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What Do Men Understand About Lifetime Risk Following Genetic Testing? The Effect of Context and Numeracy

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Objective: Genetic testing for gene mutations associated with specific cancers provides an opportunity for early detection, surveillance, and intervention (Smith, Cokkinides, & Brawley, 2008). Lifetime risk estimates provided by genetic testing refer to the risk of developing a specific disease within one's lifetime, and evidence suggests that this is important for the medical choices people make, as well as their future family and financial plans. The present studies tested whether adult men understand the lifetime risks of prostate cancer informed by genetic testing. ***Method:*** In 2 experiments, adult men were asked to interpret the lifetime risk information provided in statements about risks of prostate cancer. Statement format was manipulated such that the most appropriate interpretation of risk statements referred to an absolute risk of cancer in Experiment 1 and a relative risk in Experiment 2. ***Results:*** Experiment 1 revealed that few men correctly interpreted the lifetime risks of cancer when these refer to an absolute risk of cancer, and numeracy levels positively predicted correct responding. The proportion of correct responses was greatly improved in Experiment 2 when the most appropriate interpretation of risk statements referred instead to a relative rather than an absolute risk, and numeracy levels were less involved. ***Conclusion:*** Understanding of lifetime risk information is often poor because individuals incorrectly believe that these refer to relative rather than absolute risks of cancer.

Keywords: genetic testing, lifetime risk, numeracy, prostate cancer, risk communication

More than 1.5 million new cancer cases were expected to emerge in the United States in 2010 (Jemal, Siegel, Xu, & Ward, 2010). Genetic testing for gene alterations associated with specific cancers may provide an opportunity for early detection, surveillance, and intervention for those at increased risk (Smith, Cokkinides, & Brawley, 2008). One key feature of genetic testing that is shown to influence the health choices people make is *lifetime risk estimates* (Fanshawe et al., 2008), which refer to the risk of developing a specific disease within one's lifetime. But lifetime risk estimates are habitually provided in numeric form, which recent studies have shown is often not well understood by those who base their medical choices on it (Hanoch, Miron-Shatz, & Himmelstein, 2010; Lipkus & Peters, 2009).

Genetic testing impacts the individual in the health choices they make, such as about their diet and other health-related behaviors (Fanshawe et al., 2008), as well as their family (MacDonald et al., 2002) and financial plans (Armstrong et al., 2003), and may even be a potential source of anxiety (Heshka, Palleschi, Howley, Wilson, & Wells, 2008). Although typically communicated to patients by health care professionals, an increasing number of direct-to-consumer genetic tests are emerging, some of which can be ordered online and provide little (to no) counseling for how to interpret the results (Offit, 2008). But if people do not understand the results that genetic tests provide, then what does this mean for the medical choices they make?

In a recent study, Hanoch et al. (2010) presented to women statements of genetic risk taken from the National Cancer Institute (NCI) Web site. For many individuals, this may be their first point of call before seeking consultation. However, few women from the general public and ones previously tested or diagnosed with breast cancer correctly interpreted their lifetime risk of breast cancer based on the statements. Our first aim of the present study was to generalize the findings of Hanoch et al. by establishing whether men face similar hurdles in interpreting lifetime risk. Men are both less likely to undergo genetic testing and less likely to discuss test results with family members and thus may be less familiar with concepts of lifetime risk (Daly, 2009). On the other hand, there is some evidence to suggest that men may be more proficient, or at least more confident, when dealing with mathematical terms (Else-Quest, Hyde, & Linn, 2010). Our second aim was to understand why misinterpretations occur. In the Hanoch et al. study, women were provided the lifetime risk of developing breast cancer for those with *BRCA1/2* gene alterations (linked to increased risk of breast and ovarian cancer). But for the women from the general public, untrained in genetics, reference to genes and gene mutations, rather than the lifetime risk information, may have caused misinterpretations (Harper, 1997). In any case, we expected that understanding lifetime risk would also depend on numeracy skills, which have been shown to relate both to understanding of genetic risks (Hanoch et al., 2010; Lea, Kaphingst, Bowen, Lipkus, &

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Hadley, 2011; Lipkus & Peters, 2009; Portnoy, Roter, & Erby, 2010) and the quality of health choices people make (Reyna & Brainerd, 2007).

Given the possible difficulties that people have with interpreting genetic risks, it is important to provide health care professionals with the necessary tools for best communicating risk information. In sum, our first aim was to establish whether misinterpretations of lifetime risk are prevalent for men. Our second aim was to test whether lifetime risk information or reference to unfamiliar genetic content causes misinterpretation of genetic risks and how numeric ability is involved.

Experiment 1

Method

Participants. Following approval by the Princeton University Ethics Committee, 174 American men were recruited by the quantitative and qualitative research company Qualtrics, either by signing up directly with a Qualtrics vendor online or by responding to a Web-based advertisement, and were compensated with cash-equivalent rewards (e.g., gift cards). Where individuals failed to complete items of the questionnaire (discussed below), *n* is indicated. All participants were 46 years of age or older (mean age = 59.47 years; range = 46–81 years). Most had completed at least high school (160 of 162; 98.8%), 67 (41.4%) had completed college, and a further 13 (8.0%) had completed graduate school. Most were Caucasian (89.5%). Regarding income, 111 (68.5%) had a household income of $60,000 or less, and the remaining 51 (31.5%) had an income above $60,000. Just 13 (8.0%) had an income over $100,000.

Materials and procedure.

Risk statements. All participants were presented two statements about the lifetime risk of prostate cancer modeled on the NCI statement (see Hanoch et al., 2010). The statement that referred to a risk group with gene alterations read as follows:

> According to estimates of lifetime risk, about 16% (160 out of 1,000 individuals) of men in the general population will develop prostate cancer, compared with estimates of 48% to 80% (480–800 out of 1,000) of men with an altered *BRCA1* or *BRCA2* gene. In other words, men with an altered *BRCA1* or *BRCA2* gene are 3 to 5 times more likely to develop prostate cancer than men without alterations in those genes.

The second statement, presented to the same participants, referred instead to a risk group who smoke—a risk factor that is both well advertised and linked to male cancers (including prostate cancer; Zu & Giovannucci, 2009) and thus should be realistic. It is important to note that this removes reference to "genetic content." The smoking statement read as follows:

> According to estimates of lifetime risk, about 12% (120 out of 1,000 individuals) of men in the general population will develop prostate cancer, compared with estimates of 24% to 60% (240–600 out of 1,000) of men who smoke. In other words, men who smoke are 2 to 5 times more likely to develop prostate cancer than men who do not smoke.

The two statements were presented to each participant in a different random order. It was ensured that the risk information differed between the two statements. Ninety (vs. 84) participants completed the genetic statement first. Below each statement, participants were asked to select from four options the most appropriate interpretation, which read as follows:

> "Prostate cancer will develop in 48% to 80% of men who are found to have *BRCA1* or *BRCA2* alterations" (Option 1). "Men who are found to have alterations in the genes called *BRCA1* or *BRCA2* have 48% to 80% higher chance of developing prostate cancer than men who do not have these alterations" (Option 2). "Prostate cancer will develop in all men aged 48 to 80" (Option 3). "Men who have *BRCA1* or *BRCA2* alterations will exhibit 48% to 80% of the symptoms associated with prostate cancer" (Option 4).

For the smoking statement, the four options instead referred to a risk group who smoke.

Lifetime risk concepts. Following completion of the second statement (either genetic or smoking), participants were asked separately about the population risk and that for the risk group (who either smoke or have gene alterations). For population risk, they were asked, "We would like to ask you now to imagine 1,000 men from the general population. How many of them will develop prostate cancer? ___ Think of them as Group A."

For the risk group (smoking or gene alteration), they were asked, "And now please image 1,000 men with *BRCA1* or *BRCA2* gene alterations. How many of them are likely to develop cancer? ___ Think of them as Group B."

For the smoking statement, the risk group instead referred to a risk group who smoke.

Numeracy scale. Following completion of both risk statements, participants completed the 11-item numeracy scale developed by Lipkus, Samsa, and Rimer (2001). The demographic items followed completion of the numeracy scale.

Data analysis. Our regression analyses included numeracy (as a continuous variable), smoking status (smoker, nonsmoker, or ex-smoker), and previous testing for prostate cancer. Age, income, and education may also relate to risk interpretation and so were also included.

Results

Just under half of participants (77 of 162; 47.5%) had previously been screened for prostate cancer, comparable with larger studies (Bowen, Hannon, Harris, & Martin, 2011). Forty-six (28.4%) currently smoked, and 66 (40.7%) had smoked in the past. However, only 37.7% of men correctly interpreted the lifetime risk of prostate cancer (Option 1), and this was not significantly different for the genetic (37.9%) and smoking (37.4%) statements, $\chi^2(1) = 0.012$, $p = .912$. The majority believed incorrectly that a 48–80% chance of cancer meant that these individuals had a 48–80% *higher* chance of cancer (Option 2; 55.7% and 43.1% for smoking and genetic statements, respectively). A minority believed that all individuals 48–80 years of age will have cancer (Option 3; 4.0% and 5.7% for smoking and genetic statements, respectively), and few believed that all men in the risk group would exhibit 48–80% of the symptoms of cancer (Option 4; 2.9% and 13.2% for smoking and genetic statements, respectively).

Total scores on the 11-item numeracy scale (each item coded as either 1 for correct or 0 for incorrect) were entered into a multinomial logistic regression analysis along with previous testing for

prostate cancer, age, income, and education. This was done separately for the two statements. Smoking status (smoker, nonsmoker, or ex-smoker) was included as an additional predictor for the smoking statement. Few men selected either Option 3 or Option 4, so these were combined. Numerical ability positively predicted correct interpretation (Option 1) for the genetic ($b = 0.21$, $SE = 0.09$, $p = .026$) and smoking ($b = 0.57$, $SE = 0.17$, $p = .001$) statements. Older men ($b = 0.12$, $SE = 0.06$, $p = .050$, smoking statement) and those of higher income ($b = 0.27$, $SE = 0.10$, $p = .009$, genetic statement) were also more likely to choose Option 1 over Options 3 and 4, but older men were also more likely to choose Option 2 (an incorrect interpretation; $b = 0.13$, $SE = 0.06$, $p = .026$). Previous testing for prostate cancer negatively predicted correct interpretation only for the smoking statement ($b = -1.84$, $SE = 0.83$, $p = .026$).

Although a large proportion of men correctly identified the risk of cancer in the general population (66.7% for both statements), only a minority was able to identify the risk group statistic (smoking statement = 20.0%; genetic statement = 21.4%), even though both were made explicit in the statements. As shown in Figure 1 (averaged across both statements), those who correctly identified the risk group were a subset of those who identified the population risk.

Experiment 2

Fewer than 40% of participants in Experiment 1 correctly interpreted the lifetime risks of prostate cancer. When asked separately about the general population risk and that for a risk group (those who smoke or have gene alterations), many correctly interpreted the population risk, whereas only a small subset of these understood the risk group statistics. Moreover, the majority chose Option 2 for the statements, which incorrectly states the risk group statistic as a relative rather than absolute risk. Thus, in Experiment 2, we made a subtle but crucial adjustment to the wording of the most appropriate interpretation: "Prostate cancer will develop in 2 to 5 times more men who smoke than men who do not smoke," which instead refers to a relative rather than absolute risk. The remaining options were left intact. This allowed us to establish why misunderstandings for the risk group statistics emerge.

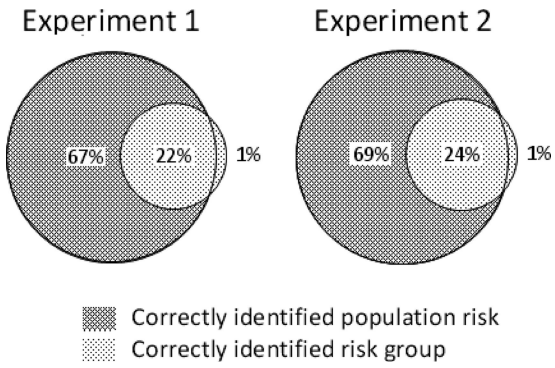

Figure 1. Venn diagram representing the percentage of participants who correctly identified the population risk of prostate cancer and that for a risk group.

Method

Participants. A total of 156 men were of a similar age to those in Experiment 1 and were recruited in the same way (mean age = 58.35 years; range = 46–93 years). Most were Caucasian (134 of 148; 90.5%), all had completed high school, 65 (43.9%) had completed college, and 21 (14.2%) had completed graduate school. Regarding income, 93 (62.8%) had a household income of $60,000 or less, 55 (37.2%) had an income of above $60,000, and 14 (9.5%) had an income above $100,000.

Materials and procedure. A procedure similar to that of Experiment 1 was used in Experiment 2. Sixty-nine participants (vs. 87) completed the genetic statement first. The only exception to Experiment 1 was that the most appropriate interpretation (Option 1) instead read, "Prostate cancer will develop in 3 to 5 times more men who have *BRCA1* or *BRCA2* alterations than men who do not have these alterations." The smoking statement referred instead to a risk group who smoke.

Results

About half of the men (52.6%) had been screened previously for prostate cancer. Those who currently smoked (23.1%) or had smoked in the past (31.4%) represented a large proportion of the participant sample. The odds of participants identifying the most appropriate interpretation (Option 1) were 2.29, $\chi^2(1) = 13.66$, $p < .001$, times greater for the smoking statement (57.7%) and 2.23, $\chi^2(1) = 12.89$, $p < .001$, times greater for the genetic statement (57.7%) compared with Experiment 1 (37.7% overall). Fewer individuals chose Option 2 (35.9% and 30.1% for smoking and genetic statements, respectively), and a minority chose Option 3 (1.9% and 30.1% for smoking and genetic statements, respectively) or Option 4 (4.5% and 8.3% for smoking and genetic statements, respectively). Our multinomial regression analyses revealed that numerical ability predicted correct responding (Option 1 vs. Options 3 and 4) for the genetic ($b = 0.28$, $SE = 0.11$, $p = .013$) but not the smoking ($b = 0.14$, $SE = 0.15$, $p = .342$) statement. There were no other significant predictors.

A high proportion of men correctly identified the population risk (62.3% and 74.7% for smoking and genetic statements, respectively), but not when asked about a risk group (17.4% and 31.0% for smoking and genetic statements, respectively). The minority who identified the risk group was a subset of those who identified the population risk (see Figure 1).

Discussion

The findings of the present study as a whole point to one conclusion. Lifetime risks in statements about genetic information are not clearly spelled out. When these refer to a risk group in comparison to the general population, it is unclear whether these should be interpreted as a relative or an absolute risk. This confusion is likely to result from the specific wording of risk statements and also appears to explain the results of Hanoch et al. (2010), who reported similar misunderstandings made by adult women about the risks of breast cancer.

Many individuals who seek genetic counseling will do so via consultation with a health care professional. The findings reported here provide some useful suggestions for how this might be

improved. For example, Pieterse, van Dulman, van Dijk, Bensing, and Ausems (2006) observed that general population risks are typically communicated to clients by health care professionals on their first visit to a clinic before providing personal risks, and both are often presented numerically. Our findings indicate that where personal risks are provided in comparison to general risks, this is likely to cause confusion and may be interpreted incorrectly as a relative rather than absolute risk. This is not a minor concern. A 48–80% *higher* chance of prostate cancer for a man who smokes compared with a nonsmoker is far lower than a 48–80% absolute risk of prostate cancer for a man who smokes. Incorrectly interpreting a personal risk as a relative rather than absolute risk would severely understate risk of disease. One possibility for consultation would be to drop information about general population risks, both on health care Web sites and in personal consultation. In doing so, the patient has only to understand his or her personal risk of cancer. This should eliminate misinterpretations of personal risk.

A potential limitation of the present study is that we oversampled Caucasian men and those of high socioeconomic status. Most participants were Caucasian (above U.S. demographics; U.S. Census Bureau, 2010) and of relatively high socioeconomic status. Across both experiments reported here, understanding of lifetime risk information was surprisingly poor. If our samples overrepresented individuals of higher numerical ability, then public understanding of health risk information may be even poorer than our present findings suggest. Information about participants' previous genetic testing was not collected as part of this study. However, Hanoch et al. (2010), using similar risk statements presented to adult women, found that neither previous diagnosis nor previous testing for breast cancer improved their interpretation of the lifetime risks of breast cancer. Thus, previous experience with genetic testing does not seem to relate to accurate risk interpretation. Finally, a number of studies have shown that presenting risk information in visual format (e.g., pictograms, graphs, etc.) could foster comprehension. Although we have not examined this possibility, we believe that this could prove to be a fruitful avenue for future studies.

The findings reported here further establish that when genetic risks are communicated in numeric form, numeric ability is involved in correct interpretation (e.g., Lea et al., 2011; Lipkus & Peters, 2009). But these findings cannot be explained by poor numeracy skills alone. Instead, misinterpretations appear to emerge from the specific wording used to communicate lifetime risk information. This finding resonates well with those of Miron-Shatz, Hanoch, Graef, and Sagi (2009) showing that changing the presentation format helps those with low numeracy.

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