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Case - SUMO-1

Description

This is the case study for unit 6 of the Course on Genomics, Ethics and Society. This case looks at the possibility of using gene therapy for enhancement purposes.

Body

Over 17 million people died from cardiovascular disease worldwide in 2008 (World Health Organization, 2013). The World Health Organization estimates that number will be over 23 million by 2030. In the U.S., approximately 600,000 people die annually from heart failure.

In order to curb this trend, many scientists and doctors have turned to cardiovascular gene therapy (Wolfram & Donahue, 2013). In gene therapy, an entirely new gene is introduced to the body, or a target gene is removed or replaced with another gene. For example, a mutated gene causing skin cancer can be replaced with a non-mutated copy of that gene in order to restore normal cell growth. Or a gene can be introduced to the body in order to help fight a relatively simple disease, like the flu.

One new development in cardiovascular gene therapy focuses on the SUMO-1 gene (Tilemann et al., 2013; Woods, 2013). The SUMO-1 gene is naturally occurring in human beings, but its activity is reduced in patients with heart failure. In studies on mice and pigs, insertion of the SUMO-1 gene reduced blood pressure and improved overall cardiovascular function. Clinical trials on SUMO-1 with human beings are just beginning. If these trials are successful, and SUMO-1 is approved for general use, doctors will have a powerful new tool for combatting cardiovascular disease.

However, a number of concerns have been raised about gene therapy (Persson & Savulescu, 2012). One worry is that gene therapy could reduce people's motivation to take responsibility for their own health. Those whose hypertension is a result of unhealthy habits (e.g., smoking), for instance, have less incentive to discontinue those habits if they know they can receive gene therapy for hypertension.

The President's Council on Bioethics, appointed in 2002 by George W. Bush, argued that imperfection—including illness and disease—is part of human nature (President's Council on Bioethics, 2003). Though the Council generally endorsed gene therapy for serious diseases, it also cautioned against the tendency to continually extend the limits of the human body. SUMO-1 gene therapy will likely extend the lives of individuals who are otherwise close to dying. If SUMO-1 therapy becomes widely available, it could also be used to improve heart function even among perfectly healthy individuals, with the effect of boosting overall health and well-being.

A related worry is that gene therapy will exacerbate inequalities, or potentially produce new forms of inequality (Savulescu, & Bostrom, 2009). For example, healthy individuals who use SUMO-1 could gain an advantage over others who cannot afford gene therapy; this therapy will be expensive. Optimal cardiovascular function allows us to pursue our goals with more vigor, and perhaps to achieve more than we would otherwise. Like unequal access to education or proper nutrition, unequal access to gene therapy could grant benefits to some people that would put others at a disadvantage.

Many ethicists have tried to clarify the difference between therapy and enhancement in order to address these worries, since therapy is arguably more permissible than enhancement (Agar, 2010; Buchanan, 2010; Savulescu & Bostrom, 2009). However, this is difficult because there are many things we do to enhance ourselves that we think of as necessary for human well-being. Medicine, nutrition, and education, for instance, raise many of the same problems as gene therapy. The widespread availability of pharmaceuticals may make us less likely to engage in healthy behaviors; nutritional supplements are often consumed specifically for the aim of perfecting ourselves; and better education gives some people advantages that others do not have.

- ***Consider a case in which a professional marathon runner wishes to receive SUMO-1 gene therapy and can afford to pay to do so. The***

runner has no heart problems, and only wants to boost performance in marathons. Assuming SUMO-1 gene therapy is not banned for competition, what ethical problems, if any, do you see with this athlete receiving an infusion of the SUMO-1 gene? Compare this to someone who wants SUMO-1 therapy because of hypertension due to a lifetime of poor habits, including smoking and lack of exercise. Which do you think is a better candidate for therapy? Would it be ethically permissible to give both individuals the therapy, only one of them, or neither of them? Explain and give reasons for your answer.

References

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