Lessons from the Past (Genetic Diversity vs. Genetic Discrimination)

(By Toshio U.-P.)

"Identifying genetic variants associated with schizophrenia would contribute to a new understanding of the brain mechanisms that lead to this disease, an important step towards being able to develop better treatments for the millions of individuals worldwide who suffer from schizophrenia."

~Dr. Anne Bassett, Director CGRP (Clinical Genetics Research Program)

In 1998, a private company called Celera Genomics challenged the publicly-funded Human Genome Project (HGP) to a sequencing 'race', claiming that its own 'shot-gun approach' would complete the total sequencing in a faster timeframe. This led to the accelerated rate at which the HGP was able to complete its sequencing of 92% of the human genome, which was officially mapped and made public by 2003 instead of 2005 like its original goal. That same year, due to global concerns over bioethics and genetic discrimination, UNESCO would adopt its International Declaration of Human Genetic Data to oversee the "collection, processing, storage and use of human genetic data" with the "aim […] to ensure the respect of human dignity and the protection of human rights." (1) In the science-fiction film Gattaca (2) of that similar period, concerns over 'genoism' are played out on the big screen, with central character Vincent played by Ethan Hawke faking his genetic profile by using the DNA of a 'borrowed ladder' called Jerome Morrow to fool space recruiters in the GATTACA Corporation and to fulfill his childhood dreams of being an astronaut. In the film, Vincent's honest ambitions of travelling to Titan are up against a radically bureaucratic system where a quick genetic profile screening through samples from blood, skin, nails, hair or urine is enough to rule out an applicant seeking to gain access to a higher level position. This similar concern was expressed by George Annas from Boston University who states the importance of "legislation to prohibit genetic discrimination in employment, health insurance, life insurance, and disability insurance." (3)

While it is well documented that during the rise of National Socialism in Germany during the 1930s "nationwide preventative screening programs to fight hereditary diseases were implemented, and research to scientifically justify these programs was funded" (4), many medical ethicists warn that such a dangerous combination of genetics and eugenics—carried out almost a century ago—could re-occur once again in a modern context where a targeted group (such as psychiatric patients) are subjected once again to similar extremes of 'depersonalization' and 'dehumanization'. In more recent times, while terms such as mental hygiene and psychiatric eugenics have been deemed obsolete or even out of date, the deterministic view of genetics and the conviction that there still is an underlying connection between one's genetic pedigree and the onset of psychiatric symptoms still persists. A quick internet search on a group called the Psychiatric Genomics Consortium (PGC) reveals that current researchers routinely conduct "meta- and mega-analyses of genomic-wide genetic data" sometimes "with a focus on psychiatric disorders." (5) While this common process of 'mining' the human genome is often now tied into the well-funded field of 'pharmacogenomics', it is debatable whether such research is done with a true health goal in mind in a world where medical “professionalism” is more often outweighed by the “ethic of commercialism” (4). In reality, the genomic research involved in the El Dorado search for cutting edge “molecular targets for new drugs” (6) is in reality a quest where patients are downgraded to powerless consumers and where health services are mere “commodities” with significant “profit” potential. (4) While debate will continue to manifest itself between advocates of genetic vs. environmental causality of mental health conditions, members of the *c/s/x/m/d/n* (*consumer/survivor/ex-patient/mad/diagnosed/neurodiverse*) community should actively be consulted in regards to their insights on the causal link between xenobiotics and psychiatric symptomology. Giving patient ‘consumers’ more prominence as research subjects would serve as an ethical safeguard and would better guide research from genome sources, preventing the use of such data as a “discriminatory tool” like the eugenicists of ages past.

Sources:

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