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The inexorable march to progress: Sadequain, Industry and Agriculture II, 1984. Section of mural on display in State Bank of Pakistan Museum, Karachi

Editor's Note

The Human Genome Project (HGP) was completed in 2003 and the subsequent push for genetic research has made human DNA a coveted material, the 'gold' of the twenty-first century. Increasingly, because of the ease with which research can be conducted in developing countries, a lot of genetic research is taking place in locations such as Pakistan and genetic testing is making its way into the clinical arena.

Our June 2022 newsletter brings together three perspectives of genetics in Pakistan, in the domains of clinical medicine and research: Farhat Moazam's essay looks at the issue of genetic tests rapidly making their way into clinical practice in developing countries like Pakistan which, juxtaposed against a lack of genetic counseling, can lead to tragic consequences for families. Zainab Afshan Sheikh, in her article describing her ethnographic study on genetic research in Pakistan, comments on the analogy of a 'gold mine.' She discusses the impact of genetic research on both local investigators and participants, including therapeutic misconception and the perception of research as a way of accessing healthcare resources. Based on data from her Master in Bioethics thesis, Natasha Anwar writes about the lack of national and institutional ethical oversight for genetic research and publications in Pakistan.

Also included in the newsletter is a short report on the International Association of Bioethics' 2021 "Award for Bioethics Service in the Face of Challenges," given to human rights activist and teacher of bioethics, Amar Jesani. Other content includes write-ups by alumni, Melba Katindi and Amjad Mahboob, about their PGD Projects, and brief reports and images of CBEC events from January to June 2022.

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GENETIC TESTS AND CLINICAL PRACTICE: A VIEW FROM PAKISTAN

Farhat Moazam

Professor and Chairperson, Centre of Biomedical Ethics and Culture, SIUT, Karachi, Pakistan

The merchant serves the purse, the eater serves his meat,
Things are in the saddle, and ride mankind
Ode, Ralph W. Emerson, philosopher-poet

A group of Karachi clinicians meet periodically to discuss issues related to healthcare. In a recent meeting, a troubled physician presented the case of a two year old child with deranged kidney functions seen in the clinic. In addition to other routine tests, blood samples were drawn from the patient and his parents (who were first cousins) for genetic screening. The parents were discovered to have a rare genetic trait which both had transmitted to the son leading to his disease. The father inquired about the cause of the child's illness and the results of genetic tests were explained to both parents. They asked no questions and left with medicines prescribed for their son. Six weeks later the mother returned alone with the child and told the physician that her husband had divorced her after hearing the genetic results.

Genetic tests identify familial genetic traits, and improper disclosure of this "shared information" can lead to unanticipated results.

This case highlights one of the several fallouts that accompany the growing availability and use of genetic tests in our part of the world. These are not "routine" medical tests that provide data specific to a patient's disease, considered as her/his private information. Genetic tests identify familial genetic traits, and improper disclosure of this "shared information" can lead to unanticipated results. Many clinicians who order genetic tests do not have the requisite knowledge and skills necessary for genetic counselling so that the potential for tragic consequences for others, especially the most vulnerable in the family, can be minimized. The possibility of this occurring is heightened due to myths, misunderstandings and biases among the general public about hereditary traits and transmission of diseases from parents to children.

The science of human genomics is complex and expanding

exponentially. Genetic tests are a byproduct of the increased funding for research in this field often at the cost of important "traditional" research including public health. These tests are promising tools but they are still evolving, and their potential for benefits versus harms to patients is under global debate. Physicians, competent as they may be in their own specialty, are not educated in this field in medical college nor are they exposed to it during postgraduate training. The increase in the number of genetic tests ordered is occurring in the absence of professionals (physicians and/or non-physicians) with requisite training in interpreting complex genetic findings and skills to counsel patients in making informed choices. Many physicians I meet are unaware that genetic counselling sessions should be initiated before ordering tests and must continue following the results, and that like any other clinical intervention, patients/families have the right to refuse to undergo these tests.

The Genetic Testing in Emerging Economies (GenTEE) Project (2013), a systematic survey of genetic services across eight countries in three continents, revealed that a majority of front line physicians lacked knowledge about the genetic basis of diseases, interpretation of genetic test results, and need for genetic counselling of patients. The number of certified genetic counsellors (non-physicians) ranged from 0.06 to 0.2 per million population (PMP) whereas the recommended ratio is 6-12 PMP. The suggested ratio for medical geneticists (physician specialists in genetic medicine) is 3-5 PMP. To the best of my knowledge Pakistan, with a population of well over 200 million, currently has only 3 or 4 medical geneticists.

The GenTEE survey also revealed that genetic tests conducted in emerging economy countries are beyond the reach of most patients as they are available almost exclusively in the private sector and are exorbitantly expensive. In Pakistan the cost of genetic tests related to breast cancer can range (in 2019, certainly more today) from US\$160 to over US\$200. According to a colleague in

a large cancer hospital in the country, if these tests reveal that Herceptin, a drug that can control growth of cancer cells, is indicated, the cost of this treatment amounts to thousands of dollars affordable by only 1% of their patients.

a tool is only as good as the hand that wields it, the mind that guides it, and a heart capable of seeing beyond the biological certainties of disease

Better understanding of the human genome can provide additional tools to clinicians who take care of patients. However a tool is only as good as the hand that wields it, the mind that guides it, and a heart capable of seeing beyond the biological certainties of disease. Prudent application of science in clinical practice should factor in ethical, social and other considerations to minimize harms to patients and families. Otherwise, to paraphrase Ralph Emerson, we run the risk of science in the saddle riding mankind rather than the other way around.

BIOETHICIST AND ACTIVIST, AMAR JESANI, WINS IAB'S 2021 AWARD

In an online event on March 1, 2022, Dr. Amar Jesani received the "Award for Bioethics Service in the Face of Challenges" for 2021, from the International Association of Bioethics (IAB). The award is conferred on individuals who have "put bioethics into action, mobilizing knowledge into impact, doing so in the face of challenges."

The 2021 award for bioethics service recognized Dr. Jesani's long-term activism against human rights violations, his contributions to ethics in the fields of public health, medicine and research, and his sustained efforts for the advancement of bioethics. Dr. Jesani is the co-founder of *Medical Ethics* - a newsletter which evolved into the academic publication, the *Indian Journal of Medical Ethics* - and teaches bioethics in multiple settings, including the Centre of Biomedical Ethics and Culture, (CBEC, SIUT), Karachi, where he is visiting faculty.

The event was moderated by the President of the IAB, Dr. Vardit Ravitsky, Professor, Bioethics Program, School of Public Health, University of Montreal, Canada, and Senior Lecturer on Global Health and Social Medicine, Harvard Medical School, USA. It began with a keynote lecture and presentation by Dr. Jesani, "Bioethics is not a luxury: Activism for equity and against prejudice." In his presentation, Dr. Jesani spoke of the evolution of activism surrounding medicine and ethics in India, the factors that have successfully sustained the *Indian Journal of Medical Ethics* and the challenges now facing bioethics.

Dr. Jesani's presentation was followed by commentaries by invited panelists, Drs. Farhat Moazam, Chair, CBEC, SIUT, Pakistan, Lisa Schwartz, Arnold L. Johnson Chair in Health Care Ethics, McMaster University, Canada and Julian Sheather, Specialist Advisor, (Ethics and Human Rights), British Medical Association, UK, who discussed important aspects of Dr. Jesani's talk. Commenting on a point raised by Dr. Jesani – about the way bioethics is currently 'done' around the world – Dr. Moazam remarked that contemporary bioethics focuses more on the individual's 'right to do something,' rather than on the right thing to do. At the conclusion of the panelists' commentaries, the floor was opened for discussion to a large, international audience.



A screenshot of the panel discussion during the IAB's online award ceremony on March 1, 2022, in honour of Dr. Jesani - (Clockwise, from top left): Drs. Lisa Schwartz, Vardit Ravitsky, Farhat Moazam, Amar Jesani and Julian Sheather

GENETIC RESEARCH IN LOCAL REALITIES OF SCARCITY AND HOPE

Zainab Afshan Sheikh

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How do people engage in genetic research in Pakistan – and why? Since 2015, I have been studying the development of genetic research in Pakistan with this question at the core. I have followed genetic researchers as they approach and collect blood samples and other health related and personal information from families in different localities in Pakistan. Families, where multiple members have genetic conditions. Families who are struggling to even get by.

The collections are done in the context of international research collaborations and funded by laboratories in high-income countries. There is much at stake when research agendas, scientists working on the ground, and families dealing with genetic conditions meet – each with their own hopes and concerns. Early on in my research, I realized that a set of specific traits made Pakistani communities ‘relevant’ settings for studying genetics in a global context. When I attended conferences, did interviews, and read academic papers on genetics in Pakistan, the extensive access to families with genetic disorders was described as a ‘goldmine’ for research.

Due to cultural forms of kinship associated with consanguinity – over 60% of marriages in Pakistan are between first or second cousins – high levels of biological specificities in the form of genetic conditions are inherited across generations. However, referring to presumed high rates of genetic conditions in a country as a ‘goldmine’ can be subjugating language, particularly given the international context and colonial legacy of data extraction from vulnerable populations in the Global South. In most cases, ongoing genetic research does not have any direct benefit for people in Pakistan. Rather the results contribute to research agendas defined by research laboratories in the Global North, aiming to understand human biological differences and further the development of personalized medicine and more effective treatment in high income countries.

Researchers in Pakistan are working under a global structure of inequality in health and wealth, and unequal power relations between research stakeholders. Interestingly, I found that the ‘goldmine’ framing was also used by Pakistanis, almost like a strategy to attract

researchers and international collaborators. I realized that global collaborations bring resources to Pakistan in other ways: Researchers get access to resourceful laboratories, advanced technologies and research opportunities that are not present or accessible in Pakistan – and they use this access in different forms of action to improve public health in their own local setting.

One example of this is the establishment of a prenatal screening service for thalassemia in the area where my research was conducted. The service consists of medical tests performed during pregnancy to detect thalassemia, and is not an element of the research. Rather, it is based on an urgent need in society. Thalassemia, which is rare in Europe, is common in Pakistan. A particular classification of thalassemia, beta-thalassemia major, is described as the most common genetic disorder in Pakistan with an estimated nine million carriers, while 40,000 children are registered as transfusion dependent and 5,000–9,000 children are born annually with the condition.

The research laboratory teamed up with a hospital department that had the clinical expertise to establish the screening service. They have successfully put in place a relevant medical service defined and handled purely by local



An illustration of the living conditions of one family who participated in genetic research - photo by Zainab Afshan Sheikh, December 2015, Punjab, Pakistan.

researchers and clinicians against a backdrop of no available treatment options, restrictive abortion laws, and numerous logistical challenges. In this way, researchers are harnessing nation-building efforts.

I believe that there is insufficient focus in academic debates on such efforts to create local relevance from international genetic research collaborations. Medical genetics in low and middle income countries has to deal with different issues and challenges than in high-income countries. We need to talk about relevance if we wish to mobilize genetic research as a means for improving public health in countries grappling with large health disparities.

We also need to look closer at what happens in research encounters where families, dealing with severe genetic conditions, share their samples and health related data with researchers. One thing that is often highlighted in academic and societal debates in this context is the question of informed consent. Informed consent is an ethical procedure in research that has been discussed extensively, commonly with a set of default assumptions about information and how it should be provided. I wanted to know how regulatory ideals about information transfer made sense from the empirical vantage point of research participants in Pakistan. Not surprisingly, I found that information practices, needs and wishes relate to much more than consent practice.

The ideals of being able to control and audit information propagated by ethics policies are at odds with the local reality in Pakistan, in common with other research settings in the world. Across contexts, studies have shown that people do not seem to remember, use or recall specific information

given in conjunction with the consent process: their choice of participation does not build on the information provided. However, I observed specificities related to the cultural and logistical context of data collection in Pakistan: Researchers would often travel far to get to families with specific genetic conditions, and because of this, families would rarely reject sharing their samples or other health information. Families enrolled in the genetic research often could not read and therefore they rarely received written standardized information introducing the genetic research and its purpose. Instead, various forms of alternative information traveled by word of mouth: From the researchers wanting to recruit research participants, information spread to local communities who heard about it through their friends, families, doctors, teachers, etc.

Many people stated that it was only the head of the family who was able to process the complex information about the research, the only one with “samajh”. When I would later talk to the head of family, often a male figure, he would frequently express many doubts about what the research was for. Few people articulated an understanding that they had participated in research. Many were hopeful that the researchers would help them with their condition through reports or treatment. They requested information on how to obtain treatment, diagnosis, or other forms of clarification about disease and family planning. They undeniably needed a basic health service infrastructure that could help answer their questions. Instead, they got researchers who did their best – at times failing – to counsel them and provide information about the lack of available treatment options. Despite this, families persistently invested hope in the research encounters.

While these insights might answer some of the questions about ‘how people are engaging in genetic research in Pakistan’, we need to also focus on a different type of question: How might it, or should it, be different? In my study, the grounding of medical genetics in Pakistan emerged out of the maneuvering efforts of researchers facing unmet medical and social needs and challenges in their communities. We need to consider whether this is a legitimate avenue for strengthening the healthcare sector in Pakistan and providing opportunities to increase knowledge, wealth and create access to care - or whether genetic research as it develops in Pakistan is reproducing and feeding off global and local inequalities. There are many questions. While we will probably never have a clear answer to most of them, it is of utmost importance to keep raising them.

Following a tradition that extends back centuries in South Asia, the water bearer in this picture begins his early morning round delivering water to the inhabitants of a glass market in Karachi. He brings water from the neighborhood hand pump in his Mashk, a large goatskin bag with a shoulder strap, and supplies it to market shops lacking access to water. Traditionally, this work was done by the lowest caste of Muslims known as Behishti (people of heaven), but in many areas with a Muslim majority, Christians performed this labor. Despite the country's increasing urbanization, this practice is still alive in the old areas of Karachi.



The Maashki (Water Bearer) of Ranchore Lane, Karachi - Photo by Farid bin Masood, June 2022, used with permission

KING SOLOMON'S MINES

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The biblical Solomon, a king of Israel and son of King David, was renowned for his wisdom, power and his fortune, often described as one of the largest in the ancient world. But while Solomon's famed wealth is a story as old as the ages, the popular fascination with locating a portion of this fantastic fortune is a far more recent affair. The idea of mines full of riches was first introduced in the late 19th century by author H. Rider Haggard in his adventure novel, *King Solomon's Mines*, whose publication coincided with a boom in archaeological discoveries of ancient sites in the Middle East and Africa.

Today the most precious treasures are genes, genomes, and genetics.

The treasure then was gold, silver, and gems. Today the most precious treasures are genes, genomes, and genetics. Genetic research is a scientific discipline that investigates the role of genes in human disease. If we can decipher the precise gene or sequence that is responsible for a particular disease, we can develop more targeted and specific treatments. It is the potential applications of this knowledge that has research groups and big pharma investing a great deal of time, money and effort into identifying the genetic mechanisms underlying disease. With the advent of newer technologies that enable us to introduce targeted changes in genomes to correct defects (gene-editing), genetics has moved from science fiction into reality.

Traditionally, scientists have genetically engineered mice to 'knock out' genes in order to evaluate their function. Once they have discovered what the gene does, it is possible to make new drugs that can either block a gene (if it is harmful), or enhance its positive functions (if it is useful). However, while such research is informative, evidence from studies in animal knockouts often does not hold for humans. Genetically engineering humans to study genes is not possible, however natural human 'knockouts' exist in different populations around the world.

Consanguineous marriages, which are common in Pakistan, are much more likely than unions between unrelated people to result in human knockouts. With



CBEC Forum - On March 12, 2022, police surgeon, Dr. Summaiya Syed Tariq led a hybrid session "In the Bowels of Society: Reflections of a Police Surgeon from Karachi." Moderated by CBEF faculty, Ms. Sualeha Shekhani, the session discussed ethical challenges encountered by Dr. Tariq in her forensic work.

growing interest in genomes in this part of the world and knowledge that such research has caused ethical challenges in other countries, it is important to evaluate the status in Pakistan to identify gaps so that we can ensure safeguards and good practice for future studies.

"Mirror, mirror on the wall...who is the most ethical of us all?" is the title of a study that I conducted three years ago to understand if there were ethical guidelines available for genetic studies and to then analyse and describe the extent to which researchers in Pakistan comply with existing ethical standards. Pakistan's National Bioethics Committee (NBC) has published several clinical ethics guidelines and listed a review of genetic research studies. However, it has issued no guidelines for genetic research, gene therapy or gene editing studies.

I consulted 'The International Compilation of Human Research Standards, 2019 edition' compiled by the Office for Human Research Protections (OHRP), U.S. Department of Health and Human Services, to identify local, regional and international standards for genetic research. Once I had identified the guidelines, I searched for research studies published from January 2017 to December 2018. These studies were assessed for a number of ethical standards: informed consent, conflict of interest, and IRB review. These categories were complemented by author, institution, the

disease studied, study type, and NBC review. This analysis of ethical standards included a total of 52 studies. According to the data I collected, over 90% of the research was conducted through international collaborations. 19/52 publications were first author studies by a Pakistani researcher based at a Pakistani institution, but most (39/52) were collaborations with either a UK or US based institution. Funding for 57% of the studies was solely from an international funding agency.

The highest number of publications were related to blindness, deafness, neurological and developmental disorders (24/52), with 45% conducting whole exome sequencing. No gene editing or gene therapy studies were identified. Many of the genome-wide association and consortium studies using biological material or genetic data from Pakistan had not been submitted for IRB review, and no study mentioned a review by the NBC or a material transfer agreement. No genetic counselling was offered to support participants in any of the studies. There was no clear reference to any community engagement activities or awareness sessions. Although informed consent was mentioned in most studies, a blanket statement that “consent was taken” does not indicate the quality or understanding of the process.

Pakistan, like many LMICs, does not have strong internal or national oversight and accountability.

International research guidelines presuppose an established system of accountability and oversight. However, Pakistan, like many LMICs, does not have strong internal or national oversight and accountability. There is an overwhelming expectation about the integrity of the researcher and his/her familiarity with ethics. Many of the guidelines tend to focus on individual obligations. Discussions of institutional imperatives, broad social goals or collective responsibility are rarely concrete.

Although no human gene therapy or gene editing studies were identified, gene editing technology is being explored in agricultural research in Pakistan. Applications of this tool will transition to microbial and human genetics and it is vital that we establish systematic changes for compliance, oversight and accountability. The findings from my study provide a foundation of behavioural practices for researchers. It is a starting point to develop systematic changes.

RESEARCH AND PUBLIC HEALTH ETHICS WORKSHOP SHALAMAR HOSPITAL LAHORE, MARCH 18-19, 2022



Participants of the “Research and Public Health Ethics” workshop with CBEC faculty and alumni at Shalamar Hospital, Lahore

Dr. Farkhanda Ghafoor, PGD alumnus, invited CBEC faculty, Dr. Aamir Jafarey and Ms. Sualeha Shekhani to conduct a two-day workshop focusing on core areas of research and public health ethics. The faculty was also joined by alumni based in Lahore, including Dr. Mariam Hassan and Dr. Natasha Anwar.

The workshop brought together a diverse group of participants including healthcare professionals, researchers and Institutional Review Board (IRB) members. The introductory session highlighted key differences between therapy and research so that participants could reflect on their roles as researchers and clinicians, and the ethical issues that may arise when these two roles conflict. Ethical issues associated with specific study designs were also discussed.

The workshop also tackled the problem of authorship. In a session cleverly titled “Authorship Blues,” issues surrounding authorship were discussed using a case based on a scenario commonly encountered in many institutions across Pakistan. CBEC’s locally produced movie, “Publish or Perish” was also used to drive the message home.

The interactions during the workshop were lively, relying fundamentally on discourse, and making use of local examples shared by both facilitators and participants.



Images from KBG meetings at CBEC in 2022 (clockwise from top left): SIUT healthcare professionals at the February 2022 meeting; Mr. Farid Bin Masood showing the image of Spiderman in a session on language and bioethics; KBG participants engrossed in a session on the ethics of advertising in the June 2022 meeting; Dr. Riffat Moazam Zaman, one of the founding members of the KBG, at the March 2022 meeting

KBG COMES BACK TO CBEC IN 2022

Initiated in 2004, the Karachi Bioethics Group (KBG) is a common platform for healthcare professionals and other individuals interested in bioethics. It serves to raise and discuss ethical concerns that are important in the local context, as well as to help individuals stay updated by discussing various aspects of ethical medical practice. KBG members meet every second month for sessions hosted by a public or private medical institute each year.

Following the start of the COVID-19 pandemic in Pakistan in early 2020, KBG meetings went online and there was a significant decline in participation. As the host for KBG meetings in 2022, CBEC shifted to a hybrid format with online participation combined with limited on-site attendance. For the first time, the meetings were also opened up to virtual participants outside Karachi. Both measures have helped to increase the number of participants.

The first two meetings of the year focused on a review of Drug Regulatory Authority of Pakistan's (DRAP) act on ethical pharmaceutical marketing in February, and the issues surrounding genetic counselling in Pakistan, in March. The third meeting of 2022 centred on the ethics of advertisement. An initiative that has proven successful is the inclusion in the meetings of brief discussions on bioethics through the lens of humanities.

INTRODUCING RESEARCH ETHICS TO COMMUNITY PARALEGALS IN KENYA

Melba Katindi

Advocate High Court, Founding Partner Katindi and Company, Nairobi, Kenya

From June 2021 to March 2022, I conducted teaching sessions to introduce basic research ethics knowledge to community paralegals supporting key populations in Kenya. This project was a requirement of my Postgraduate Diploma in Biomedical Ethics (PGD) from CBEC. I decided to develop sessions for community paralegals as they have become invaluable in resource-limited settings by helping marginalized key populations navigate legal challenges.

Although they constitute a small proportion of the population, HIV prevalence among key populations is much higher - an estimated 33% as against the general population prevalence of 4.76%. Evidence demonstrates that key populations have limited access to HIV prevention and treatment due to stigma, social exclusion, and broad criminalization of their activities. The criminalization of high HIV-risk behavior, such as same-sex sexual conduct, sex work, and drug use in Kenya, raises unusual ethical challenges that also affect research.

10 male and 10 female community paralegals from 12 organizations providing legal advocacy to sex workers, persons who use drugs, and men who have sex with men across six counties in Kenya, enrolled in the project. A hybrid approach was used, combining virtual and in-person sessions. This enabled discussions on critical areas requiring ethical consideration in research on vulnerable populations, with discussions on the informed consent process eliciting the most interest. While acknowledging the complexities in determining decision-making capacity - particularly among active drug users - participants agreed that it was inappropriate to assume that all drug users automatically lack capacity.

Another area that was largely contested was the researcher's reporting obligations in the context of at-risk adolescent involvement in criminalized activities. The majority felt that such disclosure would negatively impact trust and discourage access to health services. The issue of incentives for economically vulnerable key populations was also hotly debated. Participants also discussed the impact of cultural and legal perceptions on the review and approval of research on sex work, drug use and same sex



Participants display their certificates at the end of the project

conduct. Feedback from participants indicated that the use of case studies, short video discussions and interviews made the sessions engaging and relatable. Participants agreed that the sessions helped them appreciate their role in empowering a highly researched population and resolved to disseminate research ethics awareness through their work.

This project has inspired me to advocate for improved mechanisms at institutional as well as national regulatory levels to enhance protection of key populations in research. With 32 research ethics committees currently accredited in Kenya, we are now establishing linkages for community paralegals to get involved as lay members who contribute to an understanding of the unique contexts of key populations.



Participants engaged in group work during a session

BRINGING PHARMACY STUDENTS INTO THE BIOETHICS FOLD

Amjad Mahboob

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CBEC's Postgraduate Diploma in Biomedical Ethics (PGD) opened new venues for discussion on ethics in patient-physician interactions, research, public health, media and industry. Being both a student in a diverse group, and a teacher of many health cadres, I had opportunities to reflect on situations from different vantage points.

I realized that the least explored perspectives were those of pharmacy students, who have a five months clinical clerkship as a requirement for a Pharm.D degree at our institution, the University of Swabi, Khyber Pakhtunkhwa. They are the most inquisitive about interactions with patients, but also the most naive about the workings of healthcare systems. In hospital settings, pharmacy students are not given much importance and their questions ignored - but I always find their queries very relevant.

In general, clinical ethics discussions revolve around patient-doctor interface and other players are considered less significant. But pharmacists are as important as doctors - be it in patient interaction or in human subject research. Particularly during COVID-19 vaccine trials, I observed that at many stations, research pharmacists had leading roles and were the key people answering questions related to vaccine development and side effects. I suspected that our pharmacy curriculum lacked depth and friends in the pharmacy academia confirmed that the clinical and research ethics components in their undergrad curriculum were rudimentary and outdated.

At this point, I made the 'eccentric' decision of focusing my PGD project on pharmacy students instead of the traditional doctors/trainees/nurses cohorts, with the intention of gradually developing it into a regular module in the undergrad pharmacy curriculum. I discussed my views with faculty in the Department of Pharmacy at Swabi University and they were enthusiastic. They agreed to pilot this module to final year students and submit it to the pharmacy council academic board for approval for future modules.

I can still recall the 'huh?' in my CBEC teachers' response to the project, but they remained tolerant and supportive. During project sessions, my cohort was dedicated and interactive. The most memorable day was when my



Dr. Amjad Mahboob (front row, centre) with pharmacy students on the concluding day of the project

pharmacy students attended a hospital session run by an international organisation about an implementation research related to nutrition. The students challenged presenters about the consent form and its details, surprising both the audience and facilitators, leading to a decision to develop and share a comprehensive consent form before the formal start of research. I felt like my job was done and the message transferred.

The concluding day of the project was attended by faculty members from the University of Swabi and the Dean of the Medical College. They appreciated the project and showed their support by formally including the ethics module into the undergraduate curriculum.

I believe that biomedical ethics should be a mandatory component of pharmacy curriculums, moving us from physician-pharma relations to physician-pharmacist-pharma relations, and from patient-pharma interactions to patient-pharmacist-pharma interactions. This will have a positive impact on both clinical care and biomedical research involving pharmacists.



SCAN QR CODE
to view
BIOETHICSLINKS ONLINE

CBEC-SIUT WORKSHOP: BASICS OF ACADEMIC WRITING KARACHI, JUNE 23, 2022

Anika Khan

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Workshop participants engaged in a writing activity during the pre-lunch session of the workshop “Basics of Academic Writing,” held on June 23, 2022

On June 23, 2022, CBEC organized a one day workshop focusing on academic writing skills for its faculty, alumni and healthcare professionals from the Sindh Institute of Urology and Transplantation (SIUT). Running a workshop on English academic writing skills had been on the faculty’s agenda for quite some time but this was the first formal full day event dedicated to academic writing held at the Centre.

For most Pakistanis who enter scientific professions such as medicine, writing skills tend to take a back seat. Even individuals who come from a background of the humanities or social sciences are not taught academic writing skills explicitly. Rather, they acquire academic writing skills through experience - or, if they are fortunate - through good mentors. An added layer of complexity for Pakistani writers is the challenge of converting their thoughts (which are generally in Urdu) into clear, comprehensible, written English.

Entitled “Basics of Academic Writing,” the June workshop was an attempt to provide participants with fundamental skills and concepts that could help improve their written work. The event was run by Dr. Shahid Shamim, Associate Faculty, CBEC, and Ms. Kanwal Zehra and Ms. Rabiya Khalid of Dow University of Health Sciences (DUHS), Karachi, both of whom have a background in linguistics and are currently pursuing their doctoral degrees. The workshop was attended by 18 participants on-site at CBEC.

The first session of the workshop, run by Ms. Rabiya Khalid and Dr. Shahid Shamim, aimed to help participants improve their academic writing by looking at sentences and paragraphs to identify issues with structure, coherence and the flow of ideas. Most participants seemed to find this a useful session, particularly as there were many opportunities for hands-on practice. Commenting on his writing skills, one of the participants (a clinician) remarked that the last time he had focused on English grammar and structure had been in middle school.

The second session of the workshop, conducted by Ms. Kanwal Zehra and Dr. Shahid Shamim, focused on critical reading and paraphrasing. While this session conveyed important points about understanding written material and incorporating it appropriately into academic writing, some of the information seemed to be more suited to reviewers of academic articles. Participants generally felt that despite hands-on activities, there was a lot of material and they needed more time and practice to absorb it.

The final session was dedicated to feedback on samples of participants’ written work but participants generally felt that the feedback was insufficient due to time constraints. However, they took away helpful information about the mechanics of writing, particularly in the first session of the workshop. Overall, the workshop was a useful learning experience for both participants and facilitators.

‘THEN AND NOW’ OF CLINICAL PRACTICE; THE DUALITY OF MODERN MEDICINE DOW UNIVERSITY OF HEALTH SCIENCES (DUHS) KARACHI, JUNE 03, 2022

A clinical ethics workshop titled “ ‘Then and Now’ of Clinical Practice; The Duality of Modern Medicine” was organized and run by Drs. Farhat Moazam and Bushra Shirazi at the Dow University of Health Sciences (DUHS). The event was a pre-conference workshop arranged by the Pakistan Islamic Medical Association (PIMA) and was the first on-site CBEC workshop to take place after more than two years of online interaction.

One of the fallouts of the COVID-19 pandemic was that face-to-face workshops regularly conducted by CBEC at different institutions, went on the back burner. These on-site interactions, which served as tools for introducing bioethics and making participants aware of ethical issues in healthcare, were replaced by webinars which had a different agenda and were less conducive to interaction. The successful interaction during the workshop at DUHS reinforced the need for such events in healthcare forums.



Some participants of the clinical ethics workshop at DUHS, along with CBEC faculty, Drs. Bushra Shirazi and Farhat Moazam (front row, second and third from the right). Also seated (fifth from right), Dr. Shahid Shahim, Associate Faculty, CBEC

The format of the workshop was an interactive discussion led by CBEC faculty on the duality that now characterizes modern medicine and the potential for negative repercussions for patients. Participants were then shown a CBEC teaching video, “More than meets the eye,” which linked the discussion to medical management of a quadriplegic patient. Discussion on the video highlighted how clinical practice often remained limited to procedural action whereas clinicians were also required to reflect on socio-cultural, economic and religious issues influencing medical practice.

The event was well attended with about 30 participants, clinicians, faculty and medical students, who engaged in a fruitful dialogue on the duality of modern medicine. It was particularly heartening to see younger workshop participants making relevant comments and highlighting moral discomforts they faced as healthcare providers.



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