

# Centre of Biomedical Ethics and Culture

## Bioethics Links

In the lead article, Dr. Taymiya R. Zaman discusses how the discipline of history helps us reexamine our ways of looking at the world. The rest of the newsletter focuses on CBEC's alumni and students, including the graduating PGD (Class of 2018). Thesis abstracts provide a glimpse into research being conducted by MBE students (Class of 2019) while brief reports highlight the involvement of alumni in bioethics activities. Also included is a report by Dr. Aamir Jafarey on an ongoing Fogarty funded collaboration between CBEC and the Kenya Medical Research Institute (KEMRI).  
Editor

### What does History have to do with Ethics?

*Taymiya R. Zaman\**

When most people think about the word "history," they think history refers to "things that happened in the past." But to historians, History with a capital H is a discipline that teaches you how to think about the past. To do so, we read sources written by people from the past as a means of understanding them on their own terms. Reading sources from the past (primary sources) is harder than it looks, not just because they are often written in languages we do not speak, but also because of a human tendency to project our own norms and values onto others.

To people from the distant past, our norms would have made no sense. For instance, we live in a world made up of nations, fixed boundaries, and passports, but people living in say, the Mughal Empire in seventeenth century India, would find the idea of a nation strange. They would understand natural boundaries, such as those created by a river or a mountain range, but they would not understand boundaries that had to do with imaginary lines drawn across land by human beings. Similarly, modern people are likely to believe we should elect our leaders. But people in the past would have felt that a world in which anyone could govern was a world that had succumbed to

disorder because governance was for those with divine lineage only. Consequently, when we ask questions of the past, we must make sure we are not imposing values that matter to us, e.g. equality or democracy, onto others to whom these values would not have held much meaning.

What does this have to do with ethics? Historians study change over time, and like everything else, ethical norms too change with time. When a historian studies ethics, she does not ask if something is right or wrong. Instead, she asks why a community believed something to be right or wrong and what *Continued on page 5*



August 14, 2018, Clinical Ethics module - Hard at work on a national holiday, faculty, staff and students celebrate Pakistan's 71st Independence Day the CBEC way.

\*Taymiya R. Zaman, Associate Professor and Historian, University of San Francisco, USA

This section features short abstracts describing ongoing research studies being conducted by CBEC's four Master in Bioethics students (Class of 2019), for their thesis requirements. The topics reflect the students' varied interests and professional backgrounds.

### **Decoding Genetic Studies in Pakistan: Identification of Ethical Issues from Pakistan with a Comparative Analysis of Studies from the Region**

*Natasha Anwar\**

“Mirror, mirror on the wall...who is the most ethical of us all?”

To date, there has been no review of the status of genetic research in Pakistan, the types of diseases being investigated, and if studies have been designed and implemented to ensure high ethical standards. An analytical review of genomics research can help identify ethical issues to ensure ethics is embedded in the design and implementation of subsequent research.

The aim of this study is to describe the range of genetic research being conducted in Pakistan, and to determine whether these studies meet established ethical standards. The availability of national ethical guidelines will be documented and reviewed to assess their impact on local practices. This review will also draw comparisons with studies conducted in India to explore differences and similarities with the aim of identifying best practices and awareness among researchers with respect to established standards and guidelines. India and Pakistan share social, cultural and economic similarities; in addition, the Indian Council for Medical Research (ICMR) has provided comprehensive guidelines for Indian researchers working in genomics. Since 2006, these guidelines include a separate chapter which discusses ethical issues raised by genetic testing and research both in terms of the individual and

society at large.

Studies included in this review will be identified using two search engines: PubMed, and Google Scholar. The keywords used to search for articles will be: gene, genetics, human, research, Pakistan and India. Articles will be reviewed to screen for mention of the following ethical standards: a) IRB review b) informed consent c) conflict of interest d) declaration of funding source and for international collaborative studies, e) mention of review by the National Bioethics Committee. Finally, I will develop recommendations to improve practices and provide a better framework for ethical researchers in Pakistan.

### **Caregiving of the Elderly: A Phenomenological Study from Karachi, Pakistan**

*Sualeha Siddiq\**

The elderly hold an esteemed position in traditionally collectivist societies where the values of familial obligation and filial piety govern interactions within the kinship circle. Caregiving of the elderly typically falls within the domain of families in societies like Pakistan. Existing literature views caregiving in numerous ways: it is considered a moral experience, helping us become more humane, a way of self-mastery; it is experiential but has also been regarded as a 'burden' in quantitative psychological literature. In Pakistan, most studies fall in the latter category. The process and experience of caregiving has various social and ethical dimensions. Hence, this thesis attempts to understand the experience of caregiving in the way it is 'lived.'

Using phenomenology, a *Continued on page 3*

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\*Sualeha Siddiq, Lecturer, Centre of Biomedical Ethics and Culture, SIUT, Karachi

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mode of qualitative inquiry, the thesis will explore the lived experiences of daughters and daughters-in-law who provide informal care to the elderly. The phenomenon under consideration is informal caregiving to those above 65 years of age who require significant assistance in at least two tasks of daily living, for example, toileting, feeding, etc. Utilizing purposive sampling, the experiences of these caregivers will be documented through ten in-depth interviews, in order to arrive at the essence of the caregiving experience.

The research has particular relevance in the contemporary world considering the increase in life expectancy and the ageing population. In particular, the research hopes to uncover the role of religion and culture in perceptions about caregiving in Pakistani society. A strong motivation for choosing this topic has been what I have observed while growing up: the way my grandparents have been cared for, how the women in my family have been at the forefront of caregiving, and the multitude of ways it has transformed them. A major limitation is that I will only be looking at a selected segment of society.

### **Assessment of Knowledge, Attitude and Practice of Healthcare Ethics among Mount Kenya University Nursing, Clinical and Medical Students**

*Francis Muregi\**

Globally, nurses are in the front line of primary healthcare, and nursing care involves prolonged direct personal contact of an emotional nature with patients. It is now a universally accepted tenet that for a successful healthcare system, healthcare providers must also be ethically and culturally sensitive. In Kenya, the teaching of healthcare ethics is discretionary, tutors lack formal training in ethics, and students are not formally examined on ethics knowledge or

\*Francis Muregi, Professor, Medical Biochemistry, Mount Kenya University, Kenya

awareness. Furthermore, ethics training for students is not evident in practice. I hypothesize that since teaching of healthcare ethics is almost non-existent in nursing training in Kenya, nurses may acquire their healthcare ethics during practice. In this study, we propose to evaluate awareness, knowledge and attitude of nursing ethics of Mount Kenya University direct-entry Bachelor of Science Nursing (BSN) students and Registered Nurses (RNs) upgrading to BSN students. A cross-sectional study will be carried out following ethical clearance by the Ethics Review Committee of Sindh Institute of Urology and Transplantation (SIUT).

Through convenience sampling, 100 participants will be recruited from 4 groups (25 participants per group) namely: upgrading student RNs at level 2, upgrading student RNs at completion level, direct entry students in their second year, and direct entry students in their fourth year of study. A self-administered, structured questionnaire with close-ended questions will be administered to students on signing a consent form. Descriptive analyses and tests for associations using Chi-square will be done for all data for comparison of knowledge and attitude towards practical ethical problems among all groups of participants.

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MBE students (Class of 2019), pictured during an academic module  
Standing from left to right: Francis Muregi, Sharmeen Khan, Natasha Anwar and Sualeha Shekhani



*"Assessment of Knowledge,..." From page 3*

It is envisaged that the findings of this work will reveal the gap in healthcare ethics in the nursing profession in Kenya, with an ultimate object of informing the development of a holistic healthcare ethics curriculum to be integrated in nursing training in Kenya.

### **Pakistan's Domestic Violence Legal Regime - A Critical Analysis**

*Sharmeen Khan\**

Domestic violence is a heinous crime that can destroy society's primary building block, the family. In Pakistan, as in most developing countries, domestic violence is widespread, poorly reported and poorly understood. However, in the last few years, majority of the provinces in Pakistan have made concerted efforts to target domestic violence. But the question, whether these laws are effective and are capable of bringing significant reduction in prevalence of domestic violence in Pakistan, remains.

My thesis will focus on analyzing current legislation around domestic violence in comparison to past legislation (specifically, whether the current legislation has enhanced enforceability in comparison to the past) and in the context of *Shariah* law.

To determine its adequacy and efficacy, I will be reviewing the definition of domestic violence as well as protective mechanisms and punitive measures for offenders in the current legislation. I hope to also review how domestic violence is defined in Pakistan in comparison to international standards. Furthermore, I will be reviewing literature that analyzes domestic violence legislation, including international and national academic publications as well as legislation around domestic violence in Pakistan. In view of Pakistan's Objective Resolution, I also plan to understand and review *Shariah* philosophy toward domestic violence law.

My methodology includes two exploratory interviews with a former member

of the Council of Islamic Ideology and former Justice of Pakistan Federal Shariat Court, and the head of Forensics Department in Jinnah Hospital, Karachi. In light of the interviews I will be exploring the input of Islamic *Shariah* Law towards domestic violence legislation, as well as reviewing procedural aspects related to domestic violence reporting.

It is my hope that in my review, I will be able to potentially identify areas for improvement in the current laws which may also lead to some recommendations for the future.

### **CBEC Alumni: Snapshot of Bioethics Activities**

The annual CBEC alumni report looks at the impact made by 81 graduates from the Postgraduate Diploma in Biomedical Ethics and Master in Bioethics programs in the field of bioethics. The following data captures alumni involvement in bioethics related activities, from 2007 to 2017.

✍ CBEC alumni had 96 publications in academic journals and the lay press. Of these, 53 were published in local journals and 43 in international journals.

✍ One of the outcomes of our academic programs has been networking and collaboration between alumni. This has resulted in 20 publications that were jointly authored by alumni.

✍ CBEC alumni participated in 277 conferences, seminars and workshops. Out of these, 212 were national events and 65 were international.

✍ Currently, 37 CBEC alumni are members of Institutional Review Boards, 47 are involved in teaching bioethics, and 25 are reviewers of academic journals.

\*Sharmeen Ali Khan, Corporate Lawyer, Amgen, Dubai, UAE

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vocabularies, frames of reference and historical forces shaped that community's beliefs. When studying ancient India, for instance, instead of asking whether people had equal rights (given that the notion of “rights” is a modern one), it is more germane to ask how people went about performing their duties in the world, based on their sense of what was right. When we alter our frame of inquiry to include the perspectives of those radically different from us, we harness history's potential to teach us how to let go of how we see the world, and to take on the lens of someone else from an entirely different time and place. In doing so, we come back to ourselves anew. This is similar to coming back home to our country after having visited a foreign place; we have come face to face with difference and that has taught us more about ourselves.

In popular culture, I frequently hear the phrase “medieval barbarism.” When we wish to describe a norm or custom that is distasteful, we resort to describing it as though it was of the past and does not belong in a present that should ideally be better than the past. When I teach students about the Mughal Empire (1526-1857), for instance, or about the Ottoman Empire (1299-1922), students often say it was barbaric for princes to kill their own brothers on their way to the throne or for fathers to kill their sons. For many, the act of killing a brother is difficult to reconcile with the artistic, literary, and architectural achievements associated with Mughal and Ottoman kings. As students have often voiced, how is it possible for someone to take over the throne by killing his own and then proceed to feed the poor, build beautiful gardens and monuments, and even be committed to values of justice and mercy?

Historians frequently deal with questions

beginning with “how could they?” in their classrooms, and these questions are usually directed towards people from the past believed to possess ethical standards inferior to our own. One way to respond to this is to point out that violence and mercy are part of the contradictions that make up the human story: all of us are capable of both good and evil. The more interesting exercise is to ask students what they would do were they an ailing king struggling to keep his throne while surrounded by ambitious sons. Or if they were like the Mughal king Aurangzeb (d. 1707), a capable, competent military general who was constantly overlooked by his father in favor of a brother less competent? Which son would they choose in the first scenario? And what would they do to the less capable brother in the second, were he to be designated heir to a throne they didn't think he deserved? Suddenly, a number of students find themselves making similar choices as people did in the past.

Much of our discipline consists of reading sources produced by people living through the times we are studying, connecting to what is universally human about these individuals: the search for meaning or the articulation of a vision for justice, for instance, while attuning ourselves to what is profoundly different about the times in which they lived. Eventually, the study of history makes the past feel familiar and this gives us new ways to view the present. We find ourselves responding to the “how could they?” that surfaces in history classrooms by turning the gaze on ourselves and asking instead, “how could we?” People from the past would likely be horrified by things we live with, such as nuclear warfare, the ability to kill another human being by pressing a button thousands of miles away, and the use of chemical

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## CK-BTI, one year report

*Aamir Jafarey\**

The CBEC-KEMRI Bioethics Training Initiative, funded by a 5 year training grant from the Fogarty International Centre of the National Institutes of Health, USA commenced its activities in October-November, 2017. The program aims to develop and offer multi-pronged, broad based training programs, modeled on existing Karachi based CBEC programs (PGD and MBE), but suitable for the East African context.

To attempt a trans-national, trans-continental academic collaboration is a big undertaking. Given that the two collaborating institutions had no history of formal partnership the challenge seemed even greater, but the 2 Co-Directors of the program and their teams are determined to make it happen.

In the initial years, CK-BTI is offering Certificate Courses in Research Ethics, Public Health Ethics, and Clinical Ethics, and a Practicum on IRB management. The Postgraduate Diploma and Masters in Bioethics will begin after 2021. The program began in 2017 with two Certificate Courses and a Practicum back to back in October and November, to make up for time lost in administrative details before we could actually launch the program. The second round of the Research and Public Health Certificate Course was held in July 2018, along with the Practicum week, followed by the Clinical Ethics Certificate Course in September 2018. Each Certificate Course accepted from 25-30 professionals for training from an average pool of 60 plus applicants.

While the Certificate Courses are open to participants from across Kenya and other

East African nations, the week-long Practicum for IRB management is also offered to 5 Pakistani candidates each year. This kind of IRB management experience is not available in Pakistan, and the training with the Scientific and Ethical Review Unit (SERU) of KEMRI presents an invaluable experience for participants.

The international Advisory Board of the program as well as the Curriculum Committee met first in 2017 to formulate a strategy for steering the program in the desired direction.

The second and more substantive curriculum development exercise took place in September 2018. The initial working draft for the topics to be taught and their learning objectives was prepared in Karachi and brought to Nairobi where during a two day intensive workshop, each proposed topic and learning objective was discussed in detail between the CBEC team and the Nairobi team. This was followed by three rounds of discussion by the Nairobi team after the workshop, to thrash out the details of the contents and other details. Their recommendations will now be reviewed by the CBEC team in Karachi and a consensus curriculum document will be discussed in April 2019.



Workshop participants taking a break between sessions in Nairobi, Kenya.

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



## CBEC graduates PGD students, Class of 2018



PGD, Class of 2018, at the start of the academic year

In December 2018, CBEC's eighth batch of students (listed below) completed their Postgraduate Diploma in Biomedical Ethics (PGD). The eleven graduating students take bioethics to their institutions in 2019 by implementing bioethics projects they prepared during the PGD year.

**Muhammad Ikram Ali**

Assistant Professor, Sahara Medical College, Narowal

**Project:** "Biomedical ethics for beginners"

**Murtaza Dhrolia**

Assistant Professor, The Kidney Centre, Karachi

**Project:** "Bioethics training sessions for potential members of Hospital Ethics Committee at The Kidney Centre Postgraduate Training Institute (TKC), Karachi"

**Sajid Hussain**

Assistant Professor, Ayub Medical College, Abbottabad

**Project:** "Introduction of biomedical ethics to postgraduate residents of Paediatrics B ward, Ayub Teaching Hospital, Abbottabad"

**Syed Mudassir Laeeq**

Assistant Professor, Sindh Institute of Urology & Transplantation, Karachi

**Project:** "Introduction of Bioethics to Residents of Gastroenterology at Sindh Institute of Urology and Transplantation, Karachi, Pakistan"

**Aamir R. Memon**

Lecturer, Peoples University of Medical & Health Sciences, Nawabshah

**Project:** "Introduction of a Bioethics Course to Physiotherapy Students and Faculty in Nawabshah"

**Gideon Cornel Msee**

Assistant Research Officer

Administration SERU, KEMRI, Kenya

**Project:** "Introducing Bioethics through Discourse and Debates at the Scientific and Ethics Review Unit (SERU) Secretariat of the Kenya Medical Research Institute (KEMRI)"

**Yvonne Opanga**

Monitoring Evaluation & Research Assistant

Amref Health Africa, Nairobi, Kenya

**Project:** "Development and Piloting of a Curriculum on Research Ethics Certificate Course at Amref International University in Nairobi, Kenya"

**Rafia Tabassum**

Assistant Professor, Peoples University of Medical & Health Sciences, Nawabshah

**Project:** "Introducing Biomedical Ethics to Postgraduate Trainees of Anaesthesiology Department at Peoples University of Medical & Health Sciences for Women"

**James N. Wanja**

SERU, Compliance Officer,

KEMRI, Kenya

**Project:** "Conducting Bioethics Trainings in Various Research Centres at Kenya Medical Research Institute (KEMRI)"

**John Weru**

Assistant Professor, Aga Khan Hospital,

Nairobi, Kenya

**Project:** "Introduction of Biomedical Ethics to First Year Resident Students at Aga Khan University Hospital, Nairobi"

**Faisal Ziauddin**

Assistant Professor, Ziauddin University, Karachi

**Project:** "Introducing Basic Concepts of Medical Bioethics to Primary Care Physicians Practicing in Underprivileged Area of Karachi"

**SIMS Convocation, 2018**

December 14, 2018



CBEC faculty with MBE and PGD alumni at the convocation: (Sitting, from left to right) Sualeha Siddiq, Ali Asghar Lanewala, Aamir Jafarey, Farhat Moazam, Bushra Shirazi, Anika Khan, Tashmeem Razzaki, Nida Wahid Bashir (Standing, from left to right) Syed Ali Azmat Abidi, Inayatullah Memon, Naima Zamir, Naima Rasool, Rubina Naqvi, Yasmeen Wajahat, Mahjabeen Khan, Sajid Sultan, Asma Nasim, Salman Ahmed Tipu, Habiba Sharaf Ali, Faisal Rashid Khan, Abeer Salim, Nazli Hossain, Shabana Tabassum, Quratulain Omaer, Perwaiz Ahmed Makhdoom, Afshan Bandedali, Qudsia Hassan, Saleha Anwar, Madiha, Muhammad Fayyaz, Fasiha Mazhar, Tayyaba Batool, Jamshed Akhtar, Ambreen Munir, Farkhanda Ghafoor, Shahid Shamim and Abdul Ghani Sasoli

On Friday, December 14, 2018, Sindh Institute of Medical Sciences (SIMS), the degree awarding body for the Sindh Institute of Urology and Transplantation (SIUT), held its second convocation for alumni of four academic units at SIUT: the Centre of Biomedical Ethics and Culture (CBEC), the ZA School of Medical Technology, the School of Nursing and the Centre of Human Genetics and Molecular Medicine.

The event was the first convocation organised by SIMS since the inception of CBEC's formal academic programmes. Out of 81 alumni of CBEC's Master in Bioethics and Postgraduate Diploma programs, 35 attended the convocation, some traveling from Quetta, Lahore, Hyderabad, Jamshoro, Dera Ghazi Khan, Islamabad and Multan for the event. Those participating included

alumni from academic cycles from 2006 to 2017.

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weapons. The same may be true of people from the future: in a few hundred years, the world may well have run out of oil, and people might wonder why we fought wars and killed one another over it. If the discipline of history still exists, it would offer people from the future the possibility of evaluating us on our own terms as well.

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