Published in final edited form as:
Curr Cardiovasc Risk Rep. 2011 February ; 5(1): 7–9.

Despite Underestimated Familial Risk by Self-Report, Family History Correlates with Perceived Risk and Worry about Chronic Diseases Such as Coronary Heart Disease and Diabetes

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Introduction

The Family Healthware™ Impact Trial (FHITr) was a cluster-randomized controlled trial of a Internet-based tool that recorded each participant's family history of specific conditions and stratified his/her familial risk. The trial assessed whether participants in the intervention arm changed their health behaviors and use of medical services after using the Internet-based tool.

Aims

This article reports the associations between familial risk as assessed by the Internet-based tool and risk perception, worry, and perceived control of six conditions, including coronary heart disease (CHD) and diabetes.

Methods

This trial recruited 3,786 patients aged 35–65 years from 41 primary care sites in the United States who did not have one of the six conditions of interest: CHD, diabetes, stroke, breast cancer, colon cancer, and ovarian cancer. All participants answered baseline questions about health behaviors and their perceived personal risk, worry, and sense of control concerning the six conditions. The 2,330 participants at the 23 intervention sites then used the Internet-based Family Healthware™ tool (US Centers for Disease Control, Atlanta, GA) which asked about first- and second-degree family members with any of the six conditions. Based on these responses, participants at the intervention sites were stratified as having "weak," "moderate," or "strong" familial risk and were given prevention recommendations specific to their risk profiles. Participants at the control sites were given brief, generic messages. This article limits its analyses to the intervention arm and used multivariate analysis of variance to compare the perceived risk, worry, and control for each condition among participants with weak, moderate, and strong familial risk after adjustment for gender, age, health status, health behaviors, body mass index, education, and practice site.

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Disclosure Jason L. Vassy reports no potential conflict of interest relevant to this article. James B. Meigs reports no potential conflict of interest relevant to this article.

Results

The 2,330 participants had a mean age of 50 years and 70% were female, 91% were white, and 72% were college educated. For all six conditions, greater perceived risk was moderately correlated with greater worry (Pearson correlation coefficients 0.30–0.53; $P<0.001$ for all), but greater perceived risk was only weakly associated with lower control for most conditions. In general, participants rarely worried about these conditions and thought they could prevent all of the conditions except ovarian cancer. After multivariate adjustment, increased familial risk category was associated with increased perceived risk and worry ($P < 0.001$ for most comparisons) but not perceived control. Step-wise regression models that also included demographic and personal risk factors showed that family history–risk category explained 2–16% of the variance in perceived risk for the six conditions. Forty-eight percent to 79% of people with moderate or strong familial risk thought they were at average or below-average risk. Only 4–12% with average or below-average risk thought they had moderate or strong familial risk.

Discussion

A stronger familial history of each of six conditions is associated with increased perceived risk and worry about that condition. Patients have an optimistic bias about their familiar risk for these six conditions.

Comments

Although medical care providers may be entering a new era of “personalized medicine,” their efforts at targeted prevention and therapy will be only as good as their ability to collect personalized information from their patients. Hundreds of genetic tests are now available to clinicians, and an accurate family history might help guide their targeted use [1]. Such a detailed family history, however, may be a casualty of the increasing workload placed on medical providers [2].

Recognizing the current gaps in clinical medicine’s risk assessment methodology, the Office of Genomics and Public Health at the Centers for Disease Control and Prevention (CDC) sponsored the FHITr Trial from 2005 to 2007 to evaluate the use of a patient-driven, Internet-based risk assessment tool. This tool ascertained a participant’s health behaviors, including diet, exercise, smoking, and cancer screening, in addition to a detailed family history of six common conditions in first- and second-degree relatives. Evidence-based risk algorithms then delivered personalized risk and prevention messages to the participants [3]. Of the 15.7% of invitees who participated in the study, the risk tool found that the majority were at greater than average risk for a least one condition, which was significantly under-appreciated by the participants themselves before they used the tool. The directionality, however, was consistent: participants at greater familial risk perceived their risk as greater and worried more about that condition. Perceived risk, however, was not associated with the amount of control they felt in being able to prevent the disease.

Current questions concerning disease risk might be grouped into two large categories: how do we accurately assess risk and how do patients interact with that risk assessment? In August 2009, the National Institutes of Health (NIH) State-of-the-Science Conference on Family History and Improving Health reported that we have much work to do to answer these questions [2]. It found that self-reported family history can be specific but very insensitive for many conditions. For CHD and diabetes, the Framingham Offspring Study reported a sensitivity of 44% and 51–61%, respectively, but specificities of 100% [4]. Whether the targeted addition of genetic testing might improve risk assessment is an active

area. In Framingham, the addition of a genetic risk score for diabetes did not meaningfully improve the risk prediction achieved by traditional demographic, anthropometric, and laboratory risk factors alone [5,6], but risk prediction should improve as genetic knowledge increases.

Nevertheless, how patients interact with such risk assessment is a result of the complex interplay among numerous factors, including health beliefs, attitudes, and degree of self-efficacy. Risk might be a motivator, and the main report from the FHITr trial will address whether the Internet-based tool changes health behaviors [3]. In the meantime, the NIH conference found very few studies on whether a familial risk assessment improves motivation. Perhaps equally importantly, familial risk assessment seems not to significantly increase anxiety in the weeks afterwards [2]. We are starting to accumulate an evidence base on whether conveying genetic risk can be a motivator. The Risk Evaluation and Education for Alzheimer's Disease (REVEAL) trial in patients with a family history of Alzheimer's disease found that participants who learned that they carried the ε4 risk allele were more likely than non-carriers to report improvements in diet and exercise 1 year after disclosure [7]. Similarly, the Genetic Counseling and Lifestyle Change for Diabetes Prevention (GC/LC) trial will address whether disclosure of increased genetic risk improves health behaviors in patients already at high clinical risk for type 2 diabetes (http://clinicaltrials.gov identifier NCT01034319). How an individual interprets and acts on risk information, be it familial or genetic, will have significant bearing on the clinical efficacy of such new risk assessment tools.

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