

Centre of Biomedical Ethics and Culture

Bioethics Links

This edition features a lead article by Dr. Elizabeth Bukusi about her evolving interest in bioethics and a collaborative bioethics program between CBEC and the Kenya Medical Research Institute, (KEMRI) that began this year. Dr. Aamir Jafarey provides a brief report on this program's first academic activities in Nairobi, in November 2017. Also included are first person narratives by CBEC alumni and a formal announcement of CBEC's designation as the 9th WHO Collaborating Centre for Bioethics. Editor

CBEC-KEMRI Bioethics Training Initiative: My Journey to Bioethics

*Elizabeth Bukusi**

“It is a month now, a month later than I had expected to hear back from the ethics review committee. I wonder what is taking them so long. It cannot be so difficult to review and to send comments back.” After waiting somewhat impatiently for two long months, I decided to make a phone call, whereupon a secretary told me, “Just wait, please just wait. Be patient.”

As a young, mid-level scientist, I was frustrated by systems that did not seem to work efficiently. Every time I asked a question, I was told that I did not know anything about 'ethics' and 'research regulation' and I should wait and be patient. But as a researcher it was clear to me that we were losing opportunities for doing valuable research which could potentially change the lives of people for the better. And so, I set out to try and find out, “What is this mysterious “ethics” that I do not understand?”

My first foray into Research Ethics was through an application to the University of Cape Town in a program funded by the Fogarty Center IRENSA, run by a well-known name in the Bioethics field, Dr. Solomon Benatar. Since I was enrolled as a PhD student at the University of Washington, Seattle at that time, the program's modular structure with three contact sessions during the year appealed to

me. However, when I sought institutional support, I was refused with the concern that I would be unable to devote time to two simultaneous programs. After completing my PhD, it took me six attempts before I was finally able to get into the program. On the last attempt, I think my sheer doggedness melted the administrator's heart and fortunately, I became part of the final class that was trained by Professor Benatar before his retirement from the program.

And so I started learning *Continued on page 5*



CBEC alumni with Kenyan participants in Nairobi for CK-BTI's first Research Ethics Course and Practicum. From left to right: Sarah Karanja, Nerbert Mchidi, James Diso Daniel Chai, Naima Zameer, Abeer Salim, Caroline Kithinji, Farkhanda Ghafoor, Faiz Ahmed Raza, Susan Mbanda and Nazli Hossain

*Elizabeth A. Bukusi, Chief Research Officer, Center for Microbiology Research, KEMRI, Kenya

CBEC goes to Kenya: CK-BTI Bioethics Training Initiative

*Aamir Jafarey**

This year CBEC entered into formal collaboration with the Kenyan Medical Research Institute (KEMRI) in Nairobi to establish a comprehensive, multipronged bioethics education program in Kenya over the next 5 years. The CBEC-KEMRI Bioethics Training Initiative (CK-BTI) is funded by the International Research Ethics Education and Curriculum Development Award of the Fogarty International Centre of the National Institutes of Health, USA.

What made CBEC think of Africa? Over the past 5 years, CBEC has accepted 15 students from Kenya into its academic programs. After Karachi, Nairobi now has the second largest concentration of CBEC alumni and students. Through CK-BTI, we believe that CBEC is in a position to help KEMRI develop its own bioethics programs. Over the next 3 years, an international Advisory Board consisting of individuals with a strong background in bioethics education will help guide the Curriculum Adaptation Committee and the two Program Directors, Elizabeth Bukusi and myself, to adapt the CBEC curriculum to East African needs.

By 2021, KEMRI will induct its first Postgraduate Diploma (PGD) class followed by a Master in Bioethics (MBE) class. In the intervening years, the CK-BTI program will offer Certificate Courses (CC) in Research and Public Health Ethics, Research Methodology and Clinical Ethics at different times through the year. These CCs will evolve into the modules for PGD and MBE programs.

In addition, a Practicum that provides students with hands on experience of running an Institutional Review Board secretariat has been coupled with the Research Ethics Certificate Course. Five students from Pakistan will be provided full funding each year to participate along with Kenyans in the Practicum at KEMRI's Scientific and Ethical

Review Unit (SERU). With 4 IRBs which handle about 6000 proposals yearly, SERU employs 18 people and provides an excellent practical training opportunity.



CKI-BTI activities began in Nairobi, with the Practicum followed by two certificate courses from November 20 to December 9, 2017. Five participants from public and private sector institutions of Pakistan took part in the courses. Most Kenyan participants were researchers, research regulators and IRB members, with very few clinicians. However, as the program expands, we hope to attract physicians and other health professionals. Some of the participants had previously attended research ethics related courses but with a focus on compliance and regulatory issues. Participation in the CK-BTI courses exposed them to the moral ethos behind research regulations. The courses stimulated discussion on the ethical values underlying processes, such as respect for the individual, as the basis for obtaining informed consent.

We believe that CK-BTI will provide deeper insight into the ethics discourse taking place in Africa. The challenges of developing a contextual and relevant bioethics program for Kenya and East Africa are tremendous, but so are the potential rewards.

*Aamir Jafarey, Professor, Centre of Biomedical Ethics and Culture, SIUT, Karachi

Alive like colors

*Abeer Salim and Madiha Farhan**

As I walked into the general ward for my rounds on the first day of my job, I noticed a brightly clothed patient in one bed. My first reaction was to ask the ward in-charge why the patient on A-6 was not provided a patient gown. When the in-charge answered “Oh that's Mehvish, she never wears the patient gown,” I looked at him questioningly and continued my rounds.

Next day, I approached Mehvish, a small framed woman in her early thirties, hardly four feet and a few inches tall. She was sitting upright in her bed, busy looking at her cellphone's screen. But she looked up and greeted me cheerily, “Oh you must be the new Madam. *Assalam o alaikum!*” Surprised, I responded, “*Walaikum asaalam*, and you must be the lady who needs to wear the patient gown. It's protocol.” Mehvish protested, “No, please...I don't like the deathly white gown, I like colors because they are alive, just like I am!” I had never heard a patient draw such an analogy before.

While Mehvish chatted on, I got to know that she had been a patient here for the past 15 years, and at another hospital for 5 years prior to that. Curious now, I picked up her charts while asking her what she did (other than being a patient). She responded with a sparkle in her eyes and dimples on her rather skinny but brightly smiling face that she was a school teacher. She told me proudly that she managed to maintain her routine. I felt a pang of sadness as I saw in her charts that she suffered from End Stage Renal Disease (ESRD) since the past 20 years, making her permanently dependent on dialysis. Mehvish, immediately sensed that I had understood her medical condition and said, “Here (patting her bedside chair), sit with me, let me tell you how brave I am.” She went on, “My life was normal for 9 whole years before it changed. Instead of toys and books, life handed me medicines and prescriptions.”

I was hooked to her way of narrating her tale. Mehvish explained animatedly that she was diagnosed with ESRD at the age of 10 and a renowned doctor advised a kidney transplant. Both her parents were tested and her father turned out to be a match. At this point, I wondered why she was a “permanent” dialysis patient if her father was a suitable match. Once again, she sensed and answered my unspoken question. After finding out that he was a match, her father abandoned Mehvish and her mother and left, never to return. With a hint of tears in her eyes, she explained how she felt responsible for her father's action and her mother's sufferings since then.

Wiping her eyes with the sleeve of her bright yellow and orange dress, she smiled again and concluded that she had had many complications of ESRD and 3 major surgeries. She had read about ESRD on the internet but she would not give up. Pointing to the fistula on her arm, she said “Look at my fistula. I am very lucky that this fistula is working since my dialysis started as I take good care of myself.”

The rest of my day was spent in a daze as I kept thinking about the woman who despite all odds was “alive like colors.” Was her father's decision of not donating a kidney wrong? Living in a collectivistic society, was the expectation of saving his own child so high that he had to jump ship and never look back? Could he have lived with his family with the burden of not donating a kidney while he watched her suffer? Or would it have been more just if he had the right to refuse regardless of social and societal pressures? I also could not help but wonder if the father would have left them to their fate if Mehvish had been a boy child.

It has been a year since then. She still gets dialyzed six times a week and has been critically ill twice. But she is still colorful, like life itself.

*Abeer Salim, Manager Quality Assurance, NICVD, Karachi; Madiha Farhan, Senior Nursing Manager, Tabba Kidney Institute, Karachi

Borders: What use?

*Asma Nasim**

The young man was standing beside his sister who lay on a stretcher in the emergency room. His hair and shoes were covered with dust speaking of the distance he must have traveled to reach here. I was called in for a consult. The young woman was lying unconscious. I found out that she was transplanted a kidney two years ago and had now come in with severe renal failure. The nephrologist told me that the patient was not taking her prescribed immunosuppressive drugs since the last two months which had caused graft rejection and her obviously serious condition.

The young lady was breathing deeply, and running a high temperature. She was immediately shifted to the ICU. During the rest of my day I was constantly thinking of her. Why did she stop her medication? Why did they bring her so late? Her brother looked like a Pathan. Oh those Taliban, I thought angrily. They never take care of their women.

Next day I went to the ICU. The young woman was on mechanical ventilation and dialysis. As I was leaving I found her brother and I asked him bluntly, "Why did you bring her so late?" He looked at me in despair and answered in a meek voice, "Doctor sahib, she is my only sister. We live near Taftan on the other side of the Pakistan border, in Iran. We were trying to come here for the medications but were stopped by the border police. Dr. Sahib, I touched their feet and requested them repeatedly to let us cross but the police refused. We tried for two whole months. At last they allowed us to pass, but by that time you can see how my sister's condition deteriorated." He started crying. "We live just two miles from Pakistan. The nearest place to go for medical help from our village is across the border in Pakistan. What can we do?" Anger and frustration was easily felt in his voice.

I was stunned. I had never thought of this scenario before. Iran had closed the border at Taftan in 2014 after attacks on Shiite pilgrims in the border town and both Pakistan and Iran had increased security at the border. But I had not imagined that people living in or around international borders could suffer in such a way. I felt guilty also, guilty of stereotyping, labeling all Pathans as Taliban.

Why are borders created? Who decides to create a border in a remote area where there is no demarcation of land ownership and people do not even have a clear idea of which country they are in?

Historically, people moved freely from one territory into another. As nation states began to emerge, borders became increasingly more impermeable and those seeking to enter them became 'aliens' who were viewed with suspicion. When the idea of nation states was introduced in Asia by the European colonial powers, it created problems where there were previously kingdoms inhabited by different communities. Carving out states from these loosely defined areas sometimes resulted in dividing communities that had lived together since ages and restricting their free movement across territories.

My patient lives in a place where communities had been living for centuries and moved about freely until a border was drawn between them. Due to increasing mistrust, conflicts and above all, the arbitrarily drawn border dividing people speaking the same language and sharing the same culture, their lives have become very difficult.

We need to think of solutions for modern borders which cut across traditional communities and deny people easy access to healthcare. It is tragic that my patient who lives only two miles away from Pakistan has to sacrifice her life for an artificially demarcated border.

*Asma Nasim, Infectious Diseases Specialist, Sindh Institute of Urology and Transplantation, Karachi

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about bioethics. The first shock was hearing about philosophy in the first module. I wondered where I was in high school when people did the history of the Greeks because it really did seem like Greek to me. But I did graduate with my Postgraduate Diploma in Research Ethics at the end of that year. Armed with this, I felt that I now had some qualifications that allowed me to speak about bioethics, and indeed, this allowed me to come to the table and raise my concerns. As part of my Postgraduate Diploma project, I started thinking about the challenges of the Kenya Medical Research Institute (KEMRI) ethics review system and looking for opportunities to improve it.

The second step in my bioethics journey was seeking funding to support a change in the KEMRI ethics review processes. Through the European and Developing Countries Clinical Trials Partnership (EDCTP), we were fortunate to get funded for an ethics capacity building grant which enabled us to do a thorough review of our system and overhaul the process. Coupled with this, the EDCTP grant provided funding for training so I began to explore further educational opportunities in bioethics. The one local bioethics training program required me to be away for nine months but as I was then serving as the Deputy Director (Research and Development), I could not be away from KEMRI for almost a year.

I started looking online for regional and local programs that might be modular but offered a Master’s degree. That is when I found CBEC's call for applications for the Master in Bioethics (MBE) program, and after reading about the training they offered, I was intrigued. I was accepted into the modular program which required me to travel four times to Karachi. Uniquely, CBEC's programs were

completely free and they also provided free accommodation for out of town students while the EDCTP funding paid for my travel costs to and from Karachi. The challenge was getting into an intensive program with limited seats.

Fast forward to 2014: I graduated from CBEC's MBE program. It was clear to me that my training at CBEC and my previous training at Cape Town had changed my worldview. My understanding of ethics was no longer about black and white, or about dos and don'ts. It was about looking contextually at issues, weighing the risks versus the benefits and making decisions that would help researchers but would also protect their research subjects. While in Mexico at the biennial meeting of the Association of Bioethics, I floated the idea to Dr. Aamir Jafarey, one of my mentors at CBEC: Would CBEC consider partnering with KEMRI to plan and possibly implement a training program in bioethics? It seemed to me that a modular program like the one at CBEC would attract mid to senior level people who would become the bioethics resource needed within Kenya.

Kenya at this point had over 60 universities and over 22 accredited Ethics Review Committees, but there were insufficient training programs. The third *Continued on page 6*



“Reasoning about religion: At the intersection of Logic and Ethics”
On August 12, 2017, Dr. Nauman Faizi of the Lahore School of Management Sciences (LSMS) led a CBEC Forum on religion and ways of understanding the religious “other.”

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step in my journey began when CBEC and KEMRI submitted a proposal to the Fogarty International Centre (NIH, USA) for funding the CBEC KEMRI Bioethics Training Initiative (CK-BTI), a joint academic initiative for developing bioethics capacity in the two countries. In 2017, we received funding for running the CK-BTI program for the next five years.

Why work with Pakistan? Why work with CBEC? The experience of the CBEC modules had been highly interactive and hands-on, with an international, multidisciplinary faculty. It did not just teach us the principles of bioethics or research ethics. It taught us to think broadly. It opened our minds. It changed our worldviews. I wanted the same experience for students and colleagues in Kenya by providing them with opportunities to examine their worldviews, to think critically and to question. We recently held our first two CK-BTI certificate courses in Nairobi and indeed, our first 45 participants told us, “We came thinking we know. Now what we do know is that there is so much that we do not know.”

With CK-BTI, I believe that we can change the landscape of both research and clinical ethics within Kenya and also make a difference to Pakistan. My MBE thesis was on the teaching of clinical ethics in the two oldest medical schools in Kenya. During my research, it became clear that even though clinical ethics is listed as a subject, the way it is taught, the emphasis it is given and the lack of examination leaves young doctors woefully unprepared to face moral dilemmas in their clinical practice. I believe that CK-BTI has the potential to change how we as Kenyans think about clinical ethics, and enable clinicians to ask, “How can we do this differently?”

What is the possibility of this program going into the future? The next five years should be an exciting ride. My hope is that in the future, young researchers will not just be told “wait, somebody will get back to you,”

but will get feedback that helps them reflect on ethical issues and be allowed to ask questions. It has been a privilege to grow and learn in the field of bioethics. If there is one thing that I have learned it is that nothing is constant except change, and if there is one thing that is clear, it is that my journey in bioethics has only just begun!

CBEC Designated 9th WHO Collaborating Centre for Bioethics



Scene from “Between Hope and Despair.” Left to right: Dr. Nasir Luck, Ms. Anika Khan, Dr. Abeer Salim and Dr. Raheel Memon

The Centre for Biomedical Ethics and Culture (CBEC) was designated the 9th World Health Organization (WHO) Collaborating Centre for Bioethics on August 30, 2017. As a Collaborating Centre, CBEC will conduct workshops in research and public health ethics, develop educational materials for bioethics and support WHO in the development of guidance documents in the area of global health ethics. Additionally, CBEC will be involved in collaborative work with the global network of WHO Centres for Bioethics.

The first WHO collaborative project completed under this agreement is CBEC’s bioethics video “Between Hope and Despair” about a public health crisis during an epidemic. The video can be streamed or downloaded from the CBEC website (www.siut.org/bioethics).

“Urdu Baithak” in CBEC

August 26, 2017

*Nida Wahid Bashir**

Does language affect the expression and understanding of ethical perspectives and values of an individual? To explore the answers to this question, CBEC organized an “Urdu Baithak” (Urdu Forum) on August 26, 2017. The event was significant because unlike other events organized by the Centre in recent years, all speakers were from within Pakistan and the language of the event was Urdu, the national language of the country.

Sessions in the *Urdu Baithak* were open to the public and drew a full house throughout the day. This reflected the irresistible pull of Urdu for participants from different backgrounds and geographical locations around the city.

The event began with a brief introduction to the Center by Dr. Farhat Moazam. Following this, CBEC associate faculty, Dr. Nida Wahid Bashir, invited Mr. Harris Khalique, a prominent sociopolitical writer, literary critic and poet to moderate the event.

Speakers included Dr. Nomanul Haq, a renowned scholar and writer, who discussed the evolution of human values and explored the role of language in the development of moral sensibilities. Dr. Nomanul Haq put forward the opinion that our use of language reflects our inner moral state, and using corrupted words and slang testifies to intellectual laziness and moral apathy.

His premise was challenged by the next speaker, Dr. Arfa Sayeda Zehra, a well known scholar with a scintillating style of oratory. In her discussion on the role of literature in the development of moral behavior, Dr. Arfa countered Dr. Nomanul Haq’s position, drawing examples to illustrate her viewpoint that languages

evolve and this does not necessarily imply moral degeneration. The two speakers’ perspectives were followed with great interest by a large audience, evidenced by the animated question and answer session following each talk.

The event’s last session was a recital of poetry by celebrated poets Mr. Naseer Turabi and Ms. Zehra Nigah who enlivened the scholarly discussion on moral values and language with beautiful poetic expression. Mr. Turabi recited a number of his well-known poems including “*Woh Hamsafar Tha,*” (“My Companion”) to great acclaim. Ms. Nigah, who was presiding over the session, delighted the audience with her melodious recitation of the great Pakistani poet, Faiz Ahmed Faiz’s poem “*Meray dil meray musafir*” (My heart, my traveler).

The event ended with the audience in the auditorium, and those watching online on Facebook, expressing their desire for CBEC to organize more events like the *Urdu Baithak*.



Urdu Baithak speakers and poets with CBEC faculty
Seen from left to right: Dr. Aamir Jafarey,
Dr. Nomanul Haq, Ms. Zehra Nigah, Dr. Farhat
Moazam, Dr. Arfa Sayeda Zehra, Dr. Adib Rizvi, Mr. Harris
Khalique, Mr. Naseer Turabi and Dr. Anwar Naqvi

*Nida Wahid Bashir, Consultant General Surgeon, Patel Hospital, Karachi

**CBEC's 7th Ethics Workshop for
Karachi Schools
October 7, 2017**



Participants from different Karachi schools during the gender session

The running theme for this year's workshop was discrimination at different levels of society. The workshop kicked off with a session on human rights by Ms. Anika Khan, the highlight being the "Human Rights Walk," a hands-on activity allowing participants to reflect upon human rights within Pakistani society. In another session focusing on gender and gender roles, Ms. Sualeha Shekhani utilized various methodologies including a discussion on gender portrayal in school textbooks and advertisements. This session was also used to explore myths about transgenders, with focused attention on the plight of Pakistan's *khawajasirah* (eunuch) community. Dr. Ayesha Mian, psychiatrist from Aga Khan University, spoke about the menace of bullying in schools, suggesting ways to curb it. The workshop ended with several participants developing plans to incorporate workshop material into their own school curricula.

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New academic year begins at CBEC

CBEC welcomes incoming students to its Master in Bioethics (Class of 2019) and Postgraduate Diploma in Biomedical Ethics (Class of 2018) programs. The first "Foundation Module" is scheduled from January 22 to February 3, 2018.

MBE, Class of 2019

Natasha Anwar
Molecular Pathology
Aga Khan University,
Lahore

Sharmeen Khan
Corporate Law
Amgen, Dubai

Francis Muregi
Research/Biochemistry
Mount Kenya University
Nairobi

Sualeha Siddiq
Social Sciences
Centre of Biomedical
Ethics and Culture, SIUT
Karachi

PGD, Class of 2018

Muhammad Ikram Ali
Forensic Medicine
Ziauddin University
Karachi

Nighat Nisar
Community Medicine
Dow University of Health
Sciences
Karachi

Murtaza Dhrolia
Nephrology
The Kidney Centre
Karachi

Yvonne Opanga
Research Administration
Amref Health Africa
Nairobi

Sajid Hussain
Pediatrics
Ayub Medical College
Abbottabad

Rafia Tabbasum
Anaesthesiology
Peoples University of
Medical & Health Sciences
Nawabshah

Syed Mudassir Laeeq
Gastroenterology
Sindh Institute of Urology &
Transplantation, Karachi

James N. Wanja
Research Administration
Kenya Medical Research
Institute, Nairobi

Aamir R. Memon
Physical Therapy
Peoples University of
Medical & Health Sciences
Nawabshah

John Weru
Palliative Medicine
Aga Khan Hospital
Nairobi

Gideon Cornel Msee
Research Administration
Kenya Medical Research
Institute, Nairobi

Faisal Ziauddin
Gastroenterology
Ziauddin University
Karachi