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The Effect of Social Problem-solving, Health Anxiety, and Psychological Distress on Breast Cancer Genetic Testing Decisions in a Sample of Healthy Women

Alexandria Muench

Philadelphia College of Osteopathic Medicine

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THE EFFECT OF SOCIAL PROBLEM-SOLVING, HEALTH ANXIETY,

AND PSYCHOLOGICAL DISTRESS ON BREAST CANCER GENETIC TESTING

DECISIONS IN A SAMPLE OF HEALTHY WOMEN

By Alexandria Muench

Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Psychology

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DEPARTMENT OF PSYCHOLOGY

Dissertation Approval

This is to certify that the thesis presented to us by _Alexandria Muench_

on the _4_ day of _May_ , 20_18_, 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

Breast cancer is a leading cause of death in women in the United States, with hereditary breast cancers accounting for approximately 10% of the diagnoses. Nevertheless, women can decrease their risk by obtaining genetic testing and are often referred for the test if one or more of their relatives has been diagnosed with breast cancer and has the BRCA/BRCA2 cancer mutation. The purpose of the current study was to examine predictors of healthy women's (ages 18 to 35) hypothetical decisions about genetic testing and prophylactic treatments for the BRCA1/BRCA2 genetic mutations by measuring social problem solving (SPS) variables, health anxiety, and psychological distress. A survey format to was used to determine whether there was a relationship between these variables, genetic testing, and/or prophylactic treatment decisions. Measures included the Social Problem-Solving Inventory-Revised, Short Form (SPSI-R:S), Health Anxiety Inventory (HAI), Brief Symptom Inventory (BSI), a demographic questionnaire, and two hypothetical vignettes. Results revealed that positive problem-solving orientation (PPO) is predictive of prophylactic treatment decisions. The results support the literature in that genetic testing decisions are difficult to predict, and other factors that have yet to be determined may be contributing to the decision. Future research should look at these relationships in larger non-hypothetical samples and in different disease groups to determine whether the results differ.

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Chapter 1: **Introduction**

Statement of the Problem

Second to skin cancer, breast cancer is the most commonly diagnosed cancer in the United States (accounting for one in three cancers) and, after lung cancer, it is a leading cause of cancer-related cause of death in women (DeSantis, Ma, Bryan & Jemal, 2014). In families with no history of breast cancer, the risk of developing breast cancer by age 30 is 4.07% and by age 50, the risk more than doubles to 8.76% (Bleyer & Welch, 2012). Moreover, as of 2016, it was estimated that there were more than 3.5 million women with a history of invasive breast cancer living in the United States (Miller et al., 2016). Compared to other cancers, breast cancer is typically diagnosed at younger ages (breast cancer median age = 61; lung cancer median age = 70; colorectal cancer median age = 68).

Although the incidence of breast cancer remains fairly low in the general population, hereditary breast and ovarian cancers (HBOC)—breast and ovarian cancers with a hereditary basis—occur in approximately 10% of the population (Daly et al. 2010; Howlader et al., 2012). HBOC are most commonly caused by mutations, also known as deleterious variances, in the BRCA1 and BRCA2 genes (D. M Eccles et al., 2015). Although the BRCA1/BRCA2 genes are implicated in the development of breast cancer, they only account for 20% of hereditary breast cancers, as a number of other hereditary cancer susceptibility genes have been identified (Antoniou et al., 2003; Crawford et al., 2017; D. M. Eccles et al., 2015).

Due to the high heritability of the BRCA1/BRCA2 mutations, first degree relatives (FDRs; those who have had a parent and/or sibling diagnosed with breast

cancer) are often referred for genetic testing services (Crawford et al., 2017). For

instance, genetic testing is encouraged if the FDR meets certain criteria, including but not

limited to a history of breast cancer prior to the age of 50 in one or more first-degree

relative(s), a family member with a known BRCA1/BRCA2 mutation, a family history of

breast cancer in one or more first-degree relatives (particularly if they are diagnosed at

younger ages), and a family member with the BRCA1/BRCA2 genetic mutation (Daly et

al., 2010; Wevers et al., 2011). Genetic testing can reduce risk, but it can also be

uncertain and anxiety provoking. Given that genetic testing is inherently ambiguous, for

some people it can have negative psychological consequences (i.e., psychological distress

or health anxiety; Butow, Lobb, Meiser, Barratt, & Tucker, 2003). For example, the

amount of uncertainty that one has about genetic testing has been found to be related to

psychological distress (Frost, Venne, Cunningham & Gerritsen-McKane, 2004).

Although uncertainty is a natural consequence of genetic testing, high degrees of

uncertainty are considered to be related to knowledge of individual risk versus perceived

risk, communication with genetic counselors (i.e., feeling fully informed), and uncertain

genetic testing results (Croyle, Smith, Botkin, Baty, & Nash, 1997; Frost et al., 2004).

Nevertheless, even with high levels of uncertainty, premorbid levels of psychological

distress have been found to be strong predictors of the degree of distress experienced

post-testing (Reichelt, Heimdal, Møller, & Dahl, 2004).

Health anxiety is the anxiety that is brought on, maintained, and exacerbated by

health-related stimuli and can be an understandable effect as people move through the

genetic testing and prophylactic treatment process (Starcevic, 2013). Health anxiety can

arise or become exacerbated at any time, such as before testing or treatment or while

waiting for the results or surgery, and even if the results are negative, health anxiety can

remain after the results have been received or after the surgery has happened. To

illustrate, Rimes and Salkovskis (2002) identified four factors that are thought to be

fundamental to the perception of threat and the subsequent experience of genetic testing

related health anxiety: (a) perceived likelihood that the illness will develop, (b) perceived

severity of illness course, (c) perceived ability cope with the illness, and (d) level of

support that will be available if the illness were to develop. In addition, self-esteem and

self-efficacy are considered to moderate the amount of health anxiety that is experienced

(Audrain et al., 1997).

The process of making genetic testing and prophylactic treatment decisions is

complicated, as it requires people to make fairly quick life-altering decisions. Social

problem-solving (SPS) can assist in this endeavor and is defined as the problem-solving

skills that people use in their natural environments (D'Zurilla & A. M. Nezu, 1982). SPS

is helpful in stressful situations and has been found to be predictive of overall adjustment

and emotional well-being (Chang, D'Zurilla, & Sanna, 2004; D'Zurilla & A. M. Nezu,

1982; Dreer et al., 2009). For example, Dreer et al. (2009) conducted correlational

research demonstrating that positive problem-solving abilities (i.e., identifying the

problem, weighing pros and cons of solutions) relate to a decrease in depression in those

with chronic diseases and their caregivers.

Not surprisingly, positive problem-solving yields positive health outcomes,

including a more positive perception of overall health, engagement in healthy lifestyle

behaviors (i.e., exercise), and adherence to medical recommendations (Dreer, Elliott &

Tucker, 2004; Elliott & Shewchuk, 2003). In fact, when SPS skills are taught to breast

cancer patients and relatives undergoing genetic testing, adaptive coping increases

(McClure, A. M. Nezu, C. M. Nezu, O'Hea, & McMahon, 2012). In sum, strong

problem-solving skills appear to be associated with multiple positive health-related

outcomes and, when applied effectively, may protect against psychological distress and

health anxiety.

Purpose of the Study

The purpose of this study was to examine the factors that may predict FDR's

BRCA1/BRCA2 genetic testing and prophylactic decisions by providing hypothetical

vignettes to a sample healthy of women between the ages of 18 and 35. The current

study evaluated whether SPS variables (i.e., problem-solving orientation, rational

problem solving, avoidance style, and impulsivity/carelessness style), psychological

distress, and health anxiety predict a healthy FDR's hypothetical choice to have genetic

testing. Information gained from this study may provide further insight into the genetic

testing and prophylactic treatment decision making process.

Chapter 2: Literature Review

Breast cancer is the most commonly diagnosed invasive cancer in women in North America and the second leading cause of cancer death in the United States (Ban & Godellas, 2014). In 2017, there was an estimated 252,710 new breast cancer diagnoses (15% of all cancer diagnoses) and approximately 40,610 breast cancer related deaths (6.8% of all cancer deaths; Surveillance, Epidemiology, and End Results Program [SEER], 2017). Nevertheless, advances in medicine (i.e., adjuvant therapy) and medical technology (i.e., screening advances) have led to earlier breast cancer detection and decreased mortality rates (1975[i]: 105.1 new cases, 31.4 new deaths; 2014[iii]: 125.3 new cases, 20.5 new deaths[iv]; Plevritis et al., 2018; SEER, 2017).

Genetic Basis of Breast Cancer

When working correctly, BRCA1/BRCA2 tumor suppressor proteins play an important role in repairing damaged deoxyribonucleic acid (DNA; Majdak-Paredes & Fatah, 2009). These proteins are integral in securing each cell's genetic material and, therefore, stopping abnormal cell growth (Majdak-Paredes & Fatah, 2009). As a result of their function, mutations in either protein can lead to tumor growth. The BRCA1/BRCA2 mutations are inherited from either parent (autosomal dominant) and occur equally in men and women; however, women are disproportionately affected (Hamilton, Lobel, & Moyer, 2009; Struewing et al., 1997). These mutations exhibit incomplete penetrance (i.e., not everyone who inherits the gene will develop cancer; Parmigiani, Berry, & Aguilar, 1998). The relationship between the mutation and cancer risk is determined not only by genetic factors but by environmental factors as well (Hamilton et al., 2009).

When a BRCA1/BRCA2 mutation is inherited, it is classified as BRCA1/BRCA2-associated HBOC (Petrucelli, Daly, & Pal, 2016). In women, BRCA1/BRCA2-associated HBOC increases risk for breast and ovarian cancers, pancreatic cancer, and melanoma (cutaneous and ocular; Petrucelli et al., 2016). Although not entirely within the scope of this paper, there are additional hereditary breast cancer syndromes that are caused by mutations in other proteins (Thull & Vogel, 2004). Additional hereditary breast cancer syndromes include site-specific breast cancer (which may be associated with mutations in the BRCA1/BRCA2 genes), Cowden syndrome (CS) or multiple hamartoma syndrome, LieFraumeni syndrome (LFS), Peutz-Jegher syndrome (PJS), ataxia-telangiectasia (AT) syndrome, and low-penetrance breast cancer allele CHEK2*1100delC (Thull & Vogel, 2004). The risk for HBOC cancers are dependent on which mutation occurs (BRCA1 or BRCA2; Petrucelli et al., 2016).

BRCA1/BRCA2 Risk Factors

Having a comprehensive knowledge of the risk factors for the BRCA1/BRCA2 mutation is the first step in making informed prophylactic treatment decisions (i.e., mastectomy and oophorectomy). Recent literature suggests that awareness of risk prior to genetic testing can predict levels of psychological distress post-testing (higher risk increases psychological distress; Cicero et al., 2017; Himes et al., 2016). Yet, even with this knowledge, the risk factors are complex and uncertainty persists pre- and post-testing. Genetic testing is typically recommended in patients who have personal and/or family histories (first, second, or third degree relative) and any of the following characteristics: (a) two or more family members diagnosed with breast cancer, with at least one diagnosed at less than 50 years of age; (b) three or more family members

diagnosed with breast cancer at any age; (c) family history of male breast cancer; (d) a

breast cancer diagnosis prior to age 51; I past or current diagnosis of ovarian cancer; (f)

history of multiple primary breast cancers in one or both breasts; (f) personal or family

history of triple-negative (estrogen receptor-negative, progesterone receptor-negative,

and human epidermal growth factor receptor [HER2/neu] 2-negative) breast cancer,

particularly when diagnosed before age 60 years; (g) a relative with the BRCA1/BRCA2

mutation (Kim, Puymon, Qin, Guru, & Mohler, 2013).

In HBOC families at high risk for the BRCA1/BRCA2 mutation, age is an

important factor. The U.S. Preventive Services Task Force (USPSTF) reviewed the

literature and provided recommendations for risk assessment, genetic counseling, and

genetic testing for the BRCA1/BRCA1 mutations for asymptomatic women with a family

history of breast or ovarian cancer (Moyer, 2014). The USPSTF recommends women

from high risk families undergo genetic testing at age 18, even though the risk of

developing breast cancer in the 18 to 24 age range is only approximately 1% (Moyer,

2014; Patenaude et al., 2013).

Despite low risk in some women who test positive, decreasing the risk of breast

cancer begins early and continues throughout the lifespan. The National Comprehensive

Cancer Network (NCCN; 2018) outlined the following guidelines for BRCA mutation-

positive women: (a) women between the ages of 18 and 24 should begin monthly breast

self-exams (BSE) at the end of menses, (b) at age 25, BRCA1/BRCA2 positive mutation

carriers are highly advised to begin receiving clinical breast exams from their

obstetrician-gynecologist (OB-GYN) every 6 to 12 months and getting annual breast

MRIs with contrast, and (c) from age 30 to 75, women are strongly encouraged to continue to receive their annual breast MRIs along with annual mammographies.

In addition to age, environmental factors can increase the risk of developing breast cancer in mutation carriers (Friebel, Domchek, & Rebbeck, 2014). In a meta-analysis completed by Friebel et al. (2014), 44 studies were reviewed to assess for potential BRCA1/BRCA2 protein risk modifiers. Certain reproductive factors and environmental exposures were found to influence breast cancer risk separately in each gene, specifically oral contraceptive use, smoking (greater than 4 years), nulliparity, and earlier age at menarche (Table 1; Friebel et al., 2014).

Table 1

Risk Modifiers in BRCA1/BRCA2 Mutation Carriers

	BRCA1	BRCA2
Reproductive	• Nulliparity versus Parity: Each live birth decreases risk • Breastfeeding: Reduced risk if breastfeeding occurred for longer than one year • Age at Menarche: Reduced risk with later age	• Nulliparity versus Parity: More than three live births decreases risk • Breastfeeding: Null results reported • Age at Menarche: Null results reported
Exposures	• Oral contraceptive use: Increased risk • Smoking: Possible risk. Results inconsistent.	• Oral contraceptive use: Increased risk • Smoking: Increased risk

Note. Data for risk modifiers in BRCA1/BRCA2 mutation carriers from Friebel et al. (2014)

Race and Ethnicity

Even with advancements in medical treatment and technology, there continues to be racial and ethnic differences in diagnosis, survival, and treatment access (Iqbal, Ginsburg, Rochon, Sun, & Narod, 2015). This has been found to be especially true in African American women, about whom there has been research to support differences between the biology of their tumors and those of other races/ethnicities (Iqbal et al., 2015). For example, Newman et al. (2006) identified 20 studies in which survival rates were reported and found that, even after adjusting for socioeconomic status (SES), African American ethnicity was an independent and significant predictor of poorer survival from breast cancer. In regard to treatment access, McCarthy et al. (2016) reported differences in recommendations for BRCA1/BRCA2 testing between white and black women, where black women are less likely to receive a recommendation for genetic testing from an oncologist or surgeon. While the reasons were unclear the authors suggested the physician's concerns about costs and lack of insurance coverage and the possibility of an incomplete family history (McCarthy et al., 2016; Murff, Byrne, Haas, Puopolo, & Brennan, 2005). Samson et al. (2016) also showed that despite being screened for breast cancer, Black women are at a higher risk of being diagnosed in later stages and having a poorer chance for survival. Low adherence, which can be accounted for by socioeconomic factors, may contribute to these findings (e.g.,, lack of insurance leading to nonadherence to treatment recommendations; Adams et al., 2009).

Women minorities are also often suspicious of their medical providers, subsequently increasing the chance for low adherence and poor treatment outcomes (Table 2; Matthews, Sellergren, Manfredi, & Williams, 2002). To combat the patient's

uneasiness, evidence suggests that medical providers should pay close attention to their

own biases, as they can impact patients' communication styles and self-concepts (Ashton

et al., 2003). Additional recommendations include providing adequate time and

appropriate prompts to allow the patient ask questions and express concerns (Ashton et

al., 2003).

Table 2

Age-Adjusted Rates of Diagnosis and Survival by Race in Breast Cancer

	Age-adjusted diagnosis rates (per 100,000)	Survival rates (crude 10-year)
Non-hispanic white	129	80%
Black	123	66%
Hispanic American	94	82%
Asian	93	78%

Note. Data for rates of diagnosis and percentage of survival from Howlader et al. (2012)

Genetic Testing

Genetic testing is a type of medical test that identifies mutations in DNA proteins

(Calzone & Biesecker, 2002). Genetic tests are routinely performed prenatally to assess

for chromosome abnormalities in the fetus (Calzone & Biesecker, 2002). Outside of

prenatal care, genetic testing is now being used to assess for risk for various diseases

(Calzone & Biesecker, 2002). The three types of genetic testing that are available are

carrier, pre-symptomatic, and predisposition. Carrier testing is typically done to look at

reduced enzyme activity in recessive gene mutations, as reduced enzyme activity can be

indicative of specific types of gene mutations (e.g., cystic fibrosis; Mansoura & Collins,

1998). In conditions such as Alzheimer's disease, pre-symptomatic testing determines

with certainty if the disease will develop. Finally, predisposition testing is used in

healthy people to determine their risk of developing a disease (e.g., BRCA1/BRCA2

mutation; Mansoura & Collins, 1998).

Predisposition testing is linked to an increase in distress and anxiety because of

the chance for uncertain outcomes, as testing results can be positive or negative, and

include variants of uncertain significance (VUS) falling between 0.05 and 0.949

probability of pathogenesis (B. K. Eccles, Copson, Maishman, Abraham, & D. M. Eccles,

2015; Lumish et al., 2017). Moreover, the incidence of VUS differs based on race and

ethnicity (African Americans = 21%; European Americans = 5% to 6%; Lindor, Goldgar,

Tavtigian, Plon, & Couch, 2013). Lumish and colleagues (2017) surveyed 232 patients

with HBOC who had previously undergone pre-symptomatic genetic testing and found

that those who reported increased distress had no prior history of cancer and had received

a VUS. Conversely, patients who have received pre-symptomatic genetic testing for

Huntington's disease (HD) trend toward less distress post-testing, but this result is

contingent on whether one is a mutation carrier and the disease in question, as being a

mutation carrier in HD means that there is a 100% chance that the disease will develop

(Crozier, Robertson, & Dale, 2015).

Genetic testing uptake rates vary and are determined by a myriad of factors,

including personal and/or family history of breast cancer. For instance, among FDRs, the

possibility that a positive test could mean the need for prophylactic treatment can

complicate matters further and increase the risk for the onset of psychological distress

(Metcalfe et al., 2010; Schwartz et al., 2002). Another factor contributing to the

complexity of genetic testing and prophylactic decisions is that genetic testing uptake

rates vary; research has yet to determine exactly what causes this variability. It is clear

that personal and/or family history of breast cancer impacts decisions, but the type of

research design (e.g., hypothetical vs real) appears to have an impact on the amount of

genetic testing uptake that is reported (Ropka, Wenzel, Phillips, Siadaty & Philbrick,

2006). For example, Ropka et al. (2006) systematically reviewed 40 studies and

determined that the mean genetic testing uptake in BRCA1/BRCA2 FDRs was 66%

(range = 20% to 96%) in hypothetical studies and 59% (range = 25% to 96%) in real

scenarios. To summarize, the large amount of variance in genetic testing and

prophylactic treatment uptake rates are most likely due to study methodology as well as

the variety of personal and environmental factors that contribute to the decision.

Genetic Testing and Psychological Variables

   Psychological distress. As genetic testing has been on the rise, so has the

discussion about the role that psychological variables play in the process. Psychological

distress is defined as a persistent worry, anxiety, and decreased mental health in response

to a stressful life event (Audrain et al., 1997). Baum, Friedman, and Zakowski (1997)

proposed a model, based on Lazarus and Folkman's (1984) theory of stress and coping to

explain the relationship between stress and genetic testing. The authors proposed that

individuals at risk for genetically inherited diseases that received positive results and

were also low in coping skills, support, and/or psychosocial resources would have higher

stress levels (Baum, Friedman, & Zakowski, 1997).

Similarly, Hamilton and Bowers (2007) developed a theory of genetic vulnerability where they outlined six concepts that contribute to one's distress pre and post-testing: (a) experiencing cancer within the family, (b) testing for a mutation, (c) understanding disease risk, (d) foregrounding the disease, (e) responding to knowledge of genetic vulnerability, and (f) altering or avoiding the family history of disease. In addition, a prior occurrence of cancer in the family can influence how one copes throughout the genetic testing and prophylactic process (Hamilton & Bowers, 2007).

In other words, the authors found that a past history of cancer in the family can impact perceived risk, the amount of distress that is felt in respect to telling one's family about the test result (i.e., foregrounding: bringing the disease to the forefront), the ability to cope with the results of the genetic test, and how one incorporates the information into one's prior experiences with the disease (Hamilton & Bowers, 2007). Ultimately, the decision-making process is highly influenced by past experiences, especially if the cancer occurred within the immediate family system (Hamilton & Bowers, 2007).

Although not applied formally, the themes of Baum et al. (1997) and Hamilton and Bowers (2007) are seen throughout the BRCA1/BRCA2 genetic testing literature. For example, Fletcher et al. (2006) determined factors associated with psychological distress in first-degree female relatives (N = 624) of newly diagnosed cancer patients. Fletcher and colleagues found that greater optimism was associated with low cancer-related and general distress; however, avoidance of disease-related stimuli and a close relationship with the cancer patient resulted in higher levels of cancer-specific distress and low levels of general distress (Fletcher et al., 2006).

Ringwald et al. (2016) reviewed 1,243 studies that included measures of psychological distress, anxiety, and depression among cancer-affected BRCA1/BRCA2 mutation carriers post-genetic testing. The results of this review were contradictory. In general, a positive test result increased depression, distress, and anxiety for 12 months post-testing (Ringwald et al., 2016); however, the authors also identified multiple studies which found the opposite, in which both cancer-affected and non-affected mutation carriers did not display increased levels of depression or anxiety (e.g., Claes et al. 2004; Schwartz et al. 2002).

Smith et al. (2008) also assessed psychological distress and quality of life in those with a family and personal history of breast cancer. Interestingly, findings indicated that women who declined to be tested reported a higher incidence of distress compared to women who received negative or uncertain results. Consistent with previous literature, women who received a positive result experienced heightened distress for a short period of time (approximately three months), with distress levels returning to baseline a few months after the results were received (Smith et al., 2008).

In general, it is clear that there is significant variability with regard to the way people respond to and are affected by genetic testing decisions. The inconsistency in the psychological distress literature could be attributed to individual variation in decision making and problem-solving processes, availability of pre-testing genetic counseling services, levels of general psychological distress pre-testing, demographic variables, past history of cancer, and past psychiatric history (e.g., premorbid depression and anxiety; Catania et al., 2016; Reichelt, Møller, Heimdal, & Dahl, 2008; Ringwald et al., 2016). Overall, the research demonstrates several themes: (a) genetic testing can prove

psychologically beneficial for many individuals, (b) not knowing results of genetic

testing tends to have a negative impact on distress levels, and (c) perceived risk (i.e., the

amount of risk a person thinks he or she has of developing the disease) seems to be

heightened in women who decline genetic testing. Given the inconsistent findings, more

research is needed understand fully how genetic testing decisions are made and the

psychological impact that occurs both pre- and post-testing and in regard to prophylactic

treatment.

        Health anxiety. Health anxiety—which has a lifetime prevalence of

approximately 5% and is now classified as illness anxiety disorder in the fifth edition of

the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*)—is persistent

anxiety about health that includes little to no somatic complaint (American Psychiatric

Association, 2013; Starcevic, 2013; Tyrer et al., 2014). Typically, within medical illness,

a cognitive-behavioral (CB) model of health anxiety is applied. The CB model of health

anxiety is based on Lazarus and Folkman's (1984) theory, which states that, in the

absence of psychological arousal, how life events are appraised depends on whether the

situation is deemed "good" or "bad," as well as the perceived causes of the event.

Therefore, a situation that is appraised as a threat will be placed in a negative category

and cause feelings of fear and anxiety (Lazarus & Folkman, 1984). Comparatively, the

CB model suggests that those at risk for health anxiety interpret medical information

negatively (i.e., as a threat) and that the appraisals are influenced by preexisting health

beliefs, beliefs about the disease (i.e., belief that breast cancer will lead to role changes

and, ultimately, death), and the amount of anxiety that occurs after the appraisal has been

made (Warwick & Salkovskis, 1990).

Within the CB model of health anxiety, there are fundamental cognitions that lead to the development or maintenance of the disorder that include perceived risk both for illness diagnosis and severity, perceived ability to cope with the diagnosis, and perceived effectiveness of available treatments (e.g., chemotherapy; Salkovskis & Warwick, 2001; Warwick, 1989). The research on health anxiety, breast cancer, and genetic testing is limited, with the majority of the research measuring generalized anxiety, state/trait anxiety, or general distress. Nonetheless, Rimes et al. (2006) assessed patients'[v] (N = 218) responses to genetic counseling using the CB model of health anxiety. The results were consistent with the CB model, as study participants' preexisting health anxiety and interpretations predicted levels of health anxiety and distress post-counseling (Rimes, Salkovskis, Jones, & Lucassen, 2006). Interestingly, compared to those with a family history of colon cancer, FDRs of breast and ovarian cancer patients were significantly more anxious post-counseling (Rimes et al., 2006).

Perceived risk of having a positive genetic test is another important factor when determining the rate of health anxiety that a person may experience. Research has shown that prior to genetic testing, patients tend to overestimate their risk, but the majority of the time, anxiety returns to baseline, especially if a patient feels that he or she has a competent medical team (Burke et al., 2000; Cicero et al., 2017; Katapodi, Facione, Humphreys, & Dodd, 2005; Sanders, Campbell, Sharp, & Donovan, 2003). Nevertheless, Sanders et al. (2003) found that perceived risk and subsequent distress were dependent on whether the individual had experienced the death of a relative from the disease, because it brought about thoughts of his or her own mortality.

In addition, factors have been found to account for higher levels of both health and generalized anxiety, including older age (younger women are more agreeable to being in a surveillance program and less likely to experience health anxiety when they do not undergo genetic testing), having children, a high level of uncertainty, a current diagnosis of cancer, being unmarried, receiving a lower level of education, having a lower level of optimism, and endorsing feelings of not being in control (Audrain et al., 1997; Lodder et al., 2003).

In sum, premorbid health anxiety, preexisting interpretations about health, and experiences with cancer in the family can all impact the amount of health anxiety that occurs both before and after genetic testing. Health anxiety can increase the risk for maladaptive behaviors (i.e., avoidance); however, genetic counseling can decrease health anxiety if the following occurs: (a) the genetic counselor is aware of the individual's past medical, family, psychological, and emotional history and (b) the genetic counselor provides enough information and education that a patient believes that he or she understands his or her level of genetic risk (Meiser & Halliday, 2002).

Social problem-solving. Social problem-solving (SPS) is defined as how people solve problems in their natural environments (D'Zurilla & A. M. Nezu, 1982, 1999). In other words, SPS is the CB process that facilitates one's own coping mechanisms (adaptive or maladaptive) when faced with problems in everyday life (D'Zurilla & A. M. Nezu, 1982, 1999). SPS consists of two processes: (a) problem-solving orientation (i.e., the motivational component: a negative or positive schema that influences whether a person believes that everyday problems can be solved), and (b) problem-solving styles (i.e., the person's set of problem-solving skills: the cognitive and behavioral process that

an individual uses to determine which coping mechanisms he or she should apply to the

problematic situation; A. M. Nezu, C. M. Nezu, & Perri, 1989).

The way in which a problem is approached and solved is based primarily on how

problems were solved in the past and how those situations shaped how a person thinks

and feels about his or her ability to solve problems effectively (D'Zurilla & A. M. Nezu,

1990). Research demonstrates the effectiveness of problem-solving training (SPS applied

in a treatment protocol) in a wide variety of settings and diagnoses (e.g., breast cancer

patients and increasing adherence in diabetes management; Hill-Briggs et al., 2011;

Hopko et al., 2011). Thus, it is not surprising that recent research has shown adaptive

SPS skills to be a protective factor against the psychological distress that may occur as a

result of cancer (Hopko et al., 2011). To illustrate, when an individual applies adaptive

problem-solving processes, he or she does not see the problem as one that cannot be

solved and, thus, engages a series of skills (e.g., running through a list of possible of

solutions and their alternatives) that decrease the chance that he or she will be unhappy

with the outcome (Chang et al., 2004).

Problem orientation. Problem orientation is a schema (negative or positive) that

influences how an individual copes with the everyday problems that he or she encounters

(D'Zurilla & A. M. Nezu, 1990). A. M. Nezu et al. (1989) explains that the cognitive-

affective-behavioral response guides the problem orientation and the problem-solving

process. The cognitive subcomponent of problem orientation is a set of fixed

attributions, appraisals, and expectations about problems and problem-solving that tend to

generalize across situations (D'Zurilla & A. M. Nezu, 1990). The emotional (affective)

state is the positive (e.g., hope) or negative (e.g., anger) feelings that are experienced in

reaction to the problem (D'Zurilla & A. M. Nezu, 1990). How the individual chooses to respond to the problem (i.e., weigh pros and cons versus avoidance) is the behavioral subcomponent (D'Zurilla & A. M. Nezu, 1990). These subcomponents of problem orientation dictate whether the person has a positive problem orientation (PPO) or a negative problem-solving orientation (NPO; Chang et al., 2004).

PPO is a set of cognitive, affective, and behavioral skills that lend themselves to adaptive problem-solving abilities (Chang et al., 2004). Those with a PPO tend to have the following characteristics: (a) the ability to appraise problems as a positive challenge; (b) the belief that problems can be solved, but that solving them may take time, effort and perseverance; and (c) the belief that they have the ability to solve problems and the willingness to invest in the problem-solving process (Chang et al., 2004). Conversely, those with a negative problem orientation (NPO) tend to (a) see problems as a significant threat, (b) doubt their own ability to solve problems effectively, and (c) are easily discouraged when confronted with everyday problems (Chang et al., 2004).

A. M. Nezu et al. (1999) looked at the role of SPS in women (N = 105) with newly diagnosed cancer (41% with breast cancer). The results demonstrated the important role that adaptive (PPO) and maladaptive (NPO) problem-solving skills have in the management of cancer-related distress. More specifically, patients with a NPO, reported higher rates of depression, anxiety, and cancer-related distress (A. M. Nezu, C. M. Nezu, Houts, Friedman, & Faddis, 1999). Similarly, McClure et al. (2012) assessed problem-solving abilities, depression, and relationship satisfaction in 63 couples with one partner diagnosed with cancer. The authors found that partners who viewed solving

problems more positively were less likely to experience depression (McClure et al.,

2012).

   Problem-solving styles. Problem-solving styles are the cognitive and behavioral

processes that determine which coping mechanisms are applied to problematic situations

(D'Zurilla & A. M. Nezu, 1990). Problem-solving styles include rational problem

solving (RPS), impulsivity/carelessness style (ICS), and avoidance styles (AS; D'Zurilla

& A. M. Nezu, 1990). RPS is an adaptive problem-solving style that is defined as the

deliberate and systematic application of effective problem-solving skills (D'Zurilla & A.

M. Nezu, 1990). Successfully applying RPS requires systematically collecting

information about the problem, identifying obstacles, setting realistic goals, generating a

list of alternative solutions, hypothesizing possible consequences of each solution,

weighing the pros and cons of each of the alternatives and implementing the chosen

solution, while also evaluating the outcome (D'Zurilla & A. M. Nezu, 1990).

   In contrast to the positive and proactive RPS style, ICS and AS problem-solving

styles are considered dysfunctional. To illustrate, compared to the systematic problem-

solving skills used in RPS, ICS is marked by impulsive choices, in which there is little

thought put into how to go about solving the problem and the consequences that could

result from the chosen solution. In other words, the first solution that comes to mind is

typically the solution that is implemented (D'Zurilla & A. M. Nezu, 1990). Similarly,

AS problem-solving includes avoidant behaviors, such as procrastination (D'Zurilla & A.

M. Nezu, 1990). These individuals avoid in the hopes that the problem will resolve on its

own and, and when problems do not resolve, accountability is often placed on others

(D'Zurilla & A. M. Nezu, 1990). In sum, the consistent use of ICS and AS problem-

solving sets results in an inability to cope when confronted with problems which, over

time, lowers self-efficacy (D'Zurilla & A. M. Nezu, 1990; King et al., 2010). The

relationship between consistently poor problem solving, lower self-efficacy and

depression has been reported in both the diabetes self-management and suicidal risk

literature (D'Zurilla, Chang, Nottingham, & Faccini, 1998; King et al., 2010). In general,

the ability to apply adaptive problem-skills is related to higher self-efficacy and

optimism, which makes for improved coping and better adherence to treatment

recommendations (D'Zurilla et al., 1998; King et al., 2010).

  Problem-solving training. The research on SPS and genetic testing decisions is

limited. Yet, there is literature to suggest that problem-solving training (PST) can

decrease distress (Schwartz et al., 1998). PST is a CB intervention that teaches people

how to choose and carry out the most effective coping strategies (D'Zurilla, 1988). PST

teaches patients how to proceed systematically through the problem-solving process and

includes the following components: (a) defining the problem (i.e., obtain information

about the problem, challenging cognitive distortions, set goals), (b) generate alternative

solutions, (c) decision making, and (d) solution implementation and verification (A. M.

Nezu, C. M. Nezu, Friedman, Faddis, & Houts, 1998).

  Nezu et al. (1998) argued that cancer is a secondary stressor that makes dealing

with primary stressors (i.e., daily life events) much more stressful. Additionally, poor

premorbid problem-solving abilities increase the risk for cancer-related distress. Thus, it

is believed that improving SPS with PST can decrease general distress and cancer-related

distress (A. M. Nezu et al., 1999). Schwartz et al. (1998) demonstrated the effectiveness

of PST in 144 women who had family histories of breast cancer. The authors found that

women who received PST showed a significant decrease in cancer-related distress

(Schwartz et al., 1998).

Prophylactic Treatment

The decision about whether to obtain genetic testing is complex due to the

overlapping social, emotional, and biological consequences (Calzone & Biesecker, 2002).

To decrease breast cancer risk, prophylactic treatment (e.g., mastectomy) is often

recommended to high risk FDRs who have received positive genetic test results

(Hartmann et al., 1999). Nevertheless, the decision to undergo major life-changing

surgery is not an easy one, especially for young women (Lerman et al., 2000). There are

numerous possible post-surgical outcomes that one may endure.

Prophylactic treatments can include mastectomy (removal of either one or both of

the breasts), oophorectomy (removal of the ovaries), chemoprevention (e.g., tamoxifen),

or surveillance (e.g., frequent mammograms; Meijers-Heijboer et al., 2000). Mastectomy

is typically recommended in high risk cases, with bilateral mastectomy decreasing the

risk of breast cancer by 95% (Rebbeck et al., 2004). Although older research established

a relationship between oophorectomy and decreased breast cancer risk in BRCA1

mutation carriers, more recent research has negated this finding (Heemskerk-Gerritsen et

al., 2015; Kotsopoulos et al., 2016; Rebbeck, Kauff, & Domchek, 2009). In addition to

or combined with surgical interventions, there are chemopreventive treatments such as

tamoxifen, which is an estrogen blocker that aids in the prevention of breast cancer

(Cuzick et al., 2015). Although tamoxifen decreases breast cancer risk, it increases

menopause-like symptoms and the risk for uterine cancer, which makes the treatment

undesirable to many women (Cuzick et al., 2015).

It is should not be surprising that weighing the pros and cons of preventative options can have a psychological impact. When considering prophylactic treatments, level of cancer-related distress (i.e., anxiety; depression) can be exacerbated by younger age, past history of diagnosis, perceived risk, having young children, and a family history of cancer (Claes et al., 2005; Graves et al., 2012). In addition, changes in fertility and body image are also significant components, as many of the women who are making these decisions are younger than age 35. Conversely, there has been research that suggests that prophylactic surgery can decrease psychological morbidity due to the decrease in breast cancer risk (Brandberg et al., 2008). In general, the influence that prophylactic treatment has on the genetic testing decision cannot be underestimated.

Summary

Genetic testing decisions are complex and uncertain. The decision can be influenced by problem-solving abilities, health anxiety, and psychological distress. Previous exposure to a family member's battle with breast cancer can further intensify and confound the decision (Dreer et al., 2009). Other factors contributing to the decision-making process are lack of resources (e.g., insurance, medical care, and education) and previous health behaviors (e.g., eating habits and adherence to medical recommendations; Lipscomb et al., 2012). The implications of this study are twofold: First, the relationship between SPS, health anxiety, and psychological distress has yet to be evaluated in the context of BRCA1/BRCA2 genetic testing and prophylactic decisions. Moreover, significant findings may suggest that the assessment of one's SPS skills, health anxiety, and psychological distress should be incorporated into the pre- and post-genetic counseling sessions. The ability to predict problem-solving skills post-genetic testing

may allow medical providers to address these issues from the beginning, thus helping the

patients to feel empowered and to make decisions that are right for them. Second, by

examining SPS in relation to genetic testing, the hope was to provide a more concrete

explanation for genetic testing and prophylactic treatment decisions, as the current body

of literature is fairly small and inconsistent. Thus, using hypothetical vignettes and a

healthy sample, the aim of the current study was to determine how SPS, health anxiety,

and psychological distress influence genetic testing and prophylactic decisions.

Chapter 3: Hypothesis

This study explored the relationship between genetic testing decisions, SPS variables (i.e., problem-solving orientation, rational problem-solving style, avoidance and impulsivity/carelessness), psychological distress, and healthy anxiety. This was examined by providing a healthy population with hypothetical vignettes about specific breast cancer scenarios.

Hypothesis

It was hypothesized that when provided with hypothetical vignettes in which a first degree relative has been found to have the BRCA1 and/or BRCA2 mutation, PPO, NPO, RPS, AS, ICS, levels of psychological distress, and/or health anxiety would predict the likelihood of whether women would elect to obtain genetic testing and/or prophylactic treatment.

Rationale

Individuals who utilize RPS are able to effectively and systematically define the problem, generate alternatives, evaluate alternatives, implement solutions, and then evaluate solutions. These individuals were surmised to be more likely to feel less psychological distress than individuals who have less effective RPS skills. Conversely, individuals with poor problem-solving abilities have a difficult time solving problems effectively and have a tendency to solve problems in an impulsive and careless style. Moreover, they also have a tendency to put off solving problems. This type of dysfunctional problem-solving may lead to psychosocial distress. Similarly, persons with high levels of health anxiety tend to make negative interpretations about health information, which can lead to increased anxiety. In sum, regardless of decision,

participants who have a PPO and apply positive problem-solving skills are predicted to

be more likely to agree to both genetic testing and prophylactic treatment.

Chapter 4: Method

Research Design and Design Justification

In order to ensure the representativeness and generalizability of the sample, the

study used a cross-sectional design. The purpose of the current study was to examine the

relationship between genetic testing and prophylactic decisions, SPS variables (i.e.,

problem-solving orientation, rational problem solving, avoidance and

impulsivity/carelessness), psychological distress, and health anxiety. The variables of

interest were assessed by incorporating measures into an Internet survey format. Web-

page-based surveys offer consistency, as they appear identical to all participants, have the

ability to target a large demographic, and obtain data in a systematic fashion (Gray,

Mann, & Stewart, 2001).

Participants and Recruitment

Due to the hypothetical nature of this study, the sample was drawn from a sample

of healthy women (N = 130). An effort was made to recruit a minimum of 102

participants to reflect a .05 alpha and medium effect size (Cohen, 1992). Participants

were between the ages of 18 and 35. The method of recruitment and study design

required participants to have access to the Internet. Efforts were made to recruit persons

from diverse racial backgrounds.

Inclusion criteria. Participants considered for this study were healthy adult

women with no prior or current diagnosis of breast cancer, no family history of breast

cancer (in first or second-degree relatives), and/or had never tested positive for the

BRCA1 or BRCA2 genetic mutation. Eligible participants were between the ages of 18

and 35, as research indicates that age is the biggest predictor in the decision to agree to

genetic testing, and that women over the age of 35 are generally more willing to obtain

genetic testing (Alterkruse et al., 2010). Participants were fluent in English and at a sixth

grade reading level or higher, as determined by self-identification and the ability to

comprehend the informed consent. Participants of all races and ethnicities who met these

stated criteria were included.

　　　　Exclusion criteria. Participants with a current or prior breast cancer diagnosis,

the BRCA1 or BRCA2 genetic mutation, an FDR with a past or present history of cancer,

and/or a second degree relative diagnosed with breast cancer were excluded from the

study.

　　　　Recruitment. Recruitment for the study was done via ResearchMatch, a national

health volunteer registry that was created by several academic institutions and supported

by the U.S. National Institutes of Health as part of the Clinical Translational Science

Award (CTSA) program. ResearchMatch has a large population of volunteers who have

consented to be contacted by researchers about health studies for which they may be

eligible.

Procedure

　　　　Survey Monkey, an online resource used to create and administer surveys, was

used to obtain the data. Each survey included the informed consent, SPSI-R:S (D'Zurilla,

Nezu, & Maydeu-Olivares, 2002), Short Health Anxiety Inventory (SHAI; Salkovskis,

Rimes, Warwick, & Clark, 2002), Brief Symptom Inventory-18 (BSI-18; Derogatis,

2001), and a demographics questionnaire. The measures took approximately 30 minutes

to complete. After the survey was completed, participants were directed to a separate

survey, where they had the option to enter their e-mail addresses for a 1 in 10 chance to win a Target gift card. The lottery drawing occurred after recruitment ended.

Security. Considerable steps were taken to ensure the protection of study participants. Prior to the initiation of the study, the Institutional Review Board of the Philadelphia College of Osteopathic Medicine reviewed and approved the study. Recruitment for the study conducted through ResearchMatch and all study participants were recruited without coercion and were prompted to review the informed consent thoroughly before proceeding. Participants were not identified by their names and all data were kept confidential with the use of a secure e-mail address.

Measures

Clinical vignettes. Hypothetical vignettes were presented to study participants as two distinct clinical scenarios, one addressing genetic testing decisions and the other addressing prophylactic decisions (Appendix). Only those who indicated that they were willing to obtain genetic testing were evaluated on prophylactic decisions. Participants' responses were scored on a Likert scale (extremely unlikely; unlikely; likely; extremely likely). A neutral choice was not an option because in genetic testing and prophylactic decisions, a choice must be made; thus, choice was forced in these scenarios as well.

Social Problem-Solving Inventory-R:S (SPSI-R:S). The SPSI-R:S is a widely utilized self-report measure that assesses everyday problem-solving abilities in five domains (D'Zurilla et al., 2002). The SPSI-R:S assesses both problem orientation and problem-solving style. Domains on the measure include, NPO, PPO, RPS, ICS and AS (D'Zurilla & A. M. Nezu, 1999; Yetter & Foutch, 2014). The measure consists of 25

items with five scales and a total global score (Dreer et al., 2009). Items are assessed on

a 5-point Likert-type scale ranging from 0 (*not at all true of me*) to 4 (*extremely true of*

me; Dreer et al., 2009). The scales have a standardized mean of 100 and a standard

deviation of 15. Scores equal to or above 145 are considered to be extremely above norm

group average and scores equal to or below 55 are considered to be extremely below

norm group average (D'Zurilla et al., 2002). The items on this measure have been found

to have satisfactory predictive, convergent, structural, and discriminant validity

(D'Zurilla et al., 2002). The internal consistency ranges from .60 to .90 and the test-

retest reliability ranges from .68 to .91 (D'Zurilla et al., 2002).

Short Health Anxiety Inventory (SHAI). The SHAI is an 18-item self-report

questionnaire that measures normal health concern and more severe health anxiety

(Salkovskis et al., 2002). The SHAI includes four statements that ask about the level of

health concerns over the past 6 months (Salkovskis et al., 2002). Items are scored from 0

to 3 and are added to obtain a main score, a negative consequences score. and a total

score ranging from 0 to 54 (Alberts, Hadjistavropoulos, Jones, & Sharpe, 2013). In the

development of the SHAI, Salkovskis et al. (2002) reported norm scores among non-

psychiatric populations for illness anxiety ($M = 9.4$; $SD = 5.1$), negative consequences (M

$= 2.2$, $SD = 2.1$), and total score ($M = 12.2$, $SD = 6.2$). The authors also reported the

health anxiety norm scores for the main section ($M = 30.1$, $SD = 5.5$), negative

consequences ($M = 7.8$, $SD = 2.8$), and total score ($M = 37.9$, $SD = 6.8$; Salkovskis et al.,

2002). Alberts et al. (2013) found that the internal consistency ranged from good to

excellent (.74 to .96).

Brief Symptom Inventory-18 (BSI-18). The BSI-18 (Derogatis, 2001) is

derived from the 53 item BSI (Derogatis & Spencer, 1993), and the SCL-90-R (Derogatis

& Unger, 2010). The BSI-18 consists of three 6-item scales that measure both physical

and emotional complaints on a 5-point Likert scale that measure psychological distress

(Derogatis, 2001). Raw scores are converted into *T*-scores, and a *T*-score greater or equal

to 63 on any scale indicates a positive score for that scale. Overall distress is determined

by a *T*-score greater or equal to 63 on the Global Severity Index (GSI) or on two or more

of the subscales. The scales include somatization (SOMA), anxiety (ANX), depression

(DEPR), and the GSI (Derogatis, 2001). The BSI-18 has been found to be valid and

reliable in patients with varying medical and mental illnesses (Carlson et al., 2004).

Chapter 5: Results

Statistical Analysis

A stepwise multiple regression was conducted to test the hypothesis that the SPS variables, health anxiety, and psychological distress would predict genetic testing and prophylactic decisions. Relevant assumptions of the statistical analysis were tested. The assumptions of singularity and collinearity statistics were tested and all independent variables were found to be sufficiently separate from each other ($VIF = 1.00$). Personal information and predictor variables were analyzed with descriptive statistics (i.e., frequencies, means, standard deviations, and comparison), and Pearson product-moment correlations were conducted to identify possible relationships among variables.

Demographic Information

Descriptive statistics were calculated for all participants within the overall sample ($N = 130$) to summarize basic features of the data. The mean age of the sample was 28.42 ($SD = 3.15$). Means and frequencies were used to describe the main characteristics of the sample (Table 3). Any variable with missing data was replaced by using series means.

One hundred and twenty-four participants reported their age, with 68.48% of women being 27 or older (M = 28.42, SD = 3.15, age range: 18-35 years). Of the one hundred and thirty participants who responded to the question of marital status, 60 reported being single, six engaged, 53 married, one divorced, zero widowed and 10 lives with a domestic partner. 130 participants responded about their education, including two with a high school diploma or GED, 9 with some college, six with an Associate's Degree, 54 with a Bachelor's or four-year degree, 45 with a Master's or other graduate degree and

14 with a doctorate or other professional degree. 130 answered about their employment status, with 94 participants employed for wages, three that were self-employed, two that were out of work but not currently looking for work, give that were homemakers and 26 students.

Table 3

Participant Demographics

	%	N
Marital Status		
Single	46.15	60
Married	40.77	53
Divorced	0.77	1
Engaged	4.62	6
Living with a domestic partner	7.69	10
Education		
High School Graduate or GED	1.54	2
Some College	6.92	9
Associates Degree	4.62	6
Bachelor or 4-year degree	41.54	54
Masters or other graduate Degree	34.62	45

Doctoral or other professional degree	10.77	14
Employment Status		
Employed for wages	72.31	94
Self-employed	2.31	3
Out of work but not currently looking for work	1.54	2
Homemaker	3.85	5
Student	20.00	26

Health Behaviors

The demographics questionnaire asked questions about specific health behaviors and diagnoses, including tobacco use, alcohol and drug use, past and current medical and psychiatric diagnoses, and compliance with medical appointments and recommendations (e.g., yearly physical, monthly self-breast exams, and gynecological appointments). Out of the 130 participants who responded, 95.38% of participants denied tobacco use, 76.92% responded "yes" to current alcohol use, and 34.62% admitted to using illicit/recreational drugs (current or past use was not indicated). When asked about current medical diagnoses (N = 130), seasonal allergies (n = 6, 4.17%) and migraines (n = 6, 4.17%) were the most prevalent. Anxiety (n = 41, 28.47%) and depression (n = 41, 28.47%) were the most frequently reported psychiatric disorders among participants (N = 130), followed by posttraumatic stress disorder (n = 7, 4.86%), bipolar disorder (n = 3, 2.08%), and attention-deficit/hyperactivity disorder (n = 6, 4.17%). The majority of

participants indicated that they receive annual check-ups from their primary care

physicians (PCPs; n = 100, 69.44%) and OB-GYNs (ages 18-20: n = 25, 17.36%; ages

21-29, n = 65, 45.14%; ages 30-35, n = 58, 40.28%). In spite of these findings, more

than half of the participants reported that they do not perform breast self-exams on a

monthly basis (n = 100, 69.44%).

Hypothetical Vignettes

For Vignette 1 (Table 4), scores ranged from 1 to 5 ($M = 4.33$, $SD = 0.96$). More

than half (51%; n = 77) reported that they would be "extremely likely" to obtain genetic

testing, 36.11% (n = 52) said they "likely" would, 8.33% (n = 12) said it would be

"unlikely" for them to receive testing, and 2.08% (n = 3) said it would be "extremely

unlikely." For Vignette 2 (Table 5), participants who answered "likely" or "extremely

likely" in Vignette 1 were asked to respond to a second vignette that addressed whether

they would be open to receiving prophylactic treatment (i.e., mastectomy) if they were

found to have the BRCA1 or BRCA2 genetic mutation. One hundred twenty-nine

participants responded (range = 1-4; $M = 2.76$, $SD = 0.82$). Fifty-eight participants

(38.40%) reported that they would be "likely," 39 (25.80%) said "unlikely," 24 (15.90%)

said "extremely likely," and 8 (5.30%) said "extremely unlikely."

Table 4

Vignette 1: Descriptive Statistics Table

	%	n
Extremely Unlikely	2.0	3
Unlikely	7.9	12
Likely	34.4	52
Extremely Likely	51.0	77

Table 5

Vignette 2: Descriptive Statistics Table

	%	N
Extremely Unlikely	5.3	8
Unlikely	25.8	39
Likely	38.4	58
Extremely Likely	24.0	15.9

Social Problem-Solving

The mean score on the SPSI-R:S (Table 6) was 106.39 (SD = 13.21; range: 62-135; 63 = very much below norm group average; 135 = above norm group average). The majority of participants (N = 137) fell within the norm group average. Having average problem-solving skills increases the likelihood that one will be able to cope effectively and experience less psychological distress when negotiating stressful situations.

Table 6

Social Problem-Solving Inventory-Revised, Short Form Descriptive Statistics

Subscale	N	Minimum	Maximum	Mean	Standard Deviation

Positive Problem Orientation	137	62	131	98.94	16.61
Negative Problem Orientation	137	74	135	94.10	12.09
Rational Problem Solving	137	64	136	98.74	16.05
Impulsivity/ Carelessness Style	137	73	134	92.36	11.34
Avoidance Style	137	78	125	86.97	11.57
SPSIRS Total Score	137	63	135	106.39	13.21

Health Anxiety

The SHAI (range: 0-54) has two distinct components. The first assesses the person's perceived likelihood that he or she will become ill (illness likelihood [IL]) and the second assesses the perceived consequences of having the illness (negative consequences of illness [NC]). The mean scores (N = 137; total SHAI: $M = 29.37$, $SD = 5.63$) of the components were IL ($M = 29.37$, $SD = 5.14$) and NC ($M = 4.97$, $SD = 1.39$). Table 7 illustrates results of the SHAI.

Table 7

Short Health Anxiety Inventory Descriptive Statistics

Subscale	N	Minimum	Maximum	Mean	Standard Deviation
Illness Likelihood (IL)	140	15	46	24.40	5.14
Negative Consequence of Illness (NC)	140	3	10	4.97	1.39
Total Score	140	19	53	29.37	5.63

Psychological Distress

The BSI-18 was used assess current psychological distress over the past 7 days.

In addition to the GSI (max raw score = 72), separate scores were calculated on three

subscales: SOM, DEP, and ANX, with six questions contributing to each subscale (max

raw score = 24). The mean scores on all subscales and the GSI showed increased levels

of psychological distress. Table 8 displays results of the BSI-18.

Table 8

Brief Symptom Inventory-18 (Scaled Scores) Descriptive Statistics

Subscale	N	Minimum	Maximum	Mean	Standard Deviation
Somatization	137	41	69	48.24	7.33
Depression	137	40	74	48.91	8.50
Anxiety	137	38	81	49.21	9.01
Global Scaled Score	137	33	75	48.60	8.57

Stepwise Regression Analysis: Vignette 2

A multiple stepwise regression was completed to determine the best linear combination of scores on the SPSI-R:S, SHAI, and BSI-18 for predicting BRCA1/BRCA2 genetic testing decisions in hypothetical FDRs. It was hypothesized that the three measures as well as problem-solving orientation and styles on the SPSI-R:S (PPO, NPO, RPS, ICS, and AS) would predict the decision of whether to receive genetic testing (Vignette 1) and, if yes, prophylactic treatment. PPO significantly predicted prophylactic treatment decisions, $F(1,121) = 3.97$, $p = .05$. The adjusted R squared equaled .024, meaning that 2.4% of the variance in prophylactic treatment decisions can be predicted from PPO. Tables 9 through 13 depict the stepwise regression analysis.

Table 9

Stepwise Regression Model Summary

Model	Variable	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	PPO	.178	.032	.024	.82064

Table 10

Stepwise Regression Model Summary, Change Statistics

Model	Variable	R Square Change	F Change	Df1	Df2	Sig. F Change
1	PPO	.032	3.971	1	121	.049

Table 11

Stepwise Regression Model Summary, Excluded Variables

Model	Variable	Beta In	T	Sig.	Partial Correlation	Collinearity Statistics: Tolerance
1	NPO	.016	.153	.879	.014	.723
	RPS	.108	.954	.342	.087	.620
	ICS	.020	.218	.828	.020	1.00
	AS	-.030	-.307	.760	-.028	.854
	BSI Global Score	.084	.913	.363	.083	.957
	HAI Total Score	.094	1.02	.309	.093	.948

Table 12

ANOVA

Model		Sum of Squares	Df	Mean Square	F	Sig.
1	Regression	2.674	1	2.674	3.971	.049
	Residual	81.488	121	.673		
	Total	84.163	122			

Table 13

Collinearity Coefficients

Model	Unstandardized Coefficients B	Unstandardized Coefficient Std. Error	Standardized Coefficient B	t	Sig.
1 Constant PPO	1.88	.447	2.674	3.9	.049
Standard Score	.009	.004	.673		

Chapter 6: Discussion

Demographic Variables

In the current study, 51% of participants indicated that they would be "extremely likely" to receive genetic testing. This is less than what has been reported in prior research using hypothetical samples. As previously discussed, Ropka et al. (2006) completed a systematic review of breast cancer genetic testing uptake rates in both hypothetical and real scenarios. The authors determined that participants in hypothetical situations were more amenable to testing than participants in real situations (mean hypothetical genetic testing uptake rate = 66%; mean real genetic testing uptake rate = 59%). Indeed, the uptake rates reported in hypothetical and real breast cancer genetic testing research are variable (range = 20% to 96%; Ropka et al., 2006). The reasons for this variability are likely due to differences in study methodology, sampling strategy (i.e., reference versus convenience), recruitment setting, personal history of breast cancer, and/or family history of breast cancer (Ropka et al., 2006). To illustrate, most studies differ in how they operationally define and measure interest in genetic testing versus intent to obtain genetic testing (Glanz, Grove, Lerman, Gotay, & Le Marchand, 1999). Accordingly, the discrepancies in genetic testing uptake are partly attributable to a body of research that has been unsystematic in its methodology (Bowen, Patenaude, & Vernon, 1999).

The current study faced some of the same issues as other research completed in this area (e.g., homogenous sample; hypothetical, non-patient sample; convenience sampling). As stated previously, the hypothetical nature and the homogeneity of the sample have limited the representativeness and generalizability of the study findings to

the national FDR BRCA1/BRCA2 demographic. The overall mean age for this sample

was 28.42 years, with the majority of participants being between the ages of 27 and 35.

The mean age of women who responded that they would be "extremely likely" or

"likely" to receive genetic testing was 28.50 years. The mean age of women who

reported that they would be "extremely likely" or "likely" to obtain prophylactic

treatment (i.e., mastectomy) was 29 years. The study only included women in the 18 to

35 age range because there is research suggesting genetic testing decisions in this age

range are uniquely complex because of this particular stage of development (i.e.,

achieving independence from their parents), the reproductive and physical repercussions

of having breast cancer (i.e., childbearing, changes in sexual functioning and body

image), and the national guidelines in the U.S. (Evans et al., 2016; Patenaude et al.,

2013).

        Considering that the genetic testing research on young women FDRs is sparse, the

current study made the decision to incorporate women between the ages of 18 and 35 to

gain a better sense of the determinants of their possible distress, health anxiety, and

problem-solving processes. It is unclear whether the uptake rates reported in this study

are representative for several reasons: (a) this study was hypothetical and, because of this,

the sample cannot be generalized to women in real genetic testing situations and (b) even

though younger age is a predictor of willingness to obtain genetic testing, it may have

been helpful to include women over the age of 35. Seeing that this study was

hypothetical, that genetic testing uptake rates reported in the literature are variable, and

that little research has been done in young women in this area, it is unclear whether the

uptake rates reported in this study are representative.

Women were also asked about their marital statuses, education levels, employment statuses/types of employment, health information (i.e., medical/mental health histories), health behaviors (i.e., engagement of monthly breast exams), and uptake of yearly physicals and gynecological exams. The majority of women in this study had a bachelor's degree or higher and worked in healthcare professions. Nearly all of the women[vi] reported that they visit their PCPs for yearly physicals (69.44%); however, women do not visit the OB-GYN as frequently for their yearly or biennial appointments (ages 18-20: 17.36%; ages 21-29: 45.14%; ages 30-35: 40.28%). Correspondingly, 69.44% of women indicated that they do not give themselves monthly breast self-exams (BSE). The American Cancer Society updated the breast cancer screening guidelines, stating that monthly BSE is no longer necessary (Oeffinger et al., 2015). Nevertheless, BSE is still strongly recommended in women who are at a higher risk of developing breast cancer (NCCN, 2018). Therefore, although the study was hypothetical, the decision was made to assess for BSE in the present study. In regard to psychiatric illness, more than half the women (56.25%) in this sample reported the absence of any current or prior psychiatric disorders. Depression and anxiety occurred in 28.47% of the women but did not predict either the decision to obtain genetic testing or to seek prophylactic treatment.

None of the demographic variables were found to be significantly predictive of genetic testing and/or prophylactic decisions. The sample used in this study was homogeneous and represented a group of women who worked primarily in healthcare and who were more highly educated than women in the average population, which could account for the lack of significant findings. Nonetheless, these findings are consistent

with other research that has shown education level, marital status, and psychological distress to be poorly predictive of genetic testing and prophylactic treatment decisions (Bellcross et al., 2015; Meiser et al., 2000; Schwartz et al., 2002). A prior diagnosis of cancer, family history of cancer (particularly in a mother or sibling), levels of cancer-related distress, and degree of perceived risk are considered to be most predictive of genetic testing uptake (Bellcross et al., 2015; Meiser et al., 2000; Metcalfe et al., 2008).

The fact that women in the current study reported low attendance to OB-GYN appointments was somewhat unexpected. Yet, there is data to suggest that people who have less education and are of lower SES visit their PCPs more frequently than those who are of higher SES (Dunlop, Coyte, & McIsaac, 2000). Conversely, higher SES individuals tend visit PCPs less but are more likely to be given referrals and attend appointments with specialists (Dunlop et al., 2000). The present findings may have implications for genetic testing and prophylactic treatment access in women from low SES backgrounds. For instance, cost, logistical barriers, lack of support, and psychological distress have all been identified as important factors for not following up with genetic testing and are often issues that women from low SES backgrounds face (Willis et al., 2017). Thus, to ensure that these obstacles do not hinder medical access to specialists, it is important for medical providers to identify barriers to treatment early on. Moreover, for the purposes of the current study, findings that higher SES populations are less likely to visit their PCPs may explain the low uptake of medical visits that were reported (i.e., the sample was more highly educated and may have come from higher SES backgrounds).

Psychological Distress, Health Anxiety, and Social Problem-Solving

The goal of this study was to determine whether SPS variables (i.e., problem-solving orientation, rational problem solving, avoidance, and impulsivity/carelessness), psychological distress, and healthy anxiety predict genetic testing and prophylactic treatment decisions in a hypothetical, non-patient sample. Assessment of these variables was completed via a one-time survey in which participants were asked to complete three questionnaires and respond to two hypothetical vignettes.

Results from this cross-sectional study revealed that mean scores fell within the normal range on the BSI-18, SHAI, and SPSI-R:S (domains PPO, NPO, RPS, ICS, and AS). In other words, women in this study did not demonstrate significant levels of psychological distress or health anxiety and fell in the normal range for problem-solving orientation and ability. With the exception of PPO, none of the questionnaires were significantly predictive of willingness to obtain genetic testing or prophylactic treatments.

Specifically, scores on the BSI-18 ranged from low distress to clinically significant distress, but clinical significance was not reached for any of the scales. Likewise, SHAI scores were broad and ranged from extremely low to extremely high. Subscale scores were higher than those in average non-psychiatric populations; however, psychological distress was not found to be predictive of genetic testing or prophylactic treatment decisions. These findings are consistent with prior research in which levels of cancer-related distress and state-trait anxiety were measured after receiving genetic testing. The psychological distress level of non-carriers returned to normal range pre- to posttest and general levels of distress remained stable (Claes et al., 2005).

Women's scores on the SPSI-R:S fell within the average range. In all domains, scores on this measure ranged from below the norm group average to above the norm group average. Neither problem orientation nor problem-solving style was found to be significantly predictive of genetic testing decisions. In regard to prophylactic decisions, four out of the five domains (NPO, RPS, ICS, & AS) and the total score failed to predict any variance in prophylactic treatment choice. In contrast, PPO was found to significantly predict prophylactic treatment decisions (i.e., mastectomy).

It is worth mentioning that having children can influence genetic and prophylactic treatment decisions, even in hypothetical populations (Meijers-Heijboer et al., 2000). Regrettably, the present study did not ask participants if they had children and the opportunity was missed to evaluate this variable; however, three women in the study (between the ages of 30 and 35) indicated they were currently pregnant. In healthy women, it is widely recognized that carrying more than one baby to full-term reduces breast cancer risk (Lecarpentier et al., 2012). Conversely, there is research to suggest that increased estrogen production in pregnancy increases breast cancer risk in BRCA1 mutation carriers (Andrieu et al., 2006; Antoniou et al., 2006; Lecarpentier et al., 2012; Milne et al., 2010). The research on the risk of pregnancy and breast cancer in BRCA2 mutations is inconclusive (Friebel et al., 2014).

Of the three pregnant women, two responded that they would be willing to receive both genetic testing and prophylactic treatment. The third participant was agreeable to genetic testing but stated that she would not accept prophylactic treatment. The women did not endorse significant symptoms of psychological distress or health anxiety. Interestingly, the participants who were agreeable to both vignettes yielded RPS scores

on the SPSI-R:S that were below norm average (i.e., these women may have below average problem-solving abilities). Although these findings are not meant to indicate significance, the data emphasize the complicated decisions that premenopausal women are confronted with when making these types of decisions.

The implications of the current findings are important because PPO has been found to facilitate psychological distress reduction. McInerney-Leo et al. (2004) assessed psychological well-being in 212 individuals from HBOC families. Regardless of genetic testing decision (85% were agreeable), participants were randomized to receive either PST or client-centered counseling. Those who received PST experienced a significant decrease in distress compared to those who received client-centered counseling (McInerney-Leo et al., 2004). Thus, regardless of decision choice, a PPO during real-life genetic testing may increase confidence in the ability to make decisions, despite the outcome. These results should to be interpreted with caution, as the amount of variance that predicted prophylactic treatment decisions was small (2.4%), and it is possible that other variables in the study impacted how the question was answered (e.g., education level, age).

It is not surprising that this study did not generate significant levels of psychological distress or health anxiety but did show a relationship between PPO and treatment decisions. In the literature, individuals with a PPO typically present with decreased levels of distress and generalized problem-solving self-efficacy (i.e., the belief that one is capable of solving problems and carrying out solutions effectively; Nezu, 2004). For example, research shows that being able to assert more control over chronic pain leads to a decrease in functional impairment (Shaw, Feuerstein, Haufler, Berkowitz

& Lopez, 2001; Suso-Ribera, Camacho-Guerrero, McCracken, Maydeu-Olivares, &

Gallardo-Pujol, 2016).

The pain literature regarding self-management and control demonstrates the value

of self-efficacy (Lackner, Carosella, & Feuerstein, 1996). For example, functional self-

efficacy expectancy—the view that an individual has the ability to complete work tasks

effectively—is a better predictor of adaptive coping than psychological distress or

perceived pain control (Lackner et al., 1996). The mechanism underlying the relationship

between positive problem-solving and increased self-efficacy is thought to be the result

of operant learning (Shaw et al., 2001). Put another way, how a person responds to

problems in his or her daily life will generate behavioral responses, some of which will

be reinforced and some of which that will not be (e.g., less distress in response to genetic

testing or prophylactic decisions acts as negative reinforcement; Shaw et al., 2001).

Thus, regardless of the decision, the ability to successfully implement effective problem-

solving skills in the context of genetic testing and prophylaxis may be a protective factor

against the onset of psychological morbidity.

Implication of the Research Findings

Findings of the present study show that in hypothetical samples, levels of

psychological distress, health anxiety, and problem-solving ability are not predictive of

BRCA1/BRCA2 genetic testing decisions. In contrast, PPO is predictive of prophylactic

treatment decisions (i.e., mastectomy), whereas the other study variables are not. This

study is novel in that it is the first to show a specific relationship between problem-

solving orientation, BRCA1/BRCA2 mutation status, and prophylactic treatment

decisions. This finding advances the idea that positive problem-solving abilities aide in

the decision-making process in high risk HBOC families (Caplan, 1981; Pasacreta, 1999).

Research in genetic testing decisions in individuals at risk for the Huntington's

disease genetic mutation has demonstrated similar findings. Perceived risk, although

important, was found to be secondary to one's personality profile and coping mechanisms

(Decruyenaere et al., 1996). Similarly, a follow-up study found that individuals who

chose to obtain genetic testing were more likely to employ active problem-solving skills,

report a higher frequency of optimistic thoughts, and seek support more often (Evers-

Kiebooms, Welkenhuysen, Claes, Decruyenaere & Denayer, 2000). Nevertheless, since

this study did not find problem-solving orientation or style to be significantly predictive

of genetic testing decisions and research on SPS in prophylactic decisions is limited, it

remains unclear at this time whether findings of that nature can be applied to the current

study. Moreover, though the findings from this study are intriguing, there continues to be

a lack of consensus as to what providers should be addressing with patients (e.g.,

premorbid psychiatric illness, cancer related psychological distress versus perceived

risk). Although hypothetical, the current findings add to a growing body of research

suggesting that assessment of psychological variables and coping mechanisms should be

integrated into the initial genetic counseling session (Koch & Svendsen, 2005.

To emphasize the importance of considering SPS within the domain of

prophylactic decisions, Koch and Svendsen (2005) hypothesized that cancer genetic

testing is inherently non-directive and that effective genetic counseling provides

direction, thus increasing one's sense of autonomy and informed consent. Therefore, the

genetic counselor's task is to ensure that the patient feels fully informed about all aspects

of the genetic testing process (e.g., risk, the treatment consequences of receiving a positive result). The nature of BRCA1/BRCA2 genetic testing is to present prophylaxis as the solution the problem of the possibility of being positive for the mutation. Thus, patients engage in a process in which their problems are viewed in the context of the available solutions, which can increase optimism and self-efficacy and protect against psychological distress and health anxiety (Casey & Edgerton, 2008; Spector & Kitsuse, 2001).

It makes sense that a solution-focused strategy combined with feelings of autonomy may lead to increased optimism and self-efficacy, thus making the problem-solving and decision-making processes empowering versus distressing. Further, patients who have a stronger sense of self-efficacy, internal sense of control, and optimism may choose prophylactic approaches, which are consistent with an active rather than passive approach to problem-solving. The findings of past research and the current study highlight that providers involved in the dissemination of information on genetic risk should be take the time to ensure that patients have understood the information that has been provided to them adequately. With this in mind, successfully navigating genetic and prophylactic treatment decisions means acquiring information that may lead to or exacerbate psychological distress and health anxiety. Even though this study did not find a predictive relationship between psychological variables and genetic testing or prophylactic decisions, it revealed evidence that problem-solving ability is asserting some influence on the decision-making process. Thus, problem-solving ability may need to be considered when asking women at risk for breast cancer to make complex decisions about their future health.

Limitations of Current Study

Similar to other studies in HBOC domain, the sample used in the current study was fairly homogeneous, particularly in regard to education and profession, and may not generalize to the entire population. It is important to note that due to human error, information on race and ethnicity was not collected; however, pending IRB approval, study subjects will be contacted and asked to fill out race and ethnicity information in a separate survey. In addition, groups were not balanced by age, which led to a large proportion of study participants being older than 27.

Another limitation of this study was the use of hypothetical vignettes versus a real sample of women undergoing genetic testing and/or prophylactic treatment decisions. According to the diathesis-stress model, a life stressor such as cancer could trigger the onset of psychiatric illness (Vitaliano et al., 1998; Zubin & Spring, 1977). Thus, since the study participants were not actually in the situation of being genetically tested or having to decide whether to get a mastectomy, no stress was triggered and, consequently, they were less likely to experience psychological distress or health anxiety. These issues may limit the external validity, thus impacting the generalizability of the study.

In terms of other variables, the younger age of this cohort may have impacted level of breast cancer knowledge as well as the overwhelming willingness to receive both genetic testing and prophylactic treatment. Over the course of their lifetimes, this group of women had more access to health literacy via school and/or technology (e.g., the Internet) than generations in the past. Access to these resources may have increased the awareness of breast cancer risk, breast cancer screening, available breast cancer treatments, and the consequence of not following screening guidelines. For example,

through the use of a text messaging intervention, a recent study demonstrated a

significant increase in cervical cancer screenings (Lee, Koopmeiners, Rhee, Raveis, &

Ahluwalia, 2014). This research highlights how technology has changed the ways in

which young people in today's societies gather information to make informed medical

decisions. Finally, this study failed to consider women of Ashkenazi Jewish descent,

who are at a higher risk for breast cancer.

Future Directions

The impact of genetic testing and prophylactic decisions on psychological

functioning should not be minimized. Despite the limitations of this study, it was one of

the first to demonstrate that SPS, specifically PPO, is predictive of BRCA1/BRCA2

prophylactic treatment decisions. Future research should look at these relationships in

larger non-hypothetical samples and in different disease groups to determine whether the

results differ. More specifically, BRCA1/BRCA2 mutations are also responsible for

other cancers, most notably ovarian cancer; therefore, the next step may be to assess the

study variables in the context of ovarian cancer.

In addition, considering that SPS has been found to be quite successful in

decreasing psychological distress, it stands to reason that incorporating problem-solving

measures and problem-solving therapy into pre- and post-genetic counseling sessions

may alleviate short and/or long-term distress (McInerney-Leo et al., 2004). Accordingly,

developing a more comprehensive understanding of the ways in which SPS, health

anxiety, and psychological distress impact genetic testing and prophylactic decisions may

provide valuable insight into how to better assist patients and their families and medical

providers. Nevertheless, as previously discussed, the majority of research in this area

either has methodological issues or is sparse, which may be why there continues to be

disagreement in the literature. If possible, efforts should be made to standardize

treatment protocols (i.e., through the development of randomized control trials) and to

incorporate heterogeneous samples. Finally, further investigation of SPS, psychological

distress, and health anxiety in BRCA1/BRCA2 genetic mutations among different races,

ethnic groups, and genders is warranted.

References

Adams, S. A., Smith, E. R., Hardin, J., Prabhu-Das, I., Fulton, J., & Hebert, J. R. (2009).

    Racial differences in follow-up of abnormal mammography findings among

    economically disadvantaged women. *Cancer, 115*(24), 5788-5797.

Alberts, N. M., Hadjistavropoulos, H. D., Jones, S. L., & Sharpe, D. (2013). The Short

    Health Anxiety Inventory: A systematic review and meta-analysis. *Journal of*

    *Anxiety Disorders, 27(*1), 68-78.

Altekruse, S. F., Kosary, C. L., Krapcho, M., Neyman, N., Aminou, R., Waldron, W., ...

    & Mariotto, A. (2010). SEER Cancer Statistics Review, 1975–2007. Bethesda,

    MD: National Cancer Institute; 2010. *Blagosklonny MV and Campisi J. Cancer*

    and aging: more puzzles, more promises, 2615-2618.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental*

    disorders (5th ed.). Arlington, VA: Author.

Andrieu, N., Goldgar, D. E., Easton, D. F., Rookus, M., Brohet, R., Antoniou, A. C., . . .

    Noguès, C. (2006). Pregnancies, breast-feeding, and breast cancer risk in the

    International BRCA1/2 Carrier Cohort Study (IBCCS). *Journal of the National*

    Cancer Institute, *98*(8), 535-544.

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), 1117–1130

Antoniou, A. C., Shenton, A., Maher, E. R., Watson, E., Woodward, E., Lalloo, F., . . .

    Evans, D. G. (2006). Parity and breast cancer risk among BRCA1 and BRCA2

    mutation carriers. *Breast Cancer Research, 8(*6), R72.

Ashton, C. M., Haidet, P., Paterniti, D. A., Collins, T. C., Gordon, H. S., O'Malley, K., . .

    . Street, R. L. (2003). Racial and ethnic disparities in the use of health services.

    Journal of General Internal Medicine, *18*(2), 146-152.

Audrain, J., Schwartz, M. D., Lerman, C., Hughes, C., Peshkin, B. N., & Biesecker, B.

    (1997). Psychological distress in women seeking genetic counseling for breast-

    ovarian cancer risk: The contributions of personality and appraisal. *Annals of*

    Behavioral Medicine, *19*(4), 370-377

Ban, K. A., & Godellas, C. V. (2014). Epidemiology of breast cancer. *Surgical Oncology*

    Clinics of North America, *23*(3), 409-22.

Baum, A., Friedman, A. L., & Zakowski, S. G. (1997). Stress and genetic testing for

    disease risk. *Health Psychology*, *16*(1), 8-19.

Bellcross, C. A., Peipins, L. A., McCarty, F. A., Rodriguez, J. L., Hawkins, N. A.,

    Alford, S. H., & Leadbetter, S. (2015). Characteristics associated with genetic

    counseling referral and BRCA1/2 testing among women in a large integrated

    health system. *Genetics in Medicine*, *17*(1), 43-50.

Bleyer, A., & Welch, H. G. (2012). Effect of three decades of screening mammography

    on breast-cancer incidence. *New England Journal of Medicine, 367*(21), 1998-

    2005.

Bowen, D. J., Patenaude, A. F., & Vernon, S. W. (1999). Psychosocial issues in cancer

    genetics: from the laboratory to the public. *American Association of Cancer*

Research, 8(Suppl. 1). Retrieved from http://cebp.aacrjournals.org/content/8/suppl _1/326.2.short

Brandberg, Y., Sandelin, K., Erikson, S., Jurell, G., Liljegren, A., Lindblom, A., . . . 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*, *26*(24), 3943-3949.

Burke, W., Culver, J. O., Bowen, D., Lowry, D., Durfy, S., McTiernan, A., . . . Andersen, M. R. (2000). Genetic counseling for women with an intermediate family history of breast cancer. *American Journal of Medical Genetics Part A, 90*(5), 361-368.

Butow, P. N., Lobb, E. A., Meiser, B., Barratt, A., & Tucker, K. M. (2003). Psychological outcomes and risk perception after genetic testing and counselling in breast cancer: A systematic review. *Medical Journal of Australia, 178*(2), 77-81.

Calzone, K. A., & Biesecker, B. B. (2002). Genetic testing for cancer predisposition. *Cancer Nursing*, *25*(1), 15-25.

Caplan, G. (1981). Mastery of stress: Psychosocial aspects. *The American Journal of Psychiatry, 138*(4), 413-420. doi:10.1176/ajp.138.4.413

Carlson, L. E., Angen, M., Cullum, J., Goodey, E., Koopmans, J., Lamont, L., . . . Simpson, J. S. A. (2004). High levels of untreated distress and fatigue in cancer patients. *British Journal of Cancer*, *90*(12), 2297-2304.

Casey, C., & Edgerton, R. B. (Eds.). (2008). *A companion to psychological anthropology: modernity and psychocultural change*. Malden, MA: Blackwell Publishing Ltd.

Catania, C., Feroce, I., Barile, M., Goldhirsch, A., De Pas, T., De Braud, F., . . . Spitaleri, G. (2016). Improved health perception after genetic counselling for women at high risk of breast and/or ovarian cancer: Construction of new questionnaires— An Italian exploratory study. *Journal of Cancer Research and Clinical Oncology, 142*(3), 633-648.

Chang, E. C., D'Zurilla, T. J., & Sanna, L. J. (2004). *Social problem solving: Theory, research, and training.* Washington, DC: American Psychological Association.

Cicero, G., De Luca, R., Dorangricchia, P., Coco, G. L., Guarnaccia, C., Fanale, D., . . . Russo, A. (2017). Risk perception and psychological distress in genetic counselling for hereditary breast and/or ovarian cancer. *Journal of Genetic Counseling*, *26*(5), 999-1007.

Claes, E., Evers-Kiebooms, G., Boogaerts, A., Decruyenaere, M., Denayer, L., & Legius, E. (2004). Diagnostic genetic testing for hereditary breast and ovarian cancer in cancer patients: Women's looking back on the pre-test period and a psychological evaluation. *Genetic Testing*, *8*(1), 13-21.

Claes, E., Evers-Kiebooms, G., Denayer, L., Decruyenaere, M., Boogaerts, A., Philippe, K., & 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.

Cohen, J. (1992). A power primer. *Psychological Bulletin*, *112*(1), 155-159.

Crawford, B., Adams, S. B., Sittler, T., van den Akker, J., Chan, S., Leitner, O., . . . van't Veer, L. (2017). Multi-gene panel testing for hereditary cancer predisposition in unsolved high-risk breast and ovarian cancer patients. *Breast Cancer Research and Treatment*, *163*(2), 383-390.

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.

Crozier, S., Robertson, N., & Dale, M. (2015). The psychological impact of predictive genetic testing for Huntington's disease: A systematic review of the literature. *Journal of Genetic Counseling*, *24*(1), 29-39.

Cuzick, J., Sestak, I., Cawthorn, S., Hamed, H., Holli, K., Howell, A., . . . IBIS-I Investigators. (2015). Tamoxifen for prevention of breast cancer: Extended long-term follow-up of the IBIS-I breast cancer prevention trial. *The Lancet Oncology*, *16*(1), 67-75.

Daly, M. B., Axilbund, J. E., Buys, S., Crawford, B., Farrell, C. D., Friedman, S., . . . Kaklamani, V. (2010). Genetic/familial high-risk assessment: Breast and ovarian. *Journal of the National Comprehensive Cancer Network, 8(*5), 562-594.

Decruyenaere, M., Evers-Kiebooms, G., Boogaerts, A., Cassiman, J. J., Cloostermans, T., Demyttenaere, K., ... & Van den Berghe, H. (1996). Prediction of psychological functioning one year after the predictive test for Huntington's disease and impact

of the test result on reproductive decision making. *Journal of Medical Genetics*, *33*(9), 737-743.

Derogatis, L. R. (2001). *Brief Symptom Inventory 18*. Baltimore, MD: Johns Hopkins University.

Derogatis, L. R., & Spencer, P. M. (1993). *Brief symptom inventory: BSI.* Upper Saddle River, NJ: Pearson.

Derogatis, L. R., & Unger, R. (2010). *Symptom Checklist‐90‐Revised*. New York, NY: John Wiley & Sons, Inc.

DeSantis, C., Ma, J., Bryan, L., & Jemal, A. (2014). Breast cancer statistics, 2013. *CA: a Cancer Journal for Clinicians*, *64*(1), 52-62.

Dreer, L. E., Berry, J., Rivera, P., Snow, M., Elliott, T. R., Miller, D., & Little, T. D. (2009). Efficient assessment of social problem-solving abilities in medical and rehabilitation settings: A Rasch analysis of the Social Problem-Solving Inventory-Revised. *Journal of Clinical Psychology, 65(*7), 653-669.

Dreer, L. E., Elliott, T. R., & Tucker, E. (2004). Social problem-solving abilities and health behaviors among persons with recent-onset spinal cord injury. *Journal of Clinical Psychology in Medical Settings*, *11*(1), 7-13.

Dunlop, S., Coyte, P. C., & McIsaac, W. (2000). Socioeconomic status and the utilisation of physicians' services: Results from the Canadian National Population Health Survey. *Social Science & Medicine*, *51*(1), 123-133.

D'Zurilla, T. J., Chang, E. C., Nottingham IV, E. J., & Faccini, L. (1998). Social problem-solving deficits and hopelessness, depression, and suicidal risk in college

students and psychiatric inpatients. *Journal of Clinical Psychology*, *54*(8), 1091-
1107.

D'Zurilla, T. J., & Dryden, W. (1988). Problem-solving therapy. *Journal of Cognitive
Psychotherapy*, *2*(4), 283-284.

D'Zurilla, T. J., & Nezu, A. M. (1982). Social problem solving. *Advances in cognitive-
Behavioral Research and Therapy, 1,* 201-274.

D'Zurilla, T. J., & Nezu, A. M. (1990). Development and preliminary evaluation of the
Social Problem-Solving Inventory. *Psychological Assessment: A Journal of
Consulting and Clinical Psychology, 2*(2), 156-163.

D'Zurilla, T. J., & Nezu, A. M. (1999). *Problem-solving therapy: A social competence
approach to clinical intervention*. New York, NY: Springer Publishing Company.

D'Zurilla, T. J., Nezu, A. M., & Maydeu-Olivares, A. (2002). *Social Problem-solving
Inventory--revised (SPSI-R)*. Multi-Health Systems.

Eccles, B.K., Copson, E., Maishman, T., Abraham, J. E., & Eccles, D. M. (2015).
Understanding of BRCA VUS genetic results by breast cancer specialists. *BMC
Cancer, 15*(1), 936.

Eccles, D. M., Mitchell, G., Monteiro, A. N. A., Schmutzler, R., Couch, F. J., Spurdle, A.
B., . . . Blok, M. J. (2015). BRCA1 and BRCA2 genetic testing—Pitfalls and
recommendations for managing variants of uncertain clinical significance. *Annals
of Oncology*, *26*(10), 2057-2065.

Elliot, T., & Shewchuk, R. (2003). Social problem-solving abilities and distress among
family members assuming a caregiver role. *British Journal of Health Psychology,
8,* 149-63.

Evans, C., Hamilton, R. J., Tercyak, K. P., Peshkin, B. N., Rabemananjara, K., Isaacs, C.,
    & O'Neill, S. C. (2016). Understanding the needs of young women regarding
    breast cancer risk assessment and genetic testing: Convergence and divergence
    among patient-counselor perceptions and the promise of peer support. In
    Healthcare (Vol. 4, No. 3, p. 35). Multidisciplinary Digital Publishing Institute.

Evers-Kiebooms, G., Welkenhuysen, M., Claes, E., Decruyenaere, M., & Denayer, L.
    (2000). The psychological complexity of predictive testing for late onset
    neurogenetic diseases and hereditary cancers: implications for multidisciplinary
    counselling and for genetic education. *Social Science & Medicine*, *51*(6), 831-
    841.

Fletcher, K. E., Clemow, L., Peterson, B. A., Lemon, S. C., Estabrook, B., & Zapka, J. G.
    (2006). A path analysis of factors associated with distress among first-degree
    female relatives of women with breast cancer diagnosis. *Health Psychology*,
    25(3), 413-424.

Friebel, T. M., Domchek, S. M., & Rebbeck, T. R. (2014). Modifiers of cancer risk in
    BRCA1 and BRCA2 mutation carriers: A systematic review and meta-analysis.
    Journal of the National Cancer Institute, 106(6). doi:10.1093/jnci/dju091

Frost, C. J., Venne, V., Cunningham, D., & Gerritsen-McKane, R. (2004). Decision
    making with uncertain information: Learning from women in a high risk breast
    cancer clinic. *Journal of Genetic Counseling*, *13*(3), 221-236.

Gray, M. A. (2001, February). Chris Mann & Fiona Stewart (2000). Internet
    Communication and Qualitative Research: A Handbook for Researching Online.

In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research* (Vol. 2, No. 1).

Glanz, K., Grove, J., Lerman, C., Gotay, C., & Le Marchand, L. (1999). Correlates of intentions to obtain genetic counseling and colorectal cancer gene testing among at-risk relatives from three ethnic groups. *Cancer Epidemiology and Prevention Biomarkers*, *8*(Suppl 1), 329-336.

Graves, K. D., Vegella, P., Poggi, E. A., Peshkin, B. N., Tong, A., Isaacs, C., . . . Schwartz, M. D. (2012). Long-term psychosocial outcomes of BRCA1/BRCA2 testing: Differences across affected status and risk-reducing surgery choice. *Cancer Epidemiology and Prevention Biomarkers*. doi:10.1158/1055-9965.EPI-11-0991

Hamilton, R. J., & Bowers, B. J. (2007). The theory of genetic vulnerability: a Roy model exemplar. *Nursing Science Quarterly*, *20*(3), 254-264.

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*(4), 510-518.

Hartmann, L. C., Schaid, D. J., Woods, J. E., Crotty, T. P., Myers, J. L., Arnold, P. G., ... & Frost, M. H. (1999). Efficacy of bilateral prophylactic mastectomy in women with a family history of breast cancer. *New England Journal of Medicine*, *340*(2), 77-84.

Hay, J. L., Buckley, T. R., & Ostroff, J. S. (2005). The role of cancer worry in cancer screening: A theoretical and empirical review of the literature. *Psycho-Oncology*, *14*(7), 517-534.

Heemskerk-Gerritsen, B. A. M., Seynaeve, C., Van Asperen, C. J., Ausems, M. G. E. M.,

      Collee, J. M., van Doorn, H. C., . . . Mourits, M. J. E. (2015). Breast cancer risk

      after salpingo-oophorectomy in healthy BRCA1/2 mutation carriers: revisiting the

      evidence for risk reduction. *Journal of the National Cancer Institute*, *107*(5).

      doi:10.1093/jnci/djv033

Hill-Briggs, F., Lazo, M., Peyrot, M., Doswell, A., Chang, Y. T., Hill, M. N., . . .

      Brancati, F. L. (2011). Effect of problem-solving-based diabetes self-management

      training on diabetes control in a low income patient sample. *Journal of General*

      Internal Medicine, *26*(9), 972.

Himes, D. O., Clayton, M. F., Donaldson, G. W., Ellington, L., Buys, S. S., & Kinney, A.

      Y. (2016). Breast cancer risk perceptions among relatives of women with

      uninformative negative BRCA1/2 test results: the moderating effect of the amount

      of shared information. *Journal of genetic counseling*, *25*(2), 258-269.

Hopko, D. R., Armento, M. E., Robertson, S., Ryba, M. M., Carvalho, J. P., Colman, L.

      K., . . . Lejuez, C. W. (2011). Brief behavioral activation and problem-solving

      therapy for depressed breast cancer patients: Randomized trial. *Journal of*

      Consulting and Clinical Psychology, *79*(6), 834-849.

Howlader, N., Noone, A. M., Krapcho, M., Neyman, N., Aminou, R., Altekruse, S. F.,

      . . . Mariotto, A. (2012). SEER cancer statistics review, 1975-2009 (vintage 2009

      populations), National Cancer Institute. Bethesda, MD.

Iqbal, J., Ginsburg, O., Rochon, P. A., Sun, P., & Narod, S. A. (2015). Differences in

      breast cancer stage at diagnosis and cancer-specific survival by race and ethnicity

in the United States. *Journal of the American Medical Association, 313*(2), 165-

173.

Katapodi, M. C., Facione, N. C., Humphreys, J. C., & Dodd, M. J. (2005). Perceived

breast cancer risk: Heuristic reasoning and search for a dominance structure.

Social Science & Medicine, *60*(2), 421-432.

Kim, H. L., Puymon, M. R., Qin, M., Guru, K., & Mohler, J. L. (2013). NCCN clinical

practice guidelines in oncology. Retrieved from

http://www.jnccn.org/content/8/2.toc.pdf

King, D. K., Glasgow, R. E., Toobert, D. J., Strycker, L. A., Estabrooks, P. A., Osuna,

D., & Faber, A. J. (2010). Self-efficacy, problem solving, and social-

environmental support are associated with diabetes self-management

behaviors. *Diabetes Care*, *33*(4), 751-753.

Koch, L., & Svendsen, M. N. (2005). Providing solutions–defining problems: the

imperative of disease prevention in genetic counselling. *Social Science &

Medicine*, *60*(4), 823-832.

Kotsopoulos, J., Huzarski, T., Gronwald, J., Singer, C. F., Moller, P., Lynch, H. T., . . .

Senter, L. (2016). Bilateral oophorectomy and breast cancer risk in BRCA1 and

BRCA2 mutation carriers. *Journal of the National Cancer Institute*, *109*(1),

djw177. doi:10.1093/jnci/djw183

Lackner, J. M., Carosella, A. M., & Feuerstein, M. (1996). Pain expectancies, pain, and

functional self-efficacy expectancies as determinants of disability in patients with

chronic low back disorders. *Journal of Consulting and Clinical psychology*, *64*(1),

212-220.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY:

    Springer.

Lecarpentier, J., Noguès, C., Mouret-Fourme, E., Gauthier-Villars, M., Lasset, C.,

    Fricker, J. P., . . . Bonadona, V. (2012). Variation in breast cancer risk associated

    with factors related to pregnancies according to truncating mutation location, in

    the French National BRCA1 and BRCA2 mutations carrier cohort (GENEPSO).

    Breast Cancer Research, *14*(4), R99.

Lee, H. Y., Koopmeiners, J. S., Rhee, T. G., Raveis, V. H., & Ahluwalia, J. S. (2014).

    Mobile phone text messaging intervention for cervical cancer screening: Changes

    in knowledge and behavior pre-post intervention. *Journal of Medical Internet

    Research*, *16*(8), e196. doi:10.2196/jmir.3576

Lerman, C., Hughes, C., Croyle, R. T., Main, D., Durham, C., Snyder, C., . . . Lynch, H.

    T. (2000). Prophylactic surgery decisions and surveillance practices one year

    following BRCA1/2 testing. *Preventive Medicine*, *31*(1), 75-80.

Lindor, N.M., Goldgar, D.E., Tavtigian, S.V., Plon, S.E., & Couch, F. J. (2013). BR½1/2

    sequence variants of uncertain significance: A primer for providers to assist in

    discussions and in medical management. *The Oncologist. 18*(5), 518-524.

Lipscomb, J., Gillespie, T. W., Goodman, M., Richardson, L. C., Pollack, L. A., Ryerson,

    A. B., & Ward, K. C. (2012). Black-white differences in receipt and completion

    of adjuvant chemotherapy among breast cancer patients in a rural region of the

    US. *Breast Cancer Research and Treatment*, *133*(1), 285-296.

Lodder, L., Frets, P. G., Trijsburg, R. W., Klijn, J. G., Seynaeve, C., Tilanus, M., . . .

    Niermeijer, M. F. (2003). Attitudes and distress levels in women at risk to carry a

BRCA1/BRCA2 gene mutation who decline genetic testing. *American Journal of Medical Genetics Part A*, *119*(3), 266-272.

Lumish, H. S., Steinfeld, H., Koval, C., Russo, D., Levinson, E., Wynn, J., ... & Chung, W. K. (2017). Impact of panel gene testing for hereditary breast and ovarian cancer on patients. *Journal of genetic counseling*, *26*(5), 1116-1129.

Meiser, B., & Halliday, J. L. (2002). What is the impact of genetic counselling in women at increased risk of developing hereditary breast cancer? A meta-analytic review. *Social science & medicine*, *54*(10), 1463-1470.

Majdak-Paredes, E. J., & Fatah, F. (2009). Hereditary breast cancer syndromes and clinical implications. *Journal of Plastic, Reconstructive, & Aesthetic Surgery*, *62*(2), 181-189.

Mansoura, M. K., & Collins, F. S. (1998). Medical implications of the genetic revolution. *Journal of Health Care Law & Policy, 1*, 329. Retrieved from https://heinonline.org/HOL/LandingPage?handle=hein.journals/hclwpo1&div=20 &id=&page=

Matthews, A. K., Sellergren, S. A., Manfredi, C., & Williams, M. (2002). Factors influencing medical information seeking among African American cancer patients. *Journal of Health Communication*, *7*(3), 205-219.

McCarthy, A. M., Bristol, M., Domchek, S. M., Groeneveld, P. W., Kim, Y., Motanya, U. N., ... & Armstrong, K. (2016). Health care segregation, physician recommendation, and racial disparities in BRCA1/2 testing among women with breast cancer. *Journal of Clinical Oncology*, *34*(22), 2610.

McClure, K. S., Nezu, A. M., Nezu, C. M.' O'Hea, E. L., & McMahon, C. (2012). Social

problem solving and depression in couples coping with cancer. *Psycho‑Oncology*,

21(1), 11-19.

McInerney-Leo, A., Biesecker, B. B., Hadley, D. W., Kase, R. G., Giambarresi, T. R.,

Johnson, E., . . . Struewing, J. P. (2004). BRCA1/2 testing in hereditary breast and

ovarian cancer families: Effectiveness of problem‑ solving training as a

counseling intervention. *American Journal of Medical Genetics Part A, 130(*3),

221-227.

Meijers-Heijboer, E. J., Verhoog, L. C., Brekelmans, C. T. M., Seynaeve, C., Tilanus-

Linthorst, M. M. A., Wagner, A., . . . Klijn, J. G. M. (2000). Presymptomatic

DNA testing and prophylactic surgery in families with a BRCA1 or BRCA2

mutation. *The Lancet*, *355*(9220), 2015-2020.

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*(11), 2250-2257.

Meiser, B., & Halliday, J. L. (2002). What is the impact of genetic counselling in women

at increased risk of developing hereditary breast cancer? A meta-analytic review.

Social science & medicine, *54*(10), 1463-1470.

Metcalfe, K. A., Lubinski, J., Ghadirian, P., Lynch, H., Kim-Sing, C., Friedman, E., . . .

Tung, N. (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*(7), 1093-1097.

Metcalfe, K. A., Lubinski, J., Lynch, H. T., Ghadirian, P., Foulkes, W. D., Kim-Sing, C.,

. . . Ainsworth, P. (2010). Family history of cancer and cancer risks in women

with BRCA1 or BRCA2 mutations. *Journal of the National Cancer Institute*,

102(24), 1874-1878.

Miller, K. D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H., ...

& Jemal, A. (2016). Cancer treatment and survivorship statistics, 2016. *CA: a*

cancer journal for clinicians, *66*(4), 271-289.

Milne, R. L., Osorio, A., y Cajal, T. R., Baiget, M., Lasa, A., Diaz-Rubio, E., . . . Blanco,

I. (2010). Parity and the risk of breast and ovarian cancer in BRCA1 and BRCA2

mutation carriers. *Breast Cancer Research and Treatment, 119(*1), 221-232.

Moyer, V. A. (2014). Risk assessment, genetic counseling, and genetic testing for BRCA-

related cancer in women: U.S. Preventive Services Task Force recommendation

statement. *Annals of Internal Medicine*, *160*(4), 271-281.

Murff, H. J., Byrne, D., Haas, J. S., Puopolo, A L., & Brennan, T. A. (2005). Race and

family history assessment for breast cancer. *Journal of General Internal*

Medicine, 20(1), 75-80. doi:10.1111/j.1525-1497.2004.40112.x

National Comprehensive Cancer Network. (2018). Genetic/Familial High-Risk

Assessment: Breast and Ovarian (Version I.2018). Retrieved from

https://www.nccn.org/professionals/physician_gls/pdf/genetics_screening.pdf

Newman, L. A., Griffith, K. A., Jatoi, I., Simon, M. S., Crowe, J. P., & Colditz, G. A.

(2006). Meta-analysis of survival in African American and White American

patients with breast cancer: Ethnicity compared with socioeconomic status.

Journal of Clinical Oncology, *24*(9), 1342-1349.

Nezu, A. M., Nezu, C. M., Friedman, S. H., Faddis, S., & Houts, P. S. (1998). *Helping cancer patients cope: A problem-solving approach*. Washington, DC: American Psychological Association.

Nezu, A. M., Nezu, C. M., Houts, P. S., Friedman, S. H., & Faddis, S. (1999). Relevance of problem-solving therapy to psychosocial oncology. *Journal of Psychosocial Oncology*, *16*(3-4), 5-26.

Nezu, A. M., Nezu, C. M., & Perri, M. G. (1989). *Problem-solving therapy for depression: Theory, research, and clinical guidelines*. New York, NY: John Wiley & Sons.

Nezu, A. M. (2004). Problem solving and behavior therapy revisited. *Behavior therapy*, *35*(1), 1-33.

Oeffinger, K. C., Fontham, E. T., Etzioni, R., Herzig, A., Michaelson, J. S., Shih, Y. C. T., ... & Wolf, A. M. (2015). Breast cancer screening for women at average risk: 2015 guideline update from the American Cancer Society. *Jama*, *314*(15), 1599-1614.

Parmigiani, G., Berry, D. A., & Aguilar, O. (1998). Determining carrier probabilities for breast cancer-susceptibility genes BRCA1 and BRCA2. *The American Journal of Human Genetics*, *62*(1), 145-158.

Pasacreta, J. V. (1999). Psychosocial issues associated with increased breast and ovarian cancer risk: Findings from focus groups. *Archives of Psychiatric Nursing, 13*(3), 127-136.

Patenaude, Andrea F., Nadine Tung, Paula D. Ryan, Leif W. Ellisen, Larissa Hewitt,

  Katherine A. Schneider, Kenneth P. Tercyak, Julie Aldridge, and Judy E. Garber.

  "Young adult daughters of BRCA1/2 positive mothers: What do they know about

  hereditary cancer and how much do they worry?." *Psycho‐Oncology* 22, no. 9

  (2013): 2024-2031.

Petrucelli, N., Daly, M. B., & Pal, T. (2016). BRCA1-and BRCA2-associated hereditary

  breast and ovarian cancer. *Gene Reviews.* Retrieved from https://www.ncbi.nlm.

  nih.gov/sites/books/NBK1247/

Plevritis, S. K., Munoz, D., Kurian, A. W., Stout, N. K., Alagoz, O., Near, A. M., . . .

  Sprague, B. L. (2018). Association of screening and treatment with breast cancer

  mortality by molecular subtype in U. S. women, 2000-2012. *Journal of the*

  American Medical Association, *319*(2), 154-164.

Rebbeck, T. R., Friebel, T., Lynch, H. T., Neuhausen, S. L., van't Veer, L., Garber, J. E.,

  . . . Daly, M. B. (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.

Rebbeck, T. R., Kauff, N. D., & Domchek, S. M. (2009). Meta-analysis of risk reduction

  estimates associated with risk-reducing salpingo-oophorectomy in BRCA1 or

  BRCA2 mutation carriers. *Journal of the National Cancer Institute*, *101*(2), 80-

  87.

Reichelt, J. G., Heimdal, K., Møller, 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*(1), 21-28.

Reichelt, J. G., Møller, 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*(3), 245-254.

Rimes, K. A., & Salkovskis, P. M. (2002). Prediction of psychological reactions to bone density screening for osteoporosis using a cognitive-behavioral model of health anxiety. *Behaviour research and therapy*, *40*(4), 359-381.

Rimes, K. A., Salkovskis, P. M., Jones, L., & Lucassen, A. M. (2006). Applying a cognitive behavioral model of health anxiety in a cancer genetics service. *Health Psychology*, *25*(2), 171.

Ringwald, J., Wochnowski, C., Bosse, K., Giel, K. E., Schäffeler, N., Zipfel, S., & Teufel, M. (2016). Psychological distress, anxiety, and depression of cancer-affected BRCA1/2 mutation carriers: a systematic review. *Journal of genetic counseling*, *25*(5), 880-891.

Ropka, M. E., Wenzel, J., Phillips, E. K., Siadaty, M., & Philbrick, J. T. (2006). Uptake rates for breast cancer genetic testing: a systematic review. *Cancer Epidemiology and Prevention Biomarkers*, *15*(5), 840-855.

Salkovskis, P. M., Rimes, K. A., Warwick, H. M. C., & Clark, D. M. (2002). The Health Anxiety Inventory: Development and validation of scales for the measurement of health anxiety and hypochondriasis. *Psychological Medicine, 32*(05), 843-853.

Salkovskis, P. M., & Warwick, H. M. C. (2001). Making sense of hypochondriasis: A cognitive theory of health anxiety. In G. Asmundson, S. Taylor, & B. J. Cox (Eds.), *Health anxiety: Clinical and research perspectives on hypochondriasis and related conditions* (pp. 46-64). New York, NY: Wiley.

Samson, M. E., Porter, N. G., Hurley, D. M., Adams, S. A., & Eberth, J. M. (2016).

    Disparities in breast cancer incidence, mortality, and quality of care among

    African American and European American women in South Carolina. *Southern*

    Medical Journal, *109*(1), 24-30.

Sanders, T., Campbell, R., Sharp, D., & Donovan, J. (2003). Risk constructions among

    people who have a first-degree relative with cancer. *Health, Risk, & Society*, *5*(1),

    53-69.

Schwartz, M. D., Lerman, C., Audrain, J., Cella, D., Rimer, B., Stefanek, M., . . . Vogel,

    V. (1998). The impact of a brief problem-solving training intervention for

    relatives of recently diagnosed breast cancer patients. *Annals of Behavioral*

    Medicine, *20*(1), 7-12.

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*(2), 514-520.

Shaw, W. S., Feuerstein, M., Haufler, A. J., Berkowitz, S. M., & Lopez, M. S. (2001).

    Working with low back pain: Problem-solving orientation and function. *Pain*,

    93(2), 129-137.

Smith, A. W., Dougall, A. L., Posluszny, D. M., Somers, T. J., Rubinstein, W. S., &

    Baum, A. (2008). Psychological distress and quality of life associated with

    genetic testing for breast cancer risk. *Psycho-Oncology*, *17*(8), 767-773.

Spector, M., & Kitsuse, J. I. (2001). Constructing Social Problems. New Brunswick.

    Transactions Publisher.

Surveillance, Epidemiology, and End Results (SEER) Program. (2017). Research Data
(1973-2014), National Cancer Institute, DCCPS, Surveillance Research Program,
released April 2017, based on the November 2016 submission. Retrieved from
www.seer.cancer.gov

Suso-Ribera, C., Camacho-Guerrero, L., McCracken, L. M., Maydeu-Olivares, A., &
Gallardo-Pujol, D. (2016). Social problem solving in chronic pain: An integrative
model of coping predicts mental health in chronic pain patients. *Journal of Health
Psychology*, *21*(6), 1015-1025.

Starcevic, V. (2013). Hypochondriasis and health anxiety: conceptual challenges. *The
British Journal of Psychiatry, 202*, 7-8. doi:10.1192/bjp.bp.112.115402

Struewing, J. P., Hartge, P., Wacholder, S., Baker, S. M., Berlin, M., McAdams, M., . . .
Tucker, M. A. (1997). The risk of cancer associated with specific mutations of
BRCA1 and BRCA2 among Ashkenazi Jews. *New England Journal of Medicine*,
336(20), 1401-1408.

Thull, D. L., & Vogel, V. G. (2004). Recognition and management of hereditary breast
cancer syndromes. *The Oncologist*, *9*(1), 13-24.

Tyrer, P., Cooper, S., Salkovskis, P., Tyrer, H., Crawford, M., Byford, S., . . . Murphy, D.
(2014). Clinical and cost-effectiveness of cognitive behaviour therapy for health
anxiety in medical patients: A multicentre randomised controlled trial. *The
Lancet*, *383*(9913), 219-225.

Vitaliano, P. P., Scanlan, J. M., Ochs, H. D., Syrjala, K., Siegler, I. C., & Snyder, E. A.
(1998). Psychosocial stress moderates the relationship of cancer history with
natural killer cell activity. *Annals of Behavioral Medicine*, *20*(3), 199-208.

Warwick, H. M. (1989). A cognitive-behavioural approach to hypochondriasis and health

    anxiety. *Journal of Psychosomatic Research*, *33*(6), 705-711.

Warwick, H. M., & Salkovskis, P. M. (1990). Hypochondriasis. *Behaviour Research and

    Therapy*, *28*(2), 105-117.

Wevers, M. R., Ausems, M. G., Verhoef, S., Bleiker, E. M., Hahn, D. E., Hogervorst, F.

    B., . . . Aaronson, N. K. (2011). Behavioral and psychosocial effects of rapid

    genetic counseling and testing in newly diagnosed breast cancer patients: Design

    of a multicenter randomized clinical trial. *BMC Cancer*, *11*(1), 6.

    doi:10.1186/1471-2407-11-6

Willis, A. M., Smith, S. K., Meiser, B., Ballinger, M. L., Thomas, D. M., & Young, M.

    A. (2017). Sociodemographic, psychosocial and clinical factors associated with

    uptake of genetic counselling for hereditary cancer: a systematic review. *Clinical

    genetics*, *92*(2), 121-133.

Yetter, G., & Foutch, V. (2014). Exploration of the structural and convergent validity of

    the Social Problem-Solving Inventory-Revised with Native American youth.

    Cultural Diversity and Ethnic Minority Psychology, 20(2), 276-282.

Zubin, J., & Spring, B. (1977). Vulnerability: A new view of schizophrenia.

    Journal of Abnormal Psychology, *86*(2), 103-126. doi:10.1037/0021-

    843X.86.2.103

Appendix

Clinical Vignettes

1. You have a family history of Breast Cancer in one of your first-degree relatives (mom or sister). You recently found out that your mother is a carrier of the breast cancer gene. You discuss your concerns with your OB-GYN who suggests that you see a genetic specialist for further testing. The testing will determine if you carry certain genes that increase your chances of getting breast cancer. What is the likelihood that you would receive the genetic testing?

2. In the previous question you indicated you would be "Likely" or "Extremely Likely" to obtain genetic testing. Please read the information below and consider the following scenario: Based on the situation described, if you were found to have the BRCA1 or BRCA2 gene would you elect to have your breasts surgically removed to decrease your chances of getting breast cancer? Breast removal reduces the chance of getting breast cancer by 90-95%.

Endnotes

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[1]SEER (Surveillance, Epidemiology, and End Results Program) 9 Registry: Contains epidemiological information from 1973 and later for Connecticut, Detroit, Hawaii, Iowa, New Mexico, San Francisco-Oakland, and Utah. Seattle-Puget Sound and Atlanta joined Seer in 1974.

[2]SEER 13 Registry: Contains all information included in Seer 9 Registry as well as Los Angeles, San Jose-Monterey, Rural Georgia and the Alaska Native Tumor Registry. Data from 1992 and later is included for these registries. These registries report on expanded race.

[3] Number of New Cases and Deaths Per 100,000 People (All Races, Males and Females), Age-Adjusted

[4]Patients had a family history of breast, ovarian or colon cancer.

[5]Note: Groups were unbalanced, Age: 18-20: 3 subjects; 21-29: 80 subjects; 30-35: 5 subjects