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ORIGINAL RESEARCH

Why Is Cancer Genetic Counseling Underutilized by Women Identified as at Risk for Hereditary Breast Cancer? Patient Perceptions of Barriers Following a Referral Letter

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Abstract Family history information comprises an important tool in identifying and referring patients at risk for hereditary breast and ovarian cancer (HBOC) to cancer genetic counseling. Despite recommendations and support provided by numerous professional organizations, cancer genetic counseling services are underutilized by atrisk patients. This study aimed to: (1) determine the rate of genetic counseling utilization following a referral letter, (2) characterize factors (barriers and supports) which influenced uptake of services, and (3) identify potential strategies for increasing utilization. This study evaluated the uptake of cancer genetic counseling among 603 screening mammography patients identified as having an increased risk for HBOC based on National Comprehensive Cancer Network (NCCN) guidelines. At risk individuals and their primary care providers were mailed a referral letter recommending genetic counseling. Three focus groups (N = 24) were conducted to identify responses to receiving a letter recommending genetic counseling, barriers to seeking genetic counseling, and facilitating factors to utilizing these services. Participant responses were qualitatively analyzed using thematic and cross case analysis. Within one year, 50/603 (8 %) of the identified at-risk women completed a genetic counseling appointment. Participant-perceived barriers which influenced their decision not to seek genetic counseling included lack of relevance and utility, limited knowledge about genetic counseling, concerns about the genetic counseling process, and concerns about cost and insurance coverage. Participant-perceived facilitating factors which would support a decision to seek genetic counseling included greater awareness and education about genetic counseling services when receiving a referral, and improved follow up and guidance from their provider. Findings from this study support the need for patient and primary care provider education, and improved provider-patient communication to increase uptake of genetic counseling services.

Keywords Cancer genetic counseling · Utilization · Hereditary breast and ovarian cancer · Barriers · Supports

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Introduction

Approximately 1 in 8 women will develop breast cancer in their lifetime, and in 2016 an estimated 246,660 women will be newly diagnosed in the United States (Howlader et al. 2014; Siegel et al. 2016). While the majority of cancer appears sporadic, between 5 and 10 % of these diagnoses may be caused by inherited changes in a cancer predisposition gene (Schneider 2012). Family history is an important tool in identifying individuals at an increased risk of hereditary cancer. Family history can reveal factors associated with an increased likelihood of an underlying hereditary breast and ovarian cancer (HBOC) and other cancer syndromes, such as early onset breast cancer, multiple primary cancers, multiple affected family members, ovarian cancer, and Ashkenazi Jewish ancestry (Berliner et al. 2013). Identification of families at an increased risk for HBOC may have an impact on both screening and clinical management by allowing individuals to make

informed decisions about their health. These decisions may include earlier and more frequent cancer surveillance, risk-reducing surgeries and medications (National Comprehensive Cancer Network (NCCN) Guidelines Inc. 2015; Riley et al. 2012).

The National Society of Genetic Counselors (NSGC) defines genetic counseling as "the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease"(Resta et al., 2006). Cancer genetic counseling involves the identification and education of individuals at an increased risk for hereditary cancer. This process may involve family history analysis, risk assessment models, and genetic testing in order to provide an individualized cancer risk assessment (Riley et al. 2012). Numerous professional organizations, including the NSGC, American College of Medical Genetics and Genomics (ACMG), the American Congress of Obstetricians and Gynecologists (ACOG), and the National Comprehensive Cancer Network (NCCN), provide guidelines in support of the identification and management of individuals at an increased risk for HBOC ("ACOG Practice Bulletin No. 103: Hereditary breast and ovarian cancer syndrome 2009; Berliner et al. 2013; Hampel et al. 2014; National Comprehensive Cancer Network (NCCN) Guidelines Inc. 2015). Guidelines include a recent United States Preventive Services Task Force (USPSTF) release recommending the use of family history to identify women at risk for HBOC, and referral of these women to cancer genetic counseling services (Moyer 2014).

Despite evidence-based guidelines and recommendations provided by professional organizations, cancer genetic counseling services are underutilized by at-risk patients (Ayme et al. 2014; Mouchawar et al. 2005; O'Neill et al. 2006; Quillin et al. 2014; Rahm et al. 2007). Previous studies demonstrate varying, but low rates of genetic counseling uptake for individuals at an increased risk for HBOC. For instance, Quillin et al. (2014) found that among 22 high risk women without a personal history of cancer who met the 2005 USPSTF guidelines for genetic counseling referral, only one patient reported having previous genetic counseling and one had previous genetic testing without counseling. Utilization of genetic counseling services among women after receiving a provider referral was found to be approximately 30 % from studies within one non-profit health plan (Mouchawar et al. 2005; Rahm et al. 2007). Women with a personal history of breast cancer and a family history of breast and/or ovarian cancer have demonstrated uptake rates as low as 11 % (Ayme et al. 2014). Ayme et al. (2014) found a higher rate of utilization (25 %) for a sample of patients with high familial risk; moreover, those patients who underwent genetic counseling were on average younger, of higher social class, and had more female offspring than patients who did not complete genetic counseling. O'Neill et al. (2006) identified an uptake rate of 36 % among women with both a personal history of breast cancer and 10 % or greater probability of carrying a *BRCA* mutation following a referral for cancer genetic counseling.

A number of factors have been shown to hinder referral and utilization of genetic counseling services for at-risk patients. These factors occur during three key components of the uptake process: identification of at risk patients, appropriate referral by providers, and follow-through by patients on a cancer genetic counseling referral. Inadequate identification and referral of high risk patients by their providers has been documented as a barrier to the utilization of genetic counseling. Family history information may be incomplete or inconsistently documented by physicians (Acheson et al. 2000; Burke et al. 2009; Grover et al. 2004; Sweet et al. 2002), and providers may not consistently identify and refer to cancer genetic counseling services patients who meet guideline-recommendations (Levy et al. 2009).

Trivers et al. (2011) examined appropriate adherence to evidence-based recommendations for referring high risk breast and ovarian cancer patients and found only 41 % of the surveyed providers adhered to these recommendations. Bellcross et al. (2013) found that while the majority of their patients identified as high risk by 2005 USPSTF guidelines shared their family history information with their provider, less than 20 % had been referred for genetic counseling. Studies of barriers physicians face when referring patients to genetic counseling identified the most commonly reported factors to include a lack of awareness about cancer genetic counseling services, lack of updated family history information, patient disinterest, and limited knowledge about genetics, patient eligibility, insurance coverage, and referral guidelines for cancer genetic counseling services (Brandt et al. 2008; Suther and Goodson 2003).

A review of the literature by Mikat-Stevens, Larson, and Tarini (2015) also identified barriers at the health-care system level, including lack of access to genetics services. Anderson et al. (2012) found 72.9 % of young breast cancer survivors who did not complete genetic counseling and risk assessment reported that no one had recommended these services, and lack of a recommendation was the most frequently cited for non-uptake. In contrast, all but one of the 122 women who underwent genetic counseling in that study reported being told or suggested to do so by a health care professional or family member. Although the majority of genetic counseling referrals are made by primary care providers, and most providers are aware of HBOC genetic testing (Bellcross et al. 2011), over half (55–60 %) of referrals are found to be made in response to the patient initiating a discussion about their family history of cancer with their provider (Brain et al. 2000; Fraser et al. 2003).

Although referrals to cancer genetic counseling for at-risk patients are not always made, patient specific factors also contribute to a decision not to follow-through when a referral is provided. Geer et al. (2001) interviewed 37 individuals who

declined cancer genetic counseling services following a referral and found the most prevalent reasons were: concerns over insurability, cost, anticipated emotional impact, no perceived benefit, and the time commitment required for genetic counseling. Some patients may feel overwhelmed due to the timing of the referral, such as receiving it while undergoing cancer treatment or shortly after a close family member's diagnosis (Geer et al. 2001; Vadaparampil et al. 2009).

Healthcare professionals, including genetic counselors, have cited perceived patient barriers including genetic counseling not being seen as a priority, concerns about insurance, distance to appointments, lack of knowledge about the benefit of genetic counseling, discouragement by family members, and fear of the results or potential impact on family and employment (Rolnick et al. 2011). Similar barriers have also been identified in studies examining patient reasons for declining genetic testing (Cappelli et al. 1999; Foster et al. 2004; Kieran et al. 2007; Schlich-Bakker et al. 2007). Guidelines by professional organizations recommend genetic testing include pretest and posttest genetic counseling (Robson et al. 2015); therefore it is not surprising that the factors influencing uptake of both may be quite similar due to their related nature (O'Neill et al. 2006).

Purpose of the Study

Previous literature demonstrates underutilization of genetic counseling services, however variability in the characteristics of the patient populations sampled, criteria used to identify at risk patients, and whether a referral was provided make it difficult to draw definitive conclusions about the reasons for low uptake. It seems likely that the factors contributing to patients' decision to decline genetic counseling are multifaceted, and further research is needed in better understanding the barriers patients face in the clinical setting. As part of a research study, a new process to identify patients at high risk for hereditary breast cancer was introduced at the Piper Breast Center (PBC) at Abbott Northwestern Hospital (ANW; part of Allina Health). Specifically, a family history questionnaire (FHQ) based on NCCN guidelines was administered to each female patient who presented for a screening mammogram over a three month period. Under this process, patients who screened positive based on family history were sent a follow-up referral letter describing and recommending genetic counseling. Letters recommending genetic counseling were also mailed to the patient's primary care provider. We chose a two prong approach of contacting both the patient and primary care provider to attempt to increase uptake of genetic counseling services. The proportion of patients who completed a genetic counseling appointment was determined one year following this referral letter.

In the present study we investigated the uptake of cancer genetic counseling services among a population of screening mammography patients identified as having an increased risk for hereditary breast cancer. We conducted separate focus groups consisting of patients who did and did not complete a genetic counseling appointment within one year of receiving a referral. This study had three aims: (1) to determine the rate of genetic counseling utilization following a referral letter, (2) to characterize the factors which influenced uptake of these services, and (3) to identify potential strategies for increasing utilization. Identifying these barriers to genetic counseling is an important step in understanding the underutilization of cancer genetic counseling services in high risk patients and to allow for the implementation of appropriate interventions and education materials to increase uptake.

Methods

This study was approved by the Allina Health and University of Minnesota Institutional Review Boards (IRB).

Participants

Women, age 18 years and older, visiting the Piper Breast Center at Abbott Northwestern Hospital (Minneapolis, Minnesota) between February 3, 2014 and May 9, 2014 who completed a screening mammogram and screened positive for increased risk of HBOC based upon a family history questionnaire (FHQ) were eligible to participate in the study. A total of 3000 FHQs were administered to patients during this time frame. The FHQ was constructed based on selected National Comprehensive Cancer Network (NCCN, version 3.2014) criteria as a simple tool to identify patients at an increased risk for inherited breast cancer. Items included in the FHQ are shown in Fig. 1. Responding "yes" to any of the questionnaire items signaled a referral to genetic counseling.

Of the 2738 women who provided completed questionnaires, 875 screened positive as having an increased risk for hereditary cancer (Fig. 2). Women who had previously seen a cancer genetic counselor, either self-reported through the FHQ

Do any of the following apply to <u>you</u> or a <u>close family member-blood relative</u> (parent, sibling, child, aunt, uncle, niece, nephew, grandparent or first cousin)?

- Three or more relatives on the same side of family (either your mother's side or your father's side) with breast cancer
- Breast cancer at 50 or younger and at least one other relative on same side of family with breast cancer
- Ovarian cancer at any age
- Male breast cancer
- Breast cancer at age 45 or younger
- Breast cancer and Jewish ancestry

☐ **Yes** ☐ **No**

☐ **I have already had cancer genetic counseling**

Fig. 1 Items included on the family history questionnaire (FHQ)

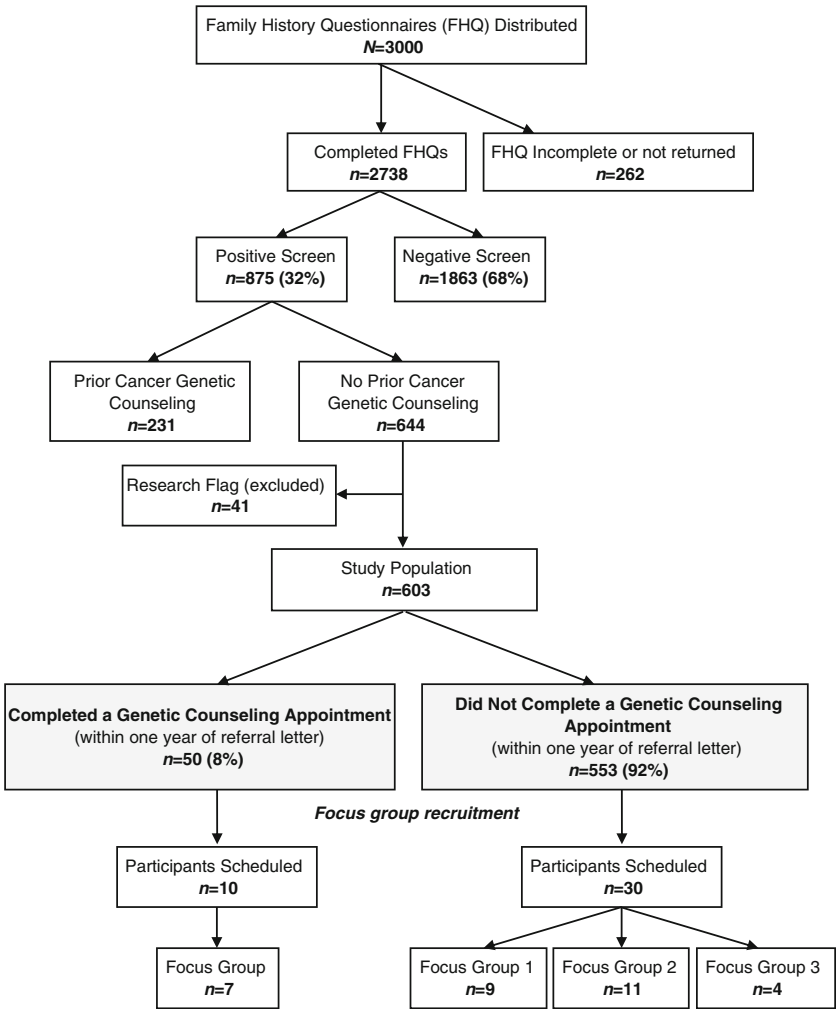

Fig. 2 Distribution of screening mammography patients and study flow chart

or as identified in their electronic health record, were excluded from this study (n = 231). An additional 41 patients were excluded from participating as they indicated they did not want their medical information included in research at Allina. A final study population included 603 women who were sent a referral letter recommending genetic counseling within two months of completing the FHQ. Letters recommending genetic counseling and directions on making a referral were also sent to their primary care providers.

The electronic health records of the women eligible for participation in this study (N = 603) were reviewed after one year post letter mailing. A cut-off of one year was chosen to avoid duplicating data collection at the time of mammogram screening where follow up is typically annually. Of these, 50 women (8 %) completed a genetic counseling appointment within a year of receiving the letter, and 553 did not. Identification of those who did and did not complete genetic counseling appointments was limited to providers within the Allina Health electronic health record. Patients who did and did not complete a genetic counseling appointment in the Allina healthcare system were then recruited for participation in separate focus groups.

Instrumentation

Focus Group Guide

A detailed focus group guide was developed by the research team for groups comprised of participants who did not complete a genetic counseling appointment. The guide consisted of eight open-ended questions and additional prompts to encourage further elaboration on the topics. Questions elicited information about three main topics:

1. Reaction to receiving a letter recommending genetic counseling: Other than receiving the letter, did your primary care provider say anything to you? Did you discuss genetic counseling with anyone else? How did receiving the letter for genetic counseling affect you?
2. Barriers to seeking genetic counseling: Why did you not seek genetic counseling? What kinds of things make it harder to make a genetic counseling appointment?
3. Facilitating factors and suggestions for patient outreach: What kinds of things make it easier to make a genetic

counseling appointment? What questions did you have about genetic counseling? What do you know about genetic counseling? Was a letter the best way to bring up topic of genetic counseling with you?

A focus group moderator used these questions to facilitate a discussion that included the participants' reactions to receiving a letter recommending genetic counseling and when deciding whether or not seek genetic counseling. Each focus group ended with 4 additional prompts allowing participants to provide suggestions in regard to referring patients to genetic counseling and providing educational materials.

A parallel version of the focus group guide was developed for the focus group of participants who did complete a genetic counseling appointment. The guide contained two additional questions: Why did you decide to seek genetic counseling? How did genetic counseling affect you?

Procedures

Participant Recruitment

A random selection of 140 eligible women who did not attend genetic counseling and whose zip code was within a 20-mile radius of the hospital zip code were mailed a letter that provided information on the study and invited them to participant in a 2-hour focus group. Included in the letter was a number to contact a member of the research team to request additional information or to be removed from the research study. Potential participants were called until recruitment goals were reached (three focus groups of women who have not completed a genetic counseling appointment, $n = 30$). Of those called, thirty-six (35.6 %) were unable to be reached, 32 (31.7 %) declined participation, 3 (3 %) disclosed prior cancer genetic counseling, and 30 (29.7 %) were scheduled for one of three focus groups. Approximately half of the scheduled participants had initiated contact with the research team by calling to request more information after receiving the invitation letter.

Due to the limited number, all 39 women who did complete a genetic counseling appointment and lived within a 20 mile radius were sent invitation letters. To reach recruitment goals (one focus group of women who have completed a genetic counseling appointment, $n = 10$), phone calls were made to 12 patients who all had requested additional information; 2 declined to participate, and 10 were scheduled for the focus group. All participants who agreed to participate were scheduled for one focus group and mailed a confirmation letter including a copy of the consent form.

Focus Groups

Four focus groups were conducted over a one month period at Abbott Northwestern Hospital. Three focus groups consisted of women who did not complete a genetic counseling appointment within the one year period. One focus group consisted of women who completed a genetic counseling appointment within that period. The focus groups were facilitated by an experienced female moderator independent of the study team. A meeting took place prior to the first focus group with the research team and the moderator to review the focus group guide and study aims. At the beginning of each focus group, participants were asked to review and sign an informed consent statement with a member of the research team present to answer questions. Participants were given a $50 gift card incentive, light refreshments and parking validation. Each focus group was audio recorded and transcribed by a professional transcription service.

Data Analysis

Transcripts from the three focus groups of participants who did not complete a genetic counseling appointment were qualitatively analyzed by the first author and audited by the second author using an inductive thematic and cross case approach to generate a codebook. Inductive analysis allows for broad themes, domains (major topic areas) and categories (more specific topics within domains) to emerge from the data across the focus groups without imposing a pre-existing framework (Patton 2002). Transcripts were reviewed multiple times through an iterative process, in which ongoing modifications were made to the themes, domains and categories to better reflect the data. The overarching themes corresponded with the groupings of interview questions discussed during the focus groups. Participant responses were often classified within multiple domains or categories due to their multifaceted nature.

Directed content analysis was used when analyzing the single focus group consisting of participants who had completed a genetic counseling appointment. Specifically, participant responses were categorized based on the previously generated codebook from the three focus groups which did not complete genetic counseling. Directed content analysis is a deductive process used to validate or extend a theoretical framework, in this case the recommendations of the focus group participants who did not complete a genetic counseling appointment (Hsieh and Shannon 2005). Data from this group were intended to provide data triangulation (MacFarlane, Veach, & Leroy, 2014). Data triangulation involves gathering data from different sources within the same study (in this case women who did and did not complete a genetic counseling appointment). "If results from these sources are consistent/overlap, then they are more coherent and trustworthy" (MacFarlane et al., 2014, p. 54). Conversely, some qualitative researchers note that data from multiple sources may yield varied meanings that individuals make of seemingly similar experiences (Grubs & Piantanada, 2010).

Results

Participant Characteristics

Of the 3000 family history questionnaires distributed to mammography patients, 2738 were completed, for a 91 % response rate. An additional 49 incomplete questionnaires were returned that did not provide an informative screening result, and therefore were not included in the analysis. Of the 2738 patients who completed the FHQ, 875 (32 %) were classified as a positive screen and mailed a letter recommending genetic counseling. From these identified patients, 603 had not received prior cancer genetic counseling and were eligible for the present study. Eligible patients were primarily white (94 %), with an average age of 58 years (Range: 30–89 years) at the time of the one year follow-up. Patients with a previous breast cancer diagnosis comprised 17.4 % of the population. Of the 603 patients identified by the FHQ, 50 (8 %) completed cancer genetic counseling within a one year period after referral letters being sent. Using a chi-square test, those who had a personal history of breast cancer are significantly more likely to complete a genetic counseling appointment than those without a personal history of breast cancer ($p<0.01$). Additional demographic characteristics are presented in Table 1.

Thirty-one of the 40 scheduled individuals participated in one of four focus groups. All participants were female with an average age of 58 years (Range: 44–83 years). Participants were predominately white (84 %), and 9 (29 %) had a personal history of breast cancer. Additional demographic characteristics of focus group participants are presented in Table 2.

Focus Group Responses

Responses from the three focus groups of participants who did not complete a genetic counseling appointment were analyzed and yielded three overarching themes corresponding to the main topics reflected in the focus group interview guide: (1) Participants' reactions and participants' reports of their providers' reactions to receiving a recommendation for genetic counseling, (2) Factors contributing to a patient's decision not to complete genetic counseling, and (3) Motivation and facilitating factors for genetic counseling uptake. Reponses from the single focus group of participants who completed genetic counseling were analyzed and included in only theme 3 to provide data triangulation.

Theme 1: Participants' Reactions and Participants' Reports of their Providers' Reactions to Receiving a Recommendation of Genetic Counseling

Nine domains reflect participant responses regarding how they and their provider reacted to receiving a letter recommending genetic counseling. Table 3 contains a summary of these domains and illustrative quotes. Of note, provider responses are based on participants' reports. Also, in focus group research, the unit of analysis is the group; therefore, the *n* for each domain represents the number of groups in which a theme emerged.

Domain 1: Participant was dismissive ($n = 3$)

Participants said they dismissed the letter after receiving it in the mail. For many, they felt that the letter was not relevant or important to them personally and was something all mammogram patients received. Others felt the letter was not meant for them. Participants felt that it was not an ideal method to recommend genetic counseling, with some stating that the letter was not compelling and was simply tossed away with their other mail.

Domain 2: Participant felt a call to action ($n = 3$)

Participants stated that the letter encouraged them to consider genetic counseling and seek out more information. For

Table 1 Demographic characteristics of the study population ($N = 603$) and patients who did ($n = 50$) or did not ($n = 553$) complete a genetic counseling appointment

	Total study population ($N = 603$)	No genetic counseling ($n = 553$)	Genetic counseling ($n = 50$)
Age in years			
Mean (Range)	58 (30–89)	59 (30–89)	56 (36–83)
Race			
White	564 (94 %)	519 (94 %)	45 (90 %)
Black or African American	25 (4 %)	22 (4 %)	3 (6 %)
American Indian or Alaska Native	6 (1 %)	5 (1 %)	1 (2 %)
Asian	3 (<1 %)	2 (<1 %)	1 (2 %)
Native Hawaiian/Pacific Islander	3 (<1 %)	3 (<1 %)	0
Declined	2 (<1 %)	2 (<1 %)	0
Personal history of breast cancer			
Yes	105 (17 %)	86 (16 %)	19 (38 %)
No	498 (83 %)	467 (84 %)	31 (62 %)

Table 2 Demographic characteristics of focus group participants ($N = 31$)

	All focus group participants ($N = 31$)	No genetic counseling participants ($n = 24$)	Genetic counseling participants ($n = 7$)
Age in years			
Mean (Range)	58 (44–83)	55 (44–74)	60 (45–83)
Race			
White	26 (84 %)	21 (87.5 %)	5 (71.4 %)
Black or African American	4 (13 %)	3 (12.5 %)	1 (14.3 %)
American Indian or Alaska Native	1 (3 %)	0	1 (14.3 %)
Personal history of breast cancer			
Yes	9 (29 %)	6 (25 %)	3 (43 %)
No	22 (71 %)	18 (75 %)	4 (57 %)

some it initiated communication with a family member or a health care provider. The letter also provided validation and served as a reminder for some participants who had considered or discussed cancer genetic counseling in the past. For the purposes of this domain, a call to action encompassed positive participant responses initiated by the letter which led to a consideration of genetic counseling.

Domain 3: Participant may revisit in the future ($n = 1$)

Participants in one focus group identified a reason to postpone genetic counseling. For one woman, the letter came during a time when she needed to take care of other priorities first. Others did not perceive any urgency in seeking genetic counseling at that time, or they were planning to wait until it was recommended by their primary care provider.

Domain 4: Participant was uncertain about follow-up ($n = 3$)

Participants were unsure about what they should do after receiving a recommendation for genetic counseling. Uncertainty included whether or not they should make an appointment, as well as how to begin that process. For some women the letter was unexpected and even overwhelming, which contributed to their uncertainty of what steps they should take next.

Domain 5: Participant did not recall receiving a letter recommending genetic counseling ($n = 3$)

Some participants across all three focus groups stated that they did not recall receiving a letter in the mail that recommended genetic counseling.

Domain 6: Provider was non-directive ($n = 2$)

Some participants stated that their health care provider appeared neither for nor against genetic counseling when the letter was brought up. These providers did not direct the patient one way or the other and left the decision about genetic counseling up to them.

Domain 7: Provider recommended genetic counseling ($n = 3$)

Some women from all three focus groups felt that their provider was supportive of the recommendation letter and encouraged them to seek genetic counseling.

Domain 8: Provider did not discuss genetic counseling ($n = 3$)

Participants from all three focus groups stated that they did not recall discussing the letter recommending genetic counseling with their provider, and that the topic of genetic counseling was not brought up.

Domain 9: Provider was dismissive of the genetic counseling recommendation ($n = 2$)

In two of the groups, some women noted that their provider recommended they not undergo genetic counseling. For the purposes of this domain, dismissive was defined as provider responses which were not supportive of the participant themselves completing a genetic counseling appointment as suggested by the letter. Reasons for not supporting the recommendation letter included concerns about insurance coverage, not deeming it necessary due to the participant's personal cancer history, and questioning who in the family was appropriate for genetic testing. For example, some providers recommended that a different family member undergo genetic counseling first in order to obtain the most informative results.

Theme 2: Factors Contributing to a Patient's Decision Not to Complete Genetic Counseling

Table 3 Domains of participants' reactions and participants' reports of their providers' reactions to receiving a recommendation for genetic counseling

Domain	Illustrative quotes
Participant was dismissive (n = 3)	".maybe it's because I have to look at so much mail when I do come home, I kind of just ignored it. It wasn't necessarily… I didn't feel like it pertained to me."
	"I'm sure I tossed it after reading it—not alarming, not shocking, but just maybe more informational. Here's something you can do if you want."
	"It didn't feel personal to me and, again, that denial thing. It was like, they were thinking of some other people. They weren't really thinking this was about me."
Participant felt a call to action (n = 3)	"When I got that letter, the whole thought of genetic testing, it totally rebuilt the plan all over again, because it's been weighing on my mind for a year."
	"I remember, I'm a visual learner, so I think they had a list of risks and I remember going through there and trying to figure out how many of these risks I had, writing it down. So I took it seriously. I took it seriously. I talked to my mom about it; I talked to my physician's assistant."
	"It was validating with what my sister had been saying, so it fit and it made it more real. It busted through the denial a little bit."
Participant may revisit in the future (n = 1)	"I did not have a sense of urgency by it [recommendation letter]. I still feel the same way. Maybe next year I'll want to take it. Maybe next year I'll want to pursue it."
	"I was going through a divorce and so I was trying to pull all these files together, my medical stuff. Everything was in such disarray; it's really taken a long time to get on top of it all. My sister had breast cancer and had the genetic testing and so I was trying… I had that information that I was trying to all pull together, so [genetic counseling is] on my docket."
Participant was uncertain about follow-up (n = 3)	"I think I was so overwhelmed by the fact that that information was given to me; I wasn't exactly sure what to do."
	"Frankly, who do you call? Who's a genetic counselor?"
	"I mean, should I be going to a genetic counselor?"
Participant did not recall receiving a letter recommending genetic counseling (n = 3)	"I don't recall getting the letter and nobody's ever suggested genetic counseling to me, so that's why I haven't."
	I never got anything that said 'you should seek genetic counseling."
Provider was non-directive (n = 2)	"She [primary care provider] was definitely leaving the decision up to me, but not saying, 'I think you really should'."
	"I think she [primary care provider] was neither pro nor against, but because I felt comfortable with the yearly mammogram, she didn't push me. So I didn't get a feeling one way or the other how she felt about it."
Provider recommended genetic counseling (n = 3)	"I came in for my mammogram in 2014. My daughter had just been diagnosed with triple negative breast cancer, and so I answered yes on the 'close family' [on the FHQ]. My physician, my internist, suggested it [genetic counseling], and what we ended up doing is, my daughter went through the genetic testing, and I didn't, but she did."
	"Mine [primary care provider] did tell me to, but I just haven't did it yet, and I don't know why. I mean I want to know."
	"I think it was the one that gave me the mammogram that suggested it [genetic counseling] and then my doctor suggested it to me. And I was like why would she say this? What does she see that I don't see? What does she know that I don't know? I mean, that's how I felt, like why are you saying this? What? I was kind of shocked by it. What is that?"
Provider did not discuss genetic counseling (n = 3)	"I don't recall my doctor ever discussing genetic counseling with me. But I had cancer in 2001, so it's another lifetime."
	"[I]f my doctor did get something [referral letter], nothing was addressed."
	I don't remember if they brought it up, but I don't recall talking to them about it."
Provider was dismissive of the genetic counseling recommendation (n = 2)	"I think the oncologist was just thinking it probably will not be approved [by insurance]. Don't go through the whole process. He helped me with a battle of paying for genotype and the insurance company didn't pay it. It took a year's worth of letter writing and reporting on his part to get it paid for. So I think it was one of those things where he knew historically what I had been through with just getting that huge bill paid for, that he just didn't think it was necessary."
	"[My doctor] said, 'Actually, that cousin who had the cancer who is still alive is the one that should get the testing.' She said, 'You need to talk to that cousin about getting tested because if she has the trait, then that could affect the rest of you and then you proceed from that point."
	"I raised the question [of genetic counseling] with my oncologist…And we decided that it wasn't necessary or appropriate. I did not have genetically linked cancer."

N=3 focus groups of participants who did not complete a genetic counseling appointment

Three domains reflect participants' perceptions of the barriers they faced with respect to seeking genetic counseling. Table 4 contains a summary of these domains, corresponding categories, and illustrative quotations.

Table 4 Domains and categories of participants' reported factors contributing to their decision not to complete genetic counseling following a recommendation

Domain	Category	Illustrative quotes
Perceived lack of relevance and utility	No perceived benefit to self or family (n = 3)	"For me, I don't need to know. I think I got to the point where it wasn't that important for me to know. I don't think I would change anything I'm doing with my life, my habits, my health."
		"I feel comfortable with the [yearly] mammogram. I think I've had three mammograms so far."
		"I had breast cancer when I was 38 years old…every woman on my mother's side of the family, for five generations, had breast cancer. I have no children. I already had it, so I know that…my risk is there, because I already had it. So for me, to what end? There would be no, there would be no point [in genetic counseling]."
		"I don't quite understand what counseling would do unless you had the disease at the point."
		"I wouldn't have genetic counseling unless I had testing, so why would I schedule a counseling appointment when I haven't had the testing? There's no reason for me to talk to a counselor when she's going to tell me go ahead and get the test."
	Genetic counseling was not a priority at the time (n = 3)	"I think it's just the immediacy of the need of the information....it [genetic counseling] wasn't critical to a decision that needed to be made about a medical issue, up front and center."
		"I was distracted I know because I had other issues. I had two hand surgeries, knee surgery, and other things going on and family drama and stuff. And I was totally distracted."
		"I guess I probably didn't look more into it [genetic counseling] because I had just gotten married at the time."
	Breast cancer in family was not perceived as genetic (n = 2)	"My mother had breast cancer, but my mom was on, she was on hormones like way into her elderly years because of another condition she had. That was probably induced by the hormones. She probably wouldn't have gotten it otherwise."
		"No one in my family, so I'm the first one [with breast cancer], so it's OK"
		"One sister did have the BRCA test at [clinic]; she came back negative"…"There's nothing for me, no BRCA markers of any kind."
		"I have a…non-genetically linked cancer, HER2-positive. There are no genetic links."
	Perception of personal cancer risk (n = 2)	"I just believe that my risk is similar to any woman walking down the street my age. Whether that's true or not, that's what I feel."
		"You know, 27 years, clear. At my age I probably won't have it [genetic counseling] done because my history right now is very good."… "right now I feel cancer free. I feel no need to have that test."
		"I know already [my cancer risk]. I've been told by my doctors what, why I'm more at risk. I know because of my background why I'm more at risk."
Limited knowledge and concerns about the genetic counseling process	Lack of knowledge about genetic counseling services (n = 3)	"Even if you decide to go and pay for the test to even know, so what's the after discussion going to be? What do I do with this information once I have it?"
		"What's the basis of their [genetic counselor's] knowledge that they can discuss it? Is it factual, is it hearsay, is it what they personally believe and what they've had of informal discussions with others? What's the basis for their discussion with us?"
		"But I want to go to see what it [genetic counseling] is, but I just need to know more information about it. I don't know what it is. I don't."
		"I don't think the benefits of it are very clear. I think it's important to explain why it's important."
		"This is like the only time I can think of where, you know, the physician didn't initiate it."
		"Where do you start? How do you go? Where do you go? What do you do? Is it a lab test? Is it a… what kind of test is it? Just not…the unknown; not knowing. Who do I go to? Do I, do I, can it be done at my primary? Do I need an order to go to the specialist? All of those things I think, cost. It is so unknown, you know."
	Anticipated emotional impact (n = 3)	"I feel like I need to know but I am scared because I don't know how I would handle it…whenever I pray, I always pray that my… none of my children or grandchildren or great grandchildren ever get cancer. I don't want them to have to go through that, so it would freak me out."
		".you know, the counseling itself, I don't want somebody to hold my hand, because I have enough to things to worry about. I just don't want to have to worry about cancer that I don't have yet, that I know of."
		"I guess my fear is the unknown like she said, the unknown…then when they tell me, I might not want to know a thing, you know? Whatever is going to happen is going to happen."
	Inconvenience and time commitment (n = 3)	"It's February. I can't tell you how many times I had to come down here to [clinic] and it was just absolutely the worst driving weather you could have had that day. Between slipping and sliding and getting

Table 4 (continued)

Domain	Category	Illustrative quotes
		yourself parked, and when you get in for your treatment you just want to break down and cry, and you haven't even done your treatment yet."
		"I've heard that you really have to go into the family history of mother and father[….]Where do I begin? How do I begin to talk to my family tree almost? [….] I guess it's a project and time consuming and do I want to ask, do I want to bother other people as well?"
		"I don't have time. I'm lucky if I do my breast exams; I get my mammogram once every five years."
	Complexity of the genetic counseling process (n = 2)	"But just taking initiative to me was going to be just a phase one of a process, because there has to be a conversation afterwards."
		"It's not like you go for a blood test and you find out what your cholesterol is and you're low in iron and they tell you take a vitamin D and iron and you walk out and you're fine. We expect it is going to be a progression of meetings and analysis and whatever."
		".once you do it, you have to make a decision what to do with that information."
		"It's a project.[….]It's a serious undertaking to do."
		"…does it have to be this complicated? Even though I think it would probably be very good, maybe, but it just, it feels like it's going to take on a life."
		"I would envision going in and hearing a lot of technical mumbo jumbo that would go over my head."
Cost and Insurance Coverage	Concerns about cost and lack of insurance coverage (n = 3)	"Insurance probably won't pay. I mean, I think insurance and the healthcare system is a huge factor for a lot of people. I have decent insurance. I'm pretty sure if I wanted to have an elective mastectomy, if it [genetic testing] turns out positive, they wouldn't pay for it and that's a huge hit financially."
		".if you've ever done it [contacted insurance company], they don't give you a straight answer; they don't give you a solid answer."
		"I just kept thinking it's going to cost a lot, and I didn't think the insurance company was going to pay for it period because there's so much already that they don't pay for."
		"I think it's revealing that people have not picked up a phone to call their insurance. To me that's very revealing, because if that was your number one concern, the only thing in your way, we would have done it"
		"I think somebody did mention to me that there was a charge for it [genetic counseling], and that was when I stopped talking about it so much because I thought I would have to pay for it."
	Concerns about insurance discrimination (n = 1)	"I recall, um, my dad had his own architecture firm, and when they were getting health insurance, a company came and talked to them and everything, and they took, they wanted blood samples. And my dad and his employees all gave blood samples, and then they were denied."

N=3 focus groups of participants who did not complete a genetic counseling appointment

Domain 1: Perceived lack of relevance and utility \

Participants described a lack of relevance pertaining to what genetic counseling services have to offer for themselves and their family, either due to their perceived lack of utility of the services or their own perception of cancer risk. For others, genetic counseling was just not a priority at the time. There are four categories.

Category 1: No perceived benefit to self or family (n = 3). Participants did not see a benefit to themselves or their family in undergoing genetic counseling. Many did not see how they would change their cancer screening or medical management, with some stating that they were comfortable with their current level of care (e.g., an annual mammogram). Some participants with a personal history of breast cancer felt that genetic counseling was unnecessary as they already understood their cancer risks and were engaged in the appropriate and necessary management. A few women did not see any benefit to their family if they did not have children, particularity daughters, or living female relatives. Additional contributory factors included not having a personal or family history of breast cancer, and not seeing the benefit of genetic counseling without first completing genetic testing.

Category 2: Genetic counseling was not a priority at the time (n = 3). Participants noted that the letter recommending genetic counseling came at a time when other life events took priority, such as marriage, divorce, or health concerns for themselves or a family member. Some participants did not regard genetic counseling as critical for their current medical care and therefore did not see the immediate need for the information.

Category 3: Breast cancer in family was not perceived as genetic (n = 2). Participants cited non-genetic factors as the cause of cancer in their family, such as hormones or environmental toxins. For some women, a family member had already undergone genetic testing with a negative result. Others did not perceive their personal or family history to be significant, particularly if they were the first person in their family to be diagnosed with breast cancer.
Category 4: Perception of personal cancer risk (n = 2). Participants in two focus groups did not perceive their cancer risk to be high enough to warrant cancer genetic counseling. For some, this was due to having reached a "medical milestone" (e.g., the number of years cancer free since their breast cancer diagnosis). Others felt they were already aware of their own cancer risk due to family history factors and did not feel the need for genetic counseling.
Domain 2: Limited Knowledge and Concerns about the Genetic Counseling Process \

Participants in all three focus groups demonstrated a limited understanding of genetic counseling and what these services have to offer. They generally perceived genetic counseling as a complex process with unknown consequences. There are four categories.

Category 1: Lack of knowledge about genetic counseling services (n = 3). The majority of women expressed a lack of knowledge and understanding about what cancer genetic counseling services have to offer. They raised questions about who genetic counselors are, the benefit and implications of genetic counseling, as well as the significance of genetic testing. Many participants were also unsure what steps would be required after receiving a referral for genetic counseling and how to set up an appointment. Some noted that a lack of direction and guidance from their provider contributed to their uncertainty in regards to beginning the genetic counseling process.
Category 2: Anticipated emotional impact (n = 3). Participants anticipated an emotional impact on themselves or their family if they pursued genetic counseling. The most predominant emotion was fear regarding the genetic test results and the unknown implications of genetic counseling.
Category 3: Inconvenience and time commitment (n = 3). Participants expressed concerns about the time commitment of genetic counseling, including burden of travel to their appointments and the time and effort required in contacting family members for history information.
Category 4: Complexity of the genetic counseling process (n = 2). Participants in two groups expressed concern about the complex and multi-step nature of genetic counseling, expecting a progression of appointments and complicated information. A few described genetic counseling as a serious decision (unlike other health care appointments) in which they must make a decision after receiving the genetic information.
Domain 3: Cost and Insurance Coverage
Category 1: Concerns about cost and lack of insurance coverage (n = 3). As a whole, participants were unsure about the insurance coverage for genetic counseling and testing, with many expecting the financial burden to be high. They expressed that cost was a major barrier in their decision to not seek genetic counseling. Most noted they did not contact their insurance company to inquire about coverage for genetic counseling or testing, citing previous difficulty obtaining a straightforward answer as a barrier.
Category 2: Concerns about insurance discrimination (n = 1). Only some members of one focus group brought up the topic of possible insurance discrimination from genetic testing.
Theme 3: Motivation and Facilitating Factors to Seeking Genetic Counseling

The following domains and corresponding categories reflect participants' views of facilitating factors and suggestions for outreach. As noted previously, these classifications are based on responses from all four of the focus groups. Participants from all four focus groups desired a stronger recommendation and guidance from their health care provider on whether they should seek genetic counseling *(n = 4)*. Of note, some women in the single focus group of participants who completed a genetic counseling appointment expressed that encouragement from their provider finally led them to make that decision. Table 5 contains a summary of domains, categories, and illustrative quotations of responses. Given their concrete nature, the categories are summarized briefly within the following domains.

Domain 1: Personal and Family Factors
Category 1: Family history of cancer (n = 4). Family history was an important factor when deciding the relevance of genetic counseling services. Many participants agreed that an individual with a family history of cancer should be offered genetic counseling. Similar to the other focus groups, women in the focus group of participants who completed a genetic counseling appointment identified having a family history of cancer an important factor in considering genetic counseling.
Category 2: Help at risk family members (n = 4). Participants noted that having family members at risk for cancer was a motivation to seek genetic counseling services, particularly for women who had daughters. Participants who had completed a genetic counseling

Table 5 Domains and categories of participants' perceptions of motivation and facilitating factors to seeking genetic counseling services

Domain	Category	Illustrative quotes
Personal and family factors	Family history of cancer (n = 4)	"My sister had breast cancer and had the genetic testing and so I was trying… I had that information that I was trying to all pull together, so it's on my docket. She did not have the BRCA gene. Then my brother got diagnosed with cancer. They're younger than me; I'm the oldest of five. Another cousin, two cousins now, have been diagnosed with cancer. It's all on my maternal side, so it's on my list." (no GC)
		"I think that women who have, or anybody for that matter, who has a strong family history of cancer should probably have, be able to have that conversation [about genetic counseling] and what happens." (no GC)
		"I didn't have a conversation with my primary care provider, but I had a conversation with my oncologist when I got the letter. He recommended that I do it, so I did it because I have some family members that had breast cancer." (GC)
	Help at risk family members (n = 4)	"I've got two daughters, so I do want to do it." (no GC)
		"I think the reason why it's [genetic counseling] weighing for me is my daughter questions me periodically and she's just turned 20. She's living with fear." (no GC)
		"…I was asking about it because I do have a daughter and granddaughters. And I don't want them to get it and I want to know if there's a possibility or greater chance of them getting it. So I should have asked more." (no GC)
		"…my daughter actually had a lump when she was twenty-three, and she went in, and it was nothing, but I started thinking I could be the first one to have the gene, you know, or I could be the first one to have the cancer. So I wanted to make sure that if I had the gene, that you know, my daughter would know, and my sister would know, and my niece and their daughter, so that they could go get tested if they wanted to afterwards, and um…if they came back positive, they could take better control of their healthcare, preventative measures, and make sure they get mammograms." (GC)
	Social support and encouragement (n2)	".with so much cancer in my mom's family, she's [sister] like sort of been on me saying, 'you know, it was good news for me, but it doesn't mean you don't have it." (no GC)
	Curiosity and desire for information (n3)	"I'm curious now. With the letter and you calling me, I'm just more curious now." (no GC)
		"I just think knowledge is power, I mean, if that's what their expertise is. I mean, to me, that's how I feel. I think the more that you know, the more educated, then you can decide, you know, what you want to do, if you want to go forward with the blood or whatever." (no GC)
		"Curiosity. I guess I wanted to know more about the genetic counseling itself, and what would be the results of that, and would that give me any direction at all, give me some things to think about" (GC)
		"I had several conversations with my primary care doctor, who really encouraged me to get all the data that I wanted, and she said genetic counseling is one way of finding out something you can't find other places." (GC)
	Interest in genetic testing (n = 2)	"If I could get a test and find out if I really have this gene." (no GC)
	Guide screening and management (n = 3)	"I'm not going to go and do, you know, remove two breasts, unless I know I'm carrying that gene." (no GC)
		"But if I know ahead of time, maybe I'd plan differently. I'd make some changes, you know, with my lifestyle." (no GC)
		"I was going to go into surgery where this could help decide what to do, and so then I went back and did the genetic screening then." (GC)
	Insurance covered genetic counseling/testing (n = 3)	If I knew my insurance covered it, if I knew the cost, if it wasn't covered, if my doctor thought it was beneficial." (no GC)
		I think it'd be nice to have two or three names of good genetic counselors that are in the Piper network, that they know what insurance we carry so they know likely which ones will accept our, my, specific insurance, and then an expectation of, you know, 'Before you come, you may want to consult your insurance company to ensure that it's covered for these reasons. (no GC)
		"Well, number one, my insurance paid for it." (GC)
Patient education	Informational needs (n = 4)	"Or if maybe the letter was maybe more, I don't want to say fine-tuned to me, you know, maybe something a little more information hey, we identified that, you know, your insurance does cover the cost of this. Hey, I can go have this done at no charge to me, or you know, whatever. To me, that written in this letter would be a free for all, or not a free for all but how to start the process, you know, here's who you can call to inquire about the test; just maybe a little more details." (no GC)
		"Just the facts and knowledge, a baseline of knowledge before we go see our primary care or our oncologist about genetic counseling. We have some intelligent information that we can ask intelligent questions, so that we are kind of on the same plain and we can be an active participant, rather than a passive player in this operation." (no GC)
		"I don't think the benefits of it are very clear. I think it's important to explain why it's important, what it is." (no GC)
		If I would've known what the end result would've been, it would've been more…I would've been quicker at it, and I probably would've called more of the relatives to really get the information, but I think it was going to be more of a waste of time. (GC)

Table 5 (continued)

Domain	Category	Illustrative quotes
	Brochures (n = 2)	"I was given a card, just a business card with someone's name on it and told, well, you could see this person for genetic counseling. I think what I was looking for was like a brochure, something that was like bold typing." (no GC)
		"If I had this flashy brochure which talked about the certifying body that these professionals were certified by and how they got educated and how I might be able to get my insurance to be onboard with this. If I just had something to work with and it wasn't so unknown." (no GC)
		"I like the idea of a brochure, a picture of a woman, it's simple and it's classic." (no GC)
	Group education meetings/seminar/class (n = 2 no GC)	"I think these [focus groups] are highly valuable. Actually, what it does for me is it energizes me for my next physical. This conversation is going to be way more take charge and way more so what if yes, so what if no, and then you can move on and know that you've done due-diligence, because you shouldn't feel embarrassed that you didn't do it or did do it, because life takes its toll on you " (no GC)
		"I would really like a group like this where somebody was in charge." (no GC)
		"[P]art of the reason I signed up for this [focus group] is because I thought, I've got to do something about this, got to do something about this. […]I think what I need is I need an interface." (no GC)
		"I like the idea of a seminar." (no GC)
	Electronic health record messages and reminders (n = 1)	"if I saw that coming in, a My Chart message from Piper, to me it would be something I would pay attention to, and even then having a chat feature. Tell me more about this." (no GC)
	Phone call reminder (n = 2)	"You can say, 'what does this mean to me? Tell me more about it.' You can just probe it a little bit." (no GC)
		"It took a phone call for me to act as well" [in regards to the focus group recruitment] (no GC)
		"I think a phone call…the only way is by people being in my face, but I always like phone calls so then I can answer the questions, like why am I at risk, why are you calling me, I don't get it. You know, I think a phone call would've been…because a letter, you can't talk to a letter, and I'm not going to take the time to call, so I would've preferred…I know if I had never heard of it, and that was the first time I had heard of it, I [inaudible 44:52.0] and then I would've wanted a phone call." (GC)
Provider communication	Stronger recommendation and guidance from health care provider (n = 4)	"I would want someone to help me, a physician or someone… I know they can't tell me what to do, but really steer me in the right direction. 'I think you strongly should do this.[…] I would want more feedback from a professional to help me make a decision." (no GC)
		"I think it would be a good idea to have it come from your primary physician and that way they might initiate the conversation when you go in for your yearly physical." (no GC)
		"If your doctor has a message about you, concerning you, they should at least send a quick call or, like, 'Hey, what do you think about this?' or, I mean, just, what do they do with that in-- what do they do with that sheet? Just put it in a file of mine?" (no GC)
		"If you would like me to consider genetic counseling, I would like to hear that from my oncologist, from my primary, from the nurse practitioner that I see on a regular basis, not some anonymous name on a form letter." (no GC)
		"I would like my doctor to get into more detail besides just saying you should, you know, look into it [genetic counseling]" (no GC)

appointment also expressed an interest in helping at risk family members, such as their sisters, nieces and daughters.

Category 3: Social support and encouragement (n = 2). While not brought up in all three groups who did not complete a genetic counseling appointment, a few participants mentioned social support and encouragement as a reason for considering genetic counseling. Members of the focus group who completed genetic counseling also mentioned encouragement from family members

Category 4: Curiosity and desire for information (n = 3). Participants in two groups who did not complete genetic counseling expressed interest in genetic counseling as a way to become more educated regarding their health decision making. Several participants expressing a new curiosity about genetic counseling after having participated in the research focus group. Participants who had completed a genetic counseling appointment cited curiosity as well as seeing genetic counseling as an opportunity to learn more.

Category 5: Interest in genetic testing (n = 2). Participants in two focus groups who did not complete a genetic counseling appointment expressed interest in genetic testing as the primary reason to undergo genetic counseling.

Category 6: Guide screening and management (n = 3). Also brought up was the utility of genetic counseling services in guiding medical management as well as prevention, particularly when making a surgical decision during breast cancer treatment. Some participants who had completed genetic counseling noted that a pending surgical decision facilitated their decision to undergo genetic counseling.

Category 7: Insurance covered genetic counseling/ testing (n = 3). Participants who had not completed genetic counseling anticipated that knowing about insurance coverage and cost prior to seeking genetic counseling would help in making that decision. Participants in the focus group who did complete a genetic counseling appointment further supported the importance of insurance coverage. For some, the decision to complete genetic counseling was facilitated by insurance covering the visit.

Domain 2: Patient Education

Participants in all four focus groups expressed limited knowledge regarding genetic counseling services and sought personalized information tailored to their own risks. Those who had not completed a genetic counseling appointment indicated that a letter alone may not be the best way to bring up the topic of genetic counseling, and they suggested other modes of communication for educating patients about genetic counseling. Suggestions included informational brochures (*n = 2*), group education meetings or seminars *(n = 2),* electronic health record messages and reminders *(n = 1)*, and telephone reminders *(n = 2)*. Participants in all four focus groups also stressed the importance of having information materials from a trusted source, such as their primary care provider or clinic.

Discussion

The purpose of this study was to determine the proportion of screening mammography patients in one healthcare network identified as having an increased risk for hereditary breast and ovarian cancer who underwent genetic counseling following a referral letter. In addition, this study aimed to investigate factors which influenced the decision to decline these services including providers' reception to receiving a referral letter. Three focus groups were conducted to identify patients' and their providers' responses to receiving a letter recommending genetic counseling, barriers to seeking genetic counseling, and facilitating factors to utilizing these services among women who did not complete genetic counseling within a one year period of referral. One additional focus group consisted of women who completed a genetic counseling appointment within that period.

Findings from this study suggest the intervention of a genetic counseling referral letter does not always lead to appropriate follow up by women identified as having an increased risk for hereditary breast cancer. Only 8 % of high risk women identified by a family history questionnaire completed a cancer genetic counseling appointment within one year of receiving a letter recommending genetic counseling. It is possible, however, that some patients may have completed genetic counseling somewhere outside the Allina Health network, making this a conservative estimate of uptake. These findings are consistent with the underutilization of cancer genetic counseling services in general demonstrated by previous studies (Ayme et al. 2014; Mouchawar et al. 2005; O'Neill et al. 2006; Quillin et al. 2014; Rahm et al. 2007). The findings also provide unique insight regarding the utility of a clinic based screening tool, combined with a recommendation letter and notification of one's primary care provider for referring high risk patients to genetic counseling.

Participants' Reactions and Participants' Reports of their Providers' Reactions to Receiving a Recommendation for Genetic Counseling

Participants were divided in their expressed receptiveness to receiving a letter suggesting genetic counseling and communication with their primary care provider. Some were dismissive of the letter, while others were receptive to it. Most participants who were dismissive cited the letter as impersonal and that cancer genetic counseling was not necessary. Receptive participants noted that the letter promoted a "call to action," prompting them to reach out to family members or initiate conversation with their health care provider about the referral. In some cases, the letter validated their consideration of genetic counseling in the past. A common domain across the three focus groups included uncertainty regarding how to respond to the letter and the next steps they should take to make an appointment. While the letter did recommend that patients request a referral from their primary care provider if interested in genetic counseling, this information may not have been presented in the most conducive manner or lacked the guidance participants desired.

While it is encouraging that some women in all three focus groups reported providers were supportive of the referral, some participants felt they did not receive enough information about the purpose and relevance of genetic counseling during the discussion. In addition, a number of participants also stated that their provider did not recommend genetic counseling for them and dismissed the letter, while others did not discuss it at all. These results may reflect findings from a previous study which found that primary care physicians were less comfortable with discussing genetics with patients compared to specialists (Brandt et al. 2008). Barriers primary care providers have faced in assessing patient risk include the presence of more immediate issues, lack of time during the visit, and a lack of knowledge and confidence in risk assessment (Sabatino et al. 2007). It is possible that the benefits of genetic counseling and relevance to their patients are not being thoroughly discussed. Some women in all three focus groups reported a lack of communication about the referral letter between them and their primary care provider. Possible reasons for a lack of communication include that not enough time had elapsed since the participants met with their primary care provider or providers not being aware of the family history

questionnaire screening process. Of note, some women from all three focus groups stated they did not recall receiving the letter in the mail, which could also be the case for providers.

Factors Contributing to Patients' Decision not to Complete Genetic Counseling

The barriers identified in this study contribute to the literature addressing the underutilization of cancer genetic counseling services. Responses from the three focus groups demonstrate the multifaceted nature of decision making. The results indicate three overarching factors which contributed to the decision not to complete genetic counseling. First, many participants perceived genetic counseling as having no benefit to themselves or their family. Reasons for lack of benefit included being comfortable with their current cancer screening or management, not having children, and perceptions of who in the family was at risk (e.g., not having female relatives or daughters). Participants also perceived a lack of urgency in needing genetic counseling, and that genetic counseling was not a priority at the time. Some women did not perceive their own cancer risk to be increased, or felt they already understood their risk. Others believed the breast cancer in their family was caused by non-genetic factors. Previous studies have identified similar factors, including no perceived benefit, genetic counseling being seen as a non-priority, and low perceived risk, as contributing to patients declining cancer genetic counseling services (Culver et al. 2001; Geer et al. 2001; Rolnick et al. 2011).

Second, limited knowledge about genetic counseling and the purpose of these services was a prevalent barrier for participants. Many perceived genetic counseling as complicated, either because they did not understand the logistics or what was involved in the process. These participants did not know what the genetic counseling process entailed, and a number of women in all three focus groups cited fear and worry about the potential cancer-related information they might receive during the appointment, particularly from genetic testing. Anticipated emotional impact has been cited by patients in prior studies (Geer et al. 2001) and also as a perceived barrier by health care providers for their patients (Rolnick et al. 2011). Wakefield et al. (2011) found the most commonly perceived reason patients thought their family members refused genetic testing was anxiety or fear about a positive test result. It is plausible that these anticipated emotions towards genetic counseling cited in our focus groups are a result of a lack of knowledge about the genetic counseling process and the distinction between genetic counseling and genetic testing.

Finally, financial concerns were consistently mentioned across the three focus groups. Participants anticipated that genetic counseling and genetic testing would come at a high cost, with some expressing concerns about the additional cost of screening and management if they were to test positive for a cancer predisposition gene. While concerns about cost were a commonly identified barrier, none of the focus group participants to our knowledge had attempted to gain more information by calling their insurance company. Participants cited previous difficulty in working with their insurance company as a barrier to finding out more about coverage and cost; however many expected that genetic counseling or testing would not be covered. Of note, one focus group did bring up concerns regarding insurance discrimination. Similar concerns about cost and insurance coverage, including insurance discrimination, have been found in prior studies (Anderson et al. 2012; Geer et al. 2001; Rolnick et al. 2011).

Motivation and Facilitating Factors for Seeking Genetic Counseling

Having a family history of breast cancer or desire to help at risk family members were important motivators for participants in considering seeking genetic counseling services, and these results are congruent with those of previous studies (Bottorff et al. 2002; Brain et al. 2000; Fraser et al. 2003; Morgan et al. 2009; Van Asperen et al. 2002; Wakefield et al. 2011). A number of researchers have found that having a personal diagnosis of breast cancer resulted in a greater concern to help family members better understand their risks (Anderson et al. 2012; Chin et al. 2005; Fraser et al. 2003; Morgan et al. 2009). While not the focus of the present study, it is noteworthy that 9 of the 31 focus group participants had a personal history of breast cancer. Additional factors found in the present study that are congruent with prior research include curiosity and a desire for more information, guidance about cancer screening and management, and an interest in genetic testing (Bottorff et al. 2002; Chin et al. 2005; Fraser et al. 2003). Insurance coverage and cost were identified as both barriers and facilitating factors by focus group participants. As noted previously, some participants expressed uncertainty about insurance coverage for genetic counseling and expected that the financial cost would be high, yet they also expressed a belief that having information about coverage and cost prior to the appointment would facilitate the decision to undergo genetic counseling. Anderson et al. (2012) identified that the top facilitating factor for young breast cancer survivors to complete genetic counseling was insurance coverage for the visit. While focus group participants who did not complete genetic counseling did not know whether their insurance would cover genetic counseling, they noted it was information that would help them in making a decision.

Participants anticipated that a discussion with their provider about genetic counseling would have been beneficial when deciding whether or not to follow up with their referral. Many women expressed a desire for a strong recommendation from their provider as to whether or not they should seek genetic counseling. Previous studies have shown the influential role of health care providers' recommendations in facilitating uptake of genetic counseling services (Anderson et al. 2012; Chin et al. 2005). Indeed, those prior findings comprise one rationale in

the present study for sending letters to primary care providers as well as patients.

The present participants stressed the importance of having informational materials from a trusted source (e.g., primary care provider or clinic) and information that is personalized to their own risks and needs. A desire for more information prior to genetic counseling is supported by Hallowell et al. (1997) findings that 65 % of their sample of women who completed a genetic counseling appointment felt inadequately prepared going into the session. Those authors suggested written material regarding the process and content of genetic counseling prior to clinic attendance. Ford et al. (2007) also identified a need to provide more information about cancer genetic counseling prior to receiving these services in order to allow for informed decision making. Participants in the present study suggested receiving a follow up phone call after obtaining the referral as a reminder and opportunity to ask questions about genetic counseling. Other suggestions included informational brochures, telephone reminders, electronic health record messages, and group meetings or seminars.

Rahm et al. (2007) found that use of a patient navigator model, in which a central person helps coordinate care, increased utilization of cancer genetic counseling services. Through this model, a follow up phone call was made within one week of sending a referral letter with the purposes of explaining the referral process, reviewing the components of a cancer genetic counseling session, clarifying the difference between genetic testing and counseling, and scheduling an appointment. Those researchers found that utilization rates increased from 31 % to 44 % when using the model. Similarly, O'Neill et al. (2006) noted that 7 of 13 patients who completed a genetic counseling appointment in their study did so only after a follow-up call.

Study Limitations and Research Recommendations

There are several limitations to the current study. First, identification of women at an increased risk for HBOC was based on self-reported personal and family history information. Second, determining the utilization of cancer genetic counseling was limited to one healthcare system in one metropolitan area, and some participants may have completed genetic counseling somewhere outside the Allina Health network. This was noted during recruitment for the focus groups when several participants indicated that they had completed a cancer genetic counseling appointment not indicated in their Allina Health electronic health records. Participants were recruited from a single mammography clinic leading to homogeneity in participant demographics. While the demographics are reflective of the women attending this particular health care system, generalizability of the findings may be limited. Of note, one focus group consisted of only four participants and may be best regarded as a small group discussion. Furthermore, findings obtained from qualitative studies are not intended to be generalized to the population of interest.

As it was not directly explored in this study, future research should address the perspectives of primary care providers when receiving a letter recommending genetic counseling for their patients and their perceptions of facilitating factors in referring patients to genetic counseling. These studies may also implement various methods of communicating a referral to at-risk patients and their providers in order to evaluate the comparative effectiveness of mode of outreach (e.g., a patient navigator model versus mailed letter) on patient follow-through with a genetic counseling referral.

Implications for Practice

Barriers in cancer genetic counseling uptake present at various phases of the referral process, whether when identifying at risk patients through a screening tool, primary care provider awareness and initiating an appropriate referral, or subsequent patient follow-through in completing a cancer genetic counseling appointment. Identifying these barriers and facilitating factors is an important step in understanding the underutilization of cancer genetic counseling services and in suggesting interventions to increase utilization by high risk patients. Findings from the present study point to a need for improved patient education regarding genetic counseling and guidance in initiating an appointment. These needs may be partially addressed through the addition of a central care person to coordinate appointments in primary care or through a patient navigator model (Rahm et al. 2007) for individuals referred to cancer genetic counseling. Educational materials may specifically address cost and insurance coverage, which was of high importance in the current study. Lack of clarity about the benefits of genetic counseling may also be addressed by enhanced provider-patient communication. Improved collaboration between primary care providers and genetics professionals will be important in raising awareness about national guidelines for identification and appropriate referral to genetic counseling (Haga et al. 2013; Wood et al. 2013). Such collaboration may be facilitated by continuing medical education for clinicians, creating referral guidelines which can be easily accessed during an appointment, and communicating feedback regarding appropriateness of referrals directly with clinicians (Scheuner et al. 2014). Scheuner et al. (2014) noted that the implementation of a electronic health record reminder to both collect family history information and make a decision regarding a referral for genetic counseling doubled the rate of referrals in a primary care women's clinic (Scheuner et al. 2014). Enhanced engagement by primary care, along with the implementation of a straightforward cancer screening tool to identify patients who are at an increased risk for hereditary cancer, appear to be instrumental in increasing the utilization of cancer genetic counseling by at risk patients.

Conclusions

The purpose of this study was to determine rate of cancer genetic counseling uptake for a sample of screening mammography patients identified at increased risk for hereditary breast cancer through a family history screening tool. In addition, we aimed to characterize barriers and supports which influenced uptake of services, and identify potential strategies for increasing utilization following a referral letter. Barriers identified by this study included perceiving genetic counseling to have low relevance and limited utility for the participant, lack of knowledge about the genetic counseling process, concerns about complexity and emotional impact, as well as concerns about cost and insurance coverage. The implementation of education resources for patients during the referral process and reinforcement of referral importance through improved provider-patient communication may help to address the underutilization of cancer genetic counseling services following a referral letter. This implementation may be facilitated by improving collaboration between primary care providers and genetics professionals in identifying at risk patients through a family history screening tool, and in increasing awareness about genetic counseling services and the referral process.

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Compliance with Ethical Standards

Conflict of Interest A. Kne, H. Zierhut, S. Baldinger, K. Swenson, P. Mink, P. McCarthy Veach, and M. Tsai declare they have no conflict of interest.

Human Studies and Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

Animal Studies No animal studies were carried out by the authors for this article.

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