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RESEARCH

# Information needs persist after genetic counseling and testing for *BRCA1/2* and Lynch Syndrome

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## Abstract

**Purpose** Research has shown that cancer genetic risk is often not well understood by patients undergoing genetic testing and counseling. We describe the barriers to understanding genetic risk and the needs of high-risk persons and cancer survivors who have undergone genetic testing.

**Methods** Using data from an internet survey of adults living in the USA who responded 'yes' to having ever had a genetic test to determine cancer risk ($N=696$), we conducted bivariate analyses and multivariable logistic regression models to evaluate associations between demographic, clinical, and communication-related variables by our key outcome of having vs. not having enough information about genetics and cancer to speak with family. Percentages for yes and no responses to queries about unmet informational needs were calculated. Patient satisfaction with counseling and percentage disclosure of genetic risk status to family were also calculated.

**Results** We found that a lack of resources provided by provider to inform family members and a lack of materials provided along with genetic test results were strongly associated with not having enough information about genetics and cancer (OR 4.54 95% CI 2.40–8.59 and OR 2.19 95% CI 1.16–4.14 respectively). Among participants undergoing genetic counseling, almost half reported needing more information on what genetic risk means for them and their family and how genetic testing results might impact future screening.

**Conclusion** High levels of satisfaction with genetic counseling may not give a full picture of the patient-provider interaction and may miss potential unmet needs of the patient. Accessible resources and ongoing opportunities for updating family history information could reinforce knowledge about genetic risk.

**Keywords** Cancer risk · Genetic counseling · Genetic testing · Decision-making · Risk communication · Uncertainty

## Introduction

Medical decision-making has become increasingly complex over the past decades. This complexity is driven in part by the growth of research on human genetic variation leading to advances in genomic technologies for the early diagnosis and prevention of diseases [1]. The risk of breast and ovarian cancer among BRCA carriers by age 70 is about 65 and 39%, respectively, and among those with Lynch syndrome, a condition linked to pathogenic mutations in DNA mismatch repair genes, the risk of colorectal cancer is 40% [2, 3]. Identifying persons with high-risk genetic mutations and their family members is a critical step in the screening, prevention, and early treatment of these cancers. However, a recurring theme from research on communicating genetic cancer risk information has been that genetic risk is not well understood [4–9]. Genetic risk evaluation is part of a comprehensive process that can include genetic counseling and testing, receipt of test results, disclosure of results to family members, and subsequent medical follow-up. Throughout this process, effective communication of genetic information and cancer risk is crucial to making informed choices about

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treatment and surveillance [5, 10]. Although primary care physicians, oncologists, and other healthcare providers can be involved in this process, genetic counselors play a key role in conveying information about cancer risk, inheritance, genetic concepts, genetic test results, cancer screening, and cancer prevention [11].

The challenges faced by genetic counselors in communicating this information stem from the uncertainty inherent in genetics as well as from limitations in the communication process itself. Mishel's theory of uncertainty posits that situations involving complexity, ambiguity, lack of information, and unpredictability about outcomes contribute to uncertainty in understanding information and in making informed medical decisions [12]. At its core, genetic risk information is complex and leans heavily on probability and statistics that can be difficult to understand, even for healthcare providers [13–15]. There can also be scientific uncertainty regarding the interpretation of test results and appropriate follow-up. For example, a result indicating a variant of unknown significance or a negative test in the face of a strong family history challenges unambiguous interpretation about future cancer risk [16]. Additionally, the concept of inheritance can differ between patients and health care providers [17]. Finally, having a deleterious genetic mutation is only one predictor of a multifactorial disease in which environmental factors and behavioral characteristics also play a role [15].

Concerns about communicating genetic information reported by oncologists and other health care providers include a lack of educational materials to provide patients [18] and lack of interventions to assist healthcare providers in discussing hereditary risk and testing [19]. In addition to the task of explaining the biomedical content of genetic information, research has also highlighted the importance of establishing rapport and empathy in the process of exchanging knowledge with patients and the need to address psychosocial concerns of patients during the counseling process [4]. Finally, it has been demonstrated that suboptimal communication about genetic information can cascade throughout the family thereby limiting the potential for reducing cancer risk [20].

The concept of uncertainty provides a framework for examining whether the communication process has successfully met the needs of persons undergoing genetic counseling and testing. More focused uncertainty typologies have been concerned with the process of communicating risk. To address the uncertainty involved in communicating genetic cancer risk, Hong proposed a typology that includes (1) uncertainty about understanding genetic information, (2) uncertainty about future cancer risk, (3) uncertainty about the usefulness of genetics, (4) uncertainty about the consequences or about how to manage information, and (5) uncertainty about what genetic test results mean for the patient's family [1].

To address the challenges in managing uncertainty, attention to the information needs of people undergoing genetic counseling and to the communication process itself are key factors [4, 21]. The key analysis examined the relative importance of demographic, clinical, and communication-related characteristics that influence participant's reporting that they have enough information about genetics and cancer to speak with family members. We conducted a descriptive study on the sources of information that would be useful for family communication. Finally, we ask whether participants were satisfied with communication they had with their genetic counselor about cancer risk (yes vs no) and whether and to which family members they disclosed their genetic test results. We use the uncertainty frameworks as described above to classify key areas of additional informational needs.

## Materials and methods

### Survey procedures

Using the internet for recruitment, this research study enrolled adults 18-years and older living in the USA who responded 'yes' to having ever had a genetic test to determine risk of developing cancer in the future. Individuals were recruited through paid ads on Facebook, Instagram, Twitter, and Google. Cancer-related advertisements were designed and posted on social media and Google to invite participants to complete the survey. Targeted ads used each site's filtering abilities that included factors such as age, gender, and keywords and phrases such as *BRCA1* and genetic testing.

Recruitment ads were first posted on December 19, 2019 and removed on April 23, 2020. After clicking on the ad, respondents were taken to the survey welcome screen informing them of their rights as a participant, including information about the study (e.g., description, time to complete, and incentive offered on completion) and that they could skip any question they did not want to answer. Upon completion of the first survey, participants were asked if they would also participate in the second survey. After providing an email address they were sent a link to the second survey. New respondents were recruited via social media to complete the second survey. Data from both surveys were used in the analyses. At the end of data collection, a total of 757 respondents completed the initial survey, of which 438 out of the total 757 respondents invited for the second survey, completed both surveys; an additional 366 respondents were newly recruited and completed the second survey for a total of 804 respondents to the second survey.

Data were obtained from two surveys conducted among people who have had genetic testing for cancer risk. Questions for the surveys were taken from nationally

representative surveys (The Health Information National Trend Survey (HINTS) and the National Health Interview Survey (NHIS) in addition to questions developed specifically for the study [22, 23]. The first was administered to those who have had genetic testing for cancer risk and contained content on communication of genetic risk among family members. The second was administered as a follow-up survey for those who completed the initial high-risk questionnaire as well as newly recruited respondents. This second survey focused on the needs and preferences for tools and resources for family communication of genetic risk and is the focus of this analysis. Each survey took on average 19 min to complete. Individual questionnaires with 50% or more of the survey questions as 'don't know' and/or 'prefer not to answer' were considered non-responsive and not included in analyses.

The NORC institutional review board (IRB) conducted a full board review and provided approval on June 15, 2016. Given the sensitive nature of the survey material, the IRB provided a Waiver of Documentation of Consent. Respondents completing the survey online gave their consent by clicking "Continue" after reading a written introduction to their rights as a participant. Upon completing the first and/or the second survey, respondents were eligible for a $5 Amazon gift card.

## Participants

The follow-up survey was completed by 803 participants with 697 reporting they had a *BRCA1/2* test or a test for Lynch syndrome or both. Those reporting 'other' genetic testing ($n = 106$) or missing the response to the outcome variable ($n = 1$) were excluded from analysis.

## Measures

### Outcomes

Participants were asked how much they agreed with the statement that they 'had enough information about genetics and cancer to speak with family members.' The 5-item response categories were dichotomized into agree/strongly agree versus disagree/strongly disagree/neither agree nor disagree. Participants were asked how satisfied they are with the communication they had with a genetic counselor about their cancer risk. The 5-item response options included very satisfied, satisfied, neither satisfied nor dissatisfied, dissatisfied, and very dissatisfied.

Uncertainty remaining after genetic counseling and testing was assessed by asking participants to respond 'yes' or 'no' to the usefulness of a series of information sources or materials for discussions about cancer family history. These choices included more discussion with genetic counselor, discussion with physician, information pamphlets, referral to support group, general information about genetic mutations, what results mean for their risk, what results mean for family members, what results mean for future cancer screenings, how to reduce cancer risk, where to go for more information, where to seek emotional or psychological support, information about insurance coverage for testing, and options for cancer prevention (see Table 3).

Finally, we asked whether participants shared their genetic test results with first-degree relatives and the number of first-degree relatives with whom they shared information.

### Demographic data

Sociodemographic characteristics included age, highest level of education, annual household income, race, ethnicity, employment (currently employed versus unemployed, retired, student, homemaker, disabled, other), and health insurance status coverage (yes vs. no). See Table 1 for categorization of variables.

### Clinical characteristics

Participants were asked whether they had been told by a doctor or health professional that they had a cancer or malignancy of any kind. We excluded non-melanoma skin cancer in reporting a yes or no response. We asked whether participants had undergone genetic testing for Lynch syndrome (or hereditary colorectal cancer) and whether they had undergone genetic testing for a *BRCA1* or *BRCA2* mutation for increased breast and ovarian cancer risk. We asked, 'What was the result of your BRCA test' and 'What was the result of your genetic test for hereditary colorectal cancer.' Options for reporting results of these tests were: 'I carry a gene mutation that is associated with a greater cancer risk for me or my family' which we categorized as a positive genetic test result; 'I was found to have a gene mutation, but it is not clear whether it is associated with cancer risk for me or my family' which we categorized as variant of unknown significance; and 'No gene mutation was found' which we categorized as negative test result. We combined positive, negative, and variant of unknown responses for *BRCA* and Lynch syndrome into one genetic testing results variable.

### Communication characteristics

Participants answered yes or no to having received genetic counseling for cancer risk, to questions about whether educational materials were provided along with genetic test result, and whether any resources to help inform family members were provided. To investigate whether knowledge could be influenced by experience of genetic testing in the family, we asked whether participants were the first

**Table 1** Characteristics of high-risk persons or cancer survivors stratified by having enough information about genetics and cancer to speak with family members

| | Had enough information about genetics and cancer to speak with family members | | |
|---|---|---|---|
| | Yes: $N=611$ | No: $N=85$ | $P$-value* |
| | $N$ (%) | $N$ (%) | |
| Demographic factors: | | | |
| AGE: mean (SD) | 48.7 (13.8) | 46.2 (13.8) | 0.13[a] |
| Sex | | | |
| Male | 39 (92.9) | 3 (7.1) | 0.84 |
| Female | 570 (87.3) | 82 (12.6) | |
| Education | | | |
| HS or less | 55 (90.2) | 6 (9.8) | 0.33 |
| Some post HS/some college | 119 (82.6) | 24 (16.7) | |
| College graduate | 233 (87.6) | 33 (12.4) | |
| Post-graduate | 201 (90.5) | 21 (9.5) | |
| Race | | | |
| NH white | 517 (87.8) | 71 (12.1) | 0.75 |
| NH black | 18 (78.3) | 5 (21.7) | |
| Hispanic | 32 (84.2) | 6 (15.8) | |
| Other or multiple race | 31 (96.9) | 1 (3.1) | |
| Employment | | | |
| Employed | 361 (89.4) | 42 (10.4) | 0.38 |
| Other | 247 (85.2) | 43 (14.8) | |
| Income | | | |
| Less than $20,000 | 41 (87.2) | 6 (12.8) | 0.57 |
| $20,000 to $49,999 | 101 (82.1) | 22 (17.9) | |
| $50,000 to $99,999 | 202 (89.8) | 22 (9.8) | |
| $100,000 to $199,999 | 152 (88.4) | 20 (11.6) | |
| $200,000 or more | 50 (92.6) | 4 (7.4) | |
| Health insurance | | | |
| Yes | 592 (87.7) | 82 (12.2) | 0.99 |
| No | 18 (85.7) | 3 (14.3) | |
| Clinical factors: | | | |
| Have you ever been told by a doctor or other health professional that you have had cancer or a malignancy of any kind | | | |
| Yes | 270 (88.0) | 37 (12.0) | 0.90 |
| No | 331 (87.6) | 46 (12.2) | |
| Genetic testing results | | | |
| Positive | 209 (92.9) | 16 (7.1) | 0.003 |
| Variant of Unknown significance | 64 (82.1) | 14 (17.9) | |
| Negative | 334 (86.5) | 51 (13.2) | |
| Communication factors: | | | |
| Received genetic counseling for cancer risk | | | |
| Yes | 519 (89.2) | 62 (10.7) | 0.008 |
| No | 85 (82.5) | 18 (17.5) | |
| Were materials provided along with your genetic test results | | | |
| Yes, materials provided | 526 (90.4) | 56 (9.6) | 0.0001 |
| No materials provided | 66 (73.3) | 24 (26.7) | |
| I was not provided with any resources to help me inform family members about what the results of my genetic test | | | |
| Yes, resources provided | 335 (95.4) | 16 (4.6) | 0.0001 |
| No resources provided | 268 (79.8) | 68 (20.2) | |
| Who was first in family to undergo testing? | | | |
| No one else tested in family | 278 (83.7) | 54 (16.3) | 0.02 |
| I was the first tested | 124 (88.6) | 15 (10.7) | |
| Other relative first tested | 207 (92.8) | 16 (7.2) | |

*Chi-square test $P$-values

[a]$t$-test $P$-value for the mean

Numbers may not sum due to non-response for item

in their family to be tested, whether other family members were tested first, or whether they were the only person in their family to be tested. We asked whether 'you have shared your most recent genetic test results with any of the following biological or blood relatives.' The question was asked for each relative separately (mother, father, sister, brother, half-brother, half-sister, daughter, son, uncle, aunt, cousin). Response categories included the following: 'yes,' 'no,' 'I plan to but not yet, I haven't decided,' 'not applicable,' and 'prefer not to answer.' We calculated the response for 'yes' for first degree relatives.

## Analysis

We first produced descriptive statistics for the sample. We calculated percentages and means for the demographic, clinical, and communication-related variables by the outcome of interest (having enough information about genetics) and tested differences using $t$-tests and Chi-square tests. Pearson Correlation coefficients and chi-square statistics were used to assess the association between variables. Results from the bivariate analysis that were statistically significant at the $P<0.20$ level were included in a multivariate logistic regression model that also included age. Odds ratios and corresponding 95% confidence intervals were calculated and results were considered statistically significant at $P<0.05$. The goodness of model fit was assessed with Hosmer–Lemeshow test statistic. Percentages for yes and no responses to queries about unmet needs and additional information were calculated. Analyses were conducted using SAS version 9.4.

## Results

The 696 participants in our survey ranged in age from 18 to 80 years. The majority were women (93.7%), non-Hispanic White (84.5%), and had a bachelor's degree or higher education level (70.7%). In addition, 58% were employed and 65.8% had an annual household income of greater than $50,000. We found that 89.5% of respondents shared genetic information with at least one-first degree relative and of those who shared genetic information, 55.4% shared with 3 or more first-degree relatives (data not shown). Most of the participants had received genetic counseling (83.3%) and 92.5% of these participants were satisfied or very satisfied with the communication they had with their genetic counselor.

Table 1 presents demographic, clinical, and communication-related unadjusted percentages of participants responding yes or no to having enough information about genetics and cancer (one participant did not respond to the outcome question about having enough information). Overall, almost 88 percent of the respondents agreed they had enough information about genetics and cancer to speak with family members. Not having enough information about genetics and cancer was more likely to be reported by those who did not receive genetic counseling or by those who did not receive materials with genetic test results or resources for informing family members. Of the clinical factors, only testing results were significantly associated with having enough information. Sociodemographic characteristics did not strongly differ by the outcome.

Table 2 presents adjusted odds ratios and 95% confidence intervals from multivariable logistic regression model for having enough information about genetics and cancer. The model included variables that were statistically significant at the 0.20 level in Table 1. Model fit was acceptable with Hosmer–Lemeshow $P$-value = 0.73.

Younger age was associated with a lack of information about genetics. Also associated with not having enough information about genetics was being the only person or the first person in the family undergoing genetic testing vs. having other family members tested first. Among those with no resources provided to help inform family members, the odds of not having enough genetic information was 4.5 times higher compared with those having resources provided (OR 4.54, 95% CI 2.40–8.59). Among those with a lack of materials being provided with genetic results, the odds of not having enough genetic information was 2.2 times higher compared to those having materials (OR 2.20, 95% CI 1.16–4.14). Reporting a lack The odds ratio for not having information among those with a variant of unknown significance vs. a negative result was elevated but not statistically significant (OR 1.77, 95% CI 0.85–3.72).

**Table 2** Adjusted odds ratios and 95% confidence intervals for characteristics associated with not having enough information about genetics and cancer to inform family members

| Effect | OR* | 95% Wald CI | | |
|---|---|---|---|---|
| | | LCI | UCI | *P*-value |
| AGE in years (continuous) | 0.97 | 0.95 | 0.99 | 0.003 |
| Genetic testing results | | | | |
| Positive vs negative | 1.10 | 0.55 | 2.21 | 0.78 |
| Variant of unknown vs negative | 1.77 | 0.85 | 3.72 | 0.13 |
| Ever received genetic counseling | | | | |
| No vs yes | 1.12 | 0.58 | 2.17 | 0.73 |
| No materials were provided along with genetic test results | | | | |
| No materials provided vs materials provided | 2.19 | 1.16 | 4.14 | 0.02 |
| I was not provided with any resources by provider to help you inform family members | | | | |
| No resources provided vs resources provided | 4.54 | 2.40 | 8.59 | 0.0001 |
| Who was first tested | | | | |
| Only I was tested vs other relative first tested | 3.87 | 1.78 | 8.44 | 0.001 |
| I was first tested vs other relative first tested | 2.86 | 1.16 | 7.07 | 0.02 |

Table 3 presents an assessment of informational needs of those who had undergone genetic counseling ($n = 575$). Agreement or disagreement with 12 types of additional information that would be useful for informing discussions about cancer family history were ranked in order of highest to lowest percentages. Among participants who had genetic counseling, almost 48% responded yes to needing more information on what genetic risk means for their family, 45% responded yes to needing more information on how genetic testing results might impact future screening, and 42.8% responded yes to needing more information on what genetic test results mean for them. The lowest percentage for endorsing additional needed information were seen for referral to support groups (21%) and information on where to go for additional emotional or psychological support (21.4%). Almost 11% of respondents found none of the suggested sources to be useful.

## Discussion

Most participants in our study had received genetic counseling and the majority reported being satisfied with the communication with their counselors. This is consistent with several studies reporting overall high levels of satisfaction with the counseling process [24, 25]. Also consistent with prior research, most respondents shared the

**Table 3** Types of information or materials that would be useful for discussions about cancer family history among participants who have undergone genetic counseling for cancer risk ($n=575$)

| | *N* (%) |
|---|---|
| What genetic testing results mean for your children, siblings, and other family members | |
| Yes | 274 (47.7) |
| No | 301 (52.4) |
| How genetic test results might impact future cancer screenings | |
| Yes | 259 (45.0) |
| No | 316 (55.0) |
| What genetic test results mean for you and your risk | |
| Yes | 246 (42.8) |
| No | 329 (57.2) |
| How to reduce cancer risk | |
| Yes | 201 (35.0) |
| No | 374 (65.0) |
| Information pamphlets or FAQs | |
| Yes | 201 (35.0) |
| No | 374 (65.0) |
| General information about genetic mutations | |
| Yes | 198 (34.4) |
| No | 377 (65.6) |
| Where to go for more information | |
| Yes | 196 (34.1) |
| No | 379 (65.9) |
| Insurance coverage for genetic testing | |
| Yes | 190 (33.0) |
| No | 385 (67.0) |
| More discussion with genetic counselor | |
| Yes | 188 (32.7) |
| No | 387 (67.3) |
| Understanding choices or options for cancer prevention | |
| Yes | 169 (29.4) |
| No | 406 (70.6) |
| Discussions with physician | |
| Yes | 135 (23.5) |
| No | 440 (76.5) |
| Where and who to go see for emotional or psychological support | |
| Yes | 123 (21.4) |
| No | 452 (78.6) |
| Referral to support group | |
| Yes | 121 (21.0) |
| No | 454 (79.0) |
| None of the above | |
| Yes | 62 (10.8) |
| No | 513 (89.2) |

Numbers may not sum due to non-response for item

results of their genetic test with relatives [26–29]. Nevertheless, our research suggests that despite high satisfaction with genetic counseling and over 90% of participants sharing genetic test results with relatives, uncertainty about the information they share remains.

A lack of materials and resources for informing relatives suggested a lack of information about genetics and cancer. Investigation to identify the most effective methods of communicating genetic test results could be useful in increasing knowledge. Existing research shows that patients have unmet

needs for information and that materials provided during results disclosure can aid family communication [8, 30, 31]. We saw that experiences with genetic testing in the family influenced knowledge about genetics and cancer. Being the only family member tested or the first in family tested were significantly associated with the perceived lack of information about genetics compared with participants whose other relatives were tested first. Our findings also suggest that shared experiences with genetic testing within families contribute to an understanding of genetic risk and cancer and of how to navigate increased risk.

Our research describes several informational needs that remain despite participants having had genetic counseling. Most of these responses speak to the uncertainty about the complexity of genetic information as well as concerns about future cancer risk and consequences of testing [5, 32]. Almost half of the study participants reported that they could use more information on what genetic testing results mean for their family. This need reflects the component of Hong's typology that addresses uncertainty about what genetic test results mean for the family. Almost 43% of the respondents would find information on the meaning of genetics and cancer risk more useful, an indication of uncertainty related to probability and complexity of information on genetics and future cancer risk. Under Hong's typology, this corresponds with the uncertainty about understanding genetic risk and uncertainty about future risk. A similar percentage of respondents (45%) expressed a need for understanding what results mean for screening which corresponds with the type of uncertainty regarding the consequences of testing. Over one-third of respondents would find general information on genetic mutations, additional sources of information, more discussion with genetic counselors, and informational pamphlets useful, which again addresses probability and complexity of genetic information. Another concern voiced by one-third of the respondents was uncertainty about health insurance coverage which also touches upon the consequences of testing. Fewer participants endorsed the need for referral to support groups or psychological support and almost 11% found none of the listed information sources useful. These findings about information needs are consistent with a recent study that found over half of patients who had received genetic counseling in a medical setting also reported seeking out additional information [33].

Many of potential information needs described in Table 3 center around the complexity of genetic risk information and the probabilistic nature of risk estimates. Knowledge about genetics and cancer risk is poor even among medical experts and well-educated persons [14] and few topic areas as complex as genetics and cancer risk are likely to be understood with a one-time 'training experience.' Ongoing surveillance for cancer among high-risk patients might provide an opportunity to revisit and update both family history information and reinforce knowledge about genetic risk. Cancer risk changes with additional diagnoses of cancer among family members signaling the need for additional genetic counseling and modification of prevention efforts. Uncertainty management then becomes an iterative process of interaction between healthcare providers and patients [34, 35]. How this can be carried out is likely to depend on the setting where genetic counseling takes place. Adding additional genetic counseling support via telephone contact was found to increase family communication among high-risk patients [36]. In addition, access to communication options such as web-based platforms, apps, or software conversation tools that can be regularly accessed may increase knowledge of genetic inheritance in some populations [37]. Including multiple healthcare providers across visits may also aid in communicating uncertain and complex information [38]. These information sources become more important with the increased use of direct-to-consumer genetic testing services.

Management of uncertainty may require more than filling knowledge gaps [32]. Medical decisions are often made within, and guided by, the framework of lived experiences of cancer in the family [39, 40]. Many people's understandings of heredity are grounded in social relationships—i.e., their concepts of kinship and closeness with relatives, and this understanding often differs from that of genetic counselors and other healthcare providers—a mismatch that can hinder truly informed decision-making [17, 41]. Reuter et al. found that patients view VUS results through their own experience based on their family's history and assign significance where there is uncertainty [42]. Objectively understood genetic inheritance has the potential to redefine aspects of family and kinship by linking close and distant relatives that may not be socially linked and by defining relatives by disorders rather than emotional kinship ties [43]. Integrating the objective and lived experiential understanding of inheritance could serve to facilitate informed decision making [39]. A framework that elicits patient's values and concerns can lead to a consensus between patients and providers about goals and shared decision regarding risk management [38].

We note several limitations that may limit the generalizability of our results. Using social media for recruitment yields a non-probability sample of unknown representativeness of the true sample of individuals having had genetic testing for cancer risk. Another limitation is that we could not validate by medical records whether participants received genetic counseling. However, we did exclude from analysis those who responded "other" to type of genetic testing. We also did not have details on the content of the counseling experience or when respondents underwent counseling and did not ask whether participants underwent multigene panel testing. Our sample included few men and participation among non-Hispanic Black persons and Hispanic persons was low. In addition, 70% of the participants

in our sample were college graduates or had post graduate education. Our sample was limited to individuals present on one of the social media sites where ads appeared and who were shown one of the ads. Individuals who were online at the time of the ad postings, spend greater amounts of time on social media, and had faster connection speeds were more likely to be shown one of the targeted recruitment ads. In addition, the survey required access to a computer or mobile device with internet access, both for recruitment and survey completion. Finally, as the survey was only offered in English, participation was limited to those with competent English proficiency.

## Conclusion

Despite research demonstrating the positive relationship between genetic counseling and knowledge about genetics [44, 45], our results indicate an ongoing need for information on what testing results mean for individuals and their families. Consistent with qualitative research on genetic counseling, [25] our research also suggests that measures of satisfaction with the genetic counseling may not give a full picture of the patient-provider interaction and may miss potential unmet information needs of the patient.

Uncertainty is an inherent part of being at a high risk of developing cancer [46] and current genomic technologies are unlikely to reduce it. Participants in our study expressed the need for additional information about future cancer risk, cancer risk reduction, and most often, what genetic testing results mean for family members—topics typically covered during genetic counseling. Accessible resources and ongoing opportunities for updating family history information could reinforce knowledge about genetic risk, as could strategies to incorporate the lived experience of cancer into discussions with healthcare providers.

**Author contributions** Lucy A. Peipins: conceptualization, methodology, investigation, writing—original draft, writing—review & editing. Sabitha Dasari: formal analysis, data curation, writing—review & editing. Melissa Viox Heim: investigation, resources, data curation, writing—review & editing. Juan L. Rodriguez: conceptualization, investigation, methodology, project administration, funding acquisition, writing—review & editing.

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**Data availability** To protect the privacy of the participants, data regarding this study is not publicly available. Data may be provided upon request in aggregate form.

## Declarations

**Conflict of interest** The authors have no conflicts of interest to declare.

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