

Drama of DNA: Narrative Genomics¹

Karen H. Rothenberg and Lynn Wein Bush

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Summary

The study of genomics is never as exciting as when an array of moral dilemmas involving research and treatment are dramatized in fiction and stagecraft. Karen Rothenberg and Lynn Wein Bush lyrically and engagingly impress upon us the realities of genomic research and experimentation in expressive, accessible, gripping and thought-provoking writing by simulating real-life situations. Centered on “narrative genomics”, the authors use characters and dramatic dialogue as a pedagogical technique to bring to life the diverse voices, varied contexts, and complex processes that encompass the nascent field of genomics as it alliteratively evolves “from base pairs to bedside.” Combining the methods of applied and narrative ethics result in a very successful presentation of the challenges genomic science pose.

Imagine subjecting yourself to genetic-genomic screening or diagnostic testing for a risk-assessment on exposure to any type of heritable disease or by way of lifestyle and ecological exposure. It sounds benign on the face of it until you receive the results and possess the information. Suddenly, the emotional and psychological burden of knowing matters that until recently “only God knew before” becomes not only daunting but creates burdensome moral and emotional dilemmas.² A physician-researcher carefully devises an Institutional Review Board (IRB) protocol for applications of genetic screening for children on the autism spectrum. The protocol includes both affected and neurotypical (unaffected) siblings. Despite the best of intentions, such tests often reveal surprising results. They pose agonizing ethical dilemmas for the researcher when the tests reveal that unaffected siblings also carry risk factors for autism with deletions or duplications in their genetic makeup, thereby identifying either current potential risk factors or in the future. What should researchers do with such genomic information? Since there is a strong possibility that the unaffected research subjects might pass on autism risk factors to their offspring, are they now entitled to this information? For parents who view themselves as neurotypical, would they want to know from Whole Genome Sequencing (WGS) that they have the same gene mutation as their child who is, for instance, affected by autism? What emotional

¹ تمت كتابة هذا البحث في إطار المشروع البحثي "توطين علم الجينوم في الخليج العربي: سؤال الأخلاق الطبية الإسلامية (Indigenizing Genomics in the Gulf Region (IGGR): The Missing Islamic Bioethical Discourse) القطري لرعاية البحث العلمي والمسجل برقم NPRP8-1620-6-057. علما بأن المسؤولية عن البيانات الواردة هنا تقع بالكامل على عاتق من قام بتأليف البحث.

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² Karen H. Rothenberg and Lynn W. Bush, *The Drama of Dna:Narrative Genomics* (New York: Oxford University Press, 2014), 90.

burden and trauma will such information have on these research subjects? Research reveal that families consisting of both affected and unaffected persons develop different behavioral patterns. Some offspring self-identify as being the possessors of ‘good genes’ and announce it publicly, and those who were endowed with ‘bad genes’ do the same. Are these hierarchies even productive? Should such screenings and language-use be allowed and encouraged? How does one evaluate and reach decisions on what action to take in such circumstances? Instead of engaging in a dry and academic deliberation, the dramatization of the relationships surrounding genomics, the authors state that this “creates the potential to stimulate self-reflection and new perceptions, sparking *the moral imagination* through the lens of others.”³

The Drama of DNA is divided into three parts consisting of six chapters. Chapter 1 serves as an introduction which lays out the main questions and issues with an emphasis on medical and research related drama narratives. Part One is titled *Narrative Genomics: Exploring Process in Context*. This part consists of chapters 2, 3 and 4; “Anticipating the Future: Genomic Protocols & Ethics Consultations”; “Informing the Future: The Process of Consent & Disclosure of Genomic Information”; and “Reframing and ‘Open Future’: The shifting landscape from NBS (Newborn Screening) to NBSeq (Newborn Sequencing)” respectively. Part Two is titled *Integrating Narrative Genomics: A Case Study Drama*, consisting only of chapter 5; “Reconceptualizing the Past, Present and Future”, highlighting information generated by Next-Generation Sequencing – What’s Next? Part Three is titled *Narrative Genomics on Stage: DNA, Society and Theatre*, closing with the final chapter 6; “Dramatizing the Past, Present, & Future: Theatrical Narratives from Genetics to Genomics.” References and an exhaustive bibliography completes the volume.

One of the most challenging aspects for all ethicists are the protocols of research. IRB committees have to deliberate amidst great confusion of what is an ethical obligation versus a legal duty. This is most acute when there is no personal relationship between the geneticist and the individual to be tested as opposed to, for example, the physician-patient relationship and confidentiality. However, IRB review panels expect personal investigators to act ethically; yet informed consent documents do not cover all the specifics when genomic information changes on a daily basis with all kinds of unanticipated contingencies. As one geneticist observes, “One day a particular variant or mutation for colon cancer is a significant finding, and the next it’s not.”⁴

Genetic information, when it lands in the public domain, can impact the ability of people acquiring life insurance, disability insurance and long-term care insurance. Some of the information generated through research and clinical studies, especially incidental findings, run the risk of getting into the medical records of the affected person and can negatively impact their careers and life chances. Genetic counsellors and consent documents are required to convey to participants the speculative risk of rejection by others, potential changes in identity and how the potential for

³ *Ibid.*, 18.

⁴ *Ibid.*, 41.

discrimination rises when genetic information is shared.⁵ Over the past few years, many studies revealed how genomic privacy cannot be guaranteed. For example, Whole Genome Sequencing (WGS) information can be identified despite attempts to keep it de-identified.⁶ Privacy concerns and patents on DNA sequence and sequence-derived intellectual property raise new challenges in law and ethics. For this reason, new laws have been introduced like the Genetic Information Nondiscrimination Act (GINA) in the US in order to protect information and rights.

Another important set of questions center around genomic newborn screening and newborn sequencing, how to treat such information and the security risks associated with it. How does such genomic information impact the child's "right to an open future"? A child's right to an open future comprises a set of moral rights children possess that are derived from the autonomy rights of adults. In other words, parents are restricted from making decisive life choices for their offspring prior to their children having an opportunity to make such decisions for themselves.

The most engaging and valuable aspect of the work of Rothenberg and Bush is the charming review and application of the multiple plays that were written over the past 25 years in the United States. Why interested scholars in genomic ethics should pursue this literature as a line of inquiry is eloquently and persuasively made by the authors. "Placed in historical context," Rothenberg and Bush write, "theatrical narratives provide a framework to reflect upon how the implications of emerging genetic technologies evolve over time and how attempts to control fate through genomic science have influenced — and been influenced by — personal and professional relationships. The drama of these human interactions is powerful and has the potential to generate fear, create hope, transform identity, and inspire empathy. These dramatic narratives are a vivid source to observe the complex implications of translating genomic research into clinical practice through the lens of other individuals."⁷

The existence of this valuable body of literature came as a revelation to the reviewer. A list of a few plays mentioned in the book are Jonathan Tolins, *The Twilight of the Golds: A Play in Two Acts*, 1994; Carl Djerassi, *Immaculate Misconception*, 2000; Caryl Churchill, *A Number*, 2002; Cassandra Medley, *Relativity*, 2006; Lisa Loomer, *Distracted*, 2009; Damien Atkins, *Lucy*, 2009; Sharr White, *The Other Place*, 2011; Dorothy Fortenberry, *The Good Egg*, 2011; and Paul Mullin, *The Sequence*, 2012. Each one of these plays reveal a complex ethical and moral dilemma related to genomics, human sexuality and the wonders and challenges of techno-science in one way or another. "The drama of these human interactions is powerful and has the potential to generate fear, create hope, transform identity, and inspire empathy," the authors write. "These dramatic narratives are a vivid source to observe the complex implications of translating genomic research

⁵ *Ibid.*, 36.

⁶ *Ibid.*, 29.

⁷ *Ibid.*, 83.

into clinical practice through the lens of other individuals.”⁸

Each of these plays bring to life many of the ethical and societal concerns we still face today. Genomic science has much to do with emerging technologies and the information this field generates to decide the future of humankind. One of the ongoing challenges that remain is how to modulate the “scientific imperative” and, if possible, on what grounds? Why do inherited ethical and moral traditions necessarily find themselves in tension and antagonism with the scientific imperative? Each of these dramatic expressions make us aware of the extent to which scientific innovations will alter human and social relationships. Furthermore, they do indeed drive home, in dramatic fashion, the impact of genetic manipulation on individual, familial, and cultural identities.⁹

Critical Evaluation

What this book strongly establishes is the diagnostic odyssey manufactured by emerging technologies and with it come entire domains of contingency. Contingency suggests that domains of certainty, tried and tested practices and theoretical conceptions of the sphere of bioethics have to be entirely revisited. Consider the case of a family with bipolar disorder, where an affected father after years of suffering committed suicide. The brother, Matt, who like his father also has bipolar disorder, in Dorothy Fortenberry’s *The Good Egg*, objects to his sister Meg’s decision to subject her embryos to genetic diagnosis for bipolar disorder, since she wishes to become pregnant through assisted reproductive technology. She hopes to have her embryos tested in order to eliminate heritable bipolar disorder. Matt vehemently objects and addresses Meg: “You are genetically editing me from the code of who we are. You’re eliminating me and you’re eliminating Dad.” Meg, too, has her own dilemmas. She thought of calling off the test several times. “I thought about it, calling up to cancel,” she says, “... but I couldn’t do it. I couldn’t handle the thought, the guilt of saying to a child ‘I could have prevented your feeling this way, but I chose not to’.”¹⁰ In other words, Meg now had knowledge that she could prevent the bipolar disorder from being transmitted to her offspring. Her offspring would possibly have known that detection technologies were available and would have worried why their mother did not prevent them from a debilitating yet preventable illness.

Given the relationship of medical technology with our bodies, an entirely new dimension of ethics is opened to us. A technologically-driven moral imperative is created at the intersection of the body, technology and genetic information. The ethical subject, like Meg, now has a sense of “reproductive accountability” unavailable to her in this manner prior to genetic technology. Now, Meg’s wavering is ended by the information and the medical intervention to provide her with a

⁸ Ibid.

⁹ Ibid., 86.

¹⁰ Ibid., 261.

bipolar gene-free embryo. The potential of ‘being’ to constantly unveil itself in a technological age is something Martin Heidegger pointed to in his essay on technology. Meg’s personal experiences in a family with bipolar disorder and the suicide of her father have produced powerful emotions, sentiments and experiences within her subjectivity to render it almost natural, if not imperative, for her to take advantage of reproductive accountability. This is in line with the thinking of the child’s right to an open future in one sense. However, what if the child grows up and wishes that he or she had something in common with their ancestors in terms of inheritable traits and genes? Does this new ethical norm of “reproductive accountability” actually put sufficient distance between eugenics and genomic science? This requires a great deal of reflection for which there are no easy answers.

Francis Collins, a pioneer of genomic science, appears as a fictional character in Paul Mullin’s play *The Sequence*. He makes an interesting comment which requires some background explanation for people who are not familiar with American popular culture. Collins makes a comment about Woody Guthrie who is an American folk hero and a singer-song writer but who also suffered from Huntington’s disease. In the play, the fictional Collins remarks: “[W]henever I or colleagues of mine get a little too self-congratulatory about the benefits of genetics, I think of Woody Guthrie.... See Woody had Huntington’s disease. One of those few diseases that genetics can predict with absolute certainty.... Genetic pathology is rarely clear-cut, but when it is, it can be merciless. And it leaves us with a kind of brutal question: once you begin to know a little bit what God knows, do you act on that limited knowledge? Do you abort Woody Guthrie?”¹¹

If anything, what this book makes abundantly clear is the growing importance of careful and advanced genetic counselling. This is an underdeveloped area and ought to be cross-pollinated with psychology and psychiatry. This aspect is not only a major component of genomics research, but it is imperative to the future and promise of genetic science. Beside bioethics growing in complexity, genetic counselling is going to be an even greater challenge.

Relevance to the IGGR Project

Besides the aspects of greater complexity in bioethics which will have to be explored, tested and devised within Muslim cultural contexts with special reference to the Gulf, what this book has forcefully highlighted is something often overlooked in Muslim contexts; the role of the moral imagination through fiction. I am unaware of the ways in which writers, novelists, poets, playwrights, readers and audiences in Muslim contexts have explored and received such difficult, baffling and yet necessary technologies and remedies in their specific contexts through the arts and literature as expressive discourses of moral imagination. The moral imagination in some ways precede both the technology and the application of this technology. Moral imagination implies that

¹¹ Ibid., 89.

our conceptions of morality or moral understandings are metaphorical and imaginatively structured. As Mark Johnson points out, our primary forms of moral imagination are concepts with prototype structure, semantic frames, conceptual metaphors, and narratives.¹² Genetic science makes us quickly realize that the pre-articulated forms of morality and ethics we had cultivated are hardly applicable. We are in an entire grey zone. Hence, as Johnson points out, we will do well to give up the illusion of absolute moral values and of radical moral subjectivism. From here, one will have to think of what is changing in moral understanding. In addition, one will have to encounter changes in the conception of moral development. This means that instead of looking for ethical, moral and juristic — *adab, akhlāq and fiqh/sharī'a* — solutions to find ethical and moral solutions, we would do well to dedicate attention to “refining our perception of character and situations and of developing empathetic imagination to take up the part of others,” writes Johnson.¹³

In pursuit of refining the moral imagination within specific Gulf contexts, it might be an idea to undertake a survey of Gulf literature — novels and plays — to see if literary figures are probing the moral imagination in narrative and through persistent questioning. If there is a dearth of such literature, then it might be an idea to adapt some of the existing American plays listed in this review to Arabic-speaking settings. If these could be performed in theaters and television dramas while monitoring and documenting the audience’s reaction, this will be an important step in expanding the moral imagination. Surely, this approach will clash with the doctrinaire absolutist understandings of moral reasoning, but even the latter is unable to address the challenges that new technological innovations are bringing to the field of bioethics. A new approach might provoke a range of possibilities in thinking. In a novel by Mohammed Achaari (Muḥammad al-Ash‘arī), *The Arch and the Butterfly (al-Qaws wa’l-Farāsha)*, there is a mention of DNA testing for someone with unknown paternity. The theme is never fully developed in the novel but this is one indication of how the scientific imagination might be entering into the everyday discourse and lived experiences of the Muslim people. There might be existing literature that explores this theme with greater complexity, and if it is available, then an inventory as well as close studies on how the moral imaginary is explored in this literature will make a major contribution to narrative bioethics.

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Johnson, Mark. *Moral Imagination: Implications of Cognitive Science for Ethics*. Chicago & London: The University of Chicago Press, 1993.

¹² Mark Johnson, *Moral Imagination: Implications of Cognitive Science for Ethics* (Chicago & London: The University of Chicago Press, 1993), 198.

¹³ *Ibid.*, 199.

Rothenberg, Karen H., and Lynn W. Bush. *The Drama of Dna:Narrative Genomics*. New York: Oxford University Press, 2014.