REVIEWS

Factors influencing women's decisions to getting tested for BRCA mutation

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ABSTRACT

Ovarian cancer is the leading cause of death among gynecological cancers. There are many risk factors that can increase a woman's susceptibility to breast and ovarian cancers, some of which are modifiable. However, non-modifiable risks for breast and ovarian cancer include the presence of genetic mutations (BRCA) increase the risk of these diseases. The purpose of this review was to identify factors, reported in the literature, known to affect women's decision to get genetic testing for BRCA1 and BRCA2 mutations for hereditary breast and ovarian cancer. A total of 31 studies that met the inclusion criteria were included in this review. Several internal and external factors, influencing women's decision to getting tested for BRCA mutations, were identified and explained. Implications for clinical practice were provided.

Key Words: BRCA, Ovarian cancer, Breast cancer, Women, Mutation, Decision

1. INTRODUCTION

Ovarian cancer is the leading cause of death among gynecological cancers. Due to its late symptom onset, many women who have ovarian cancer are diagnosed after it has spread or progressed. Estimations of new cases of ovarian cancer for 2018 are 22,240 with an estimated 14,070 deaths from the disease.[1] Estimations of new cases of breast cancer for 2018 are 266,120 with an estimated 40,920 deaths from the disease.[1] There are many risk factors that can increase a woman's susceptibility to breast and ovarian cancers, some of which are modifiable. Estimated lifetime risk for the general population of women is approximately 12.4% for breast cancer and 1.3% for ovarian cancer.[1] However, non-modifiable risks for breast and ovarian cancer include the presence of genetic mutations that increase the risk of these diseases.[1] In particular, a women who has a BRCA1 mutation has an increased lifetime risk of 72% for breast cancer and 44% for ovarian cancer while women who carry a BRCA2 mutation has an increased risk of 44% for breast cancer and 17% for ovarian cancer.[2] Because of this substantially increased risk, all women should be screened as part of their routine health visits and, if they are high-risk, should be referred for genetic counseling and possible future genetic testing for the presence of the BRCA1 or BRCA2 mutations.[3]

With the emergence of new technology, screening, and advances in genetic testing, women today are able to employ methods to decrease risk of genetically predisposed diseases such as breast and ovarian cancer. Genetic tests are available that can identify woman carrying a specific genetic mutation, which can increase the risk of breast and ovarian cancer, and other types of cancer.[4] In addition, the BRCA1 and BRCA2 gene mutations can be passed down from generation to generation from both paternal and maternal lineages. The risk for this autosomal dominate gene is 50% in offspring of a

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parent who carries the gene.[4] The presence of a BRCA1 or BRCA2 genetic mutation also increases the risk of other cancers for both male and female including prostate, pancreatic, bile duct, cervical, uterine, testicular, colon, stomach, and male breast cancer.[1]

1.1 Purpose

The purpose of this integrative review is to identify factors, reported in the literature, known to affect women's decision to get genetic testing for BRCA1 and BRCA2 mutations for hereditary breast and ovarian cancer. The findings of this review may help provide guidance to clinical practice.

1.2 Design

The design selected for this research is an integrative review. An integrative review helps to identify, analyze and synthesize findings from a variety of studies, both quantitative and qualitative, to help determine the knowledge available regarding a specific research topic.[5] Essential components of the integrative literature review include the purpose, a description of the literature search, discussion of the amount of research studies included in the review and the adequacy of that number, methods and criteria used to evaluate the rigor of the scientific studies, and a clear presentation of the findings.[6]

2. Methods

The studies included in this review were obtained from online computer searches utilizing the following databases: CINAHL, MEDLINE, and PsycINFO. The key words used were BRCA and decision. Due to an inability to further narrow the studies based on keywords, several articles were reviewed for inclusion criteria. Inclusion criteria for this review included: (a) studies published between 2010 and 2018; (b) publication in the English language; (c) studies focused on women's decisions related to getting tested for the presence of a mutation on the BRCA gene. Results yielded 268 publications in Medline Plus, 184 studies in CINAHL, and 59 studies in PsycINFO. Some of the studies did appear in more than one of the databases. After reading the abstracts, a total of 31 studies were identified to meet the inclusion criteria for this review. There were several studies that did not meet the specific criteria of decisions related to getting tested for the presence of a mutation on the BRCA gene. The search terms yielded a majority of studies related to decisions once found positive for the presence of a mutation on the BRCA gene. Retrospective studies and studies with a portion of their sample not yet tested for the BRCA genetic mutation were included in this review. Once the studies were identified, the articles were reviewed to identify all factors, both internal and external, found to have impacted a women's decision to get tested for BRCA genetic mutations.

3. Findings

This was the first integrative review to identify factors, reported in previous literature, that may affect a patient's decision to undergo genetic testing. Several internal factors related to the individual were identified including culture, religion, family involvement, risk to family, intent for risk reduction surgery, young age, and a new diagnosis of cancer. In addition, external factors not related specifically to the individual were identified including readiness of healthcare providers to provide information on genetic testing, the monopoly that Myriad laboratories had on the specific sequencing for genetic mutations on the BRCA gene, the impact of celebrity Angelina Jolie's widely publicized personal journey through genetic testing and subsequent risk reduction strategies, and access to genetic testing in rural areas. Below is an explanation of each reviewed factor.

3.1 Readiness of healthcare providers

One identified factor extrinsic to the individual is the readiness of healthcare providers to engage in discussions and appropriate referral for genetic testing. Two studies were found to have identified this as a possible factor affecting women's decision to undergo genetic testing. Crotser and Dickerson (2010) found that many women experienced turmoil related to genetic testing and felt isolated and unsupported by healthcare providers during the decision making process.[7] Additionally, as presented by Smania (2016), several advanced practice healthcare providers, specifically Nurse Practitioners may not be knowledgeable or ready to identify patients who would benefit from hereditary breast and ovarian cancer (HBOC) genetic testing.[8] The study by Smania (2016), helped to identify a point of care tool in the form of a Mobile Health Technology (MHT) application that was shown to ease the transition for healthcare providers. Point of care tools may be necessary and valuable at the bedside to assist healthcare providers in assessing patients at risk for BRCA mutations and appropriately referring them for genetic counseling and testing.[8]

3.2 Cultural/religious factors

Five studies identified culture or religious factors as playing a key role in a woman's decision to undergo genetic testing and/or counseling. One specific population, African Americans, was found in 3 studies. Cukier et al. (2012) found that African Americans experience high rates of distress associated with the perceived risk of a possible genetic mutation, especially amongst those participants with lower incomes or diagnosis of breast or ovarian cancer.[9] Hurtado-de-Mendoza, Jackson, Anderson, and Sheppard (2017) found

there is a lower rate of genetic counseling and testing among black cancer survivors. This was found to be related to decreased knowledge, self-efficacy, and lack of referral for genetic testing and counseling thus there is a need to improve the education in this group and engage in referrals as appropriate.[10] Halbert et al. (2012), however, identified African Americans having lower rates of participation in genetic counseling and subsequent testing may not necessarily be related to disparities and lack of access but rather related to values and preferences of this specific population.[11]

Another population identified in two research studies included Jewish patients. Tang et al. (2016) found in high-risk Jewish Ashkenazi populations there was an increased likelihood of undergoing genetic testing with increased self-efficacy and higher knowledge base regarding genetic testing implications. Other motivators in this group included fear of getting cancer, fear of dying of cancer and fear of passing gene onto children which lends strong support for increasing decision support tools and education to increase uptake of genetic testing in this high risk group.[12] One of the concerns identified by Bressler and Popp (2016) in specific Orthodox Jewish groups is the role of the Rabbi and faith based leaders with respect to their followers. Many Orthodox Jewish patients seek counsel from their Rabbi/leader prior to engaging in specific medicinal interventions. There is a wide discrepancy of knowledge amongst the leaders related to BRCA genetic testing and counseling and subsequent interventions directed at reducing the risk of breast and ovarian cancer. In addition, determinism is a major theme within the Orthodox Jewish community, whereby it is in God's plan what happens and the Orthodox Jewish patient may not feel preventing what is in God's plan is appropriate, especially after counsel with their faith based leaders. This can cause disconnect in patients undergoing genetic counseling and testing.[13]

3.3 Family involvement or concern for family risk

Only one study by Katapodi, Northouse, Milliron, Liu, and Merajver (2013) identified the role of family as being important to making the decision of undergoing genetic testing. The researchers found an individual undergoing genetic counseling and testing require support, perhaps from family members. They concluded by increasing family care in addition to individual care, there may be increased support for the individual which may increase the uptake of genetic counseling and testing by at-risk family members as well as the individual.[14]

Three studies identified concern for family members having an impact on uptake of genetic counseling and/or testing. A study by Bylund et al. (2011) found significant uncertainty was revealed with mothers during genetic counseling sessions. The three main themes of uncertainty were 1) the patients daughters risk of developing disease, 2) how to communicate test results to daughter, and 3) need for future screening. Practice implications include the need to address uncertainty with patients who have daughter(s) who may be at risk.[15] Uncertainty management in the form of informational support and emotional support is imperative in the genetic counseling sessions.[16] Zilliacus et al. (2011) also identified family risk and communicating to at-risk family members as having a role in women's' perceptions of advantages and disadvantages to undergoing treatment focused genetic testing.[17]

3.4 Access to genetic counseling/testing

Lack of access to counseling was reported, as a factor, by two reviewed studies. Schwartz et al. (2014) reported that many women do not have access to trained genetic counselors due to a shortage of such trained individuals. They further stated traditional healthcare providers may lack the ability to appropriately manage the needs of a person requiring genetic counseling and subsequent genetic testing. The purpose of this study was to see if telephone counseling could fill the gap of traditional face-to-face genetic counseling. It was found that telephone counseling is not inferior to in-person counseling and can be used to increase access to counseling and decrease costs associated with travel and in-person genetic counseling. Insurance reimbursement for this type of counseling may still be a barrier, but continued studies to show the efficacy of this type of counseling can encourage an increase in reimbursement for this care.[18] In a follow-up to this original study, Kinney et al. (2014) found utilizing telephone counseling may help to increase access to counseling and informed communication settings without increasing psychological distress although fewer participants choose to undergo genetic testing with this method. This may be related to several other barriers including ease of mailing test samples back and coverage of costs associated with testing.[19]

Numeracy and health literacy is a factor in all aspects of health care that may effect appropriate access to services, as well. In one study by Portnoy, Roter, and Erby (2010) it was found that health care providers should be aware of a patient's level of health literacy and numeracy to adequately tailor information given to the individual to increase comprehension of information and risk results.[20]

3.5 Surgical intervention intent

One study by Tong et al. (2015) found that a significant motivator to receiving genetic testing was the desire to undergo surgical intervention to reduce perceived risk of cancer. Of-

tentimes, a woman who has a significant family history seeks out genetic counseling and testing with the knowledge that she would like to reduce their risk of cancer. A large percentage of high risk women consenting to genetic counseling for BRCA genetic testing already have intentions of receiving risk reducing surgery; 43% risk reducing oophorectomy, 23% risk reducing mastectomy.[21]

3.6 New cancer diagnosis

The most significant factor found in 9 publications that influenced a woman's decision to undergo genetic testing was the diagnosis of cancer. Smith and Isaacs (2011) state many women newly diagnosed with breast or ovarian cancer will have many decisions to make related to treatment of the cancer. There is a definitive need to increase uptake of genetic counseling and BRCA1 and BRCA2 testing prior to decisions regarding cancer treatment and surgical interventions for women with a new diagnosis of cancer. This may help guide them to the best informed decision for managing current cancer diagnosis and reducing risk of future cancer and support them through the decision making process.[22] Having access to BRCA status prior to having surgery may also change a woman's decision on type of surgery to undergo.[23–26] There is not a perceived increase in psychological stress or burden associated with introducing rapid genetic counseling and testing at the time of diagnosis.[27,28] Women with ovarian cancer identify wanting treatment focused genetic testing information prior to undergoing surgery and treatment for ovarian cancer and prefer to have it individualized to their disease management by their oncologist, not a genetic counselor.[29] It would be beneficial to have a genetic specialist on site in cancer centers to decrease wait times and gain access to timely information prior to undergoing surgery for breast cancer.[30] Oncologist led, versus genetic counselor led, BRCAm testing for ovarian cancer patients is another option with high rates of satisfaction amongst patients and oncologists.[31]

3.7 Young age

Young age was found to be a factor in receiving genetic testing in two studies. Werner-Lin, Hoskins and Doyle (2012) found that women who are beginning their adult years have a wide variety of life trajectories that may change in a short period of time making their decisions regarding genetic testing and positive results fluid as life events change including familial status, child-bearing decisions, insurance changes, and screening recommendations which do not typically start until later years for the at risk.[32] Another study found young women have unique unmet needs and may require additional interventions to reduce decisional conflict and increase effective coping.[33]

3.8 Angelina Jolie effect

Four studies identified a celebrity having a profound impact on the uptake genetic testing. In 2013, Angelina Jolie, a famous celebrity in the US and abroad, made an announcement sharing her positive BRCA1 mutation result and subsequent prophylactic surgery management strategies. The response across the globe was identified via many studies. In the United Kingdom, there was a significant increase in women seeking referrals and genetic testing in the months following Angelina Jolie's announcement of her BRCA status and associated preventative surgeries.[34] According to Freedman, Mountain, Karina, and Schofield (2016), the Familial Cancer Program in Western Australia saw a substantial increase in referrals for genetic counseling and testing from an average of 71 a month in 2012 to an average of 181 a month in 2013 after Angelina Jolie's announcement. With this increase, however, it was found that existing programs were not sufficient and needed to develop additional strategies to manage the increased workload.[35] In the United States, there was an increase of genetic testing from 0.71 per 100,000 women in the 15 days prior to Angelina Jolie's announcement to 1.13 per 100,000 women in the 15 days after her announcement.[36] Overall, via an in-depth review of the literature after the announcement in 2013, it was found that there was an increase in uptake of genetic testing as a direct result of Angelina Jolie's announcement.[37]

3.9 Myriad lab monopoly

One extraneous factor identified in two journals outside of nursing that may have an impact on a patient receiving genetic testing and counseling included controversy associated with the patent for the BRCA1 and BRCA2 genes. According to Levy (2014), until 2013, Myriad labs had a patent on the isolated genes BRCA1 and BRCA2 leading to a decrease in access to genetic testing unless specifically done through Myriad.[38] The supreme court ruling eliminated the patent on these genes, however, the databases with the decades of history of previous genetic sequences associated with BRCA1 and BRCA2 mutations is still privately held through Myriad labs.[38,39]

3.10 Study limitations

One potential limitation of this review includes using only three search engines to search for inclusive articles and journal submissions, CINAHL, Medline Plus, and PsycInfo. This most likely resulted in articles and journals that were not included in this review and perhaps inadequate sampling. Additional limitations of this integrative literature review includes lack of specificity of the populations within the databases. When using the selected search terms, several studies came up that were not pertinent to the population

identified here which included only women who had not yet been tested for BRCA mutation. Many studies included populations of women who had been tested and who had not been tested, so there was difficulty finding study information for the specified populations. Studies that had a portion of their sample not tested for BRCA genetic mutations were included in this review. There were several studies that were retrospective for women who had been tested for the BRCA genetic mutations, but chart reviews identified these women and their decisions before getting tested and how those decisions changed after getting tested and/or having a positive result for a BRCA genetic mutation. These retrospective studies were also included.

3.11 Nursing implications

It is imperative for advanced health care professionals to empower their patients with knowledge that could potentially decrease anxiety, decrease disease risk, and aid in closer screening for the high risk individual. In addition, it impacts our practice by implementing current best guidelines in the care of our patients. By obtaining evidence-based research regarding factors that encourage or dissuade patients from receiving genetic testing and counseling, health care professionals may be able to better support and educate high risk individuals during the decision making process to help alleviate distress and aid in preventative approaches to decrease individual patient risk. Based upon the current review of the literature, the decision to undergo genetic counseling and testing may be influenced by several factors including current health status or disease state, access to services, availability and cost of test, religious and cultural factors, risk to family members, celebrity impact, age, knowledge, numeracy and health literacy, availability and cost of test, and readiness of healthcare providers. Geneticists, genetic counselors, and advanced health care providers should incorporate this knowledge when referring patients for BRCA counseling and testing to allow for the patient to be fully informed before making critical decisions to test for BRCA mutations and/or initiate strategies to manage elevated risk for breast and ovarian cancer for both the patient and their at-risk family members. They should also allow the possibility of individual patient's decision process that may not fit into any of the factors listed.

Future recommendations for research includes continuing to synthesize the data that is available based upon the many factors associated with a woman's decision to get tested for BRCA mutations. Due to the large amount of studies that are available in the databases with ambiguous search teams, it is necessary for health care professionals to continue to synthesize the data into systematic and integrative reviews based upon the many factors associated with genetic testing and counselling for BRCA mutations.

4. Conclusion

With one of the overreaching goals of Healthy People 2020 being to incorporate genetic testing for some of the most common illnesses and diseases, it is timely and pertinent to discuss the decision-making process for women who may choose to undergo genetic testing for BRCA mutations (U.S. Preventive Services Task Force, 2013). Perhaps, with a greater understanding of the variables affecting women during the decision making process, nursing professionals will better be able to tailor the counseling and screening of women for these mutations with individualized approaches. Furthermore, the education process for women prior to undergoing genetic testing for BRCA mutations can affect their overall desire to undergo further intervention to reduce disease risk. It is imperative for healthcare professionals to understand the motivating factors that contribute to women following current recommendations to reduce disease risk, while also being sensitive to variables that may negate a woman from wanting to follow current treatment recommendations. The results of this review can contribute to better strategies to incorporate before, during, and after genetic counseling and testing to prevent disease and promote the health of high risk women with positive BRCA mutations.

Conflicts of Interest Disclosure

The authors declare that there is no conflict of interest.

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