

Centre of Biomedical Ethics and Culture

Bioethics Links

In the lead article, Sualeha Shekhani writes about her interesting experience of conducting research on women prisoners in Karachi's Central Jail. In our series of writings by PGD alumni, Dr. Asma Nasim's personal narrative highlights how women struggle to achieve goals in life, while Dr. Ali Lanewala's narrative recounts the death of a young patient whose family refused treatment. Also included is a report on CBEC's seminar to take place in September 2015 on the theme "Bioethics goes to school." Editor

When Ethics Meets Law in Pakistan

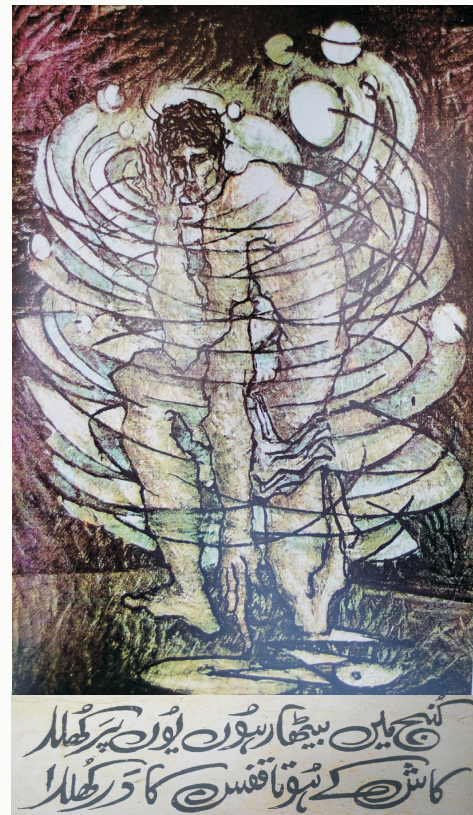
*Sualeha Shekhani**

A group of five young women walked into the tall historical building with a myriad of feelings: apprehension, excitement and a sense of purpose. We were equipped with tape recorders, notebooks, cellular phones and different aids for the purpose of research. However, to our amazement, we found out that before entering the vicinity of the 'dangerous zone', we had to hand over the different electronic devices. This included cell phones, tape recorders and even flash drives. We had arrived at the premises of Women's Central Jail, Karachi, with the objective of investigating the nature of female crime within Pakistan through conducting in-depth interviews with female prisoners. Our aim was to understand the kind of crimes women tend to commit and the possible reasons which lead them to perpetrate these acts.

What followed was a series of contradictions and surprises. We were led by a jail warden to a small room, utilized mainly as a sitting room for prisoners. We were also able to attract attention from the different women prisoners, who watched us with a mixture of curiosity, awe and resentment. We made ourselves comfortable in the room while a jail warden set out to recruit subjects for interviews. Since we were inside the room, we could not observe the way that they were being

asked to participate in the research. Three or four women arrived in a group, shy and hesitant. A constable accompanied them and stayed there during the

Continued on page 4



"My wings are ready for flight, but I am confined
How I wish the door of the cage was open"
Sadequain's illustration of a couplet by poet Ghalib
(*Mystic Expressions by Sadequain*, Topical Printers, Lahore, 2011)

*Research Assistant, Centre of Biomedical Ethics and Culture, SIUT, Karachi.

A Matter of Trust

*Ali Asghar Lanewala**

It was a routine day in a busy clinic when I received a call from the emergency department to see a very sick child who had just arrived in the hospital. I rushed to the ICU where the child had been shifted with his accompanying three male family members, the father and two paternal uncles. Ahmed was around six years of age and had been unwell for over two weeks. He was malnourished, and struggling to breathe. The family, farmers by profession, hailed from a small village in Thatta district. Ahmed was treated locally initially and when found to have kidney failure, was referred to us for further treatment. They handed me a pile of papers which included some prescriptions, referral from the local hospital and an ultrasound of kidneys which showed that he had stones in both his kidneys damaging them permanently. I assessed that we could manage Ahmed with immediate life saving measures including mechanical ventilation, dialysis and emergency decompression of the kidneys. Once the kidney functions were stable, definitive surgery for the stones may achieve complete recovery.

I could sense that the family was very uneasy insisting that they did not want any surgical intervention, that I should prescribe some medicine which they could buy so that they could take Ahmed home. I explained the severity of his condition and said, "Your child is very sick and he requires ventilator support and dialysis immediately. There is no other treatment for this problem anywhere." I also told them that our Institute provides all treatments completely free so they did not have to worry about that either. Ahmed's disease was treatable but we could not do

anything without their consent. They asked if they could discuss this amongst themselves and I said yes, requesting they not take too long because the child's condition was deteriorating rapidly.

Within a few minutes they returned and said that they did not want any treatment and wanted to take Ahmed home. I was surprised to hear that and said, "If that is what you want, nobody can stop you. But would you please reconsider your decision because I have seen many such children getting a new life." The father mumbled something but I could see that he would not speak up in the presence of his elder brother who was clearly the patriarch of the family and calling the shots. Aware of our social practices I knew that I had to convince Ahmed's uncle as the father would not make the decision. I focused on the uncle but could get nowhere as to why they wished to take Ahmed home. When I asked the father again whether he understood the situation he looked at his brother in confusion, who stared back angrily at him. The father, with tears in his eyes, told me that I should consider the uncle as Ahmed's father and left the *Continued on page 6*



It's a donkey's life: Carrying dinner but unable to eat it

*PGD Alumnus, Associate Professor, Pediatrics Nephrology, SIUT, Karachi.

Allah's Will

Asma Nasim*

I was born the second daughter in my family. "It's Allah's will, next time *inshallah*, it will be a boy," said my grandmother at my birth, munching on a piece of *mithai*. After 10 days, my *khala* (maternal aunt) gave birth to a boy. The whole family celebrated his birth with great fanfare.

My cousin and I grew up living side by side, next door. We played and became best friends. In school I was a top student, the best in every school activity. Dad was particularly very proud of me. My cousin was not very bright and struggled with his studies, surrounded by tutors and worried parents. From teachers to sisters, everybody was involved in his studies.

In the holidays during grade 10, his parents enrolled him in a top cricket coaching institute. I loved dancing and asked my mom for dancing classes. "Are you in your senses? Dance? Don't you have any other thing to do?" That was my family's response. My grandmother scolded my mom that she had made me too forward. Well, I felt guilty, really, why should I choose dancing over all other options? So I stayed at home, buried myself in books.

We entered Medical College together. I got my admission right away but he obtained his with difficulty. His parents did everything they could to get him admitted. After MBBS, he was immediately sent to USA for residency. I got interview calls from USA too, but my mom was adamant to send me only after my marriage. "How can you send your daughter alone to a foreign country?" my grandmother asked my dad. I stayed back, and got admission in a local university for my residency.

Suddenly, my mom and my grandmother became obsessed with my height and skin color. They insisted I wear high heels. I hated high heels. My grandmother brought 'Stillmans' skin bleach cream for me and forced me to apply it daily. My mom started visiting *rishta walis* (match makers). In no

time, I found myself in the drawing room with a tray in my hands and serving tea and with high heels on my feet. *Rishtas* (marriage proposals) arrived from the USA, Australia, Islamabad, etc. Mothers of prospective grooms scanned me closely and almost always had something to say about my height or my skin color. This became a vicious circle with my mom becoming increasingly obsessive about my height and I slouching more and more with guilt and exasperation.

I stood first in my residency evaluation, but I was confused. When my professor asked me what I would do in the future, I could not answer him. How could I? I did not know where I would end up after marriage, in the USA, Australia or Timbuktu? In the midst of my depression my cousin returned from the USA for a visit. He had completed his residency and was now practicing as an internist. During his visit, his mother started looking for a bride for him. And within a few weeks there she was - an extremely beautiful girl, intelligent, and smart. We all liked her. He got married, filed her papers and went back to America where she would join him. I remained trapped with my trays and drawing room rituals.

At last I got married. But I had to leave my profession because of my in-laws' wishes and then the birth of my two sons. After six years of staying at home I finally convinced my in-laws to let me return to my profession. I passed my postgraduate exam in Internal Medicine and then in Infectious Diseases specialty. After twelve years of marriage I am now a full time faculty member in a leading public, teaching hospital in Pakistan. I take care of patients who flock to us from all over the country and I am helping to train young doctors in my specialty. My cousin runs a small, private hospital in the USA.

Perhaps all this was Allah's will after all?

*PGD Alumnus, Assistant Professor, Infectious Diseases, SIUT, Karachi

“When Ethics meets Law in Pakistan” from page 1

course of the interviews. It was unclear whether this was for our safety or because the prison was wary that its 'misdeeds' and 'misconduct' would be reported to us (we had been initially mistaken as journalists or people from the press). In any case, this probably deterred the subjects from speaking freely about the nature of their crime.

We were holding conversations in a small room, with two interviews being taken at one time. During this process different jail wardens kept coming in and going out, some women had children with them who proved to be a distraction and other prisoners would occasionally interrupt the interviews to add their bit. This might have also influenced the research outcome. We also encountered something quite unexpected. *“Humein phansaya gaya hai,”* (We have been falsely accused) was a statement we heard, which was shocking. None of the women we interviewed confessed that they had committed the crime! Later, in a separate interview with a constable, we were told that the lawyers of these prisoners had advised them not to speak of their crimes. They were told to behave as 'victims' rather than as perpetrators.

We interviewed women who were in the prison for numerous reasons. Some of them had killed their husbands, one had managed to kill her entire family so that she could run away with the man she loved, and a few had kidnapped children for ransom prompted by poor socio-economic conditions. A widely publicized case, where a wife had murdered her husband and made curry out of his flesh was discussed within the jail with relish, thus leading to a natural curiosity to speak to the perpetrator. The warden who had been assigned to help us stated that it would be difficult to recruit her. We requested if we could ask her ourselves. The woman walked confidently around the large area which served

as the ground for the women prisoners, where they would sit during the day. Her fellow prisoners also steered clear of her. We approached her quite hesitantly, stating our purpose. She looked at us, up and down, and shook her head, indicating disagreement to be part of our research. We retreated after she said *“Mein kyun bataon, jab meiney kuch kya hee nahi hai,”* (Why should I tell when I have committed no crime).

Another incident also merits description. There were two women from Africa, both convicted due to drug trafficking across borders. To get a glimpse as to what could have led to this unique crime, the warden was requested to ask for their permission for inclusion within the research. They refused. However, when we were going out, finished with interviewing for that day, they approached us themselves, standing haughty and proud. They were curious about us just like we were curious about them. They asked us where we were from and inquired about our purpose for visiting the jail. Quite chatty, they remarked that our area of study (social sciences) was quite interesting. Slightly emboldened by their friendliness, one of us asked them if they would like to be part of the *Continued on page 5*



“Labels and the labelled:” Psychiatrist Dr. Ayesha Mian leads a CBEC Forum in March 2015 about sexual identity, and the ethical dilemmas faced by clinicians when working with people whose sexual orientations are different from the norm.

“When Ethics meets Law in Pakistan” from page 4

study. They declined and walked off. What struck me at this point was that the personalities and the demeanor of the women who agreed to participate versus those who declined were quite different. The latter were strong, stood tall and defiant. The former had somewhat submissive postures; two of them had also cried during the process of telling their story.

Paucity of information due to non-admittance of the crime along with the research setting made it impossible for us to meet the initial objectives of our study. I walked out of the prison with my colleagues, with a sense of unfinished business. However, I also realized that I had experienced a few realities that were unexpected and unsettling. In general, researchers would like to know the facts as much as they possibly can. We had mulled over whether to request for case files of the prisoners who were interviewed. The head of the prison had suggested this. Therefore, in essence it was legal to undertake this step. However, we considered the ethical dimension of this action. The research centered on the relationship between the interviewer and interviewee, and knowing more than what we found during the conversation would have violated this. Hence, we came to the conclusion that what may be legal might not necessarily be ethical.

I also thought over the two instances of prisoners refusing to give the interview. Had the other subjects been somehow 'coerced' to give the interview? Research ethics identifies prison populations to be vulnerable to coercion. This is where the idea of voluntary participation comes about. How many of the women had actually fully consented to be part of the investigation? In retrospect, I remembered that the warden had actually insisted that she could make any woman talk if we so desired, but we had told her to ensure that none of the prisoners were forced. We had ensured that our consent forms were in Urdu

naively assuming that the subjects would know how to read. We had also insisted that a jail warden acted as a witness to every interview. She did so but after she had belittled us for being overcautious and finicky.

I left the jail with several insights. Lack of awareness about research ethics, including voluntary participation, may lead to such behavior. It made me think that perhaps ethics of research should not be restricted to people doing the research but also made available to the general population. While leaving with a sense of unfinished business, I also concluded that research centered in the sociological world is filled with uncertainty, and therefore, research protocols require some flexibility. An illustration of this is that we were unable to use tape recorders and thus the interviews could not be recorded. This made data collection more difficult and useful information may have been lost in the process. I also realized that, as a researcher, I would have to be well-versed in ethics, and even more importantly accept the responsibility to apply this knowledge.

**National Bioethics Committee,
Pakistan meets in CBEC-SIUT**

On June 8, 2015, CBEC will host the meeting of the National Bioethics Committee (NBC), followed by a two day workshop on research and clinical ethics for members of the newly formed Sindh Provincial Bioethics Committee (PBC) and other participants from the province.

Research and clinical ethics workshops for PBC members have already been conducted in all provinces of Pakistan and in Azad Jammu and Kashmir. Participants have found these workshops useful in expanding their knowledge of research and clinical ethics.

“A Matter of Trust” from page 2

ICU with his younger brother.

I asked Ahmed's uncle whether there was anybody else I could talk to as I was unable to explain the dire situation to him. He took out his cell phone, spoke to someone and then handed the phone to me. It turned out to be his friend, a doctor in the Navy. I explained the situation to the doctor and asked for his help. The doctor told me that he had tried his best to convince the uncle but he would not agree, so we should let them take the child home. He added angrily, “These illiterate people will never change. The problem is that this man has heard that doctors often remove kidneys from patients without their knowing and is scared that this will happen to Ahmed too.” I was taken aback and said that the uncle could stand by the bedside as we treated the child. With tears running down his face the uncle finally agreed. We immediately intubated the child and obtained IV access. But before we could begin dialysis he collapsed and we had to initiate CPR. We were unable to resuscitate Ahmed.

During this entire period the crying uncle stood at the foot end of the bed and watched what we were doing. I finally turned to him and said I was sorry but we had lost Ahmed. The uncle immediately moved to the side of the bed, spread his hands protectively across his nephew's body, and said, “Now we want to take the body home.” I asked him to allow us to fill a death certificate and whether they needed help in arranging an ambulance. He replied, “No, we don't want anything. Just remove all your tubes and give him to me.” The father and younger uncle stood crying while the older uncle stood vigilantly guarding the child's body as we hurriedly removed all the tubes. The uncle picked up Ahmed in his arms and walked out of the ICU.

“Biobanks: A matrix of stakeholders, concerns and policy proposals,” March 26, 27, 2015, University of Copenhagen, Denmark

Dr. Aamir Jafarey was invited to participate in a workshop organized by the University of Copenhagen to discuss the ethical issues of biobanking.

This included discussions on transfer of biological materials such as DNA from developing countries to centres in developed countries, ways of regulating the movement of genetic material, and challenges in obtaining informed consent for research on stored material.

**“Akhlaq kay dairay main”
Urdu Ethics Workshop for Schools
April 11, 2015**



CBEC organized its first ethics workshop in Urdu for school teachers conducted by Ms. Anika Khan. Attended by twenty-three participants representing different schools of Karachi, the workshop focused on stories and group activities for critical thinking and ethical discussion. The four hour session was very interactive and incorporated material that teachers could use for discussion in classrooms.

“Bioethics goes to school” CBEC Seminar, September 19, 2015

In September 2015, the Centre of Biomedical Ethics and Culture will host a daylong seminar, “Bioethics goes to school,” highlighting the connections between ethics and education at the school and college level. Envisioned as an event that can draw together a diverse audience from among educationists, students, parents and the general public, the seminar is planned to be an interesting and novel mix of talks, dramatic interpretations of ethical issues by school and college students, poetry recitation and music.

The seminar will begin with a talk by acclaimed historian and writer, Dr. Mubarak Ali, who has written a number of books and articles on Indo-Pakistan history. In his talk, Dr. Ali will provide a historical overview of ethics education in Muslim civilizations. He will be followed by psychiatrist, Dr. Ayesha Mian, who will discuss contemporary ethical challenges in educational institutions, including discrimination against children and adolescents with disabilities.

In the next segment of the seminar the use of drama to highlight ethical issues will be the focus of a talk by dramaturgy scholar, Dr. Framji Minwalla. This will be followed by school and college students who will act in brief ethics skits that they have written and produced. Participating students are from two Karachi-based schools, Haque Academy and The Learning Tree, and from the Shaheed Zulfiqar Ali Bhutto Institute of Science and Technology (SZABIST), a college-level institution with campuses in many cities of Pakistan. Students from Haque Academy and The Learning Tree will present skits on the ethical concerns related to chimeras and social media, respectively, while the

SZABIST students are putting together a slightly longer skit on gender issues. In addition to the original and fresh perspectives that students will bring to ethics through drama, this segment will also include a debate by SZABIST students on contemporary ethical concerns.

In the afternoon, the audience will be treated to a conversation between poet and educationist, Dr. Fatema Hassan, and historian, Dr. Arfa Sayeda Zehra, on ethics in education, and poetry as a medium for teaching ethical values. The seminar will wind up with a musical performance.

Shaheed Mohtarma Benazir Bhutto Medical University (SMBBMU), Workshop on Clinical and Research Ethics, Larkana, February 24-25, 2015



Conducted by Drs. Farhat Moazam and Aamir Jafarey, this workshop was the second in a series of two Clinical and Research Ethics workshops. The first was held in October 2014 for senior faculty of the university whereas the one in February 2015 was for 30 junior and mid-career level faculty representing most of the clinical departments.

PGD and MBE Admissions: Announcement of New Academic Cycle

June 2015 onwards, CBEC invites applications for admission to the new academic cycle of the yearlong PGD (Class of 2016) and two year MBE (Class of 2017). Both academic programs will begin in January 2016. For details, please visit CBEC's website, www.siut.org/bioethics/

Appointments and promotions at CBEC

- * Dr. Elizabeth A. Bukusi was appointed Associate Faculty in May, 2015. Dr. Bukusi is Deputy Director (Research and Training) at the Kenya Medical Research Institute (KEMRI).
- * Ms. Sualeha Shekhani was inducted as Research Assistant in March, 2015. Coming from a social sciences Background, Ms. Shekhani's appointment is the first step in developing a formal research unit at CBEC.
- * Ms. Mahjabeen Munawar was inducted as Secretary in March, 2015. Prior to this, Ms. Munawar was working at Habib Public School for several years.
- * Ms. Michelle Fernandes was promoted to the post of Academic Coordinator in January, 2015.
- * Mr. Aamir Shehzad was promoted to the post of IT Officer in January, 2015.

**Centre of Biomedical Ethics and Culture
Sindh Institute of Urology and Transplantation
5th Floor, Dewan Farooq Medical Complex,
Karachi 74200, Pakistan**

Phone:(92 21) 3272 6338 Fax:(92 21) 3520 6738
Email: cbec.siut@gmail.com www.siut.org/bioethics

My work is to...

Inspired by a wonderful piece of writing by A. Papatya Bukac about her work and life, published in Brevity magazine*, CBEC faculty tried their hands at creative writing, and wrote some lines about their 'work'. A few excerpts are given below:

“My work is to teach bioethics on the morning after the morning on which one hundred and thirty four children are shot to death in their school; to bury the absurdity of doing my work”

“My work is to sow seeds to grow mighty oaks; to hope for rain and sun and favorable winds; to maintain faith that oaks can grow in deserts, and to know that some do not even in the best soil; to accept that others will sit in their shade”

“My work is to create. Create work that doesn't exist. Create ideas and then make them happen...I create doubt. I confuse...I make them doubt, make them question. And then I provide them no answers.”

“My work is to be the nexus, the pivotal point around which the spokes of my little family swing...My work is to draft and write, and write and erase and draft again. My work is to teach.”

“My work is to multitask whereas it is not the fashionable thing anymore. Be a carer, nurturer, advisor, mentor when I also want to be cared (for), nurtured, advised and counselled.”

“My work is to play god. People expect me to know who is going to live and who would succumb today...My work is to put my best efforts to help the dying children.”

“My work is to teach, motivate and be a role model to students and there is no place for an off day...My work is to do a task to the best of my ability, but my ability and audience change each time.”

*<http://brevitymag.com/nonfiction/an-address-to-my-fellow-faculty/>