

The bioethics group of the Aga Khan University, Karachi

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In recent years, the medical community the world over has witnessed increasing emphasis being placed on the ethics of medical practice. Both clinicians and researchers are now expected to be aware of and work within defined ethical guidelines. For research involving human subjects, it is becoming mandatory to get formal approval from institutional or national ethical review committees to ensure that ethical standards are met. This is becoming necessary to secure funding from agencies and also for acceptance for publication in reputed scientific journals. In the clinical setting, hospitals, patients and indeed physicians themselves are now looking towards ethics consultation services and hospital/clinical ethics committees to help resolve ethical and moral dilemmas emerging in the dispensation of health care.

As a consequence of the recent increase in its significance in clinical practice and research, bioethics has emerged as a part of medical education both at the undergraduate and postgraduate levels through much of the world. In Pakistan, at the Aga Khan University (AKU), Karachi, bioethics has been a part of the undergraduate programme for over a decade.

Although AKU medical college graduates have had formal education in bioethics, the majority of residents and faculty at this university, being graduates of other institutions, have had no exposure to bioethics. Other health-care staff like nurses also suffer from the same handicap.

Acknowledging this deficiency, a diverse group of health care professionals at the Aga Khan University formed the Bioethics Group (BG) in 1997. The motivating force behind the move was Dr Farhat Moazam, then professor of surgery and the Associate Dean, Post Graduate Medical Education. For some time, Dr Moazam had been highlighting ethical dilemmas encountered in clinical practice. She encouraged the discussion of articles on ethical issues in journal clubs, and brought out ethical aspects of care in morbidity and mortality meetings and at ward rounds, thus informally raising awareness of such issues among residents and faculty.

The original Bioethics Group, with Dr Moazam as the Chair, drew its voluntary membership from the faculty of the medical and nursing schools. Among its founding members were a surgeon, a physician, an anesthesiologist, a clinical psychologist, a nursing instructor, a neonatologist and a social scientist. Four years down the line, six of the members of the original group are still serving on the group, while a lot of 'new blood' has also been added.

The group had the following broad objectives: to assist in providing education in health-care ethics to faculty, residents and interns, and hospital staff; to conduct research on bioethical issues, and to assist staff faced with

ethical dilemmas in the decision-making process.

The group has been convening on a fairly regular basis at least twice a month for its two-hour luncheon meetings since it first met on June 20, 1997. These meetings are used as opportunities for self development as well as to plan activities to further the group's objectives.

Self education

Since none of the members of the BG had any formal training in bioethics, one of its priorities was, and still remains, self-education. Time is set aside in each meeting to discuss an article or any current issue highlighting an ethical dilemma and analysing it in light of the principles of bioethics. At present the BG is reviewing research guidelines formulated by the Council of International Organizations of Medical Sciences (CIOMS), keeping the Third World perspective in mind. It is compiling a catalogue of suggested changes to be sent to CIOMS for consideration in the guidelines' ongoing revision. Such exercises have helped the group develop a deeper understanding of research ethics in the context of the developing world.

At a more formal level, Dr. Moazam took a year's sabbatical in 1999 to obtain a Master's in Bioethics at the University of Virginia at Charlottesville, VA, USA.

Ethics Grand Rounds

Ethics Grand Rounds are a valuable educational exercise for highlighting the principles of bioethics and raising awareness on ethical issues. The BG introduced the rounds at the University in 1998. 'Death with Dignity' was the catchy title of the first Grand Round. The audience was given an opportunity to grapple with end-of-life decision making processes and the issues at stake in such situations in this part of the world.

These Grand Rounds have become a regular feature with participation from medical and nursing students, faculty, residents and interns, nursing staff and the hospital administrators. The format is quite interactive. A composite case is constructed from facts taken from an actual clinical situation that had posed an ethical dilemma in the past. A resident briefly presents the case to the audience. Following this presentation are talks by two speakers, BG members or invited faculty, who take 15 minutes each to bring out two usually conflicting views on the matter. The audience is then invited to participate and usually an intense discussion ensues for the next hour or so. A summation by the moderator wraps up the session. According to the feedback received, audiences have found the case scenarios realistic and the discussion useful and relevant. One parameter of these sessions' popularity is the fact that various hospital departments cancel their regular teaching sessions and meetings so that people can attend the Ethics Grand Rounds.

List of Bioethics Grand Rounds: March 1998: Death with dignity; May 1998: The critically-ill neonate: a right to live;

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August 1998: The patient with cancer: to disclose or not?; December 1998: Kidney for sale; March 1999: Whose rights? confidentiality vs. the right to know; September 1999: Down's dilemma; December 1999: Whose life is it anyway?; March 2000: Between the devil and the deep blue sea; August 2000: Research in the developing world; March 2001: Consent: how informed is informed?; September 2001: "Doctor, please don't tell my mother she has cancer!" The right to know vs the right to say no.

Newsletter

The BG has been publishing a newsletter since July 1998. Evolved from a one-page photocopied version to a more formal 6-8 pager printed format, the newsletter is circulated among the departments, faculty and staff of AKU and also mailed to interested individuals outside the institution. It contains news of upcoming events and reports on the BG's activities. The BG encourages individuals to express their opinions on burning ethical issues and controversies through the newsletter.

The newsletter is funded by the Dean's office and prepared entirely by BG members with no professional help in the designing and publishing process. Without dedicated secretarial help, members have often found it difficult to meet publishing deadlines with the result that the newsletter has come out rather irregularly.

Ethics consults

One of the group's original objectives had been to provide advice on moral issues encountered during patient management. As its activities became well known, the BG found itself receiving more and more 'moral queries'. Among the initial tasks was, and still remains, the screening out of management issues or financial concerns which are perceived as 'ethical dilemmas'.

The BG received its first formal Ethics Consult in November 1999. This consult concerned the management of an 18-year-old boy with Down's Syndrome, irreversibly quadriplegic for several months and ventilator dependent. His family wanted to disconnect him from the ventilator and take him home, while the physician insisted that this was tantamount to murder. With no formal experience in handling such consults, the group took on this as a challenge. After several days of interviews and deliberations, it came up with advice that was accepted by all parties involved in the conflict, including the family, physician and hospital.

In August 2001, a formal ethics consultation service was started by the newly established Hospital Ethics Committee (HEC). Interestingly, many HEC members dealing with ethics consults are also long-standing members of the BG.

Capacity building

One of the logical outcomes of BG-related activities by its members has been the development of individual capacities in the field of bioethics. The group has effectively become the 'resource pool' of bioethics for the University and for other institutions as well. Several of the BG members serve on the Hospital Ethics Committee and on the Ethical Review Committee. The University's curriculum committee has also

asked BG members to help in the incorporation of bioethics in the problem-based learning modules.

Exporting bioethics

Other institutions have also expressed interest in developing bioethics-related activities at their campuses in collaboration with BG. One such institution is the Ziauddin Medical University (ZMU), Karachi. The first combined Ethics Grand Round held at ZMU was a resounding success, and other similar rounds are planned.

BG is also interacting with ZMU to develop their institutional guidelines for ethical research, and to establish their ERC. A group of interested faculty is being formed at ZMU to carry on the work independently. Similar projects are being discussed with other institutions also.

National guidelines for ethical review of research on human subjects

The BG, along with AKU's Ethical Review Committee, organised a workshop on ethical issues of health research in developing countries from July 22 to 27, 2001. There was close collaboration with the Harvard School of Public Health, the Pakistan Medical Research Council (PMRC) and the Indian Council of Medical Research. At the end of the workshop, one day was devoted to deliberate upon forming ethical guidelines for Pakistan. A core group formed from among the BG's members is now in the process of preparing a draft of the proposed national guidelines which will be sent to the PMRC for nationwide circulation and wider input. It is hoped that through this draft will emerge the national guidelines.

The future

In the four years of its existence, BG has brought about an appreciable change in the way people look at and handle ethical issues in the clinical setting at AKU. It has evolved and implemented educational strategies to raise the general awareness of bioethics among students, health-care providers and the hospital administration. Its manpower and experience have helped establish other ethics-related committees at the institution. Finally, it has developed linkages with other institutions in the city.

Till now, the group has developed through self-education and 'on the job training'. It is perhaps time to consider formal training in bioethics for its members, towards establishing an indigenous bioethics programme at AKU. At present all members of the BG are fully employed in other clinical, administrative or academic activities; bioethics is a voluntary activity. Perhaps in the future the BG could have permanent as well as part-time members so that more ambitious projects could be taken on. If the University is ready to commit itself in this direction, the BG could in fact be a forerunner of a bioethics centre at the AKU in the foreseeable future.