Parents’ Concern About Their Own and Their
Children’s Genetic Disease Risk

Potential Effects of Family History vs Genetic Test Results

Beth A. Tarini, MD, MS; Dianne Singer, MPH; Sarah J. Clark, MPH; Matthew M. Davis, MD, MAPP

Objective: To evaluate the effect of the genetic risk information source (family history vs genetic test results) on parents’ concern about their own and their children’s genetic disease risk.

Design: Randomized trial using a Web-enabled survey.

Setting: Internet survey.

Participants: National sample of 1342 parents.

Intervention: Parents first received a vignette about their hypothetical genetic risk, randomized as either a family history assessment or genetic test results. Next, parents received a vignette about their youngest child’s hypothetical genetic risk, similarly randomized.

Main Outcome Measure: Parents’ concern about their own and their child’s genetic disease risk.

Results: The response rate was 71.2%. Parents were more likely to be concerned about their own disease risk when the risk estimate came from a family history assessment vs a genetic test result (odds ratio, 1.96; 95% confidence interval, 1.44-2.68). In contrast, information source was not associated with parents’ concern about their children’s disease risk. Parents’ level of concern about disease risk was identical for themselves and their children 73% of the time in the same scenario. When concern differed, parents almost always reported greater concern about disease risk for their children.

Conclusions: Positive family history of disease generated greater concern about parents’ own risk of inherited disease than did genetic test results. This effect was not evident for parents’ concern about their children’s risk. As genetic tests emerge and become increasingly available, physicians must not overlook the effect of family history on an individual’s concern about disease risk.


As the genetic origins of diseases become more evident and direct-to-consumer marketing of genetic testing becomes more widely available, the public will increasingly be faced with the task of considering their genetic risk of disease. Individuals’ perceptions of genetic disease risk have been shown to influence health care decisions about prophylactic surgical interventions (such as mastectomy, oophorectomy, and colectomy) and belief in the effectiveness of medications. In pediatrics, genetic risk assessment is further complicated by the fact that parents must make health care decisions based on an evaluation of their children’s genetic risk. How parents’ concern about their own genetic risk differs from their concern about their children’s genetic risk is not known.

In general, genetic risk estimates for children and adults are generated from clinical assessments of family history, genetic testing, or a combination of the two. Use of family history to assess genetic disease risk has long been an important part of medicine. However, public enthusiasm about advances in genetic technology may promote a popular sense of “genetic determinism” about genetic test results, that is, the belief that disease is mostly determined by one’s genetic constitution. There is concern that such genetic determinism may be strengthened by the growing access to genetic testing available for purchase online.

Using a nationally representative sample, we tested the hypothesis that parents would be more concerned about their own and their children’s genetic risk of disease if this risk estimate came from a genetic test re-
We conducted a randomized trial using a Web-enabled survey in a nationally representative population sample. This study was approved by the University of Michigan institutional review board.

Participants

Participants were randomly selected from a nationally representative online panel (KnowledgePanel; Knowledge Networks, Menlo Park, California) of adults (>18 years of age) compiled through probability sampling of online and offline members of the US population. KnowledgePanel members are selected using random-digit dialing of listed and unlisted numbers. Panel members are not limited to current Web users or computer owners. Panel members are recruited by telephone and, if necessary, are provided Internet access and hardware. KnowledgePanel has served as the source of randomly drawn, nationally representative samples in published peer-reviewed studies of health and health care behavior.

This study was part of a larger survey of parents and non-parents. As a result, parents were oversampled to provide sufficient statistical power to evaluate parental perceptions of disease risk.

Methods

STUDY DESIGN

Participants were randomly selected from a nationally representative online panel (KnowledgePanel; Knowledge Networks, Menlo Park, California) of adults (>18 years of age) compiled through probability sampling of online and offline members of the US population. KnowledgePanel members are selected using random-digit dialing of listed and unlisted numbers. Panel members are not limited to current Web users or computer owners. Panel members are recruited by telephone and, if necessary, are provided Internet access and hardware. KnowledgePanel has served as the source of randomly drawn, nationally representative samples in published peer-reviewed studies of health and health care behavior. We used univariate analyses to determine the distribution of the demographics of the respondents.

We used χ² tests to assess parents’ level of concern about their own disease risk, comparing parents who received the family history results with those who received the genetic test results. We repeated this analysis, focusing on parents’ concern for their children’s disease risk. Of note, we do not report findings from adult respondents who did not have a minor child living in the household; their levels of concern about disease risk were not significantly different from concern expressed by parents (data not shown).

We then performed a simple logistic regression analysis to determine the odds of a parent reporting concern (either “very concerned” or “somewhat concerned”) about their own risk of disease after receiving genetic risk information from a family history vs a genetic test result. We repeated this analysis focusing on parents’ concern for their children’s disease risk. Based on our clinical experiences and expectations, we examined the interaction between parent age and gender for each of these analyses.

We used κ statistics and descriptive bivariate statistics to examine the consistency of parents’ reported concern for themselves compared with their concern for their children when parents received the same information source (family history or genetic test results) for themselves and their child. We used χ² tests for categorical independent variables and logistic regression for continuous independent variables to explore the associations between demographic characteristics and the following outcomes: parents’ concern about their own risk of disease, parents’ concern about their child’s risk of disease, and parental report of greater concern for their children’s disease risk compared with their own. All analyses were performed using a software program (Stata 8; StataCorp, College Station, Texas).

RESULTS

The survey was presented to 1886 parents, of whom 1342 agreed to participate (response rate 71.2%). The demographic characteristics of the study population are given in the Table.
EFFECT OF INFORMATION SOURCE ON PARENTS’ CONCERN ABOUT THEIR OWN AND THEIR CHILDREN’S GENETIC DISEASE RISK

When parents received disease risk information from family history vs a genetic test result they had an increased odds of reporting concern about their own disease risk (odds ratio, 1.96; 95% confidence interval, 1.44-2.68) (Figure 2). Women were more likely to be more concerned about their disease risk than were men, regardless of the scenario (odds ratio, 1.8; 95% confidence interval, 1.32-2.46). No other demographic characteristics listed in the Table were significantly associated with a greater parental level of concern about their own disease risk, regardless of scenario. We found no interaction between parent gender and parent age with respect to parental report of concern.

Parents’ level of concern about their children’s genetic risk of disease showed a pattern that was distinct from parents’ concern about their own risk. We found no significant difference between parents’ concern about their children’s disease risk and the source of the risk information (Figure 3) (P = .29).

PARENTS’ CONCERN FOR THEMSELVES COMPARED WITH THEIR CONCERN FOR THEIR CHILDREN

When parents were randomized to the same information source for themselves and their child, 73.3% of the time they reported identical levels of concern. Parents were somewhat more consistent in their reported levels of concern when the risk information came from family history vs a genetic test (κ = 0.67 vs κ = 0.54). When parents rated concern differently, they almost always reported a higher level of concern for their children than for themselves (Figure 4). Parents were more likely to report a higher level of concern for their child than for themselves when the source of the risk information for
Individuals’ concern about their genetic risk of disease can significantly influence the decisions they make about their health. It is possible that the source from which individuals receive their genetic risk information can affect their level of concern. In hypothetical scenarios posed to a nationally representative sample, we found that parents were more likely to be concerned about their own genetic risk of disease when they received this information from a family history assessment rather than from a genetic test result. On the other hand, when contemplating their children’s genetic risk of disease, parents’ concern was not influenced by the information source. Parents were most consistent in their reported level of concern about their own genetic risk of disease when the disease risk information came from a family history.

To our knowledge, this is the first study to examine the independent effect of the source of genetic risk information while focusing on parents and their children. These findings regarding the influence of family history on parents’ concern about their own disease risk indicate that the public may not view genetic tests as deterministically as some may have feared. Rather, it seems for many adults that family history—in effect, one’s “observed” genetic destiny—trumps inherited disease risk as measured by genetic tests. Having family members who develop a disease may lead individuals to interpret their risk as more salient compared with test results that may seem more abstract.

In previous studies of hypercholesterolemia and Alzheimer disease, individuals with family histories of these diseases were influenced more strongly by a combination of genetic testing and family history results than by family history information alone. Following this work, in the present study, we sought to contrast the separate, independent effects of information provided in the context of family history vs the context of a genetic test result. We did so using hypothetical scenarios to provide the participants the opportunity to imagine a disease that might be most relevant to their lives. These findings are relevant in the context of the increasing availability of direct-to-consumer genetic testing, through which individuals without a known family history of disease may seek genetic testing information. We did not find evidence to support the fact that genetic testing results would increase parents’ concern about their own or their children’s risk of disease beyond levels conveyed through positive family history of disease.

These findings have several implications. First, like other studies, this study supports the notion that an individual’s concern about his or her disease risk is not based solely on a rational interpretation of numerical risk but rather may be affected by a variety of cognitive and emotional factors. In this study, despite the fact that we provided participants with identical numerical risk estimates, differences in the source of genetic risk information yielded varying concerns about disease risk. Second, these findings highlight the strong influence of family history considerations on individuals’ assessment of their own genetic risk. Even as genetic tests become increasingly available in the current genomic era, physicians must not overlook the influence of family history and, together with patients, should continue strides to track and evaluate family health history.

This study also generated findings that have important implications for genetic risk assessment in pediatrics. Parents generally had the same or greater concern about disease risk for their children as for themselves. However, parents were more likely to report a greater concern about their child’s disease risk compared with their own when that information was generated by a genetic test. These findings suggest generational differences in parents’ concern about their children’s genetic risk, which may affect parents’ roles as proxy decision makers for their children. Consequently, health care providers must be mindful that parents’ concern about their own genetic risk cannot be used as reliable substitutes for their concern about their children’s genetic risk.

These findings should be interpreted with some important caveats. First, we did not identify a specific disease in the vignettes. It is likely that the relative influence of family history vs genetic test results on perception of disease risk varies by the disease in question, the clinical scenario, and other real-world factors. However, the goal in this study was to evaluate the independent effect of family history and genetic test results on individuals’ perception of genetic disease risk without potential effect modification generated by a specific disease label or other situational factors. We attempted to make the disease scenario as meaningful as possible by presenting a disease that was characterized as having “severe symptoms” as an adult. Moreover, the randomized study design provides internal validity and avoids the selection biases inherent in observational studies regarding specific diseases. As a result, this study provides a basis on which to continue to examine factors that affect parents’ perceptions of their own and their children’s genetic disease risk.

In this study, we asked participants about their concern for developing a disease. We did so using a scale with a familiar format but that had not been psychometrically validated, and we did not ask about their intentions to act based on this information. However, we focused the analyses on respondents with greater levels of concern because we believed that this group would be most likely to act. Those actions could be positive (eg, engagement in healthy preventive behaviors) or negative (eg, having feelings of anxiety and helplessness). The influences that lead from heightened level of concern to positive or negative actions remain unknown.

We could not examine the effect of child age on parents’ perception of their children’s genetic disease risk. We expect, however, that the focus on a child’s risk for a disease that appears in adulthood may dampen the effect of child age, to some degree.
This survey was conducted using a nationally representative, Web-enabled panel. The participation rate among members of the panel who were contacted was 71.2%. In turn, the makeup of the panel is itself affected by a person’s desire to participate when initially contacted by panel management through random-digit-dialing methods, creating some level of participation bias. After initial enrollment in the panel, participants are not informed of the content of subsequent efforts. Thus, because panel members are not invited in the context of genetic testing research, we believe that it is unlikely that participation affected these results in a meaningful way. Despite their limitations, national surveys using Internet panels recruited through sophisticated methods have made valuable contributions to the literature on a broad variety of topics, including a recent article by Bleakley and colleagues regarding public opinions on sex education, work by Davis and Fant regarding childhood and adult vaccinations, and work by Klein and colleagues regarding patterns of adolescent smoking.

In summary, contrary to the hypothesis, we found among parents that family history as an expression of genetic risk generated greater concern about disease than did genetic test results. We also found that the source of the risk information (eg, family history or genetic test result) did not affect parents’ concern about their children’s disease risk. These findings reinforce the importance of family history in the general public’s assessment of their risk of developing various diseases and emphasize to physicians that they should be mindful of the impact of family history on a patient’s interpretation of risk. Even as technological advances in genetics make genetic tests more easily accessible and more broadly applicable, family history will likely remain a meaningful part of a health evaluation and discussions of disease risk with parents.

Accepted for Publication: April 8, 2008.
Correspondence: Beth A. Tarini, MD, MS, Child Health Evaluation and Research Unit, University of Michigan, 300 N Ingalls St, Room 6C11, Ann Arbor, MI 48109-0456 (btarini@umich.edu).

Author Contributions: All authors had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: Tarini, Clark, and Davis. Acquisition of data: Tarini and Singer. Analysis and interpretation of data: Tarini, Clark, and Davis. Drafting of the manuscript: Tarini, Clark, and Davis. Critical revision of the manuscript for important intellectual content: Tarini, Singer, Clark, and Davis. Statistical analysis: Tarini and Davis. Obtained funding: Tarini, Clark, and Davis. Administrative, technical, and material support: Singer and Clark.

Financial Disclosure: None reported.

Funding/Support: Funding for this study was provided by the Clinical Science Scholars Program at the University of Michigan (Dr Tarini).

Role of the Sponsor: The funder had no role in the design and conduct of the study; the collection, management, analysis, and interpretation of the data; and the preparation, review, and approval of the manuscript.

Disclaimer: The views expressed herein do not necessarily represent the views of the University of Michigan.

Additional Information: The research was conducted as part of the C.S. Mott Children’s Hospital National Poll on Children’s Health (http://www.med.umich.edu/mott/pch).

Additional Contributions: Achamyeleh Gebremariam, BS, assisted with the statistical analysis.

REFERENCES