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Characteristics of Genomic Test Consumers Who Spontaneously Share Results with Their Health Care Provider

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Abstract

Purpose—To evaluate the characteristics of direct-to-consumer (DTC) genomic test consumers who spontaneously shared their test results with their health care provider.

Methods—Utilizing data from the Scripps Genomic Health Initiative we compared demographic, behavioral, and attitudinal characteristics of DTC genomic test consumers who shared their results with their physician or health care provider versus those who did not share. We also compared genomic risk estimates between the two groups.

Results—Of 2024 individuals assessed at approximately 6 months post-testing, a total of 540 individuals (26.5%) reported sharing their results with their physician or health care provider. Those who shared were older ($p<.001$), had a higher income ($p=.01$), were more likely to be married ($p=.005$), and more likely to identify with a religion ($p=.004$). As assessed prior to undergoing testing, sharers also showed higher exercise ($p=.003$) and lower fat intake ($p=.02$), and expressed fewer overall concerns about testing ($p=.001$) and fewer concerns related to the privacy of their genomic information ($p=.03$). The genomic disease risk estimates disclosed were not associated with sharing.

Conclusion—In a DTC genomic testing context, physicians and other health care providers may be more likely to encounter patients who are more health conscious and have fewer concerns about the privacy of their genomic information. Genomic risk itself does not appear to be a primary determinant of sharing behavior among consumers.

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Keywords

direct-to-consumer; genomic testing; genetic risk assessment; disclosure of genetic results; consumer characteristics; personalized medicine

Introduction

Recent controversy surrounding direct-to-consumer (DTC) genomic risk profiling for common diseases has, in part, focused on whether or not testing should be accessible DTC, or alternatively if physician or other health care provider involvement should be mandated (Maves, 2011; McGuire, Evans, Caulfield, & Burke, 2010). Although the debate over this issue continues, at present, consumers are still purchasing genomic tests, and there is some degree of sharing of genomic information with physicians and other providers that occurs naturally (Bloss, Schork, & Topol, 2011; Kolor, Liu, St Pierre, & Khoury, 2009). The characteristics of individuals who spontaneously share test results with their health care provider have not been previously investigated. It has, however, been suggested that a greater understanding of this and other related issues may be informative to health care providers and may help them to better manage patients in a genomic testing context (McBride et al., 2009). Furthermore, early data suggests it may be this group of consumers, i.e., those who spontaneously share their results with their health care provider, for whom genome scanning has the greatest impact on behavior (Bloss, et al., 2011). Here we report on the baseline characteristics of a large sample of DTC genomic test consumers who spontaneously shared their genomic information with their health care provider.

Materials and Methods

The current study represents a secondary analysis of data from the Scripps Genomic Health Initiative (SGHI), a study originally designed to assess the impact of DTC genomic testing on consumer behavior. The SGHI is a large, longitudinal, cohort study of individuals who underwent testing with the Navigenics Health Compass (Navigenics). Details describing the SGHI, the Navigenics test, and the conditions included in the test have been previously reported (Bloss et al., 2010; Bloss, et al., 2011). Participants completed a baseline health assessment prior to receipt of their genomic risk information. Short-term follow-up assessment was completed an average of 5.6 months post-testing, at which time each participant was asked to indicate whether he or she shared the results with their physician or healthcare provider. Although we do not have data specifying which they shared with (i.e., a physician or other healthcare provider), the survey did include a separate question asking about sharing with a genetic counselor (GC). Thus, within the context of this study, when we refer to ‘physician’ or ‘health care provider’ sharing, we are indicating sharing with a healthcare provider who is not a GC.

For the purposes of this analysis, all demographic, behavioral, attitudinal, and personal and family history data were taken from the baseline assessment (i.e., pre-genomic-risk-disclosure), which has been previously described, (Bloss, et al., 2010; Bloss, et al., 2011).

All statistical analyses were completed using the software package SPSS. Independent-samples t-tests, chi-square tests, and Mann-Whitney U tests were used to compare sharers and non-sharers on the range of outcome variables of interest. Logistic regression was used to test for associations between genetic risk estimates and sharing, with sharing status as the dependent variable and eight covariates (gender, age, education, ethnicity, income, original versus short 3-month survey, follow-up in days, and health-related occupation) plus the condition-specific risk estimate as the independent variables.

Results

Participants

As previously reported, a total of 2037 individuals completed the short-term follow-up assessment. Of these, 2024 individuals indicated whether or not they shared their genomic test results with their physician or health care provider (shared, n=540, 26.5%) (Bloss, et al., 2011).

Demographic and Behavioral Characteristics

Comparisons of demographic and behavioral characteristics between sharers and non-sharers are presented in Table 1. Individuals who shared with their health care provider were older and had a higher annual income. Sharers were also more likely than non-sharers to be married as opposed to being divorced, single, widowed, or other. Although sharers included a higher proportion of individuals with biological children, this difference did not reach statistical significance. Sharers also showed a higher proportion of individuals who identified with a religion.

In terms of baseline behavioral characteristics (Table 1), sharers reported a greater amount of exercise per week, lower dietary fat intake, and more frequent physician visits per year. We did not find group differences in self-reported substance use or baseline anxiety levels.

Attitudes Toward Testing

In terms of attitudes toward testing, which were assessed at baseline, we found that individuals who went on to share results with their physician or health care provider initially reported fewer overall concerns about undergoing genomic testing, as well as fewer concerns specifically related to privacy issues. While a large majority of both sharers and non-sharers believed that their genomic risk information would be of great value despite not being completely predictive of disease development, a greater proportion of sharers reported this belief relative to non-sharers (Table 2).

Genomic Risk Estimates

Genomic risk estimates for the 23 conditions included on the Navigenics test were compared between sharers and non-sharers. Lupus was the only condition found to be even nominally associated with sharing behavior (p=.03).

Family and Personal Medical History

In terms of family medical history, we did not find significant associations with sharing for any of the 15 conditions assessed. In terms of personal medical history, very low sample sizes for the conditions assessed precluded reliable association analyses with sharing behavior.

Discussion

We compared demographic and behavioral characteristics, as well as attitudes toward testing between DTC genomic test consumers who elected to share their results with their physician or healthcare provider versus those who did not share. Sharers were older in age, had a higher income, were more likely to be married, and more likely to identify with a religion. Sharers also reported a greater amount of exercise and lower dietary fat intake at baseline. Perhaps most notably, at baseline, sharers expressed fewer overall concerns about the prospect of undergoing genomic testing, as well as fewer concerns specifically related to

privacy. Genomic risk estimates and family medical histories were not found to be associated with sharing.

From our findings, the types of patients physicians or other healthcare providers are likely to encounter in a genomic testing context may be those who are more proactive about their health as evidenced by the higher exercise and lower fat intake of this group at baseline. Also supporting this is the observation that at baseline sharers reported a greater number of physician visits relative to non-sharers. Although the propensity to visit a physician more often could also be a primary contributor to sharing behavior itself (i.e., with more frequent physician visits, one has a greater number of opportunities to share), non-sharers also reported an average of more than three physician visits per year. Therefore, most non-sharers would likely have also had a physician visit within the nearly 6-month follow-up period and thus would have had ample opportunity to share their results.

While it is somewhat surprising that the genomic disease risk estimates received by participants were not associated with sharing behavior, this cohort of individuals was fairly well-educated and likely had some, if not a high degree of awareness of the environmental component of the diseases assessed, as well as current concerns in the scientific and clinical community regarding the clinical validity of these tests (Burke, 2009; Eng & Sharp, 2010). As such, many participants may have felt it was unnecessary to consult a physician or other health care provider regarding their genomic risk levels specifically. Participants may also have been aware of the often-cited lack of physician knowledge with respect to genomics (Healy, 2009) and thus did not anticipate a high degree of benefit from sharing with their physician.

Limitations of the SGHI cohort are that the sample is predominantly Caucasian, well-educated, generally healthy, and has a high socio-economic status. Although the sample has been shown to be representative of the current population of genomic test consumers, it is not representative of the general public. Furthermore, of the subjects who enrolled and completed the baseline assessment, 44% did not complete follow-up and thus we do not have information on whether or not they shared their results with a health care provider. Another limitation that is specific to the secondary analysis reported here is that the survey item that asked about sharing behavior did not specify whether or not the participant shared with a physician or other healthcare provider. While physicians are still the primary healthcare providers for most Americans, other providers are often also consulted, and it is possible that characteristics of sharers or patterns of sharing may differ in the context of a more focused query where the type of provider was specified. Another limitation of this analysis relates to the fact that some individuals in our sample reported consulting a GC about their results, and it is possible that these interactions may have influenced sharing patterns with other health care providers. These latter two limitations suggest future directions for investigation.

There are some instances of genomic profiling being incorporated into clinical patient care in certain settings, but it is not currently considered “conventional” medical practice. Thus, some parallels may be drawn from the literature describing patients’ disclosure of other types of non-conventional medical practices, for example, the use of complementary and alternative medicine (CAM). One review of patient disclosures of CAM use to physicians found that the most frequently cited reasons for non-disclosure were concern of a negative reaction; patient perception that the physician does not have a need to know the information; and finally, that the physician simply did not ask, or that there was not time to discuss the issue (Robinson & McGrail, 2004). Further studies of consumers of DTC genomic services may elucidate whether non-sharers have similar and/or additional reasons for not disclosing their genomic risk information to their physicians.

A greater proportion of non-sharers had privacy concerns regarding their genomic information relative to those who shared their results with their health care provider. In this context, it is noteworthy that non-sharers represent roughly three-fourths of our study participants (nearly 1500 individuals), suggesting that many people who pursue genomic testing and place a high value on knowing their genomic information, may also prefer to keep the information private, even from their own health care provider. To the extent that empirical studies can inform and drive ongoing policy-making with respect to this nascent industry, our data raise the possibility that mandating physician or other healthcare provider involvement in DTC genomic testing may be incompatible with the views and preferences of at least some proportion of current consumers.

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Table 1

Baseline demographic and behavioral characteristics of Health Care Provider Sharers versus Non-Sharers

Variable	Sharers	Non-Sharers	p-value
Demographic			
Gender (% Female)	57.0	54.6	.33[a]
Age (Mean, SD, Range)	50.0 (12.5), 20-85	45.44 (11.6), 19-81	**<.001** [b]
Income (Median Category)	150K-199,999	100K-149,999	**.01** [c]
Education (Median Category)	Some Post-College	Some Post-College	.20 [c]
Ethnicity (% Caucasian)	84.6	84.0	.74 [a]
Marital Status (Modal Category, %)	Married, 73.2	Married, 68.0	**.005** [a]
Have Children (% Yes)	65.4	60.9	.07 [a]
Identify with Religion (%Yes)	80.5	74.2	**.004** [a]
Health-Related Occupation (% Yes)	23.5	24.2	.77 [a]
Health Insurance (% Yes)	100.0	99.4	.07 [a]
Behavioral			
Exercise (GLTEQ) (Median, SD)	27.0 (24.9)	22.3 (23.3)	**.003** [c]
Dietary Fat Score (Median, SD)	15.0 (8.1)	16.0 (7.8)	**.02** [c]
Frequency of Dr. Visits/Year	3.8	3.3	**<.001** [c]
Tobacco Use (% Yes)	5.4	6.0	.59 [a]
Alcohol Use (% Yes)	77.8	80.9	.13 [a]
Trait Anxiety (Median, SD)	31.0 (9.4)	32.0 (9.7)	.06 [c]

[a] Pearson Chi-Square

[b] Independent-Samples T Test

[c] Mann-Whitney U Test

Table 2

Baseline consumer attitudes towards testing in Health Care Provider Sharers versus Non-Sharers

Variable	Sharers	Non-Sharers	p-value
Overall concerns related to testing (% Yes) *	44.6	52.7	**.001** [a]
Learning about disease risk (% Yes) *	11.1	13.1	.24 [a]
Not knowing how would feel about results (% Yes) *	15.4	16.7	.47 [a]
Quality and reliability of the data (% Yes) *	14.8	15.0	.94 [a]
Privacy issues about the data (% Yes) *	33.2	38.5	**.03** [a]
Value Attributed to Risk Information			**<.001** [a]
Do Not Value (%)	0.2	0.1	
Somewhat Value (%)	21.7	31.1	
Greatly Value (%)	78.2	68.8	

*Note that respondents could select multiple specific concerns, thus the percentage totals within each group sum to >100%.

[a]Pearson Chi-Square