

Bioethics in the Muslim and Developing Worlds
AKU-ISMC
3-4 October, 2014

Friday, 3 October 2014

- 0930 - 1000 Welcome (Dr. **David Taylor** & Dr. **Mary Sansalone**)
- 1000 – 1030 Conference Opening (Dr. **Jamal J. Elias**)
- 1030 – 1200 Dr. **Farhat Moazam** “Teaching Bioethics in Pakistan: The principlist paradigm and social realities”
Dr. **Autumn Fiester** “Teaching Casuistry: Moral archaeology in bioethical case analysis”
(Chair: Dr. **Jamal J. Elias**)
- 1200-1215 Coffee/Tea break
- 1215-1250 Dr. **Abdallah Daar**, “Ebola: what can we learn from the West African outbreak that will inform future bioethics research?”
(Chair: Dr. **Farouk Topan**)
- 1300-1400 Lunch
- 1415-1545 Dr. **Susie Kilshaw**, “Women, Miscarriage and Motherhood Lost in Qatar”
Dr. **Junaid Razzak**, “Ethics of Life Saving Care in a Privatized Health System – resources versus fundamental duty”
(Chair: Dr. **Kathryn Spellman Poots**)
- 1600-1730 Dr. **Udo Schüklenk**, “Global Health Obligations and the Prioritization Problem in Public Health Emergencies” (Public Lecture)
- 1900-2100 Dinner (venue to be announced)

Saturday, 4 October 2014

- 0930-1100 Dr. **Aamir Jafarey**, “A Decade of doing Bioethics in Karachi: The CBEC experience”
Dr. **Aasim Ahmad**, “Education and Capacity Building in Bioethics”
(Chair: Dr. **Jamal J. Elias**)
- 1100-1115 Coffee/Tea Break
- 1115-1245 **Mehrin (“Mir”) Masud-Elias**, Esq., “The Devil’s Details: Ethical implications of key operational challenges in conducting clinical research at academic institutions”
Dr. **Murad Khan**, “Beyond Quality: Organisational ethics and organisational integrity”
(Chair: Dr. **David Taylor**)
- 1300-1400 Lunch
- 1415-1500 Dr. **Zulfiqar Bhutta** (web presentation), “Polio eradication in Pakistan: challenges and opportunities for the Aga Khan University”
(Chair: Dr. **David Taylor**)
- 1500-1515 Coffee/Tea Break
- 1515-1630 **Group Discussion** (moderated by Dr. Jamal J. Elias)

List of Participants (Alphabetical)

Dr. Aasim Ahmed is the Chairperson of the Bioethics Group at Aga Khan University, Karachi, and Dean and Chief Nephrologist at the Kidney Centre. His main areas of interest are undergraduate and postgraduate education in bioethics. He is Director of Masters of Bioethics, a programme for capacity building in bioethics in Pakistan and in Low Income EMRO countries, as well as a recipient of a training grant from Fogarty International Center, National Institutes of Health (FIC- NIH) USA.

Dr. Zulfi A. Bhutta is Husein Laljee Dewraj Professor and the Founding Chair of the Division of Women and Child Health, Aga Khan University. He also holds adjunct professorships in International Health and Family and Community Medicine at the departments of International Health at Boston University and Tufts University, respectively. He was designated a Distinguished National Professor of the Government of Pakistan in 2007. He is also the Dean of the faculty of Paediatrics of the College of Physicians and Surgeons, Pakistan, and the Chairman of the National Research Ethics Committee of the Government of Pakistan.

Dr. Abdallah Daar is Professor of Clinical Public Health and Global Health, Dalla Lana School of Public Health, and Professor of Surgery, University of Toronto. He is a member of the United Nations Secretary-General's Scientific Advisory Board, and of UNESCO's International Bioethics Committee. In 2005 he was awarded the UNESCO Avicenna Prize for Ethics of Science. He has served on the ethics committees of the International Transplantation Society and the Human Genome Organization.

Dr. Jamal J. Elias is Walter H. Annenberg Professor in the Humanities at the University of Pennsylvania and Special Advisor for the Study of Islamic Civilisations to the Provost of Aga Khan University. He has written broadly on a variety of issues related to Islamic thought, history and society.

Dr. Autumn Fiester is the Director of Education in the Department of Medical Ethics and Health Policy at the Perelman School of Medicine at the University of Pennsylvania. She is also the Director of the Penn Clinical Ethics Mediation Program and the Co-Director of the Project on Bioethics, Sexuality, and Gender Identity. Her research interests include clinical ethics, mediation, bioethics education, and LGBT bioethics.

Dr. Aamir Jafarey is Associate Professor at the Centre of Biomedical Ethics and Culture, SIUT, Karachi, Pakistan as well as a Lecturer and Consultant General Surgeon at Aga Khan University. He has been involved in bioethics related activities in Pakistan since 1997, and serves as the Coordinator of the Ethical Review Committee of SIUT.

Dr. Murad M. Khan is Professor and former Chairperson of the Psychiatry Department at Aga Khan University, specializing in the study of suicide and related ailments. He is a founding member of the Bioethics Group at Aga Khan University.

Dr. Susie Kilshaw is a Principal Research Fellow at the Department of Anthropology, University College London, where she has two ongoing research projects in Qatar, both funded by the Qatar National Research Fund. The first investigates popular understandings of genetic risk and social implications of genetic knowledge in Qatar and the second is a cross-cultural exploration (United Kingdom and Qatar) of the experience of pregnancy and miscarriage. She was a teaching fellow in Medical Anthropology and Applied Studies at University College London (2004–10). Her previous work focused on the emergence of Gulf War Syndrome in the United Kingdom, and her book on the subject, *Impotent Warriors: Gulf War Syndrome, Vulnerability and Masculinity*, was published by Berghahn Books in 2009.

Mehrin (“Mir”) Masud-Elias, Esq., is Director of Legal Affairs for the Abramson Cancer Center at the University of Pennsylvania and oversees all contractual aspects of the University’s clinical and scientific research activities in oncology. Ms. Masud-Elias previously was a corporate transactional lawyer in private practice focusing on the healthcare and life sciences industries for 10+ years. She holds several volunteer leadership and fundraising roles with various nonprofit and professional organizations and has been recognized for her professional achievements by a number of legal publications in the United States.

Dr. Farhat Moazam, a pediatric surgeon, is Professor and Founding Chairperson of the Centre of Biomedical Ethics and Culture, SIUT, Karachi, Pakistan. She is Visiting Professor, Centre for Humanism in Medicine, University of Virginia, International Fellow of The Hastings Center, New York, and member of the Board of Directors, International Association of Bioethics.

Dr. Junaid Razzak is the Section Head and Founding Chairman of the Department of Emergency Medicine, Aga Khan University. He is also the former Executive Director for health initiatives at AMANHEALTH, where he continues to serve on the advisory board, and is the founding President of the Society of Emergency Physicians, Pakistan.

Dr. Udo Schüklenk is a Professor of Philosophy at Queen’s University in Canada. He is Joint Editor in Chief of the journal *Bioethics*, and the founding editor of the journal *Developing World Bioethics*. He writes broadly on bioethical issues, both in academic publications and in media intended for wider consumption.

Dr. Kathryn Spellman-Poots is an Associate Professor at the Institute for the Study of Muslim Civilisations, Aga Khan University. Her areas of interest include gender and Islam in the Middle East and North Africa, the Iranian diaspora, and transnational migration networks. Her most recent book, *Beyond the Arab Spring: The Aesthetics of Popular Revolt and Protest*, has just been published by Edinburgh University Press.

Dr. David Taylor is the Director of the Institute for the Study of Muslim Civilisations, Aga Khan University, as well as former Acting Provost of the University. He is a scholar of Indian nationalism and of political thought, economy and mass media in India.

Dr. Farouk Topan is Associate Professor (Emeritus) and former Director of the Institute for the Study of Muslim Civilisations, Aga Khan University. He is a specialist in Swahili literature, Islam in African literature, African poetry, and identity in East Africa.

Abstracts

Abdallah Daar, “Ebola: what can we learn from the West African outbreak that will inform future bioethics research?” A large number of issues, some old and some very new, have arisen. These include the duties and responsibilities of health care personnel working in life-threatening conditions (~10 % of all current Ebola deaths)- when is the risk so high that patients can be abandoned?- is this a matter of personal choice?; the obligations of citizens to obey public health orders and the reciprocal duty of governments and society to provide support to affected communities, especially if those are put in quarantine; the use of drugs and vaccines that have not yet been tested on humans; the conditions under which clinical trials can be performed in such emergency situations; the way ethical issues are being resolved; priority setting and resource allocation; the basis for international assistance and cooperation; travel restrictions; etc. I will draw on our experience of the 2003 SARS outbreak in Toronto, and our other work in global health ethics, to discuss issues that are likely to help set a future research agenda for the AKU community. To set the scene, I will ask the audience to imagine an Ebola outbreak in Pakistan before the end of 2014.

Autumn Fiester, “Teaching Casuistry: Moral archaeology in bioethical case analysis”. One common pitfall in bioethics pedagogy is training students to identify only a limited set of principles that end up blinding them to the full range of context and obligations relevant in a particular case. This paper will demonstrate how to engage bioethics students in a process of ‘moral archaeology’ – a systematic uncovering of the moral values, interests, principles, and laws at play in an ethics dispute. Learning the bioethical method of casuistry requires pairing instruction in bioethical principles with training in the skill of mining cases for their moral content with the goal of generating an inclusive set of moral considerations that accurately represent the positions and values of all of the individuals involved in the case.

Aamir Jafarey, “A decade of doing bioethics in Karachi: The CBEC experience”. My talk will encapsulate the experience of having developed and run a three tiered bioethics programme at Pakistan’s only centre of bioethics. With no previously tested templates on which to base the academic programmes, I will discuss how our programmes have evolved with each academic cycle. I will also describe the impact of formal bioethics education on the alumni and their work.

Murad Khan, “Beyond Quality: Organisational ethics and organisational integrity”. Over the last two decades, the introduction of quality initiatives such as Total Quality Management (TQM), Continuous Quality Improvement (CQI) and International Standardization for Organisations (ISO) in healthcare systems have led to substantial improvements in patient care. Despite this, there remains a general dissatisfaction with the care provided and patients’ complaints have continued to grow. Quality concepts are mostly derived from the service and manufacturing industries, that deal with inanimate products such as soaps or washing powder. On the other hand, healthcare organisations deal with diseased and distressed human beings. The role of ethics in the care of the ill therefore becomes critical. While quality is about meeting certain standards, ethics is

about internalizing values, in particular the core values of compassion and caring, fundamental to the medical and nursing professions. These core values are under threat in today's highly commercialized world where the bottom line has become revenues and profits. In this model, patients become commodities to be bartered and exchanged, bought and sold. Healthcare organisations that move away from an ethics-driven model to a more business-driven one face greater patient dissatisfaction. The centrality of compassion as a core ethical value is critical to the effective functioning of a healthcare organisation. Everything else emanates from this core value. Quality initiatives, as all other aspects of a healthcare organisation, must be ethics-driven because quality is a by-product of ethics and not vice versa. Healthcare organisations that invest in ethics to complement quality initiatives in their processes lead to better patient care and greater patient satisfaction. Therefore, healthcare organisations must strive to become *ethical* organisations and not simply *quality* ones.

Susie Kilshaw, “Women, Miscarriage and Motherhood Lost in Qatar”. This paper focuses on the way in which a miscarriage impacts the social role of women in Qatar. Islam is a ‘pronatalist’ religion and procreation is considered to be one of the most important pillars of society. The social status of the Muslim woman, her dignity and her self-esteem are closely related to her procreation potential in the family and in society as a whole (Serour 1993: 211). By using ethnographic material I explore the way a miscarriage (*Tasqeet*) may mean lost motherhood and lost potential for the woman. However, a miscarriage also produces a particular kind of being, a ‘bird in heaven’, who protects its mother and speaks for her on Judgment Day.

Mehrin (“Mir”) Masud-Elias, “The Devil’s Details: Ethical implications of key operational challenges in conducting clinical research at academic institutions.” Clinical trials represent the crucial link between scientific discovery and medical utility. Challenges to the effective and efficient conduct of clinical research are driven primarily by the fact that cooperation among a diverse group of stakeholders is necessary. The following emerging (and interconnected) challenges to clinical research resonate in both developing and developed world contexts: (1) infrastructural concerns, including ethics committee review; (2) costs, both tangible and intangible; (3) trial design; (4) addressing the gap between clinical research and clinical practice; and (5) building the clinical trials workforce capacity. These practical hurdles have ethical implications for clinical research, and require a shift from a “micro-ethics” approach that basically addresses individual researchers as autonomous agents to a “macro-ethics” approach that looks at research communities as social networks embedded in political and cultural environments. In a globalized world with a “10/90” gap, academic institutions as lynchpins for public-private collaborations and training grounds for the next generation of citizens are in a unique position to take leadership and stewardship roles, in particular through robustly reformulated ethics review committees, in the effective planning and execution of clinical trials by working to address these challenges in order to begin the slow process of redressing this gross imbalance.

Farhat Moazam, “Teaching Bioethics in Pakistan: The principlist paradigm and social realities”. Experience with teaching bioethics in Pakistan over the last decade has highlighted to me the disconnect that exists between local cultural and religious values and socioeconomic realities, and the dominant medical ethics paradigm which is secular, principlist and perceived to be ‘universal’ in nature. Transplanting this paradigm into countries like Pakistan and teaching healthcare professionals to ‘balance’ a limited set of principles, is liable to end up as an abstract exercise in classrooms with little practical or meaningful impact on society.

Junaid Razzak, “Ethics of Life Saving Care in a Privatized Health System – resources versus fundamental duty”. Healthcare services in many developing countries are largely provided on a fee for service, privatized, for-profit/for-full sustainability model. When large populations have limited ability to pay, such a financing model is unable to respond fully to the fundamental duty to save a life. Using two case studies, the discussion will explore the ethical dimension of the need versus ability conflict in a pre-hospital and hospital based emergency system in Karachi. The presentation will highlight the following four areas: (i) mixing of medical triage system with a poorly defined and hidden financial triage; (ii) internal conflict among providers to provide life-saving care and the risk of burnout to individual physicians; (iii) perception of the “care” system from the populations’ perspective; and (iv) private philanthropic and institutional response to this ethical challenge.

Udo Schüklenk, “Global Health Obligations and the Prioritization Problem in Public Health Emergencies.” At the time of writing, the Ebola virus is still spreading in a number of West African countries. There appears to be a broad consensus that countries of the global north owe assistance that is aimed at containing and eventually ending the spread of the virus. In this presentation, I will briefly provide two competing normative accounts for why such assistance is morally obligatory, independent of considerations of self-interest. Once it is established that such global health obligations exist, it is worth asking how the limited resources that are made available on the basis of such considerations should be prioritized. Only one of the two models discussed provides a reasonable justification for particular prioritization strategies. Its implications for the ongoing international response to the Ebola outbreak in Western African nations will be discussed. This approach is contrasted against the contributions proffered by bioethicists, both in the context of international organisations as well as in other professional or informal fora. I will defend the view that most of the initial responses by bioethicists focused on subject matter irrelevant to the actual ethical challenges faced by those struggling to contain the actual epidemic in the trenches of Liberia, Sierra Leone, Guinea and Nigeria. The lesson to take away from this confirms the late James Rachels’ caution against practical philosophers and bioethicists shooting from the hip in response to the ‘issue of the day’.