

Centre of Biomedical Ethics and Culture

Bioethics Links

This edition includes perspectives from Indian and Pakistani writers about the beginning and shaping of bioethics in their countries. Dr. Aamir Jafarey describes the development of bioethics in Pakistan as an academic, physician centered field, whereas Ms. Sandhya Sirinivasan highlights its connection with activism and human rights movements in India. Dr. Sanjay Pai traces the evolution of the *Indian Journal of Medical Ethics*. Ms. Sualeha Shekhani reports on the Pakistani delegates' border crossing in January 2017 to participate in the 6th National Bioethics Conference in Pune, India.

Editor

Bioethics in Pakistan: Finding its Feet in Academia

*Aamir Jafarey**

“Double shot, extra hot, please” I said as I ordered my coffee at a Starbucks in Charlottesville, in the vicinity of the University of Virginia. The extra caffeine was required to prime my brain for the discussion that I was about to have with Dr. Farhat Moazam, who was at that time based in this quaint little university town, completing her PhD with a focus on bioethics from the Department of Religious Studies, University of Virginia.

This was 14 years ago. I had borrowed my brother's old van, and driven down from Boston, where I was pursuing my year-long Fellowship in International Research Ethics at the Harvard School of Public Health as a Fogarty Fellow, to meet Dr. Moazam. Our one point agenda was a discussion on the yet very nebulous concept of a bioethics centre in Pakistan, an idea floated a couple of years earlier by Dr. Adib Rizvi, Director of SIUT where Dr. Moazam had been doing research for her PhD.

I cannot claim that we had at that time envisioned CBEC as it has turned out today, now in its early teens. But bioethics in Pakistan predates CBEC by at least 20 years. The first formal space for bioethics was created in 1984 in the Aga Khan University (AKU) in Karachi, where biomedical ethics was gradually introduced into the curriculum

of medical students by Dr. Jack Bryant, an American public health physician and then Chairman of the Department of Community Health Sciences. This was later extended into courses at the School of Nursing at AKU. Bioethics thus earned its small space in at least one medical institution in the country.

In addition to these educational initiatives, an informal Bioethics Group (BG) was initiated at AKU in 1997 by Dr. Moazam, comprising of clinicians and nurses who had an interest in bioethics. The BG, now in its 20th year, still meets fortnightly over lunch to discuss ethical issues and has emerged as a premier self-education and discussion

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Sualeha Shekhani, Aamir Jafarey, Abeer Saleem and Nida Wahid Bashir about to cross Wagah border to enter India on their way to the 6th National Bioethics Conference in Pune - January 2017

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Bioethics in India: Activism, Advocacy and Human Rights

*Sandhya Srinivasan**

Bioethics in India has drawn strength from disconnected but sometimes overlapping movements - women's health advocacy, the community health movement, patients' groups against medical negligence, professional groups concerned about malpractice and deteriorating standards in the field, and religious as well as secular groups responding to the challenges of new medical technologies. The confluence of these different streams reflects in the shape bioethics has taken in the country.

One particular area that has raised ethical concerns, both within religious as well as secular groups in India relates to dilemmas in decision-making at the end of life. Discussions centering around these dilemmas were renewed with the growth of life-prolonging technologies and intensive care facilities. As far back as the 1960s, the Society for the Right to Die with Dignity pursued legislation on a 'living will,' withdrawal of care and medically-supported dying. Pain relief and palliative care were the focus of a few centers, some associated with religious bodies. The bioethics discourse in that period was voiced by religious organizations such as the World Federation of Catholic Medical Associations, as well as secular ones such as the Indian Society for Health, Law and Ethics.

Activist groups, particularly those focusing on women's and community health, have also influenced bioethics discussions. In the mid-1980s, women's groups in India went to court against unethical research on injectable contraceptives. These and other campaigns were supported by investigations and advocacy against the government's coercive population control policies and programs. Work to oppose unsafe, provider-controlled contraceptives and coercion within the government's programme continues, as does critiquing of the new reproductive

technologies and their use to control women's bodies in different ways.

There have been many revelations of unethical research in India, in addition to the study on injectable contraceptives. For example, in 1997, reports that government researchers had followed women with cervical dysplasia in a research study without providing treatment led to a public outcry, possibly contributing to the Indian Council of Medical Research's 2000 revision of its research ethics guidelines. The guidelines were revised once more in 2006 and a third revision is being finalized. The revisions were also timely as in 2005 multinational pharmaceutical companies started drug trials in India, and reports were emerging of unethical research and participants dying in trials. These guidelines were also essential for the new institutional review boards being established to conduct ethics review of trials. A combination of media investigation and advocacy has led to some improvements in the regulation of drug trials in the last few years.

Much of women's health advocacy has thrived within a larger health movement and women's health activists have focused on issues connected to socioeconomic determinants of health, and the right to health care. Such issues were regularly discussed at meetings that started in 1973 of the Medico Friend Circle (MFC), an informal network of activists, social scientists and medical professionals. By the 1990s, some members of MFC were focusing more specifically on ethics in healthcare.

Along with these organizations, which have often spoken on behalf of the poor, grew a more middle-class patients' rights movement, fueled by widespread evidence of malpractice by private doctors and hospitals. The public started filing cases in police stations, in state medical councils, in court and even in forums for consumer grievances. *Continued on page 7*

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The Indian Journal of Medical Ethics: A Brief History of the First 25 Years

*Sanjay A. Pai**

The Indian Journal for Medical Ethics is the official publication of the Forum of Medical Ethics Society, Mumbai (FMES) and its beginnings are intimately linked to the formation of the FMES. In the early 1990s, a small group of physicians and health activists who used to meet regularly to discuss ethical issues in medical practice in India decided that firm action was necessary - rather than merely exchanging views and opinions - and subsequently formed the FMES. One of the early activities of the new Forum was a quarterly newsletter *Medical Ethics*, which started as a 12 page affair, but soon increased in size and by 1996, morphed from a newsletter into a journal named *Issues in Medical Ethics*. Towards the end of 2003, the title was changed again to *Indian Journal of Medical Ethics*, to better reflect its geographic origins.

The journal continues to be the official journal of the FMES, but clearly has its own sterling reputation now. In 2005, the journal was indexed on Medline/PubMed, beginning retroactively from 1993. In 2014, the journal was also included in the Philosopher's Index, which is one of the leading online bibliographic databases in philosophy. This has meant that IJME has more visibility now and has researchers actively seeking to submit manuscripts.

What has made the IJME successful? The odds (but not the gods!) were clearly against it. As predicted by the Newtonian law of inertia, the initial years were bound to be the hardest, but the later years have provided difficulties of a different, and often unexpected, nature. One of the challenges has been its financial viability. On policy grounded in ethics, the IJME editors steadfastly refuse to accept donations or advertisements from industry despite the severe lack of finances.

The editorial board of the journal is also of the firm belief that research and knowledge must be offered free to all, which is why the journal went online a few years ago with free access to all its content. This meant that the journal was cannibalizing its own print circulation - and eating into its income. However, thanks to donations from philanthropic foundations and individuals, the journal has continued to be published. What has sustained the journal, often against seemingly unsurmountable odds, has been the absolute and unflinching commitment of those associated with it. The core group that initiated the journal is still closely guiding it.

Having established a successful journal, the core group of FMES/IJME has also started a series of well attended biennial National Bioethics Conferences (NBC). Even though named 'National', these conferences have a large international component and have come to be recognized as important events in the global bioethics calendar. Six conferences have so far been held at different cities and in collaboration with different local partners. These NBCs have dramatically increased the visibility of the journal as well as of Indian bioethics, both across India and the world, leading to better manuscript submissions. Deliberations within the NBCs and the articles published in the IJME reflect the broad interpretation of 'medical ethics' by the editors, and the topics covered include ethical issues in medical finance, law, corruption in medicine, journalism, surrogacy, transplantation, history, the social sciences and politics.

Whereas the FMES/IJME originated primarily as a doctor-based group in a public hospital, other individuals from concerned groups have joined the think tank of the journal. There are now

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No Borders for Bioethics

*Sualeha Shekhani**

One has to embrace some level of uncertainty when as a Pakistani you are applying for the Indian visa especially if the application is filed amidst a situation marked with tension at the border. This was the stressful situation facing a group of Pakistanis who wanted to attend the 6th National Bioethics Conference centered on the theme of “Healing and dying with dignity: Ethical issues in palliative care, end-of-life care and euthanasia,” to be held in Pune, India.

We were quite adventurous with our itinerary which included flying from Karachi to Lahore, crossing the Wagah border on foot to arrive in Amritsar, flying to Mumbai and then traveling by road to reach our final destination, Pune. But the process of waiting for the visa, which arrived on the day of our flight, was torturous. However, what we experienced during our stay in India made the agony worth it.

On January 13th, 2017, I walked into the conference centre at Pune with butterflies in my stomach with the rest of the Pakistani delegation. The extraordinarily warm welcome that we received from our hosts relaxed my nerves, allowing me to enjoy the buzz of activity at the conference. The heartening event of this day was the felicitation ceremony for SIUT’s director. As Dr. Adib Rizvi’s benevolence and his incredible contributions to the fight against organ trade in the region were narrated, I was able to truly comprehend what it means to be part of SIUT, an organization that has made its mark in a remarkable way.

As the conference proceeded, the invigorating experience that my colleagues in Pakistan had promised me materialized. The air was charged with electricity, with speakers from different backgrounds, including physicians, lawyers, individuals from advocacy groups and non-governmental organizations

and most importantly activists. Activism plays a prominent role in the way bioethics plays out in India, with an emphasis on development of laws in order to bring systemic changes in the structure of the society. Bioethics discourse in India, as it became evident to me during the conference has a more activist leaning than academic as in the case of Pakistan. Furthermore, I was also left with the impression that the Indian bioethics community is quite multidisciplinary, as the event in itself was a collaborative effort of different organizations.

On the first day of the conference, I presented a paper in which I relayed the findings of a recent CBEC study on the factors contributing to female graduates in Pakistan failing to practice medicine following graduation from medical colleges. This research was triggered by a recommendation to impose quota system restricting female admissions to fifty percent of the student body. The knowing smiles from the Indian

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Indian and Pakistani delegates at the 6th National Bioethics Conference held in Pune, India, from January 12 to 15, 2017

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forum for bioethics.

The late 1990s also saw an enhanced demand for workshops on research ethics and training for IRB members all over Pakistan, more so from Karachi. The initial interest in bioethics was limited to research ethics, driven by pragmatic reasons for training people to populate IRBs and open possibilities for research, publication and accreditation. This was not unique to Pakistan, and much of the developing world academia was scrambling to enhance capacity in this area. Many individuals, including this author, availed opportunities through programs focusing on research ethics (with some having a broader focus on bioethics as well) funded by the Fogarty International Centre of the National Institutes of Health of the US government at institutions in Canada, US, and Australia. What is noteworthy is that whereas these were all academics who took time off from their clinical work to pursue bioethics, it was purely based on their own initiative and not as a result of a focused institutional strategy to enhance bioethics capacity, with institutional support limited to granting an extended leave of absence for them. Another interesting aspect in this initial phase of formal bioethics capacity enhancement is that whereas these foreign opportunities were open to all, it was only members of the medical community that availed of them. The people who shaped bioethics in Pakistan were therefore primarily from the medical sciences, with little or no involvement of philosophers, social scientists, religious scholars or lawyers.

In Pakistan, bioethics was born in one medical university, and remained there for about 15 years, fueled primarily by individual efforts. It was only in the early 2000s that it finally became a serious academic discourse with the advent of indigenous, degree awarding bioethics programs, and a wider

circle of participants.

The first academic degree program that was offered in bioethics in the country was CBEC’s Postgraduate Diploma in Biomedical Ethics (PGD) starting in 2006, followed by a Masters in Bioethics (MBE) in 2010. Whereas both these programs are continuing to date, a Masters in Bioethics program started by AKU in 2009 with NIH funding, ceased after the funding dried up in 2012 and the university did not step in to sustain it. All these programs have been open to medical as well as non-medical applicants; however they have attracted mostly medical scientists, clinicians and researchers with very few social scientists, educationists or journalists expressing an interest in this emerging discipline.

Philosophers and religious scholars, who are generally seen to be in the leadership of bioethics initiatives in the West, have practically had to be coaxed to contribute to the discipline in Pakistan as faculty in academic sessions on philosophy and religion which are integral to any bioethics coursework. Whereas several medical institutions have now taken the initiative of starting bioethics

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Guidelines to help Teach Bioethics to Medical Students in Pakistan

In April 2017, the National Bioethics Committee, Pakistan launched a comprehensive document “Guidelines and Teachers Handbook for Introducing Bioethics to Medical and Dental Students.” This first national resource developed in the country offers guidelines for integrating bioethics into medical and dental curricula, and provides teaching tools such as case scenarios, links to videos, full length articles, etc. The document can be accessed at <https://goo.gl/WQbqb7>

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departments, and offer courses at different levels, to the best of the author’s knowledge, no philosophy department in the country offers courses in bioethics as yet.

From classrooms to boardrooms, ‘done’ while sitting on swivel chairs, bioethics in Pakistan has defined for itself an indoor trajectory and never really taken on the mantle of activism in any sustained and meaningful manner. The one major legislation on a bioethical matter, organ trade which impacted the poorest of the poor, was initiated and spearheaded by an advocacy campaign by SIUT, with the medical fraternity and media contributing. The bioethics community joined much later, after CBEC’s inauguration.

The bioethics discourse in the country has up till now generally steered clear of “non-medical” ethical issues, like the exploitative displacement of poor communities for multimillion rupee development initiatives aimed for the rich, or bonded labor, honour killings and so on. One reason for this is perhaps the preponderance of the medical fraternity in bioethics in Pakistan, and plenty of “hot” issues within the medical domain to discuss.

This rather narrow focus on clinical and research bioethics is bound to change as non-medical people pursue it as an academic discipline. Already, through CBEC, advances have been made into school systems, with structured workshops being offered to high school teachers, and sporadic sessions being organized for students.

One major challenge for bioethics to emerge as a choice destination for emerging academics is that there is practically no return on investment at the moment in the country, for anyone investing time and effort in a degree in bioethics. There is also still hardly any meaningful ‘official’ recognition for bioethics, with the Pakistan Medical and Dental Council, the College of Physicians and Surgeons of Pakistan and the Higher Education

Commission yet to make any space for bioethics in their respective domains. Even with the introduction of academic degree level educational programs in Pakistan, bioethics remains very much a personal quest with limited career options available.

**“Ethics in Challenging Times”
University of Health Sciences, Lahore,
March 20 to 21, 2017**



CBEC faculty and alumni at the Bioethics Workshop at UHS

The University of Health Sciences (UHS) and CBEC held a collaborative conference in March 2017. This was the university's first international bioethics conference. It featured talks by international and national speakers on the challenges in Asian bioethics education, research and clinical ethics and organ transplantation ethics.

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social scientists, philosophers, teachers, historians, medical ethicists, physicians, lawyers and health activists associated with the journal, either as editors or as contributors to the IJME and the NBCs. The differences in their training and thinking have enriched the journal and reflect the broad focus of bioethics in India. (References for this article are available in the online version of *Bioethics Links*, Volume 13, Issue 1)

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audience made me realize the similarities in the issues both countries grapple with. The discussion following this particular presentation was lively and animated. The Indian audience presented the rights-based argument: the imposition of quota would violate the constitutional rights of female students, making the practice discriminatory. This stood in stark contrast to the opinions of study participants who hardly ever raised this argument. However, there were many similar factors in non-practice including uncertainties of married life for females which the local Indian audience could identify with. Furthermore, during our workshop on “Medical Error and Negligence”, the Indian audience provided examples which were strikingly similar to the ones we hear in Pakistan, again revealing the commonalities between the two countries. The other two papers from the Pakistani delegation were also well-received.

What truly amazed me during those interactions was not just the exchange of knowledge that occurred but also the incredible hospitality that our Indian colleagues showed us, to the point that we were treated like royalty. We were taken around for shopping, sightseeing and to indulge in the mouth-watering Indian cuisine. As we left Pune, we were laden with *mithai*, other gifts and of course, fond memories. An unexpected flight delay prolonged our stay in India, requiring us to stay the night in Amritsar where the Golden Temple beckoned us. We were also fortunate enough to pay a visit to Jalianwala Bagh the next morning, another beautifully preserved historic site, speaking of the tragedy of colonial rule and of our shared past. The foggy morning was the ideal backdrop to our heavy *desi paratha nashta* (oh, how the butter melted in our mouths!).

And as we crossed the border to make our way to Pakistan, exhilarated yet exhausted, we were greeted with an amusing question, “*How's the weather border kay uss par [on that side of the border]?*” We replied laughingly, “*Not very different. After all, only a thin line separates us.*”

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Angry patients received support from a minority of doctors. Alongside this, a few physicians had been expressing concern through different means about the deterioration of medical education and practice in India. Some wrote in medical journals on the 'cut practice' of kickbacks for referrals. Another contribution of physicians against injustice was their efforts for the enactment of legislation banning organ trade in India in 1994.

By the late 1990s, a core group of people had received formal academic training in bioethics from programmes in the US and Europe. They came back to set up research programmes in their parent institutions, or independently wrote on these issues. In the 1990s, ethics was taught in just two or three medical colleges. Since then, a number of short courses and Master's programmes have established a cohort of medical professionals, social scientists and others who can undertake research and analysis on bioethics in India.

In 1993, a group of Mumbai-based doctors decided to stand for the Maharashtra state medical council elections, later starting a newsletter on bioethical issues. This newsletter on medical ethics is today the well established *Indian Journal of Medical Ethics*, and the articles it carries reflect the many diverse streams that contribute to the ever increasing pool of Indian bioethics.

International Bioethics Collaborative Conference April 18 to 20, 2017, CBEC, Karachi



Session on bioethics teaching methodologies underway,
April 18, 2017

CBEC hosted an international conference in collaboration with Indonesia's Centre for Bioethics and Medical Humanities (CBMH) in April 2017. Conference sessions included formal talks, tools for teaching bioethics and a case development workshop.

The inaugural session, "Promoting Bioethics in Pakistan and the Region," focused on regional and local strategies for enhancing bioethics education. Speakers included Dr. Abha Saxena of WHO, Dr. Ahmed Mandil of WHO/EMRO and Dr. Susan Vize of UNESCO. The three speakers elaborated on efforts by their organizations to promote and strengthen bioethics.

In her plenary talk, Dr. Saxena also announced that CBEC was in the process of being designated the 9th WHO Collaborating Centre for Bioethics. The final announcement is pending approval from the Ministry of National Health Services, Regulations and

Coordination, Pakistan.

Dr. Farhat Moazam spoke about the challenges involved in developing Pakistan's first bioethics centre, and Dr. Aamir Jafarey discussed CBEC's efforts to build bioethics capacity through its academic programs. In the last talk of the session, Dr. Shahid Shamim discussed the role of formal assessment of bioethics education.

The conference also offered sessions, limited to registered participants, on the theme "Tools for Teaching Bioethics." These included an Ethics Case Development Workshop and sessions on the use of images and videos as teaching tools. Another workshop was used to demonstrate role play in instructing students on the working of Hospital Ethics Committees.

The last day of the conference dealt with "Ethical Issues in Public Health Research." The sessions focused on the science and ethics of dengue virus control via vector genetic manipulation. Also presented was an ongoing study on dengue control in Indonesia involving community engagement and the difficulties in obtaining ethical informed consents.



From left to right: Dr. Ahmed Mandil (WHO/EMRO), Dr. Anwar Naqvi (SIUT), Dr. Abha Saxena (WHO) and Dr. Adib Rizvi (SIUT) during the "International Bioethics Collaborative Conference" in April 2017

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