BIOETHICS LINKS
CENTRE OF BIOMEDICAL ETHICS AND CULTURE, SIUT

VOLUME 19 ISSUE 1
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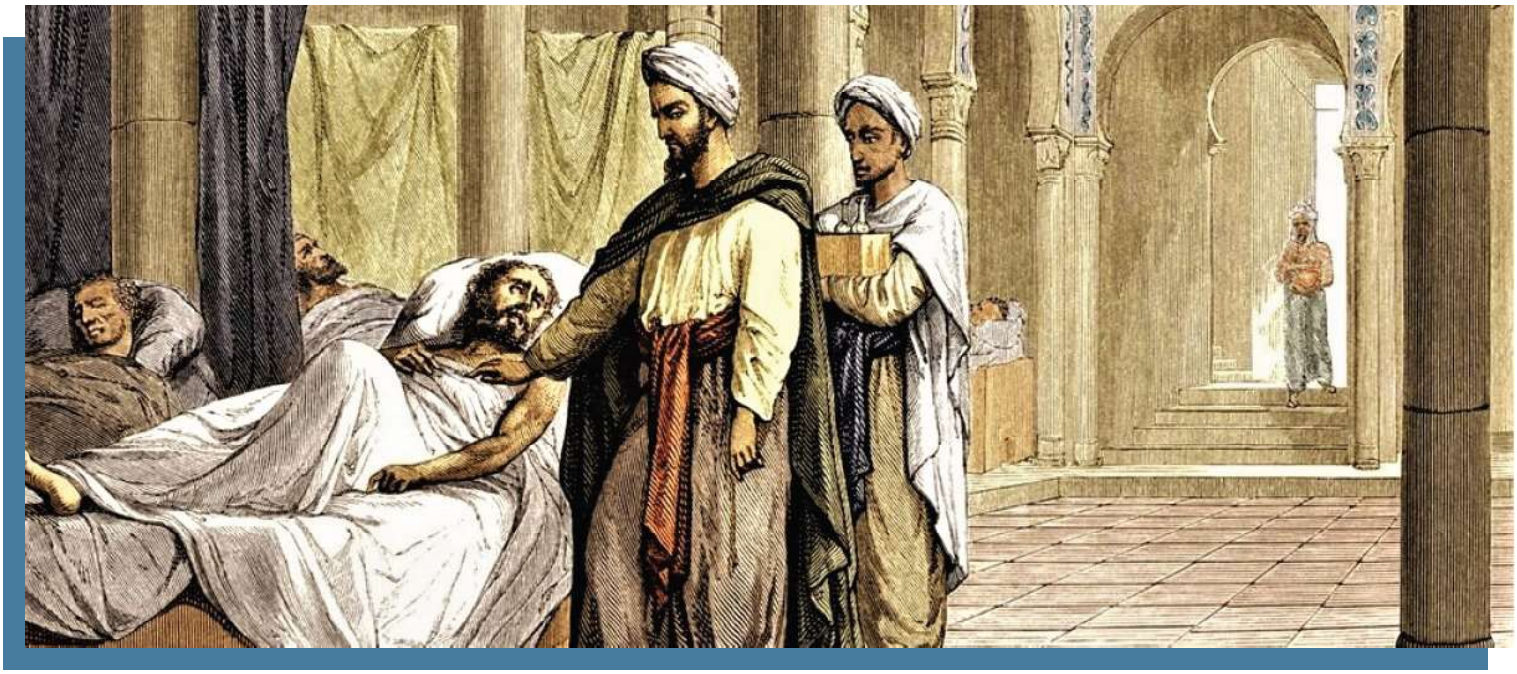

*Abulcasis à l'hôpital de Cordoue (Abulcasis in the Cordoba Hospital) painted by Jan Verhas. It features in Vie des savants illustres du moyen âge (Lives of Illustrious Scholars of the Middle Ages) authored by Louis Figuier, Lacroix, Verboeckhoven, 1867. Abu al-Qasim Al-Zahrawi (936-1013), latinized as Abulcasis, was a Muslim Spanish physician considered the father of surgery in the Middle Ages.*

## Foreword by Farhat Moazam*

"Only professionals who stand on the firing line or in the trenches
can really appreciate the moral problems of medicine"

James F. Childress, American Bioethicist

As a physician involved in bioethics education for three decades, I have observed clinical ethics increasingly eclipsed by a focus on research ethics, and debates about esoteric scientific innovations. Greater attention to the "mundane," the ethics of daily clinical practices by healthcare professionals is essential. Every interaction between a physician and her patient is an ethical encounter with the potential for harming a far larger number of populations than research does.

Ethical practice of medicine is akin to a contact sport. You need constant engagement with existing cultural norms, religious and other values, and socioeconomic realities of patients and families that can change the playing field and move goal posts. Learning to balance a limited number of rational philosophical principles will not do, and neither will, in my opinion, farming out clinical ethical problems to ethics consultation "specialists."

The primary focus of this edition of *Bioethics Links* is clinical ethics exploring some of the challenges I have identified. It offers perspectives, international and Pakistani, of those involved in addressing moral questions connected to patient care. In a way, this edition consists of communiques written from the trenches.

*Professor and Chairperson, Centre of Biomedical Ethics and Culture, SIUT

IN THIS ISSUE

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# MORAL MIDWIFERY: ONE WAY TO THINK ABOUT THE NATURE AND PURPOSE OF CLINICAL ETHICS CONSULTATION

Daryl Pullman*

In this brief reflection on the nature and purpose of Clinical Ethics Consultation (CEC), I propose that we think of the ethics consultation process as analogous to 'moral midwifery.' However, before explaining why I chose this particular analogy for explaining my understanding and approach to ethics consultation, I want to emphasize that this is only 'one way' of thinking about CEC. I emphasize this because if there is consensus on anything when it comes to understanding the nature and purpose of CEC, it is that there is no consensus on this subject.

The origins of what was to become the current practice of CEC in North America can be traced to the early 1960s in Seattle, Washington. In the early days of kidney dialysis demand far exceeded the extremely limited supply of dialysis units available. In order to deal with the ethically fraught questions regarding who would or would not receive dialysis, Seattle's Swedish Hospital organized a committee consisting of both lay and professional members to review individual cases. Labelled the 'God committee,' this body literally determined who would live and who would die.[1] Dialysis was only one of many high tech interventions making their way into mainstream medicine in the 1960s and 70s. Such technological marvels increased the power of medicine to extend the lifespan, but also presented the ethical challenge of 'unnatural selection;' where once we could only provide care and comfort while nature took its course, we now had the power to curtail and in some cases even reverse the natural course of disease. Governments and healthcare authorities began looking to the field of ethics for guidance. Hence the emergence of modern bioethics and with it CEC.[2]

However, as more hospitals and health authorities established ethics committees and ethics consultation services, questions arose about how to evaluate the effectiveness of the consultation process. The theme of a conference held in Chicago in 1995 was ostensibly the 'Evaluation of Ethics Case Consultation,' but the organizers acknowledged the difficulty of evaluating efficacy when there was no consensus on what the goals of CEC were in the first place.[3]

*Professor, Centre for Bioethics, Faculty of Medicine, Memorial University of Newfoundland, NL, Canada

There are complex reasons for requesting a CEC including issues of resource allocation, differences of opinion amongst the clinical team, or tensions between clinicians and patients and/or their families about an appropriate course of treatment. The challenge of specifying clear goals for CEC is exacerbated by the diverse backgrounds of those involved in performing this service. While some clinical ethics consultants are medically trained, others are not. There is also wide variation among models for providing CEC and the practice of ethics consultants within these models. Institutions may conduct CECs through a hospital ethics committee or a formal ethics consultation service, while others rely on a single 'ethics consultant' to provide guidance.

Ambiguities about what it means to be a clinical ethics consultant and how to assess effectiveness have persisted. In 2022, BMC Medical Ethics published an extensive scoping review of reported outcomes for CEC.[4] The review concluded that CEC suffered from a lack of standardization that was hindering "the provision of high quality intervention and CEC scientific progress." It seems not much has changed since the Chicago conference a quarter of a century earlier.

The scoping review closes with a quotation from Aristotle's Nicomachean Ethics. Aristotle states: "Our discussion will be adequate if it has as much clearness as the subject matter admits of, for precision is not to be sought for alike in all


*Dr. Aamir Jafarey (second from left) presents Dr. Daryl Pullman, Visiting Professor during the Clinical Ethics Module in May 2023, an Ajrak and Sindhi cap as tokens of appreciation from CBEC faculty. (More information available on page 10.)*

discussions . . .” Aristotle understood that we should not expect to quantify and measure outcomes in ethics in the same way that we measure scientific progress. Medicine is both art and science. Much in the realm of ethics is about the art of medicine; it deals with matters of the heart as well as the intellect. The modern penchant, while understandable, for ‘evidence based medicine’ comes up short when attempting to categorize, quantify and measure CEC. The authors of the scoping review acknowledge Aristotle’s wisdom but seem reluctant to apply it to their own study.

This brings me to my characterization of CEC as analogous to ‘moral midwifery.’ While I have worked as a clinical ethics consultant for over three decades, early on I struggled with these very issues. How would I measure whether or not I was making a difference? Modern medicine has become a system of highly specialized fields, and it is common practice to rely on specialist consultants. Although I lacked formal medical training, I had extensive post-graduate training in philosophical and applied ethics. Did I want to be seen as the ‘ethics expert’ who advised on all things ethical? While my ethics training provided certain tools for assisting in sorting through the complexities of various ethical conundrums, I resisted being characterized as the ‘moral expert.’

Socrates struggled with similar issues when approached to advice on various matters. He resisted being viewed as the expert, claiming (somewhat improbably) that he really did not know anything. He insisted that those who sought him out already knew the answers to the questions that perplexed them; his role was to act as a ‘midwife’ to assist in delivering the wisdom already residing within them.

*(References for Dr. Pullman’s article available in the online Bioethics Links, Vol. 19, Issue 1, https://siut.org/bioethics/moral-midwifery/)*

## AN OUTREACH INITIATIVE BY CBEC

Two years ago, CBEC initiated production of small video clips to be shared on its social media handles called “Perspectives from CBEC.” The primary purpose is to keep in touch with the Centre’s alumni. In these videos, several alumni have been engaged to share their perspectives on various issues in bioethics.

As an example, one series involved exploring perspectives of educators regarding the challenges in teaching bioethics in Pakistan. In another series, PGD graduates spoke about their experience of conducting ethics projects that they must carry out the year following graduation. CBEC alumni have also shared their viewpoints about the relevance of bioethics to their current professional responsibilities as well as about the future of bioethics in Pakistan.

Another goal of this initiative is to generate discourse among the wider bioethics community in Pakistan.This has involved engaging prominent individuals involved in bioethics in the country. An example of this is the recent series, which highlighted perspectives of several members (featured in the accompanying photo) of Institutional Review Boards (IRBs) across Pakistan. These individuals have extensive experience serving on IRBs in various public and private sector institutions across different cities in the country. Non-CBEC alumni participants included Dr. Aasim Ahmad (The Kidney Centre, Karachi), Dr. Munir Saleemi (The University of Lahore) and Dr. Muhammad Arshad (Liaquat National Hospital, Karachi).

They were asked to share the challenges they have faced while conducing ethical review of research. Those identified included the difficulties in maintaining well-functioning committees that comprise of adequately trained members and hold regular meetings. Additionally, participants noted the existence of political pressures from leadership, which tends to be more prominent in public sector institutions. A recurring theme throughout the narratives was a lack of awareness regarding the ethical review process among researchers with many applying for approval after the research has been conducted.

*Recordings are available at the following link:*
*https://siut.org/bioethics/archives-perspectives/*

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# THE USES OF AMBIGUITY IN CLINICAL COMMUNICATION

Paul Komesaroff*

Ambiguity in clinical communication carries both risks and benefits. It can cause anxiety and confusion or it can provide a source of expanded understanding and new ideas. While scientists usually seek certainty, clarity and the elimination of divergent shades of meaning, in clinical communication what is often required is the deliberate preservation of uncertainty, and in these cases ambiguity is the means by which this is generally achieved.

When, in the clinic, the diagnosis or likely outcome is unclear, when what happens next is, or we want it to remain, uncertain, we call on ambiguity. We use ambiguity when we want to keep open future possibilities, however remote. We make use of ambiguity when we try to understand someone who operates within a different system of beliefs or values. In these cases, we draw for new possibilities on the location and mobilisation of the gaps in language, of the spaces in which meaning is not fixed, in which words gesture toward things, ideas, emotions and experiences.

We turn to ambiguity when we ourselves are struggling to understand, when we wish to give voice to novel or difficult ideas: for example, when we are engaging in complex discussions of an ethical or philosophical nature, such as when we are trying to discern the goals of treatment or to clarify an emotional response. In these cases, ambiguity is a rich resource, a powerful motor of meaning creation. By allowing us to move within the shadow world at the boundaries of sense it enables us to fashion ideas and thoughts that have never before been articulated. It is here a weapon for conquering new territory, for driving beyond the limits imposed by conventional experience to the silent territory just outside what has hitherto been said.

When I face someone whose choices do not completely make sense to me – for example, a man with a treatable condition who refuses treatment, a woman who continues to smoke despite life threatening lung disease, the son of a man about to die who demands to keep going, no matter what the cost – I seek a way to break through the curtain of unintelligibility. To achieve this, I need to suspend my own system, my own presuppositions and standards of truth and validity. I need to make contact on a different level, to listen in a different vein: I have to try to imagine what he or she is getting at. As the patient talks I try out images and possible meanings to see if they work. I construct in my mind a system of categories of functional principles or qualities instead of causal interactions between hard organs. The task is to find common ground, a place where we can share sense.

Somewhat like talking in poetry, I open myself to a suggestiveness and an allusiveness. In almost all cases, against the odds, despite the differences in background assumptions, philosophical dispositions and expressive styles, I am able to gain a sense of his or her experience and to piece together an understanding of the broader clinical context, and the uncertainties, fears and hopes that underlie it.

The ability to deploy ambiguity is part of the everyday competence of clinical medicine. In the complex settings that there arise many modalities of communication come into play, including the utilisation of the sources of ambiguity at the edge of propositional speech: those devices, rhetorical forms, figures and tropes generally eschewed by philosophers and scientists but embraced by poets and creative writers.[4] There is in speech itself a peculiar relationship that is generated from inside it, not as part of a formal, logical deduction involving an interlocutor but with a singularity located outside the explicit subject of the

*CBEC Forum "Great Expectations: Ethics of Infectious Diseases in LMICs" held on March 18, 2023 was led by Dr. Natasha Anwar (present online), Dr. Asma Nasim (left) and Dr. Sunil Dodani. This forum created widespread interest among the audience about emerging concerns regarding antibiotic stewardship and inequitable distribution of Covid-19 vaccines between HICs and LMICs.*

*Professor of Medicine, Monash University, Monash, Australia

exchange, a singularity that is not thematised by the speech is indirectly approached by it. Therefore, speech is not a solitary or impersonal exercise of a thought or a process of mediation among contested propositions: it is a shared adventure of creation and discovery.

Boundaries and limitations always remain. There is no exact or complete transmission of information unchanged between systems of meaning. However, there is in all communication a common making sense, a mutually enriching contact, an enhanced respect and understanding. The meaning that is produced, that actually emerges from the process of dialogue between discrepant discourses, is different from the pre-existing meanings embedded within each of them. This process is therefore not one of pure translation but of the actual generation of new meanings within the specific syntactical, semantic and pragmatic contexts of the distinct discursive unities.

The conversations that occur in the clinic involve careful listening and the careful fashioning of ideas, arguments and suggestions. Often the objective is not to achieve certainty but to avoid it. In this endeavour ambiguity is a powerful and fecund resource, at least when wielded with skill and care. It provides a way to resolve differences in sense, to maintain flexibility and openness in our expressions, to preserve hope and to construct new pathways forward. It is the means by which we enter into communication where the possibilities for doing so are most remote.

*(References for Dr. Komesaroff's article available in the online Bioethics Links, Vol. 19, Issue 1, https://siut.org/bioethics/the-uses-of-ambiguity/)*

## APBEN CONGRESS IN MANILA, PHILIPPINES

June 1-3, 2023

The Asia Pacific Bioethics Education Network (APBEN), established in 2018, aims to bring together professionals working in bioethics education in the Asia Pacific region. Its membership has largely been from South East Asia and Australia but the organization is now striving to expand its membership beyond these countries. APBEN organizes yearly congresses, and the 2023 event was held at the St. Luke's Medical Center in Manila, Philippines from June 1-3, 2023. Pakistan was represented by CBEC faculty including Dr. Aamir Jafarey, Dr. Bushra Shirazi and Ms. Sualeha Shekhani participating in person, and Dr. Nida Wahid Bashir and Mr. Farid Bin Masood delivering their talks virtually.

The Congress included plenary sessions and parallel paper presentations. Dr. Aamir presented a report on the development of the NIH funded CBEC collaboration with KEMRI in Kenya and to help Nairobi develop a bioethics curriculum and train a cohort of participants in various aspects of bioethics. Dr. Bushra presented a paper discussing the challenges associated with inclusion of bioethics in medical college curricula in Pakistan. Ms. Sualeha presented a paper on the CBEC experience of converting to online bioethics education during the Covid pandemic. The Congress also included PechaKucha sessions, an innovative storytelling form that comprises 20 pictures on 20 slides for a total of 400 seconds. Ms. Sualeha, and Dr. Nida and Mr. Farid, used this mode to present different ways in which humanities can be incorporated in bioethics education.


*Dr. Bushra Shirazi gives a talk on status of bioethics in undergraduate medical curricula in Pakistan during APBEN Congress 2023, Manila, Philippines.*

CBEC faculty presentations were well received and generated lively discussion. Of special interest to the audience was CBEC faculty's use of MCQs for assessing students in their bioethics programs.

# CULTURAL INFLUENCES ON PALLIATIVE CARE PRACTICE IN PAKISTAN: A REFLECTION

Muhammad Atif Waqar*

As a palliative care physician practicing in Pakistan, my journey has been an intricate dance between the principles of palliative medicine and the cultural fabric of our society. Providing end-of-life care in a family-centered, religious society such as Pakistan necessitates navigating unique challenges, ethical quandaries, and respecting indigenous cultural norms. In this reflection, I share my experiences and shed light on the ethical questions that often arise, emphasizing the importance of cultural sensitivity in palliative care practice and the provision of end-of-life care.

In Pakistan, the concept of family extends far beyond the nuclear unit, encompassing extended relatives and close friends. It is not uncommon for several generations to reside under one roof fostering a strong sense of communal responsibility towards the elderly and terminally ill. Family ties are deeply ingrained in our social structure, and end-of-life care is predominantly centered within the family unit. Cultural norms dictate that immediate relatives assume the primary responsibility for caregiving, especially in the face of a terminal illness. Families actively participate in decision-making, often providing the primary source of emotional, physical, and spiritual support. However, this can present challenges for healthcare professionals, as differing opinions and conflicts within families can complicate the delivery of palliative care.

Religion plays an integral role in our society, and Islamic teachings greatly influence how end-of-life care is approached, both by healthcare providers as well as patients and their family members. Islamic teachings emphasize compassion, mercy, and the value of preserving life. Patients and family members often seek solace and guidance from religious and spiritual leaders during this challenging phase of their lives. Incorporating spiritual support into palliative care becomes essential, respecting individual and familial beliefs while fostering an environment of empathy and understanding.

A key ethical dilemma that one encounters is balancing the autonomy of the patient with the strong influence of family in decision-making. While Western bioethics emphasizes individual autonomy, in our society, familial consensus and collective autonomy of the familial unit often takes precedence. Striking a delicate balance between respecting patient wishes and honouring cultural values requires open communication, patient education, and family involvement in the decision-making processes.

Very often, cultural and religious beliefs impact the administration of necessary analgesia and pain relief especially at the end of life. In our society, there is a prevailing fear of addiction associated with opioid use, which can lead to reluctance in administering adequate pain relief. Misconceptions surrounding the use of opioids for pain management commonly leads to unnecessary suffering for patients. Overcoming this barrier is challenging and time-intensive; inordinate amounts of time is spent counseling and educating patients, families, and healthcare professionals about the importance of effective pain control and dispelling myths associated with opioids.

Disclosure of bad news, such as a terminal diagnosis, is another complex ethical issue influenced by cultural norms in Pakistan. We, as a society, tend to value hope and discourage frank discussions about prognosis. There is a prevalent belief that shielding patients from distressing news will preserve their hope and maintain their quality of life. This cultural norm raises ethical questions regarding the autonomy of the patient and the duty to provide accurate


*Dr. Atif Waqar teaching a session on challenges of Palliative Care in Pakistan during the May Clinical Ethics Module, using examples from his practice.*

*Assistant Professor, Aga Khan University, Karachi, Pakistan

information. I have encountered situations where patients and families requested withholding the diagnosis entirely, preferring a "need-to-know" approach. In such cases, it is best to address these requests by acknowledging their cultural perspective, while gently advocating for a balanced approach that respects the patient's autonomy and the need for informed decision-making. The real challenge lies in balancing honesty with compassion, taking into account the individual's values, beliefs, cultural background and emotional well-being. Sensitivity and gradual disclosure, while involving the patient's support network, helps to navigate this delicate situation.

Effectively addressing these ethical quandaries often requires a multifaceted approach. First and foremost, building trust and establishing a strong rapport with patients and their families is crucial. Engaging in active listening, normalization, validation of thoughts/feelings/emotions, cultural humility, and respecting diverse perspectives can foster open dialogue. Collaboration with spiritual and religious leaders as well as community influencers can also aid in dispelling misconceptions and bridging the gap between traditional beliefs and palliative care practices.

Furthermore, integrating cultural competence training within healthcare education is imperative. By equipping healthcare professionals with a nuanced understanding of cultural norms, beliefs, and values, we can foster a more inclusive approach to palliative care, ensuring that patients' needs are met holistically.

## DR. LOMABARDO AWARDED "DISTINGUISHED PROFESSOR OF LAW AND BIOETHICS" TITLE BY SIMS

During his visit to CBEC in January 2023, Dr. Lombardo was conferred the title of "Distinguished Professor of Law and Bioethics" by the Sindh Institute of Medical Sciences (SIMS) in recognition of his valuable, longstanding contributions to CBEC-SIUT.

Dr. Lombardo is Regents' Professor and Bobby Lee Cook Professor of Law at the Georgia State University. He is well-known for his expertise in bioethics and law, and renowned for his work on the history of the eugenics movement in the USA during the early 20th Century.


*A multi-disciplinary class in Law discussing Diyat and Qisas (Muslim Law on homicide), during the Foundation Module. Dr. Khalid Masud (Judge, Shariat Appellate Bench, Supreme Court of Pakistan) led this session joined by Dr. Lombardo and Ms. Sara Malkani (Lawyer, Sindh High Court) to his right.*

*Dr. Adib Rizvi (second from right), Director of SIUT presents Dr. Lombardo an Ajrak (traditional block printed cotton shawl) and Sindhi cap during the conferment ceremony, while Dr. Anwar Naqvi and Dr. Moazam look on.*

Dr. Lombardo has been associated with CBEC since its inauguration in 2004. He has been a long-term, admired teacher flying in from the USA for the Foundation Module to teach the Law and Bioethics course since 2006. Over the years, Dr. Lombardo has become a valued mentor and friend for CBEC faculty.

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# BEYOND CURING MALADIES: REFLECTIONS OF A LIVER TRANSPLANT SURGEON

Muhammad Arsalan Khan*

عشق سے طبیعت نے زیست کا مزا پایا
درد کی دوا پائی دردِ بے دوا پایا
غالبؔ

Through passion, my disposition discovered the flavors of life
I found pain with remedies and sufferings with none.
Ghalib (translation by the editor)

I work at a public hospital in Pakistan that provides all medical services, including organ transplantation, free of charge, made possible through government funding and private donations. The hospital serves a large number of underprivileged individuals from all across the country. Limited resources of most families adds to the responsibilities of the liver transplant team. These include carefully weighing the benefits of transplanting the patient, and potential risks to the donor along with the repercussions for large, interdependent families.

Transplant surgeons and coordinators must often delve deep into personal matters of the donor and recipient and their family leading to long-term relationships that begin well before the actual transplant takes place. We inquire about the size of their homes and living arrangements, the number of family members, income levels of breadwinners, quality of their water supply, and access to sufficient food. We understand that our technological success is dependent at least as much on their socioeconomic milieu as it is on the biological fitness of donor and recipient. Patients often draw us into their lives, akin to “elders” of the family, for matters extending beyond their physical maladies. And some of these stories remain indelible in my mind.

For young Talha, our hospital became a refuge from a broken family. A year after his mother generously donated her liver for his transplant, his parents divorced amid a bitter dispute. His mother remarried and moved away. His father, who had custody, had to leave for long trips for his job as a truck driver. Talha mostly lived with his *Chacha’s* (paternal uncle) family, facing hardships from his uncle's wife, who treated him like a servant. Whenever he felt overwhelmed, he would come to the hospital, as he knew we would admit him for a “workup” for his symptoms. This way he could stay in the hospital until his father returned and took him home.

*Professor, Department of Surgery, SIUT
PGD Class of 2023, CBEC-SIUT, Karachi, Pakistan

After his father died in a tragic truck accident, Talha's visits grew infrequent, until one day, gravely ill, he was brought once more to the hospital. He was severely dehydrated and in shock, reportedly suffering from diarrhea for a few days. We suspected he had been ill much longer. Despite our efforts, we were unable to save Talha. The technological success of the complex medical process was eclipsed by the social vagaries that had befallen this troubled young man.

Sana, a young teenager pleaded to us, "Doctor sahib, can you please tell my father to pay attention to us too, not just his new wife." She had received a liver transplant from her older brother a couple of years ago. She expressed frustration that her father, who had separated from her mother and remarried a younger woman, had neglected her and their household needs. We were surprised since we had known him to be a caring and involved father. This request left us a little overwhelmed due to the weight of expectations placed on us. My colleague and I nodded as we left the clinic's cubicle. We made attempts to contact the father but received no response. Her request however seemed natural to us. After all we had allowed the family to make us a part of their lives over the years.

These stories of real people in the real world are glimpses into our everyday experiences as transplant surgeons. For me, the couplet by Ghalib, the most celebrated Urdu poet of all times, offers a reflection of our pursuit in alleviating the suffering of our patients and their families. We don’t always succeed, but the essence is in the effort. That makes it worth it, every time.

*This picture taken from the CBEC Terrace, after a spell of rain, shows a view of Karachi skyline. The tallest building in Pakistan, the Bahria Icon Tower, appears in the upper half of the picture along with other high-rise buildings. The lower half shows dilapidated apartments in the vicinity of CBEC. The picture reflects the existing realities of Pakistan: the old infrastructure remains neglected while fancy new skyscrapers continue to burgeon.*

*Photo by Farid bin Masood, March 2023.*

# MORAL LANDSCAPE OF SURGICAL ONCOLOGY IN PAKISTAN

Irfan Ahmed*

The need for clinical ethics in guiding healthcare professionals in their decision-making processes is heightened in complex fields such as surgical oncology. Life-threatening diseases like cancer not only impairs quality of life of patients as they are exposed to multiple treatment regimens, but they encounter uncertainty in their daily lives as they navigate the healthcare terrain. Physicians have a crucial role to play in these situations. Drawing from my experience dealing with complex cancers whilst working in Pakistan and United Kingdom, I seek to illustrate the similarities and differences between the healthcare systems of the two countries highlighting ethical challenges heightened in this field.

How does one make informed consent from patients truly 'informed' in the Pakistani context where family continues to remain at the center of decision-making? Families often request physicians to not tell patients about their diagnosis and treatment believing that they are in the best position to decide for the patient. Some may also argue that they do so in order to protect the patient's emotional well-being. This contradicts respecting patient autonomy, a fundamental principle of modern medical ethics. In the UK, patients have better access to resources and information therefore the discussion remains patient-centric, resulting in shared decision-making. Differences in culture and level of education have an impact on the process of informed consent. Therefore, the onus lies with the physician to tailor their approaches to best suit patients' requirements so that they remain the center of care.

In Pakistan, physicians struggle with providing healthcare. In low and middle income countries, resource constraints pose additional burdens on physicians. Certain cancers require specialized surgical equipment, and specific expertise, beyond the reach of majority of the population due to high costs. Limited resources along with a huge patient load necessitates fair and transparent processes for equitable access to care. Physicians also have to contend with the moral burnout experienced that can result from making these life-altering decisions for their patients.

The risk of moral distress also increases when physicians have nothing to offer but comfort care to patients who can no longer benefit from any treatment. What should physicians offer to patients who have exhausted all treatment options? While the UK has made significant progress in integrating palliative care into the healthcare system, Pakistan is lagging far behind. Surgical oncologists over here do not have the luxury of relying upon a specialized palliative care service. They have to initiate and sustain these difficult conversations with terminal patients themselves.

The practice of surgical oncology requires an additional sensitivity since it creates ethical challenges unique to it, shaped inevitably by existing cultural and socioeconomic pressures. A special commitment and extra care is required to ensure better decision-making for patients, to preserve their dignity and ultimately minimize their suffering.

*Consultant Surgeon, Shaukat Khanum Memorial Cancer Hospital and Research Centre, Lahore, Pakistan

# CBEC FORUM "AWAZ KHAZANA: LUTFULLAH KHAN'S AUDIO ARCHIVES"

Saturday, May 6, 2023

In this CBEC Forum, Dr. Khursheed Abdullah, an Urdu literature aficionado, introduced a rapt audience to Mr. Lutfullah Khan's *Awaz Khazana* (Audio Treasures). Mr. Khan (d. 2012) spent his lifetime collecting audio recordings of renowned artists, poets, musicians, scholars, politicians and others from Pakistan and South Asia. This is the largest oral history archives in Urdu. Dr. Abdullah described the painstaking process of converting this collection into modern digital media. The archives are now accessible on social media to the delight of Urdu literature aesthetes.

# NOTEWORTHY CBEC EVENTS

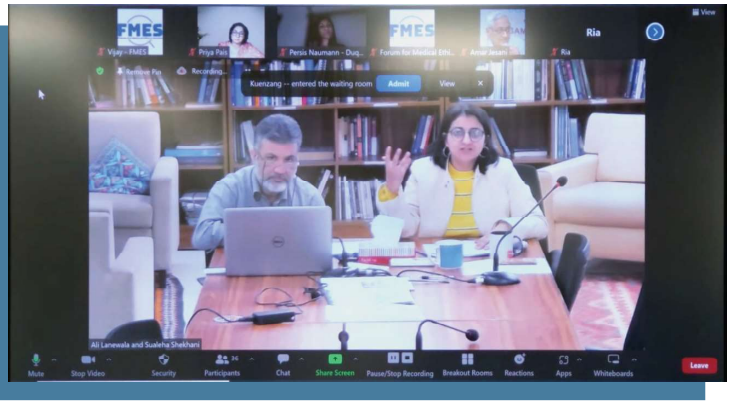
**Dr. Daryl Pullman, Visiting Professor during CBEC's Clinical Ethics Module, May 9 to May 12, 2023**

Dr. Daryl Pullman flew all the way from Newfoundland, Canada to CBEC in May 2023, his first visit to Pakistan. During the Clinical Ethics Module, he covered clinical consultation and narrative ethics, which resonated with students. He also introduced the students to medical assistance in dying, highlighting the contrasts between the American and Canadian approaches. The picture shows him (seated centre) with MBE, PGD and Certificate Course students, and CBEC faculty.

**Workshop, Khyber Medical University, Peshawar**
**March 6 to 8, 2023**

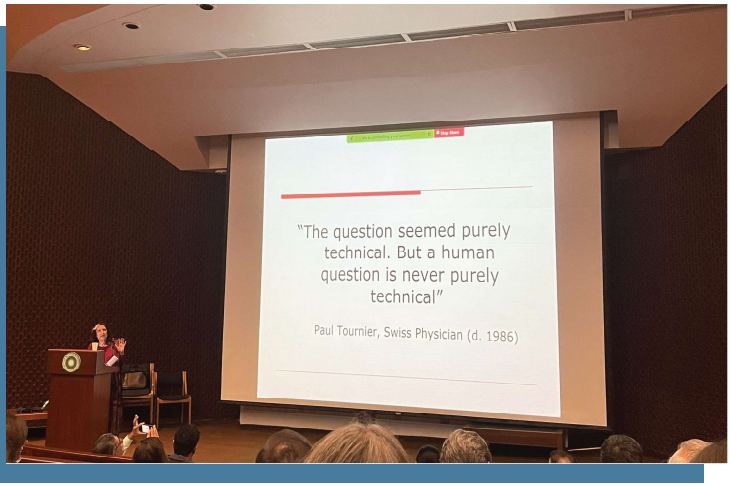
CBEC faculty Dr. Aamir Jafarey (in the picture), Dr. Nida Wahid Bashir and Ms. Sualeha Shekhani conducted a workshop, "Ethics in Healthcare." Each day was dedicated to a specific area including Public Health Ethics, Research Ethics and Clinical Ethics. Participants included graduate students from the Institute of Public Health and Social Sciences, Khyber Medical University (KMU). Such an event at KMU took place after a gap of several years.

**Indian Journal of Medical Ethics Author's Webinar Series**
**January 28, 2023**




The Indian Journal of Medical Ethics (IJME) has introduced webinar series to provide a platform for its authors to present their study findings. This webinar explored the ethical issues of providing kidney care in LMICs. Dr. Ali Lanewala (left) and Ms. Sualeha Shekhani were invited to present their paper, "Indirect costs associated with free paediatric haemodialysis in Pakistan." The event was attended by an audience extending beyond South Asian countries.

### Surgery Grand Rounds, Aga Khan University, Karachi
### March 15, 2023




Dr. Saleem Islam, recently appointed Chairperson of the Department of Surgery at Aga Khan University (AKU), has initiated inclusion of bioethics sessions in its Surgical Grand Rounds. Dr. Moazam, the founding Chairperson of this department (1985 - 1995), was invited to give the first talk on bioethics in March. She spoke about the arrival and trajectory of bioethics in Pakistan, and urged for greater focus on education and research connected to clinical ethics.

### Meeting of WHO Bioethics Collaborating Centers, Rome
### June 6-7, 2023

This annual meeting of WHO Bioethics Collaborating Centers (CCs) was the first physical meeting post-pandemic. It was attended by directors and co-directors of the CCs around the world and representatives from other bioethics centers. Dr. Andreis Reis from WHO Geneva Office and Dr. Ahmed Mandil from WHO-EMR Office were also among the attendees. They are seen along with Dr. Moazam and Dr. Aamir in the group picture above.

### Workshop, Shalamar Medical & Dental College, Lahore
### February 6-7, 2023

Dr. Farkhanda Ghafoor, PGD alumnus (2006) invited Dr. Moazam, Dr. Aamir, Dr. Bushra and Ms. Sualeha to conduct a workshop on clinical and research ethics. This workshop followed an international conference also hosted by Shalamar College, in which Dr. Moazam gave a keynote address. Dr. Farkhanda hosted a Lahore-based alumni reunion at her residence, with a scrumptious dinner with a BBQ. CBEC alumni and faculty who attended are featured in the picture.

### Research Ethics Workshop, Aga Khan University, Karachi
### March 10, 2023

Organized for a cohort being trained in research and public health ethics by the Department of Medicine, AKU, this workshop focused on basic concepts in research ethics. These included taking informed consent from vulnerable populations. Dr. Aamir Jafarey and Ms. Sualeha Shekhani ran this workshop. Case discussions based on local context were used to make the workshop relevant for the participants with background in non-communicable diseases.

# WHO-CBEC COLLABORATIVE WORKSHOP ON REVIEWING "TOOL FOR BENCHMARKING ETHICS OVERSIGHT"

March 3-4, 2023

At the request of the World Health Organization (WHO), CBEC organized a two-day workshop to review the "WHO tool for benchmarking ethics oversight of health-related research with human participants." The document is developed to assess the capacity of ethics governance structures at the institutional and national levels. The aim of the workshop was to determine the feasibility, relevance and validity of this document to the realities of LMICs.

Dr. Palitha Mahipala, WHO Representative (WR) for Pakistan, gave the opening address. Dr. Andreas Reis from WHO Geneva Office joined online to introduce the purpose of the tool. Dr. Ahmed Mandil, WHO-EMR Office, provided regional perspectives via Zoom. Dr. Arshad Altaf from the EMRO in Egypt participated in person for discussion.

Twenty-one participants, with diverse experiences in ethics governance, representing all four provinces of Pakistan, participated. Dr. Obaidullah representing Drug Regulatory Authority of Pakistan (DRAP), and Dr. Saima Pervaiz Iqbal chairing Research Ethics Committee of the National Bioethics Committee (NBC-REC), focused on ground realities drawing from their experience of membership in their respective committees.

*Workshop participants engrossed in a small group discussion critiquing the draft document of the WHO benchmarking tool.*

*Dr. Palitha Mahipala (center), WR Pakistan, addresses workshop participants with Dr. Anwar Naqvi seated on his left and Dr. Moazam on the right.*

After reviewing and critiquing the document, participants provided several suggestions. They recommended removal of a clause mandating use of online registries for governance structures at the institutional level due to its impracticality in local context. Another suggestion was that all research proposals should be reviewed irrespective of methodology given the nascent culture of research in many LMICs.

The workshop concluded with a report incorporating participant feedback, which was submitted to WHO Geneva. In a subsequent email, Dr. Reis thanked CBEC and acknowledged that the Pakistani participants "went into great details" providing "entirely new, and excellent suggestions" that will help making the tool "more feasible and practical."

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CENTRE OF BIOMEDICAL ETHICS AND CULTURE

**Address:**
7th Floor, Suleman Dawood Building
Transplant Tower, SIUT, Yaqoob Khan Road,
Karachi 74200, Pakistan.
**Phone:** (+92 21) 9921 6957
**Email:** cbec.siut@gmail.com

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