

Genes and plays: bringing ELSI issues to life

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Ethical complexities surround the promise of genomic technology and the power of genetic information as they alter conceptions of identity and dynamics within personal and professional relationships. Creative approaches such as dramatic vignettes offer a unique analytical stage for imagining the bioethical past and future. Dramatic narratives can bring to life images of differing perspectives and values when experiencing innovations in medicine. Although the scientific landscape shifts, concerns expressed in theatre from 50 years ago parallel many contemporary ELSI (ethical, legal, and social implications) issues, highlighting the ongoing struggle to appreciate the impact of emerging genetic technologies on relationships. To illuminate these

enduring concerns, we explore how perceptions and relationships have influenced—and been influenced by—genetics as portrayed through dramatic vignettes. We build on the legacy of using case vignettes as a clinical teaching modality, and believe similar value exists within the research ethics domain. The selection of dialogue discussed encompasses abbreviated excerpts from two existing and one original vignette that we staged at the ELSI 2011 Congress and various academic and health institutions.

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INTRODUCTION

Ethical complexities surround the promise of genomic technology and the power of genetic information,^{1–5} as they alter conceptions of identity and dynamics within personal and professional relationships. Creative approaches such as dramatic vignettes offer a unique analytical stage for imagining the bioethical past and future.

Theatrical narratives can illuminate both complementary and disparate views,⁶ bringing to life images^{7–9} of often conflicting experiences and perspectives when encountering new genetic technology and information. Although the scientific landscape shifts, concerns expressed in theatre from 50 years ago parallel many contemporary ELSI (ethical, legal, and social implications) issues, including the ongoing struggle to appreciate the impact of emerging genetic technologies on relationships. Therefore, to enhance our current discourse on these enduring concerns as we translate genomic innovations from “base pairs to bedside,”^{10,11} we have found it useful to reflect on their constancy by exploring how perceptions and relationships have shaped—and been shaped by—genetics as portrayed through three dramatic vignettes spanning half a century.

We build on the legacy of using case vignettes as a clinical teaching modality, to facilitate empathy (through film,^{12,13} plays,^{13–19} television,^{20,21} literature,^{22,23} narrative prose,²⁴) or bring to life legal controversies,²⁵ and believe similar value exists within the research ethics domain. The selection of dialogue (below) encompasses abbreviated excerpts from two existing and one original vignette that we have staged at various academic and health institutions over a 2-year period as part of our comprehensive bioethics project, *Innovations in*

Medicine & Imagery in Theatre. Varying lengths and combinations of dialogue were briefly rehearsed, enacted, and witnessed by groups that included bioethicists, geneticists, genetic counselors, policy makers, and students at the ELSI 2011 Congress (held in Chapel Hill, North Carolina, 11–14 April 2011), National Human Genome Research Institute, Columbia University, and University of Maryland Francis King Carey School of Law.

Session notes with near-verbatim quotes from volunteer actors and the audience at the ELSI Congress parallel many responses elicited when our dramatic vignettes have been performed elsewhere. We selected both past and current dialogue representing a small sample of possibilities that illuminate affective responses within personal and professional relationships to genomic technology with contrasting contextual subtleties.

Although celebrated as a play about dysfunctional marital relationships, Edward Albee's 1962 *Who's Afraid of Virginia Woolf*²⁶ also directly addresses many societal concerns raised by the threat of genetic manipulation and its implications for future generations. Set on a college campus, George and Martha are at their home getting acquainted with a young science professor and his wife:

GEORGE: Martha says you're in the Math Department . . .
NICK: I'm a biologist. I'm in the Biology Department.
GEORGE: You're the one's going to make all that trouble . . . making everyone the same, rearranging the chromosomes, or whatever it is. Isn't that right?
NICK: Not exactly: chromosomes.

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GEORGE: . . . do you believe that people learn nothing from history? Not that there is nothing to learn, mind you, but that people learn nothing? I am in the History Department . . . Biology, hunh? I read somewhere that science fiction is really not fiction at all . . . that you people are rearranging my genes . . . [later in dialogue]

MARTHA: (*To Nick*) Georgie-boy here says you're terrifying. Why are you terrifying? . . .

HONEY: It's because of your chromosomes, dear . . .

GEORGE: . . . Martha, this young man is working on a system whereby chromosomes can be altered . . . the genetic makeup of a sperm cell changed, reordered . . . to order, actually . . . for hair and eye color, stature . . . I imagine . . . and mind . . . All imbalances will be corrected, sifted out . . . We will have a race of men . . . test-tube-bred . . . incubator-born . . . superb and sublime . . . But of course there will be a dank side to it, too.

NICK: (*Grimly*) Now look! . . .

Much as contemporary CP Snow espoused in his *The Two Cultures and the Scientific Revolution*²⁷ regarding the differing values and perspectives of the Sciences and the Humanities, Albee is exploring the disharmony surrounding the biologist who creates and manipulates the future and the historian who reflects on the past as prologue. Their perceptions and presumptions about balancing the risks and benefits of genetic manipulation reflect the dichotomy of their worldviews. In a recent staging of this vignette at a National Human Genome Research Institute forum, a genomics researcher playing Nick shared his frustration with George's character, reflecting that this is how some scientists may feel when questioned by the bioethics community.

Albee's carefully crafted dialogue brings to life the persistence of concerns we still face today—the fear of genetic innovations transforming human relationships and individual, familial, and cultural identities. While contemporary ELSI issues echo debates of an earlier time as society continues to search for biological explanations and solutions, these persistent challenges emerge with increasing frequency as genomic advances generate more and more information.²⁸ For example, assessing the promises and perils of medical innovations are rendered more complex when these assessments depend on definitions of what is “normal.” Drama that expresses our hopes for a world free of disease and our fears for life devoid of human individuality²⁹ provides insight into who will and should determine whether a given heritable trait is good or bad enough to be subject to genetic manipulation.

Reflecting the recent acceleration of scientific technologies, Dorothy Fortenberry's 2010 *The Good Egg*³⁰ examines how preimplantation genetic diagnosis holds out the theoretical possibility for preventing the heritable transmission of bipolar disease, and dramatizes potential ethical and psychological ramifications on relationships. The tension in this play revolves

around Meg, a single woman who wants to preselect “healthy” eggs with assisted reproductive technology—supported and encouraged by her gynecologist Adrianna (unseen though referenced throughout)—and Meg's brother Matt, who resides with her and is diagnosed as bipolar, just like their dad who committed suicide:

MEG: It's a really routine procedure . . . To check for disease, abnormality, to make sure the baby's healthy and normal and—

MATT: Not bipolar . . . You didn't think I'd find out? You said they were checking for diseases—

MEG: And they are. For Huntington's and Parkinson's and Alzheimer's and MS and—

MATT: Me?

MEG: It's a new test. They just located the genes recently, and—

MATT: You're taking advantage of the technology. It's on the Metropolitan Fertility website . . . Like “New! Improved! Now with no bipolar!” . . .

MEG: It is a totally routine, common thing to do, just to be on the safe side. I like the safe side. That's all it is.

MATT: Um, no, it's rifling through a selection of babies—fine, fine of embryos—and then choosing your favorite, which is totally weird and gross and disgusting.

MEG: It didn't disgust you when I told you they were screening for Down syndrome.

MATT: That's different.

MEG: How? (He can't say.) . . . [later in dialogue]

MATT: . . . You are trying to delete me from our family. You are genetically editing me from the code of who we are. You're eliminating me and you're eliminating Dad.

The dialogue highlights an inherent moral challenge—the explicit predetermination of what type of child a person would be willing to parent—which, in this scenario, ultimately threatens Meg's relationship with her brother. The tension between the utilization of these cutting-edge technologies and the value-laden choices these innovations create raise dilemmas for individuals, families, the medical community, and society regarding limits on technologies that have the potential to change the fate of others. Dramatic vignettes can illuminate the implications for such choices to alter someone's future because of a perceived lack of normalcy, and the contentious disagreements that could arise if family members or others in society can be “deleted.”

Different judgments about “what is normal” are shaped by our experiences and cultural expectations, which directly impact how we frame our identities and those of others. In turn, these perceptions color our presumptions about the power of science and technology to control our destiny. Despite Matt's strong feelings, Meg was adamant in her beliefs that the use of these innovative technologies would provide the path to a better place.

In response to enacting this vignette, a National Human Genome Research Institute science educator remarked that even though she has never been pregnant, she felt an enormous sense of responsibility to do the “right thing”—although she was uncertain what that might be. Several researchers and social scientists witnessing the dialogue spoke of a moral conundrum: “Why was a Down’s test OK for Matt when he was so adamantly opposed to bipolar?” One noted that this vignette raised awareness of “the need to be sensitive to different views that folks have about what they are willing to parent” and another commented to be “cautious not to make value judgments about others.” In a subsequent staging, bioethics students remarked that witnessing the deteriorating relationship of the siblings brought to life the gravity of differing views on accessing emerging technologies. A science professor pointed out that acting and watching the parts in drama—experienced from a sufficient distance apart from one’s self—allowed for a “safer” discussion of the emotional and controversial issues underlying the judgments raised in *The Good Egg*.

While *The Good Egg* offers an opportunity to observe implications of cutting-edge technology in clinical practice, *It’s Not That Simple!*³¹ (Supplementary Data online)—the first in our series of original dramatic vignettes—turns to the emerging ethical challenges raised by next-generation sequencing. It illuminates the real challenges of informed consent for genomic research and sharing genetic information among family members, each with different values, and illustrates the difficulties that may arise from the multidimensional roles of the physician/researcher/geneticist through our character Dr Hardy:

DR HARDY: In fact the reason I gathered you all here today is that I have some good news. We now have a better chance to understand what’s causing your disorder—and you can be part of a new study . . .

The dynamics of this play further revolve around the Friedman family—Mom, 19-year-old Bobby and 16-year-old Amy (both with an autosomal recessive disorder), and 9-year-old Sam—as they discover and ponder the many questions raised for each of them in deciding the amount of information they want to receive after being sent home by Dr Hardy to read the informed consent form:

BOBBY: But what if Amy wants to know everything and you don’t, and it turns out both you guys have something like the *BRCA* gene you hear about so much? And what about Sam?

SAM: Don’t worry about me. I’m the healthy kid in the family.

AMY: Of course I’d want to know everything—we’d all want to know.

MOM: Don’t jump to any conclusions Amy . . . you can’t speak for the whole family . . . I would not want any

of us to know if something bad is going to happen way into the future . . .

AMY: The consent form also said something about our relatives learning results.

MOM: My relatives? . . . If the doctors find something, I’ll just keep it a secret.

BOBBY: A secret? You’re terrible at keeping secrets, Mom.

AMY: That nice genetic counselor can always tell Aunt Rachel and Aunt Sarah.

MOM: They don’t need to know anything . . .

AMY: Mom, just sign the paper and keep it simple, please.

MOM: *It’s Not That Simple!*

Following performance of this 15-minute vignette at the ELSI Congress and elsewhere, we encouraged discussion among actors and the audience. We found that our dramatic vignette helped to generate many questions about the implications of genome research on familial and professional relationships. For example, one bioethicist queried, “How would the relationship between the Friedman family and Dr Hardy be different if he or she were their regular physician as well as the PI, and would that create a therapeutic misconception?”, while another asked, “How does the amount of trust in Dr Hardy impact on the informed consent process?” Several physician-scientists concurred when their colleague commented that the play’s dialogue contributed to their “better understanding” of how professionals “feel about the [informed consent] process when talking with families.”

Many found their role challenging, exacting an emotional toll in weighing the varying interests and concerns of the family unit engaged in genomic research, including the younger child who appears not to be affected by the disorder. They remarked that the play “heightened awareness” of their responsibility to address the complexity of unique ethical and psychological developmental issues when research involves vulnerable populations such as children, either as direct participants or indirectly due to family relations. Near-verbatim session notes from the ELSI Congress reporter highlighted that the play brought to life “the responsibility of parents to try to figure these issues out for your family [when] they have ideas of their own.” There was recognition of “the perspective of the ‘healthy kid’ who is going to be victimized one way or another. But he’s not an adult, so he can’t control his own destiny.”

The dramatic vignette also stimulated reactions of frustration: “I thought the best part of the play was when they were reading the informed consent form because it helped me to understand how absurd they are . . . if you could do a dramatic reading of an informed consent form for people who actually make and do informed consent, it could be very effective.”

Our experiences using dialogue from existing theatre and our dramatic vignette suggest that this creative approach has value as a resource for fostering new perspectives with interdisciplinary groups.³² One of the ethicists participating at the Congress expressed that “plays are very powerful and can be very effective

at educating and getting professionals to think as well. It can imprint on people the emotional content of the things we do.” As a geneticist who “acted” the part of Bobby at our ELSI session reflected, “Playing a role forces you to think about things from a different perspective. Playing a surly 19 year old makes you think about the context of someone who’s really facing those issues and how it is different from our academic perspective.”

We welcome our colleagues to collaborate with us in the use of dramatic vignettes and evaluate their impact. Our goal is to facilitate greater insight and discourse surrounding the implications of genomic research on personal and professional relationships. The complexity of contemporary ELSI issues are brought to life through dramatic vignettes—“just because it is not our life, places us in a moral position that is favorable for perception and it shows us what it would be like to take up that position in life.”³³ Our experiences suggest that when the drama of human relationships surrounding genetics are enacted by the scientific, bioethical, and policy-making communities, the dialogues create the potential to stimulate self-reflection and new perceptions about their own roles as well—sparking “the moral imagination”³⁴ through the lens of others.

SUPPLEMENTARY MATERIAL

Supplementary material is linked to the online version of the paper at <http://www.nature.com/gim>

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DISCLOSURE

The authors declare no conflict of interest.

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