Management of severely malformed infants

Dr. Vasant Talwalkar (pediatric surgeon) found considerable insensitivity in doctors dealing with such infants. A senior consultant told the parents of a severely malformed baby: ‘Yeh to khota puri hai, Isko phenk do.’ (This is a dud rupee. Discard it.) The All India Institute of Physical Medicine and Rehabilitation at Haji Ali will not treat a child with incontinence though such treatment is part of their mandate. Dr. Talwalkar cautioned doctors against carrying their prejudices to their consulting rooms and inflicting them on patients and their families. Instead, we should offer the best possible treatment based on the wishes of the family, accommodate their prejudices and help them overcome these.

He also bemoaned the fact that ante-natal diagnosis becomes anti-natal diagnosis when a malformed fetus is detected!

Allocation of scarce resources - social and ethical considerations

Dr. Thakkar (orthopaedic surgeon) pleaded for the use of triage. Social and political pressures must be overcome to ensure that individuals who can be salvaged and sent back as productive members of society get preference when facilities have to be rationed.

We should use our resources optimally and do everything we can to avoid wastage. Accountability and discipline can go a long way in ensuring this. The tendency for heads of departments to create fiefdoms, duplicating equipment and facilities must be curbed. Centralisation will go a long way in ensuring efficiency.

Ethics and dental practice

Dr. Porus Turner (consultant dental surgeon) felt that dentistry, like medicine, has changed from a profession into a business. There are now good businessmen and those not-so-good. When large sums of money flow in, irregularity in dealings is inevitable.

He divided unethical practices into:

- poor quality of service - inevitable when you see large numbers of patients in limited time and perform more operations than you can possibly handle;
- cheating as when the patient is charged for crown and bridge made of gold and is provided those of an inferior metal or inserting a dental implant when it is not really needed;
- negligence as when a dental implant is driven into the maxillary sinus or into the inferior dental nerve;
- dental politics as exemplified by running the other dental surgeon down;
- advertisement in the form of posters, publicising awards which have been won thanks to carefully cultivated contacts in the corridors of power or awards from non-recognised groups.

In response to a question whether attendance at a two day course on a specialised branch of dental surgery is adequate to label oneself a specialist, Dr. Turner stated that such a course merely put you on the track. You must now educate yourself and develop your own expertise before you can call yourself a specialist. One way of doing so would be to treat the first 50 or 100 patients free of cost and documenting your results.

General Eustace D’Souza narrated an episode where a soldier already on the dental chair was hastily moved off it to make way for the Defense Secretary who had suddenly decided he needed treatment.

Conclusion

Dr. Chicot Vas told the audience of the plan drawn up by FIAMC for holding a series of meetings on various ethical dilemmas faced by doctors. It is hoped that a consensus opinion can be reached at each meeting and recommendations drawn up. On the basis of such recommendations, FIAMC and other bodies can approach the Law Commission to improve existing statutes and, if necessary, get additional laws passed to the mutual benefit of patients and doctors. He welcomes participation by all concerned individuals and groups.

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Introduction

There is a widespread feeling that there has been a general erosion of ethical standards even in professions which have been considered ‘noble’. This has prompted a soul searching exercise to understand the problems involved. Such an exercise would help since the influence of ethical conduct in positive terms is not contained or concerned within some exclusive sections and select groups but is relevant to the entirety of society. The moral basis for the unity and stability of society demands that ethical restraint must operate not only in respect to individuals but also organised groups. The intention here is not to blame any section of the society but to appreciate the dilemmas that even concerned and sensitive people face.

Broad issues

Anant Phadke delineated the broad issues for discussion: the ethical duty of the doctor towards patients, fellow doctors, society in general; ethical code to be followed by health researchers; ethical code for drug companies; issues in health education and health policy making.

Amar Jesani provided a global picture of the changing nature of medical ethics. Medical ethics, as understood today, is different from what it used to be prior to the 19th century. The formation of the General Medical Council in Great Britain, which was responsible for making medical practice professional and for regulating the profession from within, was a major step. It was at this time that the Hippocratic oath came to be accepted by many, including the General Medical Council, which penalised those who violated it. Registration with the Medical Council was made a pre-requisite to practice.

The dominant principles of medical ethics at this time were: (a) do no harm (non-maleficence), (b) do good to your patients (beneficence), (c) autonomy of the patient has to be respected, (d) doctors’ responsibility to society as consisting of more than that mere treatment of the patient.

With the adoption of the welfare state in the 1940s the issue of what kind of health care should be provided became significant since the code of ethics is by and large silent about issues such as the
Ethics, today, involves a number of gray areas especially when medical professionals are grappling with competing values. If, for instance, we insist that only a qualified practitioner should be permitted to treat a patient, what would be the role of voluntary health worker?

**Definitions**

A working explanation of terms like morality, ethics and law was offered. Ethics is an attempt to define what is right and wrong on the basis of certain general laws and involves the principle of justice. Morality is a set of rules, not necessarily based on justice, decided upon by society. Ethics concerns itself with conduct and motive while law takes into account only the act. The intention to hurt is unethical but in the eyes of the law, only when there is an actual injury does it become a cognisable act.

Discussions over the next two days focussed on: (a) ethics of general health policy, (b) ethical issues in the care of patients with AIDS, (c) ethics in health care delivery and (d) ethics in research.

**Ethics of general health policy**

Since health policy has a vast scope, it was decided to confine discussion to the role of medical professionals.

Most policy initiatives concentrated on the instrumental role of health rather than on its intrinsic importance. Health has been looked upon as a means to increase productivity and not for its own sake. As a result, the National Health Policy (1983) is basically concerned with demographic details to be achieved by the year 2000 and issues such as the Net Reproductive Rate. It does not deal with broader philosophical questions such as equitable provision of health services and on the current deprivation of certain sectors. The objectives of national policies are determined by a number of extraneous factors. They often favour the most articulate. The allocation of funds are skewed with a vast disparity between the funds allocated to rural and urban populations.

Minimum health care should form a fundamental right and be incorporated in the Constitution as such, perhaps as part of the Right to Life (Article 21). Such a step will empower the people who can now claim measures to improve health as a matter of right and not depend on the altruism of the government or official organisations. It is also necessary to provide the people a legal mechanism to seek redressal when this right is denied.

It is in this context that the issue of resource allocation acquires an ethical dimension. It is iniquitous that minimum health care is presently given a very low priority when resources are being allocated.

The issue of bringing the medical profession under the purview of the Consumers Protection Act was discussed. Some participants felt that this could change the relationship between doctor and patient as trust will give way to suspicion, the doctor viewing the patient as a potential litigant. Doctors might hesitate taking up cases where the prognosis is grim. Most held that bringing the medical profession under the CPA would confer certain beneficial results such as:

(a) medical records will be maintained more rigorously;
(b) the patient’s right to information will be respected;
(c) greater standardisation will become necessary;
(d) standards of nursing homes will have to improve.

**Ethical issues in the care of patients with AIDS**

The attitude of medical professionals towards patients whose test for HIV infection is positive or manifest full-blown AIDS needs to be addressed in view of the fact HIV infection is viewed as an occupational hazard faced by those in the health care services.

Should the test for HIV be conducted on a routine basis? Should all patients scheduled for surgery be subjected to the HIV test? Or should it be restricted only to those who lead a life style that places them at risk of such infection?

Should the HIV status be assessed during an arranged marriage? It was pointed out that testing before marriage is no assurance that the person will not contract AIDS after marriage. The possibility of fake certificates being produced was also discussed. It was felt that pre-marital dialogue was a better option.

Should a mother with a positive HIV test breast feed her child?

Is the HIV status relevant when employing an individual?

What should be done if a person gets AIDS due to medical negligence?

Can the affected person be compensated?

Is it correct to collect blood samples from those patients who show symptoms of possible HIV infection without their informed consent, especially when the diagnosis is not followed up by medical treatment?

It was suggested that patients showing a positive HIV test should be treated with the same consideration that is shown to any other patient with a serious illness. The patient with full-blown AIDS deserves the same care as that bestowed on other terminally ill individuals. It was felt that every patient should be handled as though he was a potential HIV carrier. The refusal of surgery to a patient because he/she shows a positive test for HIV is unethical.

The rights of the person testing positive for HIV infection can collide with the rights of professionals. This was the case in the Mission Hospital in Miraj which had to review its open policy towards HIV patients when one of its senior surgeons died due to AIDS possibly contracted while in service.

An impression has been created that only sex workers are responsible for the spread of AIDS. In view of this, should doctors address the question of extra-marital relationships and advocate the need to control the animal instinct? Others felt that an undue emphasis on marital status could victimise women.

It is important to ensure that more funds are allocated to deal with the predicament of AIDS but this should not be at the cost of other services.

**Ethics of health care delivery**

Unequal distribution of services is especially obvious in the delivery of health care. There is an obvious partiality towards urban centres. Even in the urban areas the poor and dispossessed are often discriminated against.

Is it ethical to emphasise the preventive aspect of health to the detriment of curative measures?

Is the state justified in withdrawing from health and other social service sectors? As tax payers do we have a right to demand services? How long can society be expected to provide free service to the people? Is the state an appropriate agency for providing health care for all? This assumes importance in view of the fact that we do not have an alternative to state medical services, especially for the poor. The feasibility of the panchayati raj system was considered. We need alternative models.

For funding the health sector, it was...
pointed that in some countries revenue was generated through special taxes that were levied on the sale of alcohol and tobacco. The question of the ethicality of such a practice was discussed as we might end up promoting a questionable habit in order to generate funds for a worthy cause.

Should the trained voluntary health worker be permitted to inject drugs (streptomycin, for example) or perform surgery under anesthesia in the absence of qualified personnel?

Where even essential medicines are not available and key personnel are not to be found, how can a doctor be expected to work?

Many practitioners, who start off by practising in the most ethical manner, are eventually entrapped by the corrupt system or find it difficult to maintain the expected standard. Though doctors are an influential and a well knit group and have successfully fought for issues such as higher wages and against those matters perceived to be against their interest such as the CPA, they have rarely raised macro-level questions such as the rights of the patient or protested against inadequate facilities in Primary Health Centers.

Is it ethical for health workers to maintain that since the government does not provide them with adequate facilities, there is nothing they can do about it? Is it not imperative that in such a situation they should voice their displeasure? By and large they seem to prefer soft options and as a result do not even venture to enter bodies like the Medical Council of India and Indian Medical Association to bring about changes for the better or counter vested interests. Most doctors do not believe it to be their duty to protest against unethical practices. There are a few honorable exceptions, such as when the unipurpose health workers in Salem protested against coercive population control policy or when members of the Maharashtra Association of Resident Doctors protested against privatisation of medical colleges and, the non-availability of drugs. Such protests are nowhere near as frequent as in the West where doctors and nurses vigorously protest against cut backs in social expenditure.

Practising doctors are likely to face a number of ethical dilemmas such as whether a terminally ill patient should be informed of impending death or whether a woman who is unlikely to conceive be told about it. The obligation of the doctor to a patient who is unable to afford to pay for his treatment is also not well understood by many. In a market economy, doctors often consider it ethical to refuse to treat such a patient. Should the doctor permit amnioncetesis or fetal sonography if the woman already has daughters and is likely to face untold hardship if yet another daughter may be predicted? Double standards were also discussed. Some of us are prone to suggest a certain line of action for others but follow a contradictory path when we are affected. One example is the advocacy of oral rehydration therapy using home made nutrient when the child of another has diarrhoea but when our own child is affected, we rush to the specialist.

The controversy pertaining to euthanasia will acquire a greater ethical dimension once organ transplantation becomes big business.

The ethics of the existence of a hierarchy within the health care structure, whereby those occupying higher echelons enjoy a favourable position with plenty of benefits as compared to those enjoyed by the village health worker was also discussed. How can we promote equity among the various sections of those working in health care?

We have often tried to build ethics without reference to the extant political and administrative system. We must strive for an universal form of health care. Should doctors be compensated by the state instead of by patients? Such a step may reduce the present state where only those who are better off are provided adequate treatment.

Ethics in research

How much transparency should a researcher maintain? Ideally, one might maintain that all research should maintain total transparency. When the matter under discussion is sensitive and a certain amount of secrecy is critical, how is the degree of transparency to be determined?

When the researcher has collected personal and sensitive information over a long period after establishing a special rapport with the subjects, would he be betraying trust if he publicises that information? Making public the results of a study on sexuality might prove distressing if it is found that many girls in a small village had pre-marital sex.

Research, per se, may not be malevolent but its interpretation might make it so. For instance, to conclude that people can pay for health services just because they are doing so now could be preposterous, because they might be doing so at a tremendous cost to themselves and because they do not have a choice.

If the intentions are malicious, then the research is unethical. The problem here is, how can one determine the true intention of the researcher? Is the researcher always clear about his intention while undertaking a study?

Several funding agencies hand out a great deal of money for various kinds of research. Most funding agencies have their own agenda and expect research to be conducted so as to meet their expectations. Is it possible for the researcher to be totally non-partisan under these circumstances? This dilemma acquires a menacing proportion when the funding agency is merely using the research project as a ruse to gain access to an area or to collect certain types of information to be used against the best interests of that society.

Informed consent is part and parcel of research design yet there are innumerable cases where the manner in which consent is obtained borders on the farcical. This violates the inviolable rights of the individual and is unscrupulous. Many honest researchers are puzzled as to the stage at which consent should be sought and the extent to which information can and should be provided to the subject. Is it always possible to tell your respondents the real objective of your study? Is consent by community leaders a substitute for that by the individuals concerned? Are women consulted when group decisions are arrived at?

Incentives provided to research subjects also came under fire. Can such practices be ethically justified?

How do we distinguish between relevant and inconsequential or futile research? This gains importance when already scarce public funds are diverted for research projects.

Not publishing results which go against the researcher’s hypothesis or the interests of the funding agency (such as a pharmaceutical firm) is a blatantly unethical act.

It was also held that a survey or research which is conducted by promising some kind of remedy or service is unethical. The same holds true when new method- ologies such as Participatory Research Action are tested without any follow up action.

The relativity of ethics needs to be looked at with greater care. We should also take into account what is referred to as situational ethics, where what might be justified in a certain environment might not be valid in another context.
We need ethics committees which double up as committees that redress complaints. Ethics committees must, by definition, monitor the ethicality of the research that was being conducted. It was noted that the functioning of the Vellore Ethics Committee has shown mixed results. An effort to study injuries to health workers and the possibility of their contracting AIDS was stalled by the administration as it did not want the workers to know about the hazards they faced. It was feared that such knowledge might provoke a rash of compensation claims.

**Summing up and plan of action**

Ethics cannot be shaped and sustained in isolation. The heuristic process requires a supportive environment. In every field of activity the component of ethical behaviour has to be identified and its dynamics worked out and appreciated and an entire culture or value-system of ethical conduct has to be built up. It is maintained and sustained by a sense of responsibility - not merely accountability to some external agency but also to something within each participant. No final or ready-made answers can be provided. What is however needed is an attempt to specify the stand that people working at the grass root level should take. We need guidelines which professionals can use when confronted by the minefield of ethical issues associated with our several health problems. Follow-up action and greater interaction will enable us to learn from each other’s experience. There should be a conscious attempt to mainstream such an effort in order to reach a larger audience.

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**Whoever takes up medicine should seriously consider the following points:**

firstly, that he must one day render to the Supreme Judge an account of the lives of those sick men who have been entrusted to his care. Secondly, that such skill and science as, by the blessing of Almighty God, he has attained, are to be specially directed toward the honour of his Maker and the welfare of his fellow-creatures: since it is a base thing for the great gifts of Heaven to become the servants of avarice or ambition. Thirdly, he must remember that it is no mean or ignoble animal that he deals with... Lastly, he must remember that he himself hath no exception from the common lot, but that he is bound by the same laws of mortality and liable to the same ailments and afflictions with his fellows. For these and like reasons let him strive to render aid to the distressed with the greater care, with the kindlier spirit and with stronger fellow-feeling.

Thomas Sydenham (1624-1689) in Medical Observations (1st edition).

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**Medical care and malpractice in our prisons**

_Sanjiv Kakar, for Seminar:_ Medicine in the prison is much discussed nowadays. I want to ask not so much on overall health status of prisoners but...there seem to be contradictions between medical power, humane, compassionate...and a certain discipline which a prison system imposes. Is there some chance of medical power being used to bring about from within an effective human rights intervention, to monitor abuses, violence, savage beating, rapes...? Do you foresee such a role for medical power?

_Kiran Bedi, Inspector-General, Prisons, 1993-1995:_ This is one of the major powers, it has legal value. It is a power I have seen being misused, by prisoners, by staff and the doctors. The doctor is dependent on the internal discipline of the prison,. If the internal prison is poor, he can hardly function. He is being threatened all the time. The gangster rules the prison...(and) intimidates the doctor. Gangsters and bullies (in Tihar jail) used to ask each morning: ‘Aaj kisne court nahin jana? Batao. Aur doctor ko bolo, inko medical lagao. Aur jinhone nahin jana, paisa nikalo. (Who does not wish to go to the court today? Tell us. And then inform the doctor to attach the medical certificate. Those who do not want to go, pay up.) This is how medical power was being misused. I have two chapters on medical power in Tihar (in my book), emerging from prisoners’ petitions.

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