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Health Beliefs Associated with Readiness for Genetic Counseling among High Risk Breast Cancer Survivors

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Abstract

Purpose: Uptake of genetic counseling among breast cancer survivors is low. We used the Health Belief Model (HBM) to explore factors associated with readiness for genetic counseling among breast cancer survivors.

Methods: Breast cancer survivors meeting NCCN genetic counseling referral criteria were recruited through clinics and community settings. Participants completed questionnaires capturing demographic and clinical information and factors guided by the HBM, including health beliefs, psychosocial variables, and cues to action. Using logistic regression, we examined whether the above variables differed based on readiness group (pre-contemplators, who did not plan to make a genetic counseling appointment, and contemplators, who planned to make a genetic counseling appointment in the next 1– 6 months).

Results: Of 111 participants, 57% were pre-contemplators and 43% were contemplators. In the multivariable model, higher cancer worry was associated with increased odds of being a contemplator (OR=2.99; 95% CI=1.37–6.54) and higher perceived barriers to genetic counseling were associated with decreased odds of being a contemplator (OR=0.31; 95% CI= 0.11–0.85). Those who reported a family member encouraged them to get tested were more likely to be contemplators (OR=3.57; 95% CI=1.19– 10.70).

Conclusions: Our results suggest key factors for predicting genetic counseling readiness include cancer worry, perceived barriers, and family influence.

Implications for Cancer Survivors: Ideally genetic counseling occurs prior to treatment, but significant advantages exist for survivors. There is need for increased genetic counseling awareness. Better understanding of factors related to survivors' decisions about counseling can inform tailored interventions to improve uptake and ultimately reduce cancer recurrence risk.

Keywords

Breast cancer; genetic counseling; health behavior; health belief model; stages of change

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Introduction

An estimated 16% of all new primary cancers diagnosed in the U.S. occur in cancer survivors [1]. In particular, female breast cancer survivors with a *BRCA* mutation have an increased risk of future cancer compared to patients without a *BRCA* mutation [2–6]. Diagnosis is the optimal time to identify, counsel, and test breast cancer patients at increased risk for hereditary cancer; however, available data suggest genetic counseling and/or genetic testing are underutilized during this time [7–10]. Thus, the survivorship care setting represents an important opportunity to provide genetic counseling and genetic testing for women at risk for hereditary cancer, and ultimately reduce the risk of second primary cancers in breast cancer patients [11].

The American Society of Clinical Oncology Breast Cancer Survivorship Plan includes genetic counseling referral for breast cancer patients with hereditary cancer risk factors. Genetic counseling provides education and counseling about hereditary breast and ovarian cancer and the process, risk and benefits of genetic testing [12]. Studies found breast cancer patients who attend genetic counseling have increased knowledge about cancer genetics, improved risk perception accuracy, and reduced anxiety and cancer related distress [13, 14]. Although the patient is responsible for the decision to engage in a health care consultation, our team and others found patients chose not to attend genetic counseling based on incomplete knowledge (e.g., misperceptions about genetic counseling/testing processes), inaccurate health beliefs (e.g., perceived susceptibility, benefits or barriers), and psychosocial factors (e.g., feeling overwhelmed with the cancer diagnosis) [8, 15–17].

The Health Belief Model postulates that people will take action if they perceive: the illness is serious (perceived severity); personal risk for the illness (perceived susceptibility); and actions taken to control the illness are effective (perceived benefits) relative to the impediments (perceived barriers) [18]. Exposure to factors that prompt action (cues to action); belief they can successfully perform the actions to control the illness (self-efficacy); and psychosocial factors (e.g., distress) may also facilitate behavior change [18–20]. In the current study, we used the HBM to explore factors associated with readiness for genetic counseling at baseline among breast cancer survivors. Participants were recruited to participate in a two-arm pilot randomized controlled trial of a psychoeducational educational intervention [21] to promote readiness for genetic counseling among breast cancer survivors.

Methods

Participants

Participant eligibility was based on 2014 National Comprehensive Cancer Network criteria for referral to a genetics professional [22]. Specifically, breast cancer survivors ≥ 18 years of age who (1) completed surgical treatment; (2) did not previously have genetic counseling; (3) had a personal diagnosis of breast cancer at or below age 50, have >2 female relatives with breast cancer, have any male relative with breast cancer, ***and/or***, any relative with ovarian cancer, (4) no documented or observable psychiatric or neurological disorders that would interfere with study participation (e.g., dementia, psychosis); (5) capable of speaking and reading standard English; (6) provided written informed consent for study participation;

and (7) had a mailing address and working telephone number. Participants were recruited through multiple sources, including an institutional cancer genetics referral database, a press release, and study fliers posted at local clinics and community settings.

Procedure

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards; the study was approved by the Chesapeake Institutional Review Board. Eligible patients were sent an introductory letter and a response form that included a toll-free contact number and email for individuals to opt out of study participation. Those who did not contact the team within two weeks were called and provided a brief study description. Interested women were screened for study eligibility and consented. Participants received a $40.00 gift card upon completion of the baseline questionnaire via paper, Internet, or by telephone.

Measures

In addition to demographic and clinical information, participants completed measures on readiness for genetic counseling, genetic counseling knowledge, and factors guided by the Health Belief Model, including health beliefs, cues to action, and psychosocial variables.

Readiness for Genetic Counseling.—The Transtheoretical Model of Health Behavior Change is a widely-used model that suggests that individuals who engage in health behavior change progress through six stages of change: pre-contemplation, contemplation, preparation, action, maintenance, and termination. Approximately 80% of at-risk populations are expected to be in pre-contemplation or contemplation stages [23]. Participants in our study reported whether they planned to make a genetic counseling appointment, and were asked an open-ended question about why they had not participated in genetic counseling. Similar to prior approaches examining stages of readiness for genetic counseling [17, 24], we used participants' reports of whether they planned to make a genetic counseling appointment to categorize those in pre-contemplation (did not plan to make an appointment) and those who were in contemplation (did plan to make an appointment in the next 1–6 months, but had not yet done so) stages.

Genetic Counseling Knowledge.—Knowledge was assessed using a 9-item validated scale developed for the current study and informed by our prior work [14, 21, 25]. Participants were asked to indicate their responses to statements such as, "I can only have genetic counseling if I know my family's health history" using "true," "false," or "don't know." Participants were given 1 point for each correct response and items were summed to create an overall knowledge score (range: 0–9).

Health Beliefs.—*Perceived Risk* was assessed using a single item [26], ''On a scale from 0 to 100, where 0 is no chance at all and 100 is absolutely certain, what do you think are the chances that you will get breast cancer sometime during your lifetime?'' *Perceived Susceptibility* and *Perceived Severity* were assessed using adapted subscales of Champion's Health Belief Model Scale [27]. All items were rated on a 5-point Likert-type scale where

lower scores indicate less perceived susceptibility/severity. The susceptibility subscale consisted of 5-items relevant to perceived chance of recurrence (Cronbach's alpha=0.84, potential range=5–25) and the severity subscale included of 2 items related to the potential impact of a recurrence on one's life (Cronbach's alpha=0.81, potential range=2–10). *Perceived Benefits* and *Perceived Barriers* to Genetic Counseling were assessed using subscales of a 20-item scale developed for the current study. All items were rated on a 5-point Likert-type scale where lower scores indicate less perceived benefit/barrier. The benefits subscale consists of 6-items relevant to learning about risks and informing decision-making (Cronbach's alpha=0.84) and the barriers subscale consists of 13-items relevant to emotional or financial costs as well as practical barriers, such as time (Cronbach's alpha=0.78). *Perceived Self-Efficacy* was assessed using an adapted version of the 5-item Champion Self Efficacy scale [28]. All items are rated on a 5-point Likert-type scale where lower scores indicate less self-efficacy (Cronbach's alpha=0.56).

Cues to Action.—*Provider Encouragement of Genetic Counseling* was assessed by asking participants to indicate their perception about whether their doctor wanted them to have genetic counseling. This item was rated on a 5-point scale (plus an option for "not applicable") where lower scores indicated that the participant believed the doctor did not want them to be tested. *Cancer Family History* was assessed by asking whether participants knew the medical history of one or both biological parents. For those reported "yes," we asked participants to identify whether any first-degree relatives (e.g. parents, siblings, children) were diagnosed with breast, pancreatic, prostate cancer, melanoma, or other cancer types. *Family Encouragement* of *Genetic Counseling* was assessed by providing a list of family members (including spouse, siblings, children) and asking participants to indicate on a scale of 1–5 (1 = strongly disagree to 5 = strongly agree) the degree to which family members want/ed them to have genetic counseling. Responses to this item were not normally distributed across the five-item range. Therefore, we dichotomized this variable; if participants indicated "strongly agree or agree" for at least one family member, this variable was coded as "yes."

Psychosocial Variables.—*Cancer Worry* was assessed by the 3-item Lerman Cancer Worry Scale (Cronbach's alpha=0.81) [29]. This scale is widely-used and designed to assess the impact of cancer worry on mood and daily functioning. Items are rated on a 4-point Likert-type scale in which lower scores indicate lower levels of worry (potential range=4–12). *Intrusiveness* (Cronbach's alpha=0.91) and *Avoidance* (Cronbach's alpha=0.85) were assessed as subscales of the 15-item Impact of Events Scale (IES) [30]. Items were rated on a 4-point Likert-type scale where lower overall scores indicate lower subjective distress. The intrusiveness subscale has 7 items such as, "I thought about it when I didn't mean to." The avoidance subscale has 8 items such as, "I tried not to talk about it."

Open Ended Responses.—Participants also were asked to write in a response to the following: "Please briefly explain why you have not attended genetic counseling."

Analysis

Data were summarized with descriptive statistics using SPSS version 24. We examined whether the demographic, clinical, and HBM variables differed based on readiness group (pre-contemplators and contemplators) using simple logistic regression to compare pre-contemplators and contemplators on all factors separately. We subsequently entered all variables into a multiple logistic regression model with a significance level of 0.1 to remain in the model. Because *intrusiveness* and *avoidance* are both subscales of the IES, only the two subscales and not the total IES score were included in the model to account for the multicollinearity between the scales. Notably, we examined the effect on the final model if we had instead dropped the subscales and kept the IES total scale instead and the final model did not change.

Results

Of the 233 women screened for eligibility, 146 met eligibility criteria, and 119 (81%) enrolled and completed a baseline questionnaire. One participant was excluded from the current analysis due to a scheduled genetic counseling appointment at baseline. Seven participants did not complete the readiness question, resulting in a sample of 111 for this analysis. As seen in Table 1, the majority of participants were non-Hispanic (n=104; 96%) White (n=102; 92%), married (n=61; 55%), and the average age was 62.9 (SD=10.5) with varying education, employment status, income, insurance, and cancer stage at diagnosis. Within our sample, 48 (43%) were contemplators and 63 (57%) were pre-contemplators.

Comparison between Pre-Contemplator and Contemplator Breast Cancer Survivors

Simple and multiple logistic regression results can both be found in Table 2. In univariable analyses, age was the only demographic variable associated with readiness and odds of being a contemplator decreased with increasing age (OR=0.96; 95% CI=0.93–0.99). There was no difference in genetic counseling knowledge between groups, but knowledge overall was relatively low; participants answered an average of 55% of true/false questions about genetic counseling correctly. We found no significant differences in contemplator and pre-contemplators' perceived risk or susceptibility for cancer. However, severity of breast cancer (OR=1.62; 95% CI=1.09–2.39), cancer worry (OR=2.33; 95% CI=1.25–4.34) and intrusive thoughts related to breast cancer (OR=1.06; 95% CI=1.01–1.11) were all positively associated with the odds of being a contemplator. The odds of being in the contemplator group increased with increasing benefits (OR=1.82; 95% CI=1.07–3.09) but decreased with increasing reported barriers (OR=0.46; 95% CI= 0.24–0.91).

Only three variables remained in the final multivariable model: cancer worry, the HBM construct of perceived barriers to genetic counseling, and the cues to action from family member encouragement. Higher cancer worry was associated with increased odds of being a contemplator (OR=2.99; 95% CI=1.37–6.54) and higher perceived barriers were associated with decreased odds of being a contemplator (OR=0.31; 95% CI= 0.11–0.85). As in univariable analysis, those who reported a family member encouraged them to get tested were more likely to be contemplators in the multivariable model (OR=3.57; 95% CI=1.19–10.70).

In analyzing differences in cues to action from the provider, we found no significant differences in perception of provider encouragement between groups. However, this may be due to the low level of provider communication about genetic counseling. Half of participants overall (50.5%) were neutral in their agreement that their provider wanted them to get genetic counseling. Responses to the open-ended question about why individuals hadn't participated in genetic counseling revealed many women simply didn't know about genetic counseling or reported it was never recommended by a physician. Typical responses to this question included:

> I was not offered counseling nor did I know it was offered where I was receiving care.

> Doctors never mentioned it to me and I never thought of it myself.

In analyzing differences in cues to action from the family, we found no significant differences in awareness of a family history of cancer. Overall, the number of participants indicating family members wanted them to get testing was low (32.1%). But those who did report a family member encouraged them to get tested were almost three times as likely to be in the contemplation stage (OR=2.77; 95% CI= 1.21–6.34). The potential influence of family members on survivors' decisions about genetic counseling was also apparent in responses to the open-ended question about why individuals hadn't participated in genetic counseling. While none of the participants discussed how their family had encouraged testing, it was clear that lack of perceived interest in genetic counseling or support from their families was a deterrent. For example, many participant responses to our open-ended question about why they had not pursued genetic counseling included a lack of family support:

> I have no children. I have a sister and cousins so I considered it, but in the end no one in my family thought it was a good idea.

> [I have not gotten the test] partly [because of] confusion about whether this would really help me and partly lack of support from family.

> My daughters don't want to know anything and I don't want to upset their lives.

Discussion

Genetic counseling provides an opportunity for breast cancer survivors to learn more about their risks for new primary cancers, and improve their outcomes, including reducing anxiety and cancer related distress [13]. In this study, we explored factors related to the Health Belief Model that may impact breast cancer survivors' readiness to engage in genetic counseling. This study is one of the few to investigate the differences between groups at different stages of contemplation prior to receiving genetic counseling, rather than comparing those who had received and not received genetic counseling [17, 31]. Of those who had not received genetic counseling, more women were in the pre-contemplation phase than the contemplation phase. Contemplators in this study were younger, but no other demographic differences were found between groups. A recent systematic review of factors associated with uptake of genetic counseling for hereditary cancers suggested a positive

association between genetic counseling uptake and education, SES and marital status, but these findings were inconsistent across studies included in the review [32].

We also found that knowledge about genetic counseling was low. Many are unaware of or have inaccurate ideas about the process, purpose, or benefits of genetic counseling. This is consistent with ther research demonstrating genetic counseling knowledge is often low in the general population and non-genetics providers [33, 34].

Health belief and affective factors played an important role in distinguishing pre-contemplators from contemplators. While perceived risk and susceptibility did not predict readiness, more breast cancer worry predicted a higher likelihood for contemplation rather than pre-contemplation. Our results suggest that both affective responses (i.e., worry) and a perceived clear path to achieve a solution (i.e. lack of barriers) may be important to progress towards behavior change. This is echoed in previous research related to genetic counseling that found that both psychosocial variables and perceived barriers were important factors for behavior change [35]. For example, though an explicit categorization into readiness stage was not done in these other studies; intention to engage in genetic counseling was related to lower perceived barriers to counseling and higher levels of concern about cancer in two ethnically diverse samples [36, 37]. In both these studies, as well as other research on genetic counseling uptake in breast cancer survivors [19, 38], participants' perception of their family's wishes and family dynamics also played an important role in their decision.

In our study, while a family member encouraging testing significantly predicted a higher likelihood to be in the contemplation stage, provider encouragement did not significantly predict stage of change. However, participants in our study reported low percentages of interpersonal encouragement from both family and providers. We and others have found that provider referral is a strong predictor of genetic counseling, but referral to genetic counseling is often low [7, 39, 40], despite national guidelines [41]. Most women in our study said their provider didn't mention genetic counseling as an option. Our qualitative findings suggest that the lack of perceived family interest or support may be an important reason why survivors do not pursue genetic counseling. For example, participants reported feeling that if no one in their family was interested or could benefit, genetic counseling wasn't worth pursuing. This perception may in fact be preventing family members from engaging in protective health behaviors that can ultimately reduce their cancer risk [42, 43]. Together these findings reinforce the need for genetic education for providers, survivors, and family members. This also suggests that multiple opportunities to discuss health behaviors, including genetic counseling, should be implemented to provide opportunities to discuss and revisit decisions.

While this study is one of the first to describe readiness for genetic counseling among breast cancer survivors, some limitations exist. Although participants hadn't engaged in genetic counseling, they were willing to participate in a study about genetic counseling. This may suggest that even our pre- contemplation group might be more open to genetic counseling than the general population. Additionally, our study had a relatively small sample and though there was high variability in income and education, there was little racial diversity. Further, it is possible differences are more apparent across a range of stages of change, such

as preparation or action [23]; comparing groups of women who had not engaged in genetic counseling may be more similar to each other than comparing women who had and had not engaged in genetic counseling. Finally, other factors that may be relevant to readiness, such as coping strategies or styles were not assessed.

There is a need to understand the benefits and barriers for breast cancer survivors in engaging in genetic counseling, which is increasingly important for survivorship care as technology advances. This study identifies factors that may influence at-risk women's readiness to receive genetic counseling. A better understanding of how survivors' perceptions of the pros and cons associated with breast cancer and genetic counseling may provide clues to more tailored interventions. This study also highlights the need to encourage more discussion about what genetic counseling is and what it can do among providers, patients, and family members. The findings underline the ongoing value of education delivered at various points during survivorship to prompt such conversations. Meeting the specific needs of women based on readiness for genetic counseling may increase uptake and ultimately reduce risk of secondary and new primary cancers.

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References

1. Travis LB. The epidemiology of second primary cancers. Cancer Epidemiol Biomarkers Prev 2006;15(11):2020–6. [PubMed: 17057028]
2. Graeser MK, Engel C, Rhiem K, Gadzicki D, Bick U, Kast K, et al. Contralateral breast cancer risk in BRCA1 and BRCA2 mutation carriers. J Clin Oncol 2009;27(35):5887–92 [PubMed: 19858402]
3. Malone KE, Begg CB, Haile RW, Borg A, Concannon P, Tellhed L, et al. Population- Based Study of the Risk of Second Primary Contralateral Breast Cancer Associated With Carrying a Mutation in BRCA1 or BRCA2. J Clin Oncol
4. Metcalfe K, Lynch HT, Ghadirian P, Tung N, Olivotto I, Warner E, et al. Contralateral breast cancer in BRCA1 and BRCA2 mutation carriers. J Clin Oncol 2004;22(12):2328–35. [PubMed: 15197194]
5. Metcalfe KA, Lynch HT, Ghadirian P, Tung N, Olivotto IA, Foulkes WD, et al. The risk of ovarian cancer after breast cancer in BRCA1 and BRCA2 carriers. Gynecol Oncol 2005;96(1):222–6. [PubMed: 15589605]
6. Kuchenbaecker KB, Hopper JL, Barnes DR, et al. Risks of breast, ovarian, and contralateral breast cancer for brca1 and brca2 mutation carriers. JAMA 2017;317(23):2402–16. [PubMed: 28632866]
7. Jagsi R, Griffith KA, Kurian AW, Morrow M, Hamilton AS, Graff JJ, et al. Concerns about cancer risk and experiences with genetic testing in a diverse population of patients with breast cancer. J Clin Oncol 2015;33(14):1584–91. [PubMed: 25847940]
8. Kurian AW, Griffith KA, Hamilton AS, Ward KC, Morrow M, Katz SJ, et al. Genetic Testing and Counseling Among Patients With Newly Diagnosed Breast Cancer. JAMA 2017;317(5):531–4. [PubMed: 28170472]
9. Levy DE, Byfield SD, Comstock CB, Garber JE, Syngal S, Crown WH, et al. Underutilization of BRCA½ testing to guide breast cancer treatment: Black and Hispanic women particularly at risk. Genetics in medicine : official journal of the American College of Medical Genetics 2011;13(4): 349–55. [PubMed: 21358336]

10. Cragun D, Weidner A, Lewis C, Bonner D, Kim J, Vadaparampil ST, et al. Racial disparities in BRCA testing and cancer risk management across a population-based sample of young breast cancer survivors. Cancer 2017.
11. Ruddy KJ, Risendal BC, Garber JE, Partridge AH. Cancer Survivorship Care: An Opportunity to Revisit Cancer Genetics. Journal of Clinical Oncology 2016;34(6):539–41. [PubMed: 26712228]
12. Braithwaite D, Emery J, Walter F, Prevost AT, Sutton S. Psychological impact of genetic counseling for familial cancer: a systematic review and meta-analysis. J Natl Cancer Inst 2004;96(2):122–33. [PubMed: 14734702]
13. Madlensky L, Trepanier AM, Cragun D, Lerner B, Shannon KM, Zierhut H. A Rapid Systematic Review of Outcomes Studies in Genetic Counseling. J Genet Couns 2017.
14. Scherr CL, Christie J, Vadaparampil ST. Breast cancer survivors' knowledge of hereditary breast and ovarian cancer following genetic counseling: an exploration of general and survivor-specific knowledge items. Public health genomics 2016;19(1):1–10.
15. Kne A, Zierhut H, Baldinger S, Swenson KK, Mink P, Veach PM, et al. Why Is Cancer Genetic Counseling Underutilized by Women Identified as at Risk for Hereditary Breast Cancer? Patient Perceptions of Barriers Following a Referral Letter. J Genet Couns 2016.
16. Vadaparampil ST, Quinn GP, Miree CA, Brzosowicz J, Carter B, Laronga C. Recall of and reactions to a surgeon referral letter for BRCA genetic counseling among high-risk breast cancer patients. Ann Surg Oncol 2009;16(7):1973–81. [PubMed: 19408048]
17. O'Neill SM, Peters JA, Vogel VG, Feingold E, Rubinstein WS. Referral to cancer genetic counseling: are there stages of readiness? Am J Med Genet C Semin Med Genet 2006;142C(4): 221–31. [PubMed: 17068804]
18. Janz NK, Champion VL, Strecher VJ, editor. The Health Belief Model San Francisco, CA: Jossey-Bass; 2002.
19. Biesecker BB, Ishibe N, Hadley DW, Giambarresi TR, Kase RG, Lerman C, et al. Psychosocial factors predicting BRCA1/BRCA2 testing decisions in members of hereditary breast and ovarian cancer families. Am J Med Genet 2000;93(4):257–63. [PubMed: 10946349]
20. Lerman C, Schwartz MD, Lin TH, Hughes C, Narod S, Lynch HT. The influence of psychological distress on use of genetic testing for cancer risk. J Consult Clin Psychol 1997;65(3):414–20. [PubMed: 9170764]
21. Scherr CL, Nam K, Augusto B, Kasting ML, Caldwell M, Lee MC, Meade CD, Pal T, Quinn GP, & Vadaparampil ST Assessment of a narrative intervention to promote genetic counseling for breast cancer survivors. Under review
22. Daly MB, Pilarski R, Axilbund JE, Buys SS, Crawford B, Friedman S, et al. Genetic/familial high-risk assessment: breast and ovarian, version 1.2014. J Natl Compr Canc Netw 2014;12(9):1326–38. [PubMed: 25190698]
23. Prochaska JO, Velicer WF. The Transtheoretical Model of Health Behavior Change. American Journal of Health Promotion 1997;12(1):38–48. [PubMed: 10170434]
24. Jacobsen PB, Valdimarsdottier HB, Brown KL, Offit K. Decision-making about genetic testing among women at familial risk for breast cancer. Psychosom Med 1997;59(5):459–66. [PubMed: 9316177]
25. Vadaparampil ST, Malo TL, Nam KM, Nelson A, de la Cruz CZ, Quinn GP. From Observation to Intervention: Development of a Psychoeducational Intervention to Increase Uptake of BRCA Genetic Counseling Among High-Risk Breast Cancer Survivors. Journal of cancer education : the official journal of the American Association for Cancer Education 2014.
26. Lipkus IM, Kuchibhatla M, McBride CM, Bosworth HB, Pollak KI, Siegler IC, et al. Relationships among breast cancer perceived absolute risk, comparative risk, and worries. Cancer Epidemiol Biomarkers Prev 2000;9(9):973–5. [PubMed: 11008917]
27. Champion VL. Revised susceptibility, benefits, and barriers scale for mammography screening. Res Nurs Health 1999;22(4):341–8. [PubMed: 10435551]
28. Champion V, Skinner CS, Menon U. Development of a self-efficacy scale for mammography. Res Nurs Health 2005;28(4):329–36. [PubMed: 16028267]

29. Lerman C, Trock B, Rimer BK, Boyce A, Jepson C, Engstrom PF. Psychological and behavioral implications of abnormal mammograms. Ann Intern Med 1991;114(8):657–61. [PubMed: 2003712]
30. Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. Psychosom Med 1979;41(3):209–18. [PubMed: 472086]
31. Ropka ME, Wenzel J, Phillips EK, Siadaty M, Philbrick JT. Uptake rates for breast cancer genetic testing: a systematic review. Cancer Epidemiol Biomarkers Prev 2006;15(5):840–55. [PubMed: 16702359]
32. Willis AM, Smith SK, Meiser B, Ballinger ML, Thomas DM, Young MA. Sociodemographic, psychosocial and clinical factors associated with uptake of genetic counselling for hereditary cancer: a systematic review. Clinical Genetics 2016:
33. Hamilton JG, Abdiwahab E, Edwards HM, Fang M-L, Jdayani A, Breslau ES. Primary care providers' cancer genetic testing-related knowledge, attitudes, and communication behaviors: A systematic review and research agenda. Journal of General Internal Medicine 2017;32(3):315–24. [PubMed: 27995427]
34. Maio M, Carrion P, Yaremco E, Austin JC. Awareness of Genetic Counseling and Perceptions of its purpose: a survey of the Canadian public. Journal of genetic counseling 2013;22(6):10.1007/s10897-013-9633-z.
35. Prochaska JO, Velicer WF, Rossi JS, Goldstein MG, Marcus BH, Rakowski W, et al. Stages of change and decisional balance for 12 problem behaviors. Health Psychol 1994;13(1):39–46. [PubMed: 8168470]
36. Cappelli M, Surh L, Humphreys L, Verma S, Logan D, Hunter A, et al. Psychological and social determinants of women's decisions to undergo genetic counseling and testing for breast cancer. Clin Genet 1999;55(6):419–30. [PubMed: 10450858]
37. Thompson HS, Valdimarsdottir HB, Duteau-Buck C, Guevarra J, Bovbjerg DH, Richmond-Avellaneda C, et al. Psychosocial predictors of BRCA counseling and testing decisions among urban African-American women. Cancer Epidemiol Biomarkers Prev 2002;11(12):1579–85. [PubMed: 12496047]
38. Schlich-Bakker KJ, ten Kroode HF, Warlam-Rodenhuis CC, van den Bout J, Ausems MG. Barriers to participating in genetic counseling and BRCA testing during primary treatment for breast cancer. Genet Med 2007;9(11):766–77. [PubMed: 18007146]
39. Bellcross CA, Leadbetter S, Alford SH, Peipins LA. Prevalence and healthcare actions of women in a large health system with a family history meeting the 2005 USPSTF recommendation for BRCA genetic counseling referral. Cancer Epidemiol Biomarkers Prev 2013;22(4):728–35. [PubMed: 23371291]
40. Cragun D, Weidner A, Lewis C, Bonner D, Kim J, Vadaparampil ST, et al. Racial disparities in BRCA testing and cancer risk management across a population-based sample of young breast cancer survivors. Cancer 2017;123(13):2497–505. [PubMed: 28182268]
41. Stuckey A, Febbraro T, Laprise J, Wilbur JS, Lopes V, Robison K. Adherence Patterns to National Comprehensive Cancer Network Guidelines for Referral of Women With Breast Cancer to Genetics Professionals. American Journal of Clinical Oncology 2016;39(4):363–7. [PubMed: 24710121]
42. Aspinwall LG, Taber JM, Kohlmann W, Leaf SL, Leachman SA. Unaffected family members report improvements in daily routine sun protection 2 years following melanoma genetic testing. Genet Med 2014;16(11):846–53. [PubMed: 24763292]
43. Taber JM, Aspinwall LG, Stump TK, Kohlmann W, Champine M, Leachman SA. Genetic test reporting enhances understanding of risk information and acceptance of prevention recommendations compared to family history-based counseling alone. Journal of Behavioral Medicine 2015;38(5):740–53. [PubMed: 26178773]

Table 1.

Participant Demographic, Clinical and HBM Related Variables by Readiness for Genetic Counseling

	Total (*n*=111)	Pre-contemplation (*n*=63)	Contemplation (*n*=48)
Demographics/Clinical			
Age	62.2 (10.8)	64.68 (10.33)	60.60 (10.45)
Hispanic			
Yes	4 (3.7)	3 (4.8)	1 (2.2)
No	104 (96.3)	59 (95.2)	45 (97.8)
Race			
White	102 (91.9)	58 (92.1)	44 (91.7)
Black	3 (2.7)	0 (0.0)	3 (6.3)
Other	6 (5.4)	5 (7.9)	1 (2.1)
Marital status			
Single	6 (5.4)	3 (4.8)	3 (6.3)
Married/Domestic Partner/Other	61 (55.0)	35 (55.6)	26 (54.2)
Divorced/Separated	26 (23.4)	15 (23.8)	11 (22.9)
Widowed	18 (16.2)	10 (15.9)	8 (16.7)
Education			
Up to GED/Diploma	26 (23.4)	13 (20.6)	13 (27.1)
Some college	35 (31.5)	21 (33.3)	14 (29.2)
College grad or beyond	50 (45.0)	29 (46.0)	21 (43.8)
Employment status			
Not employed	13 (11.9)	7 (11.1)	6 (13.0)
Employed	46 (42.2)	27 (42.9)	19 (41.3)
Retired/other	50 (45.9)	29 (46.0)	21 (45.7)
Income			
$0–34,999	41 (38.7)	26 (43.3)	15 (32.6)
$35,000–74,999	40 (37.7)	23 (38.3)	17 (37.0)
$75,000+	25 (23.6)	11 (18.3)	14 (30.4)
Insurance			
Private	58 (53.7)	34 (56.7)	24 (50.0)
Public	50 (46.3)	26 (43.3)	24 (50.0)
Stage at diagnosis			
DCIS	20 (18.2)	11 (17.7)	9 (18.8)
Stage 1	26 (23.6)	18 (29.0)	8 (16.7)
Stage 2	35 (31.8)	17 (27.4)	18 (37.5)
Stage 3	11 (10.0)	7 (11.3)	4 (8.3)
Stage 4	5 (4.5)	3 (4.8)	2 (4.2)
Don't know	13 (11.8)	6 (9.7)	7 (14.6)
Ever heard of genetic counseling			

	Total (*n*=111)	Pre-contemplation (*n*=63)	Contemplation (*n*=48)
Yes	88 (79.3)	51 (81.0)	37 (77.1)
No	21 (18.9)	10 (15.9)	11 (22.9)
Don't know	2 (1.8)	2 (3.2)	0 (0.0)
Health Beliefs			
Mean perc. susceptibility	3.07 (0.85)	2.94 (0.94)	3.24 (0.65)
Mean perc. severity	3.26 (1.06)	3.07 (1.11)	3.57 (0.92)
Mean perc. risk (1–100)	39.93 (29.0)	38.03 (28.14)	42.73 (29.65)
Mean perc. benefits	3.75 (0.82)	3.58 (0.81)	3.96 (0.83)
Mean perc. barriers	2.74 (0.62)	2.88 (0.61)	2.61 (0.59)
Mean perc. self-efficacy	3.84 (0.52)	3.83 (0.56)	3.90 (0.43)
Mean decisional conflict	3.54 (0.64)	3.68 (0.59)	3.43 (0.64)
Psychosocial Factors			
IES (total)	19.96 (16.52)	16.41 (16.34)	23.98 (16.20)
IES (intrusive subscale)	8.32 (8.71)	6.26 (7.67)	10.43 (9.47)
IES (avoidance subscale)	11.54 (9.37)	10.08 (9.61)	13.44 (9.17)
Mean cancer worry	1.93 (0.69)	1.76 (0.67)	2.12 (0.64)
Cues to Action			
Aware of parents' history			
No, don't know either	6 (5.4)	3 (4.8)	3 (6.3)
Yes, mother and father	95 (85.6)	53 (84.1)	42 (87.5)
Yes, mother only	10 (9.0)	7 (11.1)	3 (6.3)
Yes, father only	0 (0.0)	0 (0.0)	0 (0.0)
Any family member encourages genetic counseling			
No	74 (67.9)	48 (77.4)	26 (55.3)
Yes	35 (32.1)	14 (22.6)	21 (44.7)
Having FDR with *BRCA*			
Male breast cancer	2 (1.8)	0 (0.0)	2 (4.2)
Male melanoma	13 (11.7)	8 (12.7)	5 (10.4)
Male pancreatic cancer	4 (3.6)	2 (3.2)	2 (4.2)
Male prostate cancer	22 (19.8)	14 (22.2)	8 (16.7)
Male other	34 (30.6)	23 (36.5)	11 (22.9)
Female breast cancer	45 (40.5)	30 (47.6)	15 (31.3)
Female melanoma	14 (12.6)	7 (11.1)	7 (14.6)
Female pancreatic cancer	6 (5.4)	3 (4.8)	3 (6.3)
Female other cancer	42 (37.8)	27 (42.9)	15 (31.3)
HCP wants me to get genetic counseling			
Strongly disagree	8 (7.2)	5 (7.9)	3 (6.3)
Disagree	12 (10.8)	9 (14.3)	3 (6.3)
Neither	56 (50.5)	31 (49.2)	25 (52.1)

	Total (*n*=111)	**Pre-contemplation (*n*=63)**	**Contemplation (*n*=48)**
Agree	16 (14.4)	7 (11.1)	9 (18.8)
Strongly agree	3 (2.7)	3 (4.8)	0 (0.0)
N/A	16 (14.4)	8 (12.7)	8 (16.7)

Table 2.

Regression Analyses Examining the Odds of Being a Contemplator

	unadjusted OR (95% CI)	Best fit model OR (95% CI)
Demographics/ Clinical		
Age	**0.96 (0.93–0.999)**	ǂ
Hispanic		ǂ
Yes	0.44 (0.04–4.34)	
No	(ref)	
Race		ǂ
White	(ref)	
Black	n/a (not enough respondents in this category)	
Other	0.26 (0.03–2.34)	
Marital status		ǂ
Single	(ref)	
Married/Domestic Partner/Other	0.74 (0.14–3.98)	
Divorced/Separated	0.73 (0.12–4.34)	
Widowed	0.80 (0.13–5.09)	
Education		ǂ
Up to GED/Diploma	(ref)	
Some college	0.67 (0.24–1.86)	
College grad or beyond	0.72 (0.28–1.88)	
Employment status		ǂ
Not employed	(ref)	
Employed	0.82 (0.24–2.83)	
Retired/other	0.85 (0.25–2.88)	
Income		ǂ
$0–34,999	(ref)	
$35,000–74,999	1.28 (0.53–3.13)	
$75,000+	2.21 (0.80–6.08)	
Insurance		ǂ
Private	(ref)	
Public	1.31 (0.61–2.8)	
Stage at diagnosis		ǂ
DCIS	(ref)	
Stage 1	0.54 (0.16–1.83)	
Stage 2	1.29 (0.43–3.90)	
Stage 3	0.70 (0.15–3.17)	
Stage 4	0.82 (0.11–5.99)	
Don't know	1.43 (0.35–5.79)	
Ever heard of GC		ǂ

	unadjusted OR (95% CI)	Best fit model OR (95% CI)
Yes	(ref)	
No	1.52 (0.58–3.94)	
Don't know	n/a (not enough respondents in this category)	
Health Beliefs		
Mean perc. susceptibility	1.57 (0.97–2.56)	ǂ
Mean perc. severity	**1.62 (1.09–2.39)**	ǂ
Mean perc. risk (1–100)	1.01 (0.99–1.02)	ǂ
Mean perc benefits	**1.82 (1.07–3.09)**	ǂ
Mean perc barriers	**0.46 (0.24–0.91)**	0.31 (0.11–0.85)
Mean perc. self-efficacy	1.33 (0.63–2.80)	ǂ
Mean decisional conflict	0.52 (0.27–1.02)	ǂ
Psychosocial Factors		
IES (total)	1.03 (1.00–1.05)	†
IES (intrusive subscale)	**1.06 (1.01–1.11)**	ǂ
IES (avoidance subscale)	1.04 (0.997–1.08)	ǂ
Mean cancer worry	**2.33 (1.25–4.34)**	2.99 (1.37–6.54)
Cues to Action		
Aware of parents' history		ǂ
No, don't know either	(ref)	
Yes, mother and father	0.79 (0.15–4.13)	
Yes, mother only	0.43 (0.05–3.48)	
Yes, father only	n/a (not enough respondents in this category)	
Any family member encourages GC		
No	(ref)	(ref)
Yes	**2.77 (1.21–6.34)**	3.57 (1.19–10.70)
Having FDR with *BRCA*		
Male BC	n/a (not enough respondents in this category)	ǂ
Male melanoma	0.80 (0.24–2.62)	ǂ
Male pancreatic cancer	1.33 (0.18–9.77)	ǂ
Male prostate cancer	0.70 (0.27–1.84)	ǂ
Male other	0.52 (0.22–1.21)	ǂ
Female BC	0.50 (0.23–1.10)	ǂ
Female melanoma	1.37 (0.45–4.20)	ǂ
Female pancreatic cancer	1.33 (0.26–6.92)	ǂ
Female other cancer	0.61 (0.28–1.33)	ǂ
Interpersonal-provider		
HCP wants me to get GC		ǂ
Strongly disagree	(ref)	
Disagree	0.56 (0.08–3.86)	

	unadjusted OR (95% CI)	Best fit model OR (95% CI)
Neither	1.34 (0.29–6.18)	
Agree	2.14 (0.38–12.19)	
Strongly agree	n/a (not enough respondents in this category)	
N/A	1.67 (0.29–9.45)	

† Not included in the model due to multicollinearity

‡ Removed from the model during backward elimination (p<0.1 to remain in the model)