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**Choosing Between Medical Surveillance and Preventive Surgical Interventions Among
Asymptomatic BRCA Positive Women**

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N695: Alternate Plan Paper

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Abstract

Women with a known BRCA 1 or BRCA 2 genetic mutation are at an increased risk for the development of cancer, most commonly breast and uterine types. Risk reduction strategies to manage cancer risk include increased medical surveillance and various preventive surgeries. This is a deeply personal decision and one that is influenced by a variety of factors. The aim of this literature review is to identify the key factors impacting the decision-making process of a woman with a BRCA mutation and how a woman ultimately decides between the cancer risk management strategies. Six electronic databases were used to obtain the highest levels of evidence to answer the clinical question at stake. A total of 13 research articles met inclusion criteria and were examined for key findings. Upon review of the literature, it is evident that themes exist when examining the decision-making process of women carrying a BRCA mutation. The most common factor appearing to influence women's decisions is when a woman has experienced a family member diagnosed with cancer or has experienced the death of a family member from cancer; these women tend to choose a preventive surgery. Other factors that affect women in their decision-making are their stage of life with regards to relationship status and parity, the value placed on body image and the female body parts, and a variety of psychosocial factors. Medical professionals can also heavily influence how women make decisions. The findings of this review are significant for all health care providers as they engage in shared decision-making and support women with a BRCA genetic mutation who must decide upon a risk reducing strategy.

Keywords: BRCA-positive mutation, decision-making, BRCA gene, preventive surgery, risk reduction strategies, breast cancer, mastectomy, cancer risk management

Choosing Between Medical Surveillance and Preventive Surgical Interventions Among Asymptomatic BRCA Positive Women

The average lifetime risk of developing breast cancer for an American woman is approximately 12%, while the average lifetime risk of developing ovarian cancer is approximately 2% (ACOG, 2018). The risk of developing breast and ovarian cancer substantially increases in women who are found to be carriers of the BRCA gene. Women who test positive for the BRCA mutation have a 50%-80% lifetime risk of being diagnosed with breast cancer by the age of 85 (Johns et al., 2017). Women with a BRCA1 gene have a 39%-46% risk of developing ovarian cancer by the age of 70, while women with a BRCA2 gene have a 10%-27% risk of developing ovarian cancer (ACOG, 2018). Though the statistical odds distinctly demonstrate an increased risk of cancer among BRCA positive women, how a woman decides to gauge her own cancer risk and determine a treatment plan varies.

When a woman learns that she is a carrier of a BRCA mutation, the decision-making process begins. A woman must first understand the options available to reduce cancer risk; this includes several risk-reducing surgical procedures and multiple methods to increase medical surveillance. Deciding which option to pursue is a highly personal decision with a myriad of influencing factors. Previous research has demonstrated that the trajectory of the decision-making process follows a traditional medical model and is somewhat monomorphic for all women; however, more recent literature alludes to the fact that the process is much more individualized, rooted in the experiences of women's everyday lives (Hesse-Biber, 2016). Ultimately, a woman must choose a path that best aligns with her personal desires and values. Through this literature review, key factors are revealed that affect women in deciding between preventive surgery and increased medical surveillance to manage cancer risk.

Background

BRCA Mutation

The BRCA mutation places a woman at an increased risk for hereditary cancers, most commonly, breast and ovarian cancer (ACOG, 2018). Other cancers that are a possibility include those in the fallopian tubes, peritoneum, pancreas, and skin (ACOG, 2018). The function of BRCA1 and BRCA2 genes are to suppress tumors by repairing DNA breaks that can lead to cancer cell proliferation (ACOG, 2018). If these genes are found to have a mutation, they don't work properly which results in accelerated expansion of cells, often resulting in cancer (ACOG, 2018). This is the reason women are at a higher risk for a plethora of cancers when a mutation in the BRCA1 or BRCA2 gene occurs.

BRCA mutations are transmitted via an autosomal dominant pattern of inheritance from either parent (USPSTF, 2019). According to the American College of Obstetrics and Gynecology (2018), anywhere from one in 300 people to one in 800 people are found to have a BRCA1 or BRCA2 genetic mutation. The most common ethnicities linked to the mutation are Eastern or Central European Jewish, French Canadian, and Icelandic (ACOG, 2018). Routine testing for the gene is not recommended; however, certain scenarios should prompt an individual to be tested.

Genetic testing for the BRCA1 and BRCA2 mutation is highly sensitive and specific (USPSTF, 2019). According to the United States Preventive Services Task Force (2019), testing for the BRCA1/2 gene should be completed in those with a known family history of the gene, including male relatives. If the status of the mutation is not known in families, testing should begin only in individuals with known BRCA-related cancers in order to detect the presence of the gene (USPSTF, 2019). For women where family history information is limited or unknown, there is no clear direction for the assessment of the mutation (USPSTF, 2019). Access to genetic

counseling and recommended interventions for a BRCA mutation should also be considered prior to testing (USPSTF, 2019).

Once a woman chooses to undergo testing and receives positive results, the process begins to decipher personal cancer risk and determine optimal treatment outcomes. Learning of a BRCA mutation is often a stressful experience for women. A woman's pathway to making decisions about cancer risk management is complex, highly personal and involves an array of factors. A review of the literature depicts various factors that play of role in motivating women to choose between medical surveillance and a preventative surgical procedure.

Surveillance or Surgery

One pathway after discovery of a BRCA positive screen is to participate in ongoing medical surveillance. This route allows a woman to undergo frequent medical examinations and imaging to closely monitor for the development of cancer. Specific guidelines exist for the BRCA positive woman in regards to recommended medical surveillance and/or prophylactic treatment. The current guidelines by the National Comprehensive Cancer Network (NCCN) recommend a clinical breast exam by a provider every 6 months, an annual mammogram, and a breast MRI beginning at age 30 (Johns et al., 2017). The American Society of Breast Surgeons (2019) differ slightly, recommending those women with hereditary susceptibility should have an annual MRI starting at age 25 and annual mammography starting at age 30. Women should be offered yearly supplemental imaging, including contrast-enhanced breast magnetic resonance imaging, whole-breast ultrasound, molecular breast imaging, and contrast-enhanced mammography (ASBrS, 2019). Less research has been completed on ovarian cancer surveillance; therefore, the salpingo-oophorectomy procedure is the recommended approach to manage cancer risk. (Johns et al., 2017).

The second pathway to manage cancer risk with a BRCA mutation consists of multiple surgical options; this includes a single or double mastectomy, a hysterectomy, and a oophorectomy (Hesse-Biber, 2014). A mastectomy is a procedure that removes the breast components. Both a total mastectomy and a partial mastectomy exist; however, for purposes of prophylaxis, a total mastectomy is recommended to prevent any chance of cancer (Breastcancer.org, 2020). A total hysterectomy is the surgical procedure to remove the uterus and the cervix (Eske, 2020). This can also be combined with salpingo-oophorectomy which involves removing one or both of a woman's ovaries and fallopian tubes (Eske, 2020).

The decision to choose a surgical option is a complex one. Women must first understand each procedure and weigh the benefits and risks of each one. Women must also consider how these procedures may affect future fertility and body image; two factors which have different meaning for every woman. Women should consider body image, the risk of surgical complications and the potential life expectancy gain (Salhab et al., 2010). A risk-reducing surgery has been found to significantly decrease the risk of developing breast and ovarian cancer in high-risk individuals (Portnoy et al., 2015). In fact, risk reduction for breast and ovarian cancer after prophylactic mastectomy is thought to be 90%, and for salpingo-oophorectomy up to 80% (Johns et al., 2017). If the reduction in cancer risk is proven to be substantial among these procedures, then why do women opt against them? The review of the literature as described later in the paper helps answer this question and decipher the decision-making process for women.

Purpose/Clinical Question

Based upon the phenomena of interest, the following clinical question was developed in PIO format to direct the systematic review of the literature: *How do asymptomatic women with a*

BRCA positive mutation choose between medical surveillance and preventive surgical intervention/procedures?

Clinical Significance for Advanced Practice

Genetic counseling and testing have become increasingly prevalent within the medical world. Often, the first point of contact for testing or referral is in the primary care setting. Females will seek the knowledge and advice of providers regarding BRCA genetic testing; this includes whether to complete the testing, what the results mean, and the options available if positive results are received. A lack of knowledge surrounding the BRCA gene and how women make decisions regarding treatment options creates a barrier to providing exceptional care and maximizing cancer prevention. One participant in a study by Leonarczyk and Mawn (2015) validated this idea:

Having a place to go where you feel like someone is knowledgeable about all the options is really helpful, and I felt like my nurse practitioner that I see - I actually seem to be educating her a bit- in the options and the whole process, and that can give you a little bit of a sense of – not mistrust, but just feeling, you know, that you aren't necessarily being taken care of – that you are kind of guiding the ship. (p. 76)

A patient should not have to feel as though they are educating their health care provider or navigating the process alone. Advanced practice providers should understand the whole process and decision-making from a women's standpoint in order to better guide and support women.

Clinician recommendations are often based solely on physical health outcomes, however the overall impact on a woman's self-identity, emotional-well-being, and interpersonal relationships should also be considered (Howard et al., 2011). While genetic counselors may be available in some locations to support women, the primary care provider may be the point of

contact in rural or underserved communities; therefore, having the awareness and knowledge surrounding decision-making among BRCA positive woman allows the primary care provider to play a significant role in empowering and supporting these patients.

Methods

An extensive literature search was completed between the dates of October 19, 2020 and November 29, 2020 as it pertains to the clinical question. The databases utilized in this search included Academic Search Premier, CINAHL, Health Source: Nursing/Academic Edition, MEDLINE, PubMed, and PsycARTICLES. The topic areas covered by each database along with the restrictions added to the search criteria are displayed in Table 1 of the appendix. The dates of each search, the specific search terms, and the resulting number of hits are included in Table 2 of the appendix. Search term combinations included “BRCA gene,” “BRCA positive women AND decision making,” “BRCA mutation AND decision making,” “BRCA gene AND risk reduction strategies,” “BRCA gene AND surgical intervention,” “BRCA gene AND surveillance,” “BRCA positive AND decision making,” and “preventive surgery AND BRCA gene.” The limits applied to the search with each database included the dates of 2009 to 2020, the English language, and peer-reviewed articles.

Once the number of hits for each database were recorded, the author aimed to analyze results under 50 hits. The titles and abstracts were then reviewed. If the findings did not directly correlate to the clinical questions at stake, the article was excluded. Duplicates were also discarded. After excluding articles based upon title and/or abstract, the remaining articles were then reviewed in entirety. Table 3 in the appendix lists the articles that were reviewed and the rationale as to why the article was included or

excluded. Multiple articles were excluded because the study did not specifically address women who had a BRCA gene mutation. Other articles were excluded because the sample included patients with diagnosed cancer, while the phenomenon of interest includes asymptomatic women.

A total of 13 articles were included as they met the following inclusion criteria (a) subjects were women who carry a BRCA1 or BRCA2 gene mutation, (b) studies address the factors affecting decision-making in the management of cancer risk, (c) study subjects were asymptomatic, and (d) preventive surgical options such as mastectomy or salpingo-oophorectomy were considered. The chosen articles were analyzed for level of evidence, key findings to answer the clinical question, and contributions to practice. The highest level of evidence obtained were cohort studies which is classified as Level IV evidence; four of these studies were included. Two meta-synthesis were included which are Level V evidence. Six of the articles included were qualitative studies and level VI evidence. For more details regarding the level of evidence, sample sizes, findings, and implications, see Table 4 in the appendices.

Summary of the Literature

A plethora of factors are brought to the forefront when a woman is faced with a BRCA genetic mutation. Women must choose between medical surveillance or surgical interventions to manage their personal cancer risk. How a woman perceives her cancer risk and makes decisions differs from one woman to the next. For some it is clear, obvious, and straightforward; for others the decision is complex, troublesome, and taxing. A process that can be determined in a matter of days for some, can persist for years for others. The following summary of the literature describes the elements affecting how a woman calculates her cancer risk and ultimately chooses between

ongoing medical surveillance and a surgical intervention upon receiving news of a positive BRCA mutation.

Family Cancer History

A review of the literature revealed that the most common contributing factor to the decision-making process for women is the diagnosis of a close family member with cancer, as well as the death of a family member due to cancer. In a qualitative study including 64 asymptomatic women with a BRCA-positive mutation, all of the women who chose surveillance over surgical intervention reported that they had no one close to them die from cancer (Hesse-Biber & An, 2016). A few of the women in the surveillance category reported having a history of cancer in a relative; however the individual was not close to them or an emotional connection did not exist (Hesse-Biber & An, 2016). Interestingly, of the 40 women in this study who had a mother die from breast cancer, every single one chose preventive surgery over surveillance (Hesse-Biber & An, 2016).

A cohort study completed by Singh et al. (2013) including 136 unaffected BRCA mutation carriers further suggests that family history impacts how women make decisions. The authors noted that even though sizeable research on the benefits of procedures like mastectomy and bilateral salpingo-oophorectomy exist, still more women opt to continue surveillance; therefore, the objective of the study was to explore the factors that affect decision-making for women (Singh et al., 2013). Those most likely to have a mastectomy were the women who had lost their mother to breast cancer (Singh et al., 2013). Women who had experienced the death of their mother from pelvic cancer elected for a bilateral salpingo-oophorectomy (Singh et al., 2013). Overall, the findings were highly suggestive that a family history of cancer impacts how a

woman calculates her own cancer risk, even more so than actual risk estimations themselves (Singh et al., 2013).

In a qualitative study including 10 BRCA positive women by McQuirter et al. (2010), family history of breast and ovarian cancer was again proven to have a profound effect on woman and alter decision-making. The study concluded that women often reach a “pivotal point” in decision-making (McQuirter et al., 2010). A previous experience such as cancer in a loved one is one of the pivotal situations where a decision to have a prophylactic surgery became definitive (McQuirter et al., 2010). One participant who had learned of her positive genetic mutation and decided to have a prophylactic mastectomy reported “My sister had a lot of trouble with chemo[therapy], so knowing what she went through... I don’t want to go through that” (McQuirter et al., 2010, p. 316). In addition, participants mentioned how the age their mother was diagnosed affected how they calculated their cancer risk; once they reached that specific age it felt as though a cancer diagnosis would happen any day (McQuirter et al., 2010). Reflecting on previous experiences of loved ones appears to instill fear into some women and inspire them to decisively undergo a preventative surgery.

Johns et al. (2017) completed an observational study through retrospective chart review including 106 women who were BRCA positive and asymptomatic to better understand how women make decisions. They concluded that a diagnosis of cancer in a family member before the age of 50 or the death of a family member from cancer was linked to a decision to undergo preventive mastectomy (Johns et al., 2017). In their study, 36 of the participants underwent prophylactic mastectomy, while 70 of them chose surveillance (Johns et al., 2017). Overall, the occurrence of cancer in a family member plays a critical role for women in their viewpoint of self-risk ultimately impacting the decision-making process (Johns et al., 2017).

Life Stage

The life stage of a woman impacts how decisions are made. When considering the treatment options, a woman must recognize her personal role and responsibility as a mother, wife, partner, sister, and daughter in the decision-making process (Howard et al., 2011). Women at younger ages have been shown to make different decisions than women who are older based on a variety of factors. These factors include relationship status, having children or a desire to have children in the future, and the personal value placed on body image and the role of the female body parts. Overall, the breasts and ovaries have multiple functions that women cherish; therefore, inspiring women to choose medical surveillance over a surgical option.

Johns et al. (2017) found that women under age 30 more often choose surveillance over prophylactic mastectomy compared to those over age 30. Women under age 30 were recognized to place value on their breasts because of the desire to breastfeed in the future or for the overall physical appearance (Johns et al., 2017). For some women, the loss of breasts is associated with decreased self-esteem and feelings of “disfigurement” (Howard et al., 2011). In addition, women were concerned about the loss of breast sensitivity and pleasure, early menopause, and permanent infertility. These are all functional consequences that occur as a result of a risk-reducing procedure (Howard et al., 2011). One participant in the study by Howard et al. (2011) stated the following:

It's [breast] part of my body. It fed my daughter, it's part of me. I have a lot of fears and concerns with having surgery. I know most of them are silly or in my head. I think the biggest obstacle would be myself. Feeling that I'm not a woman, I'm not attractive. Will my husband still want me? (p. 509)

A woman experiences an internal battle with how to adapt to these functional consequences of risk-reducing surgery further complicating the decision-making process (Howard et al., 2011). It is important to consider that medical providers may not recommend a risk reducing surgery to younger populations because of these functional consequences (Johns et al., 2017).

Leonarczyk and Mawn (2015) completed a qualitative study including 15 unaffected carriers of a BRCA1 or BRCA 2 gene. A theme emerging in their findings was that as the stage of life shifts for women, so does her risk, as do her attitudes toward significant relationships, marriage, and childbearing (Leonarczyk & Mawn, 2015). One participant highlighted the difference in decision-making based upon age:

My daughter, having found out at age twenty-five, and me having found out at age fifty-three is completely different. I was at lunch with two sisters last year and one of ‘em was married and one of ‘em was single and the single said, “I don’t know what I’m gona do”- because she was still trying to meet guys- so she said “I don’t want to have anything major done to my body.” But the other sister who was married said “I’m gonna have my kids, two or three in a row, and then get all of this stuff taken out.” (Leonarczyk & Mawn, 2015, p. 74)

This quote validates how priorities change at different stages of life, ultimately affecting how women make decisions regarding preventative surgery.

Child status and/or the desire to have children are a major component to decision-making. Parity appears to be associated with the uptake of a prophylactic surgery (Segeber et al., 2019; Singh et al., 2013). For a woman with any children at home, surgical interventions were often found to be the only option since women wanted to be assured they would be around for their children in the future (Hesse-Biber, 2014). The risk of cancer was too great and these women

would rather undergo surgery than be faced with the possibility of being unable to watch their children grow (Hesse-Biber, 2014). Hesse-Biber and An (2016) found that the more guilt a woman felt about passing the gene along to a child, the more likely she would choose surgery over surveillance. In addition, those with daughters were more likely than those with only sons to have preventive surgery, as greater consideration was placed on passing along the BRCA gene to females (Hesse-Biber & An, 2016).

If a woman has a desire to start a family, have more children, or breastfeed, then prophylactic mastectomy and/or oophorectomy are automatically removed from the treatment options. Ovarian cancer surveillance is the only choice for younger, premenopausal women who desire children because prophylactic oophorectomy results in infertility (Leonarczyk & Mawn, 2015). Leonarczyk and Mawn (2015) reflected on this concept as one of their participants spoke of her decision to preserve fertility with the following: “I was like- there is no freakin way that this is gonna take my chance of ever having my own children” (p. 74). This is an important reason as to why some woman choose surveillance over any risk-reducing surgery. Of note, some women may choose surveillance for a period of time, and then decide to undergo a risk-reducing surgery once they have fulfilled their life aspirations.

Another factor impacting the decision-making process in women with positive BRCA findings is the level of family support she has. Hesse-Biber & An (2016) discussed that the less family support a woman experienced, the more likely she would continue with surveillance instead of risk-reducing surgery. Less family support can result in reduced urgency to make a decision and ultimately lead to delayed decision-making (Hesse-Biber & An, 2016). Overall, women are often found confiding in their support systems to determine the right treatment option. Howard et al. (2011) classified engagement with others as one of the decision-making

approaches that women use when deciding between treatment options. Women bounced thoughts off individuals close to them to sort through the complexities of their decision (Howard et al., 2011).

Psychosocial Factors

The sense of fear harbored in women impacts the decision to undergo risk-reducing surgery. Hesse-Biber (2014) reported that emotional worry and fear are strong predictors in BRCA positive women to choose a surgical route. In a study by Portnoy and Loud (2015), individuals with increased breast cancer worry were found to be four times more likely to undergo a bilateral mastectomy in comparison to women with less worry. Women sometimes feel the only option to alleviate worry and fear is to have a surgery and choosing surgery over surveillance gives them a sense of control and provides comfort that the cancer threat is being eradicated (Hesse-Biber, 2014). Some women were fearful of becoming too emotionally drained when it came time to have a routine mammogram or MRI in that it could reveal cancer; moreover, they preferred a risk-reducing surgery (Hesse-Biber, 2014).

The mental health of a woman affects how she makes decisions. If a woman's emotional health is suffering, she can't effectively absorb information or make an informed decision. For women with high anxiety, it may prevent them from complying with surveillance guidelines (Padamsee et al., 2017). Those who feel poorly about themselves and their health were more inclined to choose a surgical intervention (Padamsee et al., 2017). Howard et al. (2011) found that increased worry and distress led to immediate decision making for some women in order to prevent further distress, while others waited until their mind was clearer to focus on the decision at stake.

A cohort study by Portnoy and Loud (2015) of 120 BRCA positive women looked at how false-positive breast and ovarian cancer screening test results play a factor in how women make decisions. The findings demonstrated that false-positive test results from cancer screening instilled fear in women (Portnoy & Loud, 2015). Across the entire study, however, the worry of a false positive test result was not clearly linked to choosing a risk-reducing surgery (Portnoy & Loud, 2015). Overall, the most significant finding was that cancer-specific worry proved to be a strong predictor of surgery which is consistent with the previously discussed findings (Portnoy & Loud, 2015).

What drives a woman to feel empowered and how she navigates the acceptance of increased cancer risk influences treatment decisions. For some women, the belief stands that “what is going to happen, will happen.” Women with this attitude may choose surveillance over surgical intervention because they feel cancer is inevitable and it will be dealt with when it happens. In the study by Hesse-Biber (2014), some of the women who chose surveillance reported that they integrated a positive BRCA diagnosis into their current life and came to terms with what it meant, ultimately accepting the mutation as who they are. Some women felt they would not let a genetic mutation get in the way of their life and they would continue living life normally (Hesse-Biber, 2014). A response by one woman choosing surveillance over surgery was “We are a fix-it-up culture and sometimes we can’t fix things. If cancer comes, it comes” (Hesse-Biber, 2014, p. 778). A common belief held by the women choosing surveillance is that life is greater than a genetic mutation (Hesse-Biber, 2014). For others, the decision-making was found to be in the hands of a higher power. These women looked to God or their personal religious beliefs to help guide them through the process (Hesse-Biber, 2014).

Medical Professional Knowledge and Support

The recommendation of a health care professional can have a powerful effect on a woman's decision-making. The significance of this advice is different among women. Some women will do extensive research on their own, while others will rely heavily on the medical professional for advice. A woman's personality and style of obtaining information can alter how much trust is placed in the medical provider (McQuirter et al., 2010). The knowledge a health care professional has regarding the topic also affects how much trust a woman has and her willingness to partake in shared decision-making. Leonarczyk & Mawn (2015) found that participants were concerned about the lack of competent providers available to guide them along their decision-making process; this is particularly true in rural areas. When a lack of knowledge by the health care provider was sensed, women felt alone and that cancer risk management decisions fell largely on themselves (Leonarczyk & Mawn, 2015).

Women in one study by Hesse & Biber (2014) expressed how health care professionals had a heavy influence on their decision-making. One participant felt that her provider seemed to prefer surgery over surveillance and gave the impression that cancer is inevitable for the BRCA positive patient (Hesse & Biber, 2014). Women who feel pressured to have surgery by their health care provider may not consider long-term medical surveillance because of the influence of the provider. Howard et al. (2011) found that women did not feel the health care professional offered *enough* support in the decision-making process. Health care professionals with more of a nondirect approach in their recommendations complicated the process for these women and forced them to make the decision on their own (Howard et al., 2011).

A qualitative study by Puski et al. (2018) focused on the involvement of others in the decision-making process for BRCA positive women. Participants felt strongly about health care professionals' engagement throughout the process and several women highlighted how

collaboration with a physician to interpret their risk led to feelings of reassurance during decision-making (Puski et al., 2018). Women want to trust their health care provider and confide in them for risk management decisions (Puski et al., 2018). Overall, the health care professional is in a powerful position to affect the decision-making process for women.

Gaps in the Literature

The intent of this literature search was to include only asymptomatic women in the decision-making process. A plethora of articles also included symptomatic women or those who had current cancer; however, a majority of these articles were excluded. By extending the population of interest to both symptomatic and asymptomatic women, additional perspectives could have been included within the evidence cited here. Having a current diagnosis of cancer significantly impacts decision-making and can alter the findings as these women are often driven to have surgery because of their diagnosis (Hesse-Biber, 2014). While there is evidence of a variety of factors contributing to the decision-making process for women carrying a BRCA mutation, more research is needed on strictly asymptomatic women.

Another point to consider is that some women may choose a surgical option such as a mastectomy but wait to have a hysterectomy until later in life. These women are incorporating both a surgical option as well as medical surveillance which complicates the results of the clinical question. A more consistent approach such as studying decision-making of BRCA mutation carriers at specific ages may be useful. The limitations of the studies in this literature review included small sample sizes and participants that consisted of Caucasian, middle to upper class women. More research is needed to include women of all ethnicities and social classes to gain a broader understanding and increase the overall strength of the evidence.

Discussion

Carrying a BRCA mutation is worry-some and anxiety provoking for many women. Women who carry a BRCA mutation are six times more likely to develop breast cancer than the average woman, and 28 times more likely to develop ovarian cancer (Johns et al., 2017). A woman must consider her individual cancer risk and ultimately make life-altering decisions. A review of the current literature depicts the plethora of factors that affect how women choose between medical surveillance and preventive surgery. It is important to note that women do not necessarily consider their cancer risk based on statistical odds, but rather to reframe their risk based upon a variety of other connections which influences their decision making (Hesse-Biber, 2014). There is no solitary risk-reducing strategy that meets the expectations and concerns of all women; therefore, a variety of factors must be investigated (Salhab, 2010).

A history of cancer in the family emerged as a powerful influence leading a woman to choose a preventive surgery. Watching the experiences of a loved one dealing with cancer, or even the death of a loved one from cancer causes a woman to be more fearful and, in many cases, leads to a quick, straightforward decision to undergo surgery. The age and stage of life a woman is in affects how decisions are made. Younger women are often more inclined to partake in increased medical surveillance which can be explained by multiple factors. Women of younger ages may not yet have children and desire to have them one day, which automatically removes an oophorectomy from the treatment options. For some women, maintaining functions of the breasts such as breastfeeding, providing pleasure, and heightening physical appearance led them to choose surveillance instead of a preventive surgery. Older women may be more willing to have a risk-reducing procedure as they are through the child-bearing years and may not place the same importance on body image.

Other contributing factors impacting the decision-making process include a variety of

psychosocial factors and the level of influence of the health care professional. The amount of fear and anxiety one experiences affects how decisions are made; higher levels of worry and distress over carriage of the BRCA mutation are associated with a higher likelihood of a preventive surgery. Removing body parts and eliminating a cancer threat is a way to intervene for women with higher anxiety. For other women, having a BRCA genetic mutation doesn't appear to have the same significance. These women will accept the fact that they are carriers of the mutation and not let the mutation stand in the way or affect how they live their life.

The support and recommendations of the health care provider influence how women make decisions about treatment options. Women desire a health care professional that is knowledgeable and able to provide information about risk management. In addition, women want to foster a trusting relationship with the health care professional so that they can engage in shared decision-making. Women who did not feel supported by their health care provider feel alone in the decision-making process. Women who are less decisive about their treatment decision are more likely to rely heavily on the advice of the medical professional.

Overall, a plethora of factors must be considered when a woman learns of a positive BRCA genetic mutation and must decide upon treatment options. The journey to reaching a decision requires women to weigh the pros and cons of each option and consider what is most important to them. The factors presented in this literature review will help readers understand the viewpoint of BRCA positive women and potentially help alleviate cancer-related distress for this population; therefore, informed decisions can be made regarding the risk-reducing strategies.

Future Directions

Implications for Practice

The fear and anxiety of women surrounding a BRCA mutation can significantly impact

decision-making abilities. With increasing popularity of genetic testing, it is likely that more women will seek BRCA testing. Health care professionals, including advanced practice nurses, are in a key position to promote BRCA genetic testing and use their knowledge and expertise to support women during post-test decision-making. Ultimately, this can lead to earlier identification of cancer or prevention of cancer and improved health outcomes. Healthcare providers should have an understanding about the BRCA mutation and the treatment modalities that are available for BRCA positive patients. Decision-making among BRCA positive women is not a “one size fits all” type of process; a plethora of factors come into play when deciding on a strategy to reduce cancer risk (Hesse-Biber, 2014). This literature review identifies the key factors that contribute to decision-making for the woman carrying a BRCA mutation. By gaining awareness of these factors, health care providers can have a positive impact on women’s medical decision-making abilities and improve their overall health outcomes (Hesse-Biber & An, 2016). In addition, the health care provider can engage in shared decision-making with women resulting in decreased feelings of isolation during this process.

A crucial consideration for health care providers is having awareness that a history of cancer in the family significantly impacts women’s decisions. Family cancer experiences for women may serve to guide decision-making even more so than any statistical odds or other medical recommendations (Hesse-Biber & An, 2016). Professionals should understand the impact of the family history and strive to discuss this with patients. Whether it be in discussions to pursue genetic testing or in providing support for women who have received positive BRCA results, favorable outcomes can be achieved with regards to cancer prevention. Research demonstrates the effectiveness of risk-reducing surgeries in preventing cancer; therefore, education and decisional support may result in increased uptake of these procedures.

Learning of a positive genetic test result causes acute distress for many women; therefore, the difficulties of decision-making may be further exacerbated. Women then desire to have more information about the treatment options and seek help in making decisions (Metcalf et al., 2017). Understanding the factors explored by this review of the literature opens up another area of future development. A standardized tool for decision-making could be used in the clinical setting to further support and empower women. A randomized control trial by Metcalfe et al., (2017) found that a decisional aid utilized for women carrying a BRCA mutation was linked to a significant decrease in cancer-related distress and decision-making when choosing between treatment options. The decisional aid was a “15-page self-administered booklet that consists of key words and illustrative icons to summarize information and data regarding generic risk of breast cancer in BRCA1 and BRCA2 mutation carriers” (Metcalf et al., 2017, p. 331). The aid also included all the breast cancer preventive options available along with the risks and benefits of each strategy, the types of studies used to evaluate preventive options, and a side-by-side comparison of the pros and cons of each option (Metcalf et al., 2017). Standardizing a tool of this kind to be used in the clinic setting would be highly valuable in decreasing decisional conflict in women carrying a BRCA mutation.

Implications for Policy

Health care policy changes will help support improved practice. Health care providers should have access to educational opportunities to further understand genetic testing and how to engage in shared decision-making to support post-test decisions. Not all individuals have access to genetic counselors; therefore, the primary care provider must have the ability to provide assistance too. Armstrong (2020) argues that now is the time for primary care providers to take responsibility in implementing BRCA genetic testing so that women have the opportunity to

learn of their risk *before* a diagnosis of cancer. By increasing funding for educational programs and training, health care providers will be more knowledgeable in this area of practice while also increasing access of genetic services in rural communities.

Individuals may lack access to appropriate and effective genetic testing due to cost. Whether or not insurance covers BRCA genetic testing significantly impacts who is able to undergo testing. Coverage by Medicaid and individual market plans are particularly inadequate (Armstrong, 2020). Under the Affordable Care Act, insurance companies are required to cover testing for women who meet specific criteria such as individuals with a personal cancer history or with a known family history of the BRCA mutation (Armstrong, 2020). Even under these circumstances, the process to obtain approval for payment is extensive (Armstrong, 2020). Increased coverage for testing will be beneficial for a multitude of reasons. For women with cancer, it will help inform treatment decisions. For women who are asymptomatic, learning of a positive BRCA mutation leads to either increased medical surveillance or a preventive surgery; both options result in improved health outcomes by earlier detection of cancer or elimination of the cancer threat.

Implications for Research

Multiple opportunities for future research exist as previously described through this review of the literature. More research is needed on strictly asymptomatic women. Since a cancer diagnosis strongly impacts women's decisions, it is crucial for future studies to focus on decision-making for women who have not been diagnosed with cancer. Research studies that focus on evaluating asymptomatic women have proven to be insightful; however, a greater number of studies with higher levels of evidence would help influence and expedite changes in practice and policy.

In order to gain a deeper understanding of decision-making, future research should aim to include women of all ethnicities. Individuals of all social classes and backgrounds should also be included to better capture decision-making from a variety of populations. Upon development of a standardized tool for decision-making, further research should consist of utilizing the tool in the practice setting and evaluating its effectiveness in a diverse context. Culture, education level, and socioeconomic status are all important features to consider for future research.

Conclusion

Although an immense amount of current research on the phenomenon of interest does not exist, the literature that is available is valuable in answering the clinical question being examined. The literature demonstrates that an array of factors come into play for women making decisions about whether a preventive surgery or medical surveillance is the best option for managing cancer risk with a BRCA mutation. A history of cancer in the family proves to be a strong indicator in the pursuit for a risk-reducing procedure. In addition, a woman's life stage and a variety of psychosocial factors appear to play a critical role in the decision-making process. The knowledge and support of health care professionals affect how women make decisions. Overall, the process of decision-making for women is complex and deeply personal. Ultimately, it is the woman who makes the decision between prevention options; however, they look to health care professionals for advice in deciding which option to implement. Understanding the BRCA mutation, the risk reducing strategies, and how women make decisions is vital for health care providers caring for women impacted by positive BRCA findings. Engaging in shared decision-making will empower women and encourage favorable health outcomes.

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Appendix

Table 1

Database Search Description

Database (or Search Engine)	Restrictions Added to Search	Dates Included in Database	General Subjects Covered by Database
Academic Search Premier	English Language; Peer Reviewed	2009 to 2020	Broad range of academic topics, including nursing
CINAHL	English Language; Peer Reviewed	2009 to 2020	Covers a broad range of nursing and allied health
Health Source: Nursing/Academic Edition	English Language; Peer Reviewed	2009 to 2020	Includes all articles in medical disciplines and particularly nursing and allied health
MEDLINE	English language; Peer Reviewed;	2009 to 2020	Biomedicine and health; Life sciences, behavioral sciences, chemical sciences, chemical sciences, and bioengineering for health care professionals
PUBMED	English Language	2009 to 2020	Includes the topics of medicine, nursing, dentistry, the health care system, and preclinical sciences
PsycARTICLES	English Language; Peer Reviewed	2009 to 2020	All print journals; From American Psychological Association, the APA Educational Publishing Foundation, the and Canadian Psychological Association.

Table 2

Data Abstraction Process

Date of Search	Key Words	Results in CINAHL	Results in PubMed	Results in Academic Search Premier	Results in MEDLINE	Results in HealthSource	PschARTICLES
10.17.20	“BRCA Gene”	1952	2564	3038	2906	522	20
10.17.20	“BRCA Positive Women” AND “Decision Making”	41	50	33	10	16	19
	“BRCA Mutation” AND “Decision Making”	145	198	130	27	48	23
10.24.20	“BRCA Gene” AND “Risk reduction strategies.”	28	143	28	5	9	11
10.24.20	“BRCA gene” AND “Surgical Intervention”	9	256	16	5	7	5
	“BRCA gene” AND “Surveillance”	79	586	94	55	14	12
10.25.20	“BRCA positive” AND “Decision” OR “Decision-making”	76	14	62	17	23	20
11.19.20	“preventive surgery” AND “BRCA GENE”	6	227	64	7	21	1

***BOLD**= articles reviewed in full for match with systematic review inclusion criteria

Table 3

Characteristics of Literature Included and Excluded

Reference	Included or Excluded	Rationale
Connors, L.M., Voian, N., Shi, Y., Lally, R.M., & Edge, S. (2014). Decision making after BRCA genetic testing. <i>Clinical Journal of Oncology Nursing</i> , 18(3), E58-63.	Excluded	The study did not require women with BRCA gene; In fact most of them were negative for the gene.
Flippo-Morton, T., Walsh, K., Chambers, K., Amacker-North, L., White, B., Sarantou, T., Boselli, D.M., White Jr., R.L. (2015). Surgical decision making in the BRCA-positive population: Institutional experience and comparison with recent literature. <i>The Breast Journal</i> , 22(1), 35-44.	Excluded	The study includes both patients with cancer and without. It evaluates the uptake of surgery and surveillance but not necessarily the decision making factors/process.
Hesse-Biber, S. (2014). The genetic testing experience of BRCA-positive women: Deciding between surveillance and surgery. <i>Qualitative Health Research</i> , 24(6), 773-789.	Included	Directly evaluates decision-making of treatment options post genetic testing for BRCA mutation.
Hesse-Biber, S., & An, C. (2016). Genetic testing and post-testing decision making among BRCA-positive mutation women: A psychosocial approach. <i>Journal of Genetic Counseling</i> , 25(5), 978-992.	Included	Directly analyzed decision-making of women who opted for surgery or surveillance.
Howard, A. F., Balneaves, L.G., Bottorff, J.L., & Rodney, P. (2011). Preserving the self: The process of decision making about hereditary breast cancer and ovarian cancer risk reduction. <i>Qualitative Health Research</i> , 21(4), 502-519.	Included	Directly analyzed decision making in risk reducing strategies for women who are BRCA 1 or BRCA 2 mutation carriers

Reference	Included or Excluded	Rationale
Johns, D., Agarwal, J., Anderson, L., Ying, J., & Kohlmann, W. (2017). Breast cancer reduction decisions of the BRCA- positive patient: An observational study at a single institution. <i>Journal of Women's Health, 26</i> (6), 702-706	Included	Directly analyzes the factors affecting decision making for managing breast cancer risk in patients who are BRCA positive
Leonarczyk, T.J., & Mawn, B. E. (2015). Cancer risk management decision making for BRCA + women. <i>Western Journal of Nursing Research, 37</i> (1), 66-84.	Included	Explored the experience of cancer risk management decision making for women who are carriers of a BRCA mutation
McQuirter, M., Castiglia, L.L., Loiselle, C.G., & Wong, N. (2010). Decision-making process of women carrying a BRCA1 or BRCA2 mutation who have chosen prophylactic mastectomy. <i>Oncology Nursing Forum, 37</i> (3), 313-320	Included	Looks at the decision-making process of women with BRCA mutation when they choose prophylactic mastectomy
Mellon, S., Janisse, J., Gold, R., Cichon, M., Berry-Bobovski, L., Tainsky, M.A., & Simon, M.S. (2009). Predictors of decision making in families at risk for inherited breast/ovarian cancer. <i>Health Psychology, 28</i> (1), 38-47.	Excluded	Decision making related to cancer risk not specifically surveillance verses surgical intervention
Metcalf, K.A., Dennies, C.L., Poll, A., Armel, S., Demsky, R., Carlsson, L., Nanda, S., Kiss, A., & Narod, S.A. (2017). Effect of decision aid for breast cancer prevention on decisional conflict in women with a BRCA1 or BRCA2 mutation: A multisite, randomized, controlled trial. <i>Genetics in Medicine: Official Journal of the American College of Medical Genetics, 19</i> (3), 330-336.	Included	A tool is needed in practice to decrease emotional distress that is experienced among BRCA positive women when making decisions about treatment options
Padamsee, T.J., Wills, C.E., Yee, L.D., & Paskett, E.D. (2017). Decision making for breast cancer prevention among women at elevated risk. <i>Breast Cancer Research, 19</i> (34), 1-12.	Included	A review of decision making among women at elevated risk for breast cancer
Portnoy, D.B., Loud, J.T., Han, P.K.J., Mai, P.L., & Greene, M.H. (2015). Effects of false-positive cancer screenings and cancer worry on risk-reducing surgery among BRCA ½ carriers. <i>Health Psychology, 34</i> (7), 709-717.	Included	Discusses false positive cancer screening results and its effect on pursuing risk-reducing surgery
Puski, A., Hovick, S., Senter, L., & Toland, A.E. (2018). Involvement and influence of healthcare providers, family members, and other mutation carriers in the cancer risk management decision-making process of BRCA1 and BRCA2 mutation carriers. <i>Journal of Genetic Counseling, 27</i> (5), 1291-1301.	Included	Evaluated the decision making process of increased cancer screening or prophylactic surgery of women with BRCA mutations focusing on the involvement of others
Salhab, M., Bismohun, S., & Mokbel, K. (2010). Risk-reducing strategies for women carrying BRCA ½ mutations with a focus on prophylactic surgery. <i>BMC Women's Health, 10</i> (28),1-10.	Included	Summarizes the available literature in regards to risk-reducing strategies for BRCA positive mutation carriers
Schott, S., Vetter, L., Keller, M., Bruckner, T., Golatta, M., Eismann, S., Dikow, N., Evers, C., Sohn, C., & Heil, J. (2017). Women at familial risk of breast cancer electing for prophylactic mastectomy: frequencies, procedures, and decision-making characteristics. <i>Archives of Gynecology & Obstetrics, 295</i> (6), 1451-1458	Excluded	Does not directly answer PIO question; Looks at all women choosing preventive mastectomy, not just BRCA positive. Also doesn't address the factors contributing to decision making.

Reference	Included or Excluded	Rationale
Segerer, R., Peschel, C., Kammerer, U., Haussler, S., Wockel, A., & Segerer, S. (2020). Decision-making towards prophylactic surgeries in BRCA mutation carriers and women with familial predisposition. <i>Breast Care</i> , 15(3), 253-259.	Included	Identifies objective and emotional factors that impact the decision making process
Singh, K., Lester, J., Karlan, B., Bresee, C., Geva, T., & Gordon, O. (2013). Impact of family history on choosing risk-reducing surgery among BRCA mutation carriers. <i>American Journal of Obstetrics & Gynecology</i> , 208(4), e1-e6.	Included	Investigates factors that influence decision making regarding prophylactic surgeries among BRCA positive women
Yadav, S., Jinna, S., Pereira-Rodrigues, O. Reeves, A., Campian, S., Sufka, A., & Zakalik, D. (2018). Impact of preoperative BRCA ½ testing on surgical decision making in patients with newly diagnosed breast cancer. <i>Breast Journal</i> , 24(4), 541-548	Excluded	Analyzes patients with breast cancer rather than asymptomatic women

Table 4*Literature Review Table of All Studies Included*

Citation	Study Purpose	Pop (N)/ Sample Size (n) /Setting(s)	Design/ Level of Evidence	Variables/ Instruments	Intervention	Findings	Implications
Hesse-Biber, S. (2014). The genetic testing experience of BRCA-positive women: Deciding between surveillance and surgery. <i>Qualitative Health Research</i> , 24(6), 773-789.	To analyze the lived experiences of BRCA positive women who choose surveillance or a radical surgical option	N-64 BRCA + women	Qualitative Study Level VI	Interviews between 1-1.5 hours, recorded over the telephone	N/A	49 women had preventive surgery and 14 did not . Those who did not have surgery felt there was no guarantee to develop cancer, and some were still wishing to have children. Other barriers were cost, lack of support from medical professionals, or lack of social support. Women do not follow a “medical” decision making model. Instead, women complete an assessment of their cancer risk with contributing factors of familial history, lived experience of family member dying from cancer, social support, and	Health care professionals and organizations must understand that the decision making of BRCA + women is not a “one size fits all.” Many factors come into play. Women have discussed the struggles of putting their experiences and decision making into the medical system that did not meet their needs. A women’s perspective must be understood in order to empower women with BRCA positive status.

						information from social network.	
Hesse-Biber, S., & An, C. (2016). Genetic testing and post-testing decision making among BRCA-positive mutation women: A psychosocial approach. <i>Journal of Genetic Counseling</i> , 25(5), 978-992.	Examines the role of demographic factors in women's decision making about treatment options and to what extent do psychosocial factors influence the time at which women choose surgery	N- 303 BRCA+ women	Qualitative Study Level VI	Online survey Multidimensional impact of cancer risk assessment (MICRA) and BRCA Self-Concept Scale questionnaire	N/A	Women without children were more likely to have the surgery than those with only sons; Those with daughters were more likely to have the surgery. The more distress a woman was over positive BRCA results, the less likely to get surgery and more likely to continue surveillance. The more uncertain about familial support, the less likely a woman was to have preventive surgery. This was also true for medical uncertainty. The more guilty a woman felt about passing trait to children, the more likely to undergo surgery.	In order to maximize cancer prevention strategies, clinicians must understand the decision making from a women's standpoint. Utilizing a feminist approach that highlights specific psychosocial factors in regards to medical decision making for risk reducing surgery is an important step forward. It may empower women's medical decision making abilities and improve overall outcomes.
Howard, A. F., Balneaves, L.G., Bottorff, J.L., & Rodney, P. (2011). Preserving the self: The process of decision making about hereditary breast cancer and ovarian cancer risk reduction. <i>Qualitative Health Research</i> , 21(4), 502-519.	To understand how women make decisions regarding risk reducing strategies (cancer screening, surgery-mastectomy, salpingo-oophorectomy).	N-22	Qualitative Study Level VI	Interviews, lasting 45-90 minutes; Digitally recorded and transcribed verbatim	N/A	Overall, the decision-making process is directed toward preserving self; These included physical health, self-identity as a woman, relationships with others, and emotional well-being.	The findings of preserving self provides direction of decision support. A women's decision goes beyond strictly physical health and includes a woman's self-identity, her emotional well-being, and her relationships with others. Information based approaches are less likely to be successful than those using psychosocial interventions that help with coping and adjustment.
Johns, D., Agarwal, J., Anderson, L., Ying, J., & Kohlmann, W. (2017). Breast cancer reduction decisions of the BRCA-positive patient: An observational study at a single institution. <i>Journal of Women's Health</i> , 26(6), 702-706	To understand the factors affecting the decisions for managing breast cancer risk made by patients who are BRCA mutation positive and cancer free	N-106 Women at the Huntsman Cancer Institute Family Cancer Assessment Clinic at the University of Utah	Retrospective Cohort Study Level IV	Chart review, demographic and clinical information based on electronic health record. A logistic regression model was applied. Factors included age, marital status,	N/A	Risk reducing strategy is a very personal decision; Age of the patient, relative with breast cancer or death of a relative before age 50, and prophylactic oophorectomy all play role in which reduction strategy is chosen. Patients less than 30 often proceeded with surveillance. This age there is greater desire to keep breasts for	The decision making process is complex and a highly personal decision involving a variety of factors for the provider to consider.

				children, personal history of cancer, family history of cancer, death of relative from cancer, obesity, and oophorectomy		breastfeeding or appearance. A personal family history of cancer plays an important role in perceived self-risk. If a patient undergoes one risk reducing surgery, they are more likely to opt for others.	
Leonarczyk, T.J., & Mawn, B. E. (2015). Cancer risk management decision making for BRCA + women. <i>Western Journal of Nursing Research</i> , 37(1), 66-84.	To explore the experience of cancer risk management decision making for women who are unaffected carriers of a BRCA mutation	N-15 Facing our Risk of Cancer Empowered (FORCE) an online informational and support group	Qualitative Study, phenomenological Level VI	Interviews- 25-60 minutes; 9 in person and 6 by telephone; Videotaped	N/A	Fear related to family experiences with cancer, body image, and concerns about fertility are factors affecting decision making. Urgency to have intimate relationships and complete childbearing before prophylactic surgery were other factors.	There is a need for knowledge and support by health care providers in this area. Telehealth can connect support systems to rural communities where resources are limited.
McQuirter, M., Castiglia, L.L., Loiselle, C.G., & Wong, N. (2010). Decision-making process of women carrying a BRCA1 or BRCA2 mutation who have chosen prophylactic mastectomy. <i>Oncology Nursing Forum</i> , 37(3), 313-320	To look at the decision making process of BRCA + women who undergo prophylactic mastectomy	N-10 Recruited from an outpatient cancer prevention center in the oncology and medical genetics departments of a hospital in Montreal, Quebec, Canada	Qualitative Study Level VI	Interviews	N/A	Pivotal points to definitively have a mastectomy were testing positive for a mutation, having a personal history of breast cancer, or having a family member with breast cancer. Emotions play a vital role in decision making; It is more complicated than weighing the pros and cons. Anxiety and worry come into play.	Awareness of pivotal points may assist nurses and health care professionals
Metcalf, K.A., Dennies, C.L., Poll, A., Armel, S., Demsky, R., Carlsson, L., Nanda, S., Kiss, A., & Narod, S.A. (2017). Effect of decision aid for breast cancer prevention on decisional conflict in women with a BRCA1 or BRCA2 mutation: A multisite, randomized, controlled trial. <i>Genetics in Medicine: Official Journal of the American College of Medical Genetics</i> , 19(3), 330-336.	BRCA ½ women must make critical decisions in regards to breast cancer prevention and screening; This study evaluates the effectiveness of a decision aid for breast cancer prevention in women with a BRCA mutation	N-150 Women recruited from 4 genetic clinic in Canada and through online support network based in the US	RCT Level II	Decisional Conflict Scale questionnaire measures a person's difficulty with decision making. Secondary outcomes were cancer related distress using IES.	Decisional aid to provide support regarding breast cancer prevention	The tool did not reduce decision conflict, but was effective in decreasing cancer-related distress in the year following a receipt of positive genetic test results. Cancer related distress is elevated in the positive BRCA ½ patient but it declines over time. The tool provided lower levels of long term cancer related stress in comparison to usual care.	Utilizing a decisional aid can better support women and reduce cancer related distress when compared with usual care especially for women who are undecided about their cancer prevention strategies.

				Knowledge of breast cancer risk via questionnaire			
Padamsee, T.J., Wills, C.E., Yee, L.D., & Paskett, E.D. (2017). Decision making for breast cancer prevention among women at elevated risk. <i>Breast Cancer Research</i> , 19(34), 1-12.	To examine the various approaches high risk women use in cancer risk management and the drivers of their decisions	N/A	Meta synthesis Level V	N/A	N/A	The processing of accurate information is crucial in order for women to make appropriate decisions. Better informed women make different decisions in comparison to those where shared decision making did not take place. Providers often provide less information than high risk women want. Intuitive and emotional decision making, shaped by personal experience and instincts is usually dominant over the conscious, analytic style of decision making.	Research findings can help support and empower women to make informed and value-consistent decisions and move towards favorable health outcomes
Portnoy, D.B., Loud, J.T., Han, P.K.J., Mai, P.L., & Greene, M.H. (2015). Effects of false-positive cancer screenings and cancer worry on risk-reducing surgery among BRCA ½ carriers. <i>Health Psychology</i> , 34(7), 709-717.	To examine (a) the effect of false-positive breast and ovarian cancer screening test results on perceived cancer risk and worry (b) the joint effect of FPTR, risk perception, and worry on the choice of surgery	N-170, women, breast screening with full BRCA ½ mutation carrier	Cohort Study Level IV	Questionnaire Age, race, ethnicity, education, parity, marital status, and personal history of cancer The Brief Symptoms Inventory-18 anxiety subscale, Breast Cancer worry scale (Likert type)	N/A	False positive results were not associated with opting for risk-reducing surgery	BRCA positive women worried about their cancer risk and in turn was associated with choosing surgical management
Puski, A., Hovick, S., Senter, L., & Toland, A.E. (2018). Involvement and influence of healthcare providers, family members, and other mutation carriers in the cancer risk management decision-making process of BRCA1 and BRCA2	To examine gene carrier decision making in cancer risk management and the role of others in the decision making process	N-20 Database of patients previously seen for cancer genetic counseling	Qualitative Study Level VI	Interview guide; Recorded and transcribed verbatim	N/A	Physicians, family members, and other mutation carriers were found to play an important role in the decision making process for surgical intervention.	Women with BRCA 1 or 2 mutation who have not had cancer, are under age 40, and/or do not have current children are found to have a more difficult time throughout the decision-making process of risk management. A genetic counselor

mutation carriers. <i>Journal of Genetic Counseling</i> , 27(5), 1291-1301.							may help ease the decision making process.
Salhab, M., Bismohun, S., & Mokbel, K. (2010). Risk-reducing strategies for women carrying BRCA ½ mutations with a focus on prophylactic surgery. <i>BMC Women's Health</i> , 10(28),1-10.	Mutation carriers have multiple options including surveillance, chemoprevention, and risk-reducing surgery; The aim of this review is to provide analysis and summarize the available literature in relation to risk-reducing strategies.	N/A	Meta-synthesis Level V	N/A	N/A	Cancer risk, survival, and overall quality of life are the important factors considered for making a good decision on risk-reducing strategies. Non-surgical options provide a good body image and a quality of life but can be found to increase risk of advanced stage cancer and mortality. The surgical route ensures high protection from cancer however is associated with a number of disadvantages of invasiveness, non-reversibility, and surgical morbidity.	The management of BRCA positive mutation carriers is challenging; It should consider a woman's expectations and preferences. These preferences can be informed by good knowledge or the risk and benefits of the options considered.
Segerer, R., Peschel, C., Kammerer, U., Haussler, S., Wockel, A., & Segerer, S. (2020). Factors impacting on decision-making towards prophylactic surgeries in BRCA mutation carriers and women with familial predisposition. <i>Breast Care</i> , 15(3), 253-259.	To identify factors that impact decision making process in BRCA mutation carriers	n-95 women with BRCA mutation	Cohort Study Level IV	Questionnaire Objective variables Psychological variables	N/A	Diagnosed cancer, cancer in the family, fear of getting cancer and assumed better benefits are factors leading to preventive surgery. Reasons for surveillance include importance of physical appearance, fear of rejection of partner, fear of disordered female identity, fear of never feeling healthy again etc.	Education on the benefits of surgery and reducing overall fear should take place as prophylactic surgery has been shown to reduce cancer incidence in comparison to periodic screening
Singh, K., Lester, J., Karlan, B., Bresee, C., Geva, T., & Gordon, O. (2013). Impact of family history on choosing risk-reducing surgery among BRCA mutation carriers. <i>American Journal of Obstetrics & Gynecology</i> , 208(4), e1-e6.	Analyzes factors that influence decision making regarding prophylactic surgeries among women with BRCA mutations	N-136 unaffected women with BRCA mutation Center in Los Angeles, CA	Cohort Study Level IV	Study subjects followed for 1-11 years. Medical records, operative reports, and family pedigrees were reviewed. Data collected included age, ethnicity, parity, mutation type,	N/A	Family history has a significant impact on the uptake of risk-reducing surgeries among BRCA mutation carriers. Women who lost their mother to breast cancer were more likely to have risk-reducing mastectomy and those who lost mother to pelvic cancer were more likely to have risk-reducing bilateral salpingo-oophorectomy. Overall, perception of cancer risk is heavily	With the increase in BRCA testing by primary care providers, the awareness of subtle factors beyond statistical risk for cancers is relevant when providing support and counseling to at risk women. Providers should educate the patient regarding her risk, but also understand the attitudes surrounding management options.

				history of breast biopsy, previous cosmetic surgery,		associated with a family history and are motivators of preventive surgery. Having children also found to be associated with uptake of prophylactic surgery.	
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