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Exploring dispositional tendencies to seek online information about direct-to-consumer genetic testing

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ABSTRACT

Varying perspectives exist regarding the implications of genetic susceptibility testing for common disease, with some anticipating adverse effects and others expecting positive outcomes; however, little is known about the characteristics of people who are most likely to be interested in direct-to-consumer genetic testing. To that end, this study examines the association of individual dispositional differences with health risk perceptions and online information seeking related to a free genetic susceptibility test. Healthy adults enrolled in a large health maintenance organization were surveyed by telephone. Eligible participants (N=1,959) were given access to a secure website that provided risk and benefit information about a genetic susceptibility test and given the option to be tested. Neuroticism was associated with increased perceptions of disease risk but not with logging on. Those scoring high in conscientiousness were more likely to log on. We found no evidence that neuroticism, a dispositional characteristic commonly linked to adverse emotional response, was predictive of online genetic information seeking in this sample of healthy adults.

KEYWORDS

Direct-to-consumer genetic tests, Information seeking, Perceived risk, Individual differences

Implications

Policy: The findings reported here suggest that early adopters of online direct-to-consumer genetic tests will not disproportionately exhibit dispositional characteristics commonly associated with negative emotional responses.

Research: Future research must begin to explore how the broadening reach of genetic tests enabled by projected cost decreases will affect the characteristics of consumers who seek tests and their responses to test offerings and feedback.

Practice: Consumers of genetic tests who present to health providers may not be especially driven by a need for emotional reassurance regarding results; these conscientious individuals may be inquisitive about the implications of results for health maintenance.

INTRODUCTION

The emergence of commercial services that provide genetic susceptibility testing directly to consumers evokes several compelling translational research questions [1, 2]. There has been considerable controversy surrounding companies offering genetic tests direct-to-consumer (DTC) [1] with greatest concerns that these tests bypass health professionals [2–6]. The majority of the risk information conveyed reflects small increases in risk (i.e., 10–30 % increased risk) raising questions about the utility of the information and the concern that seeking and receiving genetic information online may cause individuals to experience anxiety, distress, or other negative emotional responses [7, 8].

Much of what we know about the association of individual characteristics and responses to genetic testing has been drawn from research on high-risk samples of individuals affected by highly heritable conditions [9, 10]. Yet genetic testing is now accessible to a wide array of people for a variety of health conditions. For example, 30 DTC companies now provide genetic susceptibility tests for common health conditions to the general public [11]. The range of testing services provided by these companies is quite broad and includes susceptibility tests for various forms of cancer, diabetes, and cardiovascular conditions (see the report compiled by the Genetics and Public Policy Center [11] to better appreciate the wide range of tests available to consumers). This increased availability of genetic testing makes it important to explore whether those who seek information about genetic testing online may also be inclined to experience heightened risk perceptions and worry that could prompt adverse effects [12], or whether those who seek such information do so as proactive health consumers.

In this report, we explore individual dispositional characteristics previously associated with responses to threatening health information and consider whether these traits distinguish genetic information seekers from those who choose not to seek information. We analyzed data from the Multiplex Initiative, a population-based prospective study in which healthy adults were offered free genetic susceptibility testing for eight common health conditions [12].

Health information seeking and individual dispositional differences

A number of communication theories suggest that individual psychological differences will be associated with variations in information-seeking behavior [13]. Common to these theories is the centrality of risk perceptions–and the anxiety or uncertainty-prompted response to that perceived risk–as factors that ultimately influence information-seeking behavior. Consistent with these theoretical models, perceived risk has been shown to be positively associated with interest in receiving a genetic test [8] and to seeking health information online [14]. Further, the risk information seeking and processing model (RISP) posits that individual characteristics influence information seeking through a path that is mediated by an anxiety response and cognitive risk factors such as perceived susceptibility to and severity of health conditions [15]. Simply put, according to the RISP model, individual differences would generally be expected to affect information-seeking behaviors through perceptions of risk.

In parallel, risk perceptions and information seeking have been shown to be associated with a number of individual dispositional differences. In particular, we consider four dispositional traits that have strong conceptual relevance in this regard: conscientiousness, neuroticism, openness to experience, and internal health locus of control. Neuroticism, also referred to as "trait anxiety," corresponds with a tendency to experience psychological distress [16]. Conscientiousness is characterized by a sense of diligence, responsibility, and willingness to see things through [17]. In contrast, openness to experience represents intellectual curiosity, imagination, and behavioral flexibility [17]. Compared to the remaining "Big Five" personality dimensions, these three traits are more likely to affect behavior in situations that lack an obvious interpersonal element (e.g., logging on to a website to retrieve genetic risk information). Extroversion and agreeableness are not examined in this study because they are "primarily dimension[s] of interpersonal behavior" [17] (p. 6) and have been found to be unrelated to the amount of effort exerted to seek information from written documents [18]. Internal health locus of control is characterized as the general belief that health is under one's personal control rather than chance [19]. The conceptual rationale for considering these four traits is described in turn.

A considerable amount of research has established links between these dispositional traits, perceptions of health risks and information seeking. For example, individuals high in neuroticism tend to give greater attention to threat-related information, interpret ambiguous information as negative or threatening, and remember negative information better than positive [20]. Although people who are high in neuroticism are less likely to engage in some health risk behaviors [21], this combination of perceptual and memory biases may nonetheless lead them to perceive health conditions to be more severe and their personal susceptibility to be greater. As it relates to information seeking, the RISP model predicts that affective responses elicited by these risk perceptions could prompt individuals to seek genetic risk information. This may be especially likely for those highest in neuroticism–a trait that is associated with a tendency to experience elevated levels of emotional distress in a variety of contexts [22]. Indeed, neuroticism has been shown to be positively related to information seeking in healthcare contexts [23].

While individuals who are high in conscientiousness are less likely to engage in risky behaviors associated with long-term negative consequences [21, 24, 25], they also tend to believe that they are less susceptible to health risks [26]. However, those who are high in conscientiousness have been found to expend greater effort when seeking information [18] and to draw on a larger proportion of available information when solving problems [27]. Thus, those high in conscientiousness may be more inclined than others to seek health information even if they do not perceive themselves to be at greater health risk.

Similarly, openness to experience has been shown to be positively associated with health information seeking and information-seeking effort [18, 23]. The RISP model would suggest that this effect on health information seeking may be partially mediated by risk perceptions. For example, Trobst et al. [25] found that openness to experience had a positive association with perceived risk of testing positive to HIV. In discussing this association, the authors reasoned that people who are open to experience may have been both more likely to engage in behaviors that put them at greater objective health risk and to have sought out information that would make them aware of that risk. Also, online information seeking has been associated positively with an appreciation of novelty, an aspect of openness to experience [28].

Internal health locus of control (IHLC) is a dispositional trait that may influence genetic information seeking, though not necessarily as a function of perceived health risk. IHLC has been shown to be positively associated with information seeking [29–31] and proposed to be negatively associated with information avoidance [32]. Also a direct negative association between IHLC with perceived risk has been demonstrated, such that stronger internal health locus of control is associated with unrealistic optimism with regard to health risk susceptibility [33] and lower perceived health risk, overall [34].

Though many associations between individual dispositional differences and information seeking have been established in prior research, few studies have explored these associations in the context of genetic testing and genomics [cf. 14, 35]. In light of the research outlined above and the process evidenced in the RISP model, we propose three research questions: (1) Are neuroticism, conscientiousness, openness to experience, and IHLC associated with perceptions of disease susceptibility,

severity, and worry? (2) Are neuroticism, conscientiousness, openness to experience, and IHLC associated with seeking information about genetic testing? And (3) does perceived disease susceptibility, severity, and worry mediate the association of those individual difference characteristics with seeking information about genetic testing?

METHOD

Data were collected as part of the Multiplex Initiative which is described in detail elsewhere [6, 36, 37]. Briefly, the overarching aim of the Multiplex Initiative was to evaluate uptake of genetic susceptibility testing as a primary prevention strategy, specifically serving as a cue to take preventive actions including seeking health information. The target group was individuals free of disease, a target group for whom health-seeking actions could prevent the onset of chronic disease. To that end, participants were recruited from a pool of commercially insured members of the Henry Ford Health System, a large health maintenance organization (HMO) located in Detroit, MI, USA. The health plan's master patient index was used to find eligible members who self-identified as either black or white, were between 25 and 40 years of age, were assigned to a primary care physician, and had been enrolled in the HMO for at least two consecutive years. Members whose electronic medical records indicated that they had been previously diagnosed with diabetes mellitus, atherosclerotic cardiovascular disease, osteoporosis, or cancer were excluded from participating in the study. A prior diagnosis with these health conditions in particular was used as an exclusion criterion given the focus on primary prevention and the correspondence to risk information obtained from the genetic susceptibility tests. A random sample of members was drawn from the set of those who met these selection criteria, while oversampling for men, African Americans, and individuals living in census blocks where 10 % or more of the residents have a high school education or less.

Based on this sampling procedure, advance letters were sent to 6,600 potential participants describing the survey and informing them that they would be asked to participate. Eligible interviewees who completed the baseline telephone survey were sent a brochure that described the next phase of the Multiplex study and gave instructions for accessing a secure decision support website that provided information about the Multiplex genetic susceptibility test. The website was divided into four modules and included a series of follow-up assessments. At the end of the final module, participants were offered a free Multiplex genetic screening; those who accepted were later contacted to schedule an appointment to get their blood drawn for the test. The data for this report were drawn from the information provided by eligible respondents at baseline (N=1,959) as well as follow-up data that tracked participant progress through the study website. All aspects of the Multiplex study were approved by the Institutional Review Boards of the National Institutes of Health and the Henry Ford Health System.

Measures

Genetic information seeking–Our primary outcome of interest, genetic information seeking, was indicated by a single dichotomous variable that recorded whether the participant logged on to the Multiplex website (1=*yes* or 0=*no*). In total, 612 participants (32 %) logged on.

Perceptions of disease risk–Risk perceptions associated with eight common health conditions represented in the Multiplex genetic susceptibility test (i.e., colon cancer, skin cancer, lung cancer, heart disease, osteoporosis, adult onset diabetes, high blood pressure, and high cholesterol) were assessed with three variables: perceived susceptibility, perceived severity, and condition-related worry. Perceived susceptibility was measured as the respondent's subjective lifetime likelihood of having each of the eight health conditions, 1 (*not at all likely*) to 7 (*completely likely*). Perceived severity was measured with items that asked respondents to report how serious they believed each condition to be, 1 (*not at all serious*) to 7 (*very serious*). Condition-related worry was measured individually for each of the health conditions, 1 (*not at all worried*) to 7 (*very worried*). Each of these measures was standardized and then the average calculated across the eight health conditions to construct general scales of perceived susceptibility (Cronbach's α=0.82), severity (Cronbach's α=0.88), and worry (Cronbach's α=0.89) for common health conditions. For descriptive purposes, indices based on the nonstandardized measures were also computed by averaging across the eight conditions: perceived susceptibility (M=3.31, SD=1.19), perceived severity (M=6.11, SD=0.80), and worry (M=4.02, SD=1.54). Higher scores on these composite variables indicate greater perceptions of risk, on average, related to the eight health conditions included on the Multiplex genetic susceptibility test. The z-score-based indices were used in all analyses.

Individual dispositional differences–Dispositional traits were measured in the baseline survey using items derived from a public domain version of the NEO personality inventory (NEO-PI-R), a widely used self-report assessment of the "Big Five" personality types [17, 38, 39]. Rather than ask respondents to complete full inventories for the personality dimensions examined in this study, we constructed abbreviated subscales for neuroticism, conscientiousness, and openness to experience. These items were selected based on reliability and factor loading estimates derived from secondary analyses of two datasets that included responses to a larger number of inventory items. The decision to use abbreviated

scales was based on concerns that embedding a complete personality inventory into an already lengthy survey would prove too burdensome for respondents and would limit the translational implications of our findings to applications where a similarly extensive inventory could be fielded.

Response options for all the personality items ranged from 1 (*strongly disagree*) to 7 (*strongly agree*). Neuroticism was measured as the average of two items (Cronbach's α=0.63; M=3.47, SD=1.66) that asked the respondent to report the extent to which he or she "fears the worst" and is "easily bothered by things." Conscientiousness was measured with three items that asked about the respondent's tendency to "make plans and stick to them," "see things through," and "carry out plans." The average of the three items was calculated to create a conscientiousness scale (Cronbach's α=0.82; M=5.90, SD=0.98). Openness to experience was measured with four items that captured the adventurousness and intellectual curiosity dimensions of that personality type. Respondents were asked to report their level of agreement with the statements, "I prefer variety to routine," "I am interested in many things," "I can handle a lot of information," and "I enjoy thinking about things." An overall scale was computed by taking the average of these four items (Cronbach's α=0.66; M=5.84, SD=0.93) such that greater values indicate greater openness to experience. Internal health locus of control was included in the analysis as the averaged response to two items (Cronbach's α=0.61; M=5.52, SD=1.20): "The main thing that affects your health is what you yourself do," and "If you take care of yourself, you can avoid illness."

Variables included as controls–Participants reported demographic information about gender, race, marital status, and highest education level achieved. Race was included in the analyses as a three-category variable: White (37 %), Black (53 %), and other (10 %). Marital status was recorded as a dichotomous variable; respondents who were married or a member of an unmarried couple at the time the survey was completed were combined into a single category (63 %). Education was summarized as a three-level categorical variable, with the following values: high school or less (25 %), some college (38 %), or attended college for 4 years or more (37 %). The median age of eligible respondents was 35 and nearly half (47 %) were male. Because genetic information seeking in this study was indicated by logging on to a website, we also controlled for prior internet use with a single item that asked respondents to indicate whether they used email or the internet as a source of health information in the past 30 days (67 % reported yes, 14 % said they did not seek health information, and 19 % did not know or did not respond).

We also controlled for respondent perceptions of personal health and familial health risk. Perceived health (M=3.05, SD=0.66) was measured with a single item that asked respondents to rate their current health on a scale ranging from 1 (*poor*) to 4 (*excellent*). Health risk due to family history was assessed by asking respondents to indicate, to the best of their knowledge, whether each of six common diseases ran in their family (1=*yes* and 0=*no or don't know*). If the disease ran in the family, then the respondent was listed as being at risk for that disease. Conversely, if the disease did not run in the family, or if the respondent did not know if the disease ran in the family, then the respondent was listed as not being at risk due to family history. An index of health risk due to family history (M=3.14, SD=1.48) was computed by summing each participant's family health risk across the six diseases. Values greater than one on this index indicate that the respondent had a family history for multiple diseases. Lastly, a variable was included that measured the extent that respondents attributed common diseases, on average, to genetics versus behavior. This variable was derived from a series of items that asked respondents to report how much they believed that health habits and genetics determine a person's risk for developing each of the eight diseases [37]. A summary score across all eight health conditions was calculated (M=0.42, SD=0.11). Values on the resulting genetic attribution variable ranged from 0 (*completely determined by behavior*) to 1 (*completely determined by genetics*).

Statistical analyses

Bivariate correlations and ordinary least squares regression models were used to test whether personality and other psychological trait variables predict perceptions of disease risk. Multivariate logistic regression models were tested that predict genetic information seeking by personality indicators, IHLC, and disease risk perceptions. Except where noted, all multivariate analyses adjusted for age, gender, race, marital status, education, internet use, perceived personal health, family risk of common disease, and genetic attributions for disease. SPSS/PASW 18 was used for all analyses.

RESULTS

Individual dispositional differences and perceptions of disease risk

A number of dispositional differences were significantly associated with perceptions of disease risk (i.e., susceptibility, severity, and worry). Consistent with the literature reviewed above, positive bivariate correlations of neuroticism with perceived susceptibility (r=0.24, p<0.001) and worry (r=0.23, p<

0.001) were observed. Also notable were the positive correlations of conscientiousness (r=0.15, p<0.001), openness to experience (r=0.17, p<0.001), and IHLC (r=0.16, p<0.001) with perceived severity. As anticipated, conscientiousness was negatively associated with perceived susceptibility (r=−0.05, p=0.038), though we consider the size of this effect in the current context to be small by most standards [40]. Lastly, openness and IHLC were significantly associated with worry (r=0.09, p<0.001 and r=0.07, p=0.005, respectively).

Acknowledging that the observed bivariate associations do not account for possible effects attributable to other factors, we assessed the association of each individual dispositional difference with perceptions of disease risk using multivariate regression analyses that controlled for health perceptions and demographic characteristics (Table 1). Each of the three models was significant in predicting some aspects of perceived disease risk: perceived susceptibility, adjusted R^2=0.24, F (16, 1,909)=39.22, p< 0.001, f^2=0.33; perceived severity, adjusted R^2= 0.17, F (16, 1,914)=25.72, p<0.001, f^2=0.22; and worry, adjusted R^2=0.18, F (16, 1,914)=27.64, p< 0.001, f^2=0.23. Holding all else constant, associations of individual dispositional differences with risk perceptions were similar, with some exceptions, to the bivariate correlations reported above. Neuroticism was again the strongest dispositional predictor of both perceived susceptibility and worry, while IHLC was the strongest predictor of perceived severity. In fact, all four dispositional traits emerged as positive predictors of perceived severity. This differs somewhat from the results of the bivariate analysis, where the association between neuroticism and perceived severity was not statistically significant (r=0.04, p=0.054, ns). Similarly, openness emerged in the multivariate model as a significant predictor of perceived susceptibility, while conscientiousness was no longer significantly associated when controlling for other variables.

Individual dispositional differences and information seeking

Our second research question asked whether individual dispositional differences were associated with inclination to seek information about genetic testing. A positive point biserial correlation was observed between conscientiousness and logging onto the Multiplex website (r_{pb}=0.07, p=0.001). Neuroticism (r_{pb}=0.03, p=0.254, ns), openness to experience (r_{pb}=−0.04, p=0.051, ns), and IHLC (r_{pb}=−0.02, p=0.522, ns) were not found to be significantly

Table 1 | OLS regression models predicting perceived risk of disease from individual dispositional differences and control variables

Variable	Susceptibility				Severity				Worry			
	B	(SE)	*β*	*t*	*B*	(SE)	*B*	*t*	*B*	(SE)	*β*	*t*
Controls												
Age	0.01	(0.01)	0.06	2.84**	0.01	(0.01)	0.06	2.97**	0.01	(0.01)	0.07	3.14**
Gender (ref: female)	0.02	(0.03)	0.01	0.60	−0.17	(0.03)	−0.12	−5.50***	−0.03	(0.03)	−0.02	−1.05
In relationship (ref: no)	−0.05	(0.03)	−0.04	−1.74	0.01	(0.03)	0.01	0.44	−0.04	(0.03)	−0.02	−1.14
Genetic disease attribution	0.93	(0.12)	0.15	7.50***	0.52	(0.14)	0.08	3.62***	0.96	(0.15)	0.14	6.61***
Family history risk	0.14	(0.01)	0.31	14.79***	0.00	(0.01)	0.00	0.09	0.10	(0.01)	0.20	9.02***
Perceived health	−0.18	(0.02)	−0.18	−8.78***	−0.05	(0.02)	−0.05	−2.08*	−0.14	(0.02)	−0.13	−5.82***
Prior info seeking (ref: no)												
Yes	−0.02	(0.04)	−0.02	−0.53	0.04	(0.05)	0.02	0.78	−0.07	(0.05)	−0.04	−1.51
Don't know/refused	−0.06	(0.05)	−0.04	−1.32	−0.03	(0.05)	−0.02	−0.54	−0.15	(0.06)	−0.08	−2.73**
Education (ref: HS or less)												
Some college	−0.04	(0.04)	−0.03	−1.02	−0.04	(0.04)	−0.03	−1.09	−0.19	(0.04)	−0.12	−4.59***
College degree	−0.10	(0.04)	−0.08	−2.88**	−0.25	(0.04)	−0.16	−6.00***	−0.32	(0.04)	−0.21	−7.58***
Race (ref: White)												
African American	−0.12	(0.03)	−0.09	−3.90***	0.38	(0.04)	0.26	10.95***	0.03	(0.04)	0.02	0.86
Other	−0.10	(0.05)	−0.04	−1.96	0.22	(0.06)	0.09	3.90***	0.02	(0.06)	0.01	0.26
Individual dispositional differences												
Conscientiousness	−0.01	(0.02)	−0.01	−0.39	0.08	(0.02)	0.10	4.50***	0.03	(0.02)	0.04	1.79
Neuroticism	0.07	(0.01)	0.17	8.03***	0.02	(0.01)	0.05	2.30*	0.08	(0.01)	0.18	8.24***
Openness	0.04	(0.02)	0.06	2.57*	0.07	(0.02)	0.08	3.66***	0.07	(0.02)	0.09	3.96***
IHLC	0.00	(0.01)	0.00	0.02	0.08	(0.01)	0.13	5.87***	0.03	(0.01)	0.05	2.21*
Adjusted R^2	0.24***				0.17***				0.18***			
N	1,925				1,930				1,930			

Ref reference category for categorical variables, *In relationship* married or a member of an unmarried couple, *Family history risk* health risk due to family history, *Prior info seeking* used email or the internet as a source of health information in the past 30 days, *HS or less* high school graduate or less than high school is the highest level of formal education achieved, *IHLC* internal health locus of control

*p<0.05; **p<0.01; ***p<0.001

associated with logging on. When individual dispositional differences were entered into a logistic regression model that controlled for demographic characteristics and perceived health (Table 2), the overall model was significant, −2LL=2,273.21, Nagelkerke's R^2=0.07, $\chi^2(16, N=1{,}903)=102.05$, $p<0.001$. Conscientiousness (OR=1.25, $p<0.001$, 95 % CI [1.11, 1.41]) and openness to experience (OR=0.87, $p=0.022$, 95 % CI [0.77, 0.98]) were the only significant dispositional predictors of logging on in the multivariate model. Individuals who were higher in conscientiousness were more likely to log on; for every four-point increase in conscientiousness, the odds of logging on to the Multiplex website nearly doubled. Conversely, openness to experience was shown to significantly decrease the likelihood of logging on in the multivariate model. All else being equal, every one-unit increase in openness to experience increased the odds of *not* logging on by a factor of 1.15.

Perceptions of disease risk as mediators of the association between individual dispositional differences and information seeking

Our third research question concerned whether perceived disease risk mediated the association of individual dispositional differences with logging on to the Multiplex website. Following the procedure advocated by Preacher and Hayes [41, 42], we tested for mediation effects by computing bias-corrected bootstrap confidence intervals for the indirect effects between the individual dispositional difference variables through perceptions of disease risk. Evidence for mediation is found if the range of the confidence interval corresponding to the path from the predictor through a specific mediator to the criterion does not include a value of zero. We used the SPSS macro provided by Preacher and Hayes [42] to conduct the procedure and adapted it as recommended to accommodate a multiple indicator and multiple mediator model. Odds ratios for the direct effects on genetic information seeking were computed by replicating this model using the logistic regression procedure in SPSS.

In this analysis, conscientiousness, openness to experience, neuroticism, and internal health locus of control were entered as predictor variables; perceived severity, perceived susceptibility, and worry were entered as mediators; and logging onto the Multiplex website was the criterion. To maintain consistency with the other analyses reported thus far, we also included the remaining demographics and other control variables. In light of the observed

Table 2 | Binary logistic regression analyses predicting online information seeking from individual dispositional differences and control variables

Variable	*OR*	95 % CI	Wald χ^2
Controls			
Age	1.01	[0.98, 1.03]	0.33
Gender (ref: female)	0.92	[0.74, 1.13]	0.71
In relationship (ref: no)	0.89	[0.72, 1.11]	1.03
Genetic disease attribution	0.62	[0.24, 1.59]	0.99
Family history risk	1.05	[0.98, 1.13]	2.11
Perceived health	1.10	[0.94, 1.29]	1.50
Prior info seeking (ref: no)			10.04**
Yes	1.72	[1.23, 2.40]	9.95**
Don't know/refused	1.65	[1.12, 2.43]	6.44*
Education (ref: HS or less)			13.54**
Some college	1.24	[0.94, 1.63]	2.30
College degree	1.64	[1.25, 2.17]	12.43***
Race (ref: White)			26.69***
African American	0.56	[0.45, 0.70]	26.19***
Other	0.64	[0.44, 0.92]	5.69*
Individual dispositional differences			
Conscientiousness	1.25	[1.11, 1.41]	12.97***
Neuroticism	1.03	[0.97, 1.10]	0.87
Openness	0.87	[0.77, 0.98]	5.24*
IHLC	0.98	[0.90, 1.07]	0.14
−2 Log-likelihood	2,273.21***		
Nagelkerke's R^2	0.07***		
N	1,903		

OR odds ratio, *CI* confidence interval, *Ref* reference category for categorical variables, *In relationship* married or a member of an unmarried couple, *Family history risk* health risk due to family history, *Prior info seeking* used email or the internet as a source of health information in the past 30 days, *HS or less* high school graduate or less than high school is the highest level of formal education achieved, *IHLC* internal health locus of control

*$p<0.05$; **$p<0.01$; ***$p<0.001$

associations and close conceptual connection of family history and perceived health with disease risk perceptions, we also ran an alternative model that excluded these variables as controls. The two models were univocal in their interpretation, so we report only the results of the full model.

The overall model was significant, −2LL= 2,266.39, Nagelkerke's R^2=0.08, $\chi^2(19, N=1{,}898)$= 105.06, $p<0.001$. However, controlling for the other variables, no significant association was found between logging on and perceived severity (B= −0.09, SE=0.079, OR=0.914, 95 % CI [0.78, 1.07], Wald $\chi^2(1)=1.30$, $p=0.255$, ns), perceived susceptibility (B=−0.05, SE=0.112, OR=0.955, 95 % CI [0.77, 1.19], Wald $\chi^2(1)=0.17$, $p=0.683$, ns), or worry (B=−0.06, SE=0.098, OR=0.94, 95 % CI [0.78, 1.14], Wald $\chi^2(1)=0.38$, $p=0.538$, ns). Moreover, when compared to the model that included only the individual dispositional difference and control variables, the addition of these perceptions of personal risk did not significantly improve model fit, $\Delta\ \chi^2(3, N=1{,}898)=3.22$, $p=0.359$, ns.

In line with these findings, the results of the tests for mediation effects revealed that none of the indirect effects of individual dispositional differences on logging onto the Multiplex website via perceptions of disease risk were significantly different from zero. The bias-corrected bootstrap confidence intervals for all of these indirect effects ranged from a negative to positive value. Contrary to what was predicted by the RISP model, personal risk perceptions do not appear to mediate the association of conscientiousness and openness to experience with genetic information seeking.

DISCUSSION

There are several implications of these results for translational research going forward [12]. It is important to consider the public health implications of providing personalized genetic risk information to individuals with little or no involvement of genetic health professionals. On the one hand, although we found that neuroticism was associated with greater perceived susceptibility and disease-related worry as hypothesized, neuroticism was not found to differentiate participants who sought online genetic information from those who did not. On the other hand, conscientiousness–reporting a sense of responsibility, diligence, and a willingness to see things through–was positively associated with logging on to learn about the genetic test. It is possible that participants who scored high in conscientiousness perceived the pursuit of additional information about the Multiplex genetic susceptibility test to be a responsible thing to do. Thus, respondents scoring high on conscientiousness may have been interested in the potential health benefits of genetic testing, inducing them to learn more about the genetic test and what it might mean for them and their families' health. Alternatively, participants high in conscientiousness might have viewed logging on to the website as important to being a responsible study participant.

Contrary to our expectations, the odds of logging onto the Multiplex website were lower for respondents who were more open to experience. This association was only significant when controlling for the influence of conscientiousness, suggesting that shared variance between the two indicators masked the association between openness and information seeking in the bivariate model.

Still, it is unclear how to theoretically account for why there was a negative association between openness and logging on. It is possible that the offer of genetic susceptibility testing for common chronic disease risk did not represent new or particularly novel information to the Multiplex participants. Although study participants had no prior diagnosis with diabetes mellitus, atherosclerotic cardiovascular disease, osteoporosis, or cancer, there was a relatively high prevalence of behavioral risk factors including cigarette smoking, physical inactivity, and obesity [37]. Moreover, these individuals reported high levels of awareness of behavioral risk factors associated with the diseases included on the multiplex test [37]. Also, it is worth considering that some participants may have had other chronic diseases not represented in the exclusion criteria, but which are associated with an elevated risk for one or more of the multiplex diseases. If the likelihood of information seeking increases with greater openness to experience, but only when that information is in some respect novel, the negative association observed in this study might reflect that. Though not aware of their genetic risk for disease, study participants may have felt well informed about their risk in general. In that case, those with greater openness to experience may have been especially averse to seeking what they might have considered redundant information. That is, their professed ability to handle a lot of information and to engage in thought may have led them to more quickly determine that they had sufficient information about the test, obviating the need to seek out more.

Another possibility is that respondents who were more open to experience may have been less responsive to the brochure that was sent to participants with instructions for accessing the Multiplex website. Specifically, the use of an "old media" technique to cue participants about the next phase of the study may have led to a kind of selective exposure bias. If they were indeed more likely to disregard the brochure, participants with greater openness to experience might have been disproportionately less likely to log on because, in effect, they did not receive the instructions to do so.

Lastly, the lack of association between risk perceptions and information seeking also deviates from previous findings in other health contexts [13, 43] and suggests that information about genetic testing may differ from other types of health

information. In contrast to the RISP model, we found that risk perceptions had no effect on information-seeking behavior. For example, although conscientiousness was associated with increased perceptions of disease severity, these perceptions did not have a discernable influence on accessing the Multiplex website when controlling for demographic and health-related variables. Likewise, openness to experience was revealed to be positively associated with all three facets of disease risk perceptions and negatively related to logging on. However, our mediation analysis provided no evidence that the association between openness and information seeking can be attributed to perceptions of disease risk. It is relevant to note that the current study does not account for a number of other variables used in the RISP model to predict information seeking. In particular, information insufficiency is thought to further mediate associations between perceptions of risk and information seeking, as well as between individual characteristics and information seeking [15]. If increased perceptions of risk did not lead respondents to believe that the information they already had about the Multiplex genetic test was inadequate, then we may not expect to find an association between risk perceptions and information seeking. Unfortunately, measures of information insufficiency were not included on the baseline questionnaire and so a comprehensive test of the RISP model was not possible. In light of this, it may be that conscientiousness and openness to experience have a direct influence on genetic information seeking, or that this relationship is mediated by variables other than risk perceptions.

Limitations

Several caveats should be considered when interpreting the results of this study. Genetic testing through the Multiplex Initiative was provided free of charge to study participants. This situation does not reflect the majority of current genetic testing options. However, it should have reduced barriers to seeking genetic testing. It is unclear how cost of genetic testing might interact with dispositional traits to influence online information seeking. Further, the Multiplex Initiative was conducted at a single site. Although this study drew on a sizeable population-based sample, our findings nonetheless only represent patients enrolled in the Henry Ford Health System. Future studies might expand the scope of these results by replicating this work in other study populations.

Our measure of the dependent variable, logging on to the Multiplex Initiative's website, does not account for the full range of possible genetic information seeking and avoidance behaviors. Even though the internet serves as the primary source for gathering genetic information [44], participants could have sought information through other websites, other media channels, or interpersonal communication with healthcare providers, family, or friends. These forms of genetic information seeking are not reflected in these data. Moreover, with increased levels of perceived risk, it is conceivable that some individuals may actively avoid additional information that would confirm those concerns. We were unable to directly explore these many possibilities with the current dataset. Even so, the use of a specific behavioral indicator offers unique insight into online genetic information seeking among healthy adults.

Also, a number of the measures used to assess individual dispositional differences had relatively low reliability when assessed in our sample, and some variables were based on only two items. The need to assess a large number of variables as part of the Multiplex Initiative restricted the number of items that could be dedicated to measuring any one construct. As such, fewer items were selected from more comprehensive scales that had been shown previously to have suitable reliability. However, differences between the test sample and our target population may account for the disparate psychometric properties that we observed. Even though all scales were above the threshold of an unacceptable level of reliability ($\alpha \leq 0.60$) [45], the items used in this study may be limited in their ability to capture the full range of personality and trait-like individual differences that we examined. We pursued structural equation modeling to assess whether latent constructs aligned with each of our dispositional constructs. Results of the measurement model confirmed that each of our dispositional constructs were indeed unidimensional and that construct reliabilities all fell within the generally acceptable range. Thus, while these results must be replicated in other samples, the associations we observed likely were not compromised by reduced reliability of the dispositional measures.

Despite these limitations, the results of this study can begin to inform the debate about who shows up to consider DTC genetic tests. Such information is critically important for anticipating the potential social and psychological consequences of DTC approaches.

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1. Caulfield T, Ries NM, Ray PN, Shuman C, Wilson B. Direct-to-consumer genetic testing: good, bad or benign? *Clin Genet*. 2010;77:101-105.
2. Hogarth S, Javitt G, Melzer D. The current landscape for direct-to-consumer genetic testing: legal, ethical, and policy issues. *Annu Rev Genomics Hum Genet*. 2008;9:161-182.
3. Gollust SE, Hull SC, Wilfond BS. Limitations of direct-to-consumer advertising for clinical genetic testing. *JAMA*. 2002;288:1762-1767.
4. Hudson K, Javitt G, Burke W, Byers P. ASHG Social Issues Committee ASHG statement on direct-to-consumer genetic testing in the United States. *Am J Hum Genet*. 2007;81:635-637.
5. Lerman C, Narod S, Shulman K, et al. BRCA1 testing in families with hereditary breast–ovarian cancer: a prospective study of patient decision making and outcomes. *JAMA*. 1996;275:1885-1892.
6. McBride CM, Wade CH, Kaphingst KA. Consumers' views of direct-to-consumer genetic information. *Annu Rev Genomics Hum Genet*. 2010;11:427-446.
7. Berg C, Fryer-Edwards K. The ethical challenges of direct-to-consumer genetic testing. *J Bus Ethics*. 2008;77:17-31.
8. Marteau TM, Croyle RT. The new genetics: psychological responses to genetic testing. *Br Med J*. 1998;316:693-696.
9. Claes E, Denayer L, Evers-Kiebooms G, Boogaerts A, Legius E. Predictive testing for hereditary non-polyposis colorectal cancer: motivation, illness representations and short-term psychological impact. *Patient Educ Couns*. 2004;55:265-274.
10. Heshka JT, Palleschi C, Howley H, Wilson B, Wells PS. A systematic review of perceived risks, psychological and behavioral impacts of genetic testing. *Genet Med*. 2008;10:19-32.
11. Genetics and Public Policy Center. Categorized DTC genetic testing companies. http://www.dnapolicy.org/resources/CategorizedDTCGeneticTestingCompanies.pdf. Updated May 28, 2010. Accessed 17 Aug 2010.
12. McBride CM, Alford SH, Reid RJ, Larson EB, Baxevanis AD, Brody LC. Putting science over supposition in the arena of personalized genomics. *Nat Genet*. 2008;40:939-942.
13. Kahlor L. PRISM: a planned risk information seeking model. *Health Commun*. 2010;25:345-356.
14. Bernhardt JM, McClain J, Parrott RL. Online health communication about human genetics: perceptions and preferences of internet users. *Cyberpsychol Behav*. 2004;7:728-733.
15. Griffin R, Dunwoody S, Neuwirth K. Proposed model of the relationship of risk information seeking and processing to the development of preventive behaviors. *Environ Res*. 1999;80:230-245.
16. Eysenck H, Eysenck MW. *Personality and Individual Differences: A Natural Science Approach*. New York: Plenum; 1985.
17. Costa PT, McCrae RR. Normal personality assessment in clinical practice: the NEO personality inventory. *Psychol Assess*. 1992;4:5-13.
18. Heinström J. Five personality dimensions and their influence on information behaviour. *Inf Res. 2003;9*(1). http://InformationR.net/ir/9-1/paper165.html. Accessed 1 Aug 2011.
19. Wallston KA, Maides S, Wallston BS. Health-related information-seeking as a function of health-related locus of control and health value. *J Res Pers*. 1976;10:215-222.
20. Rusting CL. Personality, mood, and cognitive processing of emotional information: three conceptual frameworks. *Psychol Bull*. 1998;124:165-196.
21. Soane E, Chmiel N. Are risk preferences consistent? The influence of decision domain and personality. *Pers Individ Dif*. 2005;38:1781-1791.
22. Watson D, Clark LA. Negative affectivity: the disposition to experience aversive emotional states. *Psychol Bull*. 1984;96:465-490.
23. Flynn KE, Smith MA, Freese J. When do older adults turn to the Internet for health information? Findings from the Wisconsin Longitudinal Study. *J Gen Intern Med*. 2006;21:1295-1301.
24. MacDonald KB. Effortful control, explicit processing, and the regulation of human evolved predispositions. *Psychol Rev*. 2008;115:1012-1031.
25. Trobst KK, Wiggins JS, Costa PT Jr, Herbst JH, McCrae RR, Masters HL. Personality psychology and problem behaviors: HIV risk and the five-factor model. *J Pers*. 2000;68:1233-1252.
26. Vollrath M, Knowch D, Cassano L. Personality, risky health behaviour, and perceived susceptibility to health risks. *Eur J Pers*. 1999;13:39-50.
27. Kernan JB, Mojena R. Information utilization and personality. *J Commun*. 1973;23:315-327.
28. Finlay K, Finlay T. The relative role of knowledge and innovativeness in determining librarians' attitudes toward and use of the Internet: a structural equation modeling approach. *Libr Q*. 1996;66:59-83.
29. Hashimoto H, Fukuhara S. The influence of locus of control on preferences for information and decision making. *Patient Educ Couns*. 2004;55:236-240.
30. van Zuuren FJ, Wolfs HM. Styles of information seeking under threat: personal and situational aspects of monitoring and blunting. *Pers Individ Dif*. 1991;12:141-149.
31. Wallston KA, Wallston BS, DeVellis R. Development of the multidimensional health locus of control (MHLC) scales. *Health Educ Behav*. 1978;6:160-170.
32. Case D, Andrews JE, Johnson JD, Allard SL. Avoiding versus seeking: the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *J Med Libr Assoc*. 2005;93:353-362.
33. Hoorens V, Buunk BP. Social comparison of health risks: locus of control, the person-positivity bias, and unrealistic optimism. *J Appl Soc Psychol*. 1993;23:291-302.
34. Abele A, Hermer P. Mood influences on health-related judgments: appraisal of own health versus appraisal of unhealthy behaviours. *Eur J Soc Psychol*. 1993;23:613-625.
35. Johnson JD, Case DO, Andrews JE, Allard SL. Genomics—the perfect information-seeking research problem. *J Health Commun*. 2005;10:323-329.
36. Alford SH, McBride CM, Reid RJ, Larson EB, Baxevanis AD, Brody LC. Participation in genetic testing research varies by social group. *Public Health Genomics*. 2011;14:85-93.
37. McBride CM, Alford SH, Reid RJ, Larson EB, Baxevanis AD, Brody LC. Characteristics of users of online personalized genomic risk assessments: implications for physician–patient interactions. *Genet Med*. 2009;11:582-587.
38. Goldberg LR. A broad-bandwidth, public domain, personality inventory measuring the lower-level facets of several five-factor models. In: Mervielde I, Deary I, De Fruyt F, Ostendorf F, eds. *Personality Psychology in Europe*, vol. 7. Tilburg: Tilburg University Press; 1999:7-28.
39. International Personality Item Pool. The items in each of the preliminary IPIP scales measuring constructs similar to those in the 30 NEO-PI-R facet scales. http://ipip.ori.org/newNEOFacetsKey.htm. Updated January 15, 2007. Accessed 10 Jun 2010.
40. Cohen J. *Statistical Power Analysis for the Behavioral Sciences*. 2nd ed. Hillsdale: Erlbaum; 1988.
41. Preacher KJ, Hayes AF. Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behav Res Methods*. 2008;40:879-891.
42. Preacher KJ, Hayes AF. Indirect: SPSS macro for multiple mediation [Software]. Columbus (OH): The Ohio State University; c2008 [cited 2012 May 27]. Available from: http://www.afhayes.com/public/indirect.sps/.
43. ter Huurne EFJ, Griffin RJ, Gutteling JM. Risk information seeking among US and Dutch residents: an application of the model of risk information seeking and processing. *Sci Commun*. 2009;31:215-237.
44. Case D, Johnson JD, Andrews JE, Allard S, Kelly KM. From two-step flow to the Internet: the changing array of sources for genetics information seeking. *J Am Soc Inf Sci Technol*. 2005;55:660-669.
45. DeVellis RF. *Scale Development Theory and Applications*. London: Sage; 1991.