

Creating a more responsible public dialogue about the social, ethical, and legal aspects of genomics.

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Creating a More Responsible Public Dialogue About the Social, Ethical, and Legal Aspects of Genomics

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A regular feature of the *American Journal of Critical Care*, Current Controversies in Critical Care addresses the ethical and administrative issues faced by healthcare professionals working in today's critical care environment. We welcome letters to the Editors regarding this feature and encourage the submission of scenarios for future discussion.

Most would agree that we need a better informed and more rational public dialogue about genomics research, including cloning for therapeutic stem cell research, genetic testing, and somatic genetic therapy. The current moratorium on genetic therapy in human beings, and the recent legislation banning therapeutic use of cloning stem cells, invites a new dialogue between scientists and society in order to examine social goods, risks, and benefits of the current genomics research program. However, public dialogue is hampered by confusion and little awareness of the ways social and

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scientific concerns interact in the public debate. The science of genomics creates public disclosive spaces in the media and society in general that influence people's ways of understanding themselves and scientific agendas.

Science itself is embedded in our social worlds and imbued with meanings and goals that are social. Society and the media create symbolic and mythic structures around scientific constructs, so that it becomes hard to think about the constructs strictly in "scientific" terms or strictly in terms of ethical and social concerns. For example, people request genetic tests, believing that the tests for APOE and PSI will reveal their possible risk of developing Alzheimer's disease, though these tests are not truly predictive and currently such testing is limited to those who already have symptoms of dementia.¹

Cartesian medicine holds an "ideal" of separating the social and the medical, although this has never actually been possible in practice in either domain. Descartes' vision of the body as a mechanical physiological entity that can be isolated from the soul/spirit and mind has been responsible for much advance in medical research and efficacy in clinical medicine. With the success of Cartesian medicine, the body has come to be understood by physicians and nurses as the physiological mechanical body composed of organ systems, tissues, cells, and biochemistry. The influence of the external physical and social environments on the embodied person was downplayed, or even ignored, by Cartesian science.²

This radical separation of the social and physical is even more evident in public debates on genomic science.³ At one extreme, we have a scientific and cultural discourse on genetic determinism that excludes other influences on human life, such as internal and external environments and ongoing biological and social growth and development in time. Such genomic determinism makes the genome a singular deterministic force of nature. At the other extreme are environmentalists who focus only on the environment and nurture. The first extreme, a deterministic and reductionistic discourse, leads to discrimination and to a vision of eugenic enhancement of the population. The second extreme ignores the role of biology and the genome in creating disease and suffering.⁴

Lippman⁵ introduced the concept of geneticization, similar to medicalization, to describe self-understandings and interactions between science and society and medicine and genetics. Sociologist Dorothy Nelkin and historian Susan Lindee⁶ explore the gene as a "cultural icon." They describe how DNA has been described as the *Book of Man* and Holy grail. They note that in popular culture, the gene parallels theological narratives about personhood and the nature of immortality, and the gene has replaced the heart as a soullie source of continuity and identity. Just as the insubstantial soul has been the seat of hopes for immortality, the material DNA has been conjured up as holding the key to physical immortality, or as one headline proclaimed, "Faulty Genes Cause Aging."

According to Nelkin and Lindee in an analysis of popular cultural meanings of the gene:

. . . The gene in popular culture is more than a biological entity. It is a cultural resource that can be invoked to explain nearly every personality and behavioral trait. It is a political resource that can effectively absolve society—and even the individual—of responsibility for behavior. Genetic determinism appeals [to people] in many policy contexts therefore as a justification for passive attitudes toward social injustice and even aggressive neglect of continuing social problems. And it implies a dangerous way out of social dilemmas—suggesting that the improvement of society depends, ultimately, on the improvement of DNA.⁷(p165)

From the commercial and advertising sphere of the social world, science can take on magical properties, sometimes spurred on by unrealistic claims made by ambitious scientists hoping to inflate the price of market shares in a biotechnical company. The commercial conflicts of interest between rigorous science and advertising claims or editorials that oversell a medicine or treatment demonstrate yet another aspect of the inextricable mix of science with the social world.

As Drew Leder⁸ points out, the Cartesian corpse is a machine body. A mechanistic approach creates control by breaking things down into their most elemental parts and most basic interactions. This is an enormous power, but it causes us to focus on what we know and ignore what we don't know. In genetic therapy, there is much we do not know, for example, about the impact of even slight relocations of DNA material inserted by vectors. The vectors used to transport DNA can be lethal, as demonstrated by the tragic death of Jesse Gelsinger, who underwent genetic therapy.⁹

Ethicists and religious thinkers are not immune to unreasonable enchantment that overemphasizes the gene as uniquely sacred in its influential, or even deterministic, role in the development of the human being. Ethicist Sandro Spinsanti,¹⁰ while critical of genetic engineering, points to the perfection of technologies in genetics that will “make it possible to intervene in the deepest level of living nature.” As an ethicist /theologian, he wants to distinguish emotion from judgment; however, his own cultural and social influences intrude when he points to the evocative sacred language of the “deepest level of living nature” and the “mythological language of genetic engineering: the work of ‘sorcerer’s apprentices,’ a ‘biological time-bomb,’ the creation of superman and chimpanzee man, the production of monsters.” While there are real risks inherent in genetic engineering, Spinsanti points out that such hyperbole better fits science fiction and does little to create a rational dialogue that will narrow the gap between societal and scientific understanding of the ethical, legal, and social aspects of genomics.

Popular cultural metaphors have moved from viewing one's genotype as “winning or losing at the lottery” to a metaphor that conjures up capricious luck, genetic essentialism, and genetic fatalism (the lottery metaphor was too deterministic and unjust for most people's taste). The public discourse on genomics shifted from the lottery metaphor to a discourse on the gene's blueprint, but this also was seen as too

deterministic, even though some authors were quick to point out that blueprints can change in practice. A major metaphor of DNA now seems to be the information processing model: the computer. Such a cosmological perspective is evident in Richard Dawking's description of life as bytes and bytes of digital information. According to Dawking, human beings are survival machines primarily as a result of the gene's ability to copy itself. This is yet another example of genetic determinism.

Matt Ridley's recent popular book, *Genome: The Autobiography of a Species in 23 Chapters*, switches the information metaphor to that of text, or book, a metaphor that has religious overtones.¹¹ Hyperbole and attributing magical powers to science are evident in his book:

We, the lucky generation, will be the first to read the book that is the genome. Being able to read the genome will tell us more about our origins, our evolution, our nature and our minds than all the efforts of science to date. It will revolutionize anthropology, psychology, medicine, paleontology and virtually every other science. This is not to claim that everything is in the genes, or that genes matter more than other factors. Clearly they do not. They matter, that is for sure. . . . In just a few short years we will have moved from knowing almost nothing about our genes to knowing everything. . . . Some may protest that the human being is more than his genes. I do not deny it. There is much, much more to each of us than a genetic code. But until now human genes were an almost complete mystery. We will be the first generation to penetrate that mystery. . . . The idea of the genome as a book is not, strictly speaking, even a metaphor. It is literally true. A book is a piece of digital information, written in linear, one-dimensional and one-directional form and defined by a code that transliterates a small alphabet of signs into a large lexicon of meanings through the order of their groupings. So is a genome. . . . I was born just five years after the moment when, and just two hundred miles from the place where, two members of my own species discovered the structure of DNA and hence uncovered the greatest, simplest and most surprising secret in the universe. Mock my zeal if you wish; consider me a ridiculous materialist for investing such enthusiasm in an acronym. But follow me on a journey back to the very origin of life and I hope I can convince you of the immense fascination of the word.¹¹(p5,6,12)

In Ridley's writing about science, imagination and zeal unite to make the genome the source of powerful secrets of control. A single-factor theory wins out, and the environmental, social, and developmental aspects of human life are all but ignored. Responsible dialogue and social policy on genomic research and medicine will require scrupulous honesty and the deflation of language to more realistic promises and descriptions. To do this, we will have to abandon the illusion that it is possible to separate science, society, and embodied human beings dwelling in distinct lifeworlds. We will have to come to terms with the necessity of considering the genome as part of our common humanity, but not wholly deterministic.

The scientific decisions we make about genomic research will influence our notions of

identity and have the potential to radically shift our population in ways that we might not choose if we were able to think beyond individual choices. Certainly, gender choice is one area where individual choice can have profound implications for the society, as has been demonstrated in China during the last 50 years of choosing the lives of male children over female children.

It is impossible to create a responsible ethical and policy debate in a climate of hyperbole. The language of “personal choice” is offered as a protection against coercion related to genetic engineering, but personal choice will need to be framed in the context of social goods and social justice.

Demystification of genomic science and more realistic public understanding of the possibilities and promise of genomic science are required. The social outcomes and social influences on science cannot and should not be separated from planning and designing scientific programs. Regardless of the new possibilities offered by genomic medicine and genetic engineering, we will still have to attend to our social existence. Embodied social and biological realms are interrelated. Biological and social justice; care; and safe, nurturing environments are required for a good society and for health. Neither attention to the biological or the environment alone can fully address the human condition. We need to form new, responsible dialogues between the two.

Footnotes

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