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The effect of genetic test-based risk information on behavioral outcomes: a critical examination of failed trials and a call to action

Jehannine Austin[1,2,*]

[1]Department of Psychiatry, University of British Columbia, Vancouver, Canada

[2]Department of Medical Genetics, University of British Columbia, Vancouver, Canada

Abstract

Encouraging individuals at risk for common complex disease like heart disease, cancer and diabetes to adopt lifestyle changes (e.g. smoking cessation, exercise, proper nutrition, increased screening) could be powerful public health tools to decrease the enormous personal and economic burden of these conditions. Theoretically, genetic risk information appears to be a compelling tool that could be used to provoke at-risk individuals to adopt these lifestyle changes. Unfortunately however, numerous studies now have now shown that providing individuals with genetic test-based risk information has little to no impact on their behavior. In this article (a commentary, not a systematic review), the failed trials in which genetic information has been used as a tool to induce behavior change will be critically examined in order to identify new and potentially more effective ways forward.

Keywords

heuristics; biases; behavioral economics; lifestyle modification; behavioral change; genetic risk; diabetes; cancer; heart disease; complex disorders; genetic counseling

THE BURDEN OF COMMON COMPLEX DISEASE AND THE PROMISE OF GENETIC INFORMATION

Common diseases like heart disease, cancer, and diabetes exert an enormous burden on affected individuals and their families, as well as on healthcare systems. Risk for many of these conditions can be lowered through modifications to diet and exercise, and by quitting smoking. Further, for some of these conditions, participation in screening can allow for early intervention, which promotes the best outcomes.

The provision of genetic risk information presents a compelling theoretical strategy by which to prompt those at risk to adopt risk-reducing behaviors. However, numerous studies

*Correspondence to: Jehannine Austin, UBC Departments of Psychiatry and Medical Genetics, Rm A3-112 - 3rd Floor, CFRI Translational Lab Building, 938 W28th Ave, Vancouver, BC, V5Z 4H4. jehannine.austin@ubc.ca, phone: 604-875-2000 (ext.5943), fax: 604 875 3871.

have now tested whether receiving genetic test-based risk information encourages those at risk to engage in increased screening, smoking cessation, and/or exercise, and all have produced disappointing results (e.g.[Grant et al., 2012; Marteau et al., 2010; Weinberg et al., 2014]), even when the individuals sought out the information themselves, via direct access genetic testing [Boeldt et al 2012].

The need to develop interventions that effectively prompt at-risk individuals to engage in risk-reducing behaviors is urgent, and the cost of implementing trials is great. Thus, it is crucial to examine the trials that have been conducted to date, in an attempt to identify new – and potentially more effective – ways to realize the benefits of genomic medicine.

FOUNDED ON FLAWED ASSUMPTIONS?

To date, the interventions designed to promote behavior change among at-risk individuals that have been unsuccessfully trialed appear to have typically been founded the simple strategy of uni-directional transmission of information from researcher/healthcare provider to at-risk individual. In adopting this approach, these trials have been founded on an implicit assumption of bounded rationality – that is, our behavioral decisions are simply a product of the information we have available, and our cognitive abilities [Gigerenzer & Selten, 2002]. While at face value this assumption seems reasonable, it actually fails to account for well-established findings that heuristics and biases influence how people make decisions.

There are many heuristics and biases that influence decision-making (it is beyond the scope of this brief article to attempt to review them exhaustively), but there are two – anchoring bias and affect heuristic - that may be particularly pertinent to peoples' decisions about health behavior change when presented with genetic risk information, neither of which appears to have yet been addressed in trials.

ANCHORING BIAS

Anchoring bias refers to the tendency to anchor too heavily to the first piece of information received on a given topic. In the context of the trials of interventions in which genetic risk information is provided with a view to provoking behavior change, the first new information that is presented is likely to be about genetics. Given that people generally expect treatment or prevention strategies for a given condition to be compatible with their understanding of its cause [Walter et al, 2004], anchoring bias may lead recipients of genetic risk information to feel that behavior change as a strategy to reduce that risk may not make sense. For example, an individual who just learned of their genetic risk for diabetes could (without necessarily explicitly articulating it) feel that behavior change as a strategy to reduce risk is futile because anchoring bias leads them to over attribute the etiology of the condition to genetics – the suggested prevention strategy is incompatible with their understanding of cause of illness. Similarly, for those who enter a trial with a pre-existing genetic attribution for the illness for which they are at risk, anchoring bias may obstruct their ability to appreciate that the genetic risk information provided demonstrates that illness is not inevitable, and that there are actions that could be taken to reduce risk.

Uncovering and addressing anchoring bias through a bi-directional exchange of information between healthcare provider/researcher and at-risk individual may be key in effecting behavior change. Research is urgently needed to directly address this issue. Further, in my own clinical experience, I have seen that (for example) people can often appreciate that others' diabetes may have been caused - at least in part - by lifestyle factors, while still believing that *in their own particular circumstance* the condition was entirely genetically determined. For this reason, it would seem to be critical to ensure that the information about cause of a condition is tailored and explicitly applied to the individual in question, but again, this issue requires rigorous quantitative investigation.

AFFECT HEURISTIC

Evidence shows that emotions play a key part in analytical decision-making [Kahneman, 2011; Slovic et al., 2004]. Further, a systematic review of the existing literature on risk communication in genetics concluded that when communicating information about risks, "the supportive or emotional elements of counseling (provide) more benefits to users than the informational or educational elements" [Edwards et al., 2008].

Effectively engaging an at risk individual in a health behavior change – such as eating more healthily – might require that they overcome the affective barrier of guilt and/or shame associated with accepting the possibility that poor eating habits up until this point may have contributed to their increased vulnerability. Failing to attend - in a meaningful manner - to the emotional ramifications of the information we provide about causes of a condition acts as a barrier, not only to the individual's ability to process the information that is being provided [McCarthy-Veach et al., 2007] but also to their ability to act on that information. Conversely, by attending effectively to the emotions that can be provoked by making personal meaning from a shifting understanding of cause of a condition, people may be more empowered to engage in behavior change.

It is worth noting that many of the interventions trialed have been given monikers that include the word "counseling." This implies a psychotherapeutic attention to emotion that is not *necessarily* actually present. For example, the "lifestyle counselling" of Jorgensen et al's study [Jorgensen et al., 2014] reported using motivational interviewing which (though sometimes described as "counseling") is a "form of guiding to elicit and strengthen motivation for change", that was explicitly described by its originators as not being psychotherapeutically focused ("motivational interviewing […] is not client-centered therapy") [Miller & Rollnick, 2009].

Other studies have claimed to have used "genetic counselling" (a specialist healthcare discipline that incorporates psychotherapeutic elements [Resta et al., 2006]) to change behaviour, [Grant et al., 2012] but in fact, even though delivered by genetic counselors, these brief, information-focused interventions were not described as being designed to attend to emotion, as psychotherapeutically-oriented genetic counseling ideally would.

PSYCHOTHERAPEUTICALLY-ORIENTED GENETIC COUNSELING: A SOLUTION?

Genetic counseling (as provided by specialist-trained providers) is an intervention that is designed to help people "understand and adapt to the medical, psychological and familial implications of genetic contributions to disease" [Resta et al., 2006]. Though often thought of as being a "neutral" intervention [Blumenthal-Barby et al., 2014] in which behavioral recommendations are not made, this actually applied primarily to prenatal settings. That is, while genetic counselors do not advise people whether or not they should have children, they do – for example - suggest increased screening for individuals at high risk of cancer, or discuss the use of strategies to protect mental health amongst those at risk of psychiatric illness [Inglis et al., 2015]. Genetic counseling integrates bi-directional communication regarding illness etiology in the context of a psychotherapeutically-oriented encounter, and has been shown to increase empowerment and self-efficacy (outcomes that could be conceptualized as precursors to behavior change) [Inglis et al., 2015]. Though based on retrospective review rather than intervention study, other work has shown that genetic counseling resulted in greater adherence to medical management plans amongst patients [Rutherford et al. 2014]. As such, psychotherapeutically oriented genetic counseling warrants attention regarding its potential for integrating genetic risk information to effectively elicit behavior change in individuals at-risk for common diseases.

CONCLUSION

The public health and economic costs of common conditions like cancer, diabetes and heart disease are high, and trials of using genetic information in an attempt to effect behavior change are costly. Though behaviour change has been demonstrated to be a complex process [Michie et al, 2011], the trials of this nature that have been conducted to date appear to have been founded on the assumption of bounded rationality, and have not explicitly attended to the well-documented influence that heuristics and biases have on human decision making processes. Addressing the potential effects of the anchoring bias and affect heuristic on responses to genetic risk information may be key to effecting meaningful risk-reduction behaviors. Studies involving explicit attention to these issues are urgently needed. Broadly, given that there is variability in how interventions like "motivational interviewing" and "genetic counseling" may be operationalized (ranging from more to less psychotherapeutically oriented), there is a need for the interventions used in studies to be fully explicated in reports, with this in mind. Interventions like psychotherapeutically-oriented genetic counseling warrant investigation regarding their potential to effect health behavior change. In considering this possibility, feasibility becomes important, and concern has been raised about access to genetic counselors [Weinberg et al., 2014]. Importantly however, 1990 data were cited in support of this concern. Genetic counselor numbers in North America have grown by 75% since 2006 and most patients wait less than two weeks for an appointment (www.nsgc.org) - this compares favorably to other medical professionals' wait times, and suggests engaging with genetic counselors to address this important problem may be feasible.

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