Parents' Attitudes Toward Pediatric Genetic Testing for Common Disease Risk

WHAT'S KNOWN ON THIS SUBJECT: Direct-to-consumer genetic tests assess large panels of genetic variants associated with risk for common health conditions and traits. The swift pace of these developments raises expectations and concerns about their social and clinical impact.

WHAT THIS STUDY ADDS: As genetic susceptibility testing for common, adult-onset health conditions proliferates, pediatricians should anticipate parents' interest in testing children and be prepared to facilitate informed decision making about such testing.

abstract

OBJECTIVE: To describe parents' attitudes toward pediatric genetic testing for common, adult-onset health conditions and to identify factors underlying these attitudes.

PARTICIPANTS AND METHODS: Parents (n = 219) enrolled in a large, group-practice health plan were offered a "multiplex" genetic test for susceptibility to 8 common, adult-onset health conditions and completed an online survey assessing attitudes and beliefs about the risks and benefits of the test for their child, their willingness to consider having their child tested, and other psychosocial variables.

RESULTS: Parents viewed the benefits of pediatric testing to outweigh its risks (positive decisional balance) and were moderately interested in pediatric testing. Variables associated with positive decisional balance included greater interest in knowing about gene-health associations in their child, anticipation of less difficulty understanding their child's genetic health risks, and more positive emotional reactions to learning about their child's decreased health risks (adjusted $R^2 = 0.33$, P < .0001). Similarly, variables associated with greater parental willingness to test were being a mother (versus being a father), greater perceived risk of diseases in their child, greater interest in knowing about gene-health relationships in their child, anticipating less difficulty learning about their child's genetic health risks, anticipating more positive emotional reactions to learning about their child's decreased health risks, and positive decisional balance (adjusted $R^2 =$ 0.57, P < .0001).

CONCLUSIONS: As genetic susceptibility testing for common, adultonset health conditions proliferates, pediatricians should anticipate parents' interest in testing children and be prepared to facilitate informed decision making about such testing. *Pediatrics* 2011;127: e1288–e1295 AUTHORS: Kenneth P. Tercyak, PhD,^a Sharon Hensley Alford, PhD,^b Karen M. Emmons, PhD,^c Isaac M. Lipkus, PhD,^d Benjamin S. Wilfond, MD,^e and Colleen M. McBride, PhD^f

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KEY WORDS

NIH

genetic testing, chronic disease, risks and benefits, children, $\ensuremath{\mathsf{parents}}$

ABBREVIATION

DTC—direct to consumer

www.pediatrics.org/cgi/doi/10.1542/peds.2010-0938

doi:10.1542/peds.2010-0938

Accepted for publication Jan 20, 2011

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: The authors have indicated that they have no personal financial relationships relevant to this article to disclose.

Funded by the National Institutes of Health (NIH).

Direct-to-consumer (DTC) genetic tests assessing large panels of genetic variants associated with risk for common health conditions and traits have been lauded as one of the greatest inventions of the 21st century.¹ Yet, the swift pace of these developments raises expectations and concerns about their social and clinical impact.^{2,3}

One proposed advantage of these tests is their potential to enhance primary prevention.⁴ Individualized susceptibility feedback could be used to motivate preventive actions to reduce disease risk.^{5,6} These improvements could be most beneficial if targeted to the young and healthy before behavioral risk factors for common chronic disease become entrenched.^{7,8}

National advisory groups and professional organizations caution against predictive testing in children, largely on the basis of testing scenarios in which genetic mutations are strongly associated with the likelihood of developing serious health conditions in adulthood.9 In these scenarios, ageappropriate and effective prevention strategies also are lacking.¹⁰ The new generation of genetic tests assess susceptibility to common, multifactorial health conditions.¹¹ Here, identified genetic variants confer slight, modest increases in disease risk significant at a population level. There also are widely accepted prevention strategies that can be deployed early.^{12,13}

These "multiplex" genetic tests are offered directly to consumers via Web sites that include rhetoric and images suggesting benefits for entire families.^{14,15} One recent study¹⁶ found that 54% of survey respondents would consider DTC multiplex testing for their child, and 63% agreed parents should be able to have their child tested. The challenge for health care providers is that these tests have not been shown to have clinical utility (ie, prevent or reduce adverse health outcomes), their distribution is unregulated, and understanding of common disease genetics is low.¹⁷

As with other marketing efforts, the increasing availability of DTC genetic testing could create demand from patients for these tests within the primary care environment, including inquiries from parents directed toward their child's pediatrician about the value of pediatric genetic testing for common disease risk. In anticipation of this, we conducted a survey to characterize parents who are most likely to be interested in such testing on their child's behalf. Data for this study were collected through the Multiplex Initiative, a research project in which healthy adults were offered multiplex genetic susceptibility testing for themselves.¹⁸ Responses of a subgroup of parent participants are described. The following were our primary research questions: (1) What factors are associated with parents' perceptions of the risks and benefits of pediatric multiplex genetic testing? and (2) Which factors are associated with parents' willingness to test their child?

PARTICIPANTS AND METHODS

Setting and Subjects

The Multiplex Initiative

Our sample was drawn from the Multiplex Initiative.^{5,18} Briefly, the Multiplex Initiative was a multicenter, prospective, observational study. The sampling frame came from a large pool of members of a health management organization.¹⁹ Members in the sample were sent a letter and contacted and surveyed by telephone unless they opted out. Eligible participants then received a study brochure, access to a secure study Internet Web site (www. multiplex.nih.gov), and \$20. At the Web site, volunteers could review 4 information modules about the "multiplex genetic susceptibility test" (1. Multiplex Genetic Testing: What It Can and

Cannot Tell You; 2. Diseases and Genes on the Multiplex Genetic Test; 3. Your Rights if You Take Part in Multiplex Genetic Research; and 4. Your Decision To Be Tested or Not).²⁰ The test included 15 polymorphisms associated with increased risk for 8 common health conditions (colon, skin, and lung cancer; heart disease; osteoporosis; high blood pressure; high cholesterol; and type 2 diabetes)²¹; testing was performed by 2 independent laboratories (at Johns Hopkins University and a private vendor). The final module offered participants the test. Compensation was provided for completing each module's online survey. Sociodemographic differences existed between sampled adults who did and did not visit the study Web site.¹⁹

Ancillary Study With Parents

Individuals who completed the fifth module, regardless of their decision to test, were offered an additional \$20 incentive each to complete up to 3 ancillary studies. Our study targeted participants self-reporting as parents of children age 17 years or younger. Parents enumerated all of their children (biological, step, or otherwise) and provided each child's birth month and year and gender, and the Web site randomly selected an index child (if more than 1 child was present) that parents considered when completing the survey to reduce bias.²² Children were not offered genetic testing in this research. Institutional review boards at the National Human Genome Research Institute and the Henry Ford Health System approved this protocol.

Survey

Our survey had 46 closed-ended items developed by the authors from the behavioral disease risk and prevention and genetic testing literatures.^{23,24} Responses were given on Likert scales.

TABLE 1 Participant Characteristics

| | Total Eligible, | Declined, | Consented, | Statistic, P |
|---|-----------------|---------------|----------------|-----------------------|
| | <i>n</i> = 237 | <i>n</i> = 18 | <i>n</i> = 219 | |
| Age, mean \pm SD, y | 35.3 ± 3.6 | 36.3 ± 3.1 | 35.2 ± 3.6 | <i>t</i> = 1.24, .22 |
| Gender, <i>n</i> (%) | | | | $\chi^2 = 2.00$, .16 |
| Male | 120 (51) | 12 (67) | 108 (49) | |
| Female | 117 (49) | 6 (33) | 111 (51) | |
| Race, <i>n</i> (%) | | | | $\chi^2 =$ 2.32, .31 |
| White | 104 (44) | 5 (28) | 99 (45) | |
| Black | 106 (45) | 11 (61) | 95 (43) | |
| Other | 27 (11) | 2 (11) | 25 (11) | |
| Marital status, n (%) | | | | $\chi^2 =$ 1.06, .30 |
| Married/partnered couple | 173 (73) | 15 (83) | 158 (72) | |
| Other | 64 (27) | 3 (17) | 61 (28) | |
| Education, n (%) | | | | $\chi^2 =$ 3.05, .22 |
| High school or less | 55 (23) | 7 (39) | 48 (22) | |
| Some college | 84 (35) | 4 (22) | 80 (37) | |
| College or more | 98 (41) | 7 (39) | 91 (42) | |
| Excellent perceived health, n (%) | 56 (24) | 7 (39) | 49 (22) | $\chi^2 = 2.51$, .11 |
| BMI, mean \pm SD, kg/m ² | 29.0 ± 6.4 | 28.7 ± 4.9 | 29.06 ± 6.5 | t = -0.26, .79 |
| High Internet access, <i>n</i> (%) | 165 (70) | 12 (67) | 153 (70) | $\chi^2=$ 0.08, .78 |
| Intention to undergo genetic testing (yes), n (%) | 115 (49) | 4 (22) | 111 (51) | $\chi^2=$ 5.39, .02 |

Decisional Balance

Decisional balance assessed parents' perceived risks and benefits of their child's participation in genetic testing for common, adult-onset diseases examined in the Multiplex Initiative (10 items). Parents indicated the strength of their disagreement (1) or agreement (7) with 5 negatively worded (risk; eg, invasion of privacy, psychological discomfort, lack of utility) and 5 positively worded (benefit; eg, reassurance, knowledge, prevention) statements. Separate risk and benefit scores were derived by summing across items, divided by the number of items. The risk score was then divided by the benefit score to create a decisional balance ratio; higher ratios (where risks are greater than benefits) reflect a negative decisional balance, and lower ratios (where risks are less than benefits) reflect a positive decisional balance.²⁵ A factor analysis identified a 2-factor solution (eigen values > 1) with acceptable internal consistency (risks $\alpha = 0.79$, benefits $\alpha = 0.84$).

Willingness

Parents' willingness to consider having their child participate in genetic testing (1 = not at all likely, 7 = very likely) was assessed with a single item.

Correlates

Psychosocial correlates were parents' (1) perceptions of their child's health (1 = excellent, 4 = poor, 1 item); (2)perceptions of the severity of adultonset, chronic diseases for their child (1 = not at all serious, 7 = very serious; colon, skin, and lung cancer; heart disease; osteoporosis; high blood pressure; high cholesterol; and type 2 diabetes, 8 items, $\alpha = .89$); (3) perceived risk the child might develop these diseases over his or her lifetime (1 = not at all likely, 7 = very likely; 8items, $\alpha = .97$); (4) readiness to make changes to their child's lifestyle and health behavior (1 = yes, definitely,3 = no, definitely not, 1 item); (5) the value of knowing about gene-health and behavior-health relationships for their child (1 = not at all important,7 = very important, 2 items); (6) ambivalence toward or uncertainty about learning genetic health information about their child (1 = not at all difficult, 7 = very difficult, 1 item); (7) anticipated emotional reactions to learning news of their child's increased disease risk (positive reactions [eg, relief] $\alpha = 0.83$, 2 items; negative reactions [eg, guilt, worry] $\alpha = 0.79$, 5 items); and (8) decreased disease risk (positive reactions $\alpha = 0.96$, 2 items; negative reactions $\alpha = 0.89$, 5 items) (1 = not at all likely, 7 = very likely).

Additional participant characteristics were accessed from the Multiplex Initiative's baseline survey including parent age, gender, race, marital status, education level, perceived health (1 = excellent, 4 = poor), BMI, self-reported high access to the Internet (ie, use of the Internet at home), and intention to undergo genetic testing (assessed via the Web site's decision module; yes versus no or maybe).

Statistical Analysis

Analyses included χ^2 and Student t tests to compare the characteristics of those who consented versus declined the ancillary study with respect to sociodemographics, perceived health, BMI, access to the Internet, and whether they intended to undergo genetic testing (Table 1). Survey responses were then summarized descriptively (Table 2); associations among outcomes and predictor variables were examined via Pearson product-moment correlations (Table 3). Multivariate regression models with simultaneous entry were generated (Table 4). Predictor variables were derived from those suggestive of significant associations (P < .20), with 1 or both of the outcomes of interest at the bivariate level.^{26,27}

RESULTS

Subjects

A total of 329 (54%) of 612 participants who logged on to the Multiplex Initiative's secure Web site were offered access to the ancillary studies. Of these, 237 participants (72% of those offered access) self-identified as study eligible: 219 consented and 18 declined (92% consent rate). There were no dif-

| TABLE 2 | Parent Survey | Responses |
|---------|---------------|-----------|
|---------|---------------|-----------|

| Variable | Parents, $n = 219$, |
|--|----------------------|
| | means \pm SD |
| Perceived health of child $(1 = \text{excellent}, 4 = \text{poor})$ | 1.6 ± 0.7 |
| Perceived risk that child develops key diseases (1 = not at all likely, $7 =$ very likely)* | 3.0 ± 1.2 |
| Perceived severity to child of key diseases $(1 = not at all serious, 7 = very serious)^*$ | 5.5 ± 1.8 |
| Contemplating making child lifestyle/behavior change (1 = yes, definitely, $3 = n_0$, | 1.9 ± 0.6 |
| definitely not) | |
| value of knowing about: ($I = not at all important, I = very important)$ | 0.0 1 1 7 |
| Gene-health relationships | 6.0 ± 1.3 |
| Behavior-health relationships | 6.2 ± 1.3 |
| Difficulty learning genetic health information $(1 = not at all difficult,$ | 4.1 ± 2.0 |
| 7 = very difficult | |
| Anticipated emotional reactions to: $(1 = not at all likely, 7 = very likely)$ | |
| Increased disease risk information: | |
| Positive | 2.5 ± 1.8 |
| Negative | 4.6 ± 1.4 |
| Decreased disease risk information: | |
| Positive | 6.1 ± 1.4 |
| Negative | 2.2 ± 1.4 |
| Risks and benefits to child participating in genetic testing $(1 = \text{strongly disagree},$ | |
| 7 = strongly agree | |
| Risks (eg. psychological stress, privacy, uncertainty) | 3.1 ± 1.4 |
| Benefits (eg. reassurance, prevention) | 5.0 ± 1.3 |
| Decisional balance (risks/benefits) | 0.7 ± 0.5 |
| Willingness to consider child genetic testing $(1 = \text{not at all likely}, 7 = \text{very likely})$ | 4.3 ± 1.9 |

*Averaged across 8 health conditions (colon, skin, and lung cancer; heart disease; osteoporosis; high blood pressure; high cholesterol; and type 2 diabetes).

ferences between participants and nonparticipants (see Table 1).

In total, 445 children were enumerated (mean age: 8.8 years, SD: 5.2 years): 424 (95%) were younger than age 18 years, 224 (50%) were female, and 397 (89%) were the parents' biological children. The 219 index children were, on average, 9.9 years of age (SD: 4.9 years), 113 (52%) were female, and 193 (88%) were the parents' biological children.

Parents were, on average, 35 years of age; fathers (49%) and mothers (51%) were equally represented; 45% were white; 72% were married or partnered; and 42% were college graduates (see Table 1). With respect to health status, 22% of parents reportedly were in excellent health; the average BMI score was 29 kg/m² (overweight). As defined by this study, 70% were "high" users of the Internet (ie, daily Internet users with home access). Overall, 51% of parent respondents intended to undergo multiplex genetic testing.

Attitudes Toward Children's Health Risks and Genetic Testing

Index children (Table 2) were perceived to be in good or excellent health (mean: 1.6, SD: 0.7) and at relatively low risk for developing the diseases in question (mean: 3.0, SD: 1.2). Parents perceived these diseases to be severe (mean: 5.5, SD: 1.8) and contemplated making changes to their child's lifestyle to control disease risks (mean: 1.9, SD: 0.6). Parents endorsed relatively equally and strongly the value of knowing about gene-health relationships (mean: 6.0, SD: 1.3) and behaviorhealth relationships (mean: 6.2, SD: 1.3) in their child. With respect to testing, parents anticipated moderate difficulty learning about and actually understanding their child's genetic disease risks (mean: 4.1, SD: 2.0). Parents expected to react negatively to increased disease risk information (mean: 4.6, SD: 1.4) and positively to decreased disease risk information (mean: 6.1, SD: 1.4). The benefits of pediatric testing (mean: 5.0, SD: 1.3) outweighed the risks (mean: 3.1, SD: 1.4) (positive decisional balance; mean: 0.7, SD: 0.5); parents were moderately willing to consider testing (mean: 4.3, SD: 1.9).

Factors Associated With Decision Balance Regarding Genetic Testing

Six factors were significantly associated (P < .05) (Tables 1 and 2) with parents' viewing the benefits of pediatric testing to outweigh the risks (Table 3): (1) strongly endorsing intentions to change a child's lifestyle (r = .15, P <.05); (2) valuing gene-health knowledge (r = -0.46, P < .0001); (3) valuing behavior-health knowledge (r =-0.39, P < .0001; (4) perceiving it as easy to learn about genetics (r = 0.22, P < .01; (5) anticipating positive emotional reactions to learning children's decreased disease risks (r = 0.15, P <.05); and (6) intending to undergo testing themselves (r = -0.25, P < .001).

These variables and 3 covariates (parent race, child age, and perceived risk; P > .05, P < .20) were then examined in a multivariate analysis of parents' positive decisional balance (Table 4). After controlling for parent race, child gender, and perceived risk, parents placing a higher value on knowing about gene-health relationships ($\beta =$ -0.10, P < .01), reporting it to be not difficult to learn about genetics ($\beta =$ 0.05, P < .01), and anticipating more positive emotions in response to learning about their child's decreased risks $(\beta = -0.07, P < .01)$ were significantly associated with benefits of pediatric testing outweighing the risks $(R^2 = 0.33, P < .0001).$

Factors Associated With Willingness to Consider Genetic Testing for Children

Variables independently associated with parents' willingness to consider pediatric genetic testing were (1) being the child's mother (r = -0.23, P <

| TABLE 3 | Factors Associated With Risks and Benefits and Will | lingness to Consider Child Genetic |
|---------|---|------------------------------------|
| | Testing | |

| Variable | Decisional | Willingness to Conside |
|---|---------------|------------------------|
| | Balance, r, P | Child Genetic |
| | | Testing, r, P |
| Parent | | |
| Age | -0.04, .57 | 0.05, .50 |
| Gender ($0 = female, 1 = male$) | 0.10, .15 | -0.23, .001 |
| Caucasian race ($0 = other, 1 = white$) | 0.04, .52 | -0.01, .84 |
| Marital status ($0 = other$, $1 = married/partnered$) | -0.03, .62 | -0.07, .28 |
| Education ($0 = less$ than college, $1 = college$ or more) | 0.05, .48 | 0.04, .58 |
| Child | | |
| Age | -0.09, .19 | 0.13, .06 |
| Gender ($0 = female, 1 = male$) | 0.05, .50 | -0.02, .83 |
| Biological child ($0 = no, 1 = yes$) | -0.04, .59 | 0.06, .38 |
| Perceived health of child | -0.01, .85 | 0.03, .63 |
| Perceived risk that child develops key diseases* | -0.13, .06 | 0.19, .001 |
| Perceived severity to child of key diseases* | 0.00, .99 | 0.08, .25 |
| Contemplating making child lifestyle/behavior change | 0.15, .03 | -0.13, .08 |
| Value of knowing about: | | |
| Gene-health relationships | -0.46, <.0001 | 0.48, <.0001 |
| Behavior-health relationships | -0.39, <.0001 | 0.37, <.0001 |
| Difficulty learning genetic health information | 0.22, .001 | -0.33, <.0001 |
| Anticipated emotional reactions to: | | |
| Increased risk | | |
| Positive | 0.03, .71 | -0.01,.89 |
| Negative | 0.06, .39 | -0.08, .23 |
| Decreased risk | | |
| Positive | -0.28, <.0001 | 0.13, .06 |
| Negative | 0.09, .17 | 0.05, .47 |
| Intention to undergo genetic testing | -0.25, .0002 | 0.42, <.0001 |
| Decisional balance | _ | -0.61, <.0001 |

*Averaged across 8 health conditions (colon, skin, and lung cancer; heart disease; osteoporosis; high blood pressure; high cholesterol; and type 2 diabetes).

.01), (2) perceiving the child to be at greater risk for the disease (r = 0.19, P < .01), (3) placing greater value on knowing about links between genes and health (r = 0.48, P < .0001), (4) behavior and health (r = 0.37, P < .0001), (5) feeling that it would be less difficult (ie, be accompanied by less ambivalence or uncertainty) to learn about genetics (r = -0.33, P < .0001), (6) intending to undergo testing themselves (r = -0.61, P < .0001), and (7) positive decisional balance (r = 0.42, P < .0001).

After controlling for child age, intentions to change their child's lifestyle, and anticipating positive emotional reactions to learning information about decreased genetic risks (P > .05, P <.20), we accounted for 57% of the variance in parental willingness to have their child tested ($R^2 = .57$, P < .0001). In a multivariate model, the variables that remained significant were (1) being the child's mother ($\beta = -0.50$, P <.01), (2) perceiving the child to have greater disease risk (β = 0.21, P < .01), (3) valuing knowing about genehealth links ($\beta = 0.54, P < .0001$), (4) being less conflicted in learning about genetic health information (β = -0.19, P < .01), (5) anticipating positive emotional reactions to decreased risk information about the child ($\beta =$ -0.17, P < .05), (6) intending to undergo genetic testing themselves ($\beta =$ 0.58, P < .01), and (7) perceiving the benefits of pediatric testing to outweigh the risks (β = -1.52, P < .0001).

DISCUSSION

Parents offered the Multiplex Initiative's genetic susceptibility test for common preventable health conditions tended to consider that the potential benefits (eg, reassurance, knowledge, prevention) of this test for their own child could outweigh its risks (eg, invasion of privacy, psychological discomfort, lack of utility). It is important to note that the actual risks, benefits, and utility of genetic testing for common preventable health conditions have not been established for adults or for children.28 Despite educating parents about such risks for themselves, parents enrolled in this study were inclined to have their child tested if the test was available and offered to them. To our knowledge, this study provides the first data from a diverse sample of adult consumers of multiplex genetic testing indicating factors that might influence their choices about having their child tested for genetic susceptibility to common and preventable health conditions.

Research anticipating the translation of genetic knowledge to foster better child health management must address the roles of both the parent and pediatric health care provider in this context.²⁹ It is not yet known how likely parents will be to engage providers in discussions about DTC and other genetic tests for common disease risks, before or after testing. However, given pediatricians' strong working alliances with parents,³⁰ it is reasonable to believe that such discussions will occur. Our results offer several considerations for providers to aid them in counseling parents about multiplex genetic testing. First, parents' interest in knowing about their child's genes is positively associated with both the weighing of benefits over risks and willingness to test. Genetic health information seeking is a known correlate of perceiving greater benefits of genetic testing.³¹ Parents' curiosity about genetics will likely be a motivator among early adopters, and they

| TABLE 4 | Factors Associated with Risks/Ben | efits and Willingness to Consider | r Genetic Testing for |
|---------|-----------------------------------|-----------------------------------|-----------------------|
| | Children | | |

| Variable | β | SE of eta | t | Р |
|---|-------|-------------|-------|--------|
| Decisional balance; $R^2 = 0.33$, $P < .0001$ | | | | |
| Parent gender | 0.08 | 0.06 | 1.22 | .23 |
| Child age | 0.00 | 0.01 | 0.12 | .91 |
| Perceived risk to child* | -0.04 | 0.03 | -1.63 | .11 |
| Child behavior change intentions | 0.02 | 0.05 | 0.44 | .66 |
| Knowledge of gene-health relationships | -0.10 | 0.04 | -2.81 | .006 |
| Knowledge of behavior-health relationships | -0.03 | 0.04 | -0.86 | .39 |
| Difficulty learning predictive genetic health information | 0.05 | 0.02 | 3.21 | .002 |
| Positive reactions to decreased risk | -0.07 | 0.02 | -3.02 | .003 |
| Intention to undergo genetic testing | -0.07 | 0.07 | -1.00 | .32 |
| Willingness to consider child genetic testing; $R^2 = 0.59$, $P < .0001$ | | | | |
| Parent gender | -0.50 | 0.20 | -2.49 | .01 |
| Child age | 0.01 | 0.02 | 67 | .50 |
| Perceived risk to child* | 0.21 | 0.08 | 2.60 | .01 |
| Child behavior change intentions | -0.03 | 0.16 | -0.21 | .84 |
| Knowledge of gene-health relationships | 0.54 | 0.11 | 4.79 | <.0001 |
| Knowledge of behavior-health relationships | -0.18 | 0.12 | -1.53 | .13 |
| Difficulty learning predictive genetic health information | -0.19 | 0.05 | -3.82 | .0002 |
| Positive reactions to decreased risk | -0.17 | 0.07 | -2.34 | .02 |
| Intention to undergo genetic testing | 0.58 | 0.21 | 2.79 | .006 |
| Decisional balance | -1.52 | 0.23 | -6.51 | <.0001 |

*Averaged across 8 health conditions (colon, skin, and lung cancer; heart disease; osteoporosis; high blood pressure; high cholesterol; and type 2 diabetes).

will benefit from discussions about potential downsides of testing (eg, whether results yield meaningful information, how that information might be actionable, and steps parents could take to protect their child's health independent of genetic risk).

Second, parents may not accurately anticipate their full range of reactions to risk information.32 Parents in this study more readily anticipated the positives of testing versus its negatives, and those holding the most favorable attitudes toward testing were also the most willing to have their child tested. This could leave parents unprepared and likely to experience regret after testing. From a counseling perspective, providers could help parents by "preliving" the experience of receiving their child's genetic test results to rehearse responses to different outcomes, promoting adaptation.^{33,34}

Finally, parents' who anticipated having positive emotional responses to learning their child was at lowered risk held more favorable attitudes to testing. This cognitive predisposition among parents to seek out reassuring health-related information about their child is common. In the case of multiplex testing, numerous risk variants will routinely emerge (the average adult in the Multiplex Initiative held 4 to 9 genetic risk variants). Any reassurance gained by parents will be counterbalanced by raised concerns. Pediatricians should help parents place these results into context by reviewing any interpretive reports and aiding parents in making decisions about preventive measures that might be warranted.

A striking observation is that parents intending to undergo testing for themselves held more open views on pediatric testing. Are they applying similar standards when judging testing's appropriateness for both themselves and their children? This view would not align with clinical and public health experts' views on the matter, a phenomenon also reported in cancer genetic predisposition testing.³⁵

Our work has several limitations. The Multiplex Initiative did not seek to edu-

cate parents about pediatric genetic testing: parents received information for themselves as adults via the study Web site. Our results might change with parent education. None of the DTC companies currently testing children tailor their informed consent materials to parents or minors and our methods closely approximate everyday practice. In addition, design features of the Multiplex Initiative could limit generalizability. Those who logged on to consider testing were less likely to be African American, male, and to be high Internet users,^{5,19} the offer of child testing was hypothetical, and participants received incentives for completing online surveys. We also did not collect data directly from children concerning their attitudes about pediatric genetic testing. This was beyond the scope of the Multiplex Initiative. Future research to understand the full potential of genetic testing as a means to better prevent and control disease and improve population health will be informed by considering children's attitudes.

CONCLUSIONS

Our work with parents offered genetic testing for common preventable health conditions suggests they are receptive to pediatric testing. The DTC market already has recognized this as a target audience and seems ready to embrace them: the health care system has not. Prudence dictates thoughtful consideration of these new tests in relation to children's health. It remains important for pediatricians and other pediatric health care providers to work closely with professional associations and local, state, and federal agencies to erect safeguards for DTC genetic testing for common disease risk, including regulations requiring evidence of clinical utility. These and similar efforts would better position them to help early adopters of pediatric genetic testing to make informed decisions. Pediatric providers should remain vigilant about the prospect of this occurrence and promote respectful, productive discussions with those in their care who express interest or engage in DTC testing.

ACKNOWLEDGMENTS

This work was supported by the Intramural Research Program of the National Human Genome Research Institute at the National Institutes of Health. The research also was made possible by collaboration with the health management organization Cancer Re-

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paration was supported by grants from the Ethical, Legal, and Social Implication Research Program of the National Human Genome Research Institute (R01HG002686) and from the National Cancer Institute (R01CA137625 to Kenneth P. Tercyak).

We thank the members of the Multiplex Initiative Steering Committee who provided critical review of this report (Drs Lawrence Brody, Robert Reid, Eric Larson, Andreas Baxevanis, and Sharon Kardia). Our thanks go to the study participants who all were members of the Henry Ford Health System.

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