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Communication of genetic-based risk of disease to influence behavior change

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Hollands et al recently published a systematic review in the BMJ on the impact of communicating genetic risk of disease on risk-reducing behavior. (Hollands, 2016) The basic premise was to ask if communicating genetic risk factors for certain diseases would be sufficient to cause behavior change in individuals. Specifically, would this be sufficient to cause a change in behaviors related to the development of the disease at risk. This is a well-written paper that utilizes the appropriate rigorous methodology. The conclusion is that “communicating DNA based disease risk estimates has little or no effect on risk-reducing health behavior.” A secondary outcome explored was if the DNA risk information caused a change in motivation to change behavior. Despite having only a few studies that included this outcome, there was no evidence that behavioral intent changed. This supports the main finding of the analysis as behavioral intent is typically easier to find than actual behavior change. For example, people who smoke cigarettes know that this practice is bad for their health, and many smokers have intent to quit. However the knowledge of potential adverse health outcomes seldom results in sustained quit attempts. While these results may be disappointing, they should not be unexpected. Knowledge may be necessary to cause behavior change but it is rarely sufficient.

There are many health behavior theories that are used to explain the disconnect between knowledge and action. For example, the Health Belief Model (HBM) was used to explain why persons choose whether or not to participate in medical screening programs (Becker, 1974, Janz, 1984). Some of the constructs from the HBM may help to explain the relationship between knowledge of DNA-based risk and behavior change. Perceived severity of the disease they are at risk of developing may alter a person’s willingness to engage in the recommended behavior. An individual who is informed of an increased risk of a particular disease may decide that if they actually get the disease in question, the consequences of the disease are tolerable and/or treatment options would cure the disease or reduce symptoms to a manageable level. Similarly the perceived benefit of the recommended behavior change may influence whether or not they are willing to adopt and continue the behavior change. An individual may not believe that the recommended behavior change will significantly alter their odds of contracting the disease. They may also believe that the recommended behavior change is unrelated to altering their risk of disease. There is variance in how people might value continuing their current lifestyle compared to the value of disease prevention. When an

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individual engages in the recommended behavior, there is an immediate cost. This may be financial cost, time/opportunity cost, and/or a decrease in their quality of life. The benefit of reduced risk of disease is a future benefit with no guarantee of a positive outcome. Another consideration is the perceived risk of disease. A person who is informed of increase risk of disease based on DNA may believe the risk is real; however, they may also believe this increased risk is so minimal as to not warrant any lifestyle changes. Alternately, they may believe their increased risk was so high that there is no way they will be able to avoid the disease regardless of behavior change.

None of this should be interpreted as a lack of utility of DNA-based risk information. In 2015, the American College of Medical Genetics and Genomics (ACMG) published a position statement on how to define clinical utility of genetics and genomics services. Clinical utility occurs when "...diagnoses of genetic diseases that are medically actionable with clear benefit to patient outcomes..." (ACMG, 2015) If knowledge alone is insufficient to cause behavior change, how can DNA-related risk information be used to change behavior and ultimately improve health outcomes? As suggested by Hollands et al, a good starting point is to use this information as part of the larger conversation about health care. To maximize the potential of DNA-related risks to change behaviors here are a few key points.

- The information needs to be understood by the patient. Understanding increased risk of a disease because of genetics/genomics is independent of a person's IQ. This has more to do with expertise in a certain topic area. It may seem counter-intuitive to discuss such a complex science at a 5th grade reading level with a well-educated person. However; to increase understanding and retention the interventionist should meet patients "where they are." When a patient is told by their provider they are at increased risk, how do they interpret that increase? Communication of risk as a dialogue and discussion between patient and provider is much more effective than a lecture. Giving patients the opportunity to repeat back what they heard in their own words greatly improves effective communication.
- The information has to be meaningful to the patient. In other words, why should the person care? This is analogous to the difference between statistical significance and clinical significance. Information should be perceived by individuals as accurate, unbiased, and from a trusted source. Tailored and targeted information will mean more to an individual as compared to generic statements of risk. Genetic predispositions to diseases rarely have overt signs which sometimes makes explaining the importance of the behavior change difficult.
- The information has to be actionable. A discussion on what can be done to reduce risk has to include behaviors that are under the patient's control. Additionally, the suggested behavioral goals should be specific and measureable. Discussions with individuals about behavior change are more effective if the person can articulate the recommendations in their own words and indicate a willingness to try. It should be expected that some people will be resistant to

recommended behaviors. Understanding why they are opposed to a specific recommendation is often helpful in overcoming this barrier.

- The information should be reinforced. Most successful behavior change interventions include multiple instances of the feedback, which includes reiterating the underlying risk as well as reinforcing positive behavior changes. A brief telephone follow up or text messages can also reinforce the importance of the recommended behavior change. For those who have initiated changes, this serves as a reinforcement and for those who have not, a reminder to begin. For genetic-based risk this can be especially important considering the lack of external cues to action for the individual.

Genetic-based risk can be powerful when used with evidence-based interventions such as brief motivational interviewing or Screening, Brief Intervention, Referral to Treatment which is often referred to as SBIRT. Hollands et al make mention of the one study where a “medium sized effect on behavior” was found (McBride, 2002). For this particular study the DNA information was paired with the provision of telephone counseling. Hollands et al adds an important piece to the body of literature of behavioral research. A systematic review showing the negative results of the causal relationship between provision of genetic risk information and behavior change is important to document. Additional research is needed to examine the role of genetic risk information in combination with other activities to develop efficacious behavioral interventions. For more information on the HBM and other health behavior theories, please read “Theory at a Glance” published by the National Cancer Institute (NCI, 2005).

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