

**FRAGMENTATION AND CONTROL: THE EXPERIENCES OF WOMEN AT HIGH
RISK FOR BREAST AND OVARIAN CANCER**

by

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Bachelor of Science in Nursing Honors, University of Pittsburgh, 2018

Submitted to the Graduate Faculty of

University of Pittsburgh School of Nursing in partial fulfillment

of the requirements for the degree of

Bachelor of Science in Nursing Honors

University of Pittsburgh

2018

UNIVERSITY OF PITTSBURGH

SCHOOL OF NURSING

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BRCA1 and BRCA2 are tumor suppressor genes that when mutated, are associated with increased susceptibility to several types of cancer including breast and ovarian cancer. The current standard of care for women with a BRCA mutation involves increased screening frequency and decisions around risk reduction strategies that may drastically alter their fertility and sense of womanhood. The uncertainty related to a possible cancer diagnosis may seem endless and unrelenting as these women navigate their future. Previous studies have identified the short-term distress and needs of women undergoing genetic testing and have adjusted appropriately. However, the potential for long-term distress associated with a BRCA mutation is often minimized in the literature and overlooked resulting in women managing their physical and emotional health on their own.

The purpose of this study was to explore the emotional distress and long-term support needs for women without a previous cancer diagnosis who are at high risk for breast and/or ovarian cancer, to make recommendations for practice changes to accommodate these needs. The principal investigator conducted individual in person interviews in a private space at a public location with each of the 5 participants. Participants were recruited through the Pittsburgh Chapter of the National Ovarian Cancer Coalition. The interviews were audio recorded and transcribed using a licensed transcription service. The data were then analyzed by coding and identifying themes and subthemes. The data clustered into five major themes: (1) fragmentation of genetic counselling and post-counsel, (2) coping by exercising control, (3) individualized

support, (4) support needs through the life course, and (5) the internet and accessibility of information and support. Although women have different experiences in genetic counseling and long-term support, this study suggests the needs of this population are not currently being met. The themes and subthemes identified in the qualitative data allow healthcare professionals to reevaluate their approach in supporting and informing these women as well as act as a starting point for future research regarding long-term needs, patient follow up, and the genetic counseling process.

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1.0 INTRODUCTION

The average woman has a 12% risk of developing breast cancer in her lifetime. However, the risk of breast cancer for a woman who inherits the BRCA1 or BRCA2 mutation jumps to 55-65% and 45%, respectively, by the age of 70. Similarly, the average lifetime risk of developing ovarian cancer is 1.3%, but with the BRCA1 or BRCA2 mutation, this skyrockets to 39% or 11-17%, respectively, by the age of 70 (National Cancer Institute, 2015). BRCA1 and BRCA2 are tumor suppressor genes that when mutated, are associated with several types of cancer including breast, ovarian, prostate, pancreatic, fallopian tube, and peritoneal (National Cancer Institute, 2015). A harmful mutation may be inherited from an individual's mother or father. This mutation carries serious medical as well as psychological implications such as possible prophylactic surgeries and the emotional toll of a possible future cancer diagnosis.

Women with family histories of these cancers are considered at high risk for breast and ovarian cancer. The United States Preventive Task Force has issued a Grade B recommendation that women with a family history of breast, ovarian, fallopian, or primary peritoneal cancers should be screened to determine whether the family history suggests possible association with a mutation (Moyer, 2014). Indicators that a family may be considered high-risk include a breast cancer diagnosis in any member before the age of 50, a family member with both breast and ovarian cancer, male breast cancer in any member of the family, two or more primary types of

BRCA1 or BRCA2 related cancers in a single-family member, any diagnosis of ovarian cancer, and Ashkenazi Jewish descent. It is the responsibility of health care professionals to properly screen and identify these “red flags” and refer to knowledgeable counselors so they may make informed decisions about genetic testing (National Cancer Institute, 2015).

Genetic testing can be an emotionally stressful event for women in high risk families (Baum, Friedman, Zakowski, 1997). Genetic counseling is recommended before and after genetic testing because results may necessitate making emotionally charged decisions that have lifetime consequences. Such decisions include managing risk by prophylactic surgeries, counseling other family members to be tested, or making future reproductive decisions sooner than expected. It is during genetic counseling that individuals have the opportunity to decide whether to undergo testing. In order to make an informed decision, genetic counselors discuss whether testing is appropriate, medical implications of testing, and the possibility of passing the mutation on to further generations (National Cancer Institute, 2015). If they elect to undergo testing, women are encouraged to meet with a genetic counselor again after testing for assistance in understanding their result and gaining more information about their risks and options (National Cancer Institute, 2015).

Once women receive test results they may be referred to a high-risk clinic for their follow up care or may continue care with their primary health care provider. The current standard of care for women with a BRCA mutation is increased surveillance frequency including monthly self-breast examinations starting at 18 years or upon diagnosis, annual mammograms, annual breast MRI, annual or semiannual transvaginal pelvic ultrasound, and annual or semiannual CA-125 testing (Pruthi, Gostout, & Lindor, 2010). Additionally, women may undergo chemoprevention using drugs such as tamoxifen, or raloxifene or they may undergo surgical risk

reduction such as prophylactic mastectomy or salpingo-oophorectomy (Pruthi, Gostout, & Lindor, 2010). Risk-reducing options may lower the risk of getting cancer, but despite these options, women may still experience psychological consequences (Pruthi, Gostout, & Lindor, 2010). Each preventive option may be associated with psychological implications of its own. For example, a hysterectomy and salpingo-oophorectomy may result in distress related to the desire to have children and a mastectomy may result in altered body image. Many women experience distress related to the uncertainty of their test result when anticipating undergoing genetic testing, and distress does not end with the delivery of the result. In fact, uncertainty may heighten after receiving a positive result and an overwhelming amount of information regarding risks and preventive options (Dean, 2016; Dimillo, et al., 2011; Samson, et al., 2014). Further compounding the distress associated with a positive result is the fact that although a mutation on either the BRCA1 or BRCA2 gene may be directly associated with a cancer diagnosis, not all those with a mutation will develop cancer in their lifetime. Therefore, a positive result is considered to be “predictive, not prophetic,” (Werner-Lin, 2007).

Immediately following a positive result, some women experience anger, fear, anxiety, powerlessness and vulnerability and may experience lifelong uncertainty regarding the possibility of a future cancer diagnosis, or regarding strategies to manage cancer risk (Samson, et al., 2014; Werner-Lin, 2008). The emotions related to receiving a test result triggered an emotional crisis similar to that of a life-threatening condition (Samson, et al., 2014). In 2013, the U.S. Preventive Services Task Force identified that the consequences of genetic testing on patients their families are unknown and require further research (U.S. Preventive Services Task Force, 2013). Given the potentially serious consequences of being at high risk for hereditary breast and ovarian cancer, and the lack of understanding of these consequences of this testing on

women and their families, we conducted a study to explore the emotional distress and long-term support needs for women without a previous cancer diagnosis who are at high risk for breast and/or ovarian cancer, to begin to identify practice changes to accommodate these needs.

1.1 PSYCHOLOGICAL DISTRESS

The way in which women cope with their genetic test result may be influenced by multiple pre-testing factors such as a fear of cancer from seeing it through a family member, existing high-risk perception, saturation of family history of cancer, marital status, and age (Voorwinden & Jaspers, 2016). In a study of 165 women completed questionnaires before, immediately after, and 4-6 weeks after genetic counseling and testing, women who had pre-existing worries about developing cancer, were single, and had a high-risk perception were at higher risk for psychological distress (Voorwinden & Jaspers, 2016). It is therefore important that during genetic counseling, women at high risk for psychological distress be identified through systematic assessment of these risk factors. If healthcare providers effectively screen for emotional distress around testing and cancer, they may better aid them in their new risk status by providing information on psychological services. Additionally, there is a gap in the literature regarding guidelines for interprofessional communication amongst counselors and the primary healthcare providers of the women tested for a BRCA mutation. Continuity of care is vitally important in this population to ensure women are properly cared for emotionally and medically.

Women with a BRCA mutation without a previous cancer diagnosis (sometimes called “previvors”) are at risk for negative consequences associated with unmanaged uncertainty, emotional distress, and poor medical decision making (Dean, 2016). A qualitative study

conducted in 2015 explored the uncertainty present in the daily lives of BRCA-positive women with no previous cancer diagnosis. Phone interviews conducted with 34 women found that the major themes regarding uncertainty in their risk status were associated with medical uncertainty (the need for surgeries, a possible cancer diagnosis, etc.) and familial uncertainty (the ability to have children, the possibility of passing along the mutation to future generations, etc.) (Dean, 2016).

Many “previvors” live under the notion that “it’s not *if* I get cancer, it’s *when*” (Dean, 2016). The fear of an uncertain future in regard to increased screening frequency, the panic of finding a lump or spot, or cancer scares provides an overwhelming burden for this population of women (Dean, 2016). The uncertainty regarding the risk of a future cancer diagnosis is then potentiated by traumatic memories of family members with breast and/or ovarian cancer and the fears that they may have passed along this mutation to their children or that they may leave their children too soon (Dean, 2016), thus contributing to general overall feelings of uncertainty regarding their and their family’s wellbeing throughout life (Dean, 2016; Dimillo, et al., 2011; Samson, et al., 2014). Furthermore, the distress related to uncertainty does not decrease over time and may fluctuate during various stages of women’s lives (Dean, 2016; Dimillo, et al., 2011; Samson, et al., 2014; van Oostrom, et al., 2011). A qualitative study in 2011 interviewed six women with a family history of hereditary breast and ovarian cancer (HBOC) and at least one family member with a BRCA mutation. The major themes identified in this study described uncertainty centered around ongoing medical implications and existential implications. The results of this study highlight the feelings of powerlessness and vulnerability to a cancer diagnosis causes distress that contribute to long lasting distress (Dimillo, et al., 2011).

Previous studies have explored the short and long term psychological impacts of being at high risk for HBOC and have further reinforced the need for psychological support and follow up for those at high risk for HBOC (Lodder, et al., 2000; Voorwinden & Jaspers, 2016). The literature is unequivocal that women experience significant short-term distress around genetic testing and counseling (Baum, Friedman, & Zakowski, 1997; Di Prospero, et al., 2001; Lodder, et al., 2000; van Oostrom, et al., 2003; Voorwinden & Jaspers, 2016; Werner-Lin, 2008; Werner-Lin 2007). This short-term distress is related to the anxiety surrounding the delivery of a positive test result and the negative consequences associated with it.

Several studies suggest that this distress is short lived and decreases over time, with no long-term consequences (Reichelt, Heimdal, Moller, & Dahl, 2004; Reichelt, 2008). In a study conducted in 2012, the psychological wellbeing of women was tested at 2 months and 1 year following a positive test result using the Hospital Anxiety and Depression (HADS) scale. The results of this study concluded that a positive result was not associated with clinically significant anxiety or depression at short or long-term follow-up (Bosch, et al., 2012). However, other studies suggest that women do experience distress related to a positive genetic test result. Distress is especially prevalent among young women without a previous cancer diagnosis as evidenced by a qualitative study of 22 young women. Open-ended interviews with women without a previous cancer diagnosis showed that distress was significant surrounding child-bearing and a future cancer diagnosis (Werner-Lin, 2007). Distress has been found immediately after testing (Di Prospero, et al., 2001; Lodder, et al., 2000), and up to a year after testing (Bish, Sutton, Jacobs, Ramirez, & Hodgson, 2002; Bosch, et al., 2012).

One reason for the contradictory evidence surrounding existence of long-term distress after genetic testing may be the studies' definition of distress. Some studies define "distress" as

clinically significant levels of anxiety or depression (Bosch, et al., 2012; Reichelt, Heimdal, Moller, & Dahl, 2004) whereas others define “distress” as a more general emotional reaction associated with uncertainty about the future (Werner-Lin, 2008). It is vital to identify the difference between clinically significant levels of anxiety and depression and emotional distress associated with a harmful BRCA mutation. The absence of clinically diagnosed anxiety and depression in women with a BRCA mutation does not indicate that significant distress is not present (Werner-Lin, 2008). Additionally, quantitative methods of identifying distress in this population (e.g. surveys) may not be capturing women’s distress at short or long term due to constricting questions.

The literature surrounding the prevalence and characterization of long-term distress among women with a BRCA mutation is scant and contradictory. For health care professionals to conclude that women at high risk of HBOC do not experience any form of distress related to their risk status is of significant concern and may deprive women of needed support.

1.2 LONG-TERM SUPPORT

With the ambiguity of risks and the overwhelming information regarding increased frequency of screenings and preventive options, many women struggle to truly understand the information received and may have difficulty integrating this information into their daily lives (Werner-Lin, 2008). Some evidence suggests that distress cannot simply be reduced with an influx of information, but may be managed through effective patient-provider communication (Dean, 2016).

Currently it is not part of standard practice to provide accessible, ongoing support to assist these women in adapting this information and managing future fears and uncertainties. Consequently, women may be faced with maintaining their own emotional wellbeing independently. While already grappling with the ambiguity of their futures, women should not carry the burden of searching for support through stressful times on their own (Werner-Lin, 2008). Despite the lack of consensus across studies, several have highlighted the crucial importance of providing ongoing support for women at high risk at various phases of their life-course. Evidence has shown the benefits of making supportive resources part of the genetic testing routine to better aid these women (Werner-Lin, 2008; Werner-Lin, 2007; Hughes & Phelps, 2010).

However, as each woman is unique, various avenues of support may be more effective than others (Hughes & Phelps, 2010) depending upon women's individualized needs and preferences. Even if available, not everyone will see the benefits of professional support services. Many women rely solely on informal support networks such as family, partners, and friends (Werner-Lin, 2008). Although these informal networks provide general benefits to women's wellbeing, they may not provide sufficient psychosocial support, especially for those women who experience social isolation (Werner-Lin, 2008). Support groups (peer or professionally led) have proven successful in providing a sense of understanding among these women and studies have indicated that when available, BRCA positive women have expressed interest in participating (Di Prospero, et al., 2001; Hughes & Phelps, 2010).

Much like the literature around prevalence and characterization of long-term distress among women with a BRCA mutation, the literature is similarly inconclusive regarding whether the needs of women with a harmful BRCA mutation are being met, either through professional,

personal, or social support. The wellbeing of women who are at high risk for HBOC involves their physical, mental, and emotional health. Inheriting a BRCA mutation is permanent. The uncertainty, distress, and powerlessness related to the mutation can seem endless and unrelenting in the lives of women as they make life-altering decisions in multiple transitional periods of their lives. In order to achieve the best physical and psychological outcomes, it is crucial to better understand the distress experienced by these women and how to best support each of them. Therefore, we conducted an exploratory study to identify and better understand the needs of women at high risk for breast and ovarian cancer.

2.0 METHODS

The long-term support needs of women at high risk for breast and/or ovarian cancer were explored through face to face in-depth individual interviews using a semi-structured interview guide. Interviews were held in a private meeting room of a restaurant in Pittsburgh, PA. Face to face interviews allowed the interviewee to discuss and elaborate on complex subjects and ideas that otherwise may not have been uncovered using other techniques.

2.1 PARTICIPANTS

Participants were recruited through the Pittsburgh chapter of the National Ovarian Cancer Coalition (NOCC) and through fliers located in high-risk clinics in the Pittsburgh area. Women were eligible to participate if they self-identified as being at high risk for breast and/or ovarian cancer. Due to the fact this study is exploring the distress needs of women at high risk, any woman who “felt as though she were at high risk” and experienced related distress was eligible. To ensure a broad sample of high-risk women, participants were required to be over the age of 18 and living in the greater Pittsburgh area and surrounding counties and were of any race/ethnicity, socioeconomic status, religion, or sexual orientation. Because women experience high cancer-related distress (Bish, Sutton, Jacobs, Ramirez, & Hodgson, 2002), women with a previous or current cancer diagnosis were excluded from the study.

2.2 PROCEDURES

2.2.1 Recruitment

The University of Pittsburgh Institutional Review Board approved the study protocol prior to recruitment. Potential participants were recruited through the NOCC via a recruitment letter attached to the NOCC monthly newsletter. Two weeks after the newsletter was distributed, follow up postcards were sent by the NOCC using their mailing list. Additionally, we placed fliers in high-risk clinics throughout the greater Pittsburgh area inviting women interested in the study to contact the research team. Participants were provided light refreshments in appreciation for taking part in the research study.

2.2.2 Interviews

The principal investigator (PI) was trained in qualitative interviewing by an expert from the University of Pittsburgh Graduate School of Public Health. The PI conducted each participant interview. The consent statement was reviewed with each participant before the interview began and the participant was reminded that she had the opportunity to opt out or discontinue the conversation at any time. The PI was permitted to audio record each interview. During each interview, the interviewer utilized therapeutic communication skills and attempted to create a safe environment where participants could openly discuss their experiences and sensitive topics. The principal investigator was able to build a rapport with each participant through body language, eye contact, validation, and reinforcing the expertise of each participant on these subjects. Prior to each interview, each participant consented to participate with the assurance of

anonymity and confidentiality of all recorded and demographic data. All identifiable information was removed from transcripts and demographic forms and the digital recordings were stored securely to maintain anonymity. The audio recordings were uploaded to a secure transcription service and were saved without any personal identifiers. At the beginning of each interview, the participant filled out a basic demographic form to permit characterization of the demographics of the sample. A copy of the demographic form can be found in Appendix A.

The interviews were held in a private meeting room at a restaurant in Pittsburgh, PA. The setting was specifically chosen to allow an informal and comfortable environment for the women. Food and drinks were provided to furthermore allow women to feel comfortable and relaxed. Each interview began with light talk while the interviewer and interviewee enjoyed refreshments and began to build a rapport. The principal investigator then used a semi-structured interview guide with multiple questions meant to build a meaningful conversation. The interview guide can be found in Appendix B. Basic questions were used at the beginning of the interview, with question complexity increasing as the interview progressed and trust and rapport were achieved. Questions were purposefully open-ended and broad to allow each participant latitude to interpret the question for herself and uncover her own perspective. Follow up questions were used to clarify or elaborate on topics to clarify the interviewer's understanding and promote deeper discussion of various themes.

Each interview varied in time but generally lasted 30-60 minutes. Recordings of the interviews were transcribed using a licensed, online transcription service and were supplemented with notes taken by the principal investigator during the interviews regarding body language, facial expressions, and tone of voice.

2.2.3 Data Analysis

The sample demographics from the preliminary forms were described using descriptive statistics and measures of central tendency and dispersion (means, standard deviations, medians, interquartile ranges) for continuous data, and proportions (*n*, percentage) for categorical data. Qualitative analysis of all interview data occurred in an iterative process involving coding, inductively identifying themes and subthemes apparent in the codes through narrative analysis and returning to the transcripts for additional coding and refinement as needed. To ensure consistency, multiple researchers analyzed each transcript and reached consensus on final codes and common themes throughout.

3.0 FINDINGS

Our sample consisted of five white women from the greater Pittsburgh area. Their age ranged from 22-57 years old with an average age of 40 years old. Three of the women had undergone genetic testing and counseling and carried a BRCA1 mutation. The remaining two participants self-identified as high risk for breast and/ovarian cancer. The number of relatives with a history of breast or ovarian cancer ranged from one to three. Detailed tables of demographic information can be found in Appendix C.

3.1 THEMES AND SUBTHEMES

The findings of the study are reported as themes and subthemes that emerged from each interview. Women's experiences with genetic counseling and living at high risk clustered into six meta-themes: (1) the fragmentation of genetic counseling and post-counsel, (2) coping by exercising control, (3) individualized support, (4) lack of belonging, (5) support needs through the life course, and (6) the internet and the accessibility of information and support. A flow chart illustrating the meta-themes and subthemes can be found in Appendix D.

3.1.1 The Fragmentation of Genetic Counseling and Post-Counsel

The first theme demonstrates the importance of interprofessional communication, follow up and referrals. Of the five participants, three underwent genetic counseling and testing. Although the details of each experience are unique, participants tell similar stories of fragmentation. There was found to be no standardization in the process. Women described their experiences as “scattered,” “rushed,” and “haphazard.” This fragmented care involves rushed or cancelled appointments and assumptions by healthcare professionals that other healthcare professionals would provide the necessary information. Two of the three received their test results over the phone with no warning they would be receiving sensitive information.

One day I was home and the phone rang, and I picked it up and not even really thinking about it. And it was just so haphazardly, the way the news was delivered.

Both expressed an inability to properly process this information due to the delivery. And once the results were delivered, there were no plans for follow up or referral communicated by the genetic counselors. Post-counseling was identified by each participant as lacking or absent all together.

If I didn't really know a lot about the stuff, I feel like I would have just been left out there hanging with no guidance...It's such an overwhelming amount of information. And I really do feel if I hadn't taken my own initiative I could've just been kind of confused and not really sure what to do and just following with what's recommended without really understanding.

Follow up, a subtheme of fragmented counseling, was not a part of women's care, though most expressed a desire to have had follow up after testing. The most one participant received was a packet of generic information in the mail weeks later.

I got some follow up materials in the mail maybe a week or so later, but there was no follow up after that either...Maybe just even a follow up call at some point

from the genetic counseling center just checking in to see how you're doing, are you coming along with your decisions.

This finding then led to another subtheme: referral to resources and medical professionals. The genetic counselors gave out minimal information regarding specialists, support groups, doctors in the area, or organizations in the area for women at high risk for breast and ovarian cancer. Instead, women verbalized that it seemed to be their own responsibility to reach out to medical professionals and search for doctors they felt they could trust. Many turned to friends and acquaintances in the healthcare profession for their opinion on the matter. However, women expressed difficulty finding a healthcare professional they felt they could fully trust.

The subtheme of knowledgeable doctors varies among different women's experiences but highlights the importance of knowledgeable healthcare providers. One participant, with the guidance of a friend involved in cancer research, found excellent specialists. She reported feeling:

they were laser-focused...to me, that was important because it made me feel like they knew what they were doing...I was of top concern to them and I just trusted everything they said.

Another participant's positive experience comes from going to the same doctor as her mother. The doctor's familiarity with this participant's family history provided the participant with the comforting feeling that her case was truly understood by the physician.

Negative perceptions of care were expressed by women feeling mismanaged and not heard. Women that went back to their gynecologists after testing felt as though they were not supported.

[You'd think] the person who is just doing your routine exam annually would know about it [being at risk] enough to support you...I felt like the gynecologist group that I am in is really good at delivering babies...I feel like every

gynecologist should just know to do ultrasounds and sonograms every six months. And I feel like I wasn't supported there.

Another participant stressed the importance of engaging in her own research to identify strong medical professionals.

But if I hadn't really been proactive, I think it could have been a nightmare of a process where I had somebody who really didn't know what was going on. I hadn't gotten any follow up calls from the gynecologist. If somebody was just sitting around waiting for someone to tell them what to do, they would probably still be waiting. [If I hadn't taken charge], I think it would have been really frustrating and scary.

In the experiences of the participants, genetic counseling has no standardized process. And in their cases, it finishes with the delivery of a test result. Support ceases, and these women are left to coordinate doctors, support, and screenings on their own. This theme of fragmentation of genetic counseling describes a process that, despite clear guidelines from the National Cancer Institute or genetic testing and counseling (National Cancer Institute, 2015), is inconsistent and not streamlined or easy to navigate.

3.1.2 Coping by Exercising Control

Another common theme amongst every participant's experience was exerting control as a means of coping with their high-risk status. Each woman exercised control in her own unique way whether through seeking education, deciding to undergo prophylactic surgeries, adhering to a diligent screening schedule, or adopting a healthy lifestyle. A substantial amount of the stress needing to be controlled is associated with a subtheme of destiny. Multiple women interviewed believed that without acting, they are /were destined to develop cancer. One woman stated:

with the statistics I feel like a ticking time bomb. It's just essentially, to me, it up to an 87% chance that I'll develop breast cancer.

She went on to state that the uncertainty of every mammogram is “maddening.” Her feelings are paralleled by another participant who expressed:

I'm okay until right before the appointment, and then that week, I turn into a different person. I'm convinced I have cancer.

Those who can act to control their risk verbalized low levels of distress as compared to those who felt they could not. One participant controlled her risk by undergoing a double mastectomy and hysterectomy upon learning of her BRCA mutation. Ten years later, she was confident she acted at the right time and felt comfortable with her risk status. The youngest participant, at age 22, controlled her own risk by maintaining a healthy lifestyle. She was self-motivated and reminded herself to eat healthy or go to the gym because she believed not doing so would leave her at higher risk to develop cancer. Another participant had plans for prophylactic surgeries and felt she was in control of her own situation because she was well-versed on her risk, the surgeries, and her recovery. Her story evoked a subtheme of empowerment. She stated:

It feels good to actually be able to take charge of that and to manage my risk...I feel empowered by it...This makes me feel like I have control

Her fear for the last decade was that she would one day develop breast cancer. Now with a tangible risk statistic and preventive options, she could manage that fear and therefore feel empowered. This subtheme is echoed by another participant that controlled her risk by diligent screenings. She believed she would not be as in control of her own health if she wasn't aware of her risk, so that in itself is empowering.

The participant that verbalized high levels of distress about her risk of developing cancer felt she had little to no control. She was scheduled to undergo a prophylactic hysterectomy a month after she discovered she was pregnant. A wrench into her plan, she was unable to envision a time in which she would be able to undergo either a mastectomy or hysterectomy. Her lack of control over her doctors and her body caused her to feel high levels of distress.

3.1.3 Individualized Support

This third theme expressed the similarities in the women's needs as well as the unique characteristics of their stories. A common subtheme of their long-term support needs was a need for an advocate and ally. Each woman desired a personal support system that encouraged them throughout decision making, appointments and moments of distress. This support came in multiple forms: close family relationships, trusting friendships, and strong self-advocacy. One participant was fortunate to have a close friend in the medical field that attended every appointment with her and acted as an advocate and confidant. She expressed:

and a lot of people will say, "you were so brave to do all that." I'm not sure. I think I would've gone through it, but I'm not sure if I didn't have her.

Another woman described being her own advocate and relying on her inner strength to support her through her journey. However, as she described the importance of self-advocacy, she also believed there is a need for a professional advocate for women at high risk. She went on to say:

I think they need an advocate...the need to sit down and have somebody who goes over extensively all these options

The benefits of an ally were expressed as one woman reported feeling as though she could not find anyone whose journey is similar to her own. She expressed:

not only are there so few people but then I feel like I'm not lining up with where they are

Another woman felt similarly stating:

I've not felt that I've been able to connect with anybody going through what I'm going through.

An ally may be able to act as a confidant and advocate that although is not in the same situation or position, may support women at high risk.

3.1.4 Lack of Belonging

The idea of isolation in their risk suggests a theme of lack of belonging. The BRCA community is only but a small part of the breast and ovarian cancer communities therefore it is difficult to find other women to relate. Additionally, since many of these women are treated by oncologists and specialists, they are surrounded by women with breast and ovarian cancer. Women reported being in the presence of women undergoing cancer treatment and feeling a sense of guilt. One participant described:

I remember waiting there, and there were all these people there who had cancer. And I remember sitting there feeling so lucky...and it almost made me feel guilty at times...they're probably like, 'why are you here? You're healthy.'

Another woman felt similarly at a support group meeting as the only woman who was at high risk but didn't have cancer. She remembered sitting in the group feeling:

I guess their struggles of what they are going through was so much more significant than me just sitting there like, ‘I have this thing, and I don’t know what to do.’

This sense of not belonging was associated with women at high risk minimizing their own emotional distress due to the fact that someone “has it worse.” Furthermore, women who minimized their distress were unlikely to seek out support. The BRCA-positive sister of a participant had not sought out any support options because, “she hasn’t actually like had cancer. She just has the gene for it.” Although not mentioned by every participant, the theme of lack of belonging was a powerful theme amongst some women at high risk for breast and ovarian cancer.

3.1.5 Support Needs Through the Life Course

As with every area of life, the women’s needs change as they progress in their journey. For example, the support needs of a twenty-year-old may be vastly different than a fifty-year-old. This is evident in the accounts of numerous women. Children, responsibilities, life goals and body image all play a role in decision making when it comes to prophylactic surgeries. A participant explains:

I’m okay with having breast reconstruction surgery. But if I were in my 20s or 30s and I found this information out, that’s totally different.

A subtheme of linked lives is a factor in their specific needs. Distress related to life course is highly correlated with the age and time a family member was diagnosed with or died from breast or ovarian cancer. One woman expressed:

so now that I'm the same age as my aunt, that's where I'm getting scared. Because my aunt was dead by the time she was my age.

Another participant recounted:

I'm the age now of when my mom was first diagnosed...I was getting paranoid and I need to do something.

They believe without action they may be destined to get cancer as their relatives did.

Stages of life and age are key factors in determining the needs of women at high risk for breast and ovarian cancer. Each journey is different and it is important to determine where they are to then determine where they plan to go. A participant explained:

I'm in the position in my life where I can...I'm in like the perfect situation to be going through this. But what about the person who doesn't, who's trying to manage this just like their full-time job and their children? How in the world are they going to make all this work?

However, because each woman is unique, age may require vastly different support options in different women. One woman explained she acted prophylactically at a young age so she could recover easier and take advantage of her good health. A young participant however maintains her health with diet and exercise and believes she is healthy enough to wait to medically intervene or undergo genetic testing. The life course is an important factor in determining the needs of women at high risk for breast and ovarian cancer.

3.1.6 The Internet and Accessibility of Information and Support

Finally, the theme of the internet, social media, and accessibility of information summarizes a point made by several participants, that women are seeking support that healthcare professionals are not providing. Social media can play many roles in the daily lives of the entire population.

Study participants noted that in their lives, the internet and social media provided an outlet for venting, a source of other women's horror stories, a means of education, and a sense of community. A subtheme of social media highlights the positives and negatives in the wellbeing of these women. For example, one woman, who is particularly active in the Instagram community, describes a positive, strong community of women. Yet, another participant active in the Facebook communities explains:

the problem is, with the Facebook groups, they're kind of scary, and they tend to have a very negative [view] where they almost scare you too much.

She describes no positive stories and only the narratives of women with negative outcomes after mastectomies or hysterectomies; "it's a train wreck and I keep reading it." However, she sees a positive effect from the community feeling, sparse encouragements from others and the wealth of information women post about their doctors, treatment courses and surgery.

The dangers of inaccessible and inaccurate information online is another subtheme present. Women seemingly lack information from their healthcare providers and are sent online to research on their own. This research can include treatments, surgeries, doctors, and warning symptoms. The problem arises in that most accurate research articles are not comprehensible to the average American. One participant states:

Honestly, I don't even know how many research studies that's geared toward me as a patient, it's geared towards the doctors...there isn't a good organization of layman's term version of what this research means.

Women are unable to understand the researched information so they seek information elsewhere that may be inaccurate, skewed, or very specific to various conditions. The women expressed that this kind of factual information is something that should be delivered by genetic counselors or primary care providers at the beginning of their journey. A participant proposes:

If you're dealing with women who are in this population have a guidebook, some guidelines for them...I feel like it's something that'd be really simple.

Overall, participants report that healthcare providers do not provide information, support, or validation to these women. Therefore, they are counterproductively seeking out social media and the internet which may result in negative consequences such as increased levels of distress.

4.0 DISCUSSION

This study set out to explore the experiences of women at high risk for breast and ovarian cancer with genetic counseling and long-term support after testing. The data in this study found a fragmented genetic counseling process, a sense of lack of belonging by this population, a need for tailored support for women, and the importance of control as a coping method, needs across the life course, and accurate information support. The women in this study verbalized needs that are not currently being met by healthcare providers.

The data in this study suggest that women may be unsupported by a fragmented genetic counseling process. Women described their experiences as “rushed” and “haphazard” and two of the three participants received sensitive test results over the phone. Genetic testing and counseling, an already overwhelming process, may be further complicated with “scattered” care. Although there is an extensive amount of literature regarding genetic testing and counseling, of the participants that underwent testing and counseling, there appears to be a practice gap in the actual implementation of genetic counseling recommendations. However, it is possible that genetic counselling may be more streamlined than is evidenced by the data and the participants may have been individuals that fell through the cracks of the genetic counselling process. The current fragmentation of genetic counseling experienced by our participants may result in negative long-term consequences for this population of women.

In the experiences of the women in this study, the delivery of a test result is associated with genetic counselors transferring responsibility of follow up and care to primary care providers and gynecologists. Multiple women verbalized a desire to have had follow up and support after testing and reported coordinating care and support independently. Another participant felt she couldn't comprehend any of the research she discovered on the subject. The data suggests that these women require specialized information and support from highly-trained providers such as genetic counselors or specially trained physicians, nurse practitioners or nurses. This study supports previous research concluding that young women from HBOC families have information and support needs that are not currently being met (Evans, et al., 2016). Due to conflicting recommendations from families or primary care providers, women require a source of accurate information such as detailed, frequent information support by genetic counselors (Evans, et al., 2016). For example, this information may involve follow ups at various points of the lifecourse (as childbearing ceases or body image needs change), information individualized to each woman's needs, or information located online or in an accessible format. The data in our study suggest women are seeking information, support and validation from sources on the internet. Two participants were active in Facebook and Instagram communities to find that support and validation. However, dangers arise when the information they are finding is inaccurate or biased.

Additionally, the data in this study suggest peer support is an important factor in the wellbeing of women at high-risk for breast and ovarian cancer. The women in this study confirmed that individualized support is lacking in healthcare and could be introduced through advocates, allies, and navigators. Well-trained advocates would benefit women by giving them a voice and ensuring timely, evidence-based care. It is evidenced that this population of women

may lack self-advocacy skills and are in need of individual support. Additionally, an advocate may act as an ally and confidant to support them emotionally as well as medically. The results of our study are congruent with previous research that concluded low levels of satisfaction with peer support may result in increased psychological distress (O'Neil, et al., 2017). Our results reinforce that women are keenly interested in strong peer support to guide them through this process and act as a confidant or advocate.

The data in this study confirm that these women are in fact experiencing long-term, significant distress related to their risk status. Our data is congruent with previous research that concludes women do experience short and long distress (Werner-Lin, 2008). Some literature concludes this population is not experiencing distress because their distress levels don't meet the standards of clinically diagnosed anxiety or depression (Bosch, et al., 2012; Reichelt, Heimdal, Moller, & Dahl, 2004). However, distress is not required to reach clinical levels of anxiety or depression to be significant in the lives of women. Additionally, the use of qualitative data collection and analysis, as compared to quantitative, allowed women to expand on their distress without the confining statements of a survey or questionnaire. Furthermore, quantitative studies often use rating scales and questionnaires that ask participants to rate distress in the short term, for example, the past seven days. Women may not experience active distress during any particular week. Yet, these same women may experience intermittent high levels of distress, as suggested by our participants who noted that important events such as screening visits and anniversaries of relatives' diagnoses or deaths are stressful events in their lives.

The distress identified in this study is largely regarding the identification and coordination of quality care. This supports previous literature stating that distress is associated with low satisfaction with information (O'Neil, et al., 2017). Preoccupation and distress

associated with care coordination may be due to the limited interaction time between interviewer and participants. However, this may be because women are focusing on tangible sources of stress rather than existential issues that are associated with a positive genetic test result.

The theme of control as a coping method requires further research to determine the relationship between control and distress levels. The women verbalized that the more in control they felt, the less distress they experienced. The data suggests that the women in this study may be at risk for psychological consequences if they are unable to find a means of control. However, given the exploratory nature of this study, further research on control and genetic risk is required to better understand the dynamic of this coping method.

Although participants' stories echo many of the same themes, each woman is unique and there is no singular approach to support. This finding supports prior studies that determine life trajectories such as awareness of breast cancer in family or loss of mother to breast cancer may influence decisions around preventive surgeries and risk reductive options (Hamilton, Williams, Bowers, & Calzone, 2009) Additionally, the needs of each woman change as she progresses throughout her life. It is evidenced by our data that the needs of a 20-year-old, a child-bearing mother, and a soon to be grandmother may be vastly different. For example, a child-bearing mother had more factors affecting surgical options such as children and responsibilities than a 20-year old. Whereas the participant scheduled for surgery in the upcoming month felt it was the perfect time to approach preventive options. Timing and social factors should be recognized by women's care providers and included in care planning across the women's life trajectory (Hamilton, Innella, & Bounds, 2015). Life course needs should guide genetic counseling and post-counseling support.

The women in this study are seeking information, support, and validation from healthcare professionals. The information gained in this study results in an implication for nursing practice. A nurse may act as an advocate, care coordinator, and navigator and may be a more accessible support system for this group of women. In future clinical practice, nurses caring for the population of women at high risk for breast and ovarian cancer should be aware of possible support needs. The theme of lack of belonging may result in minimizing their risk and not seeking care. The concept of “previvors” experiencing significant distress associated with uncertainty is congruent with previous literature (Dean, 2016). If women at high risk continue to feel as though their risk is not worthy of support, they will not pursue what they need. It is the responsibility of healthcare professionals, such as nurses, to identify these support needs and provide tailored support accordingly.

Findings from this study advance the existing knowledge related to the needs of women at high risk for breast and ovarian cancer. In addition to confirming findings from prior literature that women’s psychosocial support needs are not currently being met, our findings suggest that providing accessible information and support individualized to each woman may be associated in lower levels of psychological distress. In particular, there is a gap in the literature regarding the long-term needs of women at high-risk for breast and ovarian cancer. The themes and subthemes of this data can guide further research in peer support, genetic counseling, and post-counseling so that these women are better able to manage their psychological distress associated with their high-risk status. The exploratory, qualitative data in this study allow greater understanding of this population of women that with further research may shape current practice and care of women at high risk for breast and ovarian cancer.

4.1 LIMITATIONS

Our study does have several limitations that must be acknowledged. Due to practical constraints such as time and resources, our sampling frame was limited to a single source of potential participants, the Pittsburgh chapter of the NOCC. While we did send a follow up postcard to increase our response rate, participant accrual was lower than anticipated and therefore restricted our sample size. Given the lower than anticipated sample size, we cannot say with full confidence that our data achieved full saturation. However, the themes of this study were echoed uniformly across all five participants with little divergence suggesting that we attain a reasonable approximation of saturation. Additionally, each interview was only for one hour at one point in time so it is possible that this study was unable to uncover all the needs of this population. However, this study was able to identify tangible needs that are readily changeable by healthcare professionals.

Due to the cross-sectional design of this study, we are unable to extensively determine the long-term needs of women at high-risk for breast and ovarian cancer. In particular, we cannot draw firm conclusions regarding the evolution of needs across the life course. However, the distribution of our participants' age ranges and their description of needs according to age and stage allows us to potentially theorize about the influence that life course may have on the differing needs of women at different times in their lives.

The women in this study were identified and recruited through the National Ovarian Cancer Coalition. In this sample there is a possibility of a self-selection bias. The women identified may not be presentative of the general population of women at high risk and may be participating due to their negative associations with genetic counseling and their own care. Additionally, recruitment from the NOCC may cause the family histories of the sample to be

skewed and their distress associated with their risk may be different than woman who have family histories of breast cancer. Lastly, given our population was entirely white, we cannot infer about the needs of minority women. Minority women may have an entirely different spectrum of needs which cannot be inferred from our study.

4.2 IMPLICATIONS FOR FURTHER RESEARCH

Researchers and healthcare professionals can use this data to guide further research on the gap in support needs for women at high risk for breast and ovarian cancer. A survey of a larger sample of women would help to determine if there is a widespread practice gap in genetic counseling and evidence-based practice guidelines, or whether our results represent a subset of women whose experience is not universal. A larger sample could also help to identify risk factors and develop a risk profile of women at risk of psychological distress and unmet needs after genetic testing. A longitudinal study would serve to illuminate our preliminary findings regarding changing needs of women at risk of HBOC across the life course.

The topic of advocates and allies is one that is worthy of future follow up. The experiences of women may be positively impacted by the presence of an advocate and confidant throughout their journey as a woman at high-risk. The theme of the internet and accessible information highlights a need for information support for these women. Further research on accurate internet sources, guides given by genetic counselors, or follow up information containing information pertinent to each part of the life course would be beneficial so that these women may make informed decisions regarding their care and preventive strategies.

5.0 CONCLUSIONS

This study explores the long-term support needs from the experiences of five women at high-risk for breast and ovarian cancer. The data in this study add to prior literature that states the needs of women at high risk are not currently being met. The themes and subthemes identified in the qualitative data allow healthcare professionals to reevaluate their approach in supporting and informing these women as well as act as a starting point for future research regarding long-term needs, patient follow up, and the genetic counseling process. Future research is necessary to further explore these needs and the interventions to further the wellbeing of women at high-risk for breast and ovarian cancer.

APPENDIX A

BASIC DEMOGRAPHIC QUESTIONNAIRE

1. What is your age?
2. Which of the following best describes your current marital status?
 - Never married
 - Currently married
 - Living with partner/significant other
 - Widowed
 - Separated
 - Divorced
 - Other (specify)
3. How many years have you been at your current marital status?
4. What is your race?
 - White
 - Black or African American
 - American Indian
 - Alaska Native
 - Native Hawaiian or other Pacific Islander
 - Asian
 - Unknown
 - Other (specify)
5. Which of the following best describes your current living situation?

- Live alone
- Live with roommates
- Live with family
- Live with significant other

6. Do you have any children?

- Yes
- No

If YES please specify number

7. How important is religion or spirituality in your life?

- Not at all important
- Somewhat important
- Extremely important

8. What number of your aunts, grandmothers, or direct family members have been diagnosed with breast and/or ovarian cancer?

9. Have you ever undergone genetic testing for the BRCA1 or BRCA2 gene?

- Yes
- No

If YES, did you receive genetic counseling?

10. Are you positive for the BRCA1 or BRCA 2 gene?

- Yes, BRCA1
- Yes, BRCA2
- No
- Unknown

APPENDIX B

SEMI-STRUCTURED INTERVIEW GUIDE

1. Tell us your name and one way you unwind at the end of a long day.
2. Tell me about how you found out about your high-risk status.
3. Tell me a bit about how being at high risk for breast and/or ovarian cancer affects your life?
4. How do you maintain your wellbeing physical and emotionally as a woman at high risk?
5. Tell me about the resources you know of for women at high risk?
Follow Up Questions: Do you use them? Why or why not?
6. In a perfect world, what long-term support options would you use based on your needs, what would those look like?

APPENDIX C

SAMPLE DEMOGRAPHICS

Table C1: Basic Demographics

Age	Marital Status	Time in Marital Status	Race	Living Situation	Children	Spirituality
42	Divorced	7 years	White	Alone	None	Extremely
57	Married	35 years	White	Lives with family	Yes, 2	Extremely
44	Living w/ SO	2.5 years	White	Lives with SO	None	Somewhat
35	Married	10 years	White	Lives with family	Yes, 5	Somewhat
22	Single	1 year	White	Lives with roommates	None	Extremely

Table C2: HBOC Demographics

Relatives with HBOC History	Testing or Counseling Experience	BRCA Mutation
2	Yes, Yes	Yes, BRCA1
1	No	No
1	Yes, Yes	Yes, BRCA1
3	Yes, Yes	Yes, BRCA1
1	No	No

APPENDIX D

META-THEMES AND SUBTHEMES

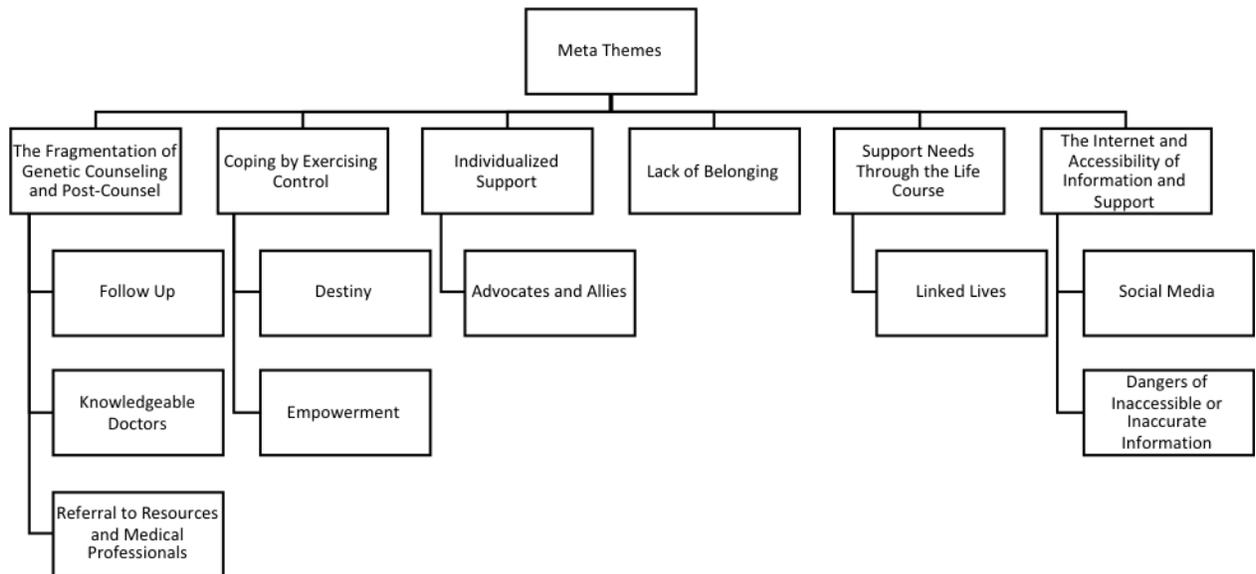


Figure D1: Themes and Subthemes

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