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Subjective but not Objective Numeracy Influences Willingness to Pay for BRCA1/2 Genetic Testing

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Subjective but not objective numeracy influences willingness to pay for *BRCA1/2* genetic testing

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Abstract

A positive test result for *BRCA1/2* gene mutation is a substantial risk factor for breast and ovarian cancer. However, testing is not always covered by insurance, even for high risk women. Variables affecting willingness to pay (WTP) have implications for clinic-based and direct-to-consumer testing. The relative impact of objective and subjective numeracy on WTP, in the context of worry, perceived risk (of having the mutation and developing breast cancer) and family history, was examined in 299 high-risk women, not previously tested for *BRCA1/2*. Objective and subjective numeracy correlated positively with one another, yet only subjective numeracy correlated (positively) with WTP. This could not be explained by educational level or worry. In line with the numeracy result, other objective factors including family history, age, and Ashkenazi descent were not correlated with WTP. Perceived risk of having a mutation was also correlated with WTP, though perceived risk of developing breast cancer was not, perhaps because it lacks direct connection with testing. Thus, subjective confidence in the ability to interpret test results and perceived risk of a positive test result are more important drivers in paying for BRCA1/2 testing than factors more objective and/or further removed from the testing itself (e.g., perceived risk of developing cancer, family history). Findings underscore the need for genetic counselling that makes probabilistic information accessible and intelligible, so as to build confidence and promote accurate perception of mutation risk and ultimately better decision-making.

Keywords: genetic testing; breast cancer, *BRCA1* and *2*, subjective numeracy, willingness to pay.

1 Introduction

With the advent of more accurate and affordable genetic testing (Myriad, 2007), genetic testing is moving beyond the purview of the physician, with many genetic tests available over-the counter via a direct-to-consumer (DTC) approach that treats the consumer rather than the physician as the end-user (e.g., 23andme.com). In the present study the focus is on the test for *BRCA1* and *BRCA2* gene mutations—known risk factors for the development of breast and ovarian cancer (Squiers et al., 2010). As insurance does not always fully or even partially cover the cost of the test, women contemplating *BRCA1/2* genetic testing face the important dilemma of how much they would be willing to pay (WTP) for this test. WTP may be influenced by both objective and subjective factors, including actual numeric skill and perceived comfort with numeric data of the type produced by the test. This decision applies to testing that occurs in conventional, clinic-based settings, as well as in direct-to-consumer testing.

Numeracy, the ability to understand and manipulate numbers, has been shown to play a role in understanding medical risk information (Donelle, Arocha, & Hoffman-Goetz, 2008; Hanoch, Miron-Shatz, & Himmelstein, 2010; Peters & Levin, 2008; Schwartz, Woloshin, Black, & Welch, 1997), and to lead to better financial decisions (Wood et al., 2011). Indeed, low numeracy is pervasive and results in more constrained informed patient choice, reduced medication compliance, limited access to treatments, impaired risk communication, and ultimately poorer medical outcomes (Nelson et al., 2008; Nelson, Moser, & Han, 2013). Objective numeracy scales examine comprehension of frequency, probability and percentages (Schwartz et al., 1997; Lipkus, Samsa, & Rimer, 2001). In contrast, the subjective numeracy scale (SNS) measures perceived ability to perform various mathematical operations and preference for the use of numeric rather than textual information (Fagerlin et al., 2007). SNS can differen-

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tiate among people with objectively low and high numeracy skills across different demographic groups, but, compared with the objective scale questions, SNS is quicker to administer and provides a more agreeable experience for participants (Galesic & Garcia-Retamero, 2010; Fagerlin et al., 2007). This latter point has practical implications, as some patients may be reluctant to complete an objective numeracy questionnaire but still agree to complete the SNS questionnaire.

A crucial element in validating the SNS scale was showing its correlation with objective numeracy (Fagerlin et al., 2007). Objective and subjective numeracy have also been shown to correlate positively in a representative sample of the US population (Nelson, Moser & Han, 2013), as well as in German and US samples (Galesic & Garcia-Retamero, 2009), and in older adults, who make relatively more decisions about their medical care (Rolison, Wood, Hanoch & Liu, 2013). However, some evidence suggests that subjective and objective numeracy do not measure an identical construct (Liberali et al., 2012). Studies examining the link between numeracy, whether objective or subjective, and WTP for genetic testing, are sparse. To bridge this gap in the literature, we examined the relative impact of objective and subjective numeracy on WTP for *BRCA1/2* testing.

We recruited high-risk women, with a family history of breast or ovarian cancer, from the registrants of the Cancer Genetics Network (CGN). On top of the family history for these specific women, breast cancer is the most prevalent cancer among women with a family history of breast cancer; thus as a group, these women are highly motivated to consider *BRCA1/2* testing to alert family members and consider treatment options, including enhanced surveillance of breast cancer for early detection. However, understanding the exact risk associated with the *BRCA1/2* gene mutation is difficult (Hanoch et al., 2010). The difficulty may reduce WTP to varying degrees, depending upon objective and/or subjective numeracy. Further, other objective (e.g., age, family history) and subjective (e.g., perceived risk of mutation and/or disease, worry that the testing may lead to discovery of illness) factors may also affect WTP.

We expected that objective and subjective numeracy would be positively correlated. Further, as test results consist primarily of numeric information, we hypothesized that women with higher numeracy—both subjective and objective—would be more likely to pay more for the testing, with a greater role for subjective numeracy, given that it reflects actual perception of facility with numbers (Fagerlin et al., 2007). As older age is a risk factor for breast cancer (National Cancer Institute, 2013), we also hypothesized that older women would be more likely to pay more for testing. Likewise, we hypothesized that the more risk-related family history a woman has (Ashkenazi origin; having a relative who tested positive for *BRCA 1/2;* and number of relatives with breast or ovarian cancer) the higher her WTP for *BRCA1/2* testing. In addition, we expected a higher WTP in women who are more worried that the test might detect illness as well as those with higher perceived risk of mutation and developing the disease.

2 Method

2.1 Participants

Eligible participants were female registrants in the Cancer Genetics Network (CGN), a US national population-based cancer registry. Inclusion criteria were being unaffected by breast or ovarian cancer, not previously tested for the *BRCA1/2* mutation, and with at least one relative diagnosed with breast cancer at age 45 or younger, two or more relatives diagnosed with breast cancer at age 50 or younger, at least one relative diagnosed with ovarian cancer, or at least one relative diagnosed with male breast cancer. Consent was obtained and the survey completed via emails from the local CGN branch. The CGN is a U.S. network of centers that serves as a resource for investigators conducting research on the genetic basis of human cancer susceptibility, integration of this information into medical practice, and behavioral, ethical, and public health issues associated with human genetics. A core data set is available on each registrant and contains information on socio-demographic characteristics (though not income information).

Our participants were recruited and registered in the CGN database by local hospital clinics. They initially provided CGN with baseline data including demographics, family history, and disease history. After obtaining approval from the centers' Institutional Review Boards and consent from all study participants, we extracted a de-identified data set containing the relevant data from the CGN database for analysis. The Appendix shows their characteristics.

2.2 Procedure

Respondents completed an online survey. They were assured that no knowledge of genetics was required to participate and that their identifying information would remain confidential. Respondents were told that the survey would take about 30 minutes. They had an option of receiving a $30 gift card and could skip any question that made them uncomfortable. Willingness to pay (WTP) for *BRCA1/2* mutation testing was the primary variable of interest. Correlates examined were number of relatives with breast or ovarian cancer, presence of family member(s) testing positive, of Ashkenazi (Eastern European Jewish) descent,

perceived risk of having a mutation, perceived risk of developing breast cancer, worry that the test might find illness, objective numeracy, subjective numeracy, and age. Variables were computed as follows:

***Willingness to Pay (WTP) for BRCA Genetic Testing*:** Responses to the survey question: "How much money would you be willing to spend on getting tested for the *BRCA1* and *BRCA2* gene mutations? $_____." Participants were instructed to assume that testing was not covered by their medical insurance.

***Number of Relatives with Breast or Ovarian Cancer*:** Number of relatives with breast or ovarian cancer from the CGN database.

***Family Member(s) with Positive Test Result*:** The concatenated responses to questions from the CGN database, asking "Has anyone in your family ever tested positive for a *BRCA1* mutation?" and likewise for *BRCA2*. Response options were "No", "Yes", "Not Sure", and "Rather Not Answer" (not selected by any participants). We recorded the responses as "Yes" (coded '3') if the response to either question was "Yes", "No" (coded '1') if the response to both questions was "No", and "Unknown" (coded '2') for all other cases.

***Of Ashkenazi (Eastern European Jewish) Descent*:** Response options for this CGN database variable were "Yes", "No", or "Unknown". "No" and "Unknown" were combined for analysis purposes. Values of this variable were "No or Unknown" (coded '0') or "Yes" (coded '1').

***Perceived Risk of Having the BRCA1/2 Mutation*:** Responses to the survey question: "What do you think the chances are that you have the *BRCA1* or *BRCA2* gene mutation?" Participants responded by placing an "X" on a number line running from 0 to 100%.

***Perceived Risk of Developing Breast Cancer*:** Responses to the survey question: "What do you think is the chance of you developing breast cancer?" Again, participants responded by placing an "X" on a number line running from 0% to 100%.

***Worried that Test Might Lead to Discovery of Illness*:** Responses to this survey question were on a 5-point scale with options of "Not Worried At All" ('1'), "Slightly Worried" ('2'), "Of Medium Worry" ('3'), "Worried" ('4'), and "Very Worried" ('5').

***Objective Numeracy*:** Respondents completed three survey questions to test facility with numbers (e.g., how many of 1,000 coin flips would come up heads) (Schwartz et al., 1997). Each question was scored as correct ('1') or incorrect ('0'). Total number correct was analysed.

***Subjective Numeracy*:** As part of the survey, participants completed the SNS (Fagerlin et al., 2007). The overall SNS score analysed was the average rating across all eight SNS questions, with one of the questions reverse coded.

***Age*:** Participant age (in years) from the CGN database.

3 Results

Of 961 eligible participants invited to complete the online survey, 459 consented and completed the survey, yielding a response rate of 48%. Of these (based on information from both the CGN database and the survey), 315 participants had not previously been tested for the *BRCA1/2* mutation, and of these, 299 (mean age = 50.08 years, *sd* = 7.73; 72% college graduates; 78% married/cohabiting) responded to the survey question regarding WTP. The present study focuses on these 299, who were not previously tested. Of these participants, the distribution of WTP responses was positively skewed, 69% of participants offering to pay $\leq$\$100 (22% of all participants offered \$0), 29% offering to pay >\$100 to \$500, and the remaining 2% offering to pay \$1000 or more. Mean WTP was \$143.66 (*sd* = 191.57). For total objective numeracy (possible scores: 0 to 3), the range was 0–3, with a mean of 2.01 and a standard deviation of 0.93. For the SNS (possible scores: 1 to 6), the range was 2–6, with a mean of 4.72 and a standard deviation of 0.83.

WTP was significantly correlated with subjective numeracy (r = .150, P = .009) but not with objective numeracy (r = −.057, P = .326), and these two correlations were significantly different from one another (Steiger's [1980] Z = 3.05, P = .002) despite the substantial correlation between objective numeracy and subjective numeracy (r =.361, P < .001).

Educational level (less than college graduate vs. college graduate or graduate school) could not explain the differential correlation between type of numeracy and WTP, as educational level was correlated with both subjective (r =.182, P = .002) and objective (r =.185, P = .001) numeracy, and not with WTP (r = −.011, P = .853).

Similarly, worry that the test might find illness could not explain the differential correlation between type of numeracy and WTP, as worry was (negatively) correlated with both subjective (r = −.154, P = .008) and objective (r = −.138, P = .017) numeracy, and not with WTP (r = .066, P = .252).

WTP was also significantly correlated with perceived risk of having a mutation (r = .162, P = .007), but not with perceived risk of developing breast cancer (r = .043, P = .478), though these two correlations were not significantly different from one another (Steiger's Z = 1.71, P = .087).

None of the other variables was correlated with WTP: number of relatives with breast or ovarian cancer (r = .080, P = .215), Ashkenazi descent (r = .034, P = .556), or age (r = −.039, P = .497). Similarly, presence of family member(s) testing positive did not predict WTP (r = −.011, P = .845), though only four of our participants reported having such a relative (see Appendix).

4 Discussion

In view of expected growth in the prevalence of genetic testing and patient autonomy in making testing decisions, coupled with the deleterious effect of low numeracy on medical outcomes (Nelson et al., 2008; Nelson et al., 2013), this study examined the impact of numeracy upon willingness to pay for *BRCA1/2* testing in women reporting a family history of breast and ovarian cancer. The findings indicate that women with higher subjective numeracy reported a higher WTP for genetic testing, but the same result was not obtained for women with higher objective numeracy or other objective risk factors, including age and family history. Further, this pattern of results could not be explained by educational level or worry. Results also showed a higher WTP for women who perceived a greater risk of having the mutation. Taken together, these results support the claim that subjective or emotional factors directly related to the testing are the most important determinants of perceived value (as measured by WTP).

Our finding that WTP is related to subjective but not objective numeracy is consistent with research suggesting that risk assessment is not performed solely through cognitive lenses, or "risk as analysis", but is also based on instinctive and intuitive reactions, or "risk as feeling" (Lowenstein, Weber, Hsee, & Welch, 2001). Indeed, research in a variety of contexts has shown that personal experience has led people to perceive hazards as more frequent, themselves as potential future victims, and to think about risk more often and with greater clarity (Weinstein, 1989). Notably, cancer worry was not related to WTP, likely because most of our participants (59%) reported no cancer worry, consistent with the distribution of cancer worry in both general and high-risk populations, but precluding empirical and theoretical conclusions (Hay, Buckley, & Ostroff, 2004).

That subjective but not objective numeracy correlated with WTP for testing suggests that comfort level with probabilistic information is more relevant to WTP for such information than actual mathematical ability. The obtained divergence in how WTP relates to subjective and objective numeracy is consistent with recent work by Liberali and colleagues (2012) showing that, although correlated, subjective and objective numeracy measure different constructs. This dovetails with the finding that although 70% of individuals considered themselves "good with numbers", only 2% answered all three Schwartz et al. (1997) objective numeracy questions correctly (Nelson et al., 2008; see also Nelson et al., 2013). Further, that numeracy was not a mere proxy for educational level is consistent with the finding that low numeracy cannot be reliably inferred on the basis of education, intelligence or other observable characteristics (Nelson et al., 2008).

One question that may arise is the degree to which our open-ended method of eliciting WTP, which involved recording a monetary amount but no financial obligation, is indicative of actual behaviour. Researchers have used various methods for WTP elicitation, including the double-bounded, dichotomous-choice approach. See, for example, a study of SNP-based testing by Neumann and colleagues (2012), who included $0 responses, as in the present study. We chose an open-ended methodology to avoid biasing women by providing a particular number as a benchmark for the cost of the test. Despite the different elicitation methods, the median (given the positive skew; skewness = 2.89, SE = .14) WTP of $100 for our participants is lower than that of Neumann et al. (2012), where average WTP ranged from $181 to $232. However, their study included women who tested for the *BRCA 1/2* mutation, albeit only women who tested negative. That women who tested had WTP similar to what they had actually paid is in line with previous findings (Baron & Maxwell, 1996). Interestingly, consumers' WTP for genetic testing, as captured by actual behaviour, appears to be even higher for some. Early adopters of DTC genome testing, who, compared to the U.S. general population, had high levels of education and household income, paid $429 to $2000 for a scan of their genetic profile and propensity to develop various diseases (Kaufman, Bollinger, Dvoskin, & Scott, 2012). These sums far exceed the WTP range of Neumann et al. (2012) using hypothetical scenarios, and what our participants indicated they would pay. However, the price of genetic testing continues to decline (e.g., as of this writing, 23andMe, Inc. is selling its health test for $99 plus a monthly information fee), and will likely continue to drop following the recent US Supreme Court ruling to disallow patenting of the *BRCA* gene (Liptak, 2013), which may lead to the availability of *BRCA* testing via DTC marketing. Thus, testing is becoming accessible to even more customers (Wolinsky, 2007), including in settings where a counsellor is not necessarily present. Indeed, a recent policy statement asserts that providers and consumers will need to think in new ways about education, counselling and informed consent in the setting of DTC genetic testing (Robson et al., 2010).

The present results have practical implications for both conventional clinic-based testing and DTC genetic testing. Although most women continue to test in clinics, the growing accessibility of DTC is particularly disturbing in light of our finding of the centrality of emotional relevance in WTP for testing. DTC marketing campaigns may increase anxiety by exploiting consumers' emotional concerns (Gollust, Hull, & Wilfond, 2002). Further, upon receipt of DTC testing results, consumers of *BRCA* test results may experience anxiety and distress (Dohany, Gustafson, Ducaine, & Zakalik, 2012), possibly attributable to inadequate counselling (Brierley et al., 2010). Our results highlight the importance of combining pre-

and post-test genetic counselling, standard for adult-onset, single gene disorder testing (Wade & Wilfond, 2006) with DTC testing to alleviate distress and guide the consumer regarding a reasonable cost/benefit analysis prior to testing and realistic implications of the result following testing. Indeed the availability of counselling in clinics may explain why women with a personal or family history report more negative beliefs about DTC and higher preferences for clinic-based testing (Gray, Hornik, Schwartz, & Armstrong, 2012). Given our findings, if the counsellor is aware that emotional relevance may distort the patient's decision, he/she will be better able to offer better, more cogent advice. Counsellors should be cognizant of the fact that women with low subjective numeracy perceive poorer quality of provider communication and are likely to require more explanation to engage in prevention behaviors (Ciampa, Osborn, Peterson, & Rothman, 2010; Nelson et al., 2008). The association between low subjective numeracy and lower WTP for *BRCA1/2* testing may be offset by promoting perception of high quality communication, as has been shown in the context of screening for colorectal cancer (Ciampa et al., 2010). Specifically, counsellors should use non-numerical presentation formats, such as graphical displays and analogies to communicate important statistical information to women with low subjective numeracy (Galesic & Garcia-Retamero, 2010).

This study has a number of limitations. For example, our study was cross-sectional, and a number of other variables may have affected our results (e.g., insurance status and coverage). That our sample was composed of high-risk, mainly white women may limit the generalizability of our results. Follow-up studies in larger, more heterogeneous samples are needed to confirm our findings and identify clear predictors of WTP. The risk-level limitation is mitigated by the fact that *BRCA 1/2* genetic testing is sought mainly by women who are at high risk for developing cancer or have already been diagnosed with cancer (Ropka et al., 2006). In this regard, rather than a limitation, the sample risk level may be viewed as a strength, in that our findings are highly relevant to the women most likely to undergo *BRCA 1/2* genetic testing.

The current findings suggest that among women with a family history of breast or ovarian cancer, women who perceive themselves as being more numerate and/or at higher risk of having the *BRCA1/2* mutation are willing to pay more for the testing, but objective numeracy and other more objective or distant factors (e.g., family history) do not impact WTP judgements. These findings suggest that WTP is primarily an emotional decision and add to the longstanding concern over offering genetic testing as a DTC free market commodity (Hudson, Javitt, Burke, & Byers, 2007), where, presumably, consumers can decide whether or not to make a purchase, and how much to pay for it.

In terms of measuring patient comprehension, the findings suggest that, when the objective numeracy scale is perceived as cumbersome, it can be replaced by the SNS. That subjective numeracy, and not objective numeracy or objective risk factors determine WTP for breast cancer testing, highlights the importance of the SNS in clinical settings.

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Appendix: Demographic and clinical characteristics (N = 299).

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Cancer center, %	Colorado	37%	110
	Duke	7%	22
	Emory	4%	12
	Johns Hopkins	12%	36
	MD Anderson	4%	11
	Univ. of North Carolina	4%	13
	Univ. of Utah	32%	95
Age, mean years (*sd*)	50.08 (7.73)		299
Highest degree or year of school completed, %	≤8 years	1%	2
	High School/GED	5%	15
	Some College/Technical	23%	69
	College+	71%	213
Marital status, %	Single	9%	26
	Married or Living Together	78%	233
	Separated	2%	5
	Divorced	10%	30
	Widowed	2%	5
Race, %	American Indian or Alaskan Native	1%	3
	Asian	1%	3
	Black or African American	1%	4
	White	95%	283
	More than one race	1%	4
	Other	<1%	1
Amount willing to pay (WTP) for *BRCA 1/2* testing, mean $ (*sd*)	$143.66 (191.57)		299
Objective numeracy (Schwartz et al., 1997) (range: 0–3), mean (*sd*)	2.01 (0.93)		296
Subjective numeracy (Fagerlin et al., 2007) (overall SNS score), mean (*sd*)	4.72 (0.83)		299
Of Ashkenazi (Eastern European Jewish) descent, %	4%		11
Any family member(s) tested positive for *BRCA1* or *BRCA2* mutation, %	No	24%	72
	Yes	1%	4
	Unknown	75%	223
Number of relatives with breast or ovarian cancer, %	1	31%	76
	2	29%	71
	3	20%	50
	4	9%	21
	5	5%	11
	6	4%	9
	7	2%	5
	>7	1%	2
Perceived risk of mutation, mean % (*sd*)	32.40% (24.47)		273
Perceived risk of developing breast cancer, mean % (*sd*)	44.54% (28.73)		274
Worried that test might find illness, %	Not Worried at All	59%	178
	Slightly Worried	18%	54
	Of Medium Worry	12%	36
	Worried	6%	18
	Very Worried	4%	12

All available data shown; amount of missing data varied across the variables. Percentages are out of the total number of participants with data.