

Ethics of gene mapping for personalized treatment



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There are many concerns about the future of the use of gene mapping for the personalisation of medicine. Whilst there are many benefits to the use of genetic testing to allow a more precise diagnosis and tailored treatments for various illnesses there is a risk of the information being abused to harm the patients. The information could be used to harm the patient's future career prospects or lead to an increase in premiums for health insurance, possibly even an outright denial of coverage. However the US government has introduced legislation to protect the rights of the people and the concerns are outweighed by the benefits to the patient's quality of life in terms of medical care.

Introduction

Mainstream medicine's always had the differential diagnosis of patients decided primarily by generalisations made from a population of patients suffering from similar symptoms. The treatment is then found by knowledge acquired by research done over the entire population of people with similar symptoms(Torrey2013).

The personalisation of medicine aims to have diagnosis and treatment tailored to patients to ensure they receive the best quality care possible. This will be done by the studying of their genetic framework to find out early if they have the genes for certain diseases. However, whilst it'll be beneficial to the treatment of the patient, this has some ethical implications which this paper will aim to discuss throughout this paper and present a balanced argument to each concern as well as coming to a clear conclusion as to whether the benefits outweigh the ethical issues

Method

Relevant papers were found using medical journal databases subscribed to by both the University of Exeter and the University of Plymouth, the Google Scholar search engine, the BMJ, the NICE database for statistics and MEDLINE(PubMed). I also used Google to find relevant news articles relevant to my case to ensure I included public opinion as well as my own. The key words and phrases I used to search online for papers were various combinations of; “ genes”, “ gene mapping”, “ personalized treatment”, “ discrimination”, “ cost to” and “ NHS”. I then narrowed my search to recent papers and news articles that were relevant to both the United Kingdom and the United States.

Discussion

What is gene mapping and how can it be used to personalize treatment?

The Human Genome Project “ mapped” the approximately 25, 000 human genes, determining what genes exist in human DNA and what their roles are in a healthy human being. Knowledge of what those genes look and behave like when they’re normal means that they can be compared with the genes of patients with medical problems to determine whether those patients’ genes are abnormal(Haga2009).

Gene mapping is the process of finding the locations of genes on the chromosomes of patients(Haga2009). It used to be done by a process called linkage analysis, where the closer two genes are to each other, the more likely that they’ll be inherited together(U. S. National Library of Medicine ®

2013). From this, patterns can be found, which can be used to determine their location on the chromosome(U. S. National Library of Medicine ® 2013).

The more modern approach is by the use of small tags achieved by two methods. The first is by the use of genetic markers such as the products of a Polymerase Chain Reaction, where single piece of DNA can be amplified by the production of up to millions of copies of the DNA fragment(Bartlett & Stirling2003). The second method is by use of enzymes specialised to bind to and cut very specific areas of DNA called restriction enzymes. The resulting fragments are separated by the process of electrophoresis and overlaps in the genetic information called “ contigs” can be used to find consensus sequences which can be used to figure out which parts of the DNA strand it was originally from, which added together gives a map of the entire sequence(Gregory2005).

Once gene mapping's occurred, it can be used to several ways to personalise treatment for the patients. It can be used to further distinguish between various diseases to insure the patient receives the highest quality and most efficient care available. For example, research done at University College London's found that there are three different locations on the DNA of patients afflicted with the disease Chron's Disease that were found to be coded for by genes(Elding et al., 2011). The three genes have different functions but were all found to be involved with the patient eventually developing Chron's Disease. This allows for further distinction between different types of Chron's disease, meaning a further personalised course of treatment.

This is similar to a result of the genomic profiling of breast cancer tumours. Four distinct types of breast cancer were found by were found by a research team at Cleveland University Hospital, meaning the cells of each subtype can be broken down and studied(University Hospitals Case Medical Center2013). By knowing the molecular underpinnings of a particular kind of breast cancer, the cure rates and, in the advanced disease setting quality of life and length of life can be improved.(University Hospitals Case Medical Center2013).

Another way gene mapping can be used to personalise medicine is by the study of pharmacogenetics, the study of the impact of genetic variation and drug responses(Galas & Hood2009). This is to customize the drug treatment and dosage to individual patients to get the most efficient and effective treatment possible. It'd mean the treatment could work faster, cheaper, and fail less often, as there'll be no need to go through multiple treatments until they work(U. S. Department of Energy Human Genome Project2003).

The use of personalised genetic medicine could save the NHS millions of pounds per year. Just purely with the disease of neonatal diabetes a reduce in cost was found as, "\$30, 437 at 30 years, \$12, 528 at 10 years, and \$23, 227 at20 years" compared to no genetic testing(Greeley et al., 2011). This is just one disease but putting into account all of the diseases this could be used for, overall millions could be saved for the NHS.

Healthcare providers can personalise medicine to have more precise diagnoses, higher quality care, better therapies, and access to more precise patient information. Furthermore the genetic information taken can be added

to large databases which can be shared with researchers and scientists worldwide.(The Genetic Information Nondiscrimination Act2008) They can use this information to take research forward at greater rates and will be beneficial.

Ethical concerns

Whilst there are many ways gene mapping can be beneficial to the treatment of patients, there are many concerns regarding how the process can be abused to violate the rights of the patients as well as have an overall negative result for the well being of the patient.

One concern is how the genetic tests will be evaluated and regulated for accuracy, reliability, and utility.(Haga2009) Whilst the treatments will be tailored to the patients to a certain degree it can never be completely specialized. The human population that this treatment will be used for will still be quite a lot of people instead of just that specific person. This will mean the tests will still have some degree of generalisations made for populations leading to less accuracy and reliability in the treatments. There could be factors leading patients to no longer fit the assumptions such as underlying conditions or lifestyle that could reduce the effectiveness of the treatments. Furthermore whilst the populations will be large enough to have generalisations made, they'll be small enough to mean less reliable results. The sample size will be small meaning the results could be less accurate as smaller populations would be more unpredictable and less stable.

Another concern is whether testing should be performed on patients suffering from incurable diseases. Pharmacogenetic testing could find gene

expressions associated with an unknown disease for which no known treatment is known, or a disease that's known to be incurable(Guttmacher & Collins2003). This could lead to the patient being upset about something they've no control over and becoming depressed(Guttmacher & Collins2003). There's potential for a large amount of decrease in mental well-being for the patient as well as a decrease in quality of life due to this depression. However, whilst the disease is currently unknown, and no treatment has yet been formulated, it doesn't mean there won't be one found in the future. Despite there being no known treatment, or information at all, for diseases the genetic mapping could be useful in the future once a treatment's been found. Lastly the process of genetic mapping may be vital in identifying or finding a treatment for the disease. In fact, some people were found to be willing to undergo testing simply to further science, in hopes it'll benefit their descendants.(G. I. N. A. 2008)

Another major concern of the use of gene mapping is how the information gathered will be used and who has access to it. One fear that's commonly expressed is that the information could be used to harm people, for example, deny them access to health insurance, employment, education, and even loans. The information could be used to discriminate between patients seeking medical insurance by increasing the price of insurance if they're found to be susceptible to diseases, or completely deny them coverage. Insurers insist that they don't currently perform genetic tests to obtain information, but the information should become available to them, citing the need to " avoid moral hazard"- the risk that patients who know they're susceptible to certain diseases will try and get insurance before they die at

normal rates.(Torrey2010) Employers may deny jobs to potential employees or restrict hours they can work if they're found to be susceptible to diseases. They may even go as far as force early retirement on them if the potential for diseases are found whilst they're already working for them.

However the US government's put in place certain legislations to protect the rights of the people. The Genetic Information Non-discrimination Act (G. I. N. A.) of 2008 is an Act of Congress of the U. S. A. designed to stop the use of genetic information in health insurance and employment(Boston Business Journal2008) The act stops insurers from denying coverage, or charging unfair amounts based solely on information found via genetic testing showing a predisposition to developing the disease in the future(Boston Business Journal2008) The legislation also stops employers from being able to use information found from genetic testing when making decisions to do with the initial hiring of employees, the firing of employees, or any decisions concerning the employees position in the company such as promotions and demotions.(Boston Business Journal2008)

The National Human Genome Research Institute(NHGRI) states that " NHGRI believes that legislation that gives comprehensive protection against all forms of genetic discrimination is necessary to ensure that biomedical research continues to advance. Similarly, it believes that such legislation is necessary so that patients are comfortable availing themselves to genetic diagnostic tests." (Godfrey2012). Whilst the legislation is slightly overly broad and may lead to an increase in frivolous law suits, it can be made less ambiguous and protect the rights of the people to lessen concerns over the future of the use of genetic mapping to personalise medicine(Godfrey2012).

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Conclusion

However despite these concerns I feel that the government, especially in the USA, is on the right tracks to providing clear legislation that'll protect the rights of people seeking to have genetic testing done with no repercussions on their lives. The legislations are fairly vague on some points but as the personalisation of medicine becomes more commonplace, a better idea of what the legislation will require can be formed and the legislation can be adjusted accordingly.

I conclude that I feel cost benefits as well as the increase on quality of life for patients outweigh any major concerns about the genetic testing and concerns regarding how the information will be used and who has access to it is currently well established and there are currently measures put in place that protect the rights of people that can be adjusted as the use of gene mapping becomes more common.

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