

Predictors of interest in direct-to-consumer genetic testing

Kate Sweeny* and Angela M. Legg

Department of Psychology, University of California, Riverside, CA 92521, USA

(Received 6 April 2010; final version received 31 July 2010)

Direct-to-consumer (DTC) genetic testing is an increasingly available option among individuals searching for information about their health risk factors and ancestry. This study is one of the first to examine predictors of interest in DTC genetic testing. Participants read one of the three types of information about DTC genetic testing (positive only, negative only or both) and reported perceptions of and intentions to pursue testing. The information which people read, their perceptions of the benefits of testing, their perceptions of the barriers to testing and anticipated regret predicted intentions to undergo testing. Interestingly, people who read both positive and negative information did not differ from people who read only negative information in their intentions to pursue testing. We discuss the implications of these findings for predicting interest in this relatively new type of genetic testing and for designing interventions to encourage (or discourage) testing.

Keywords: genetic testing; decision-making; direct-to-consumer; anticipated regret; health belief model

Introduction

With the completion of the Human Genome Project, personal genetic analysis is an increasingly feasible option for those interested in learning their genetic risk for a variety of health conditions. Genetic testing is available in many forms and offers varying predictive and diagnostic levels for myriad diseases and conditions, such as breast cancer, Huntington's disease and colorectal cancer (NHGRI, 2009). Although most genetic testing occurs within the confines of medical offices or hospitals, a recent development in genetic testing affords individuals a greater privacy by providing the opportunity to take genetic tests and receives results in their own homes. Direct-to-consumer (DTC) genetic testing services provide consumers with information about their genetic health factors and ancestry within 2–4 weeks after they return a saliva sample in a mail-from-home kit. The revolutionary nature of at-home genetic testing earned 23 and Me, an online DTC genetic testing service, the Invention of the Year award from *Time* magazine in 2008 (Caulfield, Ries, Ray, Shuman, & Wilson, 2010). This study is part of an emerging area of research effort to examine predictors of interest in DTC genetic testing.

*Corresponding author. Email: ksweeny@ucr.edu

Prevalence and usage rates of DTC genetic testing are difficult to assess given the recent emergence of these websites, but statistics on the visitations rates at one DTC testing website (23andMe.com) reveal a more than 200% increase in site traffic between April 2009 and April 2010 (Compete Site Analytics, 2010). Proponents of DTC genetic testing argue that it offers consumers a private, convenient way to obtain genetic information on over 200 diseases, conditions and traits (23 and Me, 2010). Furthermore, some researchers have suggested that DTC genetic testing may increase family communication about disease risk and family history (Gray & Olopade, 2003).

Despite claims touted by DTC genetic testing services and its supporters, some scholars have criticised this method of genetic testing (Wolfberg, 2006). Critics note that DTC genetic testing does not afford consumers an adequate degree of counselling from medical professionals (physicians or nurses) and genetic counsellors. Typically, traditional genetic testing involves a medical consultation prior to testing, some form of counselling or post-consultation after patients receive their results, or both (Benjamin et al., 1994; Calzone & Biesecker, 2002; Raymond, & Everett, 2009). Without adequate counselling by knowledgeable medical professionals, consumers may misinterpret inherently complicated genetic results or fail to acknowledge the limitations of genetic testing results.

Despite these concerns regarding DTC genetic testing, its use is increasing (Pagon et al., 2002), and with it the importance of understanding decisions to undergo testing. DTC genetic testing differs from other types of genetic testing in its corporate model and its accessibility outside the context of a medical facility, and thus it remains unclear whether predictors of other types of preventative behaviour apply to the decisions to undergo DTC genetic testing. Moreover, little is known about the best ways to encourage or discourage the use of DTC genetic testing. Although the potential risks and benefits of DTC genetic testing remain controversial, researchers cannot develop effective interventions to increase or decrease uptake of DTC genetic testing without clear evidence of the factors that prompt testing decisions.

This study examined four potential predictors of decisions to pursue DTC genetic testing, drawn from the larger literature on health behaviour decisions: two cognitive predictors (perceived benefits of testing and perceived barriers to testing) and two emotion-oriented predictors (anticipated regret over both testing and missing the opportunity to test). This approach reflects a recent but growing movement to examine emotion-oriented predictors of health behaviour alongside the more traditional 'rational' or cognitive predictors (e.g. Abraham & Sheeran, 2003; Wroe, Turner, & Salkovskism 2004).

The cognitive predictors in our study, perceived benefits and perceived barriers, derive from the health belief model (Rosenstock, 1974). The health belief model presents perceived benefits and perceived barriers as two key predictors of preventative health behaviour, and research supports the role of these perceptions in decisions to get vaccinated against influenza (Aho, 1979; Cummings, Jette, Brock, & Haefner, 1979; Larson, Olsen, Cole, & Shortell, 1979; Rundall & Wheeler, 1979), to undergo screening for high blood pressure (King, 1982), to use child safety restraints in the car (Arneson, Triplett, Hahnemann, & Merington, 1985) and to engage in frequent breast self-examinations (Champion, 1990). In the context of genetic testing, both perceived benefits of testing (e.g. increased knowledge about self and family members' health risks and to inform future health decisions) and perceived barriers to testing (e.g. potential of being rejected for health insurance

coverage or experiencing anxiety over test results) predict decisions to undergo genetic testing for colorectal cancer (Vernon et al., 1999; Bunn, Bosompra, Ashikaga, Flynn, & Worden, 2002), breast and ovarian cancer (e.g. Lerman et al., 1996; Meiser et al., 2000) and heart disease (Wroe & Salkovskis, 1999), as well as several hypothetical genetic tests (Bosompra et al., 2000; Cameron, Sherman, Marteau & Brown, 2009). This study is the first to test the applicability of these findings to DTC genetic testing.

Of note, we did not include perceived severity or perceived susceptibility in our study (two additional cognitive components of the health belief model; Becker & Rosenstock, 1984; Rosenstock, 1974) due to unique aspects of DTC genetic testing. Unlike genetic testing for specific disease outcomes (e.g. breast and ovarian cancer, Huntington's disease, etc.), DTC genetic testing provides feedback on a wide range of genetic health factors. Thus, the disease-centred predictors of perceived severity (i.e. of a particular health outcome) and perceived susceptibility (i.e. for a particular health outcome) did not make sense in the context of our study.

The emotion-oriented predictors we examined in this study are anticipated regret over testing and anticipated regret over missing the opportunity to test (i.e. over *not* testing). People experience regret following decisions that they wish they could 'do over' to make a different choice (Zeelenberg & Pieters, 2007; Zeelenberg, van Dijk, Manstead, & van der Pligt, 1998). Not only do people sometimes experience painful regret following a decision, they can also anticipate the potential for regret in advance and attempt to avoid it by making a carefully considered decision (Connolly & Zeelenberg, 2002). Specifically, people facing a decision may weigh the likelihood of regret given each of their options (e.g. pursuing DTC genetic testing *vs.* not pursuing it or waiting until a later time) and then choose the option that is least likely to result in regret (Acker, 1997; Lee, 1971; Luce & Raiffa, 1957; Zeelenberg & Pieters, 2007). Studies show that anticipated regret predicts contraceptive use and sexual behaviour (Richard, de Vries, & van der Pligt, 1998; van der Pligt & Richard, 1994), childhood vaccination (Wroe et al., 2004), HPV vaccination (Ziarnowski, Brewer, & Weber, 2009) and exercise behaviours (Abraham & Sheeran, 2003).

This study had two primary goals. First, we examined whether perceived benefits, perceived barriers and anticipated regret predicted intentions to pursue DTC genetic testing. The inclusion of both traditional components of the health belief model and emotion-oriented predictors also allowed us to contribute to a growing body of research examining 'missing pieces' of the health belief model.

Second, we examined one potential influence on these perceptions, and subsequently on intentions to test: the salience of benefits and barriers to testing. Due to the relatively recent introduction of DTC genetic testing, people likely know little about the availability of such services, the procedures involved and the pros and cons of testing. Thus, we presented participants with differing information about DTC genetic testing and hypothesised that information provided to potential DTC genetic testing consumers would significantly influence their perceptions of testing and their intentions to test. Experimental manipulations are quite rare in investigations of genetic testing decisions, and thus our study's approach is without much precedent. However, three studies of interest in genetic testing for breast cancer or heart disease manipulated people's focus on positive *versus* negative information and successfully increased testing intentions in the positive focus group (Wroe & Salkovskis, 1999, 2000). Although it remains unclear whether an information

manipulation will be effective in the context of a consumer-driven genetic test opportunity (as opposed to the more traditional medical testing procedures examined in Wroe and Salkovskis' studies), we expect that our manipulation will be similarly successful at changing people's intentions to pursue genetic testing.

In this study we provided people with either positive information about DTC genetic testing (focusing on the advantages of testing), negative information about DTC genetic testing (focusing on the disadvantages of testing) or information that included both positive and negative aspects of DTC genetic testing. Participants then reported their perceptions of the benefits of testing, the barriers to testing, anticipated regret over testing *versus* missing the opportunity to test and their intentions to test. We hypothesised that information about the advantages of DTC genetic testing would increase perceptions of the benefits of testing, and thus increase testing intentions relative to the negative and full information conditions. Although somewhat speculative, we also expected that information about the advantages of testing would increase anticipated regret over missing the opportunity to test, which would also increase testing intentions relative to the negative and full information conditions. In contrast, we predicted that information about the disadvantages of DTC genetic testing would increase perceptions of the barriers to testing (as well as anticipated regret over testing), and thus decrease testing intentions relative to the positive and full information conditions.

Methods

Participants

Participants were 99 adults between the ages of 19 and 78 ($M = 37.3$) who were recruited through web advertisements for the study. An advertisement for the study was posted on Craigslist with the title 'Quick Psychology Survey: Health Perceptions', and people participated as volunteers for no compensation. Although this method does not allow us to examine response rates *per se*, approximately 39% of people who began the survey (i.e. responded to at least the consent procedure) actually completed it. Although higher response rates are always preferable, one online survey provider estimates that a 20–30% response rate is typical when the researcher has no prior relationship with the respondents (Zoomerang, 2010).

The sample was 80% female and 71% White/Caucasian, 8% Hispanic/Latino, 6% Asian, 4% Black/African-American, 3% American Indian/Alaska Native, 2% Native Hawaiian/Pacific Islander, 2% Middle Eastern and 3% Other. Regarding education level of our sample, 7% had only a high school degree, 35% had attended some college, 40% had a college degree and 19% had some post-graduate education. Although this sample was not nationally representative, our method of recruitment provided a sample that likely represents the population who would be most likely to spontaneously investigate their options for DTC genetic testing through the internet (predominantly Caucasian females) and is consistent with sample demographics from past studies exploring consumer intentions to test (Gray et al., 2009; Wideroff, Vadaparampil, Breen, Croyle, & Freedman, 2003). Of course, the sample that began the survey but did not complete it may have differed from the sample that completed the survey. The data collection methods do not allow us to examine differences between these groups (most people who began the survey exited before providing any data), so we would simply note this methodological limitation.

Procedures

After providing informed consent, participants read a brief overview of DTC genetic testing. Participants were then randomly assigned to one of the three information conditions using a method in which the participants indicated the last digit of the current time (e.g. if it was 4:05 p.m., they would have selected '5'), and this selection automatically directed them to one of the three types of information. All participants then read one of the three descriptions that served as our manipulation of information type. Participants in the *positive information condition* ($n = 40$) read the following:

There are many benefits of DTC testing, including the accessibility of tests to consumers, promotion of proactive healthcare and the privacy of genetic information. In fact, DTC testing is as easy as ordering a kit online, sending a saliva sample and then reading your results online in as little as 2–4 weeks.

Participants in the *negative information condition* ($n = 34$) read the following:

There are some risks of DTC testing, including the lack of governmental regulation and the potential misinterpretation of genetic information. Furthermore, DTC testing is somewhat expensive, cannot provide important diagnostic information, and may not be as accurate as advertised.

Participants in the *full information condition* ($n = 21$) read both descriptions, starting with the positive information and followed directly by the negative information. The information in all conditions was accurate in reference to at least the most popular DTC genetic testing services (e.g. 23 and Me). Furthermore, we pilot tested the information to ensure that the three conditions were equivalent in terms of ease of comprehension, ease of remembering and interest. An independent sample of participants ($n = 28$) were randomly assigned to read one of the three types of information (positive only, negative only or full information) and complete a three-item measure of ease of comprehension ('To what extent was the information easy to read/easy to understand/easy to comprehend?' 1 = *not at all*; 7 = *very much*; Cronbach's $\alpha = 0.94$), a one-item measure of ease of remembering ('To what extent was the information easy to remember?') and a one-item measure of interest ('To what extent was the information interesting?'). One-way between-subjects ANOVAs comparing the three-information conditions on ease of comprehension, ease of remembering and interest revealed no differences between conditions, $F_s < 1.47$, $p_s > 0.24$.

After reading the information, participants completed several measures of their perceptions of DTC genetic testing. The questionnaire included three items measuring perceived benefits ('It's worth my time and money to undergo DTC genetic testing'; 'I think I will experience long-term benefits if I undergo DTC genetic testing'; 'The benefits of DTC genetic testing are very important to me'; Cronbach's $\alpha = 0.85$), six items measuring perceived barriers ('I'm worried about the limitations of DTC genetic testing'; 'I think DTC genetic testing is too risky'; 'I think I will experience negative consequences if I undergo DTC genetic testing'; 'It's not worth it for me to undergo DTC genetic testing'; 'Other things in my life will get in the way of undergoing DTC genetic testing'; 'I think DTC genetic testing is too costly'; Cronbach's $\alpha = 0.74$), one-item measuring anticipated regret over testing ('I think I'll regret it if I undergo DTC genetic testing') and one-item measuring anticipated regret over *not* testing ('I think I'll regret it if I miss the chance to undergo DTC genetic testing').¹ Participants responded to all items on 9-point Likert-type scales

(1 = *strongly disagree*, 9 = *strongly agree*). Finally, participants indicated their intention to pursue DTC genetic testing ('I plan to take action; I will investigate my options for DTC genetic testing and then undergo whatever type of testing is most desirable to me'; 1 = *not at all desirable*, 9 = *very desirable*) and completed the demographic items.

Results

Demographic variables

Prior to testing our hypotheses, we first examined the relationships between demographic variables and our five primary measures: intention to test, perceived benefits, perceived barriers, anticipated regret over testing and anticipated regret over not testing. Although we did not have *a priori* hypotheses regarding the relationships between demographic variables and our measures of interest, studies of other types of genetic testing find that demographic factors predict testing perceptions and decisions, albeit inconsistently (e.g. Jacobsen, Valdimarsdottir, Brown, & Offit 1997; Kinney et al., 2000; Lerman et al., 1996; Meiser & Dunn, 2000; Ramirez, Aparicio-Ting, de Majors & Miller, 2006; Roberts et al., 2004). First, we conducted independent samples *t*-tests comparing men and women on these five measures. Men and women did not differ in intention to test, $t(86) = -0.87$, $p = 0.39$, perceived benefits, $t(86) = 0.34$, $p = 0.73$ or regret over missing the opportunity to test, $t(86) = 0.27$, $p = 0.79$. However, women perceived greater barriers to testing, $t(86) = 2.24$, $p = 0.02$ and anticipated greater regret over testing, $t(86) = 2.54$, $p = 0.01$, compared to men (see Table 1 for means by gender). These findings generally are consistent with a previous study of testing intentions for a variety of self-test procedures that found that men are more likely than women to intend to self-test (Wilson et al., 2008). Of course, our study did not find an effect of gender on testing intention, but the difference in perceptions of barriers and anticipated regret over testing suggests that women did not perceive DTC testing as positively as did men.

We next conducted one-way between-subjects ANOVAs to examine the relationship between race/ethnicity and our measures of interest (using dummy codes for the eight race/ethnicity categories, which served as the predictor of each response measure) and found that race/ethnicity predicted only perceived benefits and perceived barriers, $F_s > 2.60$, $p_s < 0.02$, and not testing intentions or anticipated

Table 1. Testing intentions and perceptions by gender.

	Males		Females	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Intentions	4.1	2.3	3.6	2.3
Perceived benefits	5.4	1.7	5.2	1.9
Perceived barriers ^a	4.0	1.4	4.8	1.3
Anticipated regret over missing opportunity to test	4.6	2.5	4.4	2.3
Anticipated regret over testing ^a	2.8	1.4	4.3	2.3

Note: ^aVariables differing significantly between males and females.

Table 2. Testing perceptions by ethnicity.

	White (n = 66)	Latino (n = 7)	Asian (n = 6)	Black (n = 4)	Native Americans (n = 3)	Other/Multiple (n = 3)	Pacific Island (n = 2)	Middle Eastern (n = 2)
Intentions	3.5 (2.2)	5.4 (2.9)	4.6 (2.5)	3.3 (2.6)	1.3 (0.6)	4.7 (1.5)	7.5 (2.1)	4.0 (—)
Perceived benefits ^a	5.0 (1.7)	6.3 (2.7)	6.6 (1.3)	4.4 (2.6)	2.4 (1.0)	7.0 (0.9)	7.3 (0.9)	4.2 (1.2)
Perceived barriers ^a	4.7 (1.3)	4.6 (1.6)	4.4 (0.8)	4.9 (1.3)	6.9 (0.9)	3.2 (1.2)	3.0 (1.9)	4.6 (0.1)
Anticipated regret over missing opportunity	4.2 (2.1)	5.3 (3.2)	6.3 (2.1)	3.0 (3.4)	4.0 (1.4)	6.3 (1.5)	6.0 (1.4)	3.5 (2.1)
Anticipated regret over testing	4.0 (2.1)	5.0 (3.4)	3.0 (0.6)	4.5 (2.4)	6.0 (4.4)	1.7 (1.2)	3.0 (2.8)	4.0 (1.4)

Notes: Numbers in parentheses are standard deviations. Where no standard deviation appears, only one participant of that race/ethnicity completed the measure.

^aVariables differing significantly across race/ethnicity.

Table 3. Testing intentions and perceptions by condition.

	Positive only	Full information	Negative only
Perceived benefits	5.9 ^a (1.6)	4.8 ^b (1.9)	4.6 ^b (1.9)
Perceived barriers	4.1 ^a (1.2)	5.1 ^b (1.4)	5.1 ^b (1.2)
Anticipated regret over missing opportunity to test	5.1 ^a (2.1)	4.3 ^b (2.2)	3.7 ^b (2.3)
Anticipated regret over testing	3.3 ^a (2.1)	4.4 ^{ab} (2.3)	4.6 ^b (2.3)
Intentions	4.4 ^a (2.2)	3.2 ^b (2.2)	3.2 ^b (2.3)

Notes: Numbers in parentheses are standard deviations. Within each row, means with different subscripts are significantly different from each other according to planned contrast analyses, $p < 0.05$.

regret, $F_s < 2.08$, $p_s > 0.06$ (see Table 2 for means). The means suggest that Native Americans perceived the fewest benefits and greatest barriers, and Pacific Islanders and participants who chose 'Other' or multiple racial/ethnic categories perceived the greatest benefits and fewest barriers. However, we are hesitant to draw strong conclusions about race/ethnicity and DTC genetic testing due to the widely varying number of participants in each racial/ethnic category. Furthermore, our findings are inconsistent with a previous study of intentions to self-test, which found that Whites/Caucasians had the strongest intentions to test (Wilson et al., 2008).

Finally, we conducted bivariate correlations between age and each of our dependent measures and found no significant correlations, all $r_s < 0.13$, $p_s > 0.23$. Similarly, none of our measures correlated significantly with education level, all $r_s < 0.07$, $p_s > 0.53$. The previous study of intentions to self-test found that older people had stronger intentions to test, which is inconsistent with our finding, but that education was not a significant predictor of testing intentions (Wilson et al., 2008).

Information manipulation

To test our hypothesis that information content would influence perceptions of testing and intentions to test, we first conducted one-way between-subjects ANOVAs on the four perception measures (perceived benefits, perceived barriers and anticipated regret over testing and not testing) and on the measure of intentions (see Table 3 for means). As predicted, the information participants received significantly affected their perceptions of benefits, $F(2, 96) = 6.29$, $p < 0.01$, and barriers, $F(2, 96) = 8.44$, $p < 0.001$, and their anticipated regret over testing, $F(2, 96) = 3.94$, $p = 0.02$, and not testing, $F(2, 95) = 4.08$, $p = 0.02$. Critically, the information manipulation also affected participants' intention to test, $F(2, 96) = 3.00$, $p = 0.05$.

Planned contrasts revealed patterns in each case that generally were consistent with our hypotheses (Table 2). As hypothesised, participants in the *positive information condition* perceived the greatest benefits of testing and the fewest barriers to testing. Also as hypothesised, participants in the *positive information condition* anticipated the greatest regret over missing the opportunity to test. Regarding anticipated regret over testing, participants in the *positive information condition* anticipated less regret over testing than participants in the

negative information condition, although the difference between participants in the *positive information* and *full information* conditions did not reach significance. Finally, regarding intention to test, participants in the *positive information condition* had greater intentions than participants in both the *negative information condition* and *full information condition*.

Of note, although the *full information* condition was longer than either the *positive information* or *negative information* conditions, our results suggest that this potential confound did not influence responses on our measures of interest. That is, responses in the *full information* condition fell in between the other two conditions in all cases, suggesting that the greater amount of information did not in any way prompt extreme responding (either high or low).

Mediation analyses

We lastly examined whether perceived benefits, perceived barriers and anticipated regret mediated the relationship between information condition and intention to test. We hypothesised that the information participants read would influence their perceptions of testing and anticipated regret in regards to testing, and these perceptions would in turn predict their intentions to test. Because no demographic variable was related to intention to test, we did not include these variables in our mediation analyses. Having demonstrated relationships between the information manipulation and each of the five variables of interest (intention to test, perceived benefits, perceived barriers, anticipated regret over testing and anticipated regret over not testing), we next sought to confirm that each of the perception measures also predicted intentions (Baron & Kenny, 1986). As expected, intentions were significantly correlated with perceived benefits, perceived barriers, anticipated regret over testing and anticipated regret over *not* testing, $r_s > 0.39$, $p_s < 0.001$.

Finally, we conducted separate simultaneous multiple regression analyses for each of our mediators in which information condition and either perceived benefits, perceived barriers, anticipated regret over testing or anticipated regret over missing the opportunity to test were entered (after centring) as predictors of intention to test. In all four analyses, including the mediator in the regression model caused the effect of information to drop below significance, $\beta_s < 0.14$, $p_s > 0.18$. Furthermore, the Sobel tests for each mediator were significant, $z_s > 2.27$, $p_s < 0.03$.

Discussion

This study is one of the very few studies to explore predictors of decisions to pursue DTC genetic testing. As hypothesised, our results indicate that perceived benefits of testing, perceived barriers to testing and anticipated regret over testing *versus* not testing predicted intentions to pursue DTC genetic testing. Additionally supporting our hypotheses, we found evidence that the information people received about DTC genetic testing influenced their perceptions of benefits and barriers and their expectations about regret, and in turn their intentions to test. In all, our hypotheses received strong support. Participants who received only positive information about DTC genetic testing perceived the greatest benefit from testing, anticipated the greatest regret over *not* testing, and most importantly, had the strongest intentions to pursue testing. Participants who received only negative information about DTC

genetic testing perceived the greatest barriers to testing, anticipated the greatest regret over testing and did not differ from people who received both positive and negative information in their intentions to test. Finally, the relationship between the information people received and their intentions to pursue testing was fully mediated by perceived barriers to testing and anticipated regret over *not* testing.

Implications

Our findings have important implications for both predicting and influencing decisions to pursue DTC genetic testing. Regarding prediction, our findings suggest that decisions regarding DTC genetic testing depend on some of the same considerations that drive other health behaviour decisions. Numerous studies support the roles of perceived benefits and barriers in decisions to undertake preventative health behaviours (e.g. Aho, 1979; Arneson, 1985; Champion, 1985; King, 1982) and to undergo some types of genetic testing (e.g. Cameron & Reeve, 2006; Vernon et al., 1999; Wroe & Salkovskis, 1999). Although our study is the first we know of to examine the role of anticipated regret in genetic testing decisions, anticipated regret also predicts some preventative health behaviours (Abraham & Sheeran, 2003; van der Pligt & Richard, 1994; Wroe et al., 2004; Ziarnowski et al., 2009). Our findings provide further confirmation of the role of perceived benefits, perceived barriers and anticipated regret in health decision-making. However, our study provides an important addition to the literature on health decision-making by extending these findings to a unique and relatively unexamined area of health behaviour.

Regarding intervention, our findings suggest several considerations that may be important for encouraging (or discouraging) use of DTC genetic testing. First, our findings suggest that interventions can increase interest in DTC genetic testing by increasing perceptions of the benefits of testing, decreasing perceptions of the barriers to testing or altering expectations of regret (i.e. by increasing anticipated regret over missing the opportunity to test or decreasing anticipated regret over testing). Second, the results of our information manipulation suggest that providing exclusively positive information is likely to increase interest in testing, whereas providing exclusively negative information may not change the likelihood of testing. In our study, the testing intentions of people who received only negative information did not differ from the intentions of people who received balanced information. This intriguing finding might point to a generally negative view of DTC genetic testing (Wilde, Meiser, Mitchell & Schofield, 2010), or even the general tendency for negative information to exert more power than positive information (Baumeister, Bratslavsky, Finkenauer, & Vohs, 2001). In either case, people's apparent focus on the negative side of DTC genetic testing may be difficult to change with even balanced information. Only when people are shielded from negative information do they seem to increase their interest in testing. Although our findings support this conclusion, it merits replication.

Of course, discussion of interventions to increase uptake of DTC genetic testing may be premature. The debate over whether people should undergo genetic testing at all, and particularly DTC genetic testing, is as yet unresolved. Critics of DTC genetic testing express great concern over the lack of counselling following testing, the

potential for misinterpretation of test results and the possibility of genetic discrimination (Berg & Fryer-Edwards, 2008; Wolfberg, 2006). Consistent with the concerns of vocal critics, our study provides evidence that when making decisions about whether to undergo DTC genetic testing, people predominantly focus on the negative aspects of the procedure. As our findings demonstrate, even negative information presented alongside positive information is sufficient to reduce perceived benefits and intentions to test. We do not attempt to resolve the ethical debate over DTC genetic testing, but our findings suggest that discouraging DTC genetic testing may prove easier than encouraging people to undergo testing.

Limitations

Although our study has many strengths, most notably its use of an appropriate sample (as evidenced from previous studies indicating populations most aware of or most likely to seek out information about DTC genetic testing; see Gray et al., 2009; Wideroff et al., 2003) and the inclusion of an effective manipulation, it is not without limitations. First, as is true of the vast majority of studies of genetic testing decisions, we were unable to record actual uptake of testing. Our study concerned an actual testing opportunity, not a hypothetical or fictional procedure, and provided participants with information that would allow them to pursue testing at the conclusion of the study, but participants likely perceived a distinction between our survey and their ultimate decision to test or not test. Future research should attempt to assess the critical links between information on DTC genetic testing, perceptions of testing and uptake rates. Unfortunately, this type of research is rendered difficult, if not impossible, by the proprietary nature of information about the DTC genetic testing industry and its clients.

Second, our study did not include a 'no information' control group, in which participants would indicate their perceptions and testing intentions without exposure to any information about DTC genetic testing. Although this addition would have allowed us to examine testing intentions of our experimental groups relative to an uninformed control group, we were unsure whether 'uninformed' participants would possess sufficient information about DTC genetic testing to reliably respond to our measures. That said, future studies can target people who are already knowledgeable about the testing procedures to determine the relative impact of presenting additional positive *versus* negative *versus* balanced information.

Conclusions

Perhaps the primary difference between traditional genetic testing and DTC genetic testing lies in the corporate nature of DTC genetic testing ventures. DTC genetic testing websites are fundamentally profit-driven organisations that benefit when individuals choose to receive genetic information, and as such information about who undergoes testing and why they choose to test is not available to the general public. Our study provides much-needed evidence to illuminate the processes that drive decisions to pursue or not pursue DTC genetic testing. In addition, it reveals how the manipulation of available information substantially affects perceptions about testing and, ultimately, intentions to test.

Note

1. Although the use of single-item measures for complex constructs can reduce measurement validity, we were interested in measuring anticipation of a specific emotional experience. As is typical of other emotion measures, we felt that direct items measuring the emotion of interest would be most appropriate in this case.

References

- 23 and Me (2010). Frequently asked questions. Retrieved from www.23andme.com.
- Abraham, C., & Sheeran, P. (2003). Acting on intentions: The role of anticipated regret. *British Journal of Social Psychology, 42*, 495–511.
- Acker, M. (1997). Tempered regrets under total ignorance. *Theory and Decision, 42*, 207–213.
- Aho, W.R. (1979). Participation of senior citizens in the swine flu inoculation program: An analysis of health belief model variables in preventive health behavior. *Journal of Gerontology, 34*, 201–208.
- Ameson, S.W., Triplett, J.L., Hahnemann, B., & Merington, E. (1985). Factors affecting parental use of child automobile safety restraints. *Children's Health Care, 13*, 181–186.
- Baron, R.M., & Kenny, D.A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*, 1173–1182.
- Baumeister, R.F., Bratslavsky, E., Finkenauer, C., & Vohs, K.D. (2001). Bad is stronger than good. *Review of General Psychology, 5*, 323–370.
- Benjamin, C.M., Adam, S., Wiggins, S., Theilmann, J.L., Copley, T.T., Bloch, M., & Hayden, M.R. (1994). Proceed with care: Direct predictive testing for Huntington disease. *American Journal of Human Genetics, 55*, 606–617.
- Berg, C., & Fryer-Edwards, K. (2008). The ethical challenges of direct-to-consumer genetic testing. *Journal of Business Ethics, 77*, 17–31.
- Bosompra, K., Flynn, B.S., Ashikaga, T., Rairikar, C.J., Worden, J.K., & Solomon, L.J. (2000). Likelihood of undergoing genetic testing for cancer risk: A population-based study. *Preventative Medicine, 30*, 155–166.
- Bunn, J.Y., Bosompra, K., Ashikaga, T., Flynn, B.S., & Worden, J.K. (2002). Factors influencing intention to obtain a genetic test for color cancer risk: A population-based study. *Preventative Medicine, 34*, 567–577.
- Calzone, K.A., & Biesecker, B.B. (2002). Genetic testing for cancer predisposition. *Cancer Nursing, 25*, 15–25.
- Cameron, L.D., & Reeve, J. (2006). Risk perceptions, worry and attitudes about genetic testing for breast cancer susceptibility. *Psychology and Health, 21*, 211–230.
- Cameron, L.D., Sherman, K.A., Marteau, T.M., & Brown, P.M. (2009). Impact of genetic risk information and type of disease on perceived risk, anticipated affect, and expected consequences of genetic tests. *Health Psychology, 28*, 307–316.
- Caulfield, T., Ries, N.M., Ray, P.N., & Wilson, B. (2010). Direct-to-consumer genetic testing: Good, bad, or benign? *Clinical Genetics, 77*, 101–105.
- Champion, V.L. (1990). Breast self-examination in women 35 and older. A prospective study. *Journal of Behavioral Medicine, 13*, 523–538.
- Compete Site Analytics. (June, 2010). Site profile for 23andme.com. Retrieved from <http://siteanalytics.compete.com/23andme.com/>
- Connolly, T., & Zeelenberg, M. (2002). Regret in decision making. *Current Directions in Psychological Science, 11*, 212–216.
- Cummings, K.M., Jette, A.M., Brock, B.M., & Haefner, D.P. (1979). Psychosocial determinants of immunization behavior in a swine influenza campaign. *Medical Care, 17*, 639–649.

- Gray, S.W., O'Grady, C., Karp, L., Smith, D., Schwartz, J.S., Hornik, R.C., & Armstrong, K. (2009). Risk information exposure and direct-to-consumer genetic testing for BRCA mutations among women with a personal or family history of breast or ovarian cancer. *Cancer Epidemiology Biomarkers and Prevention*, *18*, 1303–1311.
- Gray, S., & Olopade, O.I. (2003). Direct-to-consumer marketing of genetic testing: Buyer beware. *Journal of Clinical Oncology*, *21*, 3191–3193.
- Jacobsen, P.B., Valdimarsdottir, H.B., Brown, K.L., & Offit, K. (1997). Decision-making about genetic testing among women at familiar risk for breast cancer. *Psychosomatic Medicine*, *59*, 459–466.
- King, J.B. (1982). The impact of patients' perceptions of high blood pressure on attendance at screening. *Social Science & Medicine*, *16*, 1079–1091.
- Kinney, A.Y., Choi, Y., Devellis, B., Kobetz, E., Millikan, R.C., & Sandler, R.S. (2000). Interest in genetic testing among first-degree relatives of colorectal cancer patients. *American Journal of Preventive Medicine*, *18*, 249–252.
- Larson, E.B., Olsen, E., Cole, W., & Shortell, S. (1979). The relationship of health beliefs and a postcard reminder to influenza vaccination. *Journal of Family Practice*, *8*, 1207–1211.
- Lee, W. (1971). Preference strength, expected value difference and expected regret ratio. *Psychological Bulletin*, *75*, 186–191.
- Lerman, C., Schwartz, M.D., Miller, S.M., Daly, M., Sands, C., & Rimer, B.K. (1996). A randomized trial of breast cancer risk counseling: Interacting effects of counseling, educational level, and coping style. *Health Psychology*, *15*, 75–83.
- Luce, R., & Raiffa, H. (1957). *Games and decisions: Introduction and critical survey*. Oxford: Wiley.
- Meiser, B., Butow, P., Barratt, A., Suthers, G., Smith, M., Colley, A., . . . , Tucker, K. (2000). Attitudes to genetic testing for breast cancer susceptibility in women at increased risk developing hereditary breast cancer. *Journal of Medical Genetics*, *37*, 472–476.
- Meiser, B., & Dunn, S. (2000). Psychological impact of genetic testing for Huntington's Disease: An update of the literature. *Journal of Neurology, Neurosurgery & Psychiatry*, *69*, 574–578.
- National Human Genome Research Institute (NHGRI) (August 14, 2009). Frequently asked questions about genetic testing. Retrieved on from <http://www.genome.gov/19516567>
- Pagon, R.A., Tarczy-Hornoch, P., Baskin, P.K., Edwards, J.E., Covington, M.L., Espeseth, M., . . . , Palepu, R.D. (2002). GeneTests-GeneClinics: Genetic testing information for a growing audience. *Human Mutation*, *19*, 501–509.
- Ramirez, A.G., Aparicio-Ting, F.E., de Majors, S.S., & Miller, A.R. (2006). Interest, awareness, and perceptions of genetic testing among Hispanic family members of breast cancer survivors. *Ethnicity & Disease*, *16*, 398–403.
- Raymond, V.M., & Everett, J.N. (2009). Genetic counseling and genetic testing in hereditary gastrointestinal cancer syndromes. *Best Practices and Research in Clinical Gastroenterology*, *23*, 275–283.
- Richard, R., de Vries, N.K., & van der Pligt, J. (1998). Anticipated regret and precautionary sexual behavior. *Journal of Applied Social Psychology*, *28*, 1411–1428.
- Roberts, J.S., Barber, M., Brown, T.M., Cupples, L.A., Farrer, Z.A., La Russe, S.A., et al. (2004). Who seeks genetic susceptibility testing for Alzheimers' disease? Findings from a multisite, randomized clinical trial. *Genetics in Medicine*, *6*, 197–203.
- Rosenstock, I.M. (1974). Historical origins of the Health Belief Model. *Health Education Monographs*, *2*, 1–8.
- Rundall, T.G., & Wheeler, J.R.C. (1979). Factors associated with utilization of the swine flu vaccination program among senior citizens. *Medical Care*, *17*, 191–200.
- van der Pligt, J., & Richard, R. (1994). Changing adolescents' sexual behavior: Perceived risk, self-efficacy and anticipated regret. *Patient Education and Counseling*, *23*, 187–196.

- Vermon, S.W., Gritz, E.R., Peterson, S.K., Perz, C.A., Marani, S., Amos, C.I., & Baile, W.F. (1999). Intention to learn results of genetic testing for hereditary colon cancer. *Cancer Epidemiology, Biomarkers & Prevention*, 8, 353–360.
- Wideroff, L., Vadaparampil, S.T., Breen, N., Croyle, R.T., & Freedman, A.N. (2003). Awareness of genetic testing for increased cancer risk in the year 2000 National Health Interview Survey. *Community Genetics*, 6, 147–156.
- Wilde, A., Meiser, B., Mitchell, P.B., & Schiffield, P.R. (2010). Public interest in predictive genetic testing, including direct-to-consumer testing, for susceptibility to major depression: Preliminary findings. *European Journal of Human Genetics*, 18, 47–51.
- Wilson, S., Ryan, A.V., Greenfield, S.M., Clifford, S.C., Holder, R.L., et al. (2008). Self-testing for cancer: A community survey. *BMC Cancer*, 8, 102.
- Wolfberg, A.J. (2006). Genes on the web – Direct-to-consumer marketing of genetic testing. *New England Journal of Medicine*, 355, 543–545.
- Wroe, A.L., & Salkoskis, P.M. (1999). Factors influencing anticipated decisions about genetic testing: Experimental studies. *British Journal of Health Psychology*, 4, 19–40.
- Wroe, A.L., & Salkoskis, P.M. (2000). The effects of ‘non-directive’ questioning on an anticipated decision whether to undergo predictive testing for heart disease: An experimental study. *Behaviour Research & Therapy*, 38, 389–403.
- Wroe, A.L., Turner, N., & Salkovskis, P.M. (2004). Understanding and predicting parental decisions about early childhood immunizations. *Health Psychology*, 23, 33–41.
- Zeelenberg, M., & Pieters, R. (2007). A theory of regret regulation 1.0. *Journal of Consumer Psychology*, 17, 3–18.
- Zeelenberg, M., van Dijk, W., Manstead, A., & van der Pligt, J. (1998). The experience of regret and disappointment. *Cognition and Emotion*, 12, 221–230.
- Ziarnowski, K.L., Brewer, N.T., & Weber, B. (2009). Present choices, future outcomes: Anticipated regret and HPV vaccination. *Preventative Medicine*, 48, 411–414.
- Zoomerang (2010). Zoomerang survey tips: Typical response rates. Retrieved from <http://www.zoomerang.com/Response-Rate>