towards meeting ethical aspirations described by scientists, ethicists and communities regarding SOC; to compare challenges posed in various community settings; to describe the different care and prevention strategies utilised within different studies and trial sites; and to examine how strategies are locally operationalised. This presentation will compare findings from different trials in different settings, discuss issues common to the field and those unique to specific settings, look at progress made, and make recommendations that can be considered for implementation in second generation trials.

Changing facets of ethics in transfusion medicine

Shivaram Chandrashekar

Historically it has been considered perfectly ethical and legal to buy blood for transfusion. Doctors recommended that relatives donated blood and fresh blood was always preferred. A simple VDRL test was considered sufficient to ensure safety of the blood. All this changed with the emphasis on HIV, quality, ethics and confidentiality.

Ethics in blood donation : A donor with sexual risk behavior doesn't realise that his donation is risky. A patient's relative is labelled as a "voluntary donor" and voluntary donors are given unscientific reasons to benefit, such as the benefits of donation. Blood banks are rewarded for this "noble effort".

Ethics in safe (testing) Blood: Blood is "priceless" but blood it comes at a price for testing. ELISA is the standard test but less sensitive rapid tests are legally acceptable. A follow-up of the rapid test with ELISA entails more cost. Who pays for it? If the

ELISA turns positive after the blood has been issued, will the blood bank be praised or penalised?

Ethics in safe transfusion: Use oldest blood first is the dictum but patients want the freshest. What is ethical: allowing someone to die for want of platelets or collecting surplus platelets and wasting some?

Patients, physicians, blood bankers and government want exactly the opposite of what scientific and ethical guidelines prescribe. The distinction between voluntary and relative donors is blurred, as is the incidence of infections. Giving the patient what he wants is a safer alternative to quality blood. Quality and cost contradict each other, as do law and ethics. Following law rather than ethics is a safer alternative.

Do condoms have us covered? Rethinking HIV/AIDS programmes in India

Sonia J Cheruvillil, Bhavana Nancherla

Over the past decade, HIV/AIDS has gained enormous prominence in international health as one of the most pressing epidemics facing the global South. There has been much written about intervention successes and failures, as well as the critical relationship between HIV/AIDS and human rights. Less understood is how the whirlwind of action from multilateral, bilateral, and private funders, and both government and non-governmental organisations (NGOs) has altered the Indian landscape of HIV/AIDS programming. In order to take advantage of copious funding streams, many NGOs have rearranged infrastructure and resources to tackle this public health emergency - though accommodation often occurs with little attention to capacity-building, or at the cost of existing service provisions. Such intervention often has a split effect, enabling acknowledgement of traditionally marginalised communities hardest hit by the epidemic, but failing to address the persisting climate of social and legal discrimination faced by these populations. This phenomenon manifests a contradiction of increasing importance to practitioners, activists, and ethicists alike.

This paper attempts to untangle the effects that HIV/AIDS has exerted on India's public service and activist spaces. It begins with an overview of HIV/AIDS work in India and the roles that various sectors have historically played. The paper defines a continuum of service-based versus rights-based approaches and discusses significant models for HIV/AIDS prevention and management within this framework. The authors critically examine India's "NGO culture" to demonstrate how shifting funding trends simultaneously nurture and undermine commitment to the principles of autonomy and justice.

Establishing a clinical ethics committee: five years of experience in Pakistan

Rehana S Kamal

In spite of all the problems and the unequal distribution of health care in developing countries there are no guidelines

available for the application of ethical principle in health care.

The need for a hospital ethics committee (HEC) was felt at the Aga Khan University Hospital. The committee's mandate is to facilitate the establishment of a community of health professionals who are sensitive to issues of ethics in health care. The committee was to provide two specific services; ethics consults and education. An outline of the goals of the committee was drawn up. These included developing terms of reference (TOR), education, awareness in the hospital regarding the existence and functions of the committee and developing and initiating an ethics consultation process. After three months of deliberations a final draft for the TOR was prepared and approved by the Hospital Board. A programme of continuing self-education of committee members through journals, case discussions and by attending workshops and conferences was drawn up.

The consultation will be provided by HEC to serve as an important mechanism for resolving moral and ethical dilemmas in patient care. Awareness regarding the existence and functions of the HEC was achieved by making presentations in different departments of the hospital, by distributing flyers and publishing a three monthly newsletter, and by conducting workshops.

In the past five years a total number of 60 consults have been held. The majority were related to end-of-life issues. Others related to the lack of resources, conflicts within families, social and cultural background and issues relating to autonomy.

Profile of members of ethics committees in hospitals and research organisations in Pune city

Sanjay Mehendale

The appropriate constitution of ethics committees (ECs) might ensure high quality review of research proposals. We studied the profile of EC members of Pune-based health and research organisations.

55 ethics committee members representing 12 health and bio-medical research institutions in Pune city completed the structured questionnaires. Their profiles were analysed.

Among the respondents, 9(16%) were EC chairpersons, 4(7%) were member secretaries and 42(77%) were members. They represented ECs of hospitals (64%), research organisations (25%) or NGOs (11%). The majority of them (80%) had become EC members on their own interest. The majority were men (73%) and above 40 years of age (87%). Nearly 55% had more than 20 years of research experience. The average affiliation with the EC was four years (range 1-15 years) with backgrounds from medicine (51%), social science/ social work (25%), biological sciences (14%), law, (4%) and others (6%). Ethical principles were correctly known to 42% members. Chairpersons/ secretaries were more likely to have a medical background (10/13 Vs. 18/42, $p=0.032$) and formal training in ethics (8/13 Vs. 9/42, $p=0.011$) compared to others. None of the chairpersons/secretaries were

either stakeholders or community representatives. EC members were well-educated; 62% with MD/ PhD and 33% postgraduates. Long-term EC members were more likely to attend meetings ($p=0.0058$).

Most ECs had appropriate constitutions and members were generally senior by age, highly educated, interested and well-experienced in research. The representation of lawyers, ethicists, women and common people needs to be increased. EC members had less than desired clarity on ethical issues and ethical principles. Formal training of EC members on ethical principles and practices is crucial.

Concerns of potential participants: are the ICMR Guidelines 2000 adequate?

Mala Ramanathan

In the Indian context, the ICMR guidelines for biomedical research are used to guide the ethical review of biomedical research. This paper describes an attempt to examine the perceptions of one of the stakeholders in the research process -potential participants. Their concerns regarding the required safeguards in a research process are usually not considered, even though the ultimate requirement for the study is their informed consent and participation. The aim of this paper is to identify the concerns of potential participants in biomedical research in view of the kind of protections offered under the ICMR guidelines.

The perceptions of these key persons were obtained using focus group discussions (FGDs). As most community members were not aware of ethics committees, discussions were initiated with a video coverage of a hypothetical ethics committee meeting. Four FGDs were conducted in the state of Kerala in India, which has the highest levels of literacy (above 90%) in the country. Understandings of informed consent processes, spreading of risk, fairness and justice, review processes for research involving human subjects, etc were explored in the FGDs.

The participants felt that most of the principles outlined in the ICMR guidelines were adequate for protecting human subjects in biomedical research. However, their understanding of the risk of participation included unanticipated health consequences of participation. A need for compensation for such problems was identified.

The study extends the understanding of risk-benefit analysis to include the unforeseen risks involved in participation.

Time to plug the holes in the National Blood Policy

Shailaja Tetali, C Balagopal

In 1997 the Supreme Court of India passed a ruling banning paid blood donations. The National Blood Policy, 2002, strongly advocates non-remunerated voluntary blood donation (VBD) and unambiguously rejects replacement donation. But the ground reality is different.

Patients advised to undergo surgery must often travel to far-off cities for treatment. The onus for arranging blood for the patient

is on his poor relative, who must find a replacement for every unit of blood required for the surgery. Outside the hospital gates, he finds "relatives" who are only too willing to donate blood for a large fee. It is difficult to check if this contact is indeed the patient's relative.

What is the use of having a ruling from the highest court of law, and a policy on paper, if it is not implemented? In 39 countries, which include developing countries with much smaller human resources, 100% of blood collected is from VBD, as opposed to 50% in India.

The safest blood comes from healthy altruistic volunteers who take pride in being regular donors, not from people who sell their blood to mitigate their financial problems. One of the great roadblocks preventing the development of an effective VBD service is a lack of sufficient forward planning by the relevant political authorities. It has been documented that the most important factor for good VBD service is commitment from the government.

It is imperative that the government bans replacement donation with immediate effect, and actively promote VBD.

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IJME's National Bioethics Conference-2

This supplement of the *Indian Journal of Medical Ethics* contains some important material for participants. In addition to the conference programme and abstracts of papers to be presented at the various sessions, we present here messages from the organisers, keynote speakers and other well-wishers. Also included are short bionotes of all those presenting papers, organising workshops or chairing sessions.

This is just a brief preview of the rich and varied discussions that we expect at the second NBC. We look forward to your active participation in making this a memorable event.

The *Indian Journal of Medical Ethics* (formerly *Issues in Medical Ethics*) is a platform for discussion on health care ethics, with special reference to the problems of developing countries such as India. It hopes to involve all cadres of, and beneficiaries from, this system, and strengthen the hands of those with ethical values and concern for the underprivileged.

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Contributions to the journal, in the form of original papers, research findings, experiences in the field, case studies, debates, news and views on medical ethics, are welcome. All submissions must be in English and are subject to editorial review.

Contributors are requested to refer to the detailed guidelines for submission available on the journal website.