

Centre of Biomedical Ethics and Culture

Bioethics Links

Educational programs of the Center of Biomedical Ethics and Culture aim at enhancing national capacity and linkages in bioethics. In this issue, Karachi alumni of the Postgraduate Diploma Program write about personal experiences related to their ethics programs and scholarly activities. Editor

Research and Ethics: Partners not Adversaries

*Athula Samutipala **

Ethics is perceived by some as an opponent of research, or a barrier and hindrance. In this view, ethicist and researchers function on different wavelengths and inhabit different camps. But should ethics and research really be considered competing rivals? Why have the two come to be perceived in this manner by some? In my opinion, ethics and research are neither rivals nor adversaries but there are reasons for this perception.

Historically, research started first and ethics followed. Contemporary bioethics related to human subjects in research is a relatively new phenomenon. It evolved in the middle of the 20th century following reports of unethical conduct by some researchers that led to exploitation of vulnerable populations for easy and inexpensive research. There is little doubt of many examples of researchers who used or, more correctly, abused their work for personal gains and to establish authority and domination. Bioethics at its inception attracted those who were not primarily researchers themselves and tended to belong to disciplines such as theology, law, philosophy, sociology, and human rights. As “outsiders” to research, many doubted justice towards human research subjects from peer groups of the “insiders” themselves, those invested in conducting research. Researchers on the other hand believed that the bioethicist did not understand what research entails or its

importance to society. It is not difficult to understand how this can generate mutually hostile feelings.

But in reality, ethicist and researchers share a broad, common goal. Research is undertaken to bring benefits to humankind by generating new knowledge. Ethics aims to safeguard the rights of the subject participants and prevent potential physical and psychological harm that can be caused by research. Thus both groups can be said to have the welfare of humans in mind, and should not be considered adversaries or rivals.

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Alumni of CBEC's Postgraduate Diploma Program with national and international faculty at the annual dinner at Dr. Moazam's residence. A photograph on the staircase is becoming a “tradition.”

*Director, Institute for Research and Development, Columbo, Sri Lanka

CBEC's Alumni go to Tehran

*Yasmin Wajahat **

The Tenth Asian Bioethics Conference (ABC) was held at Imam Khomeini Hospital Conference Center in Tehran, Islamic Republic of Iran, from April 26 to 29, 2009. The event was organized by the Tehran University of Medical Sciences (TUMS). Pakistan was well represented in the conference especially through alumni of the Postgraduate Diploma Program (PGD) in Biomedical Ethics, a program initiated by the Center of Biomedical Ethics and Culture (CBEC), SIUT in Karachi.

There were several presentations on ethics related topics by PGD graduates and CBEF faculty. In a session on the first day, Tashmim Razaaki (PGD 2006), a molecular biologist, from the Sindh Institute of Urology and Transplantation (SIUT) in Karachi, presented the institutional guidelines she has developed in reference to Human Embryonic Stem Cell Research. She highlighted some of the differences in beliefs about the concept of fetal ensoulment, and its timing, among Muslims and how these differ from those in Western societies. On the same day, Shaukat Jawaid, chief editor of the Pakistan Medical Journalists Association, spoke about practices adopted by the pharmaceutical industry in collaboration with physicians to promote unethical practices to the detriment of patients.

The broad theme for the second day of ABC included Medical Ethics, Islamic Ethics, and contextual issues in biomedical education, with presentations by Iranian and international speakers. The panel on Bioethics Education included a talk by Aamir Jafarey, CBEF faculty member, entitled "Bioethics Education Initiatives in Pakistan: early impact of an innovative program," in which he analyzed the PGD program in biomedical ethics initiated by CBEF in 2006. Using the analogy of a hub (CBEF) and spokes (PGD graduates), he highlighted the beginnings of a successful

national impact through ethics activities being undertaken by the alumni in various institutions within Pakistan.

In the following session, Yasmin Wajahat (PGD 2006), consultant obstetrician-gynecologist from Sobraj Maternity Hospital in Karachi, presented a paper on "Teaching Bioethics at the Postgraduate Level." She shared her experience of doing this with postgraduate trainees in her hospital, and emphasized the importance of bedside teaching to enhance communication skills and obtain ethical informed consents. In his presentation, Ashraf Hussain (PGD 2007), a physician from Shifa International Medical College in Islamabad, discussed the methodology introduced by his university to integrate biomedical ethics within the system based modules for medical students. Rubina Naqvi (PGD 2006, associate CBEF faculty), a nephrologist from SIUT, presented the content and methodology of an ethics course she has developed for biotechnology students.

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CBEC team and past PGD examiners Sahin Aksoy (2nd from left) and Anoja Fernando (5th from left) at the 10th Asian Bioethics Conference, Tehran. Others from left to right: Aamir Jafarey, Tashmeem Razzaki, Rubina Naqvi, Bushra Shirazi, Ashraf Hussain and Yasmin Wajahat.

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Birth of a Bioethics Group in Ziauddin University, Karachi

*Nausheen Saeed **

Background: In June of 2008, events involving a pregnant patient diagnosed to have a fetus with Down's syndrome led to a heated debate among physicians of the Ziauddin University (Kemari Campus) where I work. The couple had requested termination of the pregnancy, a decision with which the doctor complied. Following the procedure however, the parents became emotional and requested that the doctor resuscitate the baby at any cost. Efforts at resuscitation failed and he expired after two hours. Ethical issues which arose for concerned physicians included whether the decision to terminate the pregnancy at that stage was appropriate or not, should subsequent attempts to resuscitate the baby have been undertaken at all, and the emotional repercussions on the parents. During these discussions many faculty members felt the need to have organized bioethics related activities in the campus.

At that time, I was enrolled in the Postgraduate Diploma Program in Biomedical Ethics (PGD, Class of 2008) of the Center of Biomedical Ethics and Culture (CBEC) in Karachi. One of the requirements of PGD is that all students, prior to graduation, develop and initiate a sustainable bioethics related "project" in their parent institutions. It was the events and discussions around the above mentioned patient that made me think that it was time to develop a bioethics group on our campus which could help educate faculty and staff to address such issues.

The Idea: I organized an informal meeting of interested colleagues in August 2008 in which we worked out terms of references, membership criteria, and frequency of meetings (monthly). It was decided that the primary objective would be self education and capacity building using an informal, friendly style. As

coordinator of the group, I would be responsible for keeping the minutes, and for circulating reading material to members ahead of scheduled meetings. A catchy acronym, BEGZ, was agreed upon for the newly conceived Bioethics Group of Ziauddin.

In subsequent meetings, it was decided that BEGZ would focus on core, practical issues faced in daily practice including ethical questions related to beginning and end of life, pharmaceutical-physician relationships, and various forms of discrimination in society. The teaching modalities employed to highlight ethical questions would be kept flexible, simple, and interesting and include use of photographs, movie clips, local news paper items and advertisements, Urdu literature and poetry, and role play.

The Birth and First Steps: The BEGZ project was "born" with its first official meeting held in January 2009, a month following my graduation from the PGD program. For this session, I chose a brief clip from an Indian movie "The Rice Plate" which shows interactions between a Hindu woman and an elderly Muslim man, and highlights religious biases and discrimination. This led to an interesting discussion on the different forms of discrimination in society. Perhaps because the vast majority of people attending were women doctors the discourse ended up with a focus on gender discrimination.

In another BEGZ meeting to consider unethical physician-pharmaceutical interactions in Pakistan, we organized a brief skit with two doctors and one staff nurse of the group playing different roles. This methodology served as an effective, attention-grabbing tool leading to a good discussion among participants. It also helped to bring the BEGZ nurse member actively to the fore, a milestone in a society in which

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*Assistant Professor, Department of Surgery, Ziauddin University, Karachi

PGD Alumni bring Bioethics to Medical Technologists in Karachi

*Moinuddin Siddiqui **

The Beginning: Formal bioethics education for healthcare professionals is a relatively recent phenomenon in Pakistan with the focus primarily on medical students and trainees within different specialties. In contrast, bioethics education for nurses and medical technologists remains a largely unexplored area. A step to address this issue was first taken by Dr Rubina Naqvi of the Sindh Institute of Urology and Transplantation (SIUT) in Karachi. While pursuing (Class of 2006) CBEC's Postgraduate Diploma Program (PGD) in Biomedical Ethics she developed, as her "ethics project," an introductory bioethics course for medical technology students. This course was approved by the Karachi University (KU) and made a mandatory component of the curricula for its medical technology schools. In January 2009, Dr. Rubina began formal bioethics sessions in the Z. A. School of Technology in SIUT, perhaps the first time this has been done within a Pakistani public sector institution.

The PGD team: KU's requirement that bioethics be taught to technology students in its affiliated schools poses major difficulties due to lack of appropriately trained teachers in the discipline. In early 2009, the coordinator for biotechnology students of the Liaquat National Hospital (LNH) and Medical College contacted CBEC seeking assistance. LNH is one of the largest hospitals in Karachi with associated medical, nursing and technology schools. CBEC passed on this request to its PGD alumni who volunteered to take on this challenge.

A group was formed consisting of Dr. Yasmin Wajahat (Class of 2006), Dr. Bushra Shirazi (Class of 2007), Dr. Nausheen Saeed (Class of 2008), and myself (Class of 2007). We saw this venture as a great opportunity to help LNH and also as an opportunity to sharpen our teaching

abilities, and held a meeting to chart out an appropriate course, its content, and schedule. Topics were divided among us and the instructional methodology was planned. In retrospect this first, intensive brain storming session served as the fundamental pillar for our venture.

Medical technologists in Pakistan interact with patients not only in the laboratories where they handle human body fluids and tissue samples, but also as technicians in operation theatres, radiology departments, and the ICU in a country short on nurses. We decided to familiarize and educate students in basics of bioethics using practical examples and to highlight ethical issues keeping cultural and social milieu of Pakistan in mind. It was evident that we were familiar with bioethical issues from a "physician's perspective" and that we would need to find ways to shift this to that of technology students, something with which we had little prior experience.

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More than what meets the eye! Shrouded ladies shopping for alluring evening wear at a downtown store in Tehran.

*Senior Lecturer, Department of Pathology, Ziauddin University, Karachi

“Research and Ethics” from page 1

It is time for researchers to be convinced of the importance of research being done ethically and to commit themselves to adhere to and promote higher ethical safeguards and standards in their work. They are in the best position to do so because they know best about the piece of research they wish to do and the methodology they will follow. Therefore, while formulating research questions and methodologies they should also consider ethics as a part of the research design. By incorporating ethical safeguards within it, researchers will be able to elevate the quality of the research itself.

However the difficulty we face as it stands today is that researchers may be experts in their subject and research methodology but many remain unfamiliar with the broader ethical issues. On the other hand, those who are experts in the field of ethics may not necessarily have expertise in research methodology related to the specific area of inquiry which they are asked to review as members of ethics review committees. Increasingly, such committees are asked to review research in many different disciplines and members cannot be expected to be knowledgeable in all these fields. I believe this makes it the duty and responsibility of the researcher himself or herself to assist the ethicist by identifying specific ethical issues in his own research and proposing proactive measures to deal with them.

A new model: Ethics as a friend of research

As a physician and researcher myself, I believe it is time for us to look for a new model in which ethics is seen as a friend of research. In order to do so, we need appropriate measures to enhance ethics knowledge and understanding among researchers and to reshape their minds so that ethics is viewed as an integral component of all research.

In this model, research and ethics assume the role of two entities in a partnership in which

ethics is seen not as an isolated activity but as an essential ingredient of the research proposal. The researcher is committed to the highest ethical standards not because someone is “out there to get you,” but because he/she understands ethical issues, believes in ethical research, and recognizes potential ethical concerns inherent in the research proposal. The researcher is equipped to deal not only with his/her own scientific research questions but is also committed to respect the basic rights of research participants, the important allies without which the research question or hypothesis cannot be addressed.

This model envisions researchers as proactive rather than reactive in their role in ethical justification of their research and in assisting ethics review committee members who may not necessarily be as well informed as they are about the research. As an example, in a study on suicide the researcher should realise that it is unethical to do nothing when a research participant is detected to have suicidal ideations, and to continue to study the phenomenon and then leave with the individual remaining at a high risk of suicide. In formulating such a research proposal the researcher must be proactive and include steps to be undertaken if such patients are detected.

Many ethical issues concerning human subject research that are the focus of immense debate within the ethics community fail to penetrate into the research communities. Is it ethical to have a placebo group for studies involving certain groups of patients? What happens if a patient refuses to participate in the research project but expects to be provided the associated therapy? Can a researcher pose the study as routine care rather than research, and how is therapeutic misconception to be dealt with? In a model based on a research and ethics partnership, researchers will make greater efforts to keep abreast of new ethical concerns that arise with advances in biomedical and

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technological fields.

Researchers must begin to accept their accountability to the public as human research involves fellow humans, uses public resources, and relies on existing knowledge which lies in the public domain. They have a social responsibility to ensure that some public benefit results from their research even though some may not always be immediate as in the form of a quantifiable product and may occur late as is the case with the discovery of genes. However, while formulating research proposals, researchers have an obligation to take into account any negative implications of their research findings on participants and the community at large.

In the model I propose, researchers must also accept professional ethical codes that are the norms of the scientific community. Each individual undertaking research plays a relative role in the history of knowledge gathering and scientific advancement. A particular study can only solve a part of a complex puzzle and researchers, knowingly or unknowingly, build on the knowledge accumulated by their predecessors. Every researcher has a moral duty to acknowledge when knowingly using other people's ideas and work, and must learn to be assertive and challenge those who do not. It is equally important that researchers of today make their knowledge available to peers and pass their experience on to successors who can advance it further for the common good.

I believe that a model in which researchers begin to internalize ethics as a component of sound research, rather than seeing it as an irritating external road block to their work, can bring an end to the often adversarial relationship that currently exists between research and ethics.

“CBEC’s Alumni go to Tehran” from page 2

This has been approved by Karachi University (KU) with a recommendation that it be offered in all KU affiliated institutions.

Bushra Shirazi (PGD 2007, associate CBEC faculty), a surgeon from Ziauddin University in Karachi, presented a survey she has conducted on 101 surgeons exploring their knowledge about ethics in general and the Code of Ethics published by the Pakistan Medical and Dental Council. Based on her results, revealing large scale unfamiliarity in both areas, she recommended the need for appropriate medical curricula and relevant workshops and seminars to address these deficiencies.

The ABC, with 80 international delegates from 25 countries, proved to be a great learning experience. It provided opportunities to interact and share ideas with people from different countries and enhance our knowledge about bioethics. An added bonus for PGD alumni was to experience the Iranian culture and society including local dress codes such as mandatory head covering (*hijab*) for women, and trousers and shirts but no neckties for men. We also noted that, in contrast to the use of English which has become the norm in most international conferences, in Tehran all announcements and presentations made by the Iranians were in the Persian language. (Head phones were available for English translations.)

In addition to the excellent academic program, our Iranian hosts had also organized several interesting social events for the delegates. The highlights included a visit to the National Museum of Medical History, a dinner hosted by the Mayor of Tehran, and a visit to the Palace of Raza Shah Pahlvi.

CBEC Announces Academic Programs Commencing November 2009



Postgraduate Diploma in Biomedical Ethics, Class of 2010



Masters in Bioethics, Class of 2011

For information and application forms, please visit www.siut.org/bioethics

“Birth of a Bioethics Group” from page 3

nurses are seldom active partners in doctors' activities.

Looking to the Future: BEGZ is in its infancy right now, but a group that began with 11 individuals has grown to 17 members in the period of eight months. These include three nurses, three postgraduate residents, and consultants from surgery, dermatology, psychiatry, obstetrics and gynecology, ophthalmology, and ENT. Increasing interest in BEGZ has occurred primarily through information disseminated through word of mouth. My hope is that over time more individuals on our campus will join us as I believe that such bioethics groups can be an excellent way to raise consciousness about the many professional ethical dilemmas we face daily.

Similar bioethics groups have also been successfully established by PGD alumni in the Shifa Medical College in Islamabad and the Shaukat Khanum Cancer Memorial Hospital in Lahore. The coordinators of these groups regularly exchange their views and experiences through the online “pgd alumni forum,” a helpful way to learn from one another. Perhaps what we are trying to accomplish in bioethics in Pakistan is best captured in the couplet of poet Majrooh Sultanpuri:

میں اکیلا ہی چلا تھا جانبِ منزل مگر
لوگ ساتھ آتے گئے اور کارواں بنا گیا

*“Heading for the destination, I had set off all alone,
People joined me one by one; now we are a caravan”*

**Recent CBEC publication in the
Hastings Center Report**

(39, no. 3, 2009): 29-44

**“Conversations with Kidney Vendors in
Pakistan: An Ethnographic Study”**

Farhat Moazam, Riffat Moazam Zaman, and
Aamir M. Jafarey

Paper accessible free at: <http://www.thehastingscenter.org>

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Bringing Bioethics to Technology

Students: Our class consisted of 20, third year biotechnology students with whom we took a total of eleven sessions over the spring semester. Students were introduced to practical issues such as informed consent, conflict of interest, privacy and confidentiality, patients' rights versus obligations of healthcare professionals, vulnerabilities, etc. We used simple, interactive, case scenarios and short movie clips to help students identify ethical issues and encourage group discussions. Our use of role play during the session on informed consent and doctor patient relationships, in which Dr. Salahuddin (Class of 2007) was roped in as one of the “actors,” was particularly successful.

We found students to be enthusiastic about bioethics, a subject that was entirely new for them. The methodology we used was vastly different from the passive mode of education. We found students to be enthusiastic about bioethics, a subject that was entirely new for them. The methodology we used was vastly different from the passive mode of education that is still the norm in many institutions in Pakistan. Over time we observed students becoming increasingly confident and interactive, willing to raise ethical issues and to participate in the discourse. In a hierarchical society, with physicians at the apex, this is an accomplishment. I believe the reason for this was our attempt to maintain a friendly environment so that students would not hesitate to ask questions. Students were also allowed to express their views in Urdu as many were not fluent in English, and because we believe that ethics has no language boundaries.

Conclusion: My colleagues and I came away with many useful lessons through our interactions with the LNH students. Perhaps the most important was that we learnt to see and teach ethics from other healthcare professionals' points of view. The response of our students was overwhelmingly positive, and

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their progress was a great motivating factor for us. The bioethics examination results (MCQs and open ended questions which we were asked to design) in bioethics indicate understanding and thought process among the students. All except two students scored 85% in the mid terms (results of the finals are pending).

None of this would have been possible without close collaboration among our group, in every step from the planning to the implementation. In addition, the flow of encouragement we received from other PGD alumni colleagues through internet postings on the “pgd-alumni group” made it an even greater experience for us.



CBEC students engrossed in an online training course during their Research Ethics Module. The internet *gali* (corridor) is used by the students for all computer and internet related work.

صدیوں کا سفر
مراصلہ بس اک محدود جلوہ ہے
یہ آنکھیں وسعت افلاک کی
رعنائیوں کو داو کیسے دیں
کہ میں نے آسمان کو
روزن زنداں سے دیکھا ہے
ادا جعفری

*A Journey of Centuries
My share in life is one of limited glimpses,
How can these eyes fathom the vastness
And the splendors of the firmaments?
I gaze at the universe
Through the window in my prison walls
Ada Jafarey*

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