

Living with the Genome: Ethical and Social Aspects of Human Genetics¹

**By: Angus Clarke and Flo Ticehurst (eds.)
New York: Palgrave Macmillan, 2006, 327 pp.**

Review By: Dr. Ayman Shabana

Modern genetics has ushered a new phase in human history and revolutionized human understanding of how living organisms are constituted and how they function. More particularly, it has revealed the processes associated with the transmission of inheritable features and characteristics to subsequent generations. The new knowledge that it generates brings promises of unprecedented preventive, as well as therapeutic, possibilities, especially as far as inherited diseases are concerned. These unprecedented possibilities are by no means limited to the fields of healthcare and life sciences as they touch many other aspects of our lives. However, as much as this genetic revolution has given rise to new exciting potentials, it has also raised important ethical questions pertaining to the production and application of genetic knowledge. It is within this context of the double-edged nature of modern genetics that *Living with the Genome: Ethical and Social Aspects of Human Genetics* has to be placed. Although written in 2006, the book still provides a useful introduction to the range of moral, legal, and social implications of modern genetic research and technology. It comprises 42 articles on a wide range of topics under the general theme of social and ethical aspects of modern genetics. These articles are drawn from the *Encyclopedia of the Human Genome* (one of the co-editors of the book, Angus Clarke, was also the editor of the “ethics and society” section of this reference work). The book is intended to enhance the readership of these topics by making these articles available to a wider audience beyond specialists in human genetics.

In terms of its basic subject matter, genetics aim to study how living organisms both change and maintain their basic characteristics over time. This study is undertaken at three distinct levels: life of the cell, life of an individual organism, and history of the population of a particular species. Genome stands for the entire set of genes (of an individual organism or of an entire population) and genomics refers to the study of genes in this collective sense. Modern genetics trace its roots to important discoveries during the 19th century (Mendel’s attribution of inheritance to certain particles, discovery of chromosomes, development of statistics and its application to hereditary processes, and Darwin’s theory of evolution), which inspired further developments during the 20th century (identification of DNA as the chemical basis of heredity and development of molecular biology). The past few decades have witnessed increased interest in the deployment of genetics in medical research and practice with the hope of identifying genes associated with particular diseases, while developing effective ways not only to treat but also to prevent the occurrence of such diseases at the individual and collective (population) levels. Genetics is also used in the

¹ "This research was made possible by the NPRP grant “Indigenizing Genomics in the Gulf Region (IGGR): The Missing Islamic Bioethical Discourse”, no. NPRP8-1620-6-057 from the Qatar National Research Fund (a member of The Qatar Foundation). The statements made herein are solely the responsibility of the author[s]."

development of new drugs as well as their administration for certain diseases or even tailoring them for individual patients. The use of genetic examination in healthcare and medical practices is already replacing traditional physiological and biochemical methods and is expected to increase even further in the future. Important examples include confirmation of the diagnosis of certain diseases in individual patients and screening for certain disorders within particular groups or populations. Yet, as noted above, despite these remarkable therapeutic potentials of modern genetics, it raises a host of ethical, legal, and social concerns that include choice of research agendas and availability of research funding for particular diseases, access to and proper use of genetic information, and legal as well as psychological implications of genetic examination. The articles selected for inclusion in this volume explore a wide array of these concerns with varying degrees of length and depth, which are divided into six main parts (prefaced by general editorial introductions): The Human Genome Project: Genetic Research and Commercialization; Genetic Disease: Implications for Individuals, families and Populations; Disability, Genetics and Eugenics; Genetics and Society: Information, Interpretation and Representation; Genetic Explanations: Understanding Origins and Outcomes; and Reproduction, Cloning and the Future.

The first part of the book comprises eight articles offering a useful historical account of the Human Genome Project (HGP), with a particular focus on the debate over the commercialization of genetic information, which was one of the driving forces behind this project until its successful completion in 2003 (two and a half years prior to the scheduled deadline in 2005). This debate was fueled by two competing views and visions for the project. The first was championed by the private sector, as represented by Celera Corporation, and the second was represented by an international consortium consisting of major public and state-sponsored research entities. While the first advocated patenting and monopolizing genome sequencing data as new inventions, the second insisted that genomic data should remain freely available as a non-commercial shared human resource for further research and development. The struggle between these two forces was hardly limited to the scientific and research sectors as the debate gained public momentum. The US president, Bill Clinton, and the UK Prime Minister, Tony Blair, issued a joint statement in 2000, which was perceived as supporting the view advocated by the international consortium. Eventually a difficult agreement was reached by both parties prior to the release of concurrent versions of the first draft of human genome sequencing in 2001. Other contributions in this section provide various perspectives on the rationale, objectives, and implications of the HGP, which overall are not quite sanguine. Contrary to the usual hype emphasizing the miraculous achievements of genetic technology, these contributions identify and highlight significant issues that tend to be glossed over due to the usual and unquestionable embracement of technology and its equation with progress. Chief concerns that run through these contribution include: commodification of genetic data, ownership and subsequent use of genetic material, distinction between a novel invention and mere discovery of nature; implications of the control of the human gene pool for future generations; obtaining informed consent in genetic research; and exaggerated expectations of/for gene therapy. At the global level, these concerns reflect larger tensions between multinational capitalist interests on the one hand and rights of indigenous people and their claim over native resources on the other.

The second part includes seven articles covering a wide range of ethical concerns associated with genetic diseases. This includes psychological dimensions of genetic counseling, particular concerns relevant to specific vulnerable groups such as children, measures of risk assessment for genetic diseases, perception of susceptibility for genetic diseases in light of the interaction between genetic and environmental factors, and varying implications of genetic screening in different cultural contexts. Genetic counseling is a process that aims to enhance understanding of a genetic condition and to explore possibilities to either avoid or cope with such a condition. It is often pursued for either health risk or reproductive purposes. Although it focuses primarily on scientific explanation of a particular genetic condition, it may also address religious and metaphysical questions that patients and their families feel they must address. This is particularly important in multi-religious or multi-cultural contexts reflecting various meanings for universal experiences of illness and suffering. In general, genetic counseling is guided by three main ethical principles: autonomy of the individual or couple, right to full information, and utmost level of confidentiality (p. 115). Genetic testing of vulnerable groups such as children presents additional ethical concerns, which have to be evaluated through a comprehensive harm benefit analysis. Testing of children is particularly problematic due to the difficulty of obtaining informed consent, which in this case would depend on their ability to participate in the decision-making process. One of the unique consequences of genetic testing is that it brought to public attention the issue of genetic risk for, or susceptibility to, particular health conditions not only for the individual undertaking the test but also for close family members. This, in turn, raises important questions with regard to adequate measures to handle cases involving genetic risk and also whether/how information concerning risk for others could be revealed. Research shows that perception of susceptibility to genetic diseases is dynamic and varies according to several factors, such as family history, gender, age, and economic standards. Some studies even question the utility of genetic testing for certain conditions, especially when positive results may lead to a fatalistic attitude of resignation rather than proactive behavioral changes (p. 105). Studies also show that the effective use of genetic counseling may depend on several contextual factors, which include cultural background and religious attitudes towards certain procedures such as abortion (119-28).

The third part consists of five articles discussing the relationship between disability and genetics. Each of these contributions address the issue from a particular perspective ranging from a historical investigation of problematic precedents, lingering traces of these precedents in contemporary practices, distinction between Western and non-Western outlooks on this issue, perception and implications from a human rights perspective, and examination of a particular disability group. Historical accounts of the contentious relationship between disability and genetics often start with the indelible eugenic practices of the Nazi period, which were undertaken for the purpose of a larger social vision of racial hygiene. These practices included several examples ranging from positive eugenics to enforced sterilization and even euthanasia. Abuses of scientific research at the expense of socially undesirable groups during the first half of the 20th century in Europe and elsewhere (particularly in the US) have continued to haunt genetic research as the term “genetic” was often used to replace the now infamous “eugenic” (p. 142). Some of the important traces of eugenics in contemporary research revolve around exploration of genetic explanation for criminal behavior as well as genetic screening especially in regions witnessing higher rates of genetic

diseases due to inbreeding or lower rates of migration, where genes causing diseases tend to cluster over time. On the other hand, traces of positive eugenics could be found in the creation of sperm and ova banks, particularly the ones obtained from individuals possessing desirable physical and cognitive traits (p. 144-5). Experience in other parts of the world demonstrate the varying perspectives on these issues as the debates surrounding the Chinese Maternal and Infant Health Care Law (1994) clearly demonstrate. These debates point out the importance of the historical, social and cultural background that informs related discussions in different contexts. Studies show that attitudes within disability rights groups toward genetics are not monolithic. While some oppose genetic research on the grounds that it tends to define disability in biological terms, others embrace it with the hope that it can lead to treatment through gene therapy. Still, others adopt a more nuance stand regarding prenatal selection on the basis of personal choice. As discussions over the sexual and procreative rights of individuals with intellectual disabilities demonstrate, as much as prenatal testing is a public health issue, it is also an issue of ethics, social justice, and human rights. This is particularly important in light of the absence of an automatic or simple correlation between learning disabilities in parents and similar conditions in their future children (p. 163).

The fourth part focuses on several social issues related to the employment of genetics in the creation of medical profiles. It consists of seven contributions dealing with topics including the emergence of the gene as a significant cultural icon, perception of the interplay between genetic and environmental factors, confidentiality of genetic information, implications of genetic data for insurance purposes, and the role of genetic factors in the confirmation of racial and cognitive stereotypes or in the definition of criminal responsibility. Heightened media attention to the role of genetics in the definition, one's identity, if not destiny, has transformed the gene into a powerful cultural symbol. The gene has increasingly been used as the locus of personhood and has consequently acquired the sacred status attributed to the soul or other similar entities in different cultures. Consecration of the role of genetics, however, raises serious human rights risks and may even inspire rejuvenation of eugenic practices (p. 175). Studies show that lay perception of inheritance (and its interaction with environmental factors) does not always correspond with standard scientific explanations offered at school or the clinic. On average, however, interest in scientific explanations increases when deemed salient for individual situations or concerns. Modern genetics has problematized traditional cultural notions of kinship and descent. This is evident in the application of assisted reproductive technologies enabling novel procreative methods, particularly within cultural contexts where genetic and social definitions of parenthood are not coextensive (p. 184-7). Some of the most important ethical concerns that modern genetics gave rise to are associated with boundaries of individual privacy and confidentiality of personal (genetic) information. The main ethical challenge in this regard remains: how to reconcile concerns for individual privacy with others' right to have access to shared genetic information. These privacy and confidentiality concerns may have significant social and even economic implications such as one's ability to obtain affordable health insurance. In the recent past, biological factors were used for the definition of one's cognitive characteristics (e.g. craniology and phrenology). Although advances in genome mapping reveal the insignificance of genetic factors in accounting for group differences, researchers warn that genetics could still be used to sustain racial and ethnic

stereotypes on the basis of notions of inherent superiority and inferiority (p. 205). Similarly, increased reliance on the genetic basis of behavioral characteristics raises the risk of transforming established notions of criminal justice and responsibility.

The fifth part focuses on the general theme of genetic explanations, particularly of behavioral traits and evolutionary arguments. It consists of seven contributions dealing with the manner in which genes are used for explanatory purposes within the context of the HGP, evolutionary accounts of natural selection, emergence of counter evolutionary accounts such as creationism and intelligent design, genetic reductionism and determinism, reinforcement of racial and ethnic characteristics. Most of these contributions point out the limitation of exclusive reliance on genes for explanatory purposes and call instead for a more nuanced account for the interplay of genetic as well as environmental factors.

The final part, comprising eight contributions, is devoted to the interaction between genetics and modern reproductive technologies in terms of regulation, range of choices, feminist perspectives, particular procedures, distributive justice, and impact on the future. Modern biomedical technology has unleashed a “reproductive revolution” that forces reexamination of the regulatory aspects of parenthood. Regulation may include private individual control, professional self-regulation, community control, legislative measures, or a combination of these options. Countries vary widely with regard to the legislative model that they adopt, which range from total neutrality and non-interference to strict restrictions. Ultimately, any regulatory model that a country eventually chooses would depend on a number of contextual considerations and “nuances in tradition, religion, culture, economics, and wealth” (p. 272). The debate on the range of choices that assisted reproductive technologies offer revolves around a distinction between medical (therapeutic) and non-medical uses of these technologies. In the case of the debate on cloning, for example, the distinction is often made between therapeutic cloning, which is perceived as useful, and reproductive cloning, which is depicted as dangerous and harmful. In general, while a liberal approach would issue from a permissibility presumption on the basis of fundamental rights and freedoms, a restrictive approach would be driven by concerns such as disrupting natural order and playing God. Feminist perspectives on genetic and reproductive technologies point out latent discriminatory effects of these technologies as well as their potentials for decreasing rather than increasing women’s rights. The example of sex selection is quite illustrative. While some argue that it can be permitted in limited cases that require family balancing, others argue that it should not be allowed because it sustains demeaning stereotypes about women since it is almost always undertaken to get rid of female fetuses. The range of possibilities that modern genetic and reproductive technologies generate would ultimately raise moral questions on fair distribution of benefits and burdens in society as well as on potential implications for future generations.

The richly diverse collection of contributions that *Living with the Genome* contains offers only a glimpse of the range of concerns that biomedical technology has engendered. With the extremely fast pace of technical advances in this field, new discoveries or inventions spark new questions and launch new debates to examine their ethical, legal, and social implications. Yet, this book remains a useful starting point as it captures some of the most important issues that remain as

relevant now as they were when the book was published in 2006. It also serves as a useful introduction to the larger work it draws on: the *Encyclopedia of the Human Genome*. The main limitation of the book, however, is its limited scope of coverage as it focuses almost exclusively on the Western geographic as well as intellectual context, with very few exceptions (e.g. chapter on the Maternal and Infant Health Care Law in China, p. 147; brief references to discriminatory sex selection practices in India, p. 293; and Muslim ban on gamete donation, p. 276). This is somehow understandable because these discussions coincided with the rise of the early waves of genetic and reproductive technology in the West, particularly in the second half of the 20th century. Nevertheless, considering the increasingly globalized nature of our world and the global influence of Western medicine, experts and practitioners at the international level are also joining these bioethical discussions. At the practical level, the availability of the latest applications of biomedical technology, especially to those who can afford it regardless of where they happen to live, has also stirred similar debates over important bioethical concerns. The book, therefore, calls for comparative analysis of the various ethical, legal, and social issues that it highlights in order to reflect the diversity and richness of particular societies, cultures, and religious traditions. Such comparative analysis would also highlight important parallels and similarities in various social and cultural contexts. One interesting example that the book discusses is the case of the deCODE project in Iceland (pp.56-63), which can provide important lessons for countries, especially those with small populations. The case highlights the critical role that regulators should play in ensuring compliance to ethical standards and proper conduct of genetic research.

Within the Muslim context, bioethical debates can also be traced to the two factors mentioned above: globalization of the medical curriculum (including bioethics), and the arrival of various applications of biomedical technology. Bioethical deliberations in the Muslim world, however, have drawn heavily on the Islamic normative tradition, particularly on the Islamic legal tradition. Researchers often point out that bioethical discourses in the Muslim world are dominated by the Islamic legal discourse, which is evident in the increasing volume of legal opinions (fatwas) on almost each of the issues addressed in this book. One of the main problems with these disparate fatwas is the lack of a consistent methodology for the examination of bioethical issues. The past few decades have witnessed serious efforts on the part of jurists and medical experts to provide systematic examination of bioethical issues with the goal of developing guidelines that should inform professional practices as well as national policies and legislation. These collaborative efforts have been facilitated by a number of national and transnational institutions, as well as a number of academic and research centers. Although, for the most part, the development of a comprehensive Islamic bioethical framework remains work-in-progress and the general state of bioethics differs from one national context to another, empirical research shows that in order for any treatment of bioethical issues to be taken seriously, it has to engage in this evolving body of Islamic normative literature. With regard to genomic research, important examples include the recommendations of the Islamic Organization for Medical Sciences (1998), the resolution of the Islamic Fiqh Council of the Muslim World League (2002), and the resolution of the International Islamic Fiqh Academy of the Organization of Islamic Cooperation (2013). These statements provide guidelines for various procedures associated with genomic research, such as gene therapy, genetic engineering, genetic testing, genetic counseling, and reprogenetics. In general, while these

statements praise the remarkable potentials of genomic research, they urge careful evaluation of any procedure involving intervention or manipulation of the human genome. They also warn against any commercial exploitation or monopolization of genetic materials.