Online Ethics Center
FOR ENGINEERING AND SCIENCE

Selected Issues in Depth - Human Genetic Therapies and Human Enhancement

Description

Part of unit 6 of the Course on Genomics Ethics and Society, this section provides video clips looking at the therapeutic significance of genomics and other forms of genetics in medicine, ethical issues raised, and the use of genomics for human enhancement purposes. This section includes clips from talks given by Dr. Nierman from the Crag Venter Institute and Dr. Basl from the Philosophy Department of Northeastern University.

Body

We begin our "Selected Issues In Depth" for this unit by looking at the therapeutic significance of genomics and other forms of genetics in medicine. Some of the video clips we've included here have Powerpoint slides inserted in them to help you to see what the speaker is talking about. You can pause the video in order to take a closer look at these slides.

Our first speaker here is Dr Nierman from the Craig Venter Institute.
Dr Nierman explains some of the key scientific ideas and terms that are central to thinking about genomic diseases and therapy. First he explains the importance of genomic medicine right now, in the context of genetic tests carried out on his grand-daughter when she was born:

Following this introduction, Dr Nierman provides an overview of some of the important scientific information we need to know to understand the role of genomics in therapy. When considering why diseases, such as cancer, occur it is important to understand that the human genome contains more than 3 billion DNA bases. Dr Nierman provides a quick introduction to the human karyotype (the organized profile of a person's chromosomes) to frame our understanding of genomic therapy.

More specifically, Dr Nierman focuses on the genomic information we need to understand the biology of cancers. Cell replication is an imperfect process. There are 75 trillion cells in the human body and because of the large number of cells and the imperfect replication process, some errors can lead to rogue cells: cancers. Dr. Nierman points out that most introduced variation at the DNA level occurs in somatic cells (ie, not in germline cells) via insertions and deletions, and are thus not heritable.

Next, Dr Nierman focuses on the importance of genetic inheritance. More specifically, the meaning of the terms genotype and phenotype are explained. The classic example of Mendelian inheritance, the law of segregation of alleles and the law of independent assortment, is discussed in relationship to the occurrence of human Mendelian (single gene disorder) diseases. Towards the end of the clip Dr. Nierman gives examples of Mendelian diseases that provides some context for the next clip.

Here, Dr Nierman discusses Mendelian diseases, single gene disorders that often run in families, such as Huntington's disease. Huntington's disease, along with many other rare recessively inherited diseases are now often screened for. These screening tests are a good example of how genomic medicine is currently being used.

However, as Dr Nierman here points out, most diseases are not Mendelian, single-gene diseases, but have a much more complex combination of causes, in which genetics plays some part. These complex diseases are important because of the substantial health burden they present to society. Recent advances in genomic sequencing technology are beginning to allow researchers to scan whole

human genomes for single nucleotide polymorphisms (SNPs) that can be used to tease out causes and suggest possible therapies for these complex diseases.

The next topic Dr Nierman discusses is genome sequencing and the Human Genome project. The Human Genome Project ended in 2003. Not only did this undertaking provide valuable insight into complex human diseases, but it ushered in the era of genomics by introducing high throughput massively parallel sequencing technology. The cost effectiveness of these technologies, along with analytical genome wide association studies (GWAS), improved the ability of researchers to link disease phenotypes with affected genotypes, providing a springboard into untangling complex diseases and cancers. As Dr. Nierman notes, new sequencing technology is not perfect, and we still have work to do to improve the identification of genome assembly variants.

Human genome sequencing has an important role to play in the diagnosis of disease. As suggested in the previous clip, new sequencing technology is cheap and fast, but nonetheless care must be exercised when using it in a clinical setting. Dr. Nierman discusses the results of a comparative study suggesting that there is some concern about the replicability of studies when they use different sequencing platforms, and this raises questions about their ability to diagnose human diseases. Still, it is only a matter of time until genomics is fully integrated into the clinical diagnostic toolbox.

Now Dr Nierman can move on to consider a number of examples of medical conditions to which genomic medicine is currently making a contribution, or is likely to make a significant contribution in the near future. He begins by thinking about cancers:

And he considers genomics and cancer therapy: Using genomics, risk for complex diseases can be assessed using multimarker tests. Along with risk assessment, Dr. Niermandiscusses the use of targeted therapeutics, particularly for cancers, that can improve cancer treatment outcomes.

Elaborating on the last clip, Dr. Nierman talks about the genetics of celiac disease, discussing a case in his own family. More specifically, he explains the use

of genomic testing for known diseases in the context of complex risk percentages and analytical algorithms.

Finally he looks at some recent work on pneumonia and genetics:

Dr Nierman has introduced many of the ways in which genomic medicine is currently being used. One further area of importance is the possibility genomic medicine offers for reasonably affordable personal therapy, based on the genetic profile of individuals: Dr Mendelsohn, who works in Personalized Cancer Therapy at the MD Anderson hospital in Houston has some thoughts on this:

THE ETHICS OF HUMAN ENHANCEMENT

Dr Nierman's work helps us to see both what's currently available in terms of genomic therapies and what might be around the corner in terms of genomic medicine for Mendelian diseases, cancer, pneumonia and many other major public health concerns. However, as we discussed in the 'background material' for this unit, there's a further concern here: a concern about the use of genetics in enhancement. As we've already noted, there are significant disputes about how to distinguish between "therapy" and "enhancement". But there are some potential changes that clearly look like enhancement, and that raise particularly pressing ethical issues. Dr John Basl, from the Philosophy Department at Northeastern University, joins us to talk about some of the ethical issues enhancement raises - both "intrinsic" concerns (concerns about the technology itself) and "extrinsic concerns" - concerns about the consequences of using the technology. He begins his talk by outlining the range of different ethical positions that might be taken with regard to human enhancements:

Dr. Basl introduces introduces the role of intrinsic concerns in arguments for and against human enhancement. These intrinsic concerns include worries about "naturalness", playing God, and the ways in which genetic enhancements might not be virtuous. However, he goes on to argue against these intrinsic arguments, for four reasons: 1) what he calls Status Quo bias; 2) the difficulty in distinguishing between therapy and enhancement; 3) the idea of political neutralism; and 4) intrinsic versus all-things-considered arguments.

The first two of these objections to intrinsic arguments are considered in the following clip.

Next, Dr. Basl focuses in on the second two of the objections to intrinsic factors discussed in the last video: political neutralism and intrinsic versus all-things-considered arguments. The premise of neutralism is that political policies, related to enhancement in this case, must be able to be accepted by people of diverse views in a liberal society; but this approach is problematic if intrinsic concerns are controversial (as they are here). Second, Dr. Basl discusses the intrinsic versus all-things-considered approach. While intrinsic concerns may exert their pull on us, he argues that just being *intrinsic* doesn't make a concern *decisive*. Given all of the available information, sometimes intrinsic concerns can be outweighed by extrinsic concerns, of the kind he goes on to discuss in later clips, meaning that making alternative decisions and policies may be appropriate.

Extrinsic concerns relate to the outcomes of using human enhancement, rather than being in-principle objections. Here Dr. Basl elaborates on three of these concerns: 1) personal safety; 2) social utility; and 3.) social injustice. Human enhancement technologies, he argues, have the potential to exacerbate existing social inequality and unequal distribution; these effects should be considered when developing policies regulating the technology.

Next, the role of philosophy in addressing extrinsic concerns about human enhancement is highlighted. Dr. Basl introduces three ways in which philosophy can be important to this argument: 1) identification of risks and concerns, 2) conceptual clarification, and 3) evaluation of solutions. Dr. Basl then proceeds by illustrating how philosophers can help with the potential problem of the coexistence of populations containing both enhanced and unenhanced individuals.

Finally, Dr. Basl discusses moral status enhancements. When a being has moral status, we have to take its needs or interests into account when we make decisions. Dr Basl argues that some kinds of enhancement may change moral status or moral significance. His particular concern is with the testing of potential human enhancements on animals. Suppose animals are enhanced in ways that increase their sensitivity to suffering. This would, he argues change our moral obligations

towards these animals. However, since animals can't communicate such changes, we won'f necessarily know whether they have undergone them. This means there's potential for causing animals significant suffering without knowing it. This would be, Dr Baslargues, a major ethical problem.

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