Call for Research Papers Islamic Ethics and the Genome Question

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Center for Islamic Legislation & Ethics (CILE) Doha, Qatar

Background Paper

The 20th century has been called the century of the gene, reaching a pinnacle moment at the beginning of the 21st century. This was on 26 June 2000 when the US president Bill Clinton highlighted the successful completion of the first ever survey of the entire human genome, epitomized in the Human Genome Project. This breathtaking incident was compared to the "moonshot", equivalent to the meticulous planning through to the successful landing of humans on the moon and to the splitting of the atom. In contrast, some critical voices have cautioned against the unfounded or exaggerated genomic exceptionalism represented in a sometimes pervasive tendency to hype up the impact of genomics, especially with regards to healthcare. Both the rise of genomics as a research field and the intense debate surrounding its potential impact on healthcare have generated an unstoppable flow of deep and complex ethical questions, which we have incorporated here under the broad heading of the "Genome Question", referred to henceforth as the GQ.*

Before laying out examples of the themes and detailed questions in which this call-forpapers is interested, we would like to clarify: (1) what we exactly mean by the GO and (2) the breadth of the scope of both the GQ and Islamic ethics.

(1) The Genome Question (GQ)

The GQ refers not only to a set of questions raised by the cutting-edge technologies of genomics which the Islamic ethical tradition would ordinarily respond to by providing immediate and shortterm answers through judgements on their applications. We argue that the GQ goes much deeper than such normative moral deliberations on how to use certain technologies in particular situations. Genomics itself needs to be critically examined, e.g. why and how did it come into existence and which sources of knowledge should be employed to address its ethical questions? We also need to think deeply about the way genomics should/can be framed and approached from an Islamic ethical perspective, e.g. is it a question of simply directing tools in the right direction (question of wisdom of using neutral tools) or is it a question of new technologies which are going to construct and (re)shape our very reality or at least our perception and views of this reality (question of addressing distinct worldview imperatives)?

(2) The Scope

^{*} Full-text introductory works on genomics which explain its basic information and key questions for nonspecialists are available at request. For the applicants interested in this material, please see contact details mentioned in the section "Practical Information & Deadlines".

The scope of the GQ is considerably broad to the extent that it encompasses the greater part of the bioethical questions, albeit usually conflated with new dimensions and complexities, which one comes across in many other fields of biomedical sciences like assisted reproductive technologies, genetic enhancement, research involving human subjects, genetic engineering, etc. Thus, dealing with the GQ will eventually lead to taking the whole field of bioethics into consideration.

The breadth and depth of the GQ should also be coupled with recognizing the considerably broad scope of Islamic ethics, so that Islamic ethics can effectively address the challenges posed by the GQ. Although we totally defend the centrality of Islamic jurisprudence (*fiqh*) in developing ethical discourse rooted in the Islamic tradition, we equally problematize the proposition which reduces Islamic ethics to *fiqh* only. Besides *fiqh*, many other disciplines should be employed and mobilized in order to produce a rigorous and productive Islamic ethical discourse on the GQ. Such disciplines include, but not limited to, philosophy, theology, Sufism, Quran exegesis, Hadith commentaries and belles-lettres (*adab*). Submissions which address the GQ from the perspective of one of these disciplines or, preferably, combine more than one, are all welcome. Below, we give some illustrative examples of the themes and detailed questions which prospective applicants may address in their submitted abstracts and subsequent papers.

(3) Themes and Detailed Questions: Illustrative Examples

• Genomics: Negotiating the scope, boundaries and objectives

From the very beginning, the main promise of genomics was to cure stubborn diseases like Alzheimer's, diabetes and cancer by attacking their genetic roots. The main thesis is that understanding how combinations of disease-causing genes, not just individual genes, interact with each other and with environmental factors, will lead to the development of new drugs, to individually designed treatments and possibly even to the correction of gene flaws before birth. In other circumstances, intervention can be preventive in nature, taking the form of guidelines to recommend changes in lifestyle habits so as to lower one's susceptibility to certain diseases. Applied in these ways, genomics remains within the conventional boundaries of medicine, namely providing curative or preventive tools for healthcare.

However, the wealth of information provided by genomics, updated almost on a daily basis, has increasingly demonstrated the possibility of not just 'fixing' the problems of those who have gene flaws (curing the sick) but also 'improving' the performance of those who already have good functioning genes (enhancing the healthy). Enhancement technologies range from nootropics capable of enhancing cognitive abilities to distraction osteogenesis, a surgical technique capable of increasing height through limb lengthening. As a further clarifying example, we can refer to erythropoietin (EPO), a hormone produced by the kidneys that stimulates red blood cell production. The injection of EPO was first introduced to help dialysis patients (curing the sick). Today, EPO injection has become a popular performance enhancer for distance runners, cyclists, and cross-country skiers (enhancing the healthy). This technique improves the production of oxygen-carrying red blood cells which is a key factor in endurance. After successful trials on animals, scientists are now working on humans to develop EPO gene therapy, so as to be able to insert a new copy of the gene that produces the EPO. This may lead soon to genetically modified runners and cyclists who will be able to generate higher-than-normal levels of their own natural EPO. Rigorous ethical evaluation of such enhancement technologies cannot exclusively focus on their applications and

consider only how safe they are from a medical perspective. Medicine, like many other professions, is a practice with *telos* (purpose or goal) which guides and constrains it. Thus, what should be questioned first is the *telos* rather than the praxis (specific application), e.g. can/should enhancement be part of the goals of genomics or medicine in general? If yes, on what ethical grounds? And would it then be scaled as equal, less or even more significant than the other two objectives, namely treatment and prevention?

We try here to give a clue to how prospective submissions can contribute to this debate. One can think of examining the discourse on the objectives of medicine (magasid al-tibb) in the Islamic tradition and how (un)changeable these objectives are in the light of various spatial and temporal circumstances. An in-depth and critical study of this discourse can be of added value to addressing questions like "what is genomics for?" "Why is it developed, used, and esteemed?" "Toward what ends is it taking us?" As a follow-up step, one would further examine the possible similarities and differences between medical treatment and enhancement from an Islamic ethical perspective and how these (dis)similarities may affect a whole range of religious rulings (ahkam) pertinent to various applications of enhancement technologies. It is to be noted that the subtle, but crucial, differences between medical treatment and enhancement still did not find their way to the mainstream Islamic bioethical discourse on genomics, which is still usually labeled as a new form of medical treatment. Insights from Islamic theology and philosophy can also help studying the connections and relations between enhancement on one hand and key ethical concepts on the other hand, including human agency and ethical excellence. One needs to ask questions like: "to whom will the achievements of the above-mentioned genetically-enhanced runners and cyclists be credited - to the athletes themselves, or to the ones who developed the EOP gene therapy for them?" The same questions would also apply if enhancement technologies were employed for achieving religious purposes like memorizing the Quran in a better and faster way. To problematize the issue a bit more, do enhancement technologies pose a threat to human agency on the basis of which persons are to be blamed or praised for the performances?

Islamic Ethics: Revisiting Key Concepts

Islamic ethics, as a consistent and coherent system, is composed of a vast network of concepts, each of which contributes to the edifice of this system. The exponential increase in knowledge about humans' genetic make-up continue to question, problematize and sometimes even challenge many of our taken-for-granted perceptions of ethical concepts. Through this call-for-papers, we are looking for submissions which can provide fundamental inquiries and analyses of some key ethical concepts relevant to the field of genomics. Below are a few representative examples:

(i) What makes us distinctively human? Which factors make the members of the human species so diverse and different from each other? The wealth of information provided by genomics often has a bearing on these questions, influencing how we define and understand ourselves, how identities are formed and constituted. The complete sequence of the human genome made researchers think deeply about how far our genes dictate our humanness. Some ethicists spoke about the human genome as a biological living constitution which remakes how we, as individuals and as a species, interpret our obligations to each other and to other entities on earth. Others went even further, asking whether the genome is the secular equivalent of the soul. We welcome submissions which can engage with these questions and debates from an Islamic ethical

perspective. One can think of revisiting the discussions on the nature of the soul in various Islamic disciplines (e.g. the dualist theories advocated by Muslim philosophers versus the monist, physicalist models proposed by theologians) in the light of the newly revealed knowledge. Similarly relevant are the discussions on the distinctive and vital functions of the soul whose critical revision may help us differentiate between the enhancement technologies which are trying to modify the body and those which intervene in the work of the soul.

(ii) Determining the boundaries between what is 'normal/natural' and 'abnormal/unnatural' is another dilemma which genomics considerably added to its original elusiveness and difficulty to grasp. The general rule is that preserving or restoring normalcy is an ethical act whereas the opposite is unethical. The set of questions which genomics has made indispensable in this regard include the following: what does normalcy exactly mean?; against what metrics can it be measured and judged; and what makes the alteration of normalcy an act of acceptable improvement in one case, while in another an objectionable act of changing God's creation? Genomics and related fields have shown that our genes cannot easily be divided into either normal or abnormal. For instance, the blue-eyed gene is not the defective version of the brown-eyed gene and the same can be said about the red-haired gene and the brown-haired gene. These are all just alternative versions of the same genetic 'paragraph'; all equally fit, valid and normal. To a certain degree, the same rationale even applies to the genes usually related with certain diseases like the sickle-cell mutation which can be mildly harmful for those who have one copy of it, or fatal for those who have two copies. However, people with this mutation are far less likely to have the malaria parasite. So what is (ab)normal in such cases?

Attempts to clear up the burred boundaries between what is 'normal/natural' and 'abnormal/unnatural' have a long history in the Islamic tradition. Based on a number of references in the Quran and Sunna, some of the pre-modern cosmetic practices including plucking the eyebrows and hair extension, in specific circumstances, were condemned because they were seen as part of the Satan's scheme of tempting humans to change God's creation and the innate nature of their being. The same line of argumentation was used by many contemporary Muslim religious scholars when they were asked about specific (cosmetic) surgeries which change one's external look. The source of knowledge which guided these discussions and their conclusions was scriptural in nature. What would the line of argumentation and the whole discourse look like when genomics is added as an extra source of knowledge where discussions focus particularly on 'fixing' or 'changing' genes? Does discovering the genome and reading its content mean that God has given us the permission to change human nature? Is it a call from God to transcend and remake our nature and alter it for the better? Or is it a test from God to see if we will voluntarily remain within the boundaries of God's creatures or we will strive to be rival gods and act as (co-)creators?

(iii) The perennial debate on determinism and free will has also acquired new dimensions, complexities and nuances with the advent of genomics. The more the Human Genome Project advanced the more it became clear that the number of genes in the human genome will be much less than what was earlier predicted. From initial predictions, ranging between 80,000 and 200,000, the estimated number came to be around 30,000

protein-coding genes. Both scientists and philosophers found it highly improbable that our lives can be deterministically governed by this small number of genes. They argued that our lives, even including our health in its narrow medical and biological sense, are too complex and diverse to be determined by this meager constellation of genes. However, these results did not erode the scientific fact that genes do influence human development and that there is an established connection between one's genes (genotypes) and many physical traits (phenotypes). Additionally, the connection between certain diseases and gene mutations is strikingly deterministic in the sense that the cause sometimes will be in the genes and nowhere else. For instance, if an individual has the Huntington's mutation then he/she will get the disease in a deterministic way and it does not matter if he/she smokes, takes vitamin pills, or if he/she is an athlete or an idle person.

Which insights would the expansive Islamic discussions on predestination add to the contemporary debate on genetic determinism? Conversely, what does the new information provided by genomics contribute to narrowing or maybe widening the scope of disagreements and polarizations on determinism and free will among Muslim theologians? Is it, ethically speaking, problematic or even objectionable to reveal part of someone's destiny (e.g. developing the Huntington's disease later in one's life) when genomics makes such information available? Do genetic determinism, promoted by some progressive scientists, and theological determinism, advocated by certain groups in the Islamic tradition, start from (un)identical premises or try to achieve (dis)similar ends? How demonstrable is the argument that the former is an attempt to sacralize science at the cost of belief in Omniscient God whereas the latter tries to prove the contrary?

(4) Concluding Remarks

The list of themes and questions mentioned above is by no means exhaustive. There are many further examples that may lend themselves to even more thought-provoking and critical questions, e.g. the borderline between benefits and harms (masalih wa mafasid) and how to balance between them when they compete with each other in the age of genomics, the role of economics in guiding the debate about benefit-harm assessment by sometimes giving more weight to the potential profit involved for corporations which develop expensive drugs than to the more basic but cheaper and less profitable medical treatments and preventive medicine; the seen and the unseen worlds ('alam al-ghayb wa 'alam al-shahada') and if genomics could move some information from one realm to the other, what are the ethical implications of this shift, the role of ontological and epistemological assumptions in dealing with all these questions, etc. Submissions on any of these examples and their likes are also welcome. What we do care about in the submissions is that they: (a) consider both sides of the topic (viz. Islamic ethics and genomics), as outlined in the first two sections; (b) avoid adopting an atomistic approach which delves into minute and fragmented details without linking them to the big picture; and (c) provide rigorous and in-depth analysis of the material they deal with in a way that leads to producing scholarly knowledge with added value to the addressed topic.

Practical Information & Deadlines

Prospective applicants should send:

- (a) An abstract (300-500 words), describing the research's core ideas and how they will be addressed in the light of this Background Paper, and
- (b) A brief biography (max. 500 words) outlining the applicant's academic background, main research interests and key publications.

Submissions (abstracts, bios and full papers) can be written in either **English or Arabic**.

Authors whose abstracts are accepted will receive an invitation to provide their full papers (between 7,000 and 10,000 words) within the deadline specified below. The authors of a selection of the accepted papers will be invited to participate in the seminar and the other accepted papers will be considered for the publication project.

Plan of the Refereed Publication with Brill Publishers:

In April 2016, CILE signed an agreement with Brill to launch the refereed <u>Journal of Islamic Ethics</u> (<u>JIE</u>). A thematic issue in the <u>JIE</u> is one of the planned deliverables of the abovementioned publication project "Islamic Ethics and the Genome Question". Thus, accepted submissions in this call-for-papers will undergo the usual peer-review process for inclusion in the publication project.

Benefits

CILE will offer the authors of accepted papers the following benefits:

- Refereed publication
- Cover of the costs of making the publication available via open access.

For those who will be invited to present their papers during the closed seminar, the following additional benefits apply:

- Travel and accommodation costs during the three days of the seminar.
- Translation of the submitted paper into Arabic or English.

Important Dates:

- July 31, 2016: Deadline for receiving abstracts and bios. Please read the attached Background Paper carefully before writing the abstract.
- August 15, 2016: Authors whose abstracts are accepted will be notified and invited to write the full papers.
- January 05, 2017: Deadline for receiving the full papers.
- January 31, 2017: Authors whose papers are accepted will be notified.
- February 01, 2017: Accepted papers will be sent for translation into Arabic or English.

Contact Us:

Submissions should be sent to submit@cilecenter.org. For any inquiries about this call-for-papers or about the accompanying Background Paper, please contact Dr. Mohammed Ghaly (mghaly@qfis.edu.qa) who directs the CILE research unit 'Islam and Biomedical Ethics'.