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Genetic risk and behavioural change

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Predictive genetic testing is currently used mainly for untreatable conditions, such as Huntington's disease, or prenatal detection of serious genetic disorders such as cystic fibrosis. Prenatal tests are usually accompanied by an offer of termination of affected pregnancies. Genes have now been isolated that are associated with potentially preventable diseases such as heart disease and cancer and with increased risk from smoking and obesity. This has raised the possibility of providing predictive information to many more people. Such information may eventually reduce disease by facilitating the development of better targeted and more effective treatment.

Informing people of their genetic susceptibility to disease may motivate them to change their behaviour to reduce their risks. However, changing behaviour is often difficult. In this article we review the limited evidence concerning behavioural responses to genetic information on risk. We use this and the literature on behavioural change to consider if and how behaviour might be changed in response to genetic information.

Summary points

- Changing behaviour is difficult
- Behavioural change is most likely in motivated people who participate in effective interventions
- Providing people with genetic information on risk may not increase their motivation to change behaviour and in some cases may decrease motivation
- Behavioural change may be more likely if people are persuaded that changing their behaviour can reduce the risk of an adverse health outcome and they are given access to evidence based interventions
- Further research is needed to evaluate programmes in which genetic risk information is given, including evaluation of different ways of giving information
- Effective interventions to change behaviour after provision of information on risk need to be developed

Methods

We searched Medline, PsycINFO, and the Social Science Citation Index using the following terms: health behavior; illness behavior; genetic screening or mass screening; cancer screening, health screening, mammography, or preventive medicine; genetic counselling, genetic disorders, genetic linkage, or genetics; and at risk populations. In addition, we searched citations of key papers, recent reviews of the subject, and conference proceedings (using the Web of Science).

Changing health related behaviour

Just telling people that they are at risk of developing a disease is rarely sufficient to change behaviour.[1] The interventions that are most likely to work are those that

are based on theories of behavioural change.[2 3] These theories suggest that motivation to change a health related behaviour is influenced by two sets of beliefs: firstly, beliefs about current behaviour (is it putting me at risk? will changing it reduce my risk?) and, secondly, beliefs about the ability to change behaviour (how easy will it be for me to change my behaviour? do I have the skills to adopt this new behaviour?).[4 5] Most studies use intention to change behaviour as the measure of motivation.

Although intention to change is associated with an increased likelihood of doing so, it predicts only about 30% of the variance in behavioural change. There are many reasons for this, but particularly important is the likelihood that people with good intentions fail to act on them.[6 7] Few interventions to induce change have been proved effective, and even these succeed in changing behaviour in only a minority. Interventions with evidence of effectiveness are available for smoking, physical activity, and attendance at screening programmes.[2 8]

Changing behaviour in response to genetic risk

Providing people with personalised information on risk is not new.[9] The question is whether responses will be any different if the information is based on DNA.

Responses to any information on risk are shaped by pre-existing perceptions and by the way the information is presented.[1 10] Genetic risk information could both increase and decrease motivation to change behaviour. It might increase motivation by strengthening the belief that current behaviour, combined with a genetic predisposition, is putting a person at increased risk of disease. It could also increase motivation by strengthening belief in the effectiveness of a treatment recommended on the basis of genotypic information. Alternatively, given a common perception that genetic risks are immutable, it might decrease motivation by weakening beliefs that changing behaviour will reduce risks.[11 12] Genetic risk information may also weaken belief in the ability to change behaviour—for example, among people who learn that they have a genetic vulnerability to nicotine addiction. We consider the evidence for these hypotheses in relation to three important health problems: cancer, heart disease, and smoking.

Inherited cancer

Isolation of genes for susceptibility to cancer has made it possible to provide predictive genetic testing for risk of breast cancer, hereditary non-polyposis colon cancer, familial adenomatous polyposis, and prostate cancer.[13–15] These advances enable appropriate detection and risk management strategies to be implemented years before cancer develops, with the potential to reduce mortality.[16 17] However, in order for such testing to reduce risk and mortality, people who are at risk must change their behaviour.

People with a family history of cancer vary in their use of screening. Women who are told they have an inherited predisposition to breast cancer (without genetic testing) show significant but modest increases in adherence rates to mammography screening.[18 19] However, rates of screening among people with a family history of bowel and prostate cancer are below the recommended levels and do not differ from those in the general average risk population.[20–22]

Before genetic testing was available, about 80% of women with a family history of breast cancer reported that an important motivation for such testing was to increase their use of screening and preventive options such as prophylactic surgery. However, initial data show no significant changes in screening behaviour after testing. For example, among women carriers in families with hereditary breast-ovarian cancer, 68% were adherent to mammography recommendations before BRCA1/2 testing and 68% reported adherence one year after receiving positive test results.[23] Similar rates were found in women with negative results. Little is known about the effect testing for cancer susceptibility has on other health behaviours such as smoking, activity levels, and diet.

Heart disease

People who have or perceive a family history of heart disease are not more or less likely than other people to engage in behaviours that reduce the risk of heart disease, such as not smoking or being physically active.[24 25] Perceiving a family history of heart disease was associated with a sense of fatalism in less than 15% of participants in a population based survey of over 2000 adults.[26] It remains to be seen whether people who have genetic testing to ascertain their risk of heart disease will have similar low rates of fatalism.

Although testing for an inherited predisposition to heart disease has been asserted to have no adverse psychological consequences, there is no evidence to support this assertion.[27] Among a subset of parents of newborns recalled after cholesterol screening for familial hypercholesterolaemia, positive results led to a sense of fatalism. This was based on the belief that genetically conferred risks are serious and immutable.[11] Further support for this interpretation was provided by the results of an experimental analogue study in which students were asked to imagine receiving either a DNA based risk assessment for heart disease or an unspecified risk assessment.[12] A randomised trial of the cognitive and behavioural impact of providing DNA-based risk information to relatives of patients with familial hypercholesterolaemia is currently under way.[28]

Educational resources

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Smoking

Gene variants that modify the adverse effects of health behaviours are much more common than susceptibility genes such as those that confer hereditary cancer and heart disease. An important example of gene-behaviour interaction is the genes that increase susceptibility to the adverse health effects of smoking.[29 30] Only one study has examined the effect of testing for common gene variants on smoking behaviour.[31 32] This randomised controlled trial compared the smoking beliefs and behaviours of smokers who received smoking counselling plus genetic test results indicating a twofold to threefold increased risk of smoking related lung cancer with those of smokers who received counselling only. Smokers who had genetic testing showed positive changes in perceptions of risk and beliefs about quitting. However, although they made more attempts to quit, they were no more likely to stop smoking. These preliminary results suggest that genetic information may not lead to behavioural changes, even when there is an unequivocal risk reduction strategy available.

Variants for genes involved in nicotine metabolism and the regulation of the neurotransmitters dopamine and serotonin have been associated with an increased likelihood of smoking,[33–35] smoking more cigarettes,[36] and a lower likelihood of stopping smoking.[35 37] However, these findings have not been replicated in all studies.[38 39] Such research could lead to the development of improved treatments for nicotine addiction and allow treatment to be targeted at those smokers most likely to benefit. However, the clinical integration of such information is likely to be complex. Moreover, people who are told that they are predisposed to nicotine addiction may become more fatalistic and reduce their efforts to stop smoking. Alternatively, they may be more motivated to participate in treatments tailored to their genotype because they believe that the treatments are more effective.

How might behavioural change be promoted?

The current evidence suggests that providing people with DNA derived information about risks to their health does not increase motivation to change behaviour beyond that achieved with non-genetic information. For some people, genetic information may even reduce motivation to change behaviour. Genetic information could facilitate behavioural change if people are offered effective risk reducing interventions that are tailored to their DNA based risk, as could be the case for smoking. This, however, is likely to be the exception for the foreseeable future.

People's motivation to change behaviour may be increased by strengthening two sets of beliefs: firstly their beliefs that changing behaviour can reduce risks and, secondly, their beliefs in their ability to change. The first set of beliefs might be altered by using bar charts to show health risks before and after behavioural change, similar to those used in programmes to manage cardiovascular risk.[40] Beliefs about ability to change might be altered by cognitively based interventions of the type used in cognitive behaviour therapy.[40 41] The effectiveness of these methods in increasing motivation to change behaviour in the context of genetic testing requires empirical investigation. As with all information on risk, behaviour is more likely to be changed if the information is presented as part of an intervention that is known to be effective in changing behaviour

It will also be important to ensure that people who are found not to be at increased risk do not develop a false sense of reassurance, feeling invulnerable to the adverse effects of their risky behaviour. Such people need to understand that they have a residual (albeit lower) risk of developing the condition and be encouraged to engage in risk reducing behaviours relevant for the general population.

The human genome project shows what can be achieved with sufficient resources and concerted international effort. Perhaps what is needed now is a human behavioural change project to ensure that applications from the human genome project are realised in practice.

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Giving people information about their genetic risk of developing common disease will be helpful if they can be persuaded to adopt healthy lifestyles that reduce risk