Preventive Medicine 123 (2019) 12–19

Contents lists available at ScienceDirect

Preventive Medicine

journal homepage: www.elsevier.com/locate/ypmed

Genetic counseling, genetic testing, and risk perceptions for breast and colorectal cancer: Results from the 2015 National Health Interview Survey

Erin Turbitt[a,b,*], Megan C. Roberts[c], Jennifer M. Taber[d], Erika A. Waters[e], Timothy S. McNeel[f], Barbara B. Biesecker[g], William M.P. Klein[a,c]

[a] National Human Genome Research Institute, Bethesda, MD, United States of America
[b] University of Technology Sydney, NSW, Australia
[c] National Cancer Institute, Rockville, MD, United States of America
[d] Kent State University, Kent, OH, United States of America
[e] Washington University School of Medicine in St. Louis, St Louis, MO, United States of America
[f] Information Management Services, Inc., Calverton, MD, United States of America
[g] Research Triangle Institute, International, Washington, DC, United States of America

ABSTRACT

We examined what proportion of the U.S. population with no personal cancer history reported receiving either genetic counseling or genetic testing for cancer risk, and also the association of these behaviors with cancer risk perceptions.

We used data from the 2015 National Health Interview Survey. Objective relative risk scores for breast (women) and colorectal (men and women) cancer risk were generated for individuals without a personal history of cancer. Participants' risk perceptions were compared with their objective relative risk.

Of 12,631 women, 1.2% reported receiving genetic counseling and 0.8% genetic testing for hereditary breast cancer risk. Of 15,085 men and women, 0.8% reported receiving genetic counseling and 0.3% genetic testing for hereditary colorectal cancer risk. Higher breast cancer risk perception was associated with genetic counseling (OR: 4.31, 95%CI: 2.56, 7.26) and testing (OR: 3.56, 95%CI: 1.80, 7.03). Similarly, higher perception of colorectal cancer risk was associated with genetic counseling (OR: 5.04, 95%CI: 2.57, 9.89) and testing (OR: 5.92, 95%CI: 2.40, 14.63). A higher proportion of individuals with colorectal cancer risk perceptions concordant with their objective risk (vs. discordant) had undergone genetic counseling or testing for colorectal cancer risk. Concordant risk perceptions for breast cancer were not associated with breast cancer genetic counseling or testing.

Given frequent dialogue about implementing population level programs involving genetic services for cancer risk, policy makers and investigators should consider the role of risk perceptions in the effectiveness and design of such programs and potential strategies for addressing inaccuracies in risk perceptions.

1. Introduction

Genetics play a significant role in the leading causes of death and disability including heart disease, diabetes, and cancer (Center of Disease Control and Prevention). Genetic tests to identify individuals at increased risk of breast cancer (BC) or colorectal cancer (CRC) are among the most clinically valid and useful (Rogowski et al., 2010; Murray et al., 2018). Identifying individuals at elevated risk for hereditary cancer allows for enhanced screening or preventive options such as chemoprevention or prophylactic oophrectomy (Domchek et al., 2010; Syngal et al., 2015). Cancer genetic testing of asymptomatic individuals with no personal cancer history is most commonly performed when there is a family history of cancer (Petrucelli et al., 2016). However, there has been emerging interest in instituting cancer genetic testing at the population level, including healthy individuals regardless of their cancer family history or a known pathogenic variant in a family member (Gabai-Kapara et al., 2014; Prince et al., 2017).

Little is known about how many or which individuals without a personal history of cancer have received cancer genetic counseling or testing. When considering implementation of population level screening with genetic services, baseline evidence of factors associated with such services would be highly informative, given some degree of nonadherence would be expected (Murray et al., 2018). Currently, among women with a personal history of BC, approximately 15% who are eligible undergo genetic testing (Childers et al., 2017). In one study, individuals insured by Aetna who receive BC genetic testing were more likely to be White, non-Hispanic, college educated, married, and have higher incomes (Armstrong et al., 2015). In another study conducted in a nationally representative sample, women with a family history of cancer and those with health insurance were more likely to have had BC

* Corresponding author at: Discipline of Genetic Counselling, Graduate School of Health, University of Technology Sydney, Building 7, Level 4, 67 Thomas Street, Ultimo, NSW 2007, Australia.
E-mail address: erin.turbitt@uts.edu.au (E. Turbitt).

https://doi.org/10.1016/j.ypmed.2019.02.027
Received 8 August 2018; Received in revised form 16 February 2019; Accepted 23 February 2019
Available online 25 February 2019

genetic testing (Taber et al., 2015).

Given the current absence of population level screening, genetic counseling can help individuals decide if testing is indicated and consider possible health, psychological, and personal outcomes prior to testing (Moyer, 2014). Accordingly, not all individuals who receive genetic counseling will subsequently undergo genetic testing. Pre-test genetic counseling is recommended, but individuals can access testing without first seeing a genetic counselor; for example, one might engage with a medical professional who does not have genetic counseling expertise, or obtain testing via direct-to-consumer companies (Armstrong et al., 2015; Gill et al., 2018).

1.1. Role of risk perception

Perceived risk may drive many health-related behaviors – including uptake of genetic counseling or testing (Kasparian et al., 2009; Sweeny et al., 2014). This would not be problematic if perceived cancer risk was concordant with objective risk and genetic testing is indicated; however, people tend to hold discordant risk beliefs. In particular, people tend to perceive their risk of experiencing a variety of future health conditions as lower than it actually is, or lower than average (Shepperd et al., 2015). Such *unrealistic optimism* can have either a negative or positive effect on health behaviors and outcomes (Persoskie et al., 2014a; Persoskie et al., 2014b). For example, unrealistic optimism about lung cancer risk was associated with a lower likelihood of smoking cessation in a national sample of smokers (Dillard et al., 2006a). Conversely, underestimating one's risk of cancer was predictive of better affect and life satisfaction after getting cancer (Persoskie et al., 2014b). Alternatively, individuals can perceive themselves to be at *higher* risk compared to their objective risk: a concept termed *unrealistic pessimism*, which can lead to unnecessary stress and overuse of screening (Milhabet et al., 2013). To our knowledge, the associations of risk perceptions with genetic testing and counseling – and the degree to which those perceptions are concordant with objective risk– have not been explored in a large, nationally representative sample.

We examined the proportion of the U.S. population with no personal cancer history that has had either genetic counseling or testing for hereditary cancer risk, and how risk perceptions were related to these behaviors. Specifically, we had the following research questions: (1) What proportion of individuals in the U.S. with no personal cancer history report engaging in either BC or CRC genetic counseling or testing, and what are the demographic correlates of these behaviors? (2) What is the association of risk perceptions for BC or CRC risk with reported seeking of either genetic counseling or testing? and (3) To what extent are perceived and objective cancer risk concordant and how is concordance related to seeking genetic counseling, testing, and demographic correlates? We hypothesized that higher risk perceptions would be associated with more genetic counseling and testing, and that a higher proportion of individuals who received genetic counseling or testing would have risk perceptions concordant with objective risk (vs. discordant). The data were cross-sectional, meaning that risk perceptions were assessed after engagement with genetic services, making it impossible to assess directionality. Nevertheless, this analysis provided a look at how risk perceptions might be related to use of genetic services.

2. Methods

2.1. Data source

We used publicly available data from the National Health Interview Survey which collects data in person (National Center for Health Statistics, 2018). The 2015 Person (demographic variables), Sample Adult (personal cancer history variables) and Sample Adult Cancer (genetic services, risk perception and objective risk variables) files were merged.

2.2. Measures

Four items assessed engagement with genetic services for cancer risk. Respondents were asked if they had: “ever had genetic counseling for breast cancer,” “ever had genetic counseling for colon/rectal cancer,” “ever had genetic test for breast cancer risk,” and “ever had genetic test for colon or rectal cancer risk,” with response options yes/no. Overlap among these variables is shown in Tables S1 and S2.

Risk perceptions were assessed by two items in which participants were asked to estimate their (1) “risk of breast cancer compared to the average woman” and (2) “risk of colon/rectal cancer compared to the average man/woman” with response options: 1 = more likely, 2 = less likely, and 3 = about as likely.

We calculated respondents' objective relative risk scores for BC or CRC with validated risk prediction models (see https://dceg.cancer.gov/tools/risk-assessment) using SAS software, version 9.4 (Copyright © 2002–2012 by SAS Institute Inc., Cary, NC, USA.). Relative risk rather than absolute risk was used to align best with the measure of risk perception used in this study (that is, risk compared to the average person). For BC risk, the algorithm included age, age at time of first menstrual period, age at first live birth, number of breast biopsies, number of first-degree relatives with history of BC, and race/ethnicity. For CRC risk, the algorithm included age, sex, height, weight, servings of vegetables, prior cancer screening procedures, medication use, exercise, smoking history, have menstrual periods, and first-degree relatives with history of CRC. We input “unknown” for variables not assessed in the survey (i.e., “presence of atypical hyperplasia in a biopsy” for the BC algorithm).

For CRC risk, three objective relative risk scores (rectal, proximal colon, and distal colon) were summed. Participants were stratified by 5-year age group. For each age group, participants were categorized as higher (upper quartile), mid (middle two quartiles), or lower (lower quartile) risk for BC and CRC separately. The trichotomous variables were created to match the trichotomous risk perception variable above (“more”, “about as”, or “less” likely). For BC objective relative risk scores, we excluded men, individuals under 35 years of age and those who had previously had BC (Table 1). For CRC objective relative risk scores, we excluded individuals under 50 years of age and those with a personal history of CRC (Table 1).

We created two trichotomous variables that categorized individuals as unrealistically optimistic, unrealistically pessimistic, or concordant (Waters et al., 2011) about their BC and CRC risk (see Tables S3 and S4). If participants' *risk perceptions* matched their *objective relative risk* category (e.g., respondent believed he or she was at higher risk than the average person and the risk prediction model also indicated higher risk), they were labeled as having concordant risk perceptions. Individuals were characterized as being unrealistically optimistic if their perceived risk was lower than their objective relative risk category, or unrealistically pessimistic if their perceived risk was higher than their objective relative risk category.

Demographic characteristics assessed included education level, insurance status, sex, race, ethnicity, and age.

2.3. Data analysis

Analyses were adjusted using variance estimation methodology based on sample weights in SPSS 20.0, 2011 (IBM Corp. IBM SPSS Statistics for Macintosh, Armonk, NY, USA.). The SPSS complex sample module adjusted for clustering. The full dataset included responses from 33,672 individuals, representative of the noninstitutionalized civilian U.S. population.

Prevalence and correlates with receipt of breast or colorectal cancer genetic counseling or testing – research question (RQ) 1:
Descriptive statistics were generated using weighted frequencies. Bivariate logistic regression models tested the association of

Table 1
Frequencies of demographic characteristics and main measures from the 2015 U.S. National Health Interview Survey.

	Breast cancer risk dataset (N = 12,631)[a]		Colorectal cancer risk dataset (N = 15,085)[b]	
Variable	n (unweighted)	% (weighted)	n (unweighted)	% (weighted)
Education				
Non-high school graduate	2136	15.1	2624	15.5
High school graduate	2722	21.3	3594	23.5
College	7707	63.6	8794	61.0
Ethnicity				
Non-Hispanic	10,657	86.5	13,335	89.7
Hispanic	1974	13.5	1750	10.3
Insurance				
Covered	11,586	92.4	14,233	94.9
Not covered	996	7.6	808	5.1
Race				
White	9725	84.6	12,081	87.3
Other	2225	15.4	2298	12.7
Sex				
Men	–	–	6357	45.1
Women	–	–	8728	54.9
Age (weighted mean, SE)	55.08 (0.17)		62.86 (0.12)	
Risk perception				
About as likely	5169	48.6	6119	46.6
More likely	1135	10.3	946	7.0
Less likely	4656	41.1	6227	46.4
Genetic counseling				
Yes	136	1.2	117	0.8
No	11,300	98.8	13,924	99.2
Genetic testing				
Yes	86	0.8	54	0.3
No	11,418	99.2	99.7	14,105

[a] Excludes: men, individuals under 35 years of age and those who had previously had breast cancer.
[b] Excludes: individuals under 50 years of age, and those with a personal history of colorectal cancer.

demographic characteristics and objective relative risk with genetic counseling for BC (the reference was "not had genetic counseling"). Variables for which 95%CI did not cross 1 in bivariate analyses were included in an adjusted multivariable model. The same process was used for examining CRC genetic counseling, BC genetic testing, and CRC genetic testing.

Association of risk perceptions for breast or colorectal cancer risk with genetic counseling or testing – RQ2:

A bivariate logistic regression model tested the association of risk perceptions for BC risk with the outcome of genetic counseling for BC. Variables for which 95%CI did not cross 1 in bivariate analyses were included in an adjusted multivariable model. The same process was used for examining CRC genetic counseling, BC genetic testing, and colorectal genetic testing.

Association of genetic counseling or testing for breast or colorectal cancer risk with risk belief categories – RQ3:

Bivariate multinomial logistic regression analyses tested the association of genetic counseling for BC with the outcome of risk belief category (concordant risk perceptions [reference group], unrealistically optimistic and unrealistically pessimistic). Variables for which 95%CI did not cross 1 in bivariate analyses were included in an adjusted multivariable model. The same process was used for examining CRC genetic counseling, BC genetic testing and colorectal genetic testing.

3. Results

3.1. Prevalence and correlates with genetic counseling or testing – RQ1

3.1.1. Breast cancer

A total of 136 women (of 12,631, 1.2% weighted) reported undergoing *genetic counseling* for BC risk. Having undergone genetic counseling for BC risk was associated with having attained a higher level of education and having a relatively higher objective relative risk for BC (Table 2).

Eighty-six women (of 12,631, 0.8% weighted) indicated having undergone *genetic testing* for BC risk. Correlates of having undergone BC genetic testing included higher level of education and higher objective relative risk (Table 3).

3.1.2. Colorectal cancer

A total of 117 individuals (of 15,085, 0.8% weighted) indicated having undergone *genetic counseling* for CRC risk. Of the demographic characteristics tested, having undergone genetic counseling for CRC risk was associated with having insurance (Table 2). Objective relative risk for CRC was not associated with receipt of genetic counseling.

Fifty-four individuals (of 15,085, 0.3% weighted) had undergone *genetic testing* for CRC risk. No demographic variables were associated with receipt of genetic testing, nor was objective relative risk for CRC (Table 3).

3.2. Association of risk perception for cancer with genetic counseling or testing – RQ2

For both BC and CRC, having a higher risk perception was associated with having undergone genetic counseling (Table 2) and genetic testing (Table 3).

3.3. Association of genetic counseling or testing with risk belief categories – RQ3

3.3.1. Breast cancer

Perceived risk was only moderately associated with objective relative risk (r = 0.15, 95%CI: 0.14, 0.18). Over 60% of respondents had discordant risk beliefs. The most common discordance was unrealistic optimism (n = 5127, 48.1% weighted); 12.2% (n = 1410) were

Table 2
Correlates with genetic counseling: odds ratio with 95%CI in brackets. Data from the 2015 U.S. National Health Interview Survey.

	Breast cancer genetic counseling (N = 12,631)		Colorectal cancer genetic counseling (*N* = 15,085)	
Variable	Unadjusted	Adjusted	Unadjusted	Adjusted
Risk perception				
About as likely	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)
More likely	6.26 [3.83, 10.22]	4.31 [2.56, 7.26]	5.01 [2.58, 9.93]	5.04 [2.57, 9.89]
Less likely	0.83 [0.46, 1.52]	0.95 [0.51, 1.77]	0.62 [0.35, 1.09]	0.62 [0.35, 1.08]
Objective relative risk				
Mid	1.00 (ref)	1.00 (ref)	1.00 (ref)	
Higher	5.72 [3.50, 9.34]	4.42 [2.61, 7.46]	1.27 [0.71, 2.29]	
Lower	0.72 [0.32, 0.34]	0.79 [0.35, 1.79]	0.79 [0.43, 1.44]	
Education				
No college	1.00 (ref)	1.00 (ref)	1.00 (ref)	
Some college or more	2.31 [1.33–4.00]	1.81 [1.04, 3.15]	1.37 [0.80, 2.34]	
Ethnicity				
Not Hispanic	1.00 (ref)		1.00 (ref)	
Hispanic	0.88 [0.44, 1.73]		1.06 [0.53, 2.12]	
Insurance				
Covered	1.00 (ref)		1.00 (ref)	1.00 (ref)
Not covered	0.51 [0.13, 2.10]		0.10 [0.01–0.70]	0.10 [0.01–0.73]
Race				
White	1.00 (ref)		1.00 (ref)	
Other	1.53 [0.86, 2.70]		1.69 [0.89, 3.19]	
Sex				
Men	–	–	1.28 [0.79, 2.07]	
Women	–	–	1.00 (ref)	
Age (cont.)	0.98 [0.96, 1.00]	0.98 [0.96, 1.00]	1.00 [0.97, 1.02]	

Adjusted model includes all variables for which the 95%CI did not cross 1 in bivariate analyses: for breast cancer genetic counseling this included objective relative risk, education and age; for colorectal cancer genetic counseling this included insurance.

Table 3
Correlates with genetic testing: odds ratio with 95% CI in brackets. Data from the 2015 U.S. National Health Interview Survey.

	Breast cancer genetic testing (*N* = 12,631)		Colorectal cancer genetic testing (*N* = 15,085)
Variable	Unadjusted	Adjusted	Unadjusted[a]
Risk perception			
About as likely	1.00 (ref)	1.00 (ref)	1.00 (ref)
More likely	4.82 [2.58, 8.98]	3.56 [1.80, 7.03]	5.92 [2.40, 14.63]
Less likely	0.81 [0.43, 1.54]	0.82 [0.42, 1.60]	0.75 [0.28, 2.01]
Objective relative risk			
Mid	1.00 (ref)	1.00 (ref)	1.00 (ref)
Higher	4.00 [2.14, 7.46]	3.02 [1.50, 6.10]	0.77 [0.28, 2.10]
Lower	0.95 [0.36, 2.50]	1.14 [0.44, 3.00]	0.72 [0.32, 1.62]
Education			
No college	1.00 (ref)	1.00 (ref)	1.00 (ref)
Some college or more	2.31 [1.16, 4.61]	2.01 [1.00, 4.08]	1.41 [0.68, 2.91]
Ethnicity			
Not Hispanic	1.00 (ref)		1.00 (ref)
Hispanic	0.76 [0.36, 1.59]		1.91 [0.95, 3.86]
Insurance			
Covered	1.00 (ref)		1.00 (ref)
Not covered	0.24 [0.06, 1.02]		0.30 [0.06, 1.61]
Race			
White	1.00 (ref)		1.00 (ref)
Other	0.67 [0.36, 1.26]		1.32 [0.54, 3.23]
Sex			
Men	–		1.70 [0.82, 3.56]
Women	–		1.00 (ref)
Age (cont.)	0.98 [0.96, 1.00]		1.00 [0.96, 1.04]

Adjusted model includes all variables for which the 95%CI did not cross 1 in bivariate analyses. For breast cancer genetic testing this included objective relative risk and education.

[a] Adjusted model not tested as only one variable was associated with colorectal genetic testing in bivariate analyses.

unrealistically pessimistic. The remaining women (n = 1410, 39.7% weighted) had risk perceptions that were concordant with their objective BC risk.

Discordant risk beliefs were not associated with having undergone genetic counseling for BC risk nor having had a genetic test for BC risk (Table 4). In multivariable analyses, the following demographics were associated with unrealistic optimism: Hispanic ethnicity, White race, and older age. Unrealistic pessimism was associated with lower level of education, lower income, non-White race, and younger age.

Table 4
Risk belief correlates (demographics and genetic counseling): outcome variable is risk belief category (unrealistically pessimistic, unrealistically optimistic or concordant). The reference group is concordant cancer risk belief category. Data from the 2015 U.S. National Health Interview Survey.

	Risk beliefs about breast cancer			Risk beliefs about colorectal cancer		
Variable	Unrealistically pessimistic % (weighted), OR [95% CI] (n = 1410)	Concordant % (weighted), (n = 4406)	Unrealistically optimistic % (weighted), OR [95% CI] (n = 5127)	Unrealistically pessimistic % (weighted), OR [95% CI] (n = 1983)	Concordant % (weighted), (n = 4930)	Unrealistically optimistic % (weighted), OR [95% CI] (n = 5838)
Genetic counseling						
Yes	12.3 1.22 [0.43,3.49]	39.1	48.6 0.99 [0.58,1.67]	20.0 0.77 [0.39,1.53]	57.3	22.7 0.34 [0.18,0.64]
No	12.2 ref	39.6	48.2 ref	16.0 ref	39.6	44.4 ref
Education						
No college	17.4 ref	40.7	42.0 ref	13.6 ref	38.3	48.1 ref
Some college or more	9.3 0.56 [0.46,0.68]	39.0	51.7 1.39 [1.23,1.56]	18.0 1.27 [1.08,1.50]	40.5	41.5 0.83 [0.75,0.93]
Ethnicity						
Not Hispanic	11.7 ref	41.0	47.4 ref	16.6	39.7	43.8
Hispanic	15.8 1.34 [1.03,1.76]	31.3	52.9 1.75 [1.49,2.05]	13.7 –	39.5	46.8 –
Insurance						
Covered	19.3 1.23 [0.91,1.66]	39.0	41.7 0.95 [0.76,1.20]	16.6 1.48 [1.03,2.11]	39.8	43.6 0.75 [0.59,0.95]
Not covered	11.6 ref	39.8	48.6 ref	10.5 ref	37.8	51.8 ref
Race						
White	11.4 ref	39.7	48.9 ref	16.6 ref	40.5	42.8 ref
Other	19.6 1.52 [1.24,1.87]	44.7	35.8 0.69 [0.60,0.80]	14.9 1.04 [0.84,1.30]	36.9	48.2 1.20 [1.02,1.41]
Sex						
Men	–	–	–	20.6 1.34 [1.14,1.56]	45.6	33.8 0.48 [0.43,0.53]
Women	–	–	–	12.1 ref	33.9	53.9 ref
Age	μ = 52.95, SE = 0.42 0.99 [0.98,0.99]	μ = 54.84, SE = 0.25	μ = 55.83, SE = 0.25 1.01 [1.01,1.02]	μ = 62.58, SE = 0.26 1.00 [0.99,1.01]	μ = 62.55, SE = 0.17	μ = 63.22, SE = 0.16 1.01 [1.00,1.02]

Adjusted model includes demographic characteristics for which the 95%CI did not cross 1 in bivariate analyses.

3.3.2. Colorectal cancer

Similar to BC, perceived risk was weakly associated with objective relative risk (r = 0.070, 95%CI: 0.05, 0.09). Individuals were categorized as being unrealistically optimistic (n = 5838, 44.1% weighted), unrealistically pessimistic (n = 1983, 16.3%) or had concordant risk perceptions (n = 4930, 39.7%) for their CRC risk.

In contrast to BC risk perceptions, concordant CRC risk beliefs were associated with having undergone genetic counseling. A larger proportion of individuals who had undergone genetic counseling had concordant risk beliefs compared to those who had not undergone counseling (57.3% *v.* 39.6%, respectively). Similarly, concordant risk beliefs were associated with having had a genetic test for CRC risk: a larger proportion of individuals who had undergone genetic testing had concordant risk perceptions compared to those who had not undergone genetic testing (56.3% *v.* 39.5%, respectively) (Table 5). In multivariable analyses, unrealistic optimism was associated with lower education, not having insurance, being a woman, non-White race and older age. Higher education and being a man were associated with unrealistic pessimism.

4. Discussion

We report three main findings from a nationally representative U.S. sample of asymptomatic individuals without a personal history of cancer. First, the prevalence of genetic counseling and testing for BC and CRC risk was low, with few associated demographic characteristics. Second, higher risk perceptions were associated with having undergone genetic counseling or testing for cancer risk. Third, a large proportion of the U.S. population holds discordant risk perceptions regarding their BC and CRC risk, with unrealistic optimism most common. Further, for CRC, a higher proportion of individuals with concordant risk beliefs reported having received genetic counseling or testing (vs. discordant). However, the risk belief categories were not systematically related to engagement with genetic services for BC.

Consistent with prior studies, few demographic characteristics were associated with having undergone genetic counseling or testing (Childers et al., 2017; Roberts et al., 2019). Higher education level was associated with having undergone genetic counseling or testing for BC, and having insurance was associated with having undergone genetic counseling for CRC. Previously, lack of provider recommendation, low patient awareness and inadequate access to testing appeared to explain low genetic testing rates (Childers et al., 2017). In another study, those with higher awareness about the availability of genetic tests for disease treatment were more likely to have undergone cancer genetic testing (Roberts et al., 2019). The number of individuals reporting genetic counseling or testing in this study, and others with nationally representative samples, is low, and thus power to detect demographic correlates may be low.

Our results suggest that perceived cancer risk is an important factor to consider when examining correlates with genetic services. However, the cross-sectional nature of this study means that there are multiple possible accounts for these relationships. First, individuals' cancer risk perceptions may drive their genetic counseling and testing behaviors. Risk perceptions predict many health behaviors and outcomes (e.g.,

Table 5
Risk belief correlates (demographics and genetic testing): outcome variable is risk belief category (unrealistically pessimistic, unrealistically optimistic or concordant). The reference group is concordant cancer risk belief category. Data from the 2015 U.S. National Health Interview Survey.

	Risk beliefs about breast cancer			Risk beliefs about colorectal cancer		
Variable	Unrealistically pessimistic % (weighted), OR [95% CI] (n = 1410)	Concordant % (weighted), (n = 4406)	Unrealistically optimistic % (weighted), OR [95% CI] (n = 5127)	Unrealistically pessimistic % (weighted), OR [95% CI] (n = 1983)	Concordant % (weighted), (n = 4930)	Unrealistically optimistic % (weighted), OR [95% CI] (n = 5838)
Genetic test						
Yes	14.5 1.42 [0.60,3.36]	36.8	48.7 1.03 [0.59,1.82]	23.3 0.84 [0.34, 2.11]	56.3	20.4 0.27 [0.10, 0.72]
No	12.2 ref	39.7	48.1 ref	16.2 ref	39.5	44.3 ref
Education						
No college	17.4 ref	40.7	42.0 ref	13.6 ref	38.3	48.1 ref
Some college or more	9.3 0.55 [0.46,0.67]	39.0	51.7 1.39 [1.23,1.56]	18.0 1.25 [1.06,1.46]	40.5	41.5 0.84 [0.75,0.93]
Ethnicity						
Not Hispanic	11.7 ref	41.0	47.4 ref	16.6	39.7	43.8
Hispanic	15.8 1.35 [1.03,1.76]	31.3	52.9 1.76 [1.50,2.06]	13.7 –	39.5	46.8 –
Insurance						
Covered	19.3 1.19 [0.88,1.60]	39.0	41.7 0.95 [0.75,1.19]	16.6 1.46 [1.02,2.08]	39.8	43.6 0.73 [0.58,0.92]
Not covered	11.6 ref	39.8	48.6 ref	10.5 ref	37.8	51.8 ref
Race						
White	11.4 ref	39.7	48.9 ref	16.6 ref	40.5	42.8 ref
Other	19.6 1.53 [1.25,1.87]	44.7	35.8 0.69 [0.60,0.79]	14.9 1.02 [0.82,1.27]	36.9	48.2 1.20 [1.02,1.39]
Sex						
Men	–	–	–	20.6 1.32 [1.13,1.54]	45.6	33.8 0.47 [0.42,0.52]
Women	–	–	–	12.1 ref	33.9	53.9 ref
Age	μ = 52.95, SE = 0.42 0.99 [0.98,0.99]	μ = 54.84, SE = 0.25	μ = 55.83, SE = 0.25 1.01 [1.01,1.02]	μ = 62.58, SE = 0.26 1.00 [0.99,1.01]	μ = 62.55, SE = 0.17	μ = 63.22, SE = 0.16 1.01 [1.00,1.02]

Adjusted model includes demographic characteristics for which the 95%CI did not cross 1 in bivariate analyses.

physical activity, vaccination) (Zahrt and Crum, 2017; Brewer et al., 2007). Perceived risk is also associated with uptake of genetic counseling, in particular among cohorts with large proportions of unaffected individuals (Willis et al., 2017).

Alternatively, engagement with genetic services could lead to higher cancer risk perceptions. This hypothesis is unlikely, given prior research that genetic counseling either decreases or does not change cancer risk perceptions (Mikkelsen et al., 2007; Gurmankin et al., 2005) (see also research on anchoring and adjustment (Simmons et al., 2010)). It is more plausible that individuals engaging with genetic services for cancer risk have higher baseline risk perceptions that remain higher than baseline levels of individuals in the population. Indeed, individuals receiving genetic counseling continue to overestimate their risk after counseling (Gurmankin et al., 2005), and baseline cancer risk perceptions are higher among those being recommended for genetic counseling compared to controls (Mikkelsen et al., 2007). It is further possible that our results represent a combination of these hypotheses. For example, 1) lower cancer risk perceptions could lead to lower engagement with genetic services, 2) lower risk perceptions could result from engaging in genetic testing and learning of low risk, or 3) lower risk perceptions could result from engaging in genetic testing and displaying defensive responses to learning of high risk.

4.1. Discordant breast cancer risk beliefs

The correlation between perceived and objective relative risk for BC was weak (r = 0.15), and many individuals had discordant BC risk beliefs. We extend prior work about the prevalence and correlates of unrealistic optimism and pessimism for BC risk (Waters et al., 2011) by investigating associations of these discordant risk beliefs with genetic services. Although higher risk perception was associated with genetic counseling and testing, these higher risk perceptions did not necessarily match individuals' objective relative risk categories. In other words, contrary to our hypothesis, neither genetic counseling nor testing was associated with concordant cancer risk beliefs. This suggests that for BC, engagement with genetic services may not result in BC risk perceptions concordant with objective risk. Similarly, while Aspinwall and colleagues saw changes in risk perceptions immediately following genetic testing for melanoma risk, these estimates returned to baseline risk perceptions over time (Aspinwall et al., 2014). The demographic characteristics associated with the BC risk belief categories in the present study were similar to the results of a study with a previous NHIS sample (Waters et al., 2011).

4.2. Discordant colorectal cancer risk beliefs

The correlation between perceived risk and objective relative risk for CRC was also weak (r = 0.07). Many of the factors in the objective relative risk algorithm are lifestyle risks such as vegetable consumption and BMI. This low correlation between perceived and objective relative risk aligns with research showing a lack of association of lifestyle factors with risk perceptions for CRC (Hay et al., 2006; Robb et al., 2004a). Thus, people may have a poor understanding about the lifestyle risks contributing to CRC. Consistent with prior research (Dillard et al., 2006b; Klein et al., 2010), our results also suggest that individuals are generally not adept at estimating their own cancer risk.

In contrast to the BC risk findings in our study, more individuals who had engaged with genetic services for CRC had risk perceptions that were concordant with their objective risk, and fewer were unrealistically optimistic compared to individuals who had not engaged with genetic services. The contrasting findings between the two cancer types are notable. Individuals may be more likely to have pre-determined risk beliefs for BC that are less influenced by learning objective risk, for example through counseling or testing, compared to beliefs about CRC. Perhaps knowledge and awareness about BC is higher in the general public, compared to CRC, as it is discussed more frequently (Blanchard et al., 2002; Covello and Peters, 2002).

We extend prior work about correlates with risk perceptions for colorectal risk (Hay et al., 2006; Robb et al., 2004b), through generating objective risk scores and examining unrealistic optimism and pessimism for CRC in a nationally representative sample. The correlation of older age with unrealistic optimism resonates with what others have found (Hay et al., 2006; Robb et al., 2004b). However, the associations of risk perceptions for CRC with sex, education and other socioeconomic characteristics we report are novel (Hay et al., 2006). Prior studies have not accounted for objective relative risk scores as we were able to do in this study. A higher proportion of those with higher socioeconomic status (insured, higher education level, White) had risk perceptions concordant with their objective risk for CRC, perhaps because they are more attuned to the contribution of lifestyle and other risk factors to developing CRC. Future research should test this idea.

4.3. Implications for practice and research

Universal population genetic testing for BC and CRC risk has been proposed, which would include asymptomatic individuals regardless of family history (Murray et al., 2018; Gabai-Kapara et al., 2014; Prince et al., 2017). Our results show that engagement with genetic services among such individuals is still relatively uncommon. Furthermore, of those who had a genetic test for either BC or CRC risk, approximately 60% also received genetic counseling. The remaining 40% of individuals who received testing did not engage with a genetic counselor, suggesting that professional guidelines were not adhered to in many cases. This finding requires further investigation.

We found that those who are engaging with genetic services are not necessarily those at the highest risk. Addressing inaccuracies in risk perception at the population level may be an essential component of wide-scale attempts to increase genetic testing and use of counseling. Insurance status was one of the few demographic variables associated with engagement of genetic services (namely, genetic counseling for CRC), which has implications for access to these services at a population level. More work is also needed on the impact of providing genetic services to unaffected populations, in particular regarding engagement with preventive services such as screening or surgery. Although a universal screening program would aim to identify those at higher genetic risk, and thus eligible for preventive options, it is unknown whether asymptomatic individuals found to be at higher risk would seek these preventive options. Our results could inform development of policy or practices that involve population-level genetic testing.

4.4. Limitations

Although we calculated objective risk estimates for BC and CRC, there is no single tool used for genetic counseling referral among unaffected individuals. As such, we cannot determine whether it was appropriate for individuals who had counseling or testing to have received those services. In our study, objective risk scores simply provide an objective lifetime cancer risk and do not necessarily indicate eligibility for genetic testing or counseling. Although the risk algorithms selected for this study are widely used and well-validated, different tools produce different risk scores. We do not know the results of respondents' genetic tests; therefore, we cannot determine who is at higher risk for developing cancer based on genetic results, nor whether the genetic results influenced cancer risk perceptions. Finally, study populations for the BC and CRC analyses were overlapping but not identical. Although we do account for age and sex in our models, variation in study populations may limit our ability to directly compare findings across cancer types.

5. Conclusion

Engagement with genetic services among asymptomatic individuals without a personal history of cancer in the U.S. population is low and is associated with higher risk perceptions for BC and CRC. More individuals who had engaged with genetic services had risk perceptions concordant with their objective risk for CRC compared to those who had not engaged with genetic services. This association was not detected for individuals who had engaged with genetic services for BC risk. Population level screening programs should consider the impact of genetic counseling and testing on risk beliefs, and strategies to address inaccuracies in risk perception at the population level.

Conflict of interest

The authors declare there is no conflict of interest.

Acknowledgments

This secondary analysis was supported by the National Human Genome Research Institute Intramural Research Program.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ypmed.2019.02.027.

References

Armstrong, J., Toscano, M., Kotchko, N., Friedman, S., Schwartz, M.D., Virgo, K.S., Lynch, K., Andrews, J.E., Loi, C.X.A., Bauer, J.E., 2015. Utilization and outcomes of BRCA genetic testing and counseling in a national commercially insured population: the ABOUT study. JAMA Oncology 1 (9), 1251–1260.

Aspinwall, L.G., Taber, J.M., Kohlmann, W., Leaf, S.L., Leachman, S.A., 2014. Perceived risk following melanoma genetic testing: a 2-year prospective study distinguishing subjective estimates from recall. J. Genet. Couns. 23 (3), 421–437.

Blanchard, D., Erblich, J., Montgomery, G.H., Bovbjerg, D.H., 2002. Read all about it: the over-representation of breast cancer in popular magazines. Prev. Med. 35 (4), 343–348.

Brewer, N.T., Chapman, G.B., Gibbons, F.X., Gerrard, M., McCaul, K.D., Weinstein, N.D., 2007. Meta-analysis of the relationship between risk perception and health behavior: the example of vaccination. Health Psychol. 26 (2), 136–145.

Center of Disease Control and Prevention. *Leading Causes of Death.* [cited 2018 June]; Available from: https://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm.

Childers, C.P., Childers, K.K., Maggard-Gibbons, M., Macinko, J., 2017. National estimates of genetic testing in women with a history of breast or ovarian cancer. J. Clin. Oncol. 35 (34), 3800–3806.

Covello, V.T., Peters, R.G., 2002. Women's perceptions of the risks of age-related diseases, including breast cancer: reports from a 3-year research study. Health Commun. 14 (3), 377–395.

Dillard, A.J., McCaul, K.D., Klein, W.M., 2006a. Unrealistic optimism in smokers: implications for smoking myth endorsement and self-protective motivation. J. Health Commun. 11 (S1), 93–102.

Dillard, A.J., McCaul, K.D., Kelso, P.D., Klein, W.M., 2006b. Resisting good news: reactions to breast cancer risk communication. Health Commun. 19 (2), 115–123.

Domchek, S.M., Friebel, T.M., Singer, C.F., Evans, D.G., Lynch, H.T., Isaacs, C., Garber, J.E., Neuhausen, S.L., Matloff, E., Eeles, R., 2010. Association of risk-reducing surgery in BRCA1 or BRCA2 mutation carriers with cancer risk and mortality. JAMA 304 (9), 967–975.

Gabai-Kapara, E., Lahad, A., Kaufman, B., Friedman, E., Segev, S., Renbaum, P., Beeri, R., Gal, M., Grinshpun-Cohen, J., Djemal, K., 2014. Population-based screening for breast and ovarian cancer risk due to BRCA1 and BRCA2. Proc. Natl. Acad. Sci. 111 (39), 14205–14210.

Gill, J., Obley, A.J., Prasad, V., 2018. Direct-to-consumer genetic testing: the implications of the US FDA's first marketing authorization for BRCA mutation testing. JAMA 319 (23), 2377–2378.

Gurmankin, A.D., Domchek, S., Stopfer, J., Fels, C., Armstrong, K., 2005. Patients' resistance to risk information in genetic counseling for BRCA1/2. Arch. Intern. Med.

165 (5), 523–529.
Hay, J., Coups, E., Ford, J., 2006. Predictors of perceived risk for colon cancer in a national probability sample in the United States. J. Health Commun. 11 (S1), 71–92.
Kasparian, N.A., Meiser, B., Butow, P.N., Simpson, J.M., Mann, G.J., 2009. Genetic testing for melanoma risk: a prospective cohort study of uptake and outcomes among Australian families. Genetics in Medicine 11 (4), 265–278.
Klein, W.M., Lipkus, I.M., Scholl, S.M., McQueen, A., Cerully, J.L., Harris, P.R., 2010. Self-affirmation moderates effects of unrealistic optimism and pessimism on reactions to tailored risk feedback. Psychol. Health 25 (10), 1195–1208.
Mikkelsen, E.M., Sunde, L., Johansen, C., Johnsen, S.P., 2007. Risk perception among women receiving genetic counseling: a population-based follow-up study. Cancer Detect. Prev. 31 (6), 457–464.
Milhabet, I., Duprez, C., Krzeminski, A., Christophe, V., 2013. Cancer risk comparative perception and overscreening behaviours of non-carriers from BRCA1/2 families. European Journal of Cancer Care 22 (4), 540–548.
Moyer, V.A., 2014. Risk assessment, genetic counseling, and genetic testing for BRCA-related cancer in women: US Preventive Services Task Force recommendation statement. Ann. Intern. Med. 160 (4), 271-281.
Murray, M.F., Evans, J.P., Angrist, M., Chan, K., Uhlmann, W.R., Doyle, D.L., Fullerton, S.M., Ganiats, T.G., Hagenkord, J., Imhof, S., 2018. A proposed approach for implementing genomics-based screening programs for healthy adults. NAM Perspectives. https://doi.org/10.31478/201812a.
National Center for Health Statistics. *Data File Documentation, National Health Interview Survey*. 2015 [cited 2018 January]; Available from: https://www.cdc.gov/nchs/nhis/nhis_2015_data_release.htm.
Persoskie, A., Ferrer, R.A., Nelson, W.L., Klein, W.M., 2014a. Precancer risk perceptions predict postcancer subjective well-being. Health Psychol. 33 (9), 1023–1032.
Persoskie, A., Ferrer, R.A., Nelson, W.L., Klein, W.M., 2014b. Precancer risk perceptions predict postcancer subjective well-being. Health Psychol. 33 (9), 1023–1032.
Petrucelli, N., M.B. Daly, and T. Pal. *BRCA1-and BRCA2-associated hereditary breast and ovarian cancer*. GeneReviews 2016 [cited 2018 June]; Available from: https://www.ncbi.nlm.nih.gov/sites/books/NBK1247/.
Prince, A.E., Cadigan, R.J., Henderson, G.E., Evans, J.P., Adams, M., Coker-Schwimmer, E., Penn, D.C., Van Riper, M., Corbie-Smith, G., Jonas, D.E., 2017. Is there evidence that we should screen the general population for Lynch syndrome with genetic testing? A systematic review. Pharmacogenomics and Personalized Medicine 10, 49–60.
Robb, K.A., Miles, A., Wardle, J., 2004a. Subjective and objective risk of colorectal cancer (UK). Cancer Causes Control 15 (1), 21–25.
Robb, K.A., Miles, A., Wardle, J., 2004b. Demographic and psychosocial factors associated with perceived risk for colorectal cancer. Cancer Epidemiology and Prevention Biomarkers 13 (3), 366–372.
Roberts, M.C., E. Turbitt, and W.M. Klein, Psychosocial, attitudinal and demographic correlates of cancer-related genetic testing in the 2017 Health Information National Trends Survey. *Journal of Community Genetics* 2019: (in press) [accepted 20 December 2018].
Rogowski, W.H., Grosse, S.D., John, J., Kaariainen, H., Kent, A., Kristofferson, U., Schmidtke, J., 2010. Points to consider in assessing and appraising predictive genetic tests. Journal of Community Genetics 1 (4), 185–194.
Shepperd, J.A., Waters, E.A., Weinstein, N.D., Klein, W.M., 2015. A primer on unrealistic optimism. Curr. Dir. Psychol. Sci. 24 (3), 232–237.
Simmons, J.P., LeBoeuf, R.A., Nelson, L.D., 2010. The effect of accuracy motivation on anchoring and adjustment: do people adjust from provided anchors? J. Pers. Soc. Psychol. 99 (6), 917–932.
Sweeny, K., Ghane, A., Legg, A.M., Huynh, H.P., Andrews, S.E., 2014. Predictors of genetic testing decisions: a systematic review and critique of the literature. J. Genet. Couns. 23 (3), 263–288.
Syngal, S., Brand, R.E., Church, J.M., Giardiello, F.M., Hampel, H.L., Burt, R.W., 2015. ACG clinical guideline: genetic testing and management of hereditary gastrointestinal cancer syndromes. Am. J. Gastroenterol. 110 (2), 223–263.
Taber, J.M., Chang, C.Q., Lam, T.K., Gillanders, E.M., Hamilton, J.G., Schully, S.D., 2015. Prevalence and correlates of receiving and sharing high-penetrance cancer genetic test results: findings from the Health Information National Trends Survey. Public Health Genomics 18 (2), 67–77.
Waters, E.A., Klein, W.M., Moser, R.P., Yu, M., Waldron, W.R., McNeel, T.S., Freedman, A.N., 2011. Correlates of unrealistic risk beliefs in a nationally representative sample. J. Behav. Med. 34 (3), 225–235.
Willis, A.M., Smith, S.K., Meiser, B., Ballinger, M.L., Thomas, D.M., Young, M.A., 2017. Sociodemographic, psychosocial and clinical factors associated with uptake of genetic counselling for hereditary cancer: a systematic review. Clin. Genet. 92 (2), 121–133.
Zahrt, O.H., Crum, A.J., 2017. Perceived physical activity and mortality: evidence from three nationally representative US samples. Health Psychol. 36 (11), 1017–1025.