Islamic Ethics & Genomics: Specialized Knowledge as Public Discourse

Prepared By

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On January 30th, 2019 a public seminar was organized by the Research Center of Islamic Legislation and Ethics (CILE), in collaboration with Sidra Medicine, World Innovation Summit for Health (WISH), Qatar Genome Programme (QGP), and Weill Cornel Medicine-Qatar (WCMQ). The seminar makes part of the research project "Genomics, Islamic Ethics, and Public Engagement (GIEPE): Towards Bridging the Knowledge and Communication Gaps", funded by the Qatar National Research Fund (QNRF), as part of the program "Path Towards Personalized Medicine (PPM)".

The seminar "Islamic Ethics & Genomics: Specialized Knowledge as Public Discourse" was hosted by Sidra Medicine which accredited the seminar as part of its Continuing Medical Education (CME) program for scientists, physicians, and other healthcare professionals. Besides highlighting the GIEPE project, the seminar highlighted the recent CILE peer-reviewed publication ***Islamic Ethics and the Genome Question*** (Brill, 2019).

The panel was moderated by Dr. Mohammed Ghaly (Professor of Islam and Biomedical Ethics) who is the Lead Principal Investigator (LPI) of the GIEPE project and the editor of the published volume. The list of the other panelists included:

- Dr. Khalid Fakhro (Human Genetics at Sidra Medicine, WCM-Q)
- Dr. Khalid Al-Ali (Qatar Ministry of Education and Higher Education)
- Dr. Eman Sadoun (Qatar Ministry of Public Health (MoPH))
- Dr. Said Ismail (Qatar Genome Programme)

Background & Main Themes

During virus research in 1952, the two scientists Alfred Hershey and Martha Chase showed that deoxyribonucleic acid (DNA) is the material which was becoming "transformed." Subsequently, in 1953, the double helix structure of DNA was proposed by James Watson and Francis Crick, which was a turning point in biology because of the principle that structure defines the function. In 1962 they were awarded the Nobel Prize for their historic feat. Fast-forward to 2003, the international Human Genome Project announced the first successful

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sequencing of a human genome – the entire genetic code of a human. By 2015, the PPM program was launched in partnership with QGP and QNRF. In 2017, the second cycle of the PPM program began with a focus on community engagement, ethics, and policy in precision medicine.

DNA is composed of genes which carry the informational and instructional machinery for body cells and can be mutated and inherited. Precision medicine or personalized medicine, is the beginning of revolutionary transformations in healthcare meant to design tailored treatments and disease prevention modalities based on individual genetic makeup. It allows for a more precise diagnosis and improved patient outcomes. Furthermore, the Islamic ethical tradition comprises an integral part of the moral world of Muslim individuals and societies. Thus, it is of paramount significance to facilitate and foster public understanding of, and engagement with, genomics and its associated ethical questions. The objective is to equip people with tools to help them make informed decisions on related complex dilemmas. At the same token, it is also meant to empower individuals and societies to be the agents of their own health, contribute to setting the research agenda, and to influence policy-making. Through open dialogue with concerned stakeholders and with the public, a foundation of public trust and awareness will be built which will serve the success of genomic research and its possible applications including personalized medicine. This seminar contributed to these discussions with the aim of decreasing the gap between genomics, Islamic ethics, and public discourse.

Five Talks

Besides the introductory remarks given by Dr. Ghaly, five talks were given by the abovementioned panelists and the seminar was concluded by a Q&A session.

(1) *Islamic Ethics and the Genome Question* by Mohammed Ghaly

Ghaly spoke about the significance of the interdisciplinary expertise, by bridging the knowledge gaps between genomics and Islamic ethics, to provide reliable information that can gain public trust. On the other hand, he stressed the significance of developing tools to reach out to the public to compete with popular tools and phenomena like "Dr. Google" and "Shaykh Google" which make use of tools with communication powers yet, may also include unreliable and even bogus information.

Ghaly also presented the book *Islamic Ethics and the Genome Question* stressing that its content will benefit the GIEPE project. The book discusses a wide range of ethical questions raised by genomics through interdisciplinary approaches. The contributors to the book employed analytical tools, concepts, and insights from various disciplines including genomics, Quran exegesis, Islamic jurisprudence, Islamic theology, philosophy, and also perspectives from other traditions like Christian and secular ethics.

In the last part of his talk, Ghaly focused on the GIEPE project; its research agenda and prospective activities. He explained that the research team of the project will focus on addressing the questions which may raise concerns among the general public by presenting evidence-based, robust, and concurrently accessible information.

(2) *Genomics in Public Perception: Realities, Premises and, Fallacies* **By Khalid Fakhro**

Fakhro started with an overview of key concepts such as genomics, genomic technologies, and research guided personalized clinical decision making. He reviewed both the scientific aspects of these terms and also the ethical questions which they trigger. He explained how some of the recent changes in genetics research affected the central dogma of human molecular biology. Which is composed of regulated events; DNA replication, transcription to ribonucleic acids (RNA), and finally translation into protein. However, this process is proving to be more complex then specialists thought in the past. For example, at some stages, it can be the subject of feedback loop mechanisms. Fakhro maintained that the future of personalized medicine holds not only molecular-level study. Yet, it will reach multi-level omics encompassing the gene function, RNA, protein, drug metabolites, and the microbiome (gut bacteria) along with its neuronal connections. In addition, genomic technologies render scientists the capacity to examine the genetic structure of organisms from the "big" picture then to zoom in to microscopic characteristics.

Additionally, Fakhro elaborated on the advances of genomic technology capabilities which have allowed it to be more easily accessible to the public. For example, DNA sequencing has reached a drastic decrease in cost to approximately one thousand dollars and the sequencing time has become less than twenty-four hours. Such accessibility paves the road to improved diagnosis, interpretation, and the analysis of rare life-threatening diseases. Despite the fact that such a diagnosis can have negative emotional, psychological and, financial tolls on involved families. Fakhro delved into other ramifications of genomic medicine such as; noninvasive prenatal testing (NIPT), pharmacogenomics, epigenetics, gene replacement therapy, gene editing, as well as the induction of pluripotent cells (iPSC). He explains pharmacogenomics as the way in which patients respond differently to a prescribed drug based on their genetic makeup. Such an illustration is already in clinical practice, medications are prescribed for cancer treatment of tumors which specifically target driver mutations.

(3) *Regulating Genomics Transnationally: UNESCO Universal Declaration on the Human Genome* **by Khalid Al-Ali**

Al-Ali's talk focused on the "Universal Declaration of the Human Genome", issued by the United Nations Universal Educational Scientific and Cultural Organization (UNESCO). The Declaration is composed of twenty-five articles which are subdivided into seven primary aspects, namely, human dignity and the human genome; research on the human genome; solidarity and international cooperation; rights of the persons concerned; conditions for the exercise of scientific activity; and promotion as well as implementation of the principles set out in the declaration.

The Declaration encompasses the acceptance of individual biological diversity, obstinate against genetic racism or any form of discrimination that may undermine human rights and dignity. The core of the Declaration embodies three fundamental principles, namely, the human genome is part of the heritage of humanity, respect for the dignity of human rights irrespective of one's genetic formation, and a rejection of genetic determinism. Additionally, the Declaration recognizes that individual genomes are exposed to mutations and can express different phenotypes based on evolutionary factors. The Declaration highlights a number of individual rights, e.g., prior consent to all research, treatment or diagnosis; protection against any form of genetic discrimination; confidentiality of people's genetic information; and the right to "just reparation," as a direct result of intervention affecting an individual's genome.

The declaration is meant to set the standard for universal ideals, principles, and ethical practices for human genetic research intended to balance ethical concerns, protection of the dignity of man, and rights. It adheres to universal solidarity and calls for international cooperation to protect families and populations who are vulnerable to disease or disability of genetic character and to provide support to developing nations. Al-Ali also explained that the Declaration encourages the dissemination of scientific knowledge through international collaboration while observing cultural sensitivities. It declares that any advancement in genomic knowledge, biology, and medicine must be made available to every person. The responsibility of setting the scientific research policies is placed on researchers, the public and private sector, as well as the states who are collectively responsible for designing frameworks to encourage the freedom of scientific endeavors.

(4) Genomic Regulations: National and Regional Perspectives by Eman Sadoun

In her talk, Sadoun focused on the role of the MoPH as a governing body which drafts policies and regulations on genomic research in the state of Qatar. She explained that genomic policies serve to support the design and strategy of genomic research. In addition, the policies are implemented to aid the Institutional Review Boards (IRBs) in their attempt to maximize the intended benefits and minimize the possible risks of genomic research, while keeping in mind the socio-political as well as the cultural aspects of the Gulf region. The policies stress that research participants should be fully aware of their basic rights; including privacy and confidentiality of information. These should be clearly stated in an informed consent form. Privacy and confidentiality of information should be controlled through security measures such as protected passwords, encryptions, and non-disclosure agreements. As well as, the provision of assurance to research participants that strict measures will be placed to obviate any privacy breach of information. Furthermore, the Qatar MoPH is concerned with continuing education for all parties involved in genetic research as well as with raising public awareness. Deliberations continue on how and which results should be released to participants. She concluded by stating that the MoPH emphasizes the importance of public engagement pertaining to possible genomic risks.

(5) *Qatar Genome Project (QGP): Setting the National Precision Medicine Agenda* by Said Ismail

Ismail's talk presented the QGP; which has positioned Qatar as a pioneer in the region in the implementation of personalized medicine through multi-faceted approaches. This includes educational programs for community engagement on genetics in schools and an innovative and interactive representation of DNA through a DNA museum. Furthermore, it provides research support (e.g., the conference held in April 2018 "Ethics, Regulations, and Best Practices in Genomic Medicine"), clinical impact models (e.g. Q-Chip), large-scale clinical implementation such as pre-marital and newborn screenings as well as, the delivery of personal genomic reports. Genomic reports have the potential to provide information to conduct roadmaps for lifestyle changes for disease prevention. These lifestyle and nutritional aspects are crucial components in the genomic discussion because further research may lead to the discovery of their effects on epigenetics. The National survey commissioned by the QGP has shown that more than 80% of the public is interested in learning more about their genetic makeup. Concurrently, discussions on consanguinity and the possibility of negative outcomes, such as rare genetic diseases and the risk of lower fitness in populations in the Gulf region, are vital because of the deeply ingrained cultural and traditional factors.

External Links

- Open-access link to the Book *Islamic Ethics and* the *Genome Question*
- The QNRF-funded Project: Genomics, Islamic Ethics, and Public Engagement (GIEPE): Towards Bridging the Knowledge and Communication Gaps
- Open-access link to the *Journal of Islamic Ethics*