Genetic Literacy: How will we teach students to "Read the code"?

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Abstract

Building upon the existing scholarship on genetic literacy this paper offers a framework for genetic literacy that works at the intersections of culture and science, to help students at different levels build an approach to genetic information that takes into consideration the complexity and contingency of genetic knowledge. This paper will begin with a brief history of genetics, discuss the social and cultural implications of genetic knowledge, and conclude by making a case for genetics knowledge as a growing body of information and implication worthy of consideration as a literacy.

Introduction

In the wake of the eugenics movement[1], medical genetics rose in the second half of the 20th century. The history of genetics, however, begins in the mid 19th century with the publication of Mendel's "Experiments on Plant Hybridization" that demonstrated the heredity of dominant and recessive genes in pea plants (Mendel, Corcos, & Monaghan, 1993). In the first half of the 20th century Mendel's work was rediscovered and influenced the medical professions and social movements like eugenics. For example, during this period heredity was a common way for doctors to diagnose medical conditions (Rushton, 1994). After the Second World War medical genetics took shape as a distinct discipline with the development of new institutions, screening techniques, and treatments that transformed genetics from a marginalized subject in medical training to a cornerstone of professional medicine. It wasn't until the advent of the human genome project in 1990, however, that scientists were able to associate specific genes with certain physical, emotional, and cognitive characteristics (Harper, 2008). In 2003 the map of the human genome was completed and the work of matching different characteristic to the 20,000-25,000 genes discovered began.

In a parallel process to uncovering the characteristics of specific genes scientists (and later industry) began applying genetic knowledge to clone and modify the genetic characteristics of both plants and animals. The modern era of laboratory cloning began in 1958 when the physiologist Frederick C. Steward cloned carrot plants. The first genetically modified food, herbicide-resistant soybeans, was brought to market in the

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[1] Eugenics was the misguided and harmful social movement that tried to improve human capabilities and capacities by eliminating what were perceived as human genetic defects through coercive tactics that included, among other things, the control over human reproductive practices.

1990s. The first animal to be cloned was a tadpole in 1952 and the first cloned mammal was the famous sheep Dolly in 1996.

Social and Cultural Implications of Genetic Knowledge

The decoding and mass storage of the genetic codes of plants and animals along with the capacity to manipulate those codes has brought about a number of social and cultural shifts the implications of which are just beginning to be understood.

On October 7th, 2007 60 minutes broadcast a segment titled "Roots" that addressed how genetic testing companies, like African Ancestry in Washington, DC, with genetic databases are offering African Americans the opportunity to find their ancestral roots in Africa (Stahl, 2007). The segment focused on an African American woman from Harlem, Vy Higginsen. As she explores her genetic ancestry, the results of three different genetic testing companies are revealed to her. Each company provides her with different lineages in Africa from different regions and tribes. Her elation at learning her roots after the first test turns into frustration and confusion as each new set of results are given to her by the segment host, Leslie Stahl.

As a diasporic group, African Americans who descended from slaves typically cannot reconstruct their ancestral history beyond the past three or four generations because there are often no public records beyond those kept by the slave owner. The technology of genetics offers a way to create a history that wouldn't otherwise be possible to construct. Yet the complexities of heredity and migration, along with the relative early development of this technology complicate the desire of many African American's to trace their history (Dula, Royal, & Secundy, 2003; Rotimi, 2003). Often histories are revealed that may be difficult to reconcile including the estimate that up to 30% of

African Americans have a European male in their lineage as a result of slave owners raping their slaves (Willing, 2006).

In 2006, PBS broadcast a series titled "African American Lives", hosted by Henry Louis Gates, Jr (PBS, 2006) with a follow-up in 2008 with "African American Lives" 2 (PBS, 2008). In each of the series using DNA testing and genealogical research to trace the ancestry of a famous living African American. Some of the individuals included the author and poet Maya Angelou, actor Morgan Freeman, comedian Chris Rock, talk show host Oprah Winfrey, and singer Tina Turner. As in the 60 minutes episodes each person profiled is surprised, thrilled, confused, and at times saddened by the results. Actor Don Cheadle discovers that Native Americans enslaved his ancestors. Host, Professor Gates learns of his Irish roots as a descendent of an Irish king, Niall of the Nine Hostages. Gates went on to write about the process of finding Oprah Winfrey's roots and in general the possibilities and pitfalls of genealogical tracing for African Americans (Gates, 2007).

Three years after the "Roots" segment, 60 minutes broadcast another story titled "Patented Genes" which examines a court case in which the ACLU challenged the patent on human genes, of which, there are over 10,000 patents (Safer, 2010). In 1980 the supreme courts ruled that a life form, a genetically modified bacterium, could be patented. Whoever owns the gene, owns any mutations, and also owns treatments. Myriad, a firm that discovered the breast cancer gene is the only company that can test for that gene in the US at a cost of $3200. In other countries that do not honor these patents the test is considerably less money and can be done for under $300. The ACLU won the case against Myriad who is appealing the decision.

The technology of genetics is raising numerous questions in addition to those around racial identity including those related to healthcare about what the underlying code reveals and who owns that code. Women who have the genetic markers for certain types of cancers are undergoing prophylactic mastectomies and hysterectomies. The full impact of genetic technology and its influence on human knowledge, social systems, and identity will unfold in the coming decades.

The psychologist, Steven Pinker (2009) observes that humans are prone to essentialize genetic information which gives them a reason to justify certain tendencies in their personalities. He argues that genes cannot directly impact behavior, but they create the wiring and operations of the mind that impact our curiosities, securities, aptitudes, empathies, and ambitions. Pinkart notes that the behavioral geneticist Eric Turkheimer found that all human variation can be attributed to genes but that culture does play a roll in how things turn out (Turkheimer, 2000). Judith Rich Harris has asserted that the environment gives us the options to which our genes respond (Harris, 2006). Pinkart concludes that genes will never offer a direct map of temperament and personality because of the influence of environmental factors on genetic characteristics.

The emerging field of epigenetics studies how environmental factors contribute to the expression of genes. Epigeneticists have found non-DNA inheritance between organisms and cells. Genes can be turned off and on as a result of environmental factors. This has altered or amended the theory of evolution. For example, it lays credence to the work of Jean-Baptiste Lamarck whose published research on evolution predated Darwin's research and argued that evolution is influenced in part by inherited traits. His classic example is his hypothesis that giraffes developed longer necks by stretching to reach higher trees and then passing along the stretched neck to subsequent generations, each generation passing along a slightly elongated neck (Lamarck, 1963).

As this section begins to reveal, the interplay between scientific knowledge and the perceived certainty around it, and cultural factors create a complex matrix of variables that individuals must weigh and unpack when processing the various sources of genetic information that they may encounter and perhaps pursue in their life. In the following section, I begin to make a case for a broad approach to genetics in the curriculum that takes into consideration this complex matrix.

Genetic Literacy and the Curriculum

In the 21st century, an increasing number of children will be born with their parents knowing their physical, intellectual, and emotional tendencies based on some interpretation of their genetic makeup. For example, a New York Times article reported on a genetic test that claims to identify an individual's athletic potential (Macur, 2008). The article mentions Atlas Sports Genetics (http://www.atlasgene.com/), a company that sells a $149 test that promises a profile of someone's athletic capacity. The test detects one gene ACTN3 that has been linked to different kinds of athletic abilities. While the connections between the gene and athletic ability are contested, parents are using this test to see if their child has the potential to be a professional athlete or earn an athletic scholarship to college. This test is just one of a growing number of tests that are and will be offered to identify cognitive, emotional, and physical profiles of children. The genetic knowledge that parents bring to this information will have implications for what they do with this information. More specifically, parents' and educators' interpretations of this information will have a large impact on the expectations that they bring to educational institutions and individual students and groups. Tremendous problems arise when these expectations are grounded in widespread misunderstandings of genetics which permeate society (Molster, Charles, Samanek, & O'Leary, 2009).

For example, immigration officials in the UK are using genetic testing on African asylum seekers in an effort to catch those who are lying about their nationality. A number of scientists in the UK have criticized the program as based on bad science (Travis, 2009). In another instance multiple states including Texas, Michigan, and Minnesota are storing genetic information from newborn children, often without parents consent, that can be linked back to individuals (Stein, 2009). Understanding these practices and responding to them as informed citizens in democratic societies will require new types of literacy.

Current State of Genetic Literacy

Recent research shows that adult's knowledge of genetics is often limited (Haga, 2006). Lanie et al., (2004) found that only 34% of the adults that they surveyed across the US alluded to the knowledge that genes are located in every cell, 24% incorrectly stated that the brain was the main location of human genes, and a mere 14% mentioned genes in association with DNA or chromosomes. These are all fundamental (mis)understandings of genetics that must be mastered in order to comprehend more complex genetic concepts including genetic testing; genetic manipulation in plants, animals, and humans; and gene therapy.

A study of adults in western Australia found that most respondents understand the basic links between genes, inheritance and risk of disease, but significantly fewer understood the biological mechanisms driving these concepts (Molster, et al., 2009).

Around 1 in 5 of those surveyed incorrectly indicated heart disease, cancer, and high blood pressure were either all genetic or all environmental influences. A similar proportion misunderstood the meaning of genetic susceptibility to disease and the interplay between lifestyle and genotype, over-emphasizing the role of genetics. The evidence of this study shows people develop situated understandings of genetics through experience, which can impact upon genetic-related decisions and actions.

There have been few attempts to address genetic literacy from a larger social and cultural context. Jennings (2004) has developed one model of genetic literacy that tries to take into account the potential for genetics to bring on new forms of discrimination and domination. He notes, "genetic literacy may require, as its complement and supplement, some new forms of genetic citizenship. (p. 39)". Jennings first identifies what has been the predominant approach to genetic literacy, the public health model in which informed, prudent consumers of genetic services keep with the mission of public health. He then goes on to define a broader notion of genetic literacy through a democratic model that considers two forms of citizenship that genetic literacy will enable and empower people to practice: deliberative citizenship and informed consumerism. The democratic model of genetic literacy that he proposes will help to answer the following questions: (1) what are the nature and effects of genetic knowledge? (2) what constitutes legitimate social control of genetic knowledge in a democracy? and (3) what are the prerequisites for, and conditions of, social and moral learning about genetics in a diverse, pluralistic society?

While Jennings paper raises some important issues around genetic literacy, it only offers a general sense of what a more broad based genetic literacy might look like and does not address the specific form a genetic literacy curriculum might take. A logical next step that builds upon the existing scholarship on genetic literacy would be to offer more detailed theorizing and suggestions for educators to debate.

Definitions of literacy have focused on both educational (e.g., reading and writing) and sociological/economic (e.g., being able to function in society) perspectives. A definition that combines both perspectives was suggested by Hillerich who said that: "Literacy is that demonstrated competence in communication skills which enables the individual to function, appropriate to his [or her] age, independently in his [or her] society and with a potential for movement in that society (Hillerich, 1976, p. 53)." This project takes this dualistic approach to literacy. Therefore, if we define literacy as both the ability to understand one's needs and interests and the power to act, to protect, and promote those needs and interests then it makes sense to treat genetics as a unique area of literacy.

Toward a Model of Genetic Literacy

For this project I define genetic literacy as ***the capacity to apply relevant STEM knowledge in order to make well-reasoned and scientifically grounded decisions about personal and social problems that genetics can address and create***. The specific competencies associated with genetic literacy include:

- A basic understanding of genetic mechanisms in plants, animals, and humans.
- The capacity to think through the environmental, physical, social and cultural impacts of genetic understanding and manipulation on individuals, the environment and social groups based on ethnicity, class, race, gender.

- The ability to act on the assessment of theses impacts based on principles that take into consideration personal, social, and environmental well being.

Guided by Jennings model, I will draw upon existing research about genetic knowledge and underreprestended groups to offer an approach to genetic literacy that takes into consideration the diverse needs and perspectives of groups who are often left out of technical discourses. For example, Roter, Erby, Larson, & Ellington (2009) found that patients with restricted literacy (below 8th grade level) could better understand genetics-related information when it was provided with greater dialogue interactivity and more personally contextualized information. Lewis (2004) concluded that it's important to consider students' everyday views to help address the misconceptions that students have about the genotypic and phenotypic expression of genes. Looking at 9-15 year olds' ontological and epistemological conceptions of genetics Venville, Gribble, & Donovan (2005) concluded that students' (mis)perceptions about genetics are strongly based on their cultural origins and mass media representations and depictions.

Building a Genetic Literacy Curriclum

As I mentioned in the previous section I am arguing that genetic literacy should have three main components: STEM knowledge, the capacity to think through different levels of social and personal concerns, and the knowledge to act on assessments of these different levels of social concern. In the following sections I outline a broad approach to genetic literacy focusing on these three components.

STEM Knowledge

There has been a great deal of public discourse and educational priorities given to the constellation of subjects known as STEM: Science, Technology, Engineering, and

Mathematics. This collection of subjects has been promoted as the key to the economic and social future of advanced nations. All four of these areas have implications for genetic literacy.

As shown in some of the examples from the previous section scientific knowledge about genetics is an evolving body of information. As this knowledge changes through different fields like epigenetics, it is important that genetics education from the earliest levels is not taught as a static body of knowledge. Instead a genetics science curriculum should instill a curiosity in students in which students question the assumptions under which scientific knowledge about genetics is based. The jump between Mendelian genetics and ideas about inheritance based on the study of peas does not easily translate to more complex organisms where interactions between genes and the environment contribute to the manifestation of genetic phenotypes and genotypes. An important aspect of teaching genetics is the use of probability to study inheritance, a topic that typically falls into the domain of mathematics.

Teacher's knowledge of teaching probability is considered lacking. Greer and Mukhopadhyay's (2005) went so for as to characterize the instruction of probability as "impoverished." Genetics is one area to enliven probability instruction. As students' knowledge of genetics and probability becomes more sophisticated they can more accurately explore the interactions between genes, genetic expression, and environmental factors.

Engineering is an applied field in which technical knowledge (e.g., about materials, electronics, computer software, etc.) is put to use to solve a design problem, often resulting in a product to be sold. The field has acquired a number of stereotypes that have limited its attractiveness to diverse populations based on gender and race (Heyman, Martyna, & Bhatia, 2002). Even for those who begin to study engineering, the retention of underrepresented groups in undergraduate engineering programs has been limited (Felder, Felder, Mauney, Charles E. Hamrin, & Dietz, 1995). This lack of diversity has the potential to lead to a monoculture where stereotypes persist, attitudes about what makes interesting design problems vary little, and approaches to design processes do not change. Engineers will play an important role as societies forge into a genetic future. Genetic engineers will look at genetic design questions based on the role and responsibilities to which they believe an engineer should adhere. The identity of an engineer does not, however, begin to be forged at the beginning of their professional training program. It starts from the earliest part of their education when they learn what engineers do. Thinking about how a curriculum teaches about the roles and responsibilities of engineers and scientist should be a central concern for a genetic literacy curriculum.

Technologies are never neutral tools. They shape the experiences of the people that they touch in both anticipated and unanticipated ways. For example, different transportation technologies like airplanes have made various aspects of a globalized world possible by making geography less of a limitation in conducting human affairs. However, they also bring about many consequences to that convenience including a dependence on fossil fuels and pollution, to name a few. As individuals are taught about technology throughout their educational experiences, it is vital that students are able to critically analyze the impact of a technology, whether it be a genetic test for a particular physical or cognitive characteristic or a genetic health intervention that makes it possible to alter one's genetic probabilities.

Social Assessment

Assessing the implications of genetics-related issues is multi-tiered. The impacts of genetic technologies or policies are always both personal and social. A return to Jennings democratic model of genetic literacy may be helpful to unpack the consequences of genetic knowledge and policies. If you recall he proposes that individuals are able to answer the following questions: (1) what are the nature and effects of genetic knowledge? (2) what constitutes legitimate social control of genetic knowledge in a democracy? and (3) what are the prerequisites for, and conditions of, social and moral learning about genetics in a diverse, pluralistic society?

The first question asks citizens to look at two aspects of genetic knowledge, the nature and effects. The nature of knowledge is often framed as scientific and therefore objective. This is clearly not the case. The results of any study or application of scientific knolwedge have limitations and contingencies. When citizens frame genetic knowledge as limited and contingent, they begin at a starting point of questioning, rather than uncritical acceptance. The effects of knowledge are always both personal and social affecting some subset of society. Asking about effects of knowledge requires an individual to think about themselves in relation to groups with which they might not have an affinity. For example consider the UK example in which databases of genetic information was used by immigration officials. Such a policy may not impact a citizen of a country, however, it is important that they see the application of this type of knowledge not only on the people that it impacts, but even more broadly about the precedents that this type of policy establishes about the application of genetic testing.

The second question Jennings asks relates to the control of knowledge about genetics. As I mentioned previously, governments have stored citizen's genetic information without their knowledge or consent. What rights do individuals have about the control of their unique genetic fingerprint and profile? What is the balance of individual rights and the public good? Storing individual genetic information may be very helpful for the purposes of disease control and solving crimes, however, where is the line drawn when that information will be used for particular types of profiling where someone's probabilities are high in regard to particular types of behaviors, diseases, or physical characteristics. The answers are not easy, but the questions are important to ask.

Jennings final question points to the processes that some must engage with in order to answer the previous two questions. He asks, "what are the prerequisites for, and conditions of, social and moral learning about genetics in a diverse, pluralistic society". If we start with the last component of this question, we begin with the context of a society that is diverse and pluralistic. He asks us to challenge the notion of a monoculture and consider all questions related to genetic literacy in relation to a society that has many viewpoints that may not agree. After establishing this context, he posses the following challenges, "What are the prerequisites for social and moral learning about genetics and what are the conditions for social and moral learning about genetics?"

Part one of this question asks what must someone know in order to think socially and morally about genetics. A few things come to mind. They must have some sense of individual social responsibility. In other words, they should have some developing notion about what an individual should contribute to maintain social order. This would begin with an idea about social order and what it means to live in a just world. These are not easy questions to answer, where individuals maintain a broad spectrum of viewpoints. Part two of Jennings third question asks citizens in democracy to delimit the conditions for social and moral learning about genetics. This questions gets to the ownership of genetic information. Who has a right to this knowledge and under what circumstances? When is a person's right to know trumped by the public good and vice a versa?

The ultimate question that all of Jennings' questions come to relates to social agency and what should the individual, an institution, and a society do, if anything, once they have answered a question.

Social Agency

Social agency is the personal capacity that an individual feels to create change in a particular context. That context can be an interpersonal encounter or something broader that creates change in the conditions of multiple people. Social agency amounts to action: action to question knowledge, action to speak or be silent, action to say "yes" or "no" to a test, policy, policy, product, or finding, action to ask more questions, action to challenge long held assumptions in oneself and others; and action to convince others to participate in a coordinated action. These are just a few of the types of behaviors associated with agency. There are various personal and cultural factors that contribute to a sense of agency. By including agency as a component of a genetic literacy curriculum, educators will provide students with the desire and belief to put the knowledge that they gain about genetics to use in ways that integrate the personal and social implications of their agency. Not only will they begin to think about the implications of their actions, but about the different types and levels that are possible for them.

Conclusion

As genetic screening becomes more common place and specific characteristics about learning capacities around areas like mathematical abilities, memory capacity, problem solving, are mapped to specific constellations of genes, the education of individuals may likely change. Modern educational practices have been founded on atomizing knowledge (e.g., subjects, skills) and associating the components of knowledge of knowing with specific characteristics (e.g., different intelligences). As knowledge and the process of knowing evolve to address the proliferation of genetic information as a result of electronic communication, digital storage, and mass media, genetic potential will continue to be woven into the discourses of education. The exact form it will take cannot be exactly predicted, however, there are some historical precedents that may provide a clue to what can be anticipated. In the 20th century the integration of scientific methods into educational research and discourse through particular technologies like statistics influenced among other things the use of standardized tests to track students by their performance. This led to a form of comparison and hierarchy in education that highlighted differences between students. Standing on the shoulders of these discourses, genetic knowledge has the potential, if not placed in proper context in the curriculum, to maintain and possibly increase existing inequities.

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