

Fear of Cancer Recurrence in Young Breast Cancer Survivors: Impact on Surveillance Behaviors

by

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Dedicated to Dale, you would have been so proud.

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Abstract

Introduction: Fear of recurrence (FOR) has been studied in various populations of patients with cancer e.g. colon, prostate, and breast. Breast cancer survivors are often faced with the lingering fear that the cancer may reoccur. It is estimated over 232,000 women diagnosed with breast cancer in 2014 FOR has the possibility to impact the lives of thousands of women. Yet, little is known about FOR in women diagnosed with breast cancer at a young age and are young breast cancer survivors (YBCS). These cancer survivors need additional support, as the probability they will develop another cancer is high.

Purpose: The purposes of this study were to 1) describe FOR in a large, statewide sample of YBCS 2) to explore predictors of FOR and 3) to determine if FOR is a mediator for breast cancer surveillance, namely mammograms and clinical breast exams (CBE).

Methods: This secondary data analysis examines baseline data collected for an efficacy trial, aiming to increase breast cancer surveillance and use of cancer genetic services among YBCS and their high risk family members. Fear of recurrence was examined in 863 YBCS identified and recruited through the Michigan cancer registry. Participants completed a survey including instruments that measured FOR, quality of life (mental and physical), self-efficacy in managing breast cancer, perceived breast cancer risk, knowledge of breast cancer risk factors, family support, and current breast cancer surveillance practices.

Findings: Results of this study suggest predictors of FOR in young breast cancer survivors include African American race, lower level of education, belief that cancer

development is by chance, and increased level of anxiety. The strongest predictor of FOR was low level of self-efficacy in managing breast cancer. Being negative for the *BRCA1* genetic marker was found not to be associated with FOR in this population. FOR did not mediate surveillance mammograms or clinical breast exams.

Conclusion: Knowing what predicts young breast cancer survivors to experience FOR is important in lessening FOR. Employing screening measures to determine patients at risk for experiencing FOR may lessen this problem

Chapter 1

Introduction

The statistics regarding breast cancer occurrence, survival, and death are alarming. The American Cancer Society estimates 232,670 women will be diagnosed with breast cancer and 40,000 women will die of breast cancer in 2014 (American Cancer Society, 2014). The overall five year survival rate for breast cancer patients is 89.2% (Howlander et al., 2013). Currently, about 1 in 4 cancer survivors in the United States is a breast cancer survivor (Rowland & Bellizzi, 2008). Given these overwhelming figures it is important to understand what women with breast cancer find most problematic. Fear of recurrence (FOR) is often at the top of the list. Lebel, Rosberger, Edgar, & Devins (2007) revealed of the four most common stressors breast cancer survivors face, FOR was deemed the most stressful. FOR has been identified as an unmet need among cancer survivors and their families (Baker, Denniston, Smith, & West, 2005; Lebel, Tomei, Feldstain, Beattie, & McCallum, 2013; Mellon & Northouse, 2001; Turner et al., 2013).

While older studies have reported FOR as a concern in 89-94% of women with breast cancer (Polinsky, 1994), the research in this literature review report FOR an issue for 39%-70% of women studied (Baker et al., 2005; Befort & Klemp, 2011; Cappiello, Cunningham, Knobf, & Erdos, 2007; McGinty et al., 2012; Stanton, Ganz, Rowland, Meyerowitz, Krupnick, & Sears, 2005; Stephens, Osowski, Fidale, & Spagnoli, 2008; Thewes et al., 2012; van den Beuken-van Everdingen et al., 2008).

Definition of Fear of Recurrence

FOR has been defined as fear of breast cancer coming back in the same breast or another area of the body, or a new breast cancer in either breast (Johnson Vickberg, 2003). Although the exact makeup of FOR is unknown, it has been suggested that it is a combination of emotion (fear) and cognition (threat), that is generated by internal (somatic) and external (e.g. conversations regarding cancer) cues (Custers et al., 2013). FOR is multi-dimensional, encompassing emotional, physical, and spiritual realms of one's life (Cannon, Darrington, Reed & Loberiza, 2011; Johnson Vickberg, 2003; Simard, Savard, & Ivers, 2010). A systematic review reported that FOR was associated with poor quality of life (Sammarco & Konecny, 2008; van den Beuken-van Everdingen et al., 2008), decreased emotional wellbeing, increased anxiety, fatigue, and physical symptoms (Koch, Jansen, Brenner, & Arndt, 2012). FOR has also been shown to be a barrier to follow up care and surveillance (Thompson, Littles, Jacob, & Coker, 2006). Research has shown women with breast cancer adjust well physically to living with the disease (Stephens et al., 2008) but FOR can last for decades beyond the original diagnosis (Hodgkinson et al., 2007; Johnson Vickberg, 2003; Lebel et al., 2007; Ness et al., 2013).

Purpose/Specific Aims

The purpose of this study, was 1) describe FOR in a large, statewide sample of YBCS to investigate what factors predict FOR in YBCS, 2) to determine who is at greatest risk of experiencing FOR, and 3) to determine if FOR has a mediating effect for breast cancer surveillance, namely mammograms and clinical breast exams (CBE) use. It is hypothesized that FOR has a mediating effect on breast cancer surveillance.

Chapter 2

Theoretical Framework and Literature Review

The Stress and Coping Theory (Lazarus & Folkman, 1984) was used as a theoretical model to guide this study and to organize findings from the literature into meaningful categories. Stress is defined as situations which exceed the person's ability to cope (Lazarus & Folkman, 1984). Coping is defined by Lazarus and Folkman (1984) as thoughts and behaviors that people use to manage stressors. The Stress and Coping Theory posits that when faced with a stressor, e.g. disease, cognitive appraisal is used to determine if it is a threat to one's well-being. If the person feels this threat is manageable problem-focused coping is used. This may include information seeking, information sharing, and disease surveillance. Conversely if the treat is perceived as beyond one's ability to cope, emotion-focused coping may be used. This may include avoidance and lead to a lack of follow-up and surveillance (Lazarus & Folkman, 1984). For this patient population stressors included triggers, symptoms, perceived risk, and a second cancer diagnosis. All demographic information was categorized as antecedents. Factors that were included as coping resources were spirituality, religion, self-efficacy, and family support. A diagrammatic representation of the conceptual framework is found in Figure 1.

The method used to identify articles for this literature review included a keyword search, a forward citation search and a backward citation search. Searches were conducted using three electronic databases, CINAHL, MEDLINE, and PsychINFO, limiting the dates of publication between 2000-2013. Search terms included: breast cancer survivor, fear of recurrence, fear of cancer recurrence, worry about recurrence, and concern about recurrence. Articles were further

restricted to English language, female breast cancer patient, and presentation of empirical findings; qualitative or quantitative reports of data. This resulted in numerous articles and all duplicates were excluded. This review covers 57 articles found to meet the above criteria as diagrammed in Figure 2.

Factors Associated with FOR

Demographics

Multiple studies have examined the relationship between patients' demographic characteristics and level of FOR (Bower et al., 2005; Costanzo et al., 2007; Crane-Okada et al., 2012; Komblith et al., 2007; Lebel et al., 2013; Mellon, Kershaw, Northouse, & Freeman-Gibb, 2007; Johnson Vickberg, 2003; Mc Ginty et al., 2012; van den Beuken-van Everdingen et al., 2008; Ziner et al., 2012).. Younger age, most often defined as age 50 and younger, was associated with greater FOR in all studies included in this review. A number of reasons have been postulated, including younger age is associated with higher levels of distress (Costanzo et al. 2007), younger survivors have less adaptation skills than older survivors (Komblith et al., 2007), more aggressive breast cancers occur in younger women which leads to more aggressive treatment regimens (van den Beuken-van Everdingen et al., 2008), and breast cancer in this age group is "unexpected or off schedule" (Johnson Vickberg, 2003, p. 22). Costanzo et al. (2007) suggested that younger women may experience greater FOR since they have not considered themselves at risk for developing a life threatening illness or have not had peers with serious health issues. This explanation was also corroborated by research by Komblith et al. (2007) who found that younger women experienced greater FOR and attributed it to having less coping skills related to illness and the possibility of death. FOR also has been found to impact treatment

decision making. Young women with breast cancer were found to overestimate their risk of developing cancer in the other breast and chose bilateral mastectomy. The researchers explained that although the women understood removing the unaffected breast did not increase survival FOR impacted their decision (Rosenberg, et al. 2013).

Older survivors have fears of their cancer returning, but research has shown these fears were less bothersome when compared to the fears of younger breast cancer survivors (Yoo Levine, Aviv, Ewing, & Au, 2010). Yoo and colleagues (2010) found older breast cancer survivors to be worried more about dependence on others than FOR. Mellon et al., (2007) found age at time of diagnosis to impact both the cancer survivor and the caregiver, but in an opposite direction. Survivors with younger caregivers were found to have greater FOR and caregivers with younger survivors had greater FOR (Mellon et al., 2007). FOR also influenced surveillance behavior; younger survivors were also seen to become hyper-vigilant in self-assessment, have more physician office or clinic visits, and use more healthcare resources than older survivors (Thewes et al., 2012).

Ethnicity and Race

According to the American Cancer Society (2014) fewer African American women develop breast cancer compared to Caucasian women; however, African American women are more likely to die from breast cancer than their Caucasian counterparts. Reasons for this disparity include African American women are often diagnosed at a later stage of cancer when it is less likely to respond to treatment and they often have greater co-morbidities. Other variables for this disparity include less access to medical care and less cultural and social support (Bibb,

2001). The difference in incidence of breast cancer among the races has led to studies to determine how FOR impacts women of different races and ethnicities.

Ethnicity and race have also been studied and were linked to FOR in breast cancer survivors. Researchers have compared the level of FOR reported by Caucasian women and women from other races or ethnicities. (Befort & Klemp, 2011; Deimling, Bowman, Sterns, Wagner, & Kahana, 2006; Gil et al., 2004; Janz et al., 2011; Johnson Vickberg, 2001; Katz et al., 2010; Kelly, Shedlosky-Shoemaker, Porter, Desimone, and Andrykowski, 2011; Russell, Von Ah, Gielser, Storniolo, & Haase, 2008). They found that Caucasian women reported more FOR than their African American counterparts. However, two studies including primarily African American women reported conflicting findings. Deimling et al. (2006) and Russell et al. (2008) found that African American breast cancer survivors reported less FOR and less cancer worries.

While reporting less FOR may be seen as a positive aspect, Deimling and colleagues (2006) suggest that survivors who experience less concern for developing a second cancer may be less diligent in self-monitoring or participating in follow up surveillance. African American women were also found to have less perceived risk of recurrence when compared to Caucasian women and this perception may lead to less follow up surveillance (Liu et al., 2011). An exploratory qualitative study of African American women showed FOR can be either a facilitator or a barrier to seeking follow up care (Thompson et al., 2006). For some women, FOR motivated them to participate in follow up care in order to be observant for symptoms of recurrent disease. Conversely, other women in the same study found FOR to be a barrier to follow up care as they were afraid of the possibility of another cancer diagnosis (Thompson et al., 2006).

Studies of Latina breast cancer survivors have also examined their experience with FOR (Janz, 2011; Sammaro & Konecny, 2008). Janz and colleagues (2011) studied African American, Caucasian, and Latina women and found significant differences. Forty six percent of low acculturated Latinas reported the highest level of FOR, compared with 25% of high acculturated Latinas, 14% of Caucasians, and 13% of African American survivors (Janz et al., 2011). Janz and colleagues (2011) believed these differences in FOR to be related to difficulty in communication, ease of understanding information, and coordination of care programs. A study of women living in the Appalachian region of the United States found these women also report high levels of FOR. This was thought to be secondary to lack of health education resources and health care facilities (Kelly, et al. 2011). Johnson Vickberg (2003) suggests that Latina women may perceive recurrence as more severe and may have increased worry about the end result of a recurrent tumor and subsequent treatment. Understanding the difference in FOR experiences among women of different races and ethnicities helps to build a foundation for culturally competent care.

Education Level

The education level of breast cancer survivors has also been studied to determine if there is an impact on the level of FOR. The findings have been mixed. In a study of 203 breast cancer survivors, Clayton and colleagues found education to be inversely related to FOR; lower educated women had higher levels of FOR (Clayton, Mishel, & Belyea, 2006). The authors suggest women with higher education may be better equipped to sort out the facts versus the myths regarding breast cancer recurrence (Clayton et al., 2006). This finding was corroborated by research done by Ashing-Giwa and colleagues (2011) who found women with less education to have greater FOR. Janz and colleagues (2011) studied 2290 women and found similar results;

an inverse relationship between education and FOR. Conversely, Costanzo et al. (2007) found women who had more than 12 years of education but less than a college degree had the highest levels of FOR. The authors postulate that perhaps women who have higher level of education are better able to utilize medical information or communicate better with healthcare practitioners, although it was unclear why women with less education have overall less FOR (Costanzo et al. 2007). Finally, a study of 136 women, reported that their higher education level was associated with increased health and role worries due to an increase in triggers of FOR (van den Beuken-van Everdingen, et al., 2008).

Urban versus Rural Dwelling Women

Women of geographically identified groups have also been studied. Rural women make up one of the largest medically underserved groups in the United States (Befort & Klemp, 2011). However, insufficient research has been done regarding their needs compared to urban women (Katz et al., 2010). The Appalachian women of Ohio (Katz et al., 2010) and women living in rural areas of Kansas (Befort & Klemp, 2011) were studied to determine how FOR impacts their breast cancer survivorship. Katz and colleagues (2010) found that Appalachian Ohio breast cancer survivors had less overall concerns than their urban counterparts; however the most common worry of both the urban and rural women was FOR. Beyond FOR, the concerns of rural women centered on difficulty finding and understanding cancer related information. These women also reported more concerns with paying medical bills, health insurance issues, and the need for support groups than their urban counterparts (Katz et al., 2010). The concerns of urban women that were not seen in the rural population were related to diet and herbal supplements and relaxation techniques (Katz et al., 2010).

In order to determine if the psychosocial needs of rural breast cancer survivors differed from their urban counterparts, Befort and Klemp (2011) studied breast cancer survivors in Kansas. The women were separated into categories based on the geographic location where they lived. The authors found 68% of women who were premenopausal at time of diagnosis were troubled with FOR compared to 47% of women who were postmenopausal at diagnosis (Befort & Klemp, 2011). This is in-keeping with other studies which found women of younger age more bothered with FOR (Costanzo et al., 2007; Crane-Okada et al. 2012; Komblith et al., 2007; Johnson Vickberg, 2003; Lebel et al., 2013; Mellon et al., 2007; Mc Ginty et al., 2012; van den Beuken-van Everdingen et al., 2008; Ziner et al., 2012). This also supports other studies which have shown that women who live in rural areas are more prone to FOR because these women often have greater numbers of mastectomies and adjuvant chemotherapy, both have been shown to increase rates of FOR (Constanso et al., 2007). Also women in rural areas have less social support which also leads to greater FOR (Bettencourt, Schlegel, Talley, & Molix, 2007).

Treatment type and FOR

The type of treatment received has also been examined to determine its effect on a survivor's FOR. The severity of the disease was not found to be correlated with the amount of worry experienced by 406 breast cancer survivors (Mathews, Ridgeway, Warren, & Britton, 2002). However, type of surgery was associated with FOR. Women with a mastectomy were found to have less FOR than women who elected to have lumpectomy (Costanzo et al., 2007; Janz et al., 2005), possibly because survivors who had a mastectomy thought that more extensive surgery would get rid of the cancer (Costanzo et al., 2007). Women whose cancer was diagnosed as ductal carcinoma in-situ (DCIS) were found to overestimate their risk of recurrence (Liu, et al. 2010). This confusion was thought to be due to the similarity of treatment methodology for

DCIS and stage I breast cancer (Liu, et al., 2010). Survivors also reported FOR related to the chemotherapy and/or radiation treatments causing a second cancer (Deimling, et al., 2006).

Some research indicates that FOR is higher in women who have had chemotherapy (Costanzo et al., 2007; Janz et al., 2005; Johnson Vickberg, 2003). Johnson Vickberg (2001) found survivors who had previous chemotherapy feared the need for future chemotherapy as much as death. Costanzo et al. (2007) contends that this fear may be due to the side effects associated with chemotherapy and the fact that women who undergo chemotherapy may have more severe disease. This finding was especially true among young cancer survivors who commonly have more aggressive cancer requiring more aggressive treatment. The stage of the disease was not seen as contributing to FOR (Taylor et al., 2012; Thewes, Bell, & Butow, 2013; Johnson Vickberg, 2003). According to Johnson Vickberg (2003) FOR is influenced by factors beyond the stage of the disease, but more research is needed to discern what those factors may be.

Radiation therapy was also found to be a variable in FOR experience of breast cancer survivors (Janz et al., 2011; Liu, et al. 2010). Women who received radiation therapy following breast conserving surgery were found to underestimate their risk of recurrence (Liu et al., 2010). The authors surmised this may be due to the fact the women believed they had less severe disease and therefore were at lower chance for recurrence (Liu et al., 2010).

Time Since Diagnosis

The time since diagnosis and the level of FOR was studied and the findings are contradictory. Gil and colleagues (2004) and van den Beuken-vanEverdingen and colleagues (2008) found that time since diagnosis had no bearing on FOR. In contrast, Deimling et al. (2006) in a study of breast cancer survivors greater than 50 years old and more than 5 years since original diagnosis found as time from diagnosis increases the level of FOR decreases.

Triggers of FOR

FOR is often triggered by internal or external cues. In regard to internal cues, three studies reported that physical symptoms trigger increased FOR. For example, physical symptoms such as joint stiffness, pain, and fatigue were found to bring about intrusive thoughts of fear the cancer had returned (Clayton et al., 2006; Gil et al., 2004; Johnson Vickberg, 2001). However, physical symptoms such as numbness and tingling were not related to higher levels of FOR in a large study conducted by Ziner and colleagues (2012). Educating women to differentiate between everyday aches and pains from those symptomatic of breast cancer recurrence would be helpful to decrease FOR (Corder, Findlay, Broom, & Petrie, 2013).

There are also external cues that can trigger FOR. Among the external cue reported in the literature that can increase FOR are follow up doctor appointments (Johnson Vickberg, 2001, Mathews, et al., 2002), repeated blood work and mammograms (Ziner et al., 2012), and planning future oriented activities (Johnson Vickberg, 2001). In addition, hearing of someone else being diagnosed with cancer or recurrent disease was found to be a trigger of FOR (Gil et al., (2004); Johnson Vickberg, (2001). In contrast however, Ziner and colleagues (2012) did not find knowing someone with cancer to be a trigger of FOR when assessed in their large study (N=

1,228 women). This study was primarily of younger women who may not know someone else with breast cancer.

Religion and Spirituality

Spirituality and religion have an impact on the concerns about cancer recurrence. A study of 551 predominately Caucasian survivors reported that 59% of the participants had FOR; however, those survivors who deemed themselves as highly spiritual had less FOR over the cancer trajectory (Cannon et al., 2011). Similarly, in an exploratory study with 130 breast cancer survivors, Schreiber (2011) found that belief in God's presence in one's life was associated with lower FOR. Coping via religion was also found to reduce FOR in a longitudinal study of 80 breast cancer survivors (Stanton, Danoff-Burg, & Huggins, 2002). Following the teachings of the Islamic faith, Iranian women believe that cancer is the will of God (Fasishi Harandy et al, 2010). Although they readily accept this as part of their religious beliefs, their faith was found to help them accept their diagnosis and hope for a cure (Fasishi Harandy et al., 2010). These women relied on prayer to help combat FOR. A study of African American women found they turned to the use of prayer to help them cope with the FOR (Thompson et al., 2006). This finding was also seen in a study by Ashing-Giwa (2004) which revealed African American women relied on their religious beliefs to help them deal with their FOR.

FOR and the Family

The survivor is not the only person for whom FOR is an issue. Several studies have been done which show FOR is an issue for family members and caregivers as well (Kim, Carver, Spillers, Love-Ghaffari, & Kaw, 2012; Mellon et al., 2007; Mellon & Northouse, 2001). Cancer severity and caregiver FOR was found to be highly correlated. Kim et al., (2012) found

caregivers experienced greater FOR than the survivors as long as 2 years post diagnosis and that the caregiver's FOR was directly related to the survivor's physical health. In a study of 246 pairs consisting of a survivor and a family caregiver, Mellon and colleagues (2007) found a relationship between the level of family stressors and meaning of illness impacted FOR. Those families who reported high family stress and less meaning of illness were found to have higher levels of FOR. It is important to note that in this study, family members reported greater FOR than did the survivors (Mellon, et al., 2007). Mellon and Northouse (2001) found family FOR directly impacted family quality of life and that survivor FOR affected family members meaning of the illness (appraisal as the illness as threatening). This study looked at the relationship between the dyad of the survivor and the family member. Each individual person's perception of the meaning of the illness rather than that of the partner (survivor or family) had more influence on FOR. As one member's FOR increased so did the other's (Mellon & Northouse, 2001).

Conclusion

Since FOR has such a large and potentially devastating impact on breast cancer survivors it is imperative that healthcare practitioners do an assessment to screen a woman to predict her risk for FOR. The literature is replete with studies of women of various ages and their experiences with FOR but little is known regarding what predicts FOR in young breast cancer survivors. Knowing what factors predict a young woman to be at risk for fear of recurrence is an important first step in understanding how healthcare practitioners can work with their patients to help them overcome the fear associated with their diagnosis.

Chapter 3

Methods

To examine the reported level of FOR in young breast cancer survivors (YBCS) and impact on breast cancer surveillance, a secondary analysis of data gathered from an earlier study was used. In the parent study the Michigan Cancer Surveillance Program database was queried to recruit YBCS and their high risk female relative in an efficacy trial (Katapodi, et al., 2013). The Michigan Cancer Surveillance Program was enacted by law in 1984 to be a repository for reporting cases of *in situ* and invasive cancers in Michigan residents (Michigan Department of Community Health, 1978).

Participants

A sample of 3,000 YBCS, stratified by race (Black vs. White/Other) was randomly selected from the Michigan Cancer Registry and was sent up to three invitation letters and the baseline survey (Katapodi et al. 2013). The 859 YBCS of this study (response rate approximately 33%) met the eligibility criteria of the parent study, which included being female between the ages of 25-64, and diagnosed with unilateral or bilateral invasive breast cancer between the ages of 20 and 45 years old. Participants also had to be a Michigan resident at the time of diagnosis, be able to read and understand English, and not be currently pregnant, incarcerated, or institutionalized (Katapodi, et al. 2013). For further details about study selection and recruitment methods see Katapodi et al. 2013.

All data for this secondary data analysis were de-identified to ensure anonymity of study participants. The secondary data analysis protocol was reviewed by the University of Michigan Institutional Review Board and an exempt status was awarded.

Instrument

A survey with multiple instruments was used to collect participants' responses in the parent study. The data used for this secondary data analysis focused on responses relevant to YBCS FOR, quality of life (QOL), self-efficacy to manage breast cancer, family support, and breast cancer surveillance practices.

Four items from the Concerns About Recurrence Scale (CARS) were used to measure FOR. The CARS was developed specifically to measure FOR in breast cancer survivors and has been found to have high internal consistency with a reported Cronbach's alpha 0.87 (Johnson Vickberg, 2003). It has also been found to have good construct validity (van den Beuken-van Everdingen et al. 2008). The four questions utilized a 7-point Likert scale to assess the amount of time spent thinking about the cancer coming back, how often participants worry about the cancer coming back, how much does thinking that breast cancer may come back upsets participants, and how afraid they are that their cancer may come back. See Table 3.1.

An updated version of the Breast Cancer Risk Factor Knowledge Index (Katapodi & Aouizerat, 2005) was used to measure participants' knowledge of the risk factors associated with breast cancer. This instrument has been used previously and had high internal consistency with Chronbach's alpha .80 (Katapodi & Aouizerat, 2005). The updated version of the index includes 17 items that assess women's knowledge of breast cancer risk factors; possible answers include true, false, or don't know. See Table 3.2.

Barriers and facilitators to mammography screening were assessed with the Decisional Balance Scale for Mammography (Rakowski et al., 1997). The instrument has been used to predict mammogram use and measures the pros and cons of having a mammogram. See Table 3.3.

Family support for breast cancer screening was measured using the Social Support for Breast Cancer Screening instrument. This tool uses a 7 point Likert scale (1=never true, 7=always true) to assess how the participant views the helpfulness of the people in her family relative to being overall supportive and family support in illness (Katapodi, Facione, Miaskowski, Dodd, & Waters, 2002). See Table 3.4.

Participants' self-efficacy to manage breast cancer was assessed on a 7-point Likert scale with 14 items developed for the parent study See Table 3.5.

Quality of life (QOL) was measured with SF-12 which measures physical component summary (PCS) and mental component summary (MCS). The psychometric properties have been determined previously with reliability Cronbach co-efficient alpha 0.89 for PCS and 0.76 for MCS (Ware, Kosinski, & Keller, 1996). See Table 3.6.

Perceived risk was measured by asking one question which asked what they believed was their chance of getting another cancer. Women answered the question on a 10 point Likert scale from 0=Definitely will not to 10=Definitely will (Katapodi, et al. 2011, Katapodi, Dodd, Lee, & Facione, 2009).

Demographic data were collected regarding personal information and health history. Items included age, ethnicity, race, type of cancer diagnosis, type of cancer treatment, level of education, health insurance status, and employment status.

Statistical analyses

Analyses were run using Statistical Package for Social Sciences (SPSS) version 21. Descriptive statistics were done to organize the demographic data into meaningful groups. Frequency statistics were done to determine the distribution of scores for reported level of fear of recurrence. Pearson's product moment correlations were done to examine associations between the dependent variables of FOR, frequency of CBE, and frequency of mammography, and the independent variables of age, race, education, income, insurance status, routine source of care, lack of access to care due to cost, years since diagnosis, perceived risk, self-efficacy, family support, family support in illness, confidence in CBE, confidence in mammogram, and QOL.

Multiple regression analyses explored predictors of FOR and whether FOR is a mediator for frequency of CBE and frequency of mammography. See Figure 3. Variables which act as mediators provide additional information regarding how two variables are strongly associated (Bennett, 2000). In this study it was important to understand if FOR mediated surveillance use of mammogram or CBE. In order to test this step-wise regression was used.

Chapter 4

Findings

The study population was made up of 859 female breast cancer survivors aged 45-57 (mean age 51 ±6). Time since diagnosis ranged from seven to 15 years (mean time since diagnosis 11±4).

The racial make-up of the participants was categorized as white/other or black. This is in keeping with the method of data stratification in the parent study. Overall the greatest number of participants self-identified as white N=488 with 24 participants reporting as other e.g. American Indian, Arab-American, Asian. There were 313 participants who self-identified as black. The racial information of the study population is found in Table 4.1.

The current marital status for the white/other population was predominately married (n=376, 72.7%), whereas the black participants were less likely to be married (n=112, 33.1%) $X^2(4, n = 854) = 165.29, p < .000$. A complete breakdown of marital status data is found in Table 4.1.

The majority of study participants were employed full time, white/other n=274 (55.1%), black n=150 (45.5%). The most common job description was executive, managerial, or professional, whites/other n=194 (39.8%), blacks n=94 (30.1%). A large disparity was noted in income with the largest number of whites/others earning \$120,000 or greater (n=94, 18.5%) compared to Blacks (n= 20, 6.1%) whereas the greatest number of blacks (n=90, 27.4%) reported earning less than \$20,000. Complete data is found in Table 4.1.

The highest level of education was similar for all participants. The white/other participants n=197 (38.4%) attended college but did not obtain a degree. Similarly, 125 (37.2%) of black participants also attended college but did not obtain a degree. A difference was seen in the participants who completed college, whites/others n= 130 (25%) compared to black n= 60 (17%). Both categories of study participants had 2 members who attended school only through the eighth grade, white/other n=2 (0.4%), black n=2 (0.6%). The educational information for the complete study population is found in Table 4.2.

The type of cancer the participants (N=816) reported was nearly evenly distributed. Invasive carcinoma was reported by 56.4% of the participants and ductal carcinoma *in situ* (DCIS) was reported by 53.3% of the participants. Further analysis by racial groups found white/other reported invasive breast cancer n=278 (54.6%) and n=299 (58.7%) reported DCIS; blacks reported n=182 (59.3%) invasive breast cancer and n=136 (44.3%) reported DCIS.

The most commonly reported type of surgery was lumpectomy, N=335 (39%), with white/other reporting n=197 (38%), and blacks n=138 (40.6%). The next most common reported surgical treatment was single mastectomy N=219 (25.5%), with white/other reporting n=128 (24.7%), and blacks n=91 (26.8%). The totals of types of cancer diagnosis and types of surgical treatment percentages exceed 100%, because many YBCS had more than one surgery. All cancer types and surgical treatments are listed in Table 4.3

Distribution of FOR Scores

The FOR scores were measured on a Likert scale from 1 to 7. In this sample of YBCS, the mean score of FOR was 3.46 ± 1.77 . One half of the participants' reported FOR score was

below the midpoint (median score 3.25) indicating that as a whole this group was not very fearful of cancer recurring. Distribution scores are shown in Table 4.4

Correlations

The relationship between average FOR and the independent variables was investigated using Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. There were small negative correlations seen among FOR and age, education, income, lack of access to care due to cost, lack of routine source of care, years since diagnosis, family support, and family support in illness, and depression. The strongest negative correlation was found between FOR and self-efficacy to manage breast cancer. A medium positive correlation was seen between FOR and perceived risk. The results are displayed in Table 4.5.

Regression Analyses

The ability of the variables of race, education, income, marital status, insurance status, cost, years since diagnosis, perceived risk, depression, anxiety, self-efficacy, family support, family support in illness, and *BRCA1* genetic status to predict FOR in YBCS was examined using linear multiple regression. The overall model explained 35% of the variance in FOR ($F [25, 561] = 12.10, p < .001; R = .59, \text{Adj } R^2 .35$). Six variables were statistically significant predictors of FOR: self-efficacy to manage breast cancer ($b = -.256, p < .001$), perceived risk ($b = .241, p < .001$), *BRCA1* negative status ($b = -.158, p < .001$), anxiety ($b = .144, p < .001$), race ($b = .139, p < .001$), and education ($b = -.081, p < .05$). Results are displayed in Tables 4.6 and 4.7. Self-efficacy to manage breast cancer was the strongest predictor of FOR in this population.

In order to examine results for a possible mediation effect of FOR and surveillance mammogram and CBE use the frequency of these exams and correlation results were reviewed. The reported frequency of surveillance mammograms and CBE for this study sample demonstrated the majority of women received mammograms and CBE every 12 months, with more women receiving CBE than mammograms. See Table 4.8. Since there was no correlation between FOR and frequency of mammography ($r = .027, p = .444$), a mediation between FOR and frequency of mammography was not possible. However, because there was a correlation between FOR and frequency of CBE ($r = .104, p = .003$), a stepwise regression analysis was done to test if FOR mediated frequency of CBE. In the first step all independent variables were entered into the model, while FOR was entered in the second step. The initial step explained 18% of the variance in the frequency of CBE ($F [27, 509] = 4.21, p < .001; R = .438, R^2 18\%$). A small mediation effect with a 1% difference from the first step was seen in step 2 ($F [28, 508] = 4.34, p < .001; R = .440, R^2 19\%$). See Table 4.9. Significant predictors of frequency of CBE were insurance status ($b = .117, p < .05$), access to routine source of care ($b = .109, p < .05$), and intention to have CBE ($b = .088, p < .05$). See Table 4.10.

Chapter 5

Discussion

Breast cancer will be diagnosed in over 200,000 women in the United States this year and FOR will be an issue for many. This study set out to investigate what factors predict FOR in YBCS, determine who is at greatest risk for experiencing FOR, and also to determine if FOR has a mediating effect for breast cancer surveillance mammograms and CBE.

Being able to identify predictors of FOR in YBCS will be important to aid healthcare practitioners to recognize who is at risk for increased fears and possible decreased quality of life. Aim one of the study sought investigate factors which predict FOR in YBCS. These factors will be discussed below.

Results of this study found younger age was associated with increased FOR. The inverse relationship between younger age and increased level of FOR seen in this study is in-keeping with results of previous studies (Costanzo et al., 2007, Johnson Vickberg, 2003, Komblith et al., 2007; van den Beuken-van Everdingen et al., 2008). Stanton and colleagues (2002) suggest the increase in FOR in YBCS could be related to competing role responsibilities and the unexpected diagnosis in young women. Younger women often have more aggressive types of breast cancer which has been postulated to increase FOR (van den Beuken-van Everdingen et al., 2008). This study did not collect the type or stage of cancer in the participants so this association could not be studied.

Black women reported more FOR than white/others in this study. This differs from other studies which have reported African American women have less FOR than Caucasians (Befort and Klemp, 2011; Deimling et al., 2006, Gil et al. 2004; Janz et al., 2011; Johnson Vickberg, 2001; Katz et al., 2010; Kelly, Shedlosky-Shoemaker, Porter, Desimone, & Andrykowski, 2011; Russell, Von Ah, Gielser, Storniolo, & Haase, 2008). Two variables which may explain this finding are; this study was specific to YBCS whereas the reports in the literature were not, and also women in this study were on average 11 years post diagnosis it may be possible that the reported level of FOR in some women was decreased.

Lower level of education was associated with FOR in this study population. More women in this study had some college education but no degree, however, this level of education did not lessen their FOR. Research has shown this result to be consistent. Costanzo, et al., (2007) found women with greater than 12 years of education but without a degree had higher levels of FOR. Also women with this particular level of education may be more susceptible to triggers of FOR (van den Beuken-van Everdingen et al., 2008). Previous research by Clayton, Mishel, and Belyea (2006), Ashing-Giwa et al., (2011) and Janz et al., (2011) all found lower educated women had higher levels of FOR. Although it is unknown why this may be true for this population of women, the suggestion by Clayton et al., (2006) that women with higher education maybe better equipped to sort out the facts versus myths regarding breast cancer recurrence may have merit.

The results of this study found a diverging relationship between time from diagnosis and FOR. The less time from diagnosis the greater FOR reported. The women in this study population had been diagnosed as long as 15 years (mean years 11 ± 4) prior to completing the survey. It is possible that this length of time had a bearing on the results. As seen in research by

Deimling et al., (2006) once women reach five years from time of diagnosis FOR decreases. This is not entirely surprising as research has shown the definite risk of cancer recurrence decreases with time (American Cancer Society, 2014; Johnson Vickberg, 2003). This finding is contrary to the research by Gil et al. (2004) and van den Beuken-van Everdingen et al. (2008) which found time since diagnosis had no bearing on FOR. The women in Gil et al. (2004) had a mean age of 64 and were 5-9 years post diagnosis while the women in van den Beuken-vanEverdingen et al. (2008) study were greater than 60 years old and had a mean years since diagnosis of 10 years. The participants in both of these studies were older women compared to the women in the current and the mean time since diagnosis was less than in the current study which may have impacted the results.

Family support has been studied and has been shown to be very effective in helping both the cancer survivor and the family member to adapt to the stressors of the disease (Kim, Carver, Spillers, Love-Ghaffari, & Kaw, 2012; Mellon et al., 2007; Mellon and Northouse, 2001). Women in this study report not only low levels of overall family support in general but low levels of family support in illness. Lack of family support may impact FOR for these women because without family support, family stressors increase and family QOL decreases (Mellon, et al., 2007). It is unknown why these women had such low reported levels of family support. This is an area that needs to be addressed early in the disease processes in order to assess and provide appropriate social support to both patient and family members.

The results of this study found the greatest predictor of FOR in YBCS was the reported low degree of self-efficacy in managing breast cancer. According to Melchior, Buscher, Thorenz, Grochocka, Koch, & Watzke (2013) perceived self-efficacy has a large impact on one's ability to cope with cancer because of its role in regulating one's cognitions, behavior, and

coping strategies. Further research by Kretitler, Peleg, Ehrenfeld (2007), Rottmann, Dalton, Christensen, Freideriksen, and Johnansen, (2010), and Luszczynska, Mohamed, and Schwarzer (2005) further supports this as their research found self-efficacy to be essential to coping with cancer. Breast cancer self-efficacy may provide a protective effect for young breast cancer survivors who have high perceived risk of recurrence (Ziner et al., 2012.) For the results of this study, the lack of self-efficacy to manage breast cancer can be tied to a lack of coping mechanisms which leads to an increase in FOR. As seen in the conceptual model (Figure 1) secondary appraisal leads to ability to cope. If one cannot cope due to lack of self-efficacy in managing breast cancer one may not proceed with necessary medical care requirements e.g. mammograms or CBE. The lack of self-efficacy in managing breast cancer reported in this study population puts these participants at risk for increase FOR and lack of medical follow up.

Women who reported a high level of perceived risk of developing breast cancer were found to also have increased reported FOR. Perceived risk can be equated with threat appraisal. This finding was also noted in research by McGinty, Goldenberg, and Jacobsen (2012) who found women who had elevated threat appraisal and low coping appraisal experienced higher level of FOR. Coping appraisal was not measured in the current study. McGinty, Goldenberg, and Jacobsen (2012) posit that the interaction between threat and coping appraisal predicts FOR. This interaction between threat and coping is in agreement with Lazarus Theory of Stress and Coping (1984) which guided this study.

BRCA1 status was found to be a variable which predicted FOR in this study sample. Participants who were negative for the *BRCA1* mutation reported less FOR than their counterparts. This result is consistent with prior research which found women who were positive for the *BRCA1* genetic mutation reported high levels of FOR and sought aggressive surgical

treatment including prophylactic mastectomy (Graeser, et al. 2009; Meltcalfe et al, 2011; Hawley, et al. 2014). Hawley and colleagues (2014) studied 2290 women newly diagnosed with breast cancer and the extent of worry they experienced at time of treatment decision making. Nearly 20% of the women who were positive for the *BRCA1* genetic mutation considered contralateral prophylactic mastectomy. This treatment decision was found to be significantly associated with greater reported FOR although the procedure is not shown to decrease the risk of recurrence (Hawley, et al. 2014). It is not known if women in the current study chose prophylactic mastectomy as a treatment option.

Aim two of the study was to determine who is at greatest risk of experiencing FOR. Results of this study indicate less education, perceived risk of developing breast cancer, increased anxiety, low self-efficacy for managing breast cancer, positive *BRCA1* genetic status, and African American race were all predictors of increased FOR. These results, as discussed above, are congruent with results in other studies. Understanding what predicted FOR in this study sample is important. What is important to note about these 6 variables is that 3 of them are amenable to change. While health care practitioners cannot change genetic status, race, or level of education; practices can be employed to lessen anxiety, increase self-efficacy to manage disease, and acknowledge perceived risk of developing breast cancer. Methods to increase coping appraisal can help lessen anxiety (McGinty et al., 2012) and psychosocial treatment e.g. support groups can help to increase self-efficacy (Melchior, 2013). With respect to perceived risk of developing breast cancer, practitioners should assess if the patient is experiencing appropriate risk. Inordinately high perceived risk may lead to increased fear but it may also lead some women to be hyper vigilant in screening behaviors. Lessening this fear may produce unwanted deterrent to surveillance mammograms and CBE.

Overall, the reports of FOR in the present sample of YBCS were lower than what has been found in previous studies (Baker, et al., 2005, Deimling et al., 2006, Stanton et al., 2006; van den Beuken-van Everdingen et al., 2008), however, this sample was limited to YBCS only. Therefore the results may not be generalizable to other breast cancer survivors.

Clinical Implications

The clinical importance of assessing self-efficacy early in the breast cancer treatment time frame may lead to recognition by healthcare providers of patients who are at risk of FOR and special attention can be given to address this concern. Also the importance of surveillance mammogram and CBE can be emphasized and monitored. Additionally psychosocial interventions to foster self-efficacy to manage breast cancer such as support groups should be initiated at time of disease diagnosis and continue throughout treatment (Melchior et al., 2011). Additionally assessment of the woman's knowledge of breast cancer treatment regimen and goals needs to be done early and repeated often to be certain she understands the importance of surveillance. Education regarding breast cancer treatment, the importance of surveillance, and the risk of one developing a second cancer may increase self-efficacy in managing breast cancer and may decrease FOR.

Limitations

There are several limitations to note in this study. This sample included YBCS from one Midwestern state. Thus, the results of this study cannot be generalized beyond the current sample. Demographics and results may be different in other geographic areas. Other limitations of this study include being a secondary analysis of a database. Although this was rich with information and had a large number of participants there were questions that the researcher

would have liked to ask but could not. For example, it would have been interesting to know if the women made any changes to their health behavior after being diagnosed e.g. dietary changes, exercise, smoking, and if these changes to improve their health status had any impact on their FOR. Other questions of interest include, when does FOR begin, does the level of FOR vary throughout the disease, do women diagnosed with different stages of disease vary in their reported FOR? An important question that remains unanswered by this and current research in the literature: Is there an inverse relationship between self-efficacy for managing breast cancer and FOR, meaning does FOR impact one's self-efficacy for managing breast cancer or does self-efficacy for managing breast cancer impact FOR? This will be fuel for future research.

Future Research

Future research should include assessing coping strategies and if FOR changes over the duration of time from diagnosis through survivorship. As life's trials and tribulations change one's coping mechanisms may change as well as one's self-efficacy for managing breast cancer. This may impact one's FOR. Future research should also determine if the observations of this study hold true in other samples of cancer survivors including young women, breast cancers survivors with different stages and types of cancer, and women for whom a second cancer has already been diagnosed. It will also be important to determine if any interventions can be developed which impact the modifiable variables which lead to FOR.

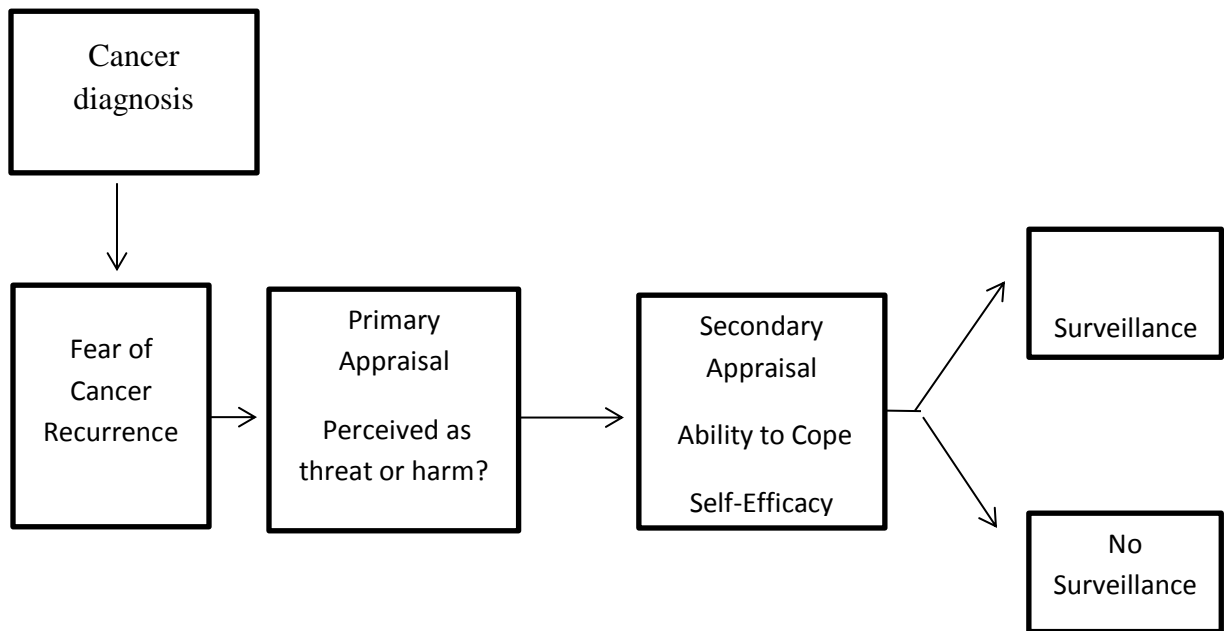


Figure 1. Conceptual Framework

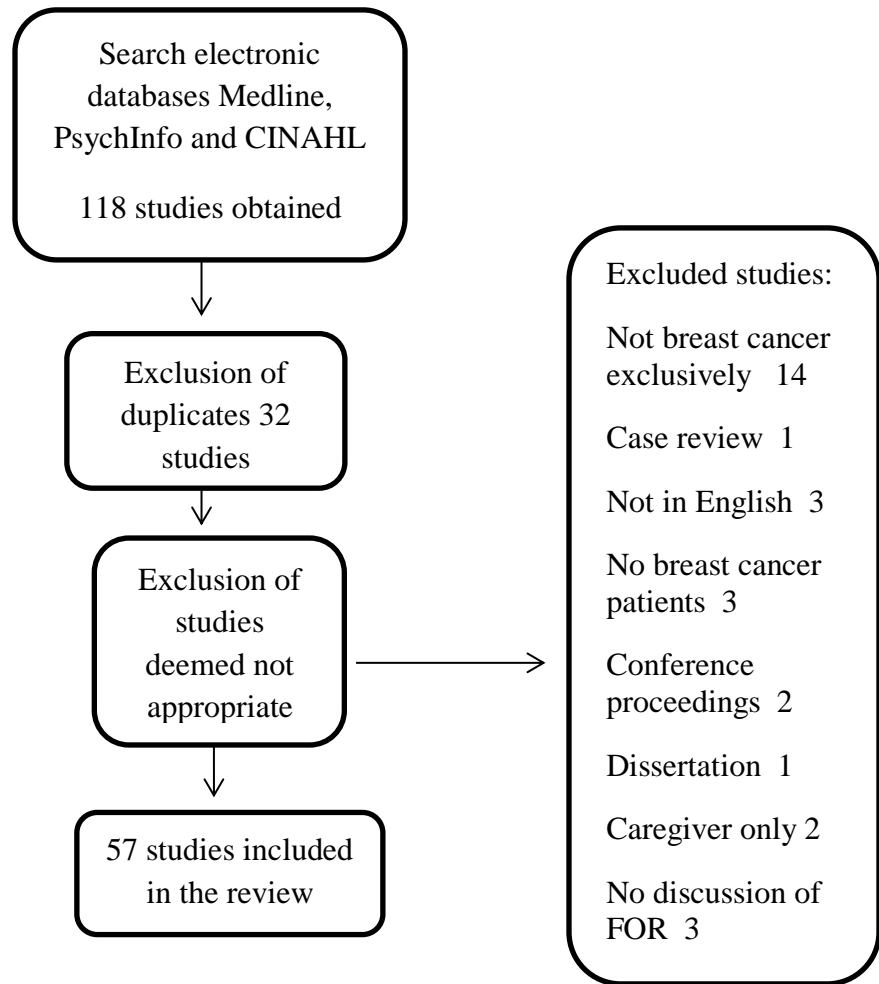


Figure 2 Diagram of studies used in literature review

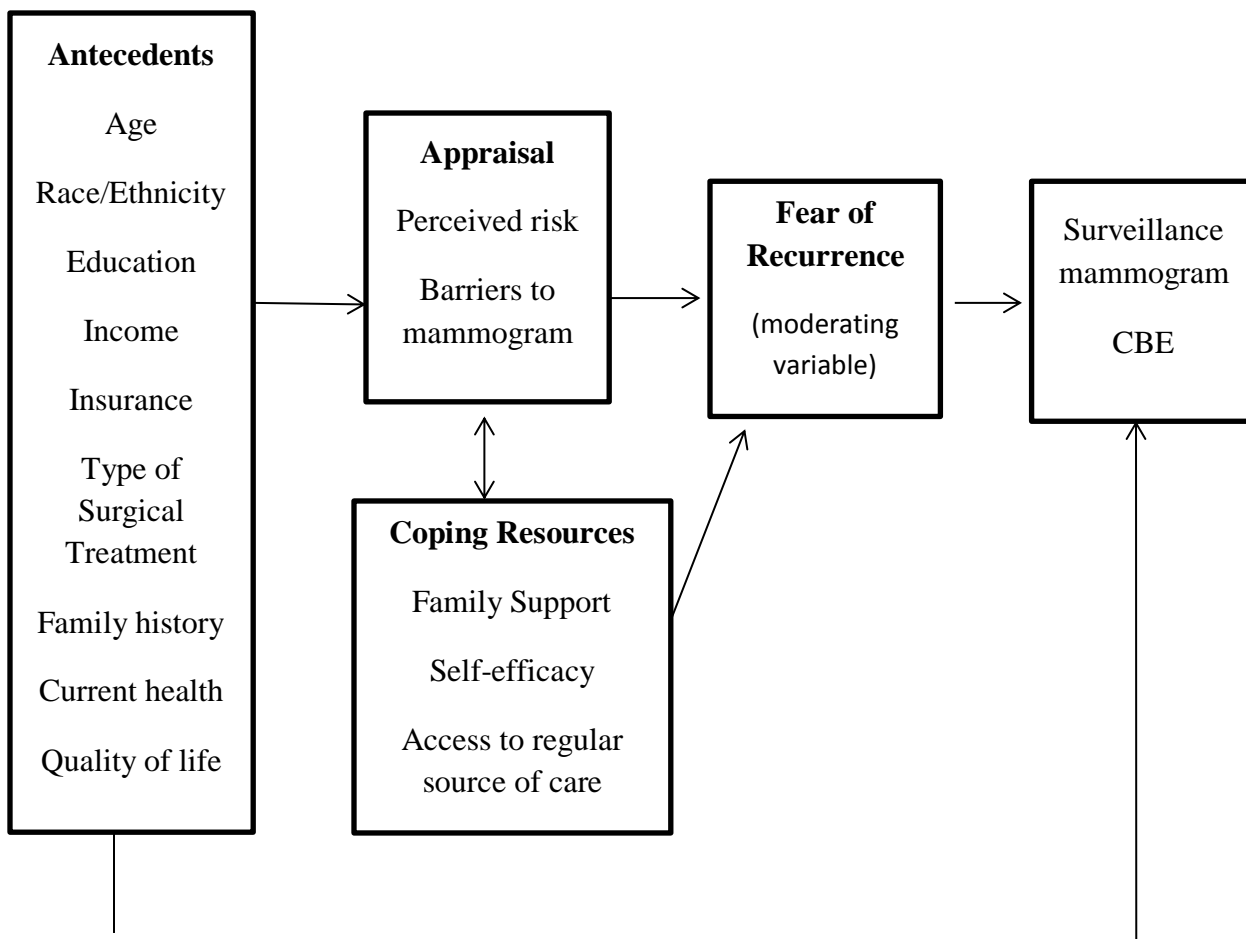


Figure 3 Mediation Model

Table 3.1

<i>Fear of Recurrence Questions</i>							
How much time do you spend thinking that your breast cancer could come back?	Not at all					All the time	
	1	2	3	4	5	6	7
How often do you worry that your breast cancer could come back?	Not at all					A great deal	
	1	2	3	4	5	6	7
How often do you worry that your breast cancer could come back?	Never					All the time	
	1	2	3	4	5	6	7
How afraid are you that your breast cancer may come back?	Not at all					A great deal	
	1	2	3	4	5	6	7

Table 3.2

<i>Breast Cancer Knowledge Index</i>			
	True	False	Don't know
A woman's risk for getting breast cancer is higher when she... ...had her first baby after she is 30 years old			
...had her first period before she is 12 years old			
...had her menopause after the age 50			
...is from Ashkenazi Jewish descent			
...had one or more breast biopsies			
...had breast cancer once before			
...has a family history of ovarian cancer			
...has a family history of breast cancer from the dad's side of the family			
...has a relative who has had both breast and ovarian cancer			
...has a relative with breast cancer in both breasts			
...has a relative diagnosed with breast cancer younger than 50 years old			
...has a male relative who had breast cancer			
...has multiple relative with breast cancer			
...has breast and ovarian cancer in the same side of the family			
...has a genetic mutation in the BRCA1 or BRCA2 genes			
...gets older			

Table 3.3

<i>Barriers and Facilitators to Use of Mammography</i>							
	Strongly disagree	Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Agree	Strongly Agree
I am more likely to go for mammograms if my doctor tells me it is important.	1	2	3	4	5	6	7
Mammograms are the best way to find breast cancer early	1	2	3	4	5	6	7
Having mammograms every year or two gives me a feeling of control over my health	1	2	3	4	5	6	7
Having mammograms every year or two give me peace of mind	1	2	3	4	5	6	7
Having mammograms causes me a lot of worry about possibly finding cancer	1	2	3	4	5	6	7
Having a mammogram is just looking for trouble	1	2	3	4	5	6	7
The cost of mammograms causes me to think twice about getting one	1	2	3	4	5	6	7
It is very hard for me to get to a place where they do mammograms	1	2	3	4	5	6	7

Table 3.4

<i>Family Support</i>							
The people in my family...	Never True	Almost Never True	Seldom True	Some-Times True	Often True	Almost Always True	Always True
Are willing to listen to me when I just need to talk	1	2	3	4	5	6	7
Give me a great deal of affection and warmth	1	2	3	4	5	6	7
Ignore or make light of my concerns	1	2	3	4	5	6	7
Support me as I try to cope with problems in my life	1	2	3	4	5	6	7
Change the topic when I discuss my concerns	1	2	3	4	5	6	7
Work as a team to manage concerns we have	1	2	3	4	5	6	7
Give me positive feedback for my attempts to cope with problems that I have	1	2	3	4	5	6	7
Offer to help me do things that are difficult for me to do	1	2	3	4	5	6	7
Do not like to talk about problems and concerns	1	2	3	4	5	6	7
Avoid talking about negative feelings and sad events	1	2	3	4	5	6	7
Disagree on how to solve problems we have	1	2	3	4	5	6	7
Hide their true feelings from each other	1	2	3	4	5	6	7
Make me feel comfortable when discussing my concerns	1	2	3	4	5	6	7
Make me feel that talking about my problems creates a lot of tension among us	1	2	3	4	5	6	7

Table 3.5

<i>Family Support in Illness</i>							
In our family, when I have a health problem...	Never True	Almost Never True	Seldom True	Some-Times True	Often True	Almost Always True	Always True
I have someone I can turn to	1	2	3	4	5	6	7
I could easily find someone to help me with my daily work	1	2	3	4	5	6	7
There is at least one person whose advise I really trust	1	2	3	4	5	6	7
There is not one to turn to	1	2	3	4	5	6	7
I can find someone to help me get to the doctor	1	2	3	4	5	6	7
I can talk to someone about my concerns and fears	1	2	3	4	5	6	7
There is someone helping me get the care that I need	1	2	3	4	5	6	7
I can get help with costs and expenses	1	2	3	4	5	6	7
There is no one to help me get the information that I need	1	2	3	4	5	6	7
I don't have anyone I can confide in	1	2	3	4	5	6	7

Table 3.6

<i>Self-Efficacy Scale</i>							
Since my breast cancer diagnosis, I am able to...	Strongly Disagree	Disagree	Some-what Disagree	Neutral	Some-what Agree	Agree	Strongly Agree
Ask for help when I have problems related to my cancer	1	2	3	4	5	6	7
Deal with the fact that I had breast cancer	1	2	3	4	5	6	7
Deal the physical symptoms related to my cancer without feeling guilty	1	2	3	4	5	6	7
Handle any fears I have about the possibility of my cancer coming back	1	2	3	4	5	6	7
Handle life situations	1	2	3	4	5	6	7
Do the things that are important to me	1	2	3	4	5	6	7
Have a productive life	1	2	3	4	5	6	7
Enjoy leisure activities	1	2	3	4	5	6	7
Work toward my personal goals	1	2	3	4	5	6	7
Deal with my emotions	1	2	3	4	5	6	7
Identify changes in my body that may be related to my cancer coming back	1	2	3	4	5	6	7
Talk with my provider about symptoms that may be related to my cancer coming back	1	2	3	4	5	6	7

Table 3.7

<i>Quality of Life</i>						
During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of your physical health?						
				No		Yes
				No		Yes
				No		Yes
During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?						
				No		Yes
				No		Yes
				No		Yes
How much of the time during the past 4 weeks...						
	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Have you felt calm and peaceful?						
Did you have a lot of energy?						
Have you felt downhearted or blue?						
Have your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, ect)?						
					No	Yes
Have you ever been told by a doctor or a nurse that you had depression?						

Table 4.1

<i>Sample characteristics</i>				
	n	%	n	%
Mean age in years (SD, range)		51(+/-6, 45-57)		
Years since diagnosis (SD, range)		11 (+/-4, 7-15)		
Race/Ethnicity*		White/Other		Black
	488	95.3	313	92.9
American Indian	12	2.3	10	3.0
Arab-American	3	0.6	0	0
Asian or Southeast Asian	8	1.6	3	0.9
Hawaiian	0	0	1	0.3
Prefer not to answer	10	2	11	3.3
Marital Status				
Single	19	3.7	91	26.9
Life Partner	17	3.3	10	3
Divorced/Separated	91	17.6	104	30.6
Widowed	12	2.3	20	5.9
Other	2	0.4	1	0.3
Employment				
Full-time	274	55.1	150	45.5
Part-time	82	16.5	23	7.0
Unemployed	22	4.4	33	10
Homemaker	40	8.0	15	4.5
Student	3	0.6	4	1.2
Retired	31	6.2	37	11.2
Unable to work	29	5.8	60	18.2
Other	16	3.2	8	2.4
Income				
Less than \$20,000	40	7.9	90	27.4
\$20,000-\$39,000	55	10.8	68	20.7
\$40,000-\$59,000	79	15.6	57	17.3
\$60,000-\$79,000	78	15.4	23	7
\$80,000-\$99,000	46	9.1	20	6.1
\$100,000-\$119,000	59	11.6	8	2.4
\$120,000 or greater	94	18.5	20	6.1
Prefer not to answer	56	11.0	43	13.1

*Total sums to greater than 100% because of multiple responses

Table 4.2

<i>Participant Education Level</i>	White/Other		Black	
	n	%	n	%
Grades 1 through 8	2	0.4	2	0.6
Grades 9 through 11	7	1.4	23	6.8
High School Graduate/ GRE/Technical School	88	17.2	77	22.9
Some College, no degree	197	38.4	125	37.2
Completed College	130	25.3	60	17.9
Postgraduate degree	89	17.3	49	14.6
Total	513	100	336	100

Table 4.3

<i>Type of Breast Cancer Diagnosis and Surgery</i>				
Cancer Diagnosis*	White/Other		Black	
	n	%	n	%
DCIS	299	58.7	136	44.3
LCIS	25	4.9	7	2.3
Atypical hyperplasia	10	2.0	2	0.7
Breast Surgery*				
No Surgery	5	1.0	10	2.9
Lumpectomy only	197	38.0	138	40.6
Lumpectomy and Mastectomy	66	12.7	62	18.2
Lumpectomy and Double Mastectomy	61	11.8	15	4.4
Mastectomy only	128	24.7	91	26.8
Double Mastectomy	62	11.9	24	7.1

*Total sums to greater than 100% because of multiple responses

Table 4.4

Distribution of Average Fear Scores

N=842		Missing=17		Mean=3.46		Median=3.25		SD=1.77		Min=1		Max=7	
Value	Frequency	Percent	Cumulative	Percent									
1.00	92	10.7	10.9										
1.25	23	2.7	13.7										
1.5	26	3.0	16.7										
1.67	1	0.1	16.9										
1.75	31	3.6	20.5										
2.00	82	9.7	30.3										
2.25	45	5.2	39.9										
2.75	23	2.7	42.6										
3.00	44	5.1	47.9										
3.25	39	4.5	52.5										
3.50	44	5.1	57.7										
3.75	19	2.2	60.0										
4.00	37	4.3	64.4										
4.25	29	3.4	67.8										
4.50	35	4.1	72.0										
5.00	36	79.3	79.3										
5.25	23	2.7	82.1										
5.50	25	2.9	85.0										
5.75	22	2.6	87.6										
6.00	27	3.1	90.9										
6.25	17	2.0	92.9										
6.33	1	0.1	93.0										
6.50	15	1.7	94.8										
6.75	8	1.0	95.7										
7.00	36	4.3	100.0										

Table 4.5

Pearson Product-Moment Correlations Between Meaningful Variables and Average Fear Score

Scale	Fear									
Fear	-									
Age		-.179**								
Education			-.129**							
Income				-.089*						
Cost					.134**					
Routine care						-.095**				
Year since diagnosis							-.166**			
Perceived risk								.326**		
Self-efficacy									-.387**	
Family support										-.165**
Family support in illness										-.176**
MCS12										
Frequency of CBE										-.079*
										.104**

*Correlation is significant at the 0.05 level (2-tailed)

**Correlation is significant at the 0.01 level (2-tailed)

Table 4.6

<i>Regression Model Summary</i>									
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F change
1	.592	.350	.321	1.41957	.350	12.102	25	561	.000

Predictors: (Constant), Misconceptions, Age, Education, Number of relatives with breast cancer, Anxiety, Marital Status, Insurance status, Multiple Cancer Diagnosis, Believe chance, Influence of others, BRCA status, Routine source of care, Barriers, Average self-efficacy, Average family support, Did not see doctor because of cost, Race status, Access, Depression, Benefits of Mammogram, Years since diagnosis, Mammogram unpleasant, Income, Susceptibility, Average family support in illness

Dependent variable: Average fear

Table 4.7

<i>Regression Coefficient Results</i>										
Constant	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Correlations			Collinearity Statistics	
	B	Std.error	Beta			Zero-order	Partial	Part	Tolerance	VIF
Ave. self-efficacy	-.381	.060	-.256	-6.372	.000	-.365	-.260	-.217	.718	1.393
Believe Chance	.178	.026	.241	6.713	.000	.294	.273	.228	.896	1.116
BRCA status	-.654	.152	-.158	-4.292	.000	-.136	-.178	-.146	.853	1.172
Anxiety	.544	.166	.144	3.277	.001	.230	.137	.112	.599	1.670
Race Status	.500	.148	.139	3.372	.001	.088	.141	.115	.682	1.466
Education	-.132	.064	-.081	-2.068	.039	-.124	-.087	-.079	.754	1.324
Worry	.291	.035	.310	8.231	.000	.319	.328	.280	.818	1.223

Dependent variable: average fear

Table 4.8

<i>Frequency of mammogram and CBE</i>						
Mammogram Frequencies	Total		White/other		Black	
	Count	Column	Count	Column	Count	Column
		N %		N %		N %
> every 12 months	78	11.4%	36	9.2%	42	14.3%
Every 12 months	541	79%	332	84.7%	209	71.3%
Every 6 months	63	9.2%	23	5.9%	40	13.7%
Every 3-4 months	3	0.4%	1	0.3%	2	0.7%
Total	685	100%	392	100%	293	100%
CBE Frequencies	Total		White/other		Black	
	Count	Column	Count	Column	Count	Column
		N %		N %		N %
> every 12 months	99	12.1%	61	12.5%	38	11.9%
Every 12 months	416	50.7%	261	52%	155	48.6%
Every 6 months	22	27.5%	135	26.9%	91	28.5%
Every 3-4 months	80	9.7%	45	9%	35	11%
Total	821	100%	502	100%	319	100%

Table 4.9

Results of Step-wise regression analysis to determine mediation effect FOR and CBE

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F change
1	.482	.183	.139	.72232	.183	4.217	27	509	.000
2	.440	.193	.149	.71839	.010	6.587	1	508	.001

Model 1 Predictors: (Constant) Confidence in CBE, Average family support, Years since diagnosis, Routine source of care, Believe chance, Multiple cancer diagnosis, Benefits of mammogram, Intent to CBE, Marital status, Number of relatives with breast cancer, Education, Anxiety, Worry about finding cancer, BRCA status, Did not see doctor due to cost, Unpleasant CBE, Average self-efficacy, Insurance status, Race status, Access, Depression, Influence of others, Misconceptions, Age, Income, Susceptibility, Average family support in illness.

Model 2 Predictors: (Constant) Confidence in CBE, Average family support, Years since diagnosis, Routine source of care, Believe chance, Multiple cancer diagnosis, Benefits of mammogram, Intent to CBE, Marital status, Number of relatives with breast cancer, Education, Anxiety, Worry about finding cancer, BRCA status, Did not see doctor due to cost, Unpleasant CBE, Average self-efficacy, Insurance status, Race status, Access, Depression, Influence of others, Misconceptions, Age, Income, Susceptibility, Average family support in illness, Average fear.

Dependent variable: Frequency of CBE

Table 4.10

<i>Predictors of CBE use</i>										
Constant	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Correlations			Collinearity Statistics	
	B	Std.error	Beta			Zero-order	Partial	Part	Tolerance	VIF
Insurance status	.431	.177	.177	2.441	.015	.211	.108	.098	.702	1.425
Routine source of care	.438	.178	.109	2.453	.015	.174	.108	.098	.812	1.231
Intention to have CBE	.043	.021	.088	2.078	.038	.144	.092	.083	.886	1.129

References

- American Cancer Society. (2014). *Cancer facts & figures for African Americans 2013-2014*. Atlanta, GA: American Cancer Society.
- Ashing-Giwa, K. T. (2011). Quality of life and psychosocial outcomes in long-term survivors of breast cancer: A focus on African American women. *Journal of Psychosocial Oncology*, 17(3-4), 47-62. doi:10.1300/J077v17n03_03
- Ashing-Giwa, K. T., Padilla G., Tajero, J., Kraemaer, J., Wright, K., Coscarelli, A., & et al. (2004). Understanding the breast cancer experiences of women: A qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psycho-Oncology*, 13(6), 408-428. doi:10.1002/pon.750
- Baker, F., Denniston, M., Smith, T., West, M.M. (2005). Adult cancer survivors: How are they faring? *Cancer*, 104, 2565-2576.
- Befort, C., & Klemp, J. (2011). Sequelae of breast cancer and the influence of menopausal status at diagnosis among rural breast cancer survivors. *Journal of Women's Health*, 20(9), 1307-1313. doi:10.1089/jwh.2010.2308
- Bennett, J. A. (2000). Mediator and moderator variables in nursing research: Conceptual and statistical differences. *Research in Nursing and Health*, 23, 415-420.

- Bettencourt, B. A., Schlegel, R. J., Talley, A. E., & Molix, L. A. (2007). The breast cancer experience of rural women: A literature review. *Psycho-Oncology, 16*(10), 875-887.
- Bibb, S. C. (2001). The relationship between access and stage at diagnosis of breast cancer in African American and Caucasian women. *Oncology Nursing Forum, 28*(4), 711-719.
- Bower, J. E., Meyerowitz, B. E., Desmond, K. A., Bernaards, C. A., Rowland, J. H., & Ganz, P. A. (2005). Perceptions of positive meaning and vulnerability following breast cancer: Predictors and outcomes among long-term breast cancer survivors. *Annals of Behavioral Medicine, 29*(3), 236-245.
- Cannon, A. J., Darrington, D. L., Reed, E. C., & Loberiza, F. R. (2011). Spirituality, patients' worry, and follow-up health-care utilization among cancer survivors. *Journal of Supportive Oncology, 9*(4), 141-148. doi:10.1016/j.suponc.2011.03.001
- Cappiello, M. C., Cunningham, R. S., Knobf, M. T., & Erdos, D. (2007). Breast cancer survivors information and support after treatment. *Clinical Nursing Research, 16*(4), 278-293. doi:10.1177/105477.3807306553
- Clayton, M. F., Mishel, M. H., & Belyea, M. (2006). Testing a model of symptoms, communication, uncertainty, and well-being, in older breast cancer survivors. *Research in Nursing & Health, 29*, 18-39. doi:10.1002/nur
- Cortner, A. L., Findlay, M., Broom, R., Porter, D., & Petrie, K. J. (2013). Beliefs about medicine and illness are associated with fear of cancer recurrence in women taking adjuvant

endocrine therapy for breast cancer. *British Journal of Health Psychology*, *18*, 168-181.
doi:10.1111/bjhp.12003

Costanzo, E. S., Lutgendorf, S. K., Mattes, M. L., Trehan, S., Robinson, C. B., Tewfik, F., & Roman, S. L. (2007). Adjusting to life after treatment: Distress and quality of life following treatment for breast cancer. *British Journal of Cancer*, *97*, 1625-1631.

Crane-Okada, R., Freeman, E., Kiger, H., Ross, M., Elashoff, D., Deacon, L., & Giuliano, A. E. (2012). Senior peer counseling by telephone for psychosocial support after breast cancer surgery: Effects at six months. *Oncology Nursing Forum*, *39*(1), 78-89.
doi:10.1188/12.ONFF.78-89

Custers, J. A. E., van den Berg, S. W., van Laarhoven, H. W. M., Bleiker, E. M. A., Gielissen, M. F. M., & Prins, J. B. (2013). The cancer worry scale detecting fear of recurrence in breast cancer survivors. *Cancer Nursing*, *00*(0), 1-7.

Deimling, G. T., Bowman, K. F., Sterns, S., Wagner, L. J., & Kahana, B. (2006). Cancer-related health worries and psychological distress among older adult, long-term cancer survivors. *Psycho-Oncology*, *15*, 306-320. doi:10.1002/pon.955

Fashi Harandy, T., Ghofranipour, F., Montazeri, A., Anoosheh, M., Bazargan, M., Mohammadi, E., . . . Niknami, S. (2009). Muslim breast cancer survivor spirituality: Coping strategy or health seeking behavior hinderance? *Health Care for Women International*, *31*(1), 88-98.
doi:10.1080/07399330903104516

Gil, K. M., Mishel, M. H., Belyea, M., Germino, B., Porter, L. S., Carlton LaNey, I., & Stewart, J. (2004). Triggers of uncertainty about recurrence and long-term treatment side effects in older african american and caucasian breast cancer survivors. *Oncology Nursing Forum*, *31*(3), 633-639. doi:10.1188/04.ONF.633-639

Graeser, M. K., Engle, C., Rhiem, K., Gadzicki, D., Bick, U., Kast, K., . . . Schlehe, B. S., R. (2009). Contralateral breast cancer risk in BRCA1 and BRCA2 mutation carriers. *Journal of Clinical Oncology*, *27*(35), 5887-5892.

Hawley, S. T., Jagsi, R., Morrow, M., Janz, N. K., Hamilton, A., Graff, J. J., & Katz, S. J. (2013). Social and clinical determinants of contralateral prophylactic mastectomy. *Journal of American Medical Association Surgery*, *149*(6), 582-589. doi:10.1001/jamasurg.2013.5689

Hodgkinson, K., Butow, P., Hunt, G. E., Pendlebury, S., Hobbs, K. M., & Wain, G. (2007). Breast cancer survivors' supportive care needs 2-10 years after diagnosis. *Supportive Care in Cancer*, *15*(5), 515-523. doi:10.1007/s00520-006-0170-2

Howlander, N., Noone, A. M., Krapcho, M., Garshell, J., Neyman, N., Altekruse, S. F., . . . Cronin, K. A. (2013). *SEER cancer statistics review, 1975-2010*. (). Bethesda, MD: National Cancer Institute.

Janz, N. K., Mujahid, M. S., Lantz, P. M., Fagerlin, A., Salem, B., Morrow, M., . . . Katz, S. J. (2005). Population-based study of the relationship of treatment and sociodemographics on quality of life for early stage breast cancer. *Quality of Life Research*, *14*, 1467-1479. doi:10.1007/s11136-005-0288-6

Janz, N. K., Hawley, S. T., Mujahid, M. S., Griggs, J. J., Alderman, A., Hamilton, A. S., . . .

Katz, S. J. (2011). Correlates to worry about recurrence in a multiethnic population-based sample of women with breast cancer. *Cancer*, 1827-1836. doi:10.1002/cncr.25740

Johnson Vickberg, S. M. (2003). The concerns about recurrence scale (CARS): A systematic measure of women's fears about the possibility of breast cancer recurrence. *Annals of Behavioral Medicine*, 25(1), 16-24.

Johnson Vickberg, S. M. (2001). Fears about breast cancer recurrence *Cancer Practice*, 9(5), 237-243. doi:10.1046/j.1523-5394.2001.009005237.x

Katapodi, M. C., & Aouizerat, B. (2005). Do women in the community recognize hereditary and sporadic breast cancer risk factors? *Oncology Nursing Forum*, 32(6), 617-623.
doi:10.1188/05.ONF.617-623

Katapodi, M. C., Dodd, M. J., Lee, K. A., & Facione, N. C. (2009). Underestimation of breast cancer risk: Influence on breast cancer screening. *Oncology Nursing Forum*, 36, 306-314.
doi: 10.1188/09.ONF.306-314.

Katapodi, M. C., Facione, N. C., Miasowski, C., Dodd, M. J., & Waters, C. (2002). The influence of social support on breast cancer screening in a multicultural community sample. *Oncology Nursing Forum*, 29(5), 845-852

Katapodi, M. C., Northouse, L. L., Milliron, K. J., Liu, G., & Merajver, S. D. (2011). Differences between women who pursued genetic testing for hereditary breast and ovarian cancer and

their at-risk relatives who did not. *Oncology Nursing Forum*, 38, 572-581. doi:
10.1188/11.ONF.572-581

Katapodi, M. C., Northouse, L. L., Schafenacker, A. M., Duquette, D., Duffy, S. A., Ronis, D. L., . . . Copeland, G. (2013). Using a state cancer registry to recruit young breast cancer survivors and high-risk relatives: Protocol of a randomized trial testing the efficacy of a targeted versus a tailored intervention to increase breast cancer screening. *Bio Med Central Cancer*, 13(97), 1-9. doi:10.1186/1471/2407-13-97

Katz, M.L., Reiter, P. L., Corbin, S., de Moor, J. S., Paskett, E. D., Shapiro, C. L. (2010). Are rural Ohio Appalachia cancer survivors needs different than urban cancer survivors? *Journal of Cancer Survivorship*, 4(2), 140-148. Doi: 10.1007/s11764-010-0115-0

Kelly, K. M., Shedlosky-Shoemaker, R., Porter, K., Desimone, P., & Andrykowski, M. (2011). Cancer recurrence worry, risk perception, and informational-coping styles among appalachian cancer survivors. *Journal of Psychosocial Oncology*, 29, 1-18.
doi:10.1080/07347332.2011.534014

Kim, Y., Carver, C. S., Spillers, R. L., Love-Ghaffari, M., & Kaw, C. (2012). Dyadic effects of fear of recurrence on the quality of life of cancer survivors and their caregivers. *Quality of Life Research*, 21, 517-525. doi:10.1007/s11136-011-9953-0

Koch, L., Jansen, L., Brenner, H., & Arndt, V. (2013). Fear of recurrence and disease progression in long-term (>=5 years) cancer survivors-a systematic review of quantitative studies. *Psycho-Oncology*, 22(1), 1-11. doi:10.1002/pon.3022

Kombirth, A. B., Powell, M., Regan, M. M., Bennett, S., Krasner, C., Moy, B., . . . Winer, E. (2007). Long-term psychosocial adjustment of older vs younger survivors of breast and endometrial cancer. *Psycho-Oncology*, *16*, 895-903. doi:10.1002/pon.1146

Kreitler, S., Peleg, D., & Ehrenfeld, M. (2007). Stress, self-efficacy, and quality of life in cancer patients. *Psycho-Oncology*, *16*(4), 329-341.

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

Lebel, S., Rosberger, Z., Edgar, L., & Devins, G. M. (2007). Comparison of four common stressors across the breast cancer trajectory. *Journal of Psychosomatic Research*, *63*, 225-232. doi:10.1016/j.jpsychores.2007.02.002

Lebel, S., Tomei, C., Feldstain, A., Beattie, S., & McCallum, M. (2013). Does fear of cancer recurrences predict cancer survivors' health care use? *Supportive Care in Cancer*, *21*, 901-

Liu, Y., Perez, M., Schootman, M., Aft, R. L., Gillanders, W. E., Ellis, M. J., & Jeffe, D. B. (2010). A longitudinal study of factors associate with perceived risk of recurrence in women with ductal carcinoma in situ and early-stage invasive breast cancer. *Breast Cancer Research and Treatment*, *124*(3), 835-844. doi:10.1007/s10549-010-0912-1

Luszczynska, A., Mohamed, N., & Schwarzer, R. (2005). Self-efficacy and social support predict benefit finding 12 months after cancer surgery: The mediating role of coping strategies. *Psychology, Health, and Medicine*, *10*(4), 365-375. doi:10.1080/13548500500093738

- Mathews, A., Ridgeway, V., Warren, R., & Britton, P. (2002). Predicting worry following a diagnosis of breast cancer. *Psycho-Oncology, 11*, 415-418. doi:10.1002/pon.600
- McGinty, H. L., Goldenberg, J. L., & Jacobsen, P. B. (2012). Relationship of threat appraisal with coping appraisal to fear of cancer recurrence in breast cancer survivors. *Psycho-Oncology, 21*, 203-210. doi:10.1002/pon.2883
- Melchior, H., Buscher, C., Thorenz, A., Grochocka, A., Koch, U., & Watzke, B. (2013). Self-efficacy and fear of cancer progression during the year following diagnosis of breast cancer. *Psycho-Oncology, 22*(1), 39-45. doi:10.1002/pon.2054
- Mellon, S., Kershaw, T. S., Northouse, L. L., & Freeman-Gibb, L. (2007). A family-based model to predict fear of recurrence for cancer survivors and their caregivers. *Psycho-Oncology, 16*, 214-223. doi:10.1002/pon.1074
- Mellon, S., & Northouse, L. L. (2001). Family survivorship and quality of life following a cancer diagnosis. *Research in Nursing and Health, 24*, 446-459.
- Metcalfe, K., Gershman, S., Lynch, H. T., Ghadirian, P., Tung, N., & ...Narod, S. A. (2001). Predictors of contralateral breast cancer in BRCA1 and BRCA2 mutation carriers. *British Journal of Cancer, 104*(9), 384-392. doi:10.1038/bjc.2011.120
- Michigan Department of Community Health. Public health code act 368 of 1978. Retrieved March/23, 2014, Retrieved from [http://www.legislature.mi.gov/\(S\(m40axjyylh5dkurhykpdf55\)\)/mileg.aspx?page=GetObject&objectname=mcl-333-1619](http://www.legislature.mi.gov/(S(m40axjyylh5dkurhykpdf55))/mileg.aspx?page=GetObject&objectname=mcl-333-1619)

- Ness, S., Kokal, J., Fee-Schroeder, K., Novotny, P., Satele, D., & Barton, D. (2013). Concerns across the survivorship trajectory: Results from a survey of cancer survivors. *Oncology Nursing Forum*, *40*(1), 35-42. doi:10.1188/13.ONF.35-42
- Polinsky, M. I. (1994). Functional status of long-term breast cancer survivors: Demonstrating chronicity. *Health Social Work*, *19*, 165-173.
- Rakowski, W.: Anderson, M. R., Stoddard, A. M., Urban, N., Rimer, B. K., Lane, D. S., Fox, S. A., & Constanza, M. (1997). Confirmatory analysis of opinions regarding the pros and cons of mammography. *Health Psychology*, *16*(16), 433-441.
- Rosenberg, S. M., Tracy, M., Sepucha, K., Gelber, S., Hirshfield-Bartek, J., Troyan, S., Morrow, M., Schapira, L., Come, S. E., Winer, E. P., Partridge, A. H. (2013). Perceptions, knowledge, and satisfaction with contralateral prophylactic mastectomy among young women with breast cancer: A cross sectional survey. *Annals of Internal Medicine*, *159*(6), 373-381. doi: 10.7326/0003-4819-159-6-201309170-00003
- Rottmann, N., Dalton, S. O., Christensen, J., Frederiksen, K., & Johansen, C. (2010). Self-efficacy, adjustment style and well-being in breast cancer patients; a longitudinal study. *Quality of Life Research*, *11*(3), 221-229.
- Rowland, J. H., & Bellizzi, K. M. (2008). Cancer survivors and survivorship research: Reflection on today's successes and tomorrow's challenges. *Hematology Oncology Clinics of North America*, *22*, 181-200. doi:10.1016/j.hoc.2008.01.008

- Russell, K. M., Von Ah, D. M., Giesler, R. B., Storniolo, A. M., & Haase, J. E. (2008). Quality of life of African American breast cancer survivors. How much do we know? *Cancer Nursing, 31*(6), E36-E45.
- Sammarco, A., & Konecny, L. M. (2008). Uncertainty among latina breast cancer survivors. *Oncology Nursing Forum, 35*(5), 844-849. doi:10.1188/08.ONF.844-849
- Simard, S., Savard, J., & Ivers, H. (2010). Fear of cancer recurrence: Specific profiles and nature of intrusive thoughts. *Journal of Cancer Survivorship, 4*, 361-371. doi:10.1007/s11764-010-013608
- Stanton, A. L., Danoff-Burg, S., & Huggins, M. E. (2002). The first year after breast cancer diagnosis: Hope and coping strategies as predictors of adjustment. *Psycho-Oncology, 11*, 93-102. doi:10.1002/pon.574
- Stanton, A., Danoff-Burg, S., Cameron, C., Collins, C., Sworowski, L., & Kirk, S. (1999). A longitudinal study of emotional expression and adjustment to breast cancer. *Annals of Behavioral Medicine, 21*(S007)
- Stanton, A. L., Ganz, P. A., Rowland, J. H., Meyerowitz, B. E., Krupnick, J. L., & Sears, S. R. (2005). Promoting adjustment after treatment for cancer. *Cancer, 104*, 2608-2613.
- Stephens, P. A., Osowski, M., Fidale, M. S., & Spagnoli, C. (2008). Identifying the educational needs and concerns of newly diagnosed patients with breast cancer after surgery. *Clinical Journal of Oncology Nursing, 12*(2), 253-258. doi:10.1188/08.CJON.253-358

- Taylor, T. R., Huntley, E. D., Sween, J., Makambi, K., Mellman, T. A., Williams, C. D., . . . Frederick, W. (2012). An exploratory analysis of fear of recurrence among African American breast cancer survivors. *International Journal of Behavioral Medicine, 19*, 280-287. doi:10.1007/s12529-011-9183-4
- Thewes, B., Butow, P., Bell, M. L., Beith, J., Stuart-Harris, R., Grossi, M., . . . Dailey, D. (2012). Fear of cancer recurrence in young women with a history of early-stage breast cancer: A cross-sectional study of prevalence and association with health behaviours. *Supportive Care in Cancer, 20*, 2651-2659. doi:10.1007/s00520-011-1371-x
- Thompson, H. S., Littles, M., Jacob, S., & Coker, C. (2006). Posttreatment breast cancer surveillance and follow up care experiences of survivors of African descent. *Cancer Nursing, 29*(6), 478-487.
- Turner, D., Adams, E., Boulton, M., Harrison, S., Khan, N., Rose, P., & ...Watson, E. K. (2013). Partners and close family members of long-term cancer survivors: Health status, psychosocial well-being and unmet supportive care needs. *Psycho-Oncology, 22*, 12-19. doi:10.1002/pon.2050
- van den Beuken-van Everdingern, M. H. J., Peters, M. L., de Rijke, J. M., Schouten H. C., van Kleff, M., & Patiyn, J. (2008). Concerns of former breast cancer patients about disease recurrence: A validation and prevalence study. *Psycho-Oncology, 17*, 1137-1145. doi:10.1002/pon.1340
- Ware, J., Kosinski, M., & Keller, S.D, (1996). A 12 item short form health survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care, 34*(3), 220-233.

Yoo, G. J., Levine, E. G., Aviv, C., Ewing, C., & Au, A. (2010). Older women, breast cancer, and social support. *Supportive Care in Cancer, 18*(12), 1521-1530. doi:10.1007/s00520-009-0774-4

Ziner, K. W., Sledge, G. W., Bell, C. J., Johns, S., Miller, K. D., & Champion, V. L. (2012). Predicting fear of breast cancer recurrence and self-efficacy in survivors by age at diagnosis. *Oncology Nursing Forum, 39*(3), 287-295.