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The Relationship Between Self-concept and Body Image in Females with Deleterious BRCA1/2 Mutations

Amanda M. Large
Philadelphia College of Osteopathic Medicine

Philadelphia College of Osteopathic Medicine

Department of Psychology

THE RELATIONSHIP BETWEEN SELF-CONCEPT AND BODY IMAGE IN FEMALES WITH DELETERIOUS BRCA1/2 MUTATIONS

Amanda M. Large

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Dissertation Approval

This is to certify that the thesis presented to us by Amanda Large

on the 9th day of May, 2015, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

Committee Members' Signatures:

Chairperson

Chair, Department of Psychology

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Abstract

Among women in the United States, breast cancer is the second most commonly diagnosed cancer and is the second-leading cause of death (American Cancer Society, 2015b). A subgroup of women with genetic mutations called BRCA1/2 mutations are at a significantly higher lifetime risk of developing breast cancer, among other cancers (Friedman, Sutphen, & Steglio, 2012). While the research base is growing with regard to women with BRCA1/2 mutations, little is known about the psychological experience of having a BRCA1/2 mutation and the challenges and obstacles that having a BRCA1/2 mutation entails throughout the lifetime. This study looked at women with BRCA1/2 mutations who had undergone a prophylactic bilateral mastectomy compared to women who had chosen to undergo surveillance methods only to manage their breast cancer risk. It was hypothesized that women who had undergone a prophylactic bilateral mastectomy would display greater experiences of stigma, greater experiences of vulnerability, and fewer mastery experiences, as well as would rate higher on investment in appearance and investment in body integrity, when compared to women who had not undergone a prophylactic bilateral mastectomy and only underwent surveillance methods. Participants in this study included women who had tested positive for a deleterious BRCA1/2 mutation who spoke and understood English and were older than the age of 18 years. These women completed an online survey that asked demographic questions, as well as questions about body image and self-concept. Two separate MANOVAs were conducted to analyze the results. No significant differences were found between groups. The

implications of these findings are discussed, as well as limitations of the study and the need for more research on this area of study.

Keywords: BRCA mutations, BRCA1, BRCA2, self-concept, body image

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Chapter 1: Introduction

Statement of the Problem

Among women, breast cancer is the second most commonly diagnosed cancer and is the second-leading cause of death (American Cancer Society, 2015b). In 2015, approximately 234,190 new cases of breast cancer were diagnosed, and approximately 40,730 deaths from breast cancer occurred (American Cancer Society, 2015b). Approximately 10 to 15% of all cases of breast cancer are the result of genetic predisposition, with the most common genetic predispositions being mutations on the BRCA1 and BRCA2 genes (Lux, Fasching, & Beckmann, 2006; Pruthi, Gostout, & Lindow, 2010). The BRCA1/2 genes are human genes that produce tumor suppressor proteins, which help repair damaged DNA (American Cancer Society, 2015a). When either of these genes is mutated or altered, DNA damage may not be repaired properly, thus increasing the likelihood that additional genetic alterations can subsequently occur, leading to cancer (American Cancer Society, 2015a). Thus, women with identified deleterious mutations on the BRCA1/2 genes have a significantly increased lifetime risk of developing breast cancer (i.e., 40 - 85%), as well as other cancers, including ovarian cancer, pancreatic cancer, and melanoma (Antoniou et al., 2003).

Genetic testing and counseling are becoming increasingly more available; however, not all individuals at risk get tested, and positive results lead to difficult discussions and decisions. For women who have undergone genetic testing and received positive results in terms of a BRCA1/2 mutation, a multidisciplinary, individualized medical evaluation and treatment approach has been demonstrated to be beneficial

(Pruthi et al., 2010). This approach offers the ability to educate those at high risk of developing cancer about prevention and risk-reducing options, as well as to provide the chance to detect cancer early and to improve survival. This approach, however, is not always available (Pruthi et al., 2010). This multidisciplinary approach typically involves a healthcare team, which may include a primary-care physician, gynecologist, breast surgeon, plastic surgeon, gynecological oncologist, and others. These healthcare professionals may collaboratively help their shared patient decide the path to take in terms of prevention, both when the individual has not had cancer and when the individual has had cancer.

The three most common preventative pathways that individuals with BRCA1/2 mutations choose from are surveillance, chemoprevention, and preventative surgery (Pruthi et al., 2010). The surveillance pathway often involves regular mammograms, breast magnetic resonance images (MRIs), and manual breast exams by a healthcare professional (Nelsen, Huffman, Fu, & Harris, 2005; Saslow et al., 2007), whereas the the chemoprevention pathway involves taking a medication designed to decrease the risk of cancer development, and the preventative surgery pathway involves a prophylactic bilateral mastectomy (PBM)(Friedman, Sutphen, & Steligo, 2012). The decision to pursue one of these pathways over another is difficult and personal; ideally, this decision is made with the support of a multidisciplinary healthcare team. Despite the support that women with BRCA1/2 mutations have through various members of the healthcare system, these women are placed in the position of choosing between the “lesser of two evils” in terms of cancer prevention efforts.

While research has begun to address the psychological impact and distress that those with BRCA1/2 mutations experience, possibly as a result of the life-changing decisions that accompany this diagnosis, much of the research focuses on the effects of genetic testing and is short term in scope. Among the studies that have examined distress in women who received positive results in terms of BRCA1/2 mutations, some women have shown increased distress post test (e.g., Dorval et al., 2008; Graves et al., 2012; Reichelt, Moller, Heimdal, & Dahl, 2008), while others have shown no change or less distress (e.g., Smith et al., 2008; Timman, Stijnen, & Tibben, 2004). This inconsistency suggests that other variables, such as preventative treatment choices, are mediating, moderating, or otherwise affecting the relationship between carriers of BRCA1/2 and distress. This absence of elevated distress also may reflect a habituation to the persistent distress associated with being in a family with hereditary breast and ovarian cancer (HBOC) syndrome (Lerman, Schwartz, Narod, & Lynch, 1997).

Increased levels of distress among carriers of BRCA1/2 mutations are associated with a greater number of unmet needs, including various emotional and functional needs, such as dealing with uncertainty about the future, fears about cancer, and identifying resources to make the most informed healthcare decisions (Farrelly et al., 2013). To meet the overall needs of this population and to ensure that women with BRCA1/2 mutations receive quality care, one must understand the process of adjustment to being at risk of hereditary breast cancer (Den Heijer et al., 2011). Ben Zur (2002) suggested that psychological resources, such as self-esteem, play a crucial role in the adjustment to stressful life events. Self-esteem in particular is strongly associated with psychological

functioning, as well as with higher levels of overall well-being in patients with cancer (Schroevers, Ranchor, & Sanderman, 2003). Self-esteem is considered one dimension of self-concept, with self-concept defined as the sense of being separate and distinct from others, as well as the awareness of the constancy of the self (Curbow, Somerfield, Legro, & Sonnega, 1990). Self-concept consists of five significant elements, all of which are affected during the diagnosis and treatment of cancer: alteration in bodily experience, discrepancy between actual and ideal self, disruption of personal relationships, self-deprecating meaning of cancer, and depression (Katz, Rodin, & Devins, 1995).

Both gynecological cancers and breast cancers have a unique and significant effect on the self-concept and body image of women (Kullmer et al., 1999). A significant impact on self-concept of patients with cancer has been demonstrated and is even more pronounced in women with recurrent disease episodes (Kullmer et al., 1999). Additionally, Esplen et al. (2009) has been suggested that one negative impact of receiving a BRCA1/2 diagnosis alone can alter one's body image and self-concept. In women with BRCA1/2 mutations, disturbances in body image have been found, specifically in terms of altered breasts and breast sensation, mistrust of body, loss of sensation or function, feeling older, loss of reproductive functioning, weight gain, and altered body shape (Hallowell, Mackay, Richards, Gore, & Jacobs, 2004; McGaughey, 2006). Any new information about oneself, such as a breast cancer or BRCA1/2 diagnosis, can threaten an existing self-concept, with the treatment/prevention options of these diagnoses also affecting body image (McConkie-Rosell & DeVillis, 2000). Body image is often impaired as a result of cancer treatments, which can include

chemotherapy, radiation, and surgery components (Kullmer et al., 1999). These impairments in body image and self-concept persist for long periods of time, as demonstrated in studies of patients with breast cancer (Lasry & Margolese, 1992; Taylor, Lichtman et al., 1995).

Owing to the presence of multiple similarities in the research between carriers of the BRCA1/2 mutation and women with breast cancer, these disturbances in self-concept and body image likely are also shared between these populations. These alterations in self-concept and body image are likely more prevalent in women with BRCA1/2 mutations who have undergone prophylactic surgery or surgery as part of breast cancer treatment, as the literature generally does not distinguish between these two groups of women. These alterations in self-concept and body image may be particularly evident in women with BRCA1/2 mutations who have undergone a PBM, as these women have experienced significantly more changes and alterations in their bodies compared to women with BRCA1/2 mutations who have chosen surveillance or chemoprevention options. Thus, a link between body image and self-concept may be more pronounced in women with BRCA1/2 mutations, especially those who have undergone a prophylactic surgery (i.e., a PBM).

Purpose of the Study

The purpose of this study is to explore self-reports of body image and self-concept in women with deleterious BRCA1/2 mutations, with a specific focus on women with deleterious BRCA1/2 mutations who have either undergone a PBM to decrease the chance of developing breast cancer or elected to engage in surveillance methods to

monitor cancer risk. Data were obtained through electronic surveys presented to women through various online methods. At present, little is known about the characteristics and needs of this population. Exploring the unique struggles that women with BRCA1/2 mutations face will help The more that is understood about the obstacles this population faces, the better the chances that medical and mental-health professionals will be able to identify problems in clients when they arise in order to ensure that the needs of this population are met to increase the overall understanding and unique needs of this population. Thus, this study adds to the growing literature base about women with BRCA1/2 mutations in terms of their obstacles and needs.

Literature Review

Breast Cancer

Among women in the United States, breast cancer is the second most commonly diagnosed cancer and is the second-leading cause of death (American Cancer Society, 2015b). Worldwide, more than 1,000,000 new cases of breast cancer are diagnosed every year (Friedman et al., 2012). In the United States, it is estimated that 234,190 new cases of breast cancer will be diagnosed in 2015, with an estimated 40,730 deaths from breast cancer occurring each year (American Cancer Society, 2015b). Breast cancer deaths have declined since 1990 as the result of an increase in public awareness, better methods of early detection and prevention, and treatment advances (Friedman et al., 2012). However, the diagnosis and death rates remain high, reinforcing the need for additional research into treatment and prevention efforts.

Types of breast cancer. Although several types of breast cancers exist, studies rarely report the types of breast cancer developed by participants or the specifics of these cancers. In general, breast cancer typically begins in the glands that produce milk (lobules) or in the tubes that carry milk to the nipple (ducts; Friedman et al., 2012). The tumors that grow within the breast are either in situ, which are early-stage breast cancers that remain within the lobules or ducts, or invasive, which have the potential to metastasize through the blood to other parts of the body (Friedman et al., 2012). This potential is true for the five main types of breast cancers: ductal carcinoma in situ (DCIS), lobular carcinoma in situ (LCIS), invasive ductal carcinoma (IDC), invasive lobular carcinoma (ILC), and inflammatory breast cancer (IBC).

DCIS is a breast cancer that develops in the milk ducts within the breast and is found to be as common as one in five new breast cancer cases (Friedman et al., 2012). This type of breast cancer is considered the earliest stage of breast cancer; however, if undetected and untreated, it has the potential to become invasive and metastasize (Friedman et al., 2012). Unfortunately, this cancer is often too small to be felt and is typically found only during a routine mammogram or MRI). Similar to DCIS, LCIS also typically cannot be felt, as it is often found during biopsies when examining suspicious lumps, microcalcifications (i.e., residue from rapidly dividing cells that may signal early cancer), or another abnormality found on a regular screening (Friedman et al., 2012). LCIS is most common in premenopausal women and is not considered a true breast cancer, as it involves the presence of abnormal cells that signal a higher-than-average risk of developing invasive breast cancer (Friedman et al., 2012).

While DCIS and LCIS represent a lack of spread of cancer beyond the ducts or lobules, IDC is a true breast cancer that has spread beyond the ducts to surrounding breast tissue (Friedman et al., 2012). IDC is the most common breast cancer, representing 80% of all cases, and is more common after age 55 years (Friedman et al., 2012). Similar to IDC, ILC is a true breast cancer that has spread beyond the lobules to surrounding breast tissue (Friedman et al., 2012). IDC represents 10% of all breast cancers and is more commonly diagnosed after age 60 years (Friedman et al., 2012). Finally, IBC is a true breast cancer that presents much differently from other breast cancers. IBC often begins with reddening or swelling of the breast rather than with a lump, and its symptoms can worsen significantly within a single day (Friedman et al., 2012). This type of cancer represents only 1 to 3% of all breast cancers and is most common in women in their fifties (Friedman et al., 2012).

Within these five main types of breast cancer, differences exist in terms of tumor characteristics and staging. In terms of tumor characteristics, the involvement and role that hormones play in the cancer are imperative in determining the best treatment for the individual. Cancers with hormone receptors are referred to as estrogen receptor-positive (ER+) and progesterone receptor-positive (PR+) and respond well to antihormone treatments that can either reduce the amount of estrogen or progesterone in the body or block the tumor's ability to use those hormones to grow (Friedman et al., 2012). Additionally, approximately one in three cancers overexpresses the HER2/neu protein, which is a protein that promotes the growth of cancer cells (Friedman et al., 2012). Cancers that are characterized by an overexpression of the HER2/neu protein respond

well to treatments that target these specific receptors. Some cancers, however, do not respond to hormone therapies (i.e.., are not ER+ or PR+) and are also not sensitive to HER2/neu treatments. These cancers are referred to as triple-negative breast cancers and represent 15% of all breast cancer diagnoses (Friedman et al., 2012).

Cancer staging is the process of determining the extent to which a cancer has developed based on the size or extent of the primary tumor and whether or not cancer has spread through the body (Friedman et al., 2012; National Cancer Institute, 2015). Staging helps physicians plan appropriate treatments, determine patient prognosis, identify possible clinical-trial options, and exchange information about patients with other healthcare providers (National Cancer Institute, 2015). Stages are represented on a scale from 0 to 4, with higher numbers indicating more extensive disease (National Cancer Institute, 2015). Stage 0 is considered a preinvasive cancer that has not spread and includes a diagnosis of DCIS (Friedman et al., 2012; National Cancer Institute, 2015). Stages 1 through 3 depend on tumor size and lymph node involvement, the greater the severity, the higher the stage (Friedman et al., 2012; National Cancer Institute, 2015). Finally, Stage 4 represents metastasized cancer, or cancer that has spread to distant tissues or organs (Friedman et al., 2012; National Cancer Institute, 2015).

Hereditary cancer. Genes contain instructions for critical body functions and hold all hereditary information and material passed from parent to child (Friedman et al., 2012). Cells often develop mutations when they divide, with some mutations occurring as a result of environmental and lifestyle influences, such as smoking, chemical exposure, or alcohol consumption (Friedman et al., 2012). However, the body frequently repairs

genetic damage before the mutation is copied to new cells (Friedman et al., 2012). At times, genetic damage cannot be repaired, sometimes as a result of a genetic mutation in a tumor suppressor gene. This unrepairable damage creates a vicious cycle of replication, resulting in passing unrepaired mutations onto the next generation of cells (Friedman et al., 2012). Similarly, if an error occurs in the egg or sperm, it may pass from parent to child in successive generations, which is the case with hereditary cancer (Friedman et al., 2012).

In recent years, scientists have discovered several genetic mutations that can contribute to an individual's risk of developing certain kinds of cancers, including breast cancer. Approximately 10 to 15% of all cases of breast cancer are the result of genetic predisposition, meaning that they are hereditary, and not sporadic breast cancers (Lux et al., 2006; Pruthi et al., 2010). Hereditary cancers differ from sporadic cancers in a variety of ways. Hereditary breast cancers often occur at an earlier age than sporadic forms of breast cancer. As a result, those at risk for hereditary breast cancer are recommended to follow different cancer screening plans different from the general population (e.g., beginning routine screening at earlier ages) and have different risk reduction strategies available to them (National Cancer Institute, 2015). Several genetic mutations have been linked to an increased risk of developing a hereditary breast cancer.

Genetic Mutations

Two categories of genes are associated with increased risk of breast cancer (Friedman et al., 2012). The first category of mutations, including BRCA1/2, TP53, PTEN, STK11, and others, is considered rare and is associated with a significant increase

in risk (Friedman et al., 2012). For example, BRCA1/2 mutations are most prevalent in the Ashkenazi Jewish community, with one in 40 of these individuals testing positive, compared to one in 350 to one in 500 in the general population (Friedman et al., 2012). A subset of this grouping of mutations includes ATM, CHEK2, PALB2, and other genes, which are linked to a higher risk of breast cancer than those in the general population, but lower risk than that associated with BRCA mutations (Friedman et al., 2012). The second group includes various single nucleotide polymorphisms, which are mutations that only slightly increase breast cancer risk (Friedman et al., 2012). Despite this multitude of genetic mutations that can contribute to the potential development of breast cancer, most incidents of hereditary breast cancer are caused by two mutated genes: the BReast CAncer1 and BReast CAncer2 (BRCA1/2) genes (Friedman et al., 2012; Lux et al., 2006; Pruthi et al., 2010).

BRCA1/2 mutations. The BRCA1/2 genes are human genes that produce tumor suppressor proteins that help repair damaged DNA (American Cancer Society, 2015a). When either of these genes is mutated or altered, DNA damage may not be repaired properly, thereby increasing the likelihood that additional genetic alterations can occur and subsequently lead to cancer (American Cancer Society, 2015a). Having two copies of each damage-repairing gene, or each BRCA1/2 gene, acts as a backup repair system: If one gene is mutated and cannot repair damage, the other one can (Friedman et al., 2012). Thus, being born with a single BRCA1/2 mutation does not guarantee the development of breast cancer, as the healthy BRCA gene can effectively and efficiently repair DNA damage as it occurs (Friedman et al., 2012). However, when both copies of a BRCA1/2

gene are mutated or not working, this damage control process is deactivated, meaning that the gene does not make the proteins that are required to repair DNA damage within the cells (Friedman et al., 2012). Over time, cells continue to divide, replicating additional damage by producing unregulated copies of the gene. This process of replicating damaged DNA leads to the development of a tumor and, in this case, breast cancer (Friedman et al., 2012).

As those with BRCA1/2 mutations already have one mutated copy of the gene, women with identified deleterious mutations on the BRCA1/2 genes have a significantly increased lifetime risk of developing breast cancer (i.e., between 40 and 85%), as well as other cancers, including ovarian cancer, pancreatic cancer, and melanoma (Antoniou et al., 2003; Friedman et al., 2012). While an average breast tumor develops over 6 to 8 years before it is large enough to be found by regular screenings, the development of breast tumors often occurs sooner for women with BRCA1/2 mutations because the first step in cancer development (i.e., disabling one copy of the protective or tumor suppressor gene) has already occurred (Friedman et al., 2012). Additionally, women with BRCA1 mutations are more likely to develop triple-negative breast cancer, and women with BRCA 2 mutations are more likely to develop ER+ and PR+ cancers; these greater probabilities are likely caused by the increased vulnerability to these particular breast cancers as a result of the lack of strength and longevity of the BRCA1/2 genes (Friedman et al., 2012).

Deleterious BRCA1/2 mutations. HBOC families are those who have strong and identifiable patterns of early-onset breast and/or ovarian cancer, as well as of other

related cancers (Friedman et al., 2012). Since 1994 to 1995, when the two most significant breast cancer susceptibility genes (i.e., BRCA1/2) were identified, those in HBOC families have been able to be tested for BRCA1/2 mutations (Miki et al., 1994; Wooster et al., 1995). Among HBOC families, only approximately 15% to 20% actually possess deleterious BRCA1/2 mutations (Lux et al., 2006). Deleterious BRCA1/2 mutations are those that are known, through identification and research, to significantly increase an individual's chance of developing cancer (Friedman et al., 2012). In the United States, the general presence of deleterious BRCA1/2 and related mutations is about 0.2% (Ponder et al., 2000).

Despite the rarity of these mutations, they are believed to account for approximately 5 to 10% of all breast cancer cases (Den Heijer, Vos et al., 2012; Szabo & King, 1995). For women who have already been diagnosed with breast cancer and are BRCA1/2 positive, their risk of contracting a second primary breast cancer is significantly elevated; this chance can be as high as 70% when breast conservation was chosen as a treatment option (Evans, Skrzynia, Susswein, & Harlan, 2005). Interestingly, members of the same HBOC family tend to develop different types of cancer at different ages, with some never developing cancer in their lifetimes (Evans et al., 2005). The clinical utility of this testing is evidenced by high rates of risk-reducing surgeries by BRCA1/2 carriers over the long term (Beattie, Crawford, Lin, Vittinghoff, & Ziegler, 2009; Evans et al., 2009; Friebel et al., 2007; Metcalfe, Birenbaum-Carmelo et al., 2008; Metcalfe, Lubinski et al., 2008; Schwartz et al., 20012), as well as the resulting decrease in morbidity and mortality (Domchek et al., 2010). Thus, knowing one's BRCA1/2 status

allows those in HBOC families to actively participate in prevention, early detection, and treatment (Bagtecky, Tondlova, Vesela, Brizekova, & Bololoucky, 1996; Miki et al., 1994), which is the reasoning behind making BRCA1/2 testing an integral part of treatment and screening for women from HBOC families (Friedman et al., 2012).

Preventative Options

Testing for BRCA1/2 mutations facilitates a decrease in morbidity and mortality related to inherited breast and ovarian cancer when close and careful clinical management is used (Borreani et al., 2014). In terms of clinical management, three main cancer risk management strategies typically are used with women with BRCA1/2 mutations: increased surveillance, chemoprevention (Friedman et al., 2012), and prophylactic surgery (Friedman et al., 2012). While the combination of self-exams, mammography, and MRI improves the odds of finding early tumors, it does not decrease the likelihood of getting cancer in this population; however, chemoprevention and prophylactic surgery decrease the likelihood of cancer occurrence in this population (Friedman et al., 2012).

Surveillance. Experts generally agree that intensive surveillance for carriers of BRCA1/2 is critical and that most cancers among carriers of BRCA1/2 are interval cancers, meaning these cancers tend to be detected during intervals between screening examinations (Friedman et al., 2012), suggesting that these cancers are often caught in early stages. However, surveillance methods do not prevent breast cancer and have not been proved to reduce breast-cancer-related death in carriers of BRCA1/2, as their efficacy with carriers of BRCA1/2 is not as well documented as with the general population (Pruthi et al., 2010). The variety of surveillance methods for breast cancer in

women with BRCA1/2 mutations currently include breast self-exams, clinical breast exams, mammography, and breast MRIs (Friedman et al., 2012). While the guidelines and recommendations for breast self-exams (i.e., monthly as early as 18 years of age) and clinical breast exams (i.e., one to two times per year starting at 25 years of age) are relatively close to the recommendations for women in the general population, the guidelines and recommendations for mammograms and breast MRIs are much different (Friedman et al., 2012).

Friedman et L. (2010) recommend that women with BRCA1/2 mutations get mammograms annually starting at 25 years of age, or between 5 and 10 years before the earliest age of breast cancer onset in the family (Friedman et al., 2012). Mammograms use low-dose x-rays to produce images of the internal breast structure and tend to find microcalcifications, tiny calcium deposits that may precede tumor growth, long before they can be felt (Friedman et al., 2012). However, some drawbacks to mammography include its tendency to miss some breast cancers, especially in younger women with dense breast tissue, and its tendency to be less sensitive than other surveillance methods (Friedman et al., 2012). Additionally, some controversy exists regarding the radiation exposure of mammography. Some experts believe that the increased lifetime exposure to radiation from beginning exposure before the age of 30 years could lead to slightly increased breast cancer risk (Friedman et al., 2012; Ronckers, Doody, Lonstein, Stovall, & Land, 2008). Owing to this concern, some physicians and healthcare professionals treating those with BRCA1/2 mutations recommend mammography not begin until 30 years of age (Friedman et al., 2012); however, one study looking at the potential risk

associated with mammography exposure in young carriers of BRCA1/2 mutations determined that mammograms were estimated to save more lives than would be lost to radiation-induced breast cancers (de Gonzalez, Berg, Visvanathan, & Robson, 2009).

Similarly, Friedman et al. (2012) recommend that women with BRCA1/2 mutations get breast MRIs annually starting at 25 years of age, or 5 to 10 years before the earliest age of breast cancer onset in the family (Friedman et al., 2012). MRI uses magnetic fields and radio waves to produce detailed images of the breast from several angles and does not produce radiation (Friedman et al., 2012). MRI may be particularly adept at finding cancers that mammograms miss, especially in premenopausal women, as MRI is a sensitive screening tool that finds abnormalities at a higher rate than mammography (Friedman et al., 2012), with this rate being approximately 80% sensitivity of malignancy detection (Pruthi et al., 2010). While most studies find MRI to be more sensitive compared to mammograms, when used together, these surveillance methods are complementary, with each having its own strengths and each tending to find some cancers better than the other (Friedman et al., 2012). For example, Lord et al. (2007) suggested that adding MRI to mammography improves malignancy detection sensitivity from 40 to 94% in young, high-risk women (Lord et al., 2007).

Chemoprevention. Some women with BRCA1/2 mutations choose chemoprevention to reduce their risk of breast cancer occurrence. Chemoprevention involves taking medications that have been proved to decrease cancer risk; while chemoprevention does not guarantee that one will never develop cancer, different chemopreventaitive medications have been shown to significantly reduce the risk of

developing cancer (Friedman et al., 2012). Two of the most common and most researched medications used for chemoprevention are tamoxifen and raloxifene, both of which are selective estrogen receptor modulators (SERMs), drugs that block estrogen (Friedman et al., 2012). Additionally, tamoxifen and raloxifene are both FDA-approved medications that reduce the risk of developing breast cancer in high-risk women (Friedman et al., 2012).

The pros and cons of chemoprevention differ depending on the particular drug that is used. In terms of tamoxifen, some of the positive effects include reducing the risk of ER+ breast cancer, decreasing the risk of invasive breast cancer, strengthening bones, lowering LDL cholesterol levels, and continuing benefits even after the drug is no longer taken (Friedman et al., 2012). Despite these various positive effects, tamoxifen possesses the potential for a variety of negative effects, including an increase in risk for blood clots and uterine cancer and the triggering of menopause-like symptoms (Friedman et al., 2012). Raloxifene shares many of the positive effects of tamoxifen, including lowering LDL cholesterol levels and strengthening bones, but it also is more effective against noninvasive breast cancer and is characterized by a lower risk of uterine cancer than tamoxifen (Friedman et al., 2012). Some of the negative effects associated with raloxifene include an increased risk for blood clots and menopause-like symptoms (although a lower risk than with tamoxifen) and declining benefits when it is no longer taken (Friedman et al., 2012). In general, SERM medications are known to cause vaginal bleeding or discharge, headaches, nausea, leg cramps, rashes, mood changes, and other serious side effects, as previously noted (Friedman et al., 2012).

Prophylactic bilateral mastectomy (PBM). Women with BRCA1/2 mutations are given the option of pursuing a PBM) by their physicians as a preventative option (Hoskins, Roy, & Greene, 2012). One of the decisions that women pursuing a PBM need to consider, with the consultation and recommendation of their physicians, is whether to undergo a total or nipple-sparing PBM. A total PBM involves the removal of 95 to 99% of the breast tissue, including the nipple, with or without the removal of the pectoral muscle (Metcalfe, Esplen, Goel, & Narod, 2004). Differently, a subcutaneous, or nipple-sparing, PBM involves the removal of 90 to 95% of the breast tissue, while preserving the nipple and skin that covers the breast (Friedman et al., 2012). Both of these options can also involve breast reconstruction, which could be performed with a variety of different methods that restore the general look and shape of breasts (Friedman et al., 2012).

As DNA testing becomes more widely available and the cosmetic results of breast reconstruction improve, PBM continues to emerge as an important option for women with BRCA1/2 mutations to decrease their overall and lifetime risk of breast cancer (Den Heijer, Seynaeve, Timman et al., 2012). Despite the obstacles and challenges associated with PBM, more women with BRCA1/2 mutations are pursuing PBM to decrease their risk of breast cancer (Hartmann et al., 2001; Lynch et al., 2006). Approximately 57% of women at high risk of breast cancer identified PBM as an option in one study (Stefanek, 1995), but generally fewer women, from 16 to 20%, identify PBM as a favorable option (Eisinger et al., 1997; Grana et al., 1994). Additionally, rates of 9 to 17% of women who express an interest in PBM choose to pursue this preventative surgery (Grana et al., 1994;

Lerman et al., 1996; Stefanek, 1995). Differences in the interest and uptake of PBM have been identified in different countries. For example, in one study, 35% of women with BRCA1/2 mutations in the United States reported considering PBM after receiving genetic testing results (Lynch et al., 1997), compared to 8% of this population in Austria (Wagner et al., 2000) and 65% of this population in Canada (Metcalfe et al., 2000).

Overall, undergoing a PBM has been shown to reduce breast cancer risk in women with BRCA1/2 mutations by 90 to 95%, meaning that women with BRCA1/2 mutations can achieve a level of breast cancer risk that is the same or less than that of the general population (Domchek et al., 2010; Hollingsworth et al., 2004; Rebbeck et al., 2004). One study found that PBM, with or without reconstruction, reduced breast cancer risk in women with BRCA12 mutations by 90 to 100%, although the impact of PBM has not been identified or described in terms of survival rates compared to intensive surveillance methods (Hartmann et al., 2001; Heemskerk-Gerritsen et al., 2013; Meijers-Heijboer et al., 2001; Rebbeck et al., 2004). PBM is often considered personally and emotionally charged and involves recurring decision making throughout the lifetime (Hoskins et al., 2012). The psychological and emotional effects of undergoing a bilateral mastectomy (BM) in survivors of breast cancer are well documented; however, the psychological and emotional effects of undergoing a PBM are not well known (Metcalfe, Esplen, Goel, & Narod, 2004). One study suggests that those who pursue BM after a cancer diagnosis compared to those who pursue PBM without a cancer diagnosis are characterized by different profiles regarding demographic and clinical characteristics, preventative choice, risk perception, cancer worry, quality of life, and satisfaction scores

(Borreani et al., 2014). While similarities may exist between these two groups of women, the research on women who underwent BM after a breast cancer diagnosis has typically focused on women from single institutions (Metcalfe et al., 2004), have not been population based (Hatcher, Fallowfield, & A'Hern, 2001), or have been based on small samples (Stefanek, Helzlsouer, Wilcox, & Houn, 1995).

Several studies have examined the psychological aspects associated with the choice of preventative strategy (Bisch et al., 2002; Bresser, Seynaeve et al., 2007; Claes et al., 2005; Lobb & Meiser, 2004; Ray, Loescher, & Brewer, 2005), as well as the impact of this choice (Bresser, Van Gool et al., 2007; Hatcher et al., 2001; Madalinska et al., 2007; Tercyak et al., 2007; ; Tiller et al., 2002). However, some of these studies compared women with different risk profiles without considering genetic-testing results (Bish et al., 2002; Claes et al., 2005; Schwartz et al., 2012), while others examined both affected and unaffected women together (Bresser, Seynaeve et al., 2007; Lobb & Meiser, 2004; Ray et al., 2005). Additionally, some studies kept affected and unaffected women separate, but focused on describing the psychological impact (i.e., distress) of genetic testing without considering chosen preventative strategies (Eijzenga, Hahn, Aaronson, Kluijt, & Bleiker, 2014). Lower levels of distress after surgery completion are associated with higher levels of satisfaction; additional variables associated with higher levels of satisfaction include satisfaction with body appearance, lower levels of life stress, fewer problems with implants, and no reconstruction after PBM (Frost et al., 2000). Another study found that breast reconstruction was a contributing factor to decreased psychological distress after surgery, as those who underwent reconstruction reported

feelings of femininity, wholeness, and normalcy (Stevens et al., 1984; Wellisch, Schain, Noone, & Little, 1985). Overall, most women appear to be satisfied post-surgery with their choice to undergo PBM, with studies showing between 70 and 97% of women reporting satisfaction and decreased cancer worry (Frost et al., 2000; Metcalfe et al., 2004).

Risk Perception and Decision Making

While more women who have experienced breast cancer get a BM, a substantial proportion of women who have not had cancer pursue a PBM (Borreani et al., 2014). One study examined 139 women with BRCA1/2 mutations in the Netherlands (Meijers-Heijboer et al., 2001). After receiving positive genetic-testing results, 76 of these women chose to undergo a PBM, with the remaining 63 choosing to be followed with a surveillance protocol. This cohort was followed for 2.9 years; during this time, none of the individuals who chose the PBM pathway were diagnosed with breast cancer, while eight of the individuals who chose to be monitored via the surveillance pathway were diagnosed with breast cancer. A significant body of research has been dedicated to determine the factors and circumstances that contribute to the decision by women with BRCA1/2 mutations to pursue a PBM instead of chemopreventaitive or surveillance pathways.

Risk is a major decision-making factor regarding genetic testing, screening and risk-reducing options, and other BRCA1/2-related issues (Hoskins et al., 2012). Perceived risk also influences the psychological and emotional effects of these decisions (Hoskins et al., 2012); this highlights the significance of accurate risk perception for

women with BRCA1/2 mutations making these potentially life-altering decisions regarding breast health (Hopwood, Howell, Lalloo, & Evans, 2003), as well as of the detriment inaccurate risk perception can have on individuals who are attempting to make risk management decisions (Kelly et al., 2005). The beliefs that people hold about their vulnerability to different diseases can serve as powerful motivational factors to engage in health behaviors (Hamilton & Lobel, 2012). For example, women who perceive themselves to be at higher risk for breast cancer are more likely to follow through with mammograms and to pursue genetic testing for BRCA1/2 mutations (Hamilton Lobel, & Moyer, 2009; Katapodi, Lee, Facione, & Dodd, 2004; McCaul, Reid, Rathge, & Martinson, 1996).

While this relationship between risk perception and health behaviors appears simple, it is multifaceted and complex (Hoskins et al., 2012). The thought processes of women with BRCA1/2 mutations are linked to information they receive from various sources (e.g., counselors, health professionals, testing reports, family, friends), their assumptions regarding the experience of having cancer, their family formation desires, and their view of the best interest of themselves and their loved ones (Hoskins et al., 2012). Thus, many nononcologic aspects of perceived risk exist, including thoughts of dying and leaving their children motherless and inflicting a traumatic experience on loved ones, are integral to the self-understanding of women with BRCA1/2 mutations as mutation carriers, of their risk, and of their decisions about managing it (Hoskins et al., 2012). Some research has suggested that the higher the risk perception of women with

BRCA1/2 mutations, the more likely they are to choose PBM over other risk management strategies, such as surveillance or chemoprevention.

Much of the research on decision making for women with BRCA1/2 mutations focuses on the decision to move forward with a PBM. Many factors are involved in choosing PMB for carriers of BRCA1/2, including fear, physician advice, concern about breast cancer (Frost et al., 2000), the desire to be proactive, intrusive cancer worry, vulnerability resulting from life stage (Hopwood et al., 2000), personal tolerance for inaction, assumptions about the experience of having cancer if they were diagnosed, family formation and planning issues, the implications of their choices for close others (Hoskins et al., 2012), depression levels, family history, having young children (Bish et al., 2002; Lobb & Meiser, 2004; Claes et al., 2005; Ray et al., 2005; Bresser, Seynaeve et al., 2007; Landsbergen, Brunner, Manders, Hoogerbrugge, & Pins, 2010), and information-processing abilities (Landsbergen et al., 2010; Watts et al., 2012). Additionally, those with higher levels of anxiety are more likely to undergo a PBM and/or to choose chemoprevention; however, these same individuals are also more likely to be dissatisfied with their decision (Ertmanski et al., 2009).

Women tend to choose PBM more often when they are younger, have children, have had breast cancer, have a strong family history of breast cancer, and overestimate their cancer risk or are characterized by high levels of cancer-related anxiety (Meiser et al., 2000; Metcalfe, Lubinski et al., 2008; Singh et al., 2013). For women who choose PBM, significant reductions in cancer risk perception often occur; this reduction is true both of women who pursue this surgery preventatively and of women who have

previously had cancer (Borreani et al., 2014). This reduction suggests that, for women with BRCA1/2 mutations, the effectiveness of the surgery was understood in terms of its potential to reduce cancer risk (Domchek et al., 2006; Lostumbo, Carbine, & Wallace, 2012). Interestingly, the risk perception after surgery remained greater than the actual residual risk, highlighting a continued pattern of risk overestimation in this group of women (Borreani et al., 2014). While decision making regarding the management of health concerns and cancer surveillance can reduce distress in the population with BRCA1/2 mutations (Esplen et al., 2004; Hamilton, 2009; Lerman et al., 1996; Lobel, Hamilton, & Moyer, 2009; Meiser, 2005; Smith et al., 2008), it can also serve to increase stress in this population (Lerman et al., 1997; Watson et al., 2004).

Testing Distress

BRCA1/2 testing poses important clinical implications for those who are carriers for these mutations (Smith et al., 2008). This testing allows carriers to make more informed healthcare choices, often leading to further screening and treatment decisions, including chemoprevention and prophylactic or more aggressive surgical procedures (Peshkin et al., 2002; Schwartz et al., 2003; Schwartz et al., 2004; Van Oostrom et al., 2003). Understanding the distress that women experience during the genetic testing process helps to clarify some of the psychological needs of this population, as well as to outline the value of surgical strategies for women at increased risk for cancer (Smith et al., 2008). Additionally, understanding distress in this population can help to reduce the interference that distress plays in the information transfer that occurs during genetic counseling, the decision-making process, and the follow-through with psychological

interventions (Cull et al., 1999; Hopwood et al., 1998). Unfortunately, while a wealth of information is available on this particular topic, the current research base presents conflicting information about the distress experienced by this segment of the population.

Increased distress. Some research suggests that those who undergo genetic testing experience increased levels of distress. A review of the literature found that women who received a positive genetic-testing result reported experiencing fear for the future, helplessness, depression and anxiety, worry about family members, and the unpredictability of their situation, and they described themselves as "ticking time bombs." Many of these experiences are common in those who are diagnosed with breast cancer (DiMillo et al., 2013). Receiving a positive BRCA1/2 mutation result has been found to be linked with increased levels of anger and distress (Croyle, Smith, Botkin, Baty, & Nash, 1997; Dorval et al., 2000), decreased quality of life, an altered self-concept, vulnerability, stigma (Esplen et al., 2009), increases in cancer perception and worry about cancer (DiProspero et al., 2001), and increased levels of anxiety and depression (Bober, Hoke, Duda, Regan, & Tung, 2004; Lerman, Seay, Balshem, & Audrain, 1995; Lindberg & Wellisch, 2004; Van Oostrom et al., 2003; Wellisch & Lindberg, 2001). Interestingly, Cukier et al. (2013) suggested that the high level of cancer-related distress experienced by this population is consistent with symptoms observed in posttraumatic stress disorder, a condition that typically occurs after a person experiences trauma that poses a threat to life of the individual or another person (Horowitz, Wilner, Kaltreider, & Alvarez, 1980). Maheu et al. (2014) added that higher anxiety levels have been found to occur and sometimes persist after genetic testing,

especially in a subgroup of carriers. This notion is supported by the research (Julian-Reynier et al., 2011; Segal et al., 2004; Van Oostrom et al., 2003). Other studies add that carrier anxiety can linger for years (Meiser & Halliday, 2002; Schwartz et al., 2002), lasting anywhere between 6 months and 5 years (Beran et al., 2008; Graves et al., 2012; Julian-Reynier et al., 2011; Van Oostrom et al., 2003).

Samson et al. (2014) found that women reacted to their positive genetictesting result as if they were diagnosed with breast cancer, even though they displayed no clinical signs or symptoms associated with breast cancer. Similarly, several other studies have shown that distress levels among carriers of BRCA1/2 mutations is higher than among the general population and are similar to distress levels found among those with breast cancer within a year of diagnosis (Braithwaite, Emery, Walter, Prevost, & Sutton, 2004; Croyle et al., 1997; Lindberg & Wellisch, 2004; Meiser et al., 2002; Meiser, 2005; Tiemsland, Soreide, & Malt, 1998). Shiloh, Drori, Orr-Urtreger, and Friedman (2009) explained that support exists for the idea that being objectively at an increased risk for cancer is cognitively represented by perceived risk and causal attributions and that these representations, rather than the objective membership in an "at risk" group, such as BRCA1/2 previvors, are associated with levels of health anxiety and worry interference. Lerman et al. (1997) found that cancer-specific distress was significantly and positively related to the use of the BRCA1 test whereas global distress was found to be unrelated to test use. Similarly, Dorval et al. (2008) explained that irrespective of cancer diagnosis, women at high risk are more inclined to report psychological distress than women in the general population, even before receiving their positive genetic-testing result.

In addition to exploring the type and level of distress experienced by carriers of BRCA1/2, some research has examined factors associated with higher levels of distress in this population. Some research has shown that women who feel stigmatized or otherwise different from others because of their increased risk for cancer experienced increased levels of distress (Lux et al., 2006). Women with BRCA1/2 mutations also appear to experience higher levels of distress when they have children, have lost a relative because of breast or ovarian cancer, doubt the validity of the resting results (Van Oostrom et al., 2003), are in a committed relationship (Beran et al., 2008), have higher levels of anxiety pre testing (Den Heijer et al., 2013; Reichelt et al., 2008), and have higher concerns related to developing cancer (Bosch et al., 2012).

Mixed results. In general, among the studies on short-term psychological distress in carriers of BRCA1/2 after disclosure of genetic-testing results, some have shown increased distress (Croyle et al., 1997; Lodder et al., 2001; Smith, West, Croyle, & Botkin, 1999; Tercyak et al., 2001; Watson et al., 2004), while others have shown no change in distress levels (Meiser et al., 2002; Reichelt, Heimdal, Moller, & Dahl, 2004; Schwartz et al., 2002). Mixed results are also found suggesting that carriers of BRCA1/2 may experience higher levels of distress in the months soon after testing (Watson et al., 2004; Meiser et al., 2002; Smith et al., 2008), with some of these differences dissipating within 1 year of receiving testing results (Arver, Haegermark, Platten, Lindblom, & Brandberg, 2004; Smith et al., 2008). Beran et al. (2008) highlighted this trend of decreased stress over time after genetic testing for women with BRCA1/2 mutations which is likely a result of decisions made during this time. For women with BRCA1/2

mutations, these months post testing often involve making decisions about prophylactic options and communicating results to family and friends, not to mention the individual's own cognitive and emotional processing of the results (Beran et al., 2008).

In terms of long-term impact of genetic testing, some studies have found that among those who have no personal cancer history, no psychological differences are present for carriers or noncarriers 1 year (Arver, Haegermark, Platten, Lindblom, & Brandberg, 2004; Borreani et al.,2014; Bosch et al., 2012; Smith et al., 2008), 3 years (Foster et al., 2007), and 5 years post testing (Van Oostrom et al., 2003). Differently, two studies from Australia and the United Kingdom reflected an increase in anxiety symptoms in women with BRCA1/2 mutations 1 year post testing (Meiser et al., 2002; Watson et al., 2004). However, another study found statistically significant, but not clinically significant, levels of genetic-testing distress in women with BRCA1/2 mutations compared with noncarriers (Halbert et al., 2011). Two recent long-term studies examining genetic-testing-specific concerns found that American women were not likely to express such concerns more than 4 years post testing (Halbert et al., 2011; Hamilton, Williams, Skirton, & Bowers, 2009), while a similar study of French women showed an increase in cancer risk perception over a 5-year follow-up period (Julian-Reynier et al., 2011).

One study suggests that some of these mixed results may be owing to some studies not separating out those with BRCA1/2 mutations who have versus who have not had cancer (Meiser, 2005). Lodder et al. (2006) concluded that among those with no cancer history, carriers of BRCA1/2 are not psychologically affected by their carrier

status; for women with BRCA1/2 mutations who have had cancer, however, some studies show no change in psychological distress while others indicate that survivors experience more distress throughout the testing process (Horowitz, Wilner, & Alvarez, 1979). Another possible explanation for the mixed results regarding increases in distress for women with BRCA1/2 mutations post testing is that the focus should be on changes in distress for these individuals: of importance may be that women with BRCA1/2 mutations do not experience decreases in distress post testing, while those who receive negative testing results do experience this decrease (Croyle et al., 1997; Lerman et al., 1996; Lodder et al., 2001; Schwartz et al., 2002). An additional possibility regarding the wealth of literature that highlights a general absence of psychological distress may reflect emotional habituation or adaptation to the persistent stresses associated with being in a HBOC family and with the repeated and reoccurring need to make significant decisions regarding one's healthcare and life planning (Baum, Cohen, & Hall, 1993).

Thus, the experience of distress in women with BRCA1/2 mutations remains unclear because of the mixed results in the literature. Despite these mixed findings, many researchers agree that a subset of the population with BRCA1/2 mutations is more likely than the rest of this population to experience distress (Braithwaite, Emery, Walter, Prevost, & Sutton, 2006; Schwartz et al., 2002). Broadstock, Michie, and Marteau (2000) reviewed 27 analyses from short-term studies that showed that pretesting emotional state was the strongest predictor of psychological distress post testing; however, no studies have examined the determinants of pretest distress, and concerns have been raised

concerning the methodology of several of these studies (Timman et al., 2004; Vadaparampil, Ropka, & Stefanek, 2005).

Distress after testing. Being faced with a great deal of new, complex, and distressing information can potentially increase the likelihood of adverse psychological reactions following testing (Roussi et al., 2010). While adapting to cancer risk, female carriers of BRCA1/2 have to make some important decisions regarding their management of this risk; these women are faced with a range of choices, including more frequent screening and preventative surgical options (Lapointe, Dorval, Nogues, Fabre, & Julian-Reynier., 2013). These women also have to face the 50/50 possibility of passing on this mutation to offspring, as well as the feelings of fear and guilt that this fear entails (Lapointe et al., 2013). Compared to women at high risk for breast and ovarian cancer without BRCA1/2 mutations, carriers of BRCA1/2 mutations tend to experience more distress in the first year after genetic testing; these distress levels may fluctuate just before and after surveillance visits and MRI result appointments, but may decrease over time after going through risk-reducing surgery and achieving satisfaction with the decisions that the individual made regarding her BRCA1/2 healthcare decisions (Harmsen, Hermens, Prins, Hoogerbrugge, & De Hulu, 2012).

One overlooked aspect of carriers of BRCA1/2 mutations is the burdens they face on a regular basis; these burdens may serve to affect the intensity of distress experienced by this population (Lynch et al., 2006). Some of the burdens faced by this population include (a) the guilt of passing the mutation to the next generation, (b) worry about successive generations getting cancer, (c) worry about themselves getting cancer, (d) and

concern about health insurance discrimination (Lynch et al., 2006). Additionally, carriers of BRCA1/2 mutations who have experienced cancer appear to experience three additional burdens that contribute to distress, including (a) feeling frustrated at having no cancer prevention guidelines, (b) thinking about how their test result has affected their work and family life, and (c) having problems finding enjoyment in life (Lynch et al., 2006). These burdens are not just confined to the initiation and process of genetic testing but may affect carriers of BRCA1/2 mutations throughout their lifespans, especially during times of decision making regarding their BRCA1/2 diagnosis and risk for HBOC (Lynch et al., 2006).

Factors influencing distress. The psychological adjustment of women who are at high risk involves both personal and social resources, with one study suggesting that personal resources are a way by which social resources may affect psychological distress (Den Heijer, Vos et al., 2012). Some of the factors, or resources, that have been found to be associated with higher levels of distress in women with BRCA1/2 mutations include experiencing stigma (Den Heijer et al., 2011; Den Heijer, Vos et al., 2012); having low income; being previously diagnosed with cancer (Cukier et al., 2013); experiencing poor communication about hereditary cancer, thereby contributing to increased anxiety and isolation (Den Heijer, Seynaeve, Vanheusden et al., 2012); and having a family history of breast cancer and/or a mother who died from breast cancer (Erblich, Bovbjerg, & Valdimarsdottir, 2000; Zakowski et al., 1997). Additionally, having young children and the profoundness of one's experience with cancer in relatives have been found to contribute to neither higher nor lower levels of distress (Lodder et al., 2001).

In terms of factors found to be associated with lower levels of distress in women with BRCA1/2 mutations, self-esteem is an important personal resource that may serve to buffer the effects of cancer-related stressors (Carpenter, 1997; Den Heijer et al., 2011; Schroevers et al., 2003) and of distress in general (Den Heijer, Vos et al., 2012). Den Heijer et al. (2011) found that self-esteem was negatively associated with general distress but was not found to be associated with breast-cancer-specific distress. Stigma, however, was found to be strongly associated with breast-cancer-specific distress, but the negative effect of stigmatization was most pronounced for women with low self-esteem (Den Heijer et al., 2011). Self-esteem and a sense of mastery reflect a sense of resilience and may serve to buffer the individual from stressful effects and emotions related to being at risk for HBOC (Den Heijer et al., 2011).

Social support during the genetic-testing process has also been found to be associated with lower experiences of distress in this population (Den Heijer, Seynaeve, Vanheusden et al., 2012; Koehly et al., 2008; Manne et al., 2004; Van Oostrom et al., 2007), with the availability of social support being more strongly associated with health outcomes than the actual use of social support (Carlsson, Bjorvatn, Engebresten, Berglund, & Natvig, 2004). While some studies specifically highlight the significance of partner support (Den Heijer, Seynaeve, Vanheusden et al., 2012), social support is important in many forms, including the nuclear family, extended family, and friends (Lapointe et al., 2013).

Social support is especially complex considering that hereditary cancer and BRCA1/2 diagnoses have a profound impact on individual family members, as well as

their communication and other interactions (DeMarco & McKinnon, 2007; Kenen, Arden-Hones, & Eeles, 2004; Lodder et al., 2001). Therefore, family system characteristics may influence the way that women learn to cope with a hereditary cancer or BRCA1/2 diagnosis, experiences that affect the family system(Den Heijer, Seynaeve, Vanheusden et al., 2012). Family patterns of openness and talking about feelings/thoughts may facilitate insight (Kennedy-Moore & Watson, 2001), and attempting to verbalize feelings about a BRCA1/2 diagnosis can help people to better understand their own thoughts and feelings (Den Heijer, Seynaeve, Vanheusden et al., 2012). Talking with others about HBOC and BRCA1/2 diagnoses can also lead to new perceptions and a broader perspective on cancer-related worry (Den Heijer, Seynaeve, Vanheusden et al., 2012), as well as contribute to a greater sense of psychological adjustment. However, this openness may prove difficult for family members who are indirectly affected by these diagnoses.

Adjusting to genetic-risk information may involve considerable challenges and pose medical, emotional, and family relationship implications (Dorval et al., 2000; Horsman et al., 2007). One of these challenges may be the process of deciding how to convey the complex, and often emotionally charged, cancer risk information with relatives at risk, intimate partners, and friends (Foster, Eeles, Arden-Jones, Moynihan, & Watson, 2004). Communication with relatives about familial cancer risk serves several purposes (D'Agincourt-Canning, 2001; Dancyger et al., 2011; Julian-Reynier et al., 2000), including information passing (e.g., telling others of the cancer risk and genetic mutation), fulfillment of personal needs (e.g., obtaining emotional support, getting

medical advice; Bosch et al., 2012), and sharing, which is key to the maintenance of close relationships and contributes to the exchange and procurement of social support (Rime, 2007). Thus, open communication within the family is also a factor associated with lower levels of distress in women with BRCA1/2 mutations (Den Heijer, Seynaeve, Vanheusden et al., 2012).

Social support is associated with better psychological adjustment over time, with one study showing that this adjustment persists up to 2 years after disclosure of genetic-testing results in women with BRCA1/2 mutations (Lapointe et al., 2013). Den Heijer, Seynaeve, Vanheusden et al. (2012) found that social support and family communication about hereditary cancer are of paramount importance in terms of long-term psychological adjustment for women with BRCA1/2 mutations. Another study that examined psychological distress in at-risk women 5 years post genetic testing showed that an open family communication style was associated with less psychological distress long term (Van Oostrom et al., 2003). It was found that open communication within the family decreased isolation and stigmatization, which was also found to be true of those women who talked openly about hereditary cancer with their intimate partners (Den Heijer, Vos et al., 2012). Overall, the decrease in stigmatization is associated with less psychological distress (Den Heijer, Vos et al., 2012), and open communication about hereditary cancer in general may be one way that social support serves to buffer psychological distress in women with BRCA1/2 mutations (Den Heijer, Seynaeve, Vanheusden et al., 2012).

Unmet needs. Unmet needs are those issues for which people perceive a need for help (Farrelly et al., 2013). Higher levels of unmet needs have been found to be

associated with higher levels of experienced distress, especially when combined with not having someone to confide in (Farrelly et al., 2013). For patients with cancer, some domains of unmet needs include assistance with daily-living activities, physical activities, psychological well-being, and obtaining treatment or prevention information (Harrison, Young, Price, Butow, & Soloman, 2009; Thewes, Meiser, Tucker, & Tucker, 2003). While little is known about unmet needs for women with BRCA1/2 mutations, one study has examined unmet needs in this population (Farrelly et al., 2013). Farrelly et al. (2013) found that women with BRCA1/2 mutations expressed a high level of unmet support needs, with almost half of the sample reporting at least six moderate to very high unmet needs, while only 9% of the sample reported no unmet needs (Farrelly et al., 2013). The most common unmet needs among the participants in this study included dealing with uncertainty about the future and dealing with fears of developing cancer (Farrelly et al., 2013). Interestingly, dealing with feelings of isolation was one of the least reported needs identified by this population (Farrelly et al., 2013). Several predictors of unmet needs for this population have also been identified, including shorter time since finding out about mutation status and being of a younger age (Farrelly et al., 2013). Some studies of survivors of breast cancer have reported a similar finding and have suggested that the needs of young women often center around fertility, premature menopause, and general impact on family planning (Thewes, Butow, Girgis, & Pendlebury, 2004; Thewes et al., 2005). Similar needs may be present in young women with BRC1/2 mutations because of the decisions that they need to make regarding risk-reducing surgeries (Farrelly et al., 2013).

Body Image

Women in general are concerned with their weight, appearance, and body (Helms, O'Hea, & Corso, 2008). One study suggests that 89% of women in the general population report concern with weight (Cash, Melnyk, & Hrabosky, 2004). Body image is an overall attitude toward one's body and is made up of how one evaluates oneself, as well as how much investment one puts into one's body image to determine one's satisfaction, happiness, or well-being (Helms et al., 2008). Stokes and Frederick-Recascino (2003) added that body image reflects a direct personal perception and self-appraisal of one's physical appearance, whereby negative thoughts and feelings related to one's body indicate a disturbance of body image and lead to dissatisfaction with oneself. Body image is defined as the mental picture of one's body; and an attitude about the physical self, appearance, and state of health, wholeness, normal functioning, and sexuality (Fobair et al., 2006). Body image is a component of a larger concept of self that, for women, includes feeling feminine and attractive (Carver et al., 1998; Cohen, Kahn, & Steeves, 1998; Hopwood, 1993; Mock, 1993; White, 2000). Additionally, Kullmer et al. (1999) added that body image is considered to be the sum of state of health, body care and outer appearance.

Body image is a complex, multidimensional construct that involves perceptions, thoughts, and feelings about the whole body and its functioning (Fingeret et al., 2014). This construct has been identified as a critical psychosocial issue for patients with cancer undergoing reconstructive surgery because they are at a high risk of experiencing bodily changes and disfigurement, as well as functional impairment (Fingeret et al., 2014). The

process of adjusting to bodily changes associated with reconstructive treatment is not static, but ongoing, as multistage procedures are often required (Fingeret et al., 2014), as is the case with women with BRCA1/2 mutations who choose to undergo a PBM. Interim outcomes may be particularly difficult for patients when cosmetic form and function have not yet been fully restored (Fingeret et al., 2014). A study that examined patients with early-stage breast cancer found that "concern about appearance" related to emotional distress and that "concern about body integrity" related to three other indices of well-being: greater loss of the sense of attractiveness and sexual desirability, greater disruption of social activities, and greater endorsement of an item assessing an alienation or estrangement from the self (Carver et al., 1998). This finding suggests that different components of body image allude to difficulties in a variety of areas in terms of psychosocial and physical functioning.

Unfortunately, little, if any, research has been conducted on the body image concerns that women with BRCA1/2 mutations experience. High rates of body image concerns have been documented for patients with head, neck, and breast cancers patients; these groups of patients are those who most often undergo reconstructive surgery (Fingeret et al., 2014). Body image disturbance is among the most common psychosocial concern reported by women with breast cancer (Fingeret et al., 2014), and as many as 75% of patients with head and neck cancers have also reported similar concerns (Fingeret et al., 2014). In a study that examined body image in adolescents with medical illnesses, Meissner (1997) found that physical problems of high impact and visibility have the greatest impact on body image. Interestingly, Pendley, Dahlquist, and Dreyer (1997)

found that in adolescent survivors of cancer, body image concerns, such as negative body image perceptions, did not develop until several years post treatment. These findings suggest that, especially for women with BRCA1/2 mutations who often undergo a lengthy and difficult reconstructive process post PBM (Friedman et al., 2012), body image may be affected by the preventative options chosen by the individual.

Breast cancer and body image. The 1987 Psychological Aspects of Breast Cancer Study Group (Pinto, Clark, Maruyama, & Feder, 2003) found that patients with breast cancer demonstrated self-deprecation, inadequate body image, and weight gain. These difficulties have continued to be characteristic in more recent studies of women with breast cancer. Przezdziecki et al. (2013) found that a considerable number of women reported experiencing body image disturbance related to their breast cancer diagnosis and treatment, a finding consistent with other studies reporting sustained body image difficulties at 12 months post diagnosis and beyond (Falk-Dahl, Reinertsen, Nesvold, Fossa, & Dahl, 2010; Hartl et al., 2010). The women in this sample expressed levels of body image disturbance greater than those reported in Hopwood, Fletcher, Lee, and Ghazal (2001) when they were validating the Body Image Scale. However, the women in the Przezdziecki et al. (2013) study had a longer time since diagnosis than the women in Hopwood et al. (2001), suggesting sustained body image disturbance (Przezdziecki et al., 2013). Therefore, one cannot assume that body image disturbance experienced by survivors of breast cancer will necessarily diminish with time (Przezdziecki et al., 2013). The potential for sustained body image disturbance especially significant considering the link between body image disturbance and self-esteem, with self-esteem serving as a

protective factor to the experience of distress and as a correlate to feeling supported by family and friends (Fobair et al., 2006).

Mastectomy and body image. Some of the most important factors affecting a woman's decision to have a lumpectomy and radiation versus a mastectomy to treat her breast cancer include anticipated negative effects on body image, anticipated disfigurement, and expected loss of femininity post surgery (Margolis, Goodman, Rubin, & Pajac, 1989), all of which are realistic concerns. The negative impact of mastectomy is well documented (Polivy, 1977), which is no surprise considering that mastectomy is an amputation that disturbs body image and alters sexual relationships for a significant period of time (Sheppard & Ely, 2008). In addition to altering body image and sexual relationships, mastectomy may also induce significant levels of psychological distress, although breast reconstruction may lead to early restoration of physical health (Al-Ghazal, Fallowfield, & Blamey, 2000; Fobair et al., 2006; Ganz et al., 1996; Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999; McGaughey, 2006). However, whether the impaired psychological functioning is the consequence of the mastectomy or of the breast cancer diagnosis itself is debatable (Metcalfe et al., 2004).

Several studies compared women who chose to have a mastectomy with those who chose breast conservation treatment options for breast cancer and found that women who chose to undergo a mastectomy were more likely to report body image dissatisfaction than those who chose breast conservation treatment options (Arora et al., 2001; Avis, Crawford, & Manuel, 2004; Beckman, Johansen, Richardt, & Blickert-Toft, 1983; Ganz, Lee, Sim, Polinsky, & Schag, 1992; Lee et al., 1992; Schain, D'Angelo,

Dunn, Lichter, & Pierce, 1994; Polivy, 1977; Taylor et al., 2002; Yurek, Farrar, & Andersen, 2000). Mock (1993) compared body image in women receiving different types of breast cancer treatments. In this study, significant differences in body image were found according to type of surgical treatment experienced. While body image was poorer in all subjects with breast cancer compared to healthy individuals, those who received conservative surgical treatment reported greater satisfaction with their bodies than those treated with either mastectomy or immediate reconstruction (Mock, 1993). Another study examined the relationship between cosmetic appearance of the breast after breast conservation surgery and psychological well-being (Al-Ghazal, Fallowfield, & Blamey, 1999). This study found a significant correlation between cosmetic outcome and depression, as well as body image (Al-Ghazal et al., 1999). These results suggest that the deformed physical appearance of a woman's breast post surgery affects her mood, as well as her feelings about herself and her view of her body (Al-Ghazal et al., 1999).

Considerable evidence shows that survivors of breast cancer may experience prolonged psychological distress, especially in terms of perception of their physical appearance and body image (Scott, Halford, & Ward, 2004), even though treatment has ended and the woman may be medically well (Przezdziecki et al., 2013). This prolonged psychological distress may be related to the finding that women with breast cancer have a particularly hard time adjusting to the disease and treatment, which are associated with significant alterations in body image and sexuality (Baucom, Porter, Kirby, Gremore, & Keefe, 2005; Bredin, 1999; Geiger et al., 2006; McGaughey, 2006; Schover et al., 1995). Some research suggests that this population struggles with self-compassion, which serves

as a protective factor for body image disturbance and psychological stress (Przezdziecki et al., 2013), and with self-consciousness, which appears to compound body image disturbances (Brandberg et al., 2008).

PBM and body image. Breast surgery involving partial or complete loss of one or both breasts may result in poorly aligned breasts and breast asymmetry, extensive scarring and alteration to the breast and/or nipple sensation, need for a breast prosthesis, possible changes to limb mobility, and lymphedema (Anderson & Johnson, 1994; Crane-Okada, Wascher, Elashoff, & Giuliano, 2008; Kadela-Collins et al., 2011; Swenson et al., 2002; Vadivelu, Schreck, Lopez, Kodumundi, & Deepak, 2008). These risks may also be true of women who chose surgery as a preventative option because of high-risk status. Women who choose to undergo a PBM often report being satisfied with their decision (Bresser et al., 2006; Frost et al., 2000; Metcalfe et al., 2004) despite findings from several studies that concluded that a substantial proportion of women reported body image problems post PBM (Anderson & Johnson, 1994; Borgen et al., 1998; Brandberg et al., 2008; Crane-Okada et al., 2008; Frost et al., 2000; Kadela-Collins et al., 2011; McGaughey, 2006; Swenson et al., 2002; Vadivelu et al., 2008), some of whom experienced body image disturbance after 1 year (Brandberg et al., 2008; Lodder et al., 2002). In a study of 370 women by Payne, Biggs, Tran, Borgen, and Massie (2000), 5% of the women reported regrets about their decisions. While there were six major reasons for this regret, two reasons were directly related to body image: dissatisfaction with the cosmetic effect of surgery and diminished self-image or sexual satisfaction (Payne et al., 2000). Six of the women who reported regret described having marked concerns about

their body image, 16 of the same grouping of women reported a lack of breast sensation, body image issues, and difficulty with clothing, and three additional women reported disfiguring scars (Payne et al., 2000). This study suggests that, for a portion of those who experience regret after PBM, body image dissatisfaction may play a role. However, the specifics of the surgeries (e.g., type of PBM, type of reconstruction) were not noted in this study, which is significant considering the notion that the more drastic and invasive the breast surgery is, the more it will affect a woman's sense of cosmetic satisfaction and psychological well-being (Al-Ghazal et al., 2000).

In contrast, some studies have suggested that the majority of women who undergo PBM experience only minor alterations in body image (Hopwood et al., 2000), while others have suggested that this population does not experience body image disturbance (Hatcher et al., 2001). Josephson, Wickman, and Sandelin (2000) found that 13 of 15 women felt that their body image was better than they had expected post PBM. Additionally, some research has found that more than 50% of those examined reported no changes in satisfaction in their appearance (Frost et al., 2000; Metcalfe et al., 2004). Den Heijer, Seynaeve, Timman et al. (2012) suggested that the mixed findings regarding levels of body image disturbance experienced by those who have undergone PBM may not be accurate because many of the observations were obtained from retrospective studies for which information on women's body image prior to PBM is not available, and consequently, changes in body image specifically as a result of PBM could not be assessed. Similarly, Brandberg et al. (2008) offered a possible alternative explanation for the low levels of body image disturbance found in the population of this study: Those

who failed to complete the 1-year follow-up assessment tended to report higher levels of body image disturbance 6 months post PBM. Thus, the result at the 1-year assessment might be an underestimation of the body image problems experienced by the sample (Brandberg et al., 2008). Den Heijer, Seynaeve, Timman et al. (2012) added that a follow-up period of 1 year may be too short to capture the assimilation of reconstructed breasts into a woman's body image, as the reconstruction process often takes several months, depending on the reconstruction technique used.

Den Heijer, Seynaeve, Timman et al. (2012) explored the course of psychological distress and body image at long-term follow-up (6-9 years) after PBM and breast reconstruction in women at risk for HBOC. Researchers found that general body image before PBM was predictive of general body image long term after PBM (Den Heijer, Seynaeve, Timman et al., 2012; Hatcher et al., 2001; McGaughey, 2006); interestingly, women's breast-related body image before PBM did not predict for breast- related body image after PBM (Den Heijer, Seynaeve, Timman et al., 2012). Additionally, Den Heijer, Seynaeve, Timman et al. (2012) found that in the first 6 months post PBM, women reported a significant increase in problems with breast-related and general body image. One study suggested that increase in body image disturbance in this population could be caused by concerns over the influence of one's BRCA1/2 status on their intimate partner relationship (Beran et al, 2008).

Self-Concept

Baumeister (1998) described self-concept as the interpretation and enactment of the idea of self in the environment. Blascovich and Tomaka (1991) further explained that

self-concept is composed of cognitive, behavioral, and affective components. The behavioral component is an aspect of the self that is observable to others, while the cognitive component is an aspect of self that is internal and private (Marsh & Hattie, 1996). The affective component of the self consists of evaluative components of the self (e.g., good or bad; Harter, 1996); this component is more commonly referred to in the literature on self-concept as self-esteem (Blascovich & Tomaka, 1991). McConkie-Rosell and DeVillis (2000) concluded that self-concept is the representation of the self based on the integration of these behavioral, cognitive, and affective components.

Specifically in terms of the cognitive component of self-concept, the schema model of self-concept (Cella et al., 2002; Markus & Keith, 1982; Markus & Wurf, 1987; Stein, 1995) best describes this component. According to this perspective, one's responses to the environment are mediated through internal structures, or self-schema, that work together to form a person's self-concept (Esplen et al., 2011). Schemas are derived from experiences (Cervone & Pervin, 2008), are content specific, and can also be formed through internalized cultural values and norms (Rodin, Silberstein, & Streigel-Moore, 1985). Self-schemas actively integrate, shape, and summarize perceptions and experiences; self-schemas are the lens through which people view and interpret the world (Markus & Keith, 1982, and can be developed about any aspect of a person, including body weight (Markus, Hamill, & Sentis, 1987), exercise (Kendzierski, 1988), and sex roles (Markus & Keith, 1982). Individuals who have a positive perception of the self are better able to cope with threat, loss, and misfortune, as compared to those with a more negative self-concept (Baumeister, 1998). Interestingly, self-concept can influence

motivations to adopt screening or engage in health-protective behaviors, as well as influence reactions and abilities to cope with negative life situations (Devins, Beanlands, Mandin, & Paul, 1997; Stein, 1995).

Both body image and self-concept develop during childhood and adolescence and undergo constant changes throughout the lifespan (Kullmer et al., 1999). Markus and Wurf (1987) suggested that self-concept has different components: a working self-concept, which may be the portion of self-concept that is more amenable to change, and core components of self-concept (e.g., self-schema) that remain relatively stable over time and throughout experiences. Foltz (1987) presented a set of components of self-concept, including the bodily self (i.e., physical function and body image), the interpersonal self (e.g., psychosocial and sexual interaction), the achievement self (e.g., job role function), and the identification self (e.g., spiritual and ethical beliefs). These components in particular are likely related to self-schema, as the schema model of self-concept suggests (Cella et al., 2002; Stein, 1995; Markus & Keith, 1982; Markus & Wurf, 1987). Additionally, Kullmer et al. (1999) suggested that self-concept is the sum of a person's feelings about the self, with five major, interrelated elements, all of which may be affected during the diagnosis and treatment of cancer: (a) alteration in bodily experience, (b) discrepancy between actual and ideal self, (c) disruption of personal relationships, (d) self-deprecating meaning of cancer, and (e) depression.

Breast cancer treatment and self-concept. In everyday life, focus on the self is not common (Denieffe & Cooney, 2010). However, an illness such as breast cancer disrupts the unity of the body and the self and may cause disruptions within one's self-

concept (Baron, 1985). The potential for damage that breast cancer and its treatment pose is relatively obvious (Foltz, 1987). The impact of a cancer diagnosis may threaten fundamental beliefs, role interpretations, and role functions, with cancer treatment influencing additional aspects of self-concept (Foltz, 1987). For example, surgery entails a defect, whether visible or not, requiring alteration in the view of the self (Foltz, 1987). The impact of breast cancer on the self occurs over time; treatments for breast cancer are accompanied by physical, psychological, and social symptoms that in turn affect self-concept (Denieffe & Cooney, 2010). Denieffe and Cooney (2010) found that women perceived breast cancer as a challenge to their sense of self, their existence, and their future goals and personal values. Charmaz (1999) added that this challenge is often the result of *illness immersion*, which involves the illness permeating all areas of life; the significant impact and changes associated with illness immersion possibly suggest that one's self-concept has been altered as a result of cancer diagnosis and treatment experiences.

Related to the aspects of self as identified by Foltz (1987), Curbow and Somerfield (1991) added that individuals bring a precancer self-concept to the situation that is unique in terms of configuration, content, and structure. However, the self-concept shifts over time as patients become immersed in their treatments and recoveries (Curbow & Somerfield, 1991) or as patients become immersed in their illness (Charmaz, 1999). Once individuals cross over into the "cancer self," they may begin to share more content and structure with others in similar situations as themselves (Curbow & Somerfield, 1991). Aspects of cancer (e.g., uncertainty of etiology and course) and cancer treatment

(e.g., multiple therapies, surgeries) serve to make patients particularly vulnerable to changes in their self-concept (Curbow & Somerfield, 1991). Mages and Mendelsohn (1979) added that the physical damage and changes that often accompany breast cancer treatment may force changes in self-concept. More specifically, women who lose one or both of their breasts as a result of cancer treatment may experience changes in their identity, sexuality, and sense of self (Manderson & Stirling, 2007), with approximately one third of survivors of breast cancer expressing distress directly related to body image after successful cancer treatment (Scott et al., 2004).

Zebrack (2000) explained that the diagnosis and treatment for cancer lead to the development of a new social role - the role of the cancer survivor - which persists throughout one's life. Cancer is not an acute event with a definite ending, but instead it is a process that extends for the rest of the lifespan (Bowman, Deimling, Smerglia, Sage, & Kahana, 2003; Clark & Stovall, 1996). Heigeson (2011) examined the extent to which 10-year survivors of breast cancer integrated cancer into their self-concepts (i.e., survivor centrality). These researchers found a moderate amount of survivor centrality in survivors of breast cancer which is consistent with the perspective that cancer is not an acute, time-limited phenomenon but instead a process that extends throughout the lifespan (Bowman et al., 2003; Clark & Stovall, 1996). Heigeson (2011) also found that younger women were more likely than older women to define themselves in terms of breast cancer survivorship, perhaps because the incongruence between the experience of a life-threatening illness and young age is greater (Heigeson, 2011).

Despite the lack of research on survivor centrality, healthcare professionals have been long aware that the integration of an illness into one's identity is a theme that emerges from discussions with survivors of cancer (Heigeson, 2011). In a study of adult survivors of childhood cancer, survivors frequently discussed the extent to which the cancer came to identify themselves (Drew, 2007). In another study of adult survivors of childhood cancer, some stated that they defined themselves in terms of the cancer and saw it as an integral part of their sense of self (Prouty, Ward-Smith, & Hutto, 2006). In another study, men and women with a history of cancer were interviewed, and issues of identity and changes in identity were explored; for some individuals in this study, survivorship was a core aspect of their identities (Little, Paul, Jordens, & Sayers, 2002). Related to survivorship is the term *previvorship,* which refers to those who carry a genetic mutation that predisposes them to various types of cancer, but have never been diagnosed with cancer (Friedman et al., 2012). Interestingly, research on previvors (e.g., women who carry BRCA1/2 mutations who have not been diagnosed with cancer) and the impact that their genetic status has had on their self-concepts shows various similarities to the research on survivors of breast cancer and various chronic illnesses.

Women with BRCA1/2 mutations and self-concept. Any new information about oneself can threaten an existing self-concept (McConkie-Rosell & DeVillis, 2000). Additionally, the centrality of a person's self-concept is maintaining physical and psychosocial well-being (Devins et al., 1997; Kendzierski, 1988; Linville, 1987; Markus, 1977). Thus, not surprisingly, knowing that one is a carrier for a genetic disorder has the potential to alter one's self-concept (Schild, 1984), and more specifically, that women

who learn they are at an increased risk of hereditary breast cancer experience alterations in self-concept (Esplen et al., 2009; McConkie-Rosell & DeVillis, 2000). McConkie-Rosell and DeVillis (2000) reflected this concept in their discussion of a "genetic identity," which is a key aspect of identity theory. This term was first used by Schild (1966), who described this term as the dimension of self-concept that develops from one's perception of one's genetic inheritance. Carrier testing presents a potential threat to self-concept because the accuracy of a DNA-based test makes the results particularly difficult to refute (McConkie-Rosell & DeVillis, 2000). Additionally, carrier testing represents a new and unplanned life event for most individuals (McConkie-Rosell & DeVillis, 2000). If the outcome of genetic testing affects a dimension of importance to the individual and cannot be refuted, learning this new information about self or family could potentially threaten self-concept (McConkie-Rosell & DeVillis, 2000).

McConkie-Rosell and DeVillis (2000) suggested that learning new information regarding genetic identity could have negative connotations resulting from one's perception of carrier status, including being inconvenient or discomforting or being demanding or restricting in a variety of areas of life. Schild (1984) suggested that the diagnosis of a genetic disorder could compromise self-concept to the point that healthy adaptation to one's carrier status may be affected. Hattie (1992) added that self-concept is multidimensional and hierarchical. This nature suggests that the weight of importance given to any one dimension varies uniquely as a function of the individual and societal value placed on that particular dimension, and supports the further examination of a component-based model of self-concept instead of a global model of self-concept in this

population (Hattie, 1992). Lim, MacLurin, Price, Bennett, and Butow (2004) found that some women with mutations experience a sense of "living with cancer" throughout their lifetimes, despite not having been diagnosed with cancer. Among younger women, self-reports of "life-changing experiences" and a reevaluation of priorities have been observed after being diagnosed as mutation positive (Hallowell, Foster, Eeles, Arden-Jones, & Watson, 2004; Lim et al., 2004).

BRCA1/2, uncertainty, and self-concept. Several researchers have observed that women with BRCA1/2 mutations commonly report changes in their perception of themselves and speak of feeling "different" from their peers (Esplen et al., 2009). One factor that may impact this self-perception is uncertainty of illness, which often accompanies the initiation of BRCA1/2 testing in the first place (Mischel, 1988). According to Mischel (1988), an inability to predict the outcome of one's illness can propel a patient into a state of uncertainty said to result from an inability to form a cognitive schema of the illness. Shaha, Cox, Talman, and Kelly (2009) completed a meta-analysis of 40 studies pertaining to those already diagnosed with breast, prostate, and colorectal cancer and found that many participants struggled with uncertainty; for women, uncertainty toward their womanhood was specifically noted. Unlike in patients fighting cancer, the very nature of BRCA1/2 mutations creates a kind of uncertainty, which is almost impossible to minimize because one cannot tackle a potentiality that may still lead to a fatal outcome (DiMillo et al., 2013). Even though these women live with the possibility of developing breast cancer, their experiences mirror those of individuals living with a chronic illness, and they must therefore adapt accordingly in a physical,

psychological, and social manner (Samson et al., 2014). One of the aspects of uncertainty that carriers of BRCA1/2 mutations must adapt to is the array of potential medical and existential implications as a consequence of possessing this genetic mutation, including the choice of whether to undergo PMB or ooperectomy (Klitzman & Chung, 2010). DiMillo et al. (2013) found that women with BRCA1/2 mutations share many aspects of the experiences described by women who have already been diagnosed with breast cancer (Liao, Chen, Chen, & Chen, 2008; Warren, 2010), including living with uncertainty (DiMillo et al., 2013).

Adjusting to the uncertainty of having a BRCA1/2 diagnosis is an important component of psychological adjustment for this population (Den Heijer et al., 2011). Psychological resources may play a crucial role in the adjustment to stressful life events, as these resources may serve to buffer against the negative impact of such events (Ben-Zur, 2002). For example, self-esteem is strongly associated with psychological functioning and has been found to be associated with lower levels of depression and higher levels of well-being in patients with cancer (Schroevers et al., 2003). Within current models of self-concept, self-esteem is considered as the generalized evaluation of the self and is only one dimension of the collection of cognitive representations that makes up self-concept (Curbow et al., 1990). Therefore, general self-esteem may not be the only aspect of self-concept that is relevant to well-being (Curbow & Somerfield, 1991). With the increased emphasis on the multidimensionality of self-concept (Marsh, 1986; Rosenberg, Schooler, Schoenbach, & Rosenberg, 1995), one must address the

specific aspects of self-concept that are most vulnerable in women at risk of hereditary breast cancer.

Potential impacts of being diagnosed as BRCA1/2 positive include feeling stigmatized, alienated, different from others, and vulnerable (Esplen et al., 2009; Markel, 1992 Rosser, 1981). These altered self-schemata can play a role in health behaviors, lead to psychological distress, and interfere with planning for one's future (Linville, 1987; Showers, 1992). Similarly, Esplen et al. (2009) suggested that the specific components of self-concept most relevant to carriers of BRCA1/2 mutations and their well-being include stigma, vulnerability, and mastery. Thus, these components of self-concept clearly are vulnerable to alteration in carriers of BRCA1/2 mutations, but also pose a negative impact once altered (Esplen et al., 2009; Linville, 1987; Showers, 1992; Markel, 1992; Rosser, 1981). Hoskins et al. (2012) found that the most favorable outcomes in terms of assimilating information about risk, arriving at a solid personal sense of cancer risk, and making decisions about risk management were found in those who effectively understood that they were not defined by their body parts or their genetic mutation. This cognitive shift, possibly a reflection of a healthy and stable self-concept, brought easier acceptance of the possible implications of their risk, including losing body parts via risk-reducing surgeries (Hoskins et al., 2012).

The relationship between body image and self-concept. Petronis, Carver, Antoni, and Weiss (2003) identified psychological investment in body image as a risk factor for disruption after breast cancer treatment; this investment may influence the degree of threat posed by breast cancer and its treatment. Many years ago, James (1890)

explained that an investment in a particular aspect of the self can create a vulnerability to distress if that aspect of self is threatened. Kullmer et al. (1999) found that gynecological and breast cancers have a special impact on a woman's self-esteem and body image, as well as a significant impact on self-concept and body image in patients with gynecological and breast cancer. Additional studies suggest that this impact can last a long time, as demonstrated specifically for patients with breast cancer (Lasry & Margolese, 1992; Taylor et al., 1995). Similarly, Helms et al. (2008) reported that breast disfigurement after breast cancer can lead to marked psychological distress in women. Effects of surgical procedures for breast cancer treatment can impact various areas of a woman's psychological functioning, including identity, confidence, mood, esteem, sexuality, self-satisfaction, and quality of life (Helms et al., 2008).

Kraus (1999) compared body image satisfaction in women pre and post surgery for breast cancer to that of women with a diagnosis of cancer and found greater body satisfaction following surgery among women who had been less concerned about body shape and size before surgery. Further, women who reported decreased bodily concerns demonstrated stronger self-concepts and identities than the women who reported they placed a high value on physical appearance (Kraus, 1999). Similarly, Helms et al. (2008) found that the less significant the body image concerns, the more stable the self-concept throughout the process of PBM. Since the breast is one aspect of a woman's overall sense of femininity and body image, disruption of its appearance causes upset in a woman's emotional well-being and self-concept as a whole (Helms et al., 2008; Vaeth, 1986).

Body image as a component of self-concept. Mock (1993) found a positive correlation between body image and self-concept, thus supporting the notion that body image is an integral component of self-concept. Self-concept themes in the body image domain include altered breasts and breast sensation, mistrust of body, loss of sensation or function, feeling older, loss of reproductive functioning, impacts of early menopause, weight gain, and altered body shape, all of which are issues faced by women with BRCA1/2 mutations (McGaughey, 2006; Hallowell, Mackay, Richards, Gore, & Jacobs, 2004). Fitts and Warren (1996) described body image as a mental picture of the physical self that includes attitudes and perceptions regarding one's physical appearance, state of health, skills, and sexuality. Mock (1993) asserted that body image is an integral part of self-concept, which is the total perception an individual holds of the self. As a composite of one's physical, personal, social, and moral-ethical self, self-concept influences the way an individual perceives the world and interacts with it (Fitts, 1971).

An understanding of body image as a component of self-concept provides a framework for studying the responses of women to treatment for breast cancer, as these responses reflect the importance of the female breast as a symbol of womanliness, sexual attractiveness, and nurturance (Mock, 1993). Loss of a body part that is significantly related to feminine identity may result in a negative alteration in body image and self-concept (Mock, 1993). The degree of negative alteration may be expected to be correlated with the degree of physical change in the body and with the meaning of the body part to the individual (Mock, 1993). While this research pertains to women who are

undergoing treatment for breast cancer, this research may extend to women without cancer who are BRCA1/2 positive and going through PBM.

Chapter 2: Research Question and Hypotheses

Research Question

How do women with deleterious BRCA1/2 mutations who choose to undergo a prophylactic bilateral mastectomy compare to those who use surveillance methods differ on measures of body image and self-concept?

Hypotheses

Hypothesis 1a

Women with deleterious BRCA1/2 mutations who have undergone prophylactic bilateral mastectomies will display greater investment in appearance on a measure of body image when compared to women with deleterious BRCA1/2 mutations who engage in surveillance methods.

Hypothesis 1b

Women with deleterious BRCA1/2 mutations who have undergone prophylactic bilateral mastectomies will display greater investment in body integrity on a measure of body image when compared to women with deleterious BRCA1/2 mutations who engage in surveillance methods.

Hypothesis 2a

Women with deleterious BRCA1/2 mutations who have undergone prophylactic bilateral mastectomies will report greater experiences of stigma on a measure of self-concept when compared to women with deleterious BRCA1/2 mutations who engage in surveillance methods.

Hypothesis 2b

Women with deleterious BRCA1/2 mutations who have undergone prophylactic bilateral mastectomies will report greater experiences of vulnerability on a measure of self-concept when compared to women with deleterious BRCA1/2 mutations who engage in surveillance methods.

Hypothesis 2c

Women with deleterious BRCA1/2 mutations who have undergone prophylactic bilateral mastectomies will report fewer mastery experiences on a measure of self-concept when compared to women with deleterious BRCA1/2 mutations who engage in surveillance methods.

Chapter 3: Methodology

Design and Design Justification

This study examined women with deleterious BRCA1/2 mutations who chose to use surveillance methods only, as well as those who chose to undergo a prophylactic bilateral mastectomy (PBM) in an effort to prevent the future occurrence of breast cancer. These women were compared in regard to proposed differences that they may have presented in terms of body image and self-concept. A between-subjects approach was used for this study, as differences between groups were examined at a single point in time.

Recruitment of Participants

The participants were recruited through online postings dispersed by the investigator. Primary recruitment resources included posts made on the following Facebook support groups that target women at high risk for cancer as a result of genetic mutations: YP's Surveillance Sisters (posted January 27, 2018), Young Previvors (posted January 27, 2018), BRCA Sisterhood (posted January 31, 2018), Mutant Strong (posted February 11, 2018), BRCA Genetic Sisters Awareness Page (posted February 11, 2018), BRCA Advanced 101/102 Journal Club (posted February 11, 2018), and this investigator's personal Facebook page (posted January 27, 2018). Before posting on these pages, the investigator elicited administrator permission to post on each of these sites.

Potential participants received a link to the online survey, as well as information describing the study and the inclusion requirements for an individual to be eligible for participation. Participation in this study was voluntary, but those who completed the

survey had the choice to be entered into a raffle to win one of three available $50 Amazon gift cards. The following recruitment message was posted to help in recruiting individuals to participate in this study:

> My name is Amanda Large, and I am a doctoral candidate in the APA-accredited program in Clinical Psychology at the Philadelphia College of Osteopathic Medicine. Under the supervision of Dr. Barbara Golden, Psy.D., ABPP, Professor and Principal Investigator, you are invited to participate in this study through which I am collecting information for my dissertation. This study will help us to more fully understand how being BRCA1/2 positive impacts how women view and think about themselves and their bodies. In order to participate in this study, you must be 18 years old or older, be able to read and understand English, have access to an electronic device on which to take the survey, and possess a deleterious BRCA1/2 mutation. All information you provide will be anonymous and confidential, you can withdraw from the study at any time, and your responses to the survey will not be tied to any personal information. By answering these questions, you may find out some things about yourself that you did not know previously, and it is possible that in some people, this may cause mild emotional discomfort. This survey will take 20-30 minutes to complete. When you are finished taking the survey, you will have the opportunity to send an email to an independent email address to enter your email in a drawing to win a $50 Amazon gift card. Your email address will not be linked to information you provide throughout the course of the survey. If you are interested in participating,

please click the following link: https://www.surveymonkey.com/r/R7P6VDK. Should you have any questions, please feel free to contact Dr. Golden at barbarago@pcom.edu. This study has been approved by the Philadelphia College of Osteopathic Medicine Institutional Review Board (protocol approval # H17-054X). Thank you in advance for your time and assistance.

This study was anonymous and connecting the identity of a participant to her responses was not possible. As such, informed consent was not required. However, prospective subjects were provided the opportunity to decide whether or not to participate in the study after they had read the information included in the posting and before they were provided with the link to the survey. The prospective participants were informed that (a) this study was designed to them help more fully understand how being BRCA1/2 positive impacts women's views and thoughts about themselves and their bodies, (b) participation was anonymous, (c) participation was completely voluntary, (d) they could withdraw participation at any time without consequences, and (e) no major risks to participating were expected, although they may experience mild emotional discomfort.

Before beginning the study, a power analysis was conducted and determined that 212 participants were needed to complete this study. Assuming that 30% of those participants came through, an estimated700 participants maximum could be involved. This power analysis is characterized by a medium effect size with 80% power at a .05 level of significance. There were two comparison groups and five dependent variables.

In order to participate in this study, potential participants had to be women older than the age of 18 years who reported having been diagnosed with a deleterious

BRCA1/2 mutation. Potential participants had to be able to read and understand English, as well as to have access to an electronic device on which the online survey could be accessed. Potential participants could not participate in the study if they were younger than 18 years of age, could not read and understand English, did not have access to an electronic device and the Internet, and did not have a deleterious BRCA1/2 mutation. A screener was built into the only survey to screen out those who did not meet inclusion criteria.

Measures

Demographic Information Questionnaire

The Demographic Information Questionnaire was designed for the purpose of gathering information relevant to this study. Information was gathered on participant demographics (e.g., age, marital status), BRCA1/2 diagnosis, chosen preventative pathway for breast cancer risk (e.g., PBM, surveillance, other), personal and familial cancer history, and various other variables related to the experience of having a BRCA1/2-positive diagnosis.

The Measure of Body Apperception (MBA)

The MBA is an eight-item measure (plus two filler items) designed to assess investment in and concern about body apperception in patients with breast cancer (Jean-Pierre et al., 2012). The MBA is a measure of the investment in, or dependence on, one's body image as a source of self-worth; it has two scales, which reflect investment in physical appearance and investment in a sense of body intactness or integrity (Carver, 2013). Initial validation of the MBA revealed a multidimensional or two-factor measure

that explained 52.2 % of the variance (Carver et al., 1998). Test–retest of the MBA revealed a correlation of r = 00.75 for each subscale over a period of 4 weeks (Carver et al., 1998). Participants responded to the 10 items of the MBA on a 4-point Likert scale that ranged from 1 (*I disagree a lot*) to 4 (*I agree a lot;* Carver, 2013). A total scale score was calculated by summing all the items of the MBA, and two subscales were calculated by calculating all of the items on each of these scales (Carver, 2013). The Investment in Appearance subscale includes Items 1, 3, 6, and 8, and the Investment in Body Integrity subscale includes Items 2, 4, 7, and 9 (Carver, 2013). A higher score indicated a stronger agreement with the MBA and a greater difficulty or disturbance in body image (Jean-Pierre et al., 2012).

The BRCA Self-Concept Scale (BSCS)

The BSCS assesses the impact of being a carrier of BRCA1/2 mutations on self-concept (Esplen et al., 2009). It consists of 17 items with Likert responses ranging from 1 (*strongly disagree*) to 7 (*strongly agree*) in ascending order, with a score of 8 corresponding to the not applicable (NA) category (Esplen et al., 2009). Three main factors are examined by this measure: Stigma, Vulnerability, and Mastery (Esplen et al., 2009). The Stigma subscale contains Items 5, 8, 9, 10, 12, 13, 16, and 17. Cronbach's alpha of the Stigma subscale was 0.87, with a mean interitem correlation of 0.45 (Esplen et al., 2009). The Vulnerability subscale includes Items 3, 4, 7, 11, and 14. Cronbach's alpha of the Vulnerability subscale was 0.76, with a mean interitem correlation of 0.38 (Esplen et al., 2009). The Mastery subscale includes Items 1, 2, 6, and 15. Cronbach's alpha of the Mastery subscale was 0.68, with a mean interitem correlation of 0.35 (Esplen

et al., 2009). Higher scores on Stigma and Vulnerability imply negative changes in self-concept, whereas a higher score on Mastery implies positive changes in self-concept (Esplen et al., 2009).

Procedure

Investigators created an online survey on SurveyMonkey to include a screener for inclusion criteria, the questions in the Demographic Information Questionnaire, MBA, and BSCS. After soliciting administrator permission, the investigator posted the survey link with accompanying solicitation statement on several Facebook support groups geared toward women at high risk of cancer as a result of genetic mutations. If a participant met the inclusion criteria, she was asked to agree to participate and was then permitted to complete the Demographic Information Questionnaire. Prior to filling out the online Demographic Information Questionnaire, participants reviewed a solicitation statement outlining the nature of the Demographic Information Questionnaire. Each individual was informed that participation was voluntary and that she was welcome to discontinue filling out the Demographic Information Questionnaire at any point without consequence. Those who did not meet eligibility criteria were informed of such and were sent to a page at the end of the Demographic Information Questionnaire thanking them for offering to participate. Participants who completed the Demographic Information Questionnaire were directed to another page where they could choose to submit their personal information for a chance to win one of three available prizes (i.e., $50.00 Amazon gift cards). This information was kept separate from the data acquired during the completion of the Demographic Information Questionnaire to ensure that anonymity was

maintained. Once all data collection was complete, the data were entered into an SPSS data set and analyzed using SPSS.

Chapter 4: Results

In this section, the results of the current investigation are presented. First, the demographic characteristics of the same are described. Second, descriptive statistics for each of the major variables are reported. Finally, the findings for each hypothesis tested are described.

Demographic Characteristics of the Sample

To investigate the differences in body image and self-concept among women diagnosed with deleterious BRCA1/2 mutations, a sample of volunteer participants was collected using an online survey created on SurveyMonkey and posted on various Facebook support groups geared toward women at high risk of cancer as a result of genetic mutations. A total of 358 participants completed the online survey. An analysis of demographic information for all individuals who completed the online survey was conducted and is shown in Table 1. If an individual withdrew from the study before completing all sections of the survey, her information was not collected or included in the final results obtained from SurveyMonkey. When there was evidence of missing data or failure to meet inclusion criteria, participants were omitted from the data analysis. Of the 358 participants who completed the survey, all were female, fluent in English, and had been diagnosed with a deleterious BRCA1/2 mutation. With regard to age, 128 respondents fell within the 35- to 44-year range (35.8%). The remainder of participants fell within the various other age groupings, ranging from ages 18 through 75 years. A total of 261 of the women were married (72.9%), and 195 reported having at least one child under the age of 18 years (54.5%).

In terms of cancer diagnosis, 22 of the participants reported having a current diagnosis of cancer (6.1%), with 105 participants reported having a history of cancer diagnosis (29.3%). When asked about family history of cancer, 323 participants reported having a family history of breast cancer (35.3%), and 186 reported a family history of ovarian cancer (20.3%), which is consistent with the BRCA1/2 population. In terms of prevention methods, 247 participants reported having previously undergone a prophylactic bilateral mastectomy (PBM; 69%). The most common surveillance methods used by participants included breast self-exams (31%) and clinical breast exams (28.7%), with breast magnetic resonance imaging (MRI; 8.9%) and mammograms (12%) being less common. This information on chosen surveillance methods makes sense when considering that most participants had undergone a PBM, as the surveillance methods common for those who have undergone this surgery are self and clinical breast exams, with breast MRI and mammograms being more common among those who have not had a PBM.

In summary, a review of the demographic data revealed that the sample contained a set of participants that is likely an accurate representation of the general BRCA1/2 population. All respondents were female English speakers who had a diagnosis of a deleterious BRCA1/2 mutation. Most women were married with children, had undergone a PBM, and engaged in active surveillance methods. Participation in this study was voluntary, and all participant information was kept anonymous.

Table 1
Demographic Characteristics of the Sample

	Response	Frequency	Valid percent
Age (years)	18-24	13	3.6
	25-34	94	26.3
	35-44	128	35.8
	45-54	74	20.7
	55-64	41	11.5
	65-74	8	2.2
	Total	358	100.0
Gender	Female	358	100.0
	Total	358	100.0
English Fluency	Yes	358	100.0
	Total	358	100.0
Deleterious BRCA1/2 mutation	Yes	358	100.0
	Total	358	100.0
Relationship status	Married	261	72.9
	Widowed	1	0.3
	Divorced	21	5.9
	Separated	4	1.1
	Domestic partnership	9	2.5
	Single but cohabitating	25	7.0
	Single never married	37	10.3
	Total	358	100.0
Children	18 yrs. and older	72	20.1
	1 yr.+ under 18 yrs.	195	54.5
	Currently pregnant	1	0.3
	No	90	25.1
	Total	358	100.0
Current cancer diagnosis	Yes	22	6.1
	No	336	93.9
	Total	358	100.0

Current cancer treatment	Chemotherapy	11	3.1
	Radiation	4	1.1
	Mastectomy	37	10.3
	Lumpectomy	1	0.3
	Other	40	11.2
	Total	93	26.0
History of cancer diagnosis	Yes	105	29.3
	No	253	70.7
	Total	358	100.0
History of cancer treatment	Chemotherapy	67	22.3
	Radiation	44	14.6
	Mastectomy	117	38.9
	Lumpectomy	40	13.3
	Other	33	10.9
	Total	301	100.0
Family history of cancer	Breast	323	35.3
	Ovarian	186	20.3
	Gynecological	58	6.3
	Melanoma	78	8.5
	Pancreatic	77	8.4
	Colon	49	5.3
	Lung	72	7.9
	Other	73	8.0
	Total	916	100.0
Identification as previvor	Yes	233	65.1
	No	105	29.3
	Unsure	20	5.6
	Total	358	100.0
Current surveillance methods	Breast self- exam	201	31.0
	Clinical breast exam	186	28.7
	Breast MRI	58	8.9
	Mammogram	78	12.0
	Other	77	11.9
	None of the above	49	7.5
	Total	649	100.0
Current chemoprevention	Yes	16	4.5

	No	342	95.5
	Total	358	100.0
History of PBM	Yes	247	69.0
	No	111	31.0
	Total	358	100.0
Future PBM			
	Yes	103	28.8
	No	214	59.8
	Undecided	41	11.5
	Total	358	100.0

**PBM = prophylactic bilateral mastectomy*

Descriptive Statistics

Participants responded to each item on the BRCA Self-Concept Scale (BSCS) using a 7-point Likert scale. Responses on this scale include 1 (*strongly disagree*), 2 (*disagree*), 3 (*somewhat disagree*), 4 (*neither agree nor disagree*), 5 (*somewhat agree*), 6 (*agree*), and 7 (*strongly agree*) in ascending order, with a not applicable (NA) category. Participants responded to each item on the Measure of Body Apperception (MBA) using a 4-point Likert scale. Responses on this scale include 1 (*I disagree a lot*), 2 (*I disagree a little*), 3 (*I agree a little*), and 4 (*I agree a lot*). To examine the distribution of responses across the rating scale levels, frequency distributions for each item on each of these scales were conducted and visually inspected. The data are not reported here; however, the frequency distributions revealed variability across the rating points for all individual items within each scale. Although the proportion of participants who selected a rating

varied, each of the rating scale points was endorsed by different proportions of individuals.

Descriptive statistics including means and standard deviations for each item on the BSCS were examined. Cronbach's alpha for the BSCS equaled .887. Cronbach's alpha for the Stigma subscale of the BSCS equaled .838. Cronbach's alpha for the Vulnerability subscale of the BSCS equaled .783. Cronbach's alpha for the Mastery subscale of the BSCS equaled .641. These values are acceptable in demonstrating the internal consistency of the BSCS total scores and subscales. Descriptive statistics including means and standard deviations for each of the items on the MBA were also examined. Cronbach's alpha for the MBA equaled .747. Cronbach's alpha for the Investment in Appearance subscale of the MBA equaled .744. Cronbach's alpha for the Investment in Body Integrity subscale of the MBA equaled .661. These values are acceptable in demonstrating the internal consistency of the BSCS total scores and subscales.

Hypothesis Testing

To test Hypotheses 1a and 1b, a MANOVA was conducted. To test Hypotheses 2a, 2b, and 2c, a separate MANOVA was conducted.

Hypotheses 1a and 1b

Hypothesis 1a predicted that women with deleterious BRCA1/2 mutations who had undergone PBMs would display greater investment in appearance on a measure of body image when compared to women with deleterious BRCA1/2 mutations who had chosen to use surveillance methods only. Hypothesis 1b predicted that women with

deleterious BRCA1/2 mutations who had undergone PBMs would display greater investment in body integrity on a measure of body image when compared to women with deleterious BRCA1/2 mutations who had chosen to use surveillance methods only.

There were two levels of the independent variable (PBM with and without surveillance vs. no PBM with use of surveillance methods). The dependent variables were investment in appearance and investment in body integrity. The dependent variables were correlated, $r(354) = 37$, $p = .000$, which permitted the use of MANOVA. The means and standard deviations by condition are shown in Table 2. The analysis revealed that Box's test, a test of the null hypothesis that the observed covariance matrices are equal across groups, was not significant, Box's $M = 7.84$, $F(6, 11{,}357.49) = 1.25$, $p = .277$. The overall multivariate statistic Wilks' lambda was not significant, Wilks' lambda = .984, $F(3, 298) = 1.57$, $p = .196$, suggesting that no differences existed between the groups on the dependent variables. As such, no further testing was justified.

Table 2
Descriptive Statistics for MBA Variables

		Mean	*SD*
Investment in Appearance	1	2.1875	0.82022
	2	2.1627	0.6708
	Total	2.1653	0.68618
Investment in Body Integrity	1	2.1319	0.58397
	2	2.1549	0.73486
	Total	2.1525	0.72028

**No PBM with surveillance = 1; PBM with/with9out surveillance = 2; MBA = Measure of Body Apperception*

Hypotheses 2a, 2b, and 2c

Hypothesis 2a predicted that women with deleterious BRCA1/2 mutations who had undergone PBMs would display greater experiences of stigma on a measure of self-concept compared to women with deleterious BRCA1/2 mutations who had chosen to use surveillance methods only. Hypothesis 2b predicted that women with deleterious BRCA1/2 mutations who had undergone PBMs would display greater experiences of vulnerability on a measure of self-concept compared to women with deleterious BRCA1/2 mutations who had chosen to use surveillance methods only. Hypothesis 2c predicted that women with deleterious BRCA1/2 mutations who had undergone PBMs would display fewer mastery experiences on a measure of self-concept compared to women with deleterious BRCA1/2 mutations who had chosen to use surveillance methods only.

There were two levels of the independent variable (PBM vs. no PBM with use of surveillance methods). The dependent variables were mastery, stigma, and vulnerability. The dependent variables were correlated as follows: stigma and vulnerability, $r(302) = .70$, $p = .000$; stigma and mastery, $r(346) = .48$, $p = .000$; and vulnerability and mastery, $r(307) = .38$, $p = .000$. These correlations met the assumption that the dependent variables be correlated for use of MANOVA. The means and standard deviations by condition are reported in Table 3. The analysis revealed that Box's test, a test of the null hypothesis that the observed covariance matrices are equal across groups, was not significant, Box's $M = 12.80$, $F(3, 45342.82) = 4.18$, $p = .006$. This violates the assumptions of MANOVA. The overall multivariate statistic Wilks' lambda was not

significant, Wilks' lambda = 1, $F(2, 351) = .059$, $p = .943$, suggesting that no differences existed between the groups on the dependent variables. As such, no further testing was justified.

Table 3
Descriptive Statistics for BSCS Variables

		Mean	*SD*
Stigma	1	3.2917	0.96451
	2	3.8227	1.25394
	Total	3.7752	1.23883
Vulnerability	1	4.2815	1.18095
	2	4.7251	1.28611
	Total	4.6854	1.2815
Mastery	1	2.2315	0.74976
	2	2.4782	0.97059
	Total	2.4561	0.9545

**No PBM with surveillance = 1; PBM with/without surveillance = 2; BSCS = BRCA Self Concept Scale*

Chapter 5: Discussion

In this chapter, the significance and implications of the findings are discussed. First, the demographic characteristics of the same are addressed. Second, the outcomes from the hypothesis testing are reviewed in light of the literature in this area. Finally, the implications, limitations, and recommendations for future studies are considered.

Demographic Characteristics

Overall, 358 women participated in this study. All of these women reported having a deleterious BRCA1/2 mutation, being able to read and understand English, and being older than the age of 18 years. The majority of the participants fell within the 35- to 44-year age range, reported being married, and reported having at least one child at home under the age of 18 years. Almost all of the participants reported having a family history of cancer, most prominently breast cancer and ovarian cancer, which is consistent with BRCA1/2 families because of increased risk of these cancers. The majority of the participants reported having previously undergone a prophylactic bilateral mastectomy (PBM and undergoing at least one form of surveillance (e.g., breast self-exams, clinical breast exams, magnetic resonance imaging [MRI], mammograms).

Outcome of Measures

The two groups that were compared included women who had PBMs regardless of whether they engaged in surveillance methods or not, and women who engaged in surveillance methods but never had a PBM. Internal consistency was found to be present for both the Measure of Body Apperception (MBA) and BRCA Self-Concept Scale (BSCS). In order to test the hypotheses, two separate MANOVAs were conducted. No

significant difference was found between groups on any of the hypotheses. For the MBA, no differences were found between groups in terms of investment in body integrity and investment in appearance. For the BSCS, no differences were found between groups in terms of experiences of stigma, experiences of vulnerability, and mastery experiences.

Implications of Findings

This study examined how women with deleterious BRCA1/2 mutations who choose to undergo a PBM compare to those who use surveillance methods differ on measures of body image and self-concept. It was hypothesized that women who chose to undergo a PBM would display greater investment in appearance, greater investment in body integrity, greater experiences of stigma, greater experiences of vulnerability, and fewer mastery experiences than those who did not have a PBM and chose to undergo surveillance methods only. Interestingly, no significant differences were found on any of the hypotheses, meaning that the hypotheses were not supported. The many potential explanations for finding no significant results include the possibility of the interaction and importance of additional variables.

Paterson, Lengacher, Donovan, Kip, and Tofthagen (2016) looked at body image in young survivors of breast cancer and found that age and type of cancer treatment had a significant impact on body image, with poorer body image being elevated to physical and psychological stress, sex and intimacy, and partnered relationships among younger women. These researchers found that body image disturbance is prevalent and often associated with other issues, such as sexual functioning, in the population of survivors of breast cancer, particularly distressing to the younger survivor population. Body image

disturbance in particular has the potential to cause difficulties in recovery from breast cancer, with younger women being at a particularly high risk for this adverse effect after treatment both because of their life stage and because of the more aggressive treatments that are often associated with the more aggressive cancers that present in younger women (Paterson et al., 2016). The results and findings of this study suggest that the relationship between body image and even seemingly minute details of an individual's treatment or cancer journey is complex and not yet completely understood.

A study by Sherman, Woon, French, and Elder (2017) looked at women who had specifically undergone a nipple-sparing mastectomy with immediate breast reconstruction and found moderately low levels of psychological distress and body image disturbance among these women. These researchers hypothesized that this particular procedure may minimize adverse psychological impacts of mastectomy and may offer the potential for better cosmetic outcomes and less body image disturbance compared to non-nipple-sparing approaches. Sherman et al. (2017) also found that increased body image disturbance was associated with psychological distress and moderated by self-compassion and appearance investment. This study suggests that the specifics of the treatment or surgery chosen by the individual or the individual's treatment team has a large effect on the individual. This suggestion was not specifically examined in the current study and therefore may have affected the results.

Notari, Notari, Favez, Delaloye, and Ghisletta (2015) examined whether women's perceptions regarding the impact of breast cancer treatment on their bodies could be partly determined by the quality of the relational context in which they live. These

researchers found that married women reported less body image disturbance than did unmarried women at all points of comparison in this longitudinal study. Their results showed that relationship satisfaction determined the level of body image disturbance more than marital status itself, suggesting that women's experiences of a sense of security and of being loved may reassure them and help them better adjust to treatment-induced physical changes (Notari et al., 2015). Thus, relationship satisfaction and support are additional areas that may have a significant impact on both body image and self-concept.

In terms of the genetic testing itself, many authors have assumed that disclosure of DNA test results by a genetic counselor has direct, consistent influence on many aspects of the counselee's life; however, Vos, Gomez-Garcia et al. (2012) found a direct influence exists only for counselees' decisions for surgery, which are directly predicted by the communication of a pathogenic or uninformative DNA test result. Additionally, Vos, Oosterwijk et al. (2012) found that the outcomes of DNA testing were better predicted by the counselees' perceptions than by the actual given genetic information. This finding confirmed the importance of perception in the process of recalling and interpreting cancer risk, as well as in making decisions about healthcare (Vos, Oosterwijk et al., 2012). Consequently, perception may also play a significant role in various aspects of the lives of women with BRCA1/2 mutations, possibly contributing to their body image and self-concept and the change in these factors throughout their lives and throughout their journey as carriers of BRCA1/2 mutations.

While each of the aforementioned studies focuses on a slightly different population than the population in this study, the general suggestion that other variables

may be affecting body image and self-concept remains the same. Such factors as different relational dynamics; the specifics of surgeries and treatments; self-compassion; and the individual's perception of testing, genetic status, and surgeries/procedures may affect the experience of body image and self-concept in women with BRCA1/2 mutations. In addition, those who responded to this survey might not have been representative of the population with BRCA1/2 mutations as a whole, making the process of studying these differences difficult, even without the possibility of additional variables.

While no significant findings were found as a result of this study, the possible explanations for this lack of significance can serve to help the researchers and professionals who work with the BRCA1/2 community, as well as the BRCA1/2 community itself. In terms of the researchers who work with this community, a variety of potential avenues of future research have been identified in terms of additional variables that may affect the experiences that carriers of BRCA1/2 mutations have, especially in terms of body image and self-concept. These additional variables can serve as a springboard of ideas for future studies and may inspire others to continue examining this particular area, as little is known about the portion of the population of those with BRCA1/2 mutations who have undergone preventative surgeries without first experiencing a BRCA1/2-related cancer.

In terms of the professionals who work with the BRCA1/2 community, many different disciplines are involved: breast surgeons, plastic surgeons, primary-care physicians, gynecologists, genetic counselors, therapists, psychologists, and more. Over

time, the more that is learned about the complexity of the experience that carriers of BRCA1/2 mutations go through, especially those who consider themselves previvors, the more that these various disciplines can learn how to assess and refer patients who seem to be struggling in different areas. Hopefully, physicians working at the front line of preventative surgeries and other medical treatments will be able to detect carriers of BRCA1/2 mutations who struggle with such issues as body image and self-concept and refer these individuals to genetic counselors, therapists, or psychologists who can best help them take care of their mental and emotional health and meet their needs in general. With more knowledge about the inner experience of this population, genetic counselors may be able to best identify and educate those in the genetic-testing phase of their journeys, while therapists and psychologists may best be able to understand the psychological makeup of this population and subsequently design interventions that may best support them throughout their lifelong journeys as carriers of BRCA1/2 mutations.

The benefits of this study are potentially endless and life changing for the population with BRCA1/2 mutations. If this study were to inspire researchers to continue learning more about this particular population, and if that continued learning were to then produce research that various mental-health and medical professionals could apply to their work with this population, the treatment that this population would receive in various domains would potentially improve. This study may also help the population with BRCA1/2 mutations learn more about themselves and their experiences and help them to become better advocates for themselves and their unmet needs. The more information that is known about the community with BRCA1/2 mutations, the better the members of

this community can learn to support one another, adding to the quality and efficacy of the community as a whole.

Limitations

While this study possesses a variety of strengths, several limitations are also evident. In terms of methodology, sample size is one limitation. Women with BRCA1/2 mutations constitute a relatively small group of individuals compared to the size of the general population. Thus, the population used in this study is substantially smaller than the whole population of women with BRCA1/2 mutations, suggesting that the results of this study may not be representative of the general population. The women who chose to participate in this study represent women with BRCA1/2 mutations who engage in online support groups and therefore may not necessarily be representative of the entire population of women with BRCA1/2 mutations. Additionally, this sample is disproportionate in terms of the number of women who have chosen to undergo PBMs versus those who have chosen surveillance methods only. Future research that focuses on larger or more representative samples of women with BRCA1/2 mutations and is able to find more women who have chosen surveillance methods only would be interesting.

Another methodological limitation involves the measures that were used in this study. The MBA has not been exclusively used with women with BRCA1/2 mutations. Additionally, the BSCS has been used only with women with BRCA1/2 mutations who have had cancer. Thus, neither of these measures has been used with this study's specific population. In the future, studies should be conducted with women with BRCA1/2 mutations and these measures in an effort to provide support for the results of this study.

Additionally, the measures used in this study were all administered online and were self-report in nature. Self-report data are limited by the fact that they cannot be independently verified and can contain several potential sources of bias. These limitations do not make the findings and results of this study less meaningful. However, they do serve as points to keep in mind when thinking about generalizability, as well as when making interpretations and drawing conclusions about the findings.

Future Studies

Future research should more generally focus on expanding the research base on those with BRCA1/2 mutations in an effort to continue to gather more information about this population, their unique experiences, and the ways that their genetic predisposition impacts their mental health and general functioning. Expanding the research base is especially important considering that most of the research on surveillance and mastectomies is focused on populations without BRCA1/2 breast cancer. Future research should also examine male individuals with BRCA1/2 mutations, as this subgroup often goes unnoticed in the research because of the smaller number of male individuals who are aware of possessing this mutation. Specifically, in terms of self-concept and body image, additional studies should focus on learning more about how BRCA1/2 mutations may impact these constructs, the implications of this impact, and interventions that could be used to help minimize any negative impact. A comparison of those who have and have not engaged in various surgery and reconstructive efforts would help to determine if this is a factor in both body image and self-concept, as well as to gather a more complete and

detailed timeline of diagnosis and procedures done in an effort to discover the variables that affect body image and self-concept for this particular population.

Future research should also make an effort to gain a more representative sample of the population with BRCA1/2 mutations, expanding research beyond those who are members of particular online support groups. While gaining a more representative sample may prove difficult because of the relatively small size of this population, doing so would allow for greater generalizability of results. These topics for future research hopefully will pave the way to helping carriers of BRCA1/2 mutations adjust to being BRCA1/2 positive, as well as to endure the difficult life decisions and medical interventions that are often associated with this diagnosis. In addition, psychological techniques and interventions could be identified to help this population cope with some difficult decisions and experiences and to help them heal, grow, and move forward with fulfilling and meaningful lives. Gaining a better understanding of the population with BRCA1/2 mutations could help shed some light on the complexity of this population and serve to better the services and care offered to this population moving forward.

References

Al-Ghazal, S. K., Fallowfield, L., & Blamey, R. W. (1999). Does cosmetic outcome from treatment of primary breast cancer influence psychosocial morbidity? *European Journal of Surgical Oncology, 25,* 571-573.

Al-Ghazal, S. K., Fallowfield, L., & Blamey, R. W. (2000). Comparison of psychological aspects and patient satisfaction following breast conserving surgery, simple mastectomy and breast reconstruction. *European Journal of Cancer, 36*(15), 1938-1943.

American Cancer Society. (2015a). *BRCA1 and BRCA2: Cancer risk and genetic testing*. Retrieved from http://www.cancer.gov/about-cancer/causes-prevention/genetics/brca-fact-sheet#q1

American Cancer Society. (2015b). *Cancer facts and figures*. Retrieved from http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-044552.pdf

Anderson, B., & Johnson, J. (1994). Restoration of body image and self-esteem for women after cancer treatment. *Cancer Practice, 2,* 345-349.

Antoniou, A., Pharoah, P. D., Narod S., Risch, H. A., Eyfjord, J. E., Hopper, J. L., … Easton, D. F. (2003). Average risks of breast and ovarian cancer associated with BRCA1 or BRCA2 mutations detected in case series unselected for family history: A combined analysis of 22 studies. *American Journal of Human Genetics, 72*(5), 117-130.

Arora, N. K., Gustagson, D. H., Hawkins, R. P., McTavish, F., Cella, D. F., Pingree, S., … & Mahvi, D. M. (2001). Impact of surgery and chemotherapy on the quality of life of younger women with breast carcinoma: A prospective study. *Cancer, 92*, 1288-1298.

Arver, B., Haegermark, A., Platten, U., Lindblom, A., & Brandberg, Y. (2004). Evaluation of psychosocial effects on pre-symptomatic testing for breast/ovarian and colon cancer pre-disposing genes: A 12-month follow-up. *Familial Cancer, 3*, 109-116.

Avis, N. E., Crawford, S., & Manuel, J. (2004). Psychosocial problems among younger women with breast cancer. *Psycho-Oncology, 13*, 295-308.

Bagtecky, J., Tondlova, H., Vesela, J., Brizekova, S., & Bololoucky, Z. (1996). Prevalence of psychopathology in patients suffering from breast and gastrointestinal cancer. *Patient Education and Counseling, 28*(2), 175-178.

Baron, R. J. (1985). An introduction to medical phenomenology: I can't hear you while I'm listening. *Annals of Internal Medicine, 103*, 606-611.

Baucom, D. H., Porter, L. S., Kirby, J. S., Gremore, T. M., & Keefe, F. J. (2005). Psychosocial issues confronting young women with breast cancer. *Breast Disease, 23*, 103-113.

Baum, A., Cohen, L., & Hall, M. (1993). Control and intrusive memories as possible determinants of chronic stress. *Psychosomatic Medicine, 55*, 274-286.

Baumeister, R. F. (1998). The self. In D. Gilbert, S. Fiske, & G. Lindzey (Eds.), *The handbook of social psychology* (pp. 680-740). New York, NY: Oxford University Press.

Beattie, M. S., Crawford, B., Lin, F., Vittinghoff, E., & Ziegler, J. (2009). Uptake, time course, and predictors of risk-reducing surgeries in BRCA carriers. *Genetic Testing and Molecular Biomarkers, 13*(51).

Beckman, J., Johansen, L., Richardt, C., & Blickert-Toft, M. (1983). Psychological reactions in younger women operated on for breast cancer: Amputation versus resection of the breast with special reference to body-image, sexual identity and sexual function. *Danish Medical Bulletin, 30*, 10-13.

Ben-Zur, H. (2002). Coping, affect and aging: The roles of mastery and self-esteem. *Personality and Individual Differences, 32,* 357–372.

Beran, T. M., Stanton, A. L., Kwan, L., Seldon, J., Bower, J. E., Vodermaier, A., & Ganz, P. A. (2008). The trajectory of psychological impact in BRCA1/2 genetic testing: Does time heal? *Annals of Behavioral Medicine, 36,* 107-116.

Bish, A., Sutton, S., Jacobs, C., Levene, S., Ramirez, A., & Hodgson, S. (2002). Changes in psychological distress after cancer genetic counselling: A comparison of affected and unaffected women. *British Journal of Cancer, 86*(1), 43-50.

Blascovich, J., & Tomaka, J. (1991). Measures of self-esteem. In J. P. Robinson, P. R. Shaver, & L. S. Wrightsman (Eds.), *Measures of personality and social psychological attitudes* (Vol. 1; pp.115-160). San Diego, CA: Harcourt.

Bober, S. L., Hoke, L. A., Duda, R. B., Regan, M. M., & Tung, N. M. (2004). Decision-making about tamoxifen in women at high risk for breast cancer: Clinical and psychological factors. *Journal of Clinical Oncology, 22*(24), 4951-4957.

Borgen, P. I., Hill, A. D., Tran, K. N., Van Zee, K. J., Massie, M. J., Payne, D., & Biggs, C. G. (1998). Patient regrets after bilateral prophylactic mastectomy. *Annals of Surgical Oncology, 5*(7), 603-606.

Borreani, C., Manoukian, S., Bianchi, E., Brunelli, C., Peissel, B., Caruso, A., … Pierotti, M. A. (2014). The psychological impact of breast and ovarian cancer preventative options in BRCA1 and BRCA2 mutation carriers. *Clinical Genetics, 85,* 7-15.

Bosch, N., Junyent, N., Gadea, N., Brunet, J., Ramon y Cajal, T., Torres, A., … Balmana, J. (2012). What factors may influence psychological wellbeing at three months and one year post BRCA genetic result disclosure? *The Breast Journal, 21,* 755-760.

Bowman, K. F., Deimling, G. T., Smerglia, V., Sage, P., & Kahana, B. (2003). Appraisal of the cancer experience by older long-term survivors. *Psycho-Oncology, 12,* 226-238.

Braithwaite, D., Emery, J., Walter, F., Prevost, A. T., & Sutton, S. (2004). Psychological impact of genetic counseling for familial cancer: A systematic review and meta analysis. *Journal of the National Cancer Institute, 96,* 122-123.

Braithwaite, D., Emery, J., Walter, F., Prevost, A. T., & Sutton, S. (2006). Psychological impact of genetic counseling for familial cancer: A systematic review and meta-analysis. *Familial Cancer, 5*, 61-75.

Brandberg, Y., Sandelin, K., Erikson, S., Jurell, G., Liljigren, A., Lindbloom, J., … & Arver, B. (2008). Psychological reactions, quality of life, and body image after bilateral prophylactic mastectomy in women at high risk for breast cancer: A prospective 1-year follow-up study. *Journal of Clinical Oncology, 20*(24), 3943-3949.

Bredin, M. (1999). Mastectomy, body image and therapeutic massage: A qualitative study of women's experience. *Journal of Advanced Nursing, 29*(5), 1113-1120.

Bresser, P. J., Seynaeve, C., Van Gool, A. R., Brekelmans, C. T., Meijers-Heijboer, H., Van Geel, A. N., … Tibben, A. (2006). Satisfaction with prophylactic mastectomy and breast reconstruction in genetically predisposed women. *Plastic and Reconstructive Surgery, 117*(6), 1675-1682.

Bresser, P. J., Seynaeve, C., Van Gool, A. R., Niermeijer, M. F., Duivenvoorden, H. J., Van Dooren, S., … & Tibben A. (2007). The course of distress in women at increased risk of breast and ovarian cancer due to an (identified) genetic susceptibility who opt for prophylactic mastectomy and/or salpingo-oophorectomy. *European Journal of Cancer, 43*(1), 95-103.

Bresser, P. J., Van Gool, A. R., Seynaeve, C., Duivenvoorden, H. J., Niermeijer, M. F., Van Geel, A. N., … & Tibben, A. (2007). Who is prone to high levels of distress after prophylactic mastectomy and/or salpingo-ovariectomy? *Annals of Oncology, 18*(10), 1641-1645.

Broadstock, M., Michie, S., & Marteau, T. (2000). Psychological consequences of predictive genetic testing: A systematic review. *European Journal of Human Genetics, 8*, 731-738.

Carlsson, A. H., Bjorvatn, C., Engebresten, L. F., Berglund, G., & Natvig, G. K. (2004). Psychosocial factors associated with quality of life among individuals attending genetic counseling for hereditary cancer. *Journal of Genetic Counseling, 13*(5), 425-445.

Carpenter, J. S. (1997). Self-esteem and well-being among women with breast cancer and women in age-matched comparison group. *Journal of Psychosocial Oncology, 15*, 59-80.

Carver, C.S. (2013). *Measure of body apperception (MBA).* Retrieved from http://www.midss.org/sites/default/files/mba.pdf

Carver, C. S., Pozo-Kaderman, C., Price, A. A., Noriega, V., Harris, S. D., Derhagopian, R. P., … & Moffatt, F.L. (1998). Concern about aspects of body image and adjustment to early stage breast cancer. *Psychosomatic Medicine, 60*, 168–174.

Cash, T. F., Melnyk, S. E., & Hrabosky, J. I. (2004). The assessment of body image investment: An extensive revision of the appearance schemas inventory. *International Journal of Eating Disorders, 35,* 305-316.

Cella, D., Hughes, C., Peterman, A., Chang, C. H., Peshkin, B. N., Schwartz, M. D., … & Lerman, C. (2002). A brief assessment of concerns associated with genetic testing for cancer: The multidimensional impact of cancer risk assessment (MICRA) questionnaire. *Health Psychology, 21*, 564-572.

Cervone, D., & Pervin, L. (2008). *Personality theory and research*. Hoboken, NJ: Wiley.

Charmaz, K. (1999). Stories of suffering: Subjective tales and research narratives. *Qualitative Health Research, 9,* 362-382.

Claes, E., Evers-Kiebooms, G., Denayer, L., Decruyenaere, M., Boogaerts, A., & Legius, E. (2005). Predictive genetic testing for hereditary breast and ovarian cancer: Psychological distress and illness representations 1 year following disclosure. *Journal of Genetic Counseling, 14*(5), 349-363.

Clark, E. J., & Stovall, E. L. (1996). Advocacy: The cornerstone of cancer survivorship. *Cancer Practice, 4*, 239-244.

Cohen, M. Z., Kahn, D. L., & Steeves, R. H. (1998). Beyond body image: The experience of breast cancer. *Oncology Nursing Forum, 25*, 835-841.

Crane-Okada, R., Wascher, R., Elashoff, D., & Giuliano, A. (2008). Long term morbidity of sentinel node biopsy versus complete axillary dissection for unilateral breast cancer. *Annals of Surgical Oncology, 15,* 1996-2005.

Croyle, R. T., Smith, K. R., Botkin, J. R., Baty, B., & Nash, J. (1997). Psychological responses to BRCA1 mutation testing: Preliminary findings. *Health Psychology*, *16*(1), 63-72.

Cukier, Y. R., Thompson, H. S., Sussner, K., Forman, A., Jandorf, L., Edwards, T., … Valdimarsdottir, H. B. (2013). Factors associated with psychological distress among women of African descent at high risk for BRCA mutations. *Journal of Genetic Counseling, 22,* 101-107.

Curbow, B., & Somerfield, M. (1991). Use of the Rosenberg Self-Esteem Scale with adult cancer patients. *Journal of Psychosocial Oncology, 9,* 113-131.

Curbow, B., Somerfield, M., Legro, M., & Sonnega, J. (1990). Self-concept and cancer in adults: Theoretical and methodological issues. *Social Science and Medicine, 31,* 115–128.

Cull, A., Anderson, E. D., Campbell, S., Mackay, J., Smyth, E., & Steel, M. (1999). The impact of genetic counselling about breast cancer risk on women's risk perceptions and levels of distress. *British Journal of Cancer, 79*(3), 501-508.

D'Agincourt-Canning, L. (2001). Experiences of genetic risk: Disclosure and the gendering of responsibility. *Bioethics, 15*, 231-247.

Dancyger, C., Wiseman, M., Jacobs, C., Smith, J. A., Wallace, M., & Michie, S. (2011). Communicating BRCA1/2 genetic test results within the family: A qualitative analysis. *Psychology and Health, 26,* 1018-1035.

De Gonzalez, A. B., Berg, C. D., Visvanathan, K., & Robson, M. (2009). Estimating risk of radiation-induced breast cancer from mammographic screening for young BRCA mutation carriers. *Journal of the National Cancer Institute, 101*, 205-209.

DeMarco, T. A., & McKinnon, W. C. (2007). Life after BRCA1/2 testing: Family communication and support issues. *Breast Disease, 27*, 127-136.

Den Heijer, M., Seynaeve, C., Timman, R., Duivenvoorden, H. J., Vanheusden, K., Tilanus-Linthorst, M., … & Tibben, A. (2012). Body image and psychological distress after prophylactic mastectomy and breast reconstruction in genetically predisposed women: A prospective long-term follow-up study. *European Journal of Cancer, 48,* 1263-1268.

Den Heijer, M., Seynaeve, C., Vanheusden, K., Duivenvoorden, H. J., Bartles, C. M., Menke-Pluymers, M., & Tibben, A. (2012). Psychological distress in women at risk of hereditary breast cancer: The role of family communication and perceived social support. *Psycho-Oncology, 20,* 1317-1323.

Den Heijer, M., Seynaeve, C., Vanheusden, K., Duivenvoorden, H. J., Vos, J., Bartles, C. M., & Tibben, A. (2011). The contribution of self-esteem and self-concept in psychological distress in women at risk of hereditary breast cancer. *Psycho-Oncology, 20,* 1170-1175.

Den Heijer, M., Seynaeve, C., Vanheusden, K., Timman, R., Duivenvoorden, H. J., Tilanus-Linhorst, M., … Tibben, A. (2013). Long-term psychological distress in women at risk for hereditary breast cancer adhering to regular surveillance: A risk profile. *Psycho-Oncology, 22,* 598-604.

Den Heijer, M., Vos, J., Seynaeve, C., Vanheusden, K., Duivenvoorden, H. J., Tilanus-Linthorst, M., … Tibben, A. (2012). The impact of social and personal resources on psychological distress in women at risk for hereditary cancer. *Psycho-Oncology, 21,* 153-160.

Denieffe, S., & Cooney, M. (2010). A meta-synthesis of women's symptoms experience and breast cancer. *European Journal of Cancer Care, 20,* 424-435.

Devins, G. M., Beanlands, H., Mandin, H., & Paul, L. C. (1997). Psychosocial impact of illness intrusiveness moderated by self-concept and age in end-stage renal disease. *Health Psychology, 16,* 529-538.

DiMillo, J., Samson, A., Theriault, A., Lowry, S., Corsini, L., Verma, S., & Tomiak, E. (2013). Living with the BRCA genetic mutation: An uncertain conclusion to an unending process. *Psychology, Health, and Medicine, 18*(2), 125-134.

Di Prospero, L. S., Seminsky, M., Honeyford, J., Doan, B., Franssen, E., Meschino, W., ... & Chart, P. (2001). Psychosocial issues following a positive result of genetic testing for BRCA1 and BRCA2 mutations: Findings from a focus group and a needs assessment survey. *Canadian Medical Association Journal, 164,* 1005–1009.

Domchek, S. M., Friebel, T. M., Neuhausen, S. L., Wagner, T., Evans, G., Isaacs, C., … & Rebbeck, T. R. (2006). Mortality after bilateral salpingo-oophorectomy in BRCA1 and BRCA2 mutation carriers: A prospective cohort study. *Lancet, Oncology, 7*(3), 223-229.

Domchek, S. M., Friebel, T. M., Singer, C. F., Evans, D. G., Lynch, H. T., Isaacs, C., … & Rebbeck, T. R. (2010). Association of risk-reducing surgery in BRCA1 or BRCA2 mutation carriers with cancer risk and mortality. *Journal of the American Medical Association, 304*(9), 967-975.

Dorval, M., Bouchard, K., Maunsell, E., Plante, M., Chiquette, J., Camden, S., … Simard, J. (2008). Health behaviors and psychological distress in women initiating BRCA1/2 genetic testing: Comparison with control population. *Journal of Genetic Counseling, 17*, 314-326.

Dorval, M., Patenaude, A. F., Schneider, K. A., Kieffer, S. A., DiGianni, L., Kalkbrenner, K. J., ... & Garber, J.E. (2000). Anticipated versus actual emotional reactions to disclosure of results of genetic tests for cancer susceptibility: Findings from p53 and BRCA1 testing programs. *Journal of Clinical Oncology, 18*, 2135–2142.

Drew, S. (2007). ‘Having cancer changed my life, and changed my life forever’: Survival, illness legacy, and service provision following cancer in childhood. *Chronic Illness, 3*, 278-295.

Eijzenga, W., Hahn, D. E., Aaronson, N. K., Kluijt, I., & Bleiker, E. M. (2014). Specific psychosocial issues of individuals undergoing genetic counseling for cancer: A literature review. *Journal of Genetic Counseling, 23*(2), 133-146.

Eisinger, F., Reynier, C., Chabal, F., Luquet, C., Moatti, J. P., & Sobol, H. (1997). Acceptable strategies for dealing with hereditary breast/ovarian cancer risk. *Journal of the National Cancer Institute Monographs, 89.*

Erblich, J., Bovbjerg, D. H., & Valdimarsdottir, H. B. (2000). Looking forward and back: Distress among women at familial risk for breast cancer. *Annals of Behavioral Medicine, 22,* 53-59.

Ertmanski, S., Metcalfe, K., Tempata, J., Glowacka, M. D., Lubinski, J., Narod, S. A., & Gronwald, J. (2009). Identification of patients at high risk of psychological distress after BRCA1 genetic testing. *Genetic Testing and Molecular Biomarkers, 13*(3), 325-330.

Esplen, M. J., Hunter, J., Leszcz, M., Warner, E., Narod, S., Metcalfe, K., … & Wong, J. (2004). A multicenter study of supportive-expressive group therapy for women with BRCA1/BRCA2 mutations. *Cancer, 101,* 2327-2340.

Esplen, M. J., Stuckless, N., Gallinger, S., Aronson, M., Rothenmund, H., Semotiuk, K., … & Wong, J. (2011). Development and validation of an instrument to measure the impact of genetic testing on self-concept in Lynch syndrome. *Clinical Genetics, 80,* 415-423.

Esplen, M. J., Stuckless, N., Hunter, J., Liede, A., Metcalfe, K., Glendon, G., …Irwin, E. (2009). The BRCA Self-Concept Scale: A new instrument to measure self-concept in BRCA1/2 mutation carriers. *Psycho-Oncology, 18,* 1216-1229.

Evans, D. G., Lalloo, F., Ashcroft, L., Shenton, A., Clancy, T., Baildam, A. S., … & Howell, A. (2009). Uptake of risk-reducing surgery in unaffected women at high risk of breast and ovarian cancer is risk, age, and time dependent. *Cancer Epidemiology, Biomarkers, and Prevention, 18*(8), 2318-2324.

Evans, J. P., Skrzynia, C., Susswein, L., & Harlan, M. (2005). Genetics and the young woman with breast cancer. *Breast Disease, 23,* 17-29.

Facing Our Risk of Cancer Empowered (FORCE; 2015). *Facing our risk of cancer empowered: Fighting hereditary breast and ovarian cancer.* Retrieved from http://www.facingourrisk.org/index.php

Falk-Dahl, C., Reinertsen, K., Nesvold, I., Fossa, S., & Dahl, A. (2010). A study of body image in long-term breast cancer survivors. *Cancer, 116*, 3549-3557.

Farrelly, A., White, V., Meiser, B., Jefford, M., Young, M., Ieropoli, S., … Duffy, J. (2013). Unmet support needs and distress among women with a BRCA1/2 mutation. *Familial Cancer, 12,* 509-518.

Fingeret, M. C., Nipomnick, S., Guindani, M., Bauman, D., Hanasono, M., & Crosby, M. (2014). Body image screening for cancer patients undergoing reconstructive surgery. *Psycho-Oncology, 23,* 898-905.

Fitts, W. H. (1971). A conceptualization of the self-concept. In W. H. Fitts, J. L. Adams, G. Radford, W. C. Richard, B. K. Thomas, & Q. W. Thompson (Eds.), *The self concept and self actualization* (pp. 11-26). Nashville, TN: Counselor Recordings and Tests.

Fitts, W. H., & Warren, W. L. (1996). *Tennessee Self-Concept Scale: Second edition*. Los Angeles, CA: Western Psychological Associates.

Fobair, P., Stewart, S. L., Chang, S., D'Onofrio, C., Banks, P. J., & Bloom, J. R. (2006). Body image and sexual problems in young women with breast cancer. *Psycho-Oncology, 15,* 579-594.

Foltz, A. T. (1987). The influence of cancer on self-concept and life quality. *Seminars in Oncology Nursing, 2*(4), 303-312.

Foster, C., Eeles, R., Arden-Jones, A., Moynihan, C., & Watson, M. (2004). Juggling roles and expectations: Dilemmas faced by women talking to relatives about cancer and genetic testing. *Psychology and Health, 19,* 439-455.

Foster, C., Watson, M., Eeles, R., Eccles, D., Ashley, S., Davidson, R., … & Evans, D. G. (2007). Predictive genetic testing for BRCA1/2 in a UK clinical cohort: Three-year follow-up. *British Journal of Cancer, 96*(5), 718-724.

Friebel, T. M., Domechek, S. M., Neuhausen, S. L., Wagner, T., Evans, D. G., Isaacs, C., … & Rebbeck, T. R. (2007). Bilateral prophylactic oophorectomy and bilateral prophylactic mastectomy in a prospective cohort of unaffected BRCA1 and BRCA2 mutation carriers. *Clinical Breast Cancer, 7*(11), 875-882.

Friedman, S. F., Sutphen, R., & Steligo, K. (2012). *Confronting hereditary breast and ovarian cancer: Identify your risk, understand your options, change your destiny.* Baltimore, MD: The Johns Hopkins University Press.

Frost, M. H., Schaid, D. J., Sellers, T. A., Slezak, J. M., Arnold, P. G., Woods, J. E., … & Hartmann, L. C. (2000). Long-term satisfaction and psychological and social function following bilateral prophylactic mastectomy. *Journal of the American Medical Association, 284*(3), 319-324.

Ganz, P. A., Coscarelli, A., Fred, C., Kahn, B., Polinsky, M. L., & Petersen, L. (1996). Breast cancer survivors: Psychosocial concerns and quality of life. *Breast Cancer Research and Treatment, 38,* 183-199.

Ganz, P. A., Desmond, K. A., Belin, T. R., Meyerowitz, B. E., & Rowland, J. H. (1999). Predictors of sexual health in women after a breast cancer diagnosis. *Journal of Clinical Oncology, 17,* 2371-2380.

Ganz, P. A., Lee, J. A., Sim, M. S., Polinsky, M. L., & Schag, C. A. (1992). Exploring the influence of multiple variables on the relationship of age to quality of life in women with breast cancer. *Journal of Clinical Epidemiology, 45,* 473-485.

Geiger, A. M., West, C. N., Nekhlyudov, L., Herrinton, L. J., Liu, I. L., Altschuler, A., … Fletcher, S. W. (2006). Contentment with quality of life among breast cancer survivors with and without contralateral prophylactic mastectomy. *Journal of Clinical Oncology, 24*(9), 1350-1356.

Grana, G., Daly, M., Sands, C., Masnt, A., Jones, T., Wagner, J., & Gillespie, D. (1994). The role of prophylactic mastectomy in managing genetic risk. *Breast Cancer Research and Treatment, 32*.

Graves, K. D., Vegella, P., Poggi, E. A., Peshkin, B. N., Tong, A., Isaacs, C., … Schwartz, M. D. (2012). Long-term psychological outcomes of BRCA1/BRCA2 testing: Differences across affected status and risk-reducing surgery choice. *Cancer Epidemiology, Biomarkers, and Prevention, 21*(3), 445-454.

Halbert, C. H., Stopfer, J. E., McDonald, J., Weathers, B., Collier, A., Troxel, A. B., & Domchek, S. (2011). Long-term reactions to genetic testing for BRCA1 and BRCA2 mutations: Does time heal women's concerns? *Journal of Clinical Oncology, 29,* 4302-4306.

Hallowell, N., Foster, C., Eeles, R., Arden-Jones, A., & Watson, M. (2004). Accommodating risk: Responses to BRCA1/2 genetic testing of women who have had cancer. *Social Science and Medicine, 59,* 553-565.

Hallowell, N., Mackay, J., Richards, M., Gore, M., & Jacobs, I. (2004). High-risk premenopausal women's experiences of undergoing prophylactic oophorectomy: A descriptive study. *Genetic Testing, 8*(2), 148–156.

Hamilton, J. G., & Lobel, M. (2012). Passing years, changing fears? Conceptualizing and measuring risk perception for chronic disease in younger and middle-aged women. *Journal of Behavioral Medicine, 35,* 124-138.

Hamilton, J. G., Lobel, M., & Moyer, A. (2009). Emotional distress following genetic testing for hereditary breast and ovarian cancer: A meta-analytic review. *Health Psychology, 28,* 510-518.

Hamilton, R. (2009). Genetics: Breast cancer as an exemplar. *Nursing Clinics of North America, 44,* 327-338.

Hamilton, R., Williams, J. K., Skirton, H., & Bowers, B. J. (2009). Living with genetic test results for hereditary breast and ovarian cancer. *Journal of Nursing Scholarship, 41*, 276-283.

Harmsen, M. G., Hermens, R., Prins, J. B., Hoogerbrugge, N., & De Hulu, J. A. (2012). How medical choices influence quality of life of women carrying a BRCA mutation. *Critical Reviews in Oncology/Hematology, 96*(3), 1-14.

Harrison, J. D., Young, J. M., Price, M. A., Butow, P. N., & Solomon, M. J. (2009). What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer 17,* 1117-1128.

Harter, S. (1996). Historical roots of contemporary issues involving self-concept. In B. A. Bracken (Ed.), *Handbook of self-concept: Developmental, social, and clinical considerations* (pp. 1-37). New York, NY: Wiley.

Hartl, K., Engel, J., Herschbach, P., Reinecker, H., Sommer, H., & Friese, K. (2010). Personality traits and psychological stress: Quality of life over 2 years following breast cancer diagnosis and psychological impact factors. *Psycho-Oncology, 19*, 160-169.

Hartmann, L. C., Sellers, T. A., Schaid, D. J., Frank, T. S., Soderberg, C. L., Sitta, D. L., … & Jenkins, R. B. (2001). Efficacy of bilateral prophylactic mastectomy in BRCA1 and BRCA2 gene mutation carriers. *Journal of the National Cancer Institute, 93,* 1633-1637.

Hatcher, M. B., Fallowfield, L., & A'Hern, R. (2001). The psychosocial impact of bilateral prophylactic mastectomy: Prospective study using questionnaires and semistructured interviews. *British Journal of Medicine, 322*(76), 1-6.

Hattie, J. A. (1992). *Self-concept*. Hillsdale, NJ: Erlbaum.

Heemskerk-Gerritsen, B., Menke-Plujmers, M., Jager, A., Tilanus-Linthorst, M., Koppert, L., Obedijn, I., … & Hooning, M., (2013). Substantial breast cancer risk reduction and potential survival benefit after bilateral mastectomy when compared with surveillance in healthy BRCA1 and BRCA2 mutation carriers: A prospective analysis. *Annals of Oncology, 24,* 2029-2035.

Heigeson, V. (2011). Survivor centrality among breast cancer survivors: Implications for well-being. *Psycho-Oncology, 20,* 517-524.

Helms, R. L., O'Hea, E. L., & Corso, M. (2008). Body image issues in women with breast cancer. *Psychology, Health, and Medicine, 13*(3), 313-325.

Hollingsworth, A. B., Singletary, S. E., Morrow, M., Francescatti, D. S., O'Shaughnessy, J. A., Hartman, A. R., … Vogel, V. G. (2004). Current comprehensive assessment and management of women at increased risk for breast cancer. *American Journal of Surgery, 187,* 349-362.

Hopwood, P. (1993). The assessment of body image in cancer patients. *European Journal of Cancer, 29A,* 276-281.

Hopwood, P., Fletcher, I., Lee, A., & Ghazal, S. A. (2001). Body image scale for use with cancer patients. *European Journal of Cancer, 37,* 189-197.

Hopwood, P., Howell, A., Lalloo, F., & Evans, G. (2003). Do women understand the odds? Risk perceptions and recall of risk information in women with a family history of breast cancer. *Community Genetics, 6,* 214 –223.

Hopwood, P., Keeling, F., Long, A., Pool, C., Evans, G., & Howell, A. (1998). Psychological support needs for women at high genetic risk of breast cancer: Some preliminary indicators. *Psycho-Oncology, 7*(5), 402-412.

Hopwood, P., Lee, A., Shenton, A., Baildam, A., Brain, A., Lalloo, F., … & Howell, A. (2000). Clinical follow-up after bilateral risk reducing ('prophylactic') mastectomy: Mental health and body image outcomes. *Psycho-Oncology, 9,* 462-472.

Horowitz, M., Wilner, M., & Alvarez, W. (1979). Impact of event scale: A measure of subjective stress. *Psychosomatic Medicine, 41,* 209-218.

Horowitz, M. J., Wilner, N., Kaltrieder, N., & Alvarez, W. (1980). Signs and symptoms of posttraumatic stress disorder. *Archives of General Psychiatry, 37*(1), 85-92.

Horsman, D., Wilson, B. J., Avard, D., Meschino, W. S., Kim Sing, C., Plante, M., … & Simard, J. (2007). Clinical management recommendations for surveillance and risk-reduction strategies for hereditary breast and ovarian cancer among individuals carrying a deleterious BRCA1 or BRCA2 mutation. *Journal of Obstetrics and Gynecological Cancer, 29*(1), 45-60.

Hoskins, L. M., Roy, K. M., & Greene, M. H. (2012). Toward a new understanding of risk perception among young female BRCA1/2 "previvors." *Families, Systems, and Health, 30*(1), 32-46.

James, W. (1890). *The principles of psychology* (Vol. 2). New York, NY: Holt.

Jean-Pierre, P., Fundakowski, C., Perez, E., Jean-Pierre, S. E., Jean-Pierre, A. R., Melillo, A. B., … & Sargi, Z. (2012). Latent structure and reliability analysis of the measure of body apperception: Cross-validation for head and neck cancer patients. *Supportive Care in Cancer, 25,* 591-598.

Josephson, U., Wickman, M., & Sandelin, K. (2000). Initial experiences of women from hereditary breast cancer families after bilateral prophylactic mastectomy: A retrospective study. *European Journal of Surgical Oncology, 26,* 351-356.

Julian-Reynier, C., Eisinger, F., Chabal, F., Lasset, C., Nogues, C., Stoppa-Lyonnet, D., … Sobol, H. (2000). Disclosure to the family of breast/ovarian cancer genetic test results: Patient's willingness and associated factors. *American Journal of Medical Genetics, 94,* 13-18.

Julian-Reynier, C., Mancini, J., Mouret-Fourme, E., Gauthier-Villars, M., Bonadona, V., Berthet, P., … & Nogues, C. (2011). Cancer risk management strategies and perceptions of unaffected women 5 years after predictive genetic testing for BRCA1/2 mutations. *European Journal of Human Genetics, 19*(5), 500-506.

Kadela-Collins, K., Schootman, M., Aft, R., Yan, Y., Dean, G., Eilers, M., & Jeffe, D. B. (2011). Effects of breast cancer surgery and surgical side effects on body image over time. *Breast Cancer Research and Treatment, 126,* 167-176.

Katapodi, M. C., Lee, K. A., Facione, N. C., & Dodd, M. J. (2004). Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: A meta-analytic review. *Preventive Medicine, 38,* 388-402.

Katz, M. R., Rodin, G., & Devins, G. M. (1995). Self-esteem and cancer: Theory and research. *Canadian Journal of Psychiatry, 40*(10), 608-615.

Kelly, K. M., Leventhal, H., Andrydowski, M., Toppmeyer, D., Much, J., Dermody, J., … & Schwalb, M. (2005). Using the common sense model to understand perceived cancer risk in individuals testing for BRCA1/2 mutations. *Psycho-Oncology, 14*, 34-48.

Kendzierski, D. (1988). Self-schemata and exercise. *Basic Applied Social Psychology, 9,* 45-59.

Kenen, R., Arden-Hones, A., & Eeles, R. (2004). We are talking, but are they listening? Communication patterns in families with a history of breast/ovarian cancer (HBOC). *Psycho-Oncology, 13*, 335-345.

Kennedy-Moore, E., & Watson, J. C. (2001). How and when does emotional expression help? *Review of General Psychology, 5*, 187-212.

Klitzman, R., & Chung, W. (2010). The process of deciding about prophylactic surgery for breast and ovarian cancer: Patient questions, uncertainties, and communication. *American Journal of Medical Genetics Part A, 152A*, 52-66.

Koehly, L. M., Peters, J. A., Kuhn, N., Hoskins, L., Letocha, A., Kenen, R., … & Greene, M. H. (2008). Sisters in hereditary breast and ovarian cancer families: Communal coping, social integration, and psychological well-being. *Psycho-Oncology, 17*(8), 812-821.

Kraus, P. L. (1999). Body image, decision making, and breast cancer treatment. *Cancer Nursing, 22*(6), 421-427.

Kullmer, U., Stenger, K., Milch, W., Zygmunt, M., Sachsse, S., & Munstedt, K. (1999). Self-concept, body image, and use of unconventional therapies in patients with gynecological malignancies in the state of complete remission and recurrence. *European Journal of Obstetrics and Gynecology and Reproductive Biology, 82*, 101-106.

Landsbergen, K., Brunner, H., Manders, P., Hoogerbrugge, N., & Pins, J. B. (2010). Educational-support groups for BRCA mutation carriers satisfy need for information but do not affect emotional distress. *Genetic Counseling, 21*(4).

Lapointe, J., Dorval, M., Nogues, C., Fabre, R., & Julian-Reynier, C. (2013). Is the psychological impact of genetic testing moderated by support and sharing of test results to family and friends? *Familial Cancer, 12,* 601-610.

Lasry, J., & Margolese, R. G. (1992). Fear of recurrence, breast-conserving surgery, and the trade-off hypothesis. *Cancer, 69,* 2111-2115.

Lee, M. S., Love, S. B., Mitchell, J. B., Parker, E. M., Rubens, R. D., Watson, J. P., … & Hayward, J. L. (1992). Mastectomy or conservation for early breast cancer: Psychological morbidity. *European Journal of Cancer, 28A,* 1340-1344.

Lerman, C., Lustbader, E., Rimer, B., Daly, M., Miller, S., Sands, C., & Balshem, A. (1995). Effects of individualized breast cancer risk counseling: A randomized trial. *Journal of the National Cancer Institute, 87*(4), 286-292.

Lerman, C., Narod, S., Schulman, K., Hughes, C., Gomez-Caminero, A., Bonney, G., … & Lynch, H. (1996). BRCA1 testing in families with hereditary breast-ovarian cancer: A prospective study of patient decision making and outcomes. *Journal of the American Medical Association, 275*(24), 1885-1892.

Lerman, C., Schwartz, M. D., Lin, T. H., Hughes, C., Narod, S., & Lynch, H. T. (1997). The influence of psychological distress on use of genetic testing for cancer risk. *Journal of Consulting and Clinical Psychology, 65*(3), 414-420.

Lerman, C., Seay, J., Balshem, A., & Audrain, J. (1995). Interest in genetic testing among first-degree relatives of breast cancer patients. *American Journal of Medical Genetics, 57,* 385-392.

Liao, M. N., Chen, M. F., Chen, S. C., & Chen, P. L. (2008). Uncertainty and anxiety during the diagnostic period for women with suspected breast cancer. *Cancer Nursing, 31,* 274-283.

Lim, J. M., MacLurin, M., Price, M., Bennett, B., & Butow, P. (2004). Short- and long-term impact of receiving genetic mutation results in women at increased risk for hereditary breast cancer. *Journal of Genetic Counseling, 13*(2), 115-133.

Lindberg, N. M., & Wellisch, D. K. (2004). Identification of traumatic stress reaction in women at increased risk for breast cancer. *Psychosomatics, 45*(1), 7-16.

Linville, P. (1987). Self-complexity as a cognitive buffer against stress-related illness and depression. *Journal of Personality and Social Psychology, 52,* 663-676.

Little, M., Paul, K., Jordens, C. F., & Sayers, E. J. (2002). Survivorship and discourses of identity. *Psycho-Oncology, 11,* 170-178.

Lobb, E., & Meiser, B. (2004). Genetic counselling and prophylactic surgery in women from families with hereditary breast or ovarian cancer. *Lancet, 363*(9424), 1841-1842.

Lobel, M., Hamilton, J., & Moyer, A. (2009). Emotional distress following genetic testing for hereditary breast and ovarian cancer: A meta-analytic review. *Health Psychology, 28*, 510-518.

Lodder, L., Frets, P. G., Trijsburn, R. W., Meijers-Heijboer, J., Klijn, J., Duivenvoorden, H. J., … & Niermeijer, M. F. (2001). Psychological impact of receiving a BRCA1/BRCA2 test result. *American Journal of Medical Genetics, 98,* 15-24.

Lodder, L. N., Frets, P. G., Trijsburg, R. W., Meijers-Heijboer, E. J., Klijn, J. G., Seynaeve, C., … Niermeijer, M. F. (2002). One year follow-up of women opting for presymptomatic testing for BRCA1 and BRCA2: Emotional impact of the test outcome and decisions on risk management (surveillance or prophylactic surgery). *Breast Cancer Research and Treatment, 73*(2), 97-112.

Lord, S. J., Lei, W., Craft, P., Cawson, J. N., Morris, I., Walleser, S., … & Houssami, N. (2007). A systematic review of the effectiveness of magnetic resonance imaging (MRI) as an addition to mammography and ultrasound in screening young women at high risk of breast cancer. *European Journal of Cancer, 43*(13), 1905-1917.

Lostumbo, L., Carbine, N. E., & Wallace, J. (2010). Prophylactic mastectomy for the prevention of breast cancer. *Cochrane Database of Systematic Reviews, 10*(11), 252-253.

Lux, M. P., Fasching, P. A., & Beckmann, M. W. (2006). Hereditary breast and ovarian cancer: Review and future perspectives. *Journal of Molecular Medicine, 84,* 16-28.

Lynch, H. T., Lemon, S. J., Durham, C., Tinley, S. T., Connolly, C., Lynch, J. F., … & Narod, S. (1997). A descriptive study of BRCA1 testing and reactions to disclosure of test results. *Cancer, 79*(11), 2219-2228.

Lynch, H. T., Snyder, C., Lunch, J. F., Karatoprakli, P., Trowonou, A., Metcalfe, K., … Gong, G. (2006). Patient responses to the disclosure of BRCA mutation tests in hereditary breast-ovarian cancer families. *Cancer Genetics and Cytogenetics, 165,* 91-97.

Madalinska, J. B., Van Beurden, M., Bleiker, E. M., Valdimarsdottir, H. B., Lubsen-Brandsma, L., Massuger, L. F., … Aaronson, N. K. (2007). Predictors of prophylactic bilateral salpingo-oophorectomy compared with gynecologic screening use in BRCA1/2 mutation carriers. *Journal of Clinical Oncology, 25*(3), 301-307.

Mages, N. & Mendelsohn, G. (1979). Effects of cancer on patients' lives: A personological approach. In G. Stone (Ed.) *Health psychology,* pp. (255-284). San Francisco, CA: Jossey-Bass.

Maheu, C., Bouhnik, A. D., Nogues, C., Mouret-Fourme, E., Stoppa-Lyonnet, D., Lasset, C., … Julian-Reynier, C. (2014). Which factors predict proposal and uptake of psychological counselling after BRCA1/2 result disclosure? *Psycho-Oncology, 23,* 420-427.

Manderson, L., & Stirling, L. (2007). The absent breast: Speaking of the mastectomied body. *Feminine Psychology, 17,* 75-92.

Manne, S., Audrain, J., Schwartz, M., Main, D., Finch, C., & Lerman, C. (2004). Associations between relationship support and psychological reactions of participants and partners to BRCA1 and BRCA2 testing in a clinic-based sample. *Annals of Behavioral Medicine, 28*(3), 211-225.

Margolis, G. J., Goodman, R. I., Rubin, A., & Pajac, T. F. (1989). Psychological factors in the choice of treatment for breast cancer. *Psychosomatics, 30*(2), 192-197.

Markel, H. (1992). The stigma of disease: Implications of genetic screening. *American Journal of Medicine, 93,* 209-215.

Markus, H. (1977). Self-schemas and processing information about the self. *Journal of Personality and Social Psychology, 35,* 63-78.

Markus, H., Hamill, R., & Sentis, K. (1987). Thinking fat: Self-schemas for body weight and the processing of weight relevant information. *Journal of Applied Social Psychology, 17,* 50-71.

Markus, H., & Keith, S. (1982). The self in social information processing. In J. Suls (Ed.), *Social psychological perspectives on the self* (pp. 41-70). Hillside, NJ: Erlbaum.

Markus, H., & Wurf, E. (1987). The dynamic self-concept: A social psychological perspective. *Annual Review of Psychology, 38,* 299-337.

Marsh, H. W. (1986). Global self-esteem: Its relation to specific facets of self-concept and their importance. *Journal of Personality and Social Psychology, 51*, 1224-1236.

Marsh, H. W., & Hattie, J. (1996). Theoretical perspectives on the structure of self-concept. In B. A. Bracken (Ed.), *Handbook of self-concept: Developmental, social, and clinical considerations* (pp. 38-90). New York, NY: Wiley.

McCaul, K. D., Reid, P. A., Rathge, R. W., & Martinson, B. (1996). Does concern about breast cancer inhibit or promote breast cancer screening? *Basic and Applied Social Psychology, 18,* 183-194.

McConkie-Rosell, A., & DeVillis, B. J. (2000). Threat to parental role: A possible mechanism of altered self-concept related to carrier knowledge. *Journal of Genetic Counseling, 9*(4), 285-302.

McGaughey, A. (2006). Body image after bilateral prophylactic mastectomy: An integrative literature review. *Journal of Midwifery and Womens Health, 51*(6), 41–49.

Meijers-Heijboer, H., Van Geel, B., Van Putten, W., Henzen-Logmans, S. C., Seynaeve, C., Menke-Pluymers, M., … & Klijn, J. (2001). Breast cancer after prophylactic bilateral mastectomy in women with BRCA1 or BRCA2 mutation. *New England Journal of Medicine, 345*(158), 159-164.

Meiser, B. (2005). Psychological impact of genetic testing for cancer susceptibility: An update of the literature. *Psycho-Oncology, 14*(12), 1060-1074.

Meiser, B., Butow, P., Friedlander, M., Baratt, A., Schnieden, V., Watson, M., … & Tucker, K. (2002). Psychological impact of genetic testing in women from high-risk breast cancer families. *European Journal of Cancer, 38*(15), 2025-2033.

Meiser, B., Butow, P., Friedlander, M., Schnieden, V., Gattas, M., Kirk, J., … & Tucker, K. (2000). Intention to undergo prophylactic bilateral mastectomy in women at increased risk of developing hereditary breast cancer. *Journal of Clinical Oncology, 18,* 2250-2257.

Meiser, B., & Halliday, J. L. (2002). What is the impact of genetic counseling in women at increased risk of developing hereditary breast cancer?: A meta-analytic review. *Social Science and Medicine, 54,* 1463-1470.

Meissner, W. W. (1997). The self and the body: The body self and the body image. *Psychoanalytic and Contemporary Thought, 20*, 419-448.

Metcalfe, K. A., Birenbaum-Carmelo, D., Lubinski, J., Gronwald, J., Lynch, H., Moller, P., … & Narod, S. A. (2008). International variation in rates of uptake of preventive options in BRCA1 and BRCA2 mutation carriers. *International Journal of Cancer, 122*. 1-15.

Metcalfe, K. A., Esplen, M. J., Goel, V., & Narod, S. A. (2003). Psychosocial functioning in women who have undergone bilateral prophylactic mastectomy. *Psycho-Oncology, 13,* 14-25.

Metcalfe, K. A., Esplen, M. J., Goel, V., & Narod, S. (2004). Psychosocial functioning in women who have undergone bilateral prophylactic mastectomy. *Psycho-Oncology, 13*(14), 14-25.

Metcalfe, K. A., Liede, A., Hoodfar, E., Scott, A., Foulkes, W. D., & Narod, S. A. (2000). An evaluation of needs of female BRCA1 and BRCA2 carriers undergoing genetic counseling. *Journal of Medical Genetics, 37*, 866-874.

Metcalfe, K. A., Lubinski, J., Ghadirian, P., Lynch, H., Kin-Sing, C., Friedman, E., … & Narod, S. A. (2008). Predictors of contralateral prophylactic mastectomy in women with a BRCA1 or BRCA2 mutation: The Hereditary Breast Cancer Clinical Study Group. *Journal of Clinical Oncology, 26,* 1093-1097.

Miki, Y., Swensen, J., Shattuck-Eidens, D., Futreal, P. A., Harshman, K., Tavtigian, S., … & Skolnick, M. H. (1994). A strong candidate for the breast and ovarian cancer susceptibility gene BRCA1. *Science, 266*(5182), 66-71.

Mischel, M. H. (1988). Uncertainty in illness. *Journal of Nursing Scholarship, 20,* 225-232.

Mock, V. (1993). Body image in women treated for breast cancer. *Nursing Research, 42,* 153-157.

National Cancer Institute. (2015). *Cancer staging.* Retrieved from http://www.cancer.gov/about-cancer/diagnosis-staging/staging/staging-fact-sheet#q1

Nelsen, H. D., Huffman, L. H., Fu, R., & Harris, E. L. (2005). Genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility: Systematic evidence review for the U.S., Preventative Services Task Force. *Annals of Internal Medicine, 143*(5), 362-379.

Notari, S., Notari, L., Favez, N., Delaloye, J., & Ghisletta, P. (2016). The protective effect of a satisfying romantic relationship on women's body image after breast cancer: A longitudinal study. *Psycho-Oncology, 26*, 836-842.

Paterson, C., Lengacher, C., Donovan, K., Kip, K., & Tofthagen, C. (2016). Body image in younger breast cancer survivors. *Cancer Nursing, 39*, 39-58.

Payne, D. K., Biggs, C., Tran, K. N., Borgen, P. I., & Massie, M. J. (2000). Women's regrets after bilateral prophylactic mastectomy. *Annals of Surgical Oncology, 7,* 150-154.

Pendley, J., Dahlquist, L., & Dreyer, Z. (1997). Body image and psychosocial adjustment in adolescent cancer survivors. *Journal of Pédiatrie Psychology, 22*, 29-33.

Peshkin, B. N., Schwartz, M. D., Isaacs, C., Hughes, C., Main, D., & Lerman, C. (2002). Utilization of breast cancer screening in a clinically based sample of women after BRCA1/2 testing. *Cancer Epidemiology Biomarkers Prevention, 11*(10), 1115-1118.

Petronis, V. M., Carver, C. S., Antoni, M. H., & Weiss, S. (2003). Investment in body image and psychosocial well-being among women treated for early stage breast cancer: Partial replication and extension. *Psychology and Health, 18*(1), 1-13.

Pinto, B. M., Clark, M. M., Maruyama, N. C., & Feder, S. I. (2003). Psychological and fitness changes associated with exercise participation among women with breast cancer. *Psycho-Oncology, 12*, 118-126.

Polivy, J. (1997). Psychological effects of mastectomy on a woman's feminine self-concept. *The Journal of Nervous and Mental Disorders, 164,* 77-87.

Ponder, B., Day, N. E., Easton, D. F., Pharoah, P., Lipscombe, J. M., Redman, K., … & Dunning, A. (2000). Prevalence and penetrance of BRCA1 and BRCA2 mutations in a population-based series of breast cancer cases. *British Journal of Cancer, 83*(10), 1301-1308.

Prouty, D., Ward-Smith, P., & Hutto, C. J. (2006). The lived experience of adult survivors of childhood cancer. *Journal of Pediatric Oncology Nursing, 23*, 143-151.

Pruthi, S., Gostout, B. S., & Lindow, N. M. (2010). Identification and management of women with BRCA mutations or hereditary predisposition for breast and ovarian cancer. *Mayo Clinic Proceedings, 85*(12), 1111-1120.

Przezdziecki, A., Sherman, K. A., Baillie, A., Taylor, A., Foley, E., & Stalgis-Bilinski, K. (2013). My changed body: Breast cancer, body image, distress and self-compassion. *Psycho-Oncology, 22*, 1872-1879.

Ray, J. A., Loescher, L. J., & Brewer, M. (2005). Risk-reduction surgery decisions in high-risk women seen for genetic counseling. *Journal of Genetic Counseling, 14*(6), 473-484.

Rebbeck, T. R., Friebel, T., Lynch, H. T., Neuhausen, S. L., Van't Veer, L., Garber, J. E., … & Weber, B. L. (2004). Bilateral prophylactic mastectomy reduces breast cancer risk in BRCA1 and BRCA2 mutation carriers: The PROSE study group. *Journal of Clinical Oncology, 22*(6), 1055-1062.

Reichelt, J. G., Heimdal, K., Moller, P., & Dahl, A. A. (2004). BRCA1 testing with definitive results: A prospective study of psychological distress in a large clinic-based sample. *Familial Cancer, 3,* 22-28.

Reichelt, J. G., Moller, P., Heimdal, K., & Dahl, A. A. (2008). Psychological and cancer-specific distress at 18 months post-testing in women with demonstrated BRCA1 mutations for hereditary breast/ovarian cancer. *Familial Cancer, 7,* 245-254.

Rime, B. (2007). Interpersonal emotion regulation. In J. J. Gross (Ed.), *Handbook of emotion regulation* (pp. 466-485). New York, NY: Guilford Press.

Rodin, J., Silberstein, L., & Streigel-Moore, R. (1985). Women and weight: A normative discontent. In T. B. Sonderegger (Ed.), *Psychology and gender: Nebraska symposium on motivation 1984* (pp. 267-307). Lincoln: University of Nebraska Press.

Ronckers, C. M., Doody, M. M., Lonstein, J. E., Stovall, M., & Land, C. E. (2008). Multiple diagnostic X-rays for spine deformities and risk of breast cancer. *Cancer Epidemiological Biomarkers Preview, 17,* 605-613.

Rosenberg, M., Schooler, C., Schoenbach, C., & Rosenberg, F. (1995). Global self-esteem and specific self-esteem: Different concepts, different outcomes. *American Sociological Review, 60,* 141-156.

Rosser, J. (1981). The interpretation of women's experience: A critical appraisal of the literature on breast cancer. *Social Science and Medicine, 15*, 257-265.

Roussi, P., Sherman, K. A., Miller, S., Buzaglo, J., Daly, M., Taylor, A., … & Godwin, A. (2010). Enhanced counseling for women undergoing BRCA1/2 testing: Impact on knowledge and psychological distress- Results from a randomized clinical trial. *Psychology and Health, 25*(4), 201-215.

Samson, A., DeMillo, J., Theriault, A., Lowry, S., Corsini, L., Verma, S., & Tomiak, E. (2014). Living with BRCA1 and BRCA2 genetic mutation: Learning how to adapt to a virtual chronic illness. *Psychology, Health, and Medicine, 19*(1), 103-114.

Saslow, D., Boetes, C., Burke, W., Harms, S., Leach, M. O., Lechman, C. D., … Russell, C. A. (2007). American Cancer Society guidelines for breast screening with MRI as an adjunct to mammography.*CA: A Cancer Journal for Clinicians, 57*(2), 75-89.

Schain, W. S., D'Angelo, T. M., Dunn, M. E., Lichter, A. S., & Pierce, L. J. (1994). Mastectomy versus conservative surgery and radiation therapy: Psychosocial consequences. *Cancer, 73*, 1221-1228.

Schild, S. (1966). The challenging opportunity for social workers in genetics. *Social Work, 11*(22), 22-28.

Schild, S. (1984). Markers for stress and criteria for ongoing counseling. *Birth Defects Original Article Series, 20*, 107–113.

Schover, L. R., Yetman, R. J., Tuason, L. J., Meisler, E., Esselstyn, C. B., Hermann, R. E., … & Dowden, R. V. (1995). Partial mastectomy and breast reconstruction: A comparison of their effects on psychosocial adjustment, body image, and sexuality. *Cancer, 75*(1), 54-64.

Schroevers, M. J., Ranchor, A. V., & Sanderman, R. (2003). The role of social support and self-esteem in the presence and course of depressive symptoms: A comparison of cancer patients and individuals from the general population. *Social Science and Medicine, 57*, 375–385.

Schwartz, M. D., Isaacs, C., Graves, K. D., Poggi, E., Peshkin, B. N., Gell, C., … & Perley, L. (2012). Long-term outcomes of BRCA1/BRCA2 testing: Risk reduction and surveillance. *Cancer, 118*(2), 510-517.

Schwartz, M. D., Kaufman, E., Peshkin, B. N., Isaacs, C., Hughes, C., DeMarco, T., … & Lerman, C. (2003). Bilateral prophylactic oophorectomy and ovarian cancer screening following BRCA1/BRCA2 mutation testing. *Journal of Clinical Oncology, 21*(21), 4034-4041.

Schwartz, M. D., Lerman, C., Brogan, B., Peshkin, B. N., Halbert, C. H., DeMarco, T., … & Isaacs, C. (2004). Impact of BRCA1/BRCA2 counseling and testing on newly diagnosed breast cancer patients. *Journal of Clinical Oncology, 22*(10), 1823-1829.

Schwartz, M. D., Peshkin, B. N., Hughes, C., Main, D., Isaacs, C., & Lerman, C. (2002). Impact of BRCA1/BRCA2 mutation testing on psychologic distress in a clinic-based sample. *Journal of Clinical Oncology, 20,* 514-520.

Scott, J., Halford, K., & Ward, B. (2004). United we stand? The effects of a couple-coping intervention on adjustment to early stage breast or gynaecological cancer. *Journal of Consulting and Clinical Psychology, 72,* 1122-1135.

Segal, J., Esplen, M. J., Toner, B., Baedorf, S., Narod, S., & Butler, K. (2004). An investigation of the disclosure process and support needs of BRCA1 and BRCA2 carriers. *American Journal of Medical Genetics Part A, 125A*(3), 267-272.

Shaha, M., Cox, C. L., Talman, K., & Kelly, K. (2009). Uncertainty in breast, prostate, and colorectal cancer: Implications for supportive care. *Journal of Nursing Scholarship, 40,* 60-67.

Sheppard, L. A., & Ely, S. (2008). Breast cancer and sexuality. *The Breast Journal, 14*(2), 176-181.

Sherman, K., Woon, S., French, J., & Elder, E. (2017). Body image and psychological distress in nipple-sparing mastectomy: The roles of self-compassion and appearance investment. *Psycho-Oncology, 26,* 334-345.

Shiloh, S., Drori, E., Orr-Urtreger, A., & Friedman, E. (2009). Being 'at risk' of developing cancer: Cognitive representations and psychological outcomes. *Journal of Behavioral Medicine, 32,* 197-208.

Showers, C. (1992). Compartmentalization of positive and negative self-knowledge: Keeping bad apples out of the bunch. *Journal of Personality and Social Psychology*, *62*(6), 1036-1049.

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. *American Journal of Obstetrics and Gynecology, 208*(4), 329.e1-329.e6.

Smith, A. W., Dougall, A. L., Posluszny, D. M., Somers, T. J., Rubenstein, W. S., & Baum, A. (2008). Psychological distress and quality of life associated with genetic testing for breast cancer risk. *Psycho-Oncology, 17,* 767-773.

Smith, K. R., West, J. A., Croyle, R. T., & Botkin, J. R. (1999). Familial context of genetic testing for cancer susceptibility: Moderating effects of siblings' test results on psychological distress one to two weeks after BRCA1 mutation testing. *Cancer Epidemiology, Biomarkers, and Prevention, 8,* 385-392.

Stefanek, M., Helzlsouer, K., Wilcox, P., & Houn, F. (1995). Predictors of and satisfaction with bilateral prophylactic mastectomy. *Preventive Medicine, 24*, 412-419.

Stefanek, M. E. (1995). Bilateral prophylactic mastectomy: Issues and concerns. *Journal of the National Cancer Institute Monographs, 17,* 37-42.

Stein, K. F. (1995). Schema model of the self-concept. *Image- The Journal of Nursing, 27,* 187-193.

Stevens, L. A., McGrath, M. H., Druss, R. G., Kister, S. J., Gump, F. E., & Forde, K. A. (1984). The psychological impact of immediate breast reconstruction for women with early breast cancer. *Plastic and Reconstructive Surgery, 73,* 619-626.

Stokes, R., & Frederick-Recascino, C. (2003). Women's perceived body image: Relations with personal happiness. *Journal of Women and Aging, 15,* 17-29.

Swenson, K., Nissen, M., Ceronsky, C., Swenson, L., Lee, M., & Tuttle, T. (2002). Comparison of side effects between sentinel lymph node and axillary lymph node dissection for breast cancer. *Annals of Surgical Oncology, 9,* 745-753.

Szabo, C. I., & King, M. C. (1995). Inherited breast and ovarian cancer. *Human Molecular Genetics, 4,* 1811-1817.

Taylor, K. L., Lamdan, R. M., Siegel, J. E., Shelby, R., Hrywna, M., & Moran-Klimi, K. (2002). Treatment regimen, sexual attractiveness concerns and psychological adjustment among African American breast cancer patients. *Psycho-Oncology, 11,* 505-517.

Taylor, S. E., Lichtman, R. R., Wood, J. V., Bluming, A. Z., Dosik, G. M., & Leibowith, R. I. (1995). Illness-related and treatment-related factors in psychological adjustment to breast cancer. *Cancer, 75,* 2506-2513.

Tercyak, K. P., Lerman, C., Peshkin, B. N., Hughes, C., Main, D., Isaacs, C., & Schwartz, M. D. (2001). Effects of coping style and BRCA1 and BRCA2 test results on anxiety among women participating in genetic counseling and testing for breast and ovarian cancer risk. *Health Psychology, 20*(3), 215-222.

Tercyak, K. P., Peshkin, B. N., Brogan, B. M., DeMarco, T., Pennanen, M. F., Wiley, S. C., … & Schwartz, M. D. (2007). Quality of life after contralateral prophylactic mastectomy in newly diagnosed high-risk breast cancer patients who underwent BRCA1/2 gene testing. *Journal of Clinical Oncology, 25*(3), 285-291.

Thewes, B., Butow, P., Girgis, A., & Pendlebury, S. (2004). The psychosocial needs of breast cancer survivors: A qualitative study of the shared and unique needs of younger versus older survivors. *Psycho-Oncology, 13*, 177-189.

Thewes, B., Meiser, B., Taylor, A., Phillips, K. A.,, Pendlebury, S., Capp, P. A., … & Friedlander, M. L. (2005). Fertility and menopause related information needs of younger women with a diagnosis of early breast cancer. *Journal of Clinical Oncology, 23*(22), 5155-5165.

Tiemsland, L., Soreide, J., & Malt, U. (1998). Posttraumatic distress symptoms in operable breast cancer III: Status one year after surgery. *Breast Cancer Research and Treatment, 47,* 141-151.

Tiller, K., Meiser, B., Butow, P., Clifton, M., Thewes, B., Friedlander, M., & Tucker, K. (2002). Psychological impact of prophylactic oophorectomy in women at increased risk of developing ovarian cancer: A prospective study. *Gynecological Oncology, 86*(2), 212-219.

Timman, R., Stijnen, T., & Tibben, A. (2004). Methodology in longitudinal studies on psychological effects of predictive DNA testing: A review. *Journal of Medical Genetics, 41*(7), 1-8.

Vadaparampil, S. T., Ropka, M., & Stefanek, M. E. (2005). Measurement of psychological factors associated with genetic testing for hereditary breast, ovarian and colon cancer. *Familial Cancer, 4*, 195-206.

Vadivelu, N., Schreck, M., Lopez, M., Kodumundi, G., & Deepak, N. (2008). Pain after mastectomy and breast reconstruction. *The American Journal of Surgery, 74*, 285-296.

Vaeth, J. M. (1986). *Body image, self-esteem, and sexuality in cancer patients* (2nd ed.). San Francisco, CA: Karger.

Van Oostrom, I., Meijers-Heijboer, E. J., Duivenvoorden, H. J., Brocker-Vriends, A. H., Van Asperen, C, J., Sijmons, R. H., … & Tibben, A. (2007). A prospective study of the impact of genetic susceptibility testing for BRCA1/2 or HNPCC on family relationship. *Psycho-Oncology, 16*, 320-328.

Van Oostrom, I., Meijers-Heijboer, H., Lodder, L. N., Duivenvoorden, H. J., Van Gool, A. R., Seynaeve, C., … & Tibben, A. (2003). Long-term psychological impact of carrying a BRCA1/2 mutation and prophylactic surgery: A 5-year follow-up study. *Journal of Clinical Oncology, 21*(20), 3867-3874.

Vos, J., Gomez-Garcia, E., Oosterwijk, J., Menko, F., Stoel, R., Van Asperen, C., … & Tibben, A. (2012). Opening the psychological black box in genetic counseling. The psychological impact of DNA testing is predicted by the counselees' perception, the medical impact by the pathogenic or uninformative BRCA1/2-result. *Psycho-Oncology, 21,* 29-42.

Vos, J., Oosterwijk, J., Gomez-Garcia, E., Menko, F., Collee, M., Van Asperen, C., … & Tibbem, A. (2012). Exploring the short-term impact of DNA-testing in breast cancer patients: The counselees' perception matters, but the actual BRCA1/2 result does not. *Patient Education and Counseling, 86,* 239-251.

Wagner, T.., Moslinger, R., Langbauer, G., Ahner, R., Fleischmann, E., Auterith, A., … & Oefner, P. (2000). Attitude towards prophylactic surgery and effects of genetic counselling in families with BRCA mutations. *British Journal of Cancer, 82*(7), 1249-1253.

Warren, M. (2010). Uncertainty, lack of control and emotional functioning in women with metastatic breast cancer: A review and secondary analysis of the literature using the critical appraisal technique. *European Journal of Cancer Care, 19,* 564-574.

Watson, M., Foster, C., Eeles, R., Eccles, D., Ashley, S., Davidson, R., … & Evans, D. G. (2004). Psychosocial impact of breast/ovarian (BRCA1/2) cancer-predictive genetic testing in a UK multi-centre clinical cohort. *British Journal of Cancer, 91,* 1787-1794.

Watts, K., Meiser, B., Mitchell, G., Kirk, J., Saunders, C., Peate, M., … & Tucker, K. (2012). How should we discuss genetic testing with women newly diagnosed with breast cancer? Design and implementation of a randomized controlled trial of two models of delivering education about treatment-focused genetic testing to younger women newly diagnosed with breast cancer. *BMC Cancer, 12*(1), 1-12.

Wellisch, D. K., & Lindberg, N. M. (2001). A psychological profile of depressed and nondepressed women at high risk for breast cancer. *Psychosomatics, 42*(4), 330-336.

Wellisch, D. K., Schain, W. S., Noone, R. B., & Little, J. W. (1985). Psychosocial correlates of immediate versus delayed reconstruction of the breast. *Plastic and Reconstructive Surgery, 76,* 713-718.

White, C. A. (2000). Body image dimensions and cancer: A heuristic cognitive behavioral model. *Psycho-Oncology, 9*, 183-192.

Wooster, R., Bignell, G., Lancaster, J., Swift, S., Seal, S., Mangion, J., … & Stratton, M. R. (1995). Identification of the breast cancer susceptibility gene BRCA2. *Nature, 378,* 789-792.

Yurek, D., Farrar, W., & Andersen, B. L. (2000). Breast cancer surgery: Comparing surgical groups and determining individual differences in postoperative sexuality and body change stress. *Journal of Consultation and Clinical Psychology*, *68*, 697-709.

Zakowski, S. G., Caldimarsdottir, H. B., Bovbjerg, D. H., Borgen, P., Holland, J., Kash, K., … & Van Zee, K. (1997). Predictors of intrusive thoughts and avoidance in women with family histories of breast cancer. *Annals of Behavioral Medicine, 19*, 362-369.

Zebrack, B. J. (2000). Cancer survivor identity and quality of life. *Cancer Practice, 8*(5), 238-242.