

Centre of Biomedical Ethics and Culture

Bioethics Links

* **CBEC graduates its first four MBE students:** To celebrate the graduation of Aamir Jafarey, Saima Perwaiz Iqbal, Anika Khan, and Bushra Shirazi (MBE, Class of 2012), this issue of *Bioethics Links* features the synopses of their theses.

* **An “international” student body for CBEC:** Although Faculty for our Postgraduate Diploma in Biomedical Ethics (PGD) and Master in Bioethics (MBE) programs is international, our students have to date been Pakistanis. Due to an increasing number of applications from outside Pakistan we believed it time to open our programs to international students. We are pleased that next student batches will include a physician from Indonesia (PGD, Class of 2012) and a researcher from Kenya (MBE, Class of 2013).
Farhat Moazam

Bioethics in Pakistan: Foreign seeds in *desi* soil

Aamir Jafarey*

اگر ہجوم صداؤں کے دیکھنا چاہو
تو شرط یہ ہے کہ پہلا سخن کہا جائے
احمد فراز

*“If you desire to witness reverberating echoes
Then it is you who must utter the first word”*

Ahmed Faraz

From one person with formal bioethics education in 1998 to over ninety people with bioethics qualifications in 2010, the growth of bioethics in Pakistan has been phenomenal. I undertook this study to explore the similarities and the differences between the *desi* (generally refers to the peoples, cultures, and products of South Asia) version of bioethics and its American precursor, and understand its increasing popularity as a discipline in the country. The study also assessed the impact and expectations of those who had undertaken this education. Open ended questions and detailed interviews were used to gather data from participants. This essay highlights some of the interesting findings.

At the time of initiation of the study in 2010, ninety three people had either completed, or were enrolled in, formal

bioethics programs leading to postgraduate diplomas or MA in bioethics. The majority of participants belonged to one of three programs offered by only two institutions in Pakistan (one in the public sector and the other in the private sector of Karachi), and a few foreign programs. Participants were divided into three groups for the sake of analysis, the Initiators (6), the Graduates (35) and the Current Students (33).

Complex political and social changes in the USA of the 60s and 70s stimulated the birth and evolution of contemporary bioethics with

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The MBE, Class of 2011, looks relieved following the acceptance of their theses. Seen from left to right: Saima Iqbal, Anika Khan, Aamir Jafarey and Bushra Shirazi

*Dr. Aamir Jafarey, Associate Professor, CBEC

Taking Ethics to a Government Girls' School in Pakistan

*Anika Khan**

My MBE thesis was based on a study in teaching ethics that I undertook at a government girls' school in Karachi. It involved nine months of fieldwork at the school where I taught ethics to fifty-eight grade five students, and trained teachers with the intention that they would continue the ethics project, once my study reached its conclusion.

I set out with a simple objective: The overarching aim of the study was to teach ethics effectively to children in a Pakistani school in a low-income locality. Other objectives soon began to radiate from the central idea and added complexity to my study. Ethics, as taught in schools in the west, is rooted in philosophy and often disconnected from religion. To be taught effectively in Pakistan, ethics would have to adapt to the local context. The day-to-day reality of the lives of my students and the schoolteachers centred round religion and the particularities of an interdependent culture. Religion informed culture just as culture shaped religious perceptions and rituals.

A number of writers have written about the "Islamisation" of the national curriculum in Pakistani schools. However, there are very few studies on education which have explored the immanent presence of religion as a source of morality in Pakistani lives. My experiences at the school indicated that religion was a primary source of ethical values for the teachers and students. Conversations and interviews with teachers showed that they could not conceive of a disconnection between religion and ethics. The paradox that arose was in the way religion was taught: despite being a vital source of ethical and moral values, religion - as it was taught - did not

sufficiently focus on the ethical and spiritual aspects of Islam. The pedagogical approaches employed by teachers were limited, and the teaching of Islamiyat mainly emphasised the learning of concrete information through rote memorisation.

In the ethics lessons at the school, I used religion as a source of values. At the same time, critical thinking activities were included to encourage moral reasoning. Using different methodologies and sources to develop a simple ethics syllabus for grade five, I tried to create an interactive classroom where value development took place through both character building and moral reasoning. The aim was to have lessons that were holistic rather than fragmented in their approach and to use sources that connected to the reality of the children's lives.

The ethics project still continues at the school. I believe that the project is

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Dr. Moazam and Dr. Jafarey at CBEC's Research Ethics workshop held at Khyber Medical University, Peshawar, from July 19 - 22, 2011. These workshops are a regular biannual event since 2009 underlining the KMU commitment to fostering ethical research.

*Ms. Anika Khan, Associate Faculty, CBEC

Patients' Perceptions on being used as “Teaching Tools” for Medical Students: A Study from Pakistan

Saima Perwaiz Iqbal*

Often, patients admitted in a teaching hospital have to bear the expenses for their health care as well as serve as “teaching tools” for medical students. The objective of my qualitative pilot study was to look at the under-researched area of using patients for medical education in Pakistan. My aim was to determine the perspectives and views of hospital admitted patients at being used to teach medical students in a private medical college, and to understand the dynamics of interactions between patients, students, and consultant doctors.

From March to June 2011 I conducted one to one interviews with twenty adult patients, and also met with focus groups of medical students and teaching faculty. In my interviews with patients I focused on their feelings and experiences during bedside teaching sessions. This essay gives a brief account of some of the most interesting findings.

I found patients to be astute, and insightful, in assessing students and physicians. For example, patients were easily able to distinguish between physicians and students even when the latter had not identified themselves as students. Patients reported students to be often “unsure” in the way they communicated with them, also “writing a lot of notes,” and spending more time at the bedside as compared to physicians.

In the hierarchical Pakistani society, many patients described medical students as *majboor* (helpless, without choices) in front of the physicians who were considered to hold authority over them. Patients

observed how students struggled to obtain faculty approval during teaching rounds, and saw them as dependent on patients' cooperation for effective presentations and good evaluations from the faculty. As several patients also saw themselves as helpless because of illness, and dependent on the doctors for treatment, this perhaps led to empathy with students on the basis of “shared *majboori*.” This is an intriguing finding I have not come across in previous literature pertaining to medical students.

In Pakistan's family centered society, it was not surprising to find patients referring to students in kinship terms. Using a familial paradigm, older patients referring to students as their *bachay* or *bachon ki tarah* (children or like their children,) or *betay aur betyoun ki tarha* (like sons and daughters). This may also reflect Pakistani cultural norms in which people are more likely to confide in and trust family members rather than strangers; addressing students in familial terms may have also helped patients feel more comfortable.

Religion emerged as another important component during my conversations with patients. Like most Pakistanis, when speaking about their illness and therapy, they used terms like *mashallah* (what Allah wishes) and *inshallah* (if Allah wills it). Many patients said that during teaching rounds, while physicians and students discussed their case in English, they recited verses from the Qur'an or the names of Allah, possibly as a means of comforting themselves. Most patients I interviewed also considered students as future healers

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*Dr. Saima Perwaiz Iqbal, Associate Professor, Shifa College of Medicine

Influence of Culture and Language: Decision-making in Breast Cancer Patients

*Bushra Shirazi**

Contemporary bioethics places a great deal of emphasis on the patient's autonomy, important aspects of which include complete disclosure about the disease, and the patient's right to make informed decisions about therapy. However, the extent of information imparted to patients may differ in various cultures. With the objective of exploring the influence of local culture on the disclosure of illness and subsequent decision-making, I conducted an empirical study in a Karachi hospital on women diagnosed with breast cancer. My study included detailed interviews with twenty four patients as well as with the female surgeon involved in their care.

One of the most interesting findings that emerged from my study was the use of language by patients and doctors. Patients I interviewed generally avoided the word "cancer" and, if the word came up during discussion, from using it as 'first person' statements. Therefore they would say that "the disease was cancer" instead of "I have cancer." The terms commonly used instead of "cancer" included *bimaari* (illness), *rasoli* (a generic word for a mass) or *yeh cheez* (this thing), while some patients called it a *khatarnak bimaari* (dangerous illness). Two patients disclosed that family members also avoided using the word cancer. One respondent expressed her annoyance at being called a "cancer patient" by junior doctors, something she said "senior" doctors did not do. In her opinion, though this word may be routine for doctors, it magnified the stress and fear of the patient. She narrated that when the oncologist asked her outright if she knew what her disease was and told her that she had cancer, she burst into tears.

Others believed that the disclosure of cancer could kill the patient. In one case where the patient could not speak Urdu, her daughter (who was acting as interpreter) told me that she used the word *rasoli* (tumor) to refer to the cancer, and had informed her mother that "a small operation" was required. Following surgery, when the mother realized that her breast had been removed, the daughter told her that it was done to prevent the *rasoli* from spreading. When I enquired if this was not deception the daughter replied, "This disease is life-threatening. But the disease does not kill a person as quickly as telling someone that your death is on its way."

Hufeland (1762-1836) said that "to prophesy death is to cause it." My study suggests that as the word cancer was interpreted as imminent death by some using euphemisms like illness or tumor may serve as a mechanism to distance the disease from death. The consulting surgeon I interviewed confirmed the taboos surrounding the word cancer, and said that the word she too routinely uses to patients is *rasoli* (tumor). In her experience with patients she said, "once the word cancer is used the [patient's] mind goes numb." She said that somewhere during multiple visits the word cancer may be mentioned, but not always.

My interviews revealed that avoiding the word cancer does not imply that patients were ignorant of the diagnosis. A patient told me, "Nobody said the word but I just knew." It seemed to me that although patients understood the malignant nature of their disease, it was considered emotionally and psychologically important to use words that "softened" the impact of the diagnosis and perhaps maintained a sense of hope.

*Dr. Bushra Shirazi, Associate Faculty, CBEAC

“Bioethics Education Conference, Bangkok”
November 9-11, 2011

UNESCO Bangkok and Chulalongkorn University organized a 3 day conference to discuss the development of a graduate bioethics program in the latter.

At the time of the conference, major parts of Thailand, including Bangkok, were flooded following extraordinary rainfalls. However, with remarkable resilience and perseverance, the Thai organizers succeeded in holding the meeting as planned.

Invited speakers shared experiences with regional programs in which they are involved. Aamir Jafarey presented the outcomes of 3 degree programs in Pakistan, one run by AKU and two by CBEC. The latter combines distance learning with on-site modules making programs suitable for fulltime professionals.



A flooded main road in Bangkok - yet the resilient Thai carry on with daily life

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doing Allah's work. Some also believed (or perhaps comforted themselves by the belief) that they were pleasing Allah by cooperating in the education of medical students. As one patient remarked, “Allah expects this small sacrifice from us for the greater good of humanity and society.”



Travel, Pakistani style: A medley of people and vegetables travel together on a truck

**International Conference at
The Leiden University, the Netherlands**
December 7-8, 2011

The Leiden University Center for the Study of Islam and Society (LUCIS) organized an international conference on December 7-8, 2011 on “Bioethics and Islamic Law.” Scholars of Islam, historians, anthropologists and physicians spoke on an array of topics ranging from classical Muslim jurisprudence to social aspects of contemporary Muslim lives.

Dr. Farhat Moazam presented a paper “Cultural and Religious Influences on Decisions about Kidney Donation: A Study from the Islamic Republic of Pakistan” based on empirical research conducted by CBEC.

The papers presented at the conference will be published in a volume of the LUCIS series, *Debates on Islam and Society*.

“EMRO-CBEC-PMRC National Workshop on Strengthening Ethical Review Committees”

Held at the Centre of Biomedical Ethics and Culture, SIUT
November 17-19, 2011

The Centre of Biomedical Ethics and Culture (CBEC), SIUT conducted a three day workshop entitled “National Workshop on Strengthening Ethical Review Committees” in collaboration with EMR-WHO and PMRC on November 17, 2011. Twenty four participants, 12 of them from out of town, participated along with 10 engaged observers. At the inaugural event, attended by about 200 people from different institutions, Dr Haytham Al Khayat, Senior Policy Advisor at EMRO, Cairo gave the keynote address entitled “The stance of Islam on science in general and human subject research in particular.” Dr Mohammad Abdur Rab, Regional Advisor, Research Policy and Cooperation from EMRO, spoke on the new guidelines for ethical review being developed by WHO.

Workshop faculty consisted of CBEC alumni including Drs. Mariam Hassan, Saima Iqbal, Bushra Shirazi, Natasha Anwar and Rana Muzaffar. In addition to revisiting the basic concepts of ethical review, various sessions also tackled

emerging ethical issues related to genetic research and Contract Research Organizations. Dr. Asad Jamil Raja spoke about his experiences in setting up ERCS at the Aga Khan Hospitals in Karachi and Nairobi. Ms. Kausar Khan took a session on ethical issues in community based research, while Dr. Aasim Ahmad led an interactive session on ethical issues in research conducted during disaster situations.



Participants at the EMRO-CBEC-PMRC National Workshop

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replicable and children from underprivileged backgrounds will respond with enthusiasm to ethics taught through interactive teaching methods. The students I worked with were extremely responsive and quick at acquiring new ways of learning. However, I see teaching standards as presenting the biggest challenge to the teaching of ethics (or other subjects) in government schools. While my experience showed that religion could not be disconnected from ethics in Pakistan, I also realised that to introduce

ethics in schools, teachers will require a lot of support and training before they can teach in interactive ways that encourage critical thinking, discussion and enquiry in classrooms.

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Interestingly, my study has led me to reflect on my own use of language as a surgeon, and a realization that I too often avoid the word cancer when speaking with my patients.

“Bioethics in Pakistan: Foreign seeds in desi soil” from page 1

with an involvement of philosophers, theologians, lawyers, feminists, sociologists and members of civil society. In contrast, bioethics in Pakistan appears to be populated largely by physicians, as initiators, teachers, as well as students. Many I interviewed traced their interest to personal experiences of observing unethical practices, and a belief that bioethics may serve as a harbinger of change in the country.

Another difference I found was that in the US and other developed countries, to a great extent, bioethics is shaping and being shaped by esoteric issues raised by biotechnological advances such as nanotechnology, human reproduction and enhancement, genetic manipulation, etc. My study participants, although interested in these areas, appeared more concerned with common issues encountered in daily life; corruption and unethical behavior in clinical and research domains, unethical interactions with pharmaceutical companies, medical malpractice, or simply, the rude behavior of physicians and nurses towards those under their care.

Strikingly, many respondents spoke of significant personal impact changing their thinking and professional conduct. Many felt

more comfortable in dealing with ethical issues but reported a mixed reception from their institutional colleagues. While some respondents noticed enhanced respect by others due to their new skills, others found the label of “bioethicist” uncomfortable. Many cautioned against a perception that bioethics qualification enables the individual to sermonize and deliver moral judgments.

There is still no “market” for bioethics teachers in Pakistan, although the recent availability of bioethics trained faculty in colleges has stimulated the inclusion of bioethics as a subject in medical and dental curricula in a few colleges. There has also been a noticeable increase in publications from Pakistan related to ethics and presence at international conferences.

Bioethics in *desi* soil seems to have germinated and appears to be shaping itself according to its environment. However, there is a risk of overpopulating the field with enthusiastic “bioethicists” with a glut in the bigger cities and paucity in other regions of the country. These are important concerns that must be addressed as the field of bioethics continues to grow in Pakistan.



The 12th Asian Bioethics Conference with the theme “Practicing Bioethics with Cultural Engagement in Asia,” was held in Taipei, Taiwan from 28th September to 1st October, 2011. Dr. Bushra Shirazi (second from right), vice president of ABA, is seen with other participants.

Research Ethics Workshop at Fatima Memorial Hospital, Lahore

December 15-16, 2011

Dr. Aamir Jafarey, along with CBEC alumni Drs. Natasha Anwar, Farkhanda Ghafoor and Naseer Chaudhry, conducted a workshop at Fatima Memorial Systems, Lahore, on December 15-16, 2011. This was the second workshop that CBEC has conducted at this hospital.

The workshop was attended by 27 participants including IRB members, faculty, and trainees from different departments of the institutions.

Next Academic Year Begins at the Centre of Biomedical Ethics and Culture

Since 2006, CBEC has successfully run a year long Postgraduate Diploma in Biomedical Ethics program (PGD) for mid-career level healthcare professionals. In 2009, CBEC introduced a two year Master in Bioethics program (MBE) for professionals in major primary fields including healthcare, social sciences, education, law, etc.

Our next academic year begins in 2012. The Foundational Module scheduled from January 9-21, lays the grounding for students to understand the connections of philosophy, religion, law, and humanities in human moral thought, and to begin thinking critically about different aspects of bioethics.

Faculty for January 2012 Foundational Module:

Abdul Wahab Suri: Member of the Board of Studies of Philosophy at the Karachi University
Farhat Moazam: Founding Chairperson and Professor Centre of Biomedical Ethics and Culture, SIUT
Aamir Jafarey: Associate Professor Centre of Biomedical Ethics and Culture, SIUT
Aasif Aslam Farrukhi: Literary critic and short-story writer, Pakistan
Mohsin Naqvi: Religious scholar and writer, member of Pakistan's National Curriculum Board, Pakistan
M. Khalid Masud: Scholar, Islamic law and contemporary issues in Muslim societies, Pakistan
Paul A. Lombardo: Professor of Law at Georgia State University College of Law, USA
Sharmeen Khan: Corporate lawyer, Head of investigative compliance for a pharmaceutical company, Dubai

MBE, Class of 2013

Sara Fatima Azfar
Social/Development Consultant
Karachi, Pakistan

Elizabeth Anne Bukusi
Researcher/Administrator
Nairobi, Kenya

Shazia Humayun Malik,
General Surgeon
Lahore, Pakistan

Bilal Fazal Shaikh,
Plastic Surgeon
Hyderabad, Pakistan

Dedi Afandi
Forensic Specialist
Pekanbaru, Indonesia

Mohsin-e-Azam
Orthopedic Surgeon
Karachi, Pakistan

Salima Farooq
Nursing Instructor
Karachi, Pakistan

Shazia Fatima
Nuclear Physician
Islamabad, Pakistan

PGD, Class of 2012

Farzana A. Hashmi
Hospital Administrator
Karachi, Pakistan

Manzar A. Khan
Orthodontist
Peshawar, Pakistan

Faheem Khan
Psychiatrist
Karachi, Pakistan

Suneel Kumar
Oral Surgeon
Karachi, Pakistan

M. Athar Majeed
Public Health Physician
Karachi, Pakistan

Naima Rasool
Paediatric Surgeon
Rawalpindi, Pakistan

Shabana Tabassum
Hospital Administrator
Karachi, Pakistan

Maaria Zafar
Physician/Lecturer
Karachi, Pakistan

Centre of Biomedical Ethics and Culture, SIUT

Full Time Faculty:	Farhat Moazam Professor and Chairperson	Anwar Naqvi Professor and Coordinator	Aamir Jafarey Associate Professor
Associate Faculty:	Bushra Shirazi Ziauddin University	Rubina Naqvi SIUT	Anika Khan READyslexics
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