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Don’t Revive Eugenics: The Importance of Minimal Disclosure in Genetic Research

As technology rapidly progresses so does genetic research. With the advent of fast processing computers, genetic researchers were able to gain insight into many different genes across a wide variety of organisms. Now that the entire human genome is available to the scientific community, people can perform research that was considered to be impossible just a few years ago. As stated in Barbara Knoppers’ article, “Human genetic research: emerging trends in ethics,” with the astounding progress being made in genetics research, new ethical issues have emerged (Knoppers, 75). These issues concern the interests and confidentiality of human subjects in genetic experiments.

A large subject of debate among genetic research ethicists is whether there should even be tight ethical regulations on genetic research involving human subjects (Knoppers, 75). Another issue is about how much consent to genetics research is considered enough (Knoppers, 76). One of the two main arguments for how much consent participants need to give is blanket consent, a form of consent that allows a subject’s genetic information to be used in future research projects. The other argument is specific consent, a form of consent that requires researchers to obtain a subject’s approval each time the subject’s genetic information is to be used (76). As described in Celia Fisher’s article “Ethics in Prevention Science Involving Genetic Testing,” one of the most debated topics regards incidental genetic findings in scientific research (Fisher, 311). When one consents to provide his or her genetic information to a study, one’s primary concern is confidentiality. The reason for this is that if a subject’s information got out to the public, a lot of it could potentially be used against him or her (Fisher 315). However, when people consent to participating in genetic research, they usually hope to get something out of it. Therefore, if people were looking to find out whether they were more genetically susceptible to cancer, they would be told that information in exchange for participation in that study. This exchange of information for participation is known as “reciprocity” (Knoppers, 75). However, research participants do not find out about a lot of their genetic information in these experiments. Often these genes are sequenced so that scientists can find out the participant’s information for research purposes (Knoppers, 76). In some instances, scientists will discover important information about the subject’s genes (Bredenoord, 41). According to Annelien Bredenoord’s article “Disclosure of Individual Genetic Data to Research Participants: The Debate Reconsidered,” these discoveries are called incidental findings. Incidental findings are discovered after initial genetic information is collected. What to do with this information is a major focus of debate (Bredenoord, 41). Should genetic researchers disclose these findings (Bredenoord, 41)?

There are two different ways to disclose incidental findings: passive disclosure, and active disclosure (Brendenoord, 42). Passive disclosure is when a patient specifically requests that their genetic information be given to them, while active disclosure is when scientists inform participants of their genetic information after they discover information deemed worthy of disclosure (42). Most of the debate regarding the disclosure of incidental findings focuses on active disclosure (42). There are several arguments about the disclosure of incidental findings, (Bredenoord, 42). The most extreme of which, argues for disclosure of all incidental findings. The other extreme pushes for a complete ban on the disclosure of any incidental findings (42). Both of these views are very tough to defend. While disclosing all incidental findings to millions of participants isn’t feasible, not disclosing any information even if it would save that subject’s life isn’t ethical (42). The two most popular arguments about disclosure are for qualitative disclosure, which advocates for the disclosure of some incidental findings, and restrictive disclosure, which pushes for no disclosure of incidental findings except to save a participant’s life (42). Those who argue for restrictive disclosure argue that scientists have no right to inform their subjects about incidental findings (42). They assert that disclosure is based on a “mistaken interpretation of autonomy” (Bredenoord, 43), that it isn’t feasible to disclose so many incidental findings to so many patients, and that there are numerous social harms that come from disclosure. The only time disclosure should be performed is in the case of a life threatening situation (42).

On the other hand, those who support qualified disclosure argue that researchers shoulddisclose some genetic information that they feel would have some form of benefit to the participant (Brendenoord 44). They argue that disclosing incidental findings is a good deed to do. Furthermore, maintaining the patient’s autonomy requires disclosure (44). According to this view, disclosing information to patients about themselves is perfectly acceptable because it is the right of patients to know about their own genetic information. Proponents of qualitative disclosure also argue that it is only fair to disclose this information because subjects are volunteering their time and that there is nothing wrong with providing clinical care in exchange for a subject’s participation in research (44). Finally, they argue that disclosing information will improve the public’s overall understanding of genetic sciences (45). According to Fisher, these arguments are often made to justify genetic research as a science that can predict future illnesses, thus allowing physicians to prevent these illnesses (Fisher, 313).

Although the arguments presented by proponents of qualitative disclosure make a good case for patient’s rights, they have several flaws in that they leave opportunity for misinterpretation of disclosed genetic information by research participants and by the general public. The largest of these flaws is that disclosing research information can set society on a dangerous track towards discrimination against others based on genetic information. Disclosing a patient’s information has a high chance of leading to social and psychological consequences, as well as a refusal by insurance companies to provide coverage for participants. Disclosing genetic information to patients will inevitably lead to discrimination based on genetic information as it runs the risk of reviving racist practices of the past that are similar to eugenics (Knoppers, 76). Therefore, research subjects should not be ensured access to individual research results, except under life threatening circumstances because that information has the potential to lead to discriminatory practices.

Disclosure can’t serve as a preventative science because there is no definite evidence that proves its efficacy. It is naive to believe that just because a researcher finds out that the subject’s genes make it more likely for the subject to get a certain disease, he or she will definitely get it. It is also unlikely that researchers would be able to do much about recently discovered genes. Even though the argument for qualitative disclosure as a preventative science states that knowing more information will allow “researchers and practitioners [to] more efficiently and effectively target those at greatest risk for disorder development,” (Fisher 310) individuals still have a large risk of being harmed. When someone receives information about genetic information that they didn’t wish to find out, they might suffer from “adverse psychological consequences” (Bredenoord, 44). Imagine being told that you have a gene that makes it very likely for you to get cancer. Wouldn’t that be traumatizing? What probably makes the patient who has just found out this information even more susceptible to depression is the inevitability of the situation. It is nearly impossible to safely change one’s own genes and most illnesses detected by genetics research are currently pretty difficult to cure. Thus disclosure wouldn’t serve as a preventative science, but rather as a prediction of the subjects’ inevitable deterioration. However, worst of all is that a lot of times, there is no certainty as to whether or not these findings are true, especially in children (Fisher, 318). Often, as time passes, the likelihood of a person having a genetically linked illness will change. Therefore due to the uncertainty, disclosure of genetic information can potentially create a large misunderstanding about different genes that will upset research participants about their own genetic identity.

The first argument made by supporters for qualified disclosure is that disclosure of incidental findings is encouraged because it promotes the autonomy of subjects (Bredenoord, 44). However, this argument is flawed because only minimal disclosure of the patient’s information will truly preserve his or her autonomy. In research experiments, patient autonomy is extremely important but disclosing genetic information to patients without their permission in most circumstances undermines their autonomy by inflicting participants with their own “burdens of disclosure” (Fisher, 311). This means that disclosing this information will give participants the saddening task of sharing with family members the existence of a disturbing hereditary trait (Fisher, 311). Therefore disclosing a patient’s information without his or her request only undermines a subject’s autonomy, which can compromise participants’ rights.

In addition, minimal disclosure of research results will prevent society from misinterpreting genetic information to harm individuals. The argument that disclosure of incidental findings will educate the public about genetics is optimistic but misguided. The public has “potential for genetic stereotyping,” (Fisher, 318) as it has misinterpreted scientific findings in the past. It can definitely do the same in the future. When Darwin proposed his theory of natural selection, the majority of the western world misinterpreted this principle and tried to apply it to justify the creation of a racial hierarchy. Racism has always existed but misinterpretation of scientific discoveries has intensified this hatred. Genetic theory in particular has had a rich history of being inappropriately applied to discriminate against people (Fisher, 318) in cases such as the European Scramble for Africa --a late 19th century imperialist movement -- and the Holocaust. In both cases, world leaders attempted to justify their actions by citing misinterpreted genetic theory. Therefore, to prevent the public from misconstruing genetic information, scientists should keep from disclosing as many incidental findings as possible.

One should also consider what would immediately happen when too many incidental findings are disclosed. As stated earlier, supporters of some disclosure of incidental findings argue that these participants will be given free clinical treatment (Bredenoord, 44)**.** That may be the case, but once genetic information is disclosed, health and life insurance companies will definitely be trying to get their hands on this information because it will end up saving them a lot of money (Bredenoord, 44). If an insurance company believes that this person will inevitably get a disease, then to maximize profits the provider will either raise the cost of insurance for that individual by a lot, or will just refuse to provide coverage to the research participants (Bredenoord, 44). This cost completely outweighs the benefits of a few free clinical treatments and also incentivizes insurance companies to discriminate against people with certain genes, essentially sowing the seeds for a society that discriminates based on genetic information. To prevent this phenomenon, and to keep participants’ genetic information from insurance companies, researchers shouldn’t disclose incidental findings.

Given all prior arguments, it is now evident that a society will discriminate based on genetic information if its individuals and institutions know a lot about their own genes. This idea isn’t novel as during the early to mid-20th century, people misinterpreted genetic principles to justify a practice called eugenics, which was used to rationalize discrimination based on genetic information (Knoppers, 76). Practitioners of eugenics tried to keep those that had physical and mental sicknesses from reproducing, sometimes through forced sterilization. They also applied these principles to race: many people tried to dissuade interracial marriage in order to preserve what they believed to be the superior gene pool (Fisher 318). Eugenics also justified the creation of racial hierarchies. Luckily, this belief has been completely disproven by scientific evidence. However, disclosing some genetic research results to participants and to the public will threaten to bring back this practice. This time, however, people will be able to cite scientific fact to falsely justify discrimination against people who have or lack certain genes (Bredenoord, 42). For example, in a society where some people have a gene that might lead to over aggressiveness, the public would perceive such people as a threat, and ostracize them.

Moreover, in a society that practices a modern form of eugenics, some genes will determine whether one is superior to another. Take for example the intelligence gene. According to Michael Reiss, there is a large potential for the existence of one or more genes that deal with human intelligence (Reiss, 1).Researching these genes is “controversial” (Reiss, 1) because many ethicists “deny…the appropriateness,” (Reiss, 1) of such research. The discovery of this gene can lead to many consequences, as some scientists believe that the problems in “measuring [intelligence] are insurmountable” (Reiss, 9). Thus, there is a high chance that even if intelligence was defined by a single gene, society would be wrongly led to believe that not having this gene would make a person non-intelligent. In addition, ethicists use “arguments from history,” (Reiss, 10) that caution scientists to avoid genetic intelligence research. “In one form, it can be maintained that the very notion of intelligence and/or genetics are so tainted with racism, sexism and classism that at least for the foreseeable future, it simply won’t be possible to carry out a…study in this area” (Reiss, 10). This is of course referring to eugenics. Thus, if intelligence genes do exist, for the sake of keeping society from dividing up into different classes based on intelligence, it would be best if researchers didn’t disclose this information to research participants (Reiss, 5). By disclosing this information, scientists run the risk of reviving eugenics. This doesn’t only apply to genetic research on intelligence as there are a plethora of other genetic research experiments where the results can be harmful to individuals and to society. Therefore, the less genetic information that scientists disclose to patients, the less likely that we will become a classist society.

Regardless of how much information genetic researchers should disclose, they should be aware of the consequences of disclosing too much research. By disclosing incidental findings that aren’t life threatening, researchers risk damaging participant’s standing with insurance companies as well as damaging them psychologically. Furthermore, disclosing too much information will threaten to revive a society where people are classified into tiers based on their genetic composition as well as a practice like eugenics, which discriminates against people based on their information. For these reasons, it is best for scientists to disclose as little genetic information from research results as possible.

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