

# Centre of Biomedical Ethics and Culture

## Bioethics Links

This issue of *Bioethics Links* has a distinctive *desi* flavor. It examines issues ranging from democracy to health care decision making, Pakistani style. Also included is a brief report of the Pakistan Federal Shariat Court's ruling on the organ transplantation law of the country.

Editor

### On Democracy in Pakistan

*I. A. Rehman\**

Pakistan has sometimes been defined as a country where every ten years or so people have waged a struggle for the restoration of democracy but have almost never tasted genuine democracy. A prominent factor that has contributed to this phenomenon is the absence of a democratic tradition compounded by the gradual replacement of elements of a historically dynamic Muslim culture with one that is rigid and backward looking. The latter trend leads to a cultural barrier to democratic governance and results in a culture-polity conflict in which the state has to expend much of its energy on fighting off social forces opposed to the principles on which its polity is or should be based.

Dr Ambedkar, the architect of the Indian Constitution, characterized such conflicts in society as living a life of contradictions. After successfully piloting the relevant bill in 1950, he noted that "in politics we will have equality and in social and economic life we will have inequality." In the past, such conflicts and contradictions have also been of concern to other indigenous scholars of societies that won independence after the Second World War; these have included Muslim thinkers who are revered by Pakistanis.

The culture of any people is complex and never easy to define or encapsulate into a few words. Abdullah Yusuf Ali, an outstanding principal of the Oriental College in Lahore, an Arabic scholar of high standing and one of the most competent translators of the Quran into English, wrote a cultural history of the people of the sub-continent. Unfortunately this book was published in Bombay in the troubled days of 1947 and has not received adequate attention or proper circulation in Pakistan. A distinctive feature of Yousuf Ali's thesis is his acceptance of European, especially British, contributions to our culture.

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Dr. Mala Ramanathan conducting a "Moral Game" with PGD and MBE students. (April 2010)

\*Secretary General, Human Rights Commission of Pakistan

## Different Moral Worlds

*Saima Iqbal, Bushra Shirazi, Anika Khan, Aamir Jafarey\**

*The teaching of bioethics around the world is prompting a deeper look at the social context that forms a backdrop to medical and ethical questions. A bioethics that evolved in the western context, emphasising individualism and rights has to adapt to settings where people are defined by their relationships within families and communities, rather than their individuality.*

*The story of Muneera, put together by the Masters in Bioethics students, Class of 2011, at the Centre for Biomedical Ethics and Culture, Karachi, is an attempt to highlight contrasting values which influence our medical decision making.*

Muneera sat by the kitchen window of her fourth floor apartment waiting for her daughter Farzana to come home from work. She sighed. She felt lonely even though she loved Farzana's two children who were all over her as soon as they got home from school chattering to her about *nani* this and *nani* that. But she felt so helpless since her leg was amputated and she could no longer drag herself up and down the stairs to visit friends. Guiltily, she reached out for the *mithai* the neighbour had left in the morning, and ate it quickly. Her son, Sohail, was arriving from Dubai the following day and both he and Farzana became very agitated when she ate anything sweet.

Muneera had not been feeling well lately. Her chest pains, her sugar levels, her blood pressure - everything seemed to be going awry. At sixty-five, she felt old and worn out. But the children would not let her be. Constantly worried about her chest pains they had taken an appointment with a doctor. "What did doctors know?" thought Muneera disparagingly.

A week later, Muneera sat in a wheelchair in the waiting area of the cardiac

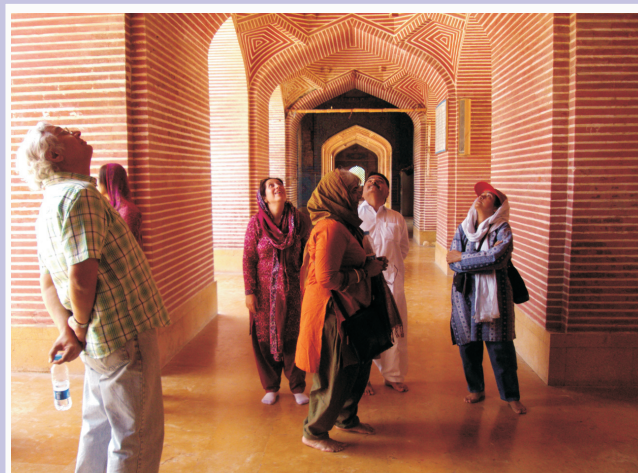
surgeon's clinic. She didn't want to be there but Sohail and Farzana had insisted.

"You have to live for our sakes. We don't have *Abba* with us anymore, and we don't want to lose you too." So she had visited the cardiologist, even undergone the tests he had suggested. Triple vessel coronary disease. Muneera was not sure what it meant although the doctor had tried to explain it to them. Something about her heart not working properly but she could have told the doctor *that*, without suffering all those tests. And she had told the children that she did not want to have an operation. It would be the death of her, she was sure of it.

"I have looked at the angiogram. You need urgent bypass surgery," the surgeon proclaimed, looking at Muneera. "There can be no two opinions on that."

"*Daikha* (See)!" exclaimed Muneera, addressing her children. "This is exactly what I had told you. He is a surgeon so he will want to do surgery."

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Drs. Amar and Mala, and CBEC students admire the famous Shah Jahan Mosque in Thatta, a masterpiece of Mughal construction from 1647.

\*Students of MBE, Class of 2011

## Federal Shariat Court of Pakistan dismisses petition against Transplantation of Organs and Tissues Law

*Farhat Moazam\**

The “Transplantation of Organs and Tissues in Pakistan, Ordinance 2007” was promulgated through a Presidential decree, and subsequently ratified as national law. This occurred despite strong resistance by an influential group of physicians with lucrative businesses involving kidney tourism. The Ordinance set up a national oversight body, the Human Organ Transplantation Authority (HOTA), prohibited unrelated organ donation (except in exceptional cases), criminalized commercial transactions including transplantation of kidneys from Pakistanis into foreigners, and recommended deceased donor programs.

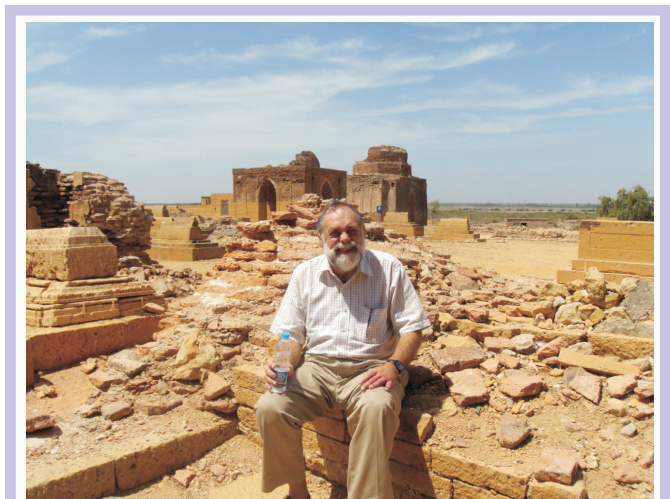
The Constitution of Pakistan stipulates that all laws in the country must conform to “the injunctions of Islam as laid down by the Holy Qur'an and Sunna.” Citizens can file a petition in the Federal Shariat Court (FSC) for review of any law which they believe does not meet this criterion. In January 2008, a group of transplant physicians filed a petition in FSC against the Government of Pakistan pleading that certain clauses of the Ordinance, contrary to Sharia, should be removed. All FSC proceedings were open to public.

The clauses challenged by the petitioners involved primarily those related to restriction of donation only to related donors, and the criminalization of kidney transplants from Pakistanis to foreigners. Muslim scholars appeared on behalf of both petitioners and the government.

It was interesting to observe Muslim scholars employ the same primary sources

of Muslim jurisprudence (the Qur'an and the Sunnah of the holy Prophet) and juristic principles to arrive at different positions. This was related to their interpretation of Scriptures and the juristic principles each chose to emphasize. Whereas many for the petitioners relied on straight deductive logic using traditional sources, those supporting the government's position were more likely to highlight local contexts and public welfare.

In April 2009, the FSC gave a unanimous decision dismissing the petition. The ruling also noted that Muslims are religiously obliged to abide by contracts they make. Therefore Pakistan, as a signatory to WHO, must honor the 2004 World Health Assembly resolution requiring that member countries undertake measures to protect vulnerable citizens from organ trade and tourism.



Dr. Richard Cash, CBEC's guest faculty at Makli, one of the worlds largest necropolis located outside Karachi.

The tombs are of kings, queens, saints, governors, military commanders, philosophers and poets, and date back to the 14th and 18th centuries.

\*CBEC Faculty





CBEC faculty returned to Khyber Medical University (KMU) in May, 2010. This was to run a second Research Ethics Workshop and to participate in a seminar entitled “Practicing ethical medicine in a challenging environment.”

Left: Dr. Moazam leading a discussion. Right: Ms Anika Khan, student MBE Class of 2011, giving a talk.

## Standby: Lights, Camera, Action!

*Amir M. Jafarey\**

CBEC is producing a series of bioethics educational videos on the theme *Local Moral Worlds*. This project, supported by UNESCO Bangkok, consists of a series of brief videos highlighting ethical issues encountered in clinical situations and human subject research. CBEC employs videos as teaching tools in its programs, and felt that locally produced videos portraying indigenous issues would be more effective. Two films have been recorded so far and a third one is under production.

The first film of the series is “The sound of silence” which focuses on aspects of the informed consent specific to the *desi* context. The second, entitled “To tell or not to tell, that is the question,” addresses the conflicts that arise when family members try to protect an elderly parent from news of his cancer while a physician considers it his

duty to fully inform the patient. The third video in the series will focus on contentious matters of pharmaceutical company funded research leading to conflicts of interest and therapeutic misconception.

Most of the “actors” for these videos are SIUT faculty and staff whose hitherto dormant acting abilities are now flourishing!



A scene being taped with Drs. Nasir Luck and Ali Lanewala while director Sharjil Baloch looks on.

\*CBEC Faculty

*“Different Moral Worlds” from page 2*

“Please *Ammi*,” pleaded Farzana, “Listen to the doctor.”

“What is this all about? Please explain?” enquired a perplexed Dr. Zahid.

“What is there to explain, Doctor *sahib*?” continued Muneera, “These two are wasting your time, and mine too. I have told them that I will not have any surgery.”

Dr. Zahid turned to his patient. “*Maa Ji*(mother),” he enquired gently, “Why don't you want to have surgery?”

“*Aray beta* (son), I am an old woman. I know I have to die one day but I do not wish to die in an operation. I want a peaceful death at home with my children around me, not in a hospital.” Muneera looked at her children. “I know you worry about me but life and death is in Allah's hands. Why are you upsetting yourself on my account?”

Farzana interjected, “How can we not worry about you, *Ammi*? We are your children. We cannot bear to see you suffering with these chest pains.”

Dr. Zahid, who had recently returned to Pakistan from the U.S, was perplexed. His years as a Professor of Cardiac Surgery had not prepared him for the medical environment in his home country. He had lost touch with the nuances of Pakistani relationships. He knew his way around the coronaries of human beings but was finding it hard to navigate the complexities of interactions within Pakistani families that he kept encountering.

He was used to interacting with *patients*; here he had to engage with entire families. In fact, the sicker the patient, the larger the number of family members eager to be involved in the decision-making process. He had been taught that disclosure of illness and the discussion of treatment is something private and confidential, between the physician and his patient. But in many Pakistani families, privacy seemed to be an alien concept illness was

collectively owned; collectively endured.

“Doctor *sahib*, can we have a word with you outside?” Sohail broke into his thoughts. Dr. Zahid had gradually become accustomed to these “corner meetings” with family members without the patient being present. He complied even though it made him uncomfortable. In the corridor outside, Dr. Zahid listened patiently to Farzana and Sohail obviously extremely concerned about their mother's health and her refusal of surgery. They felt that this was not a decision their mother could take independently as it concerned the entire family.

“Doctor *sahib*, *Ammi* is all we have,” said Farzana. “We love her dearly and it is our responsibility to take care of her. She has lived with me for years and I know her well. I think she is just afraid to have the operation but we have no other alternative.”

“I will certainly talk to your mother again and try and explain the entire situation to her,” Dr. Zahid said cautiously. “Possibly, she needs to understand the treatment options.”

“Doctor *sahib*,” pleaded Sohail. “We are giving you our consent for the surgery; give us the date for the operation. *Ammi* just needs to be convinced that she must have this operation.”

Dr. Zahid knew that informed consent depends on the capacity of the individual to understand the risks and benefits of a proposed treatment and its possible alternatives. Surrogates could only be considered if a patient was incompetent to take medical decisions independently and incapable of communicating his or her decisions. His interactions with Muneera over two clinic visits seemed to indicate that she was quite competent to take medical decisions for herself. To him her decision not to get operated, though irrational to her

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children, could not form the basis of incompetence.

“Doctor *sahib*,” insisted Sohail, on their second visit, “please give us a date for the surgery. We are wasting precious time in this convoluted argument and we risk losing our mother. Her presence means everything to us.”

Dr. Zahid was in a quandary. “Your mother is an adult with the capacity to give consent,” he replied after a pause. “We have to respect her autonomy. I will certainly talk to her again but she has a right to decline treatment if she wishes. Please understand I have to keep my patient's desire under consideration, she is my primary responsibility.”

“But Doctor *sahib*, a doctor's duty is to save lives and you know that *Ammi* will get sicker and even die if you do not operate,” said Farzana.

“Acting in a patient's best interest or beneficence - needs to be balanced against the good of individual autonomy,” explained Dr. Zahid while thinking to himself that in this case the patient's right to self-determination trumped beneficence.

Muneera's children did not agree. “Doctor *sahib*, our mother was always an independent person and has been depressed since her amputation. How can a depressed patient be competent to take health care decisions?” asked Sohail. “Surely, her condition makes it incumbent on us to decide for her?”

Dr. Zahid tried to reason with Sohail. Clinical depression was not grounds for incompetence, provided it was not causing mental impairment. Muneera had consistently demonstrated clear reasoning, even though her line of thinking was not appealing to her children.

“I don't understand you, Doctor *sahib*,” Farzana said. “*Ammi* is not in this alone.

She is part of us and we can't see her in pain. When she suffers we all suffer with her. This operation will take away at least her chest pains. To me all this talk of 'autonomy' and 'privacy,' why, that would be like abandoning her! We would never be able to forgive ourselves if something were to happen to her. Please help us do what is best for her.”

Dr. Zahid sat silent, perplexed, trapped between different moral worlds.

*Life's dilemmas, and the choices we make in response to them, are rooted in our setting. The questions we ask are often universal, but the answers we arrive at are influenced by perspectives that make up our landscape. Muneera's story cannot be disconnected from its setting - the storyline traverses the cultural topography; the narrative evolves in the social context.*

### KBG Develops Ethical Guidelines for Physician Pharmaceutical Interactions

*Nida Wahid Bashir\**

The Karachi Bioethics Group (KBG) launched its Physician-Pharmaceutical (PPI) Guidelines on November 26, 2009 in Patel Hospital. The PPI document is intended to provide guidance to physicians and healthcare institutions for ensuring ethical interactions with the Industry. These guidelines have been presented at different forums in Pakistan including Dow International Medical College, Aga Khan University, Ziauddin University, and Peoples Medical College in Nawabshah, and Khyber Medical University in Peshawar. Copies have also been forwarded to the Pakistan National Bioethics Committee, Pakistan Medical and Dental Council, and the Ministry of Health. A joint session with the Pakistan Medical Association (Karachi chapter) is being planned to discuss and disseminate the PPI document.

The KBG PPI Guidelines can be accessed at [www.karachibioethicsgroup.org](http://www.karachibioethicsgroup.org)

\*Student, PGD Class of 2010



*“On Democracy in Pakistan” from page 1*

Forty years ago Faiz Ahmed Faiz, renowned poet of Pakistan, made a signal effort to identify the components of Pakistani culture. He concluded that these included Islamic belief, the influence of other religions on the life of the people inhabiting our lands for ages, our history, geography and economic activities, professions adopted by us, systems of government we have had, and our arts.

Allama Iqbal, poet and philosopher credited for introducing the notion of Pakistan in pre-Partition days, believed in the centrality of religion in the life and polity of Muslims. However he emphasized the necessity for freeing Islamic thought from the stamp of Arab imperialism and reactivating Islamic *fiqh* that was frozen five hundred years ago. The collection of his Madras lectures, published in 1930 and given the title of *Reconstruction of Religious Thought*, clearly implied that religious thinking in Islam not only could but should be reconstructed. In one of his lectures Iqbal argued that an essential quality of Islamic thought is the dynamism and movement that exist within its ideas, and the ability of Muslim thinkers to learn from history. It can therefore be argued that religious thought that is static or frozen in time cannot qualify as Islamic thought. And yet during the 1980s in Pakistan, according to Ziaul Haq's arbitrarily defined theory, Pakistan must not move out of interpretations made by Muslim jurists six hundreds ago, a period of political decline and retreat of Muslim civilization.

For a variety of reasons Muslim thought in Pakistan has been going through a revival of regressive features, a reversal of the liberal trends that were distinctive features

of South Asian Islam. Under this influence, and the strengthening of a Saudi Arabian version of Islam, some Pakistani Muslims have become acutely conscious and brazenly intolerant of sectarian differences and non-Muslims. The revival of a quaint theory of *jihad*, the justification of violence on women and killing of innocent people, have given rise to practices that used to be considered contrary to the principles of Islam.

The past is an important source of learning so that a people may avoid courses that led earlier societies to destruction. But a desire to live in the past or attempts to solve today's crises with yesterday's instruments can be the easiest way to self-annihilation any society can adopt. In the language of politics this idea is expressed as a dictum that states/societies that do not revise the theories of their polity/social organization to stay ahead, or at least abreast, of the times are doomed to decline and disintegrate. Theories of the rise and fall of empires and civilizations by Ibn Khaldun, Spengler, and Toynbee can be tested on the principle of states' coming to grief if their theoretical assumptions and responses cannot answer the challenge of socio-economic changes.

The strength of the Marxist theory of humankind's transition through socio-economic contradictions lay in its ability to predict the course of events in a given situation, and its practitioners started faltering when their theoretical formulations lagged behind the spirit of the age. Hitler failed in his plans to revive German imperialism by starting where Kaiser was forced to leave off in 1919, and with weapons time had rendered obsolete. He

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lost because the world has moved beyond the theory of Nazism. The collapse of the Soviet Union can be traced to its reliance in 1970s and 1980s on theories whose validity had been exhausted.

The route for Pakistan's survival lies through a replacement of assumptions grounded in the bygone eras with thoughts and systems sound enough to answer the needs of tomorrow. It would be unfair to not acknowledge positive examples in Pakistan of deviations from retrogressive social patterns. The signs of a post-feudal culture in mercantile and industrial centers, such as Karachi and Faisalabad, cannot be denied. The women's resistance to Ziaul Haq's edicts about their confinement to the *char dewari* (four walls) and their exclusion from the socioeconomic mainstream boomeranged on him; women defied his regime and took to the arts and feminist initiatives with greater force than ever. And it is among “*vani* lands” such as Mianwali and the tribal areas that the revolt against this evil custom has sprouted. Similarly there are people who have found the courage and continue to fight regression fostered in the name of religion.

The basic contradictions between political processes that profess to value equality of its citizens but within an existing milieu defined by social and economic inequalities must be resolved. The question is how do we move towards a culture of equality based on reason, rationalism and a clear comprehension of the challenges we are likely to face in future? While I do not possess all the answers I can offer a few thoughts for consideration.

First and above all, the possibility of a people's ability to evolve a new society and the legitimacy of this process should be

accepted, and barriers to a society of equality need to be demolished. This will require separation of religion from politics, removal of restrictions on intra-belief debate, redistribution of land, recognition of women's equality with men and of labor with employers, and acceptance of stakeholders' right to be consulted on policies affecting them.

Special efforts will be necessary to eliminate rule by force alone. Attention must be paid to Article 3 of the Constitution of Pakistan to translate people's dream of freedom from exploitation into reality. Societies are not created through drafting policies but shaped by the systems of control over people's resources and the nature of economic relations they have with one another. Change these relations and changes in the society will follow.

The critical question is who will accomplish the task of Pakistan's rejuvenation? In the current environment of cynicism many people have concluded that the state has neither the will nor the capacity to take the steps necessary to promote a culture of equality. At the same time people seem to have lost confidence in their ability to achieve anything through their own efforts. Any step forward will depend on civil society's initiatives for changing the socioeconomic relations in the country. The people of Pakistan have to launch a movement strong enough to oblige state institutions to resolve the contradictions between the polity and the norms in the country.

All I can say is that this can be done.

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