

**THE RELATIONSHIP OF ILLNESS REPRESENTATIONS AND COPING TO
FEAR OF RECURRENCE IN BREAST CANCER PATIENTS**

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
(Nursing)
in The University of Michigan
2012

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DEDICATION

This dissertation is dedicated to all of the amazingly wonderful women, friends, patients, and study participants who have had and are now survivors of breast cancer. I have been privileged to observe your grace, fortitude, and strength. Without your influence and support this work never would have been started nor finished.

ACKNOWLEDGEMENTS

I would like to express my sincere gratitude to all the people who have made my doctoral education and this research possible. Your unwavering support over the years has greatly contributed to my success and I am forever indebted to you all.

I would like to first and foremost thank Dr. Laurel L. Northouse. You are the best mentor, advisor, and chair that anyone could ask for. Your compassion, support, and caring of me not only as a student but also as a person was extraordinary. Without your knowledge and expertise in this field this work would never have started. You are a great example for all of us who are in academia to emulate. Your ability to encourage yet firmly demand excellence has taught me to be a better researcher and a more compassionate human being.

To all of my committee members thank you for never wavering in your support of this work. Dr. Maria Katapodi thank-you for broadening my thinking and asking the tough questions that were needed to make this a better piece of writing. Dr. Brian Zikmund-Fisher for challenging the status quo and encouraging me to become a more grounded researcher. Dr. Nancy Janz for your thoughtful contemplation and expert knowledge that you easily and willingly shared.

I would like to thank my statistical team of Dr. Maher El-Masri and Dr. Kenneth Cramer. Both of whom answered many a question repeatedly yet encouraged a deep

appreciation and respect for statistical set up and analysis. What I learned from you both I will take forward with me into all my future endeavors.

Dr. Dale Rajacich for all of your kind words and support of my less than perfect writing style. You are an amazing friend, mentor, and coworker that I look forward to collaborating with for many years to come.

To all my patients, friends, and coworkers from the Alexander J. Walt Breast Center, Karmanos Cancer Center, and the University of Windsor thank you for your support and concern. Without this I would have never been able to, or felt capable of, completing this piece of work.

Lastly to my family, thank you for being there for me though out this process. David you are my rock without your support and loving care this would never have been finished. To my children Celine and Evan for realizing that learning is a lifelong affair and being the best-behaved kids a mom could ever want. To my parents Valerie and Bob Chaloux for never giving up on your less than perfect daughter. Your love, encouragement, and support were an integral part of the completion of this dream.

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ABSTRACT

BACKGROUND: Breast cancer survivors are a large and growing cohort of women who are in need of ongoing follow-up care to monitor for latent physical effects of treatment, recurrence of disease, and evaluation/treatment of psychological needs. Fear of cancer recurrence (FCR) after treatment for breast cancer is studied infrequently, even though it may be causing significant distress in breast cancer survivors. **PURPOSE:** The purposes of this study were to: 1) build scientific understanding of FCR, as an independent construct, by exploring the relationships of patient characteristics (demographics and disease), illness representations, and coping to FCR in women survivors of breast cancer and 2) to explore who frequents Internet communities of breast cancer survivors while also examining the successes and pitfalls of recruitment and study design when using participants from Internet discussion boards and/or forums. **THEORETICAL FRAMEWORK:** This study was guided by the Common Sense Model of Illness Representations. **METHODS:** This study used a cross-sectional descriptive correlational design obtaining data from a web-based survey of standardized measures with acceptable reliabilities. One hundred and seven women recruited from three Internet discussion boards participated. Pearson correlations, hierarchical and stepwise regression analysis were used to explore the relationships between the study variables and FCR. **RESULTS:** This study found that fear of cancer recurrence was related to emotional representations,

perceived consequences/severity, symptom attribution, perceived self-risk of a recurrence, and coping. It also found that the Internet was a useful, cost effective, though time-consuming way to recruit and study breast cancer survivors. CONCLUSIONS: FCR is an ongoing concern for breast cancer survivors in need of continued research. Evaluation of its multifactorial nature is needed to assist healthcare professional who specialize in survivorship care to understand the concept and to assist survivors with FCR to manage it. The Internet can be a rich source for recruitment into health sector research and with careful design and different approaches more expanded generalizable results are possible.

CHAPTER 1

INTRODUCTION

SIGNIFICANCE OF PROBLEM

Breast cancer is the second most frequently diagnosed cancer among American women (American Cancer Society (ACS), 2011-2012). It has been predicted that over 287,000, invasive and in situ, cases will be diagnosed in 2011-2012. Within the general population over 2.6 million women are alive with a history of having had breast cancer (ACS, 2011-2012). Current statistics indicate that of the women diagnosed with breast cancer, 89% will survive 5 years or longer from their initial diagnosis and treatment (ACS, 2011-2012). Many of these women, aged 40 and older, have been diagnosed and treated just within the last ten years, making this expanding group a priority for medical practitioners (ACS, 2011-2012). Breast cancer survivors are in need of ongoing follow-up care to monitor for latent physical effects of treatment, breast cancer recurrence, and evaluation/treatment of psychological needs (Alder & Page, 2008).

Post-treatment distress, a term coined by the National Comprehensive Cancer Network (NCCN), describes the non-physical consequences of cancer treatment experienced by cancer survivors and is a major concern for all cancer survivors (Vachon, 2006). Fear of cancer recurrence, is a universal non-physical consequence that breast cancer patients face, to varying degrees in their survivorship trajectory, and is contributing to post survivor distress (Bartelink, van Dam, & van Dongen, 1985; Lee-

Jones, Humphris, Dixon, & Hatcher, 1997; Miedema, Tatemichi, & MacDonald, 2004; Northouse, 1981; Vickberg, 2001, 2003; Ziner, 2008). Fear of cancer recurrence as a unique form of distress in survivorship has been associated with increased anxiety, depression, the outcome of death, fear of consequences from it and decreased quality of life (Lee-Jones et al., 1997; Ray, 1977; Simard & Savard, 2009; Van den Beuken-van Everdingen et al., 2008; Vickberg, 2001). Research to identify and intervene with women who are suffering negative effects from fear of cancer recurrence have been thwarted by inconsistent use of conceptual frameworks and limited research to help us understand factors associated with it as an independent construct.

The increasing need and overcrowding of cancer services in specialty oncology settings has resulted in breast cancer survivors being followed in primary care settings. Consequently, this makes it more challenging to locate and recruit breast cancer survivors into studies on survivorship (Ganz, 2009; Ganz et al., 2009; Hewitt, Greenfield, & Stovall, 2006). The recruitment of cancer survivors for research and design of health science studies have adapted to this challenge over the last few decades with the explosion of the World Wide Web or the Internet (from this point further to be referred to as the Internet) (Das, Ester, & Kaczmirek, 2011).

One potentially rich site for recruitment of breast cancer survivors may be within Internet cancer specific groups or communities. As use of the Internet to recruit cancer patients for studies increases, it is imperative that we understand the characteristics of cancer survivors who participate in research via Internet surveys as well as the viability of using various cancer communities for survivorship data collection. There is also need

to understand how tailored surveys used on the Internet may impact on the type of data obtained.

To build scientific understanding of fear of cancer recurrence, as an independent construct, this study explored the relationships of patient characteristics (demographics and disease), illness representations, and coping to fear of cancer recurrence in women survivors of breast cancer. As a secondary goal, to gain further understand of the impact of the Internet on study design and recruitment, this study also explored demographics and other pertinent characteristics of women recruited from breast cancer specific Internet sites. The following specific aims were addressed in this dissertation:

Specific Aim 1:

To examine whether patient characteristics influence illness perceptions of breast cancer.

Specific Aim 2:

To examine how much variance patient characteristics, illness perceptions, and coping styles, account for in fear of breast cancer recurrence.

Specific Aim 3:

To examine if coping strategies mediate or moderate the relationship between illness perceptions and fear of cancer recurrence.

Specific Aim 4:

To examine who frequents Internet communities of breast cancer survivors.

Specific Aim 5:

To examine the successes and pitfalls of recruitment from Internet discussion boards and/or forums.

Methods Used to Meet Dissertation Requirements

This dissertation used the three-article/paper format option. Chapter One examines the theoretical framework and its modifications used to guide this research. Chapter Two is a historical scientific literature review of fear of cancer recurrence from 1970 to the present scientific literature (Dissertation Paper One). Chapter Three describes the relationships between patient characteristics, illness representations, and coping to fear of cancer recurrence (Dissertation Paper Two). Chapter Four describes the characteristics of breast cancer survivors recruited from the Internet and the computerized survey method used for data collection (Dissertation Paper Three). Finally, Chapter Five summarizes the results of this dissertation discussing practice implications and directions for future research.

THEORETICAL FRAMEWORK

Common Sense Model of Illness Representations

Researchers from multiple disciplines, who have focused on fear of cancer recurrence and breast cancer survivorship, have used a variety of theoretical frameworks to guide their research (Carter, 1993; Fredette, 1995; Lasry & Margolese, 1992; Lee-Jones et al., 1997; Northouse, 1981; Vickberg, 2001, 2003; Walker, 1997; Ziner, 2008). No single theoretical framework has been consistently used or tested by researchers and none has been found to be superior for the study of fear of cancer recurrence. Leventhal, Brissette and Leventhal's (2003) Common Sense Model of Illness Representations however, supports the view that self-regulation processes are linked to the construct of fear of cancer recurrence. This has led to the development of a modified and adapted

version of the original Common Sense Model of Illness Representations that was used to guide this current study on fear of cancer recurrence.

History of Self-Regulation

Over the last 40 years, Leventhal and colleagues have conducted an extensive body of work examining self-regulation in health and illness. Leventhal's (1970) early work suggested that a certain amount of fear can motivate behavioral change and assist in the process of self-regulation. Conversely, too much fear can have the opposite effect, causing not only a fight or flight response but also the inability to self-regulate. The modified model, developed for this study, suggests that self-regulation is relevant to understanding fear of cancer recurrence. It is postulated that at a certain level fear of cancer recurrence motivates the breast cancer survivor to comply with needed follow-up. However, when this fear level is further elevated it can cause ongoing distress and an inability to self-regulate in the survivorship phase of breast cancer. A lack of self-regulation, expressed as an elevated level of fear of cancer recurrence, in the breast cancer survivorship phase may lead to a state of hyper-vigilance. This could result in unnecessary and distressing self-checking with repeat visits to medical providers demanding extreme testing that is unwarranted (Lee-Jones et al., 1997; Miedema et al., 2004). Initial exploration of the relationship between self-regulation and the fear of cancer recurrence was needed to examine if illness representations of breast cancer, a component of self-regulation, was related to level of fear of cancer recurrence (Llewellyn, Weinman, McGurk, & Humphris, 2008).

The Common Sense Model is a modification of the original work on self-regulation by Leventhal and colleagues (Cameron & Leventhal, 2003; Leventhal, Nerenz,

& Steele, 1984). This model focuses on how individual beliefs about an illness threat are a major determinant of health behaviors (Diefenbach & Leventhal, 1996). The substantive features of the original self-regulation theory have been maintained in the Common Sense Model yet expanded to make it more specific to health and illness.

Illness Representations within the Common Sense Model

The Common Sense Model maintains the original four assumptions of self-regulation: 1) active processing; 2) parallel processing; 3) stages in processing; 4) hierarchical processing, and the proposed hierarchical structure. Within the model's framework more abstract goals (e.g. do not get cancer) set the groundwork for lower level concrete behaviors or goals (e.g. eat healthy, do not smoke, use sunscreen, get yearly mammograms) to take place (Cameron & Leventhal, 2003). The Common Sense Model then takes these initial premises further by suggesting that people act as 'common sense scientists' attempting to construct an illness representation to aid them in self-regulation. These illness representations become a starting place for the individual to begin to compare new illness threats to known experiences. It allows an individual to choose appropriate coping mechanisms that may or may not have been successful in the past, to deal with new illness threats, a recurrence, or an exacerbation of a previously experienced health issue.

Illness representation development is accomplished by using a systematic process in which the individual makes conscious efforts to transform thoughts, emotions, and behaviors to achieve goals in an ever-changing environment (Leventhal et al., 2003). It is a dynamic system in which an illness representation or memory structure is made along with outcome goals (e.g. survive breast cancer treatment). These goals are continuously

being reevaluated and altered by use of various coping mechanisms based on both cognitive and emotional reactions to the presenting illness threat.

The Common Sense Model further expanded on the illness representation construct by adding the following five content domains: time line or possible illness duration consequences (acute, chronic, or cyclical); illness causes (e.g. nutrition, genetics, smoking); potential for disease cure or control (e.g. knowing that others have survived breast cancer, vs. death from it); consequences or expected severity of outcomes from the illness (e.g. may have to stop working because treatment for breast cancer will be hard), and identity of the illness (label), related to perceived symptoms associated with the illness (e.g. breast pain, a color change in the skin of the breast, arm pain)(Leventhal et al., 2003). Encoded memories from having been diagnosed with breast cancer and what happened during treatment can be drawn on in the future when the next illness event occurs (e.g. a breast cancer recurrence). Encoded memories can also be used by breast cancer survivors to make modifications in coping resources needed while undergoing treatment for breast cancer or a breast cancer recurrence (Leventhal et al., 2003).

Common Sense Model and Breast Cancer Research

Researchers have used the Common Sense Model or parts of it to guide the study of breast cancer and other types of cancer patients (Bish, Ramirez, Burgess, & Hunter, 2005; Browning, Wewers, Ferketich, Otterson, & Reynolds, 2009; Graves & Carter, 2005; Grunfeld, Hunter, Ramirez, & Richards, 2003; Hunter, Grunfeld, & Ramirez, 2003; Kritpracha, 2004; Lehto, 2004; Rozema, Völlink, & Lechner, 2009) and to explore cancer care interventions (Humphris & Ozakinci, 2008). Cameron and Leventhal (2003) describe how an illness event is a threat to survival that will evoke anxiety and fear in

persons with the outcome being psychological distress. The Common Sense Model not only provides a framework for how patients attempt to cope with and adapt to emotions evoked by a cancer diagnosis but also allows for an exploration of the cognitive processes used.

The Common Sense Model of Illness fits well with a diagnosis of breast cancer and the potential for breast cancer recurrence, even though fear of cancer recurrence is not specifically mentioned in the theory (Llewellyn et al., 2008). The theory allows for an exploration of both the cognitive and emotional aspects of distress elicited by the diagnosis of breast cancer as well as the fear that would be elicited by a cancer recurrence. Through the use of a parallel processing system, which takes into consideration emotional responses to the threat of breast cancer recurrence as well as cognitive responses, the model provides a pathway to explore how these systems are intertwined, simultaneous and recursive. The model allows for an investigation into the coping styles called upon by patients to deal with both the emotional and cognitive aspects of the threat of a breast cancer recurrence (Leventhal et al., 2003). These aspects of the Common Sense Model make it an ideal theoretical foundation to guide a more in depth exploration of the determinants and correlates of fear of cancer recurrence in breast cancer survivors.

Fear of cancer recurrence as an indicator of psychological distress has not been explored in breast cancer survivors using the Common Sense Model (Llewellyn et al., 2008). The literature supports that patient characteristics (demographic & clinical), illness representations, coping styles, and fear of cancer recurrence are related however, the extent of these relationships remains unknown (Anagnostopoulous & Spanea, 2005;

Costanzo, Lutgendorf, & Roeder, 2010; Millar, Purushotham, McLatchie, George, & Murraray, 2005; Royer, Phelan, & Heidrich, 2009; Rozema et al., 2009; Stewart et al., 2001). The midrange *Breast Cancer Survivorship Model of Predictors of Fear of Cancer Recurrence* was developed after an in-depth review of the Common Sense Model suggested that relationships, untested previously, might exist between patient characteristics (demographic and clinical), illness representations, perceived risk, coping styles and fear of cancer recurrence (see Figure 1.1). The developed model postulates that patient characteristics (demographic and clinical), illness representations, perceived risk, and coping styles may play a role in the development of fear of cancer recurrence. This mid-range model allows for an uncovering of exactly how patient characteristics (demographic and clinical), illness representations, perceived risk, coping style, and fear of cancer recurrence are related to each other and related within the model.

This expanded model (see Figure 1.1) guided the present exploration of the relationships between patient characteristics (demographic & clinical), illness representations, coping styles, and fear of cancer recurrence as the dependent variable. According to the model patient characteristics, trait anxiety, co-morbidities, and type of treatment for breast cancer contribute to the development of illness representations and perceived risk in breast cancer patients.

In the model illness representations of breast cancer consist of the five content domains of the Common Sense Model (timeline, cause, control, consequences, and illness identity/symptom attribution). These content domains were explored in their relationship to cognitive and emotional coping strategies, and fear of cancer recurrence as the dependent variable. This midrange model expanded on the original Common Sense

Model to include emotional representations and perceived risk as components of illness perception development with fear of cancer recurrence becoming the primary outcome. It was also postulated that a relationship between the independent variables of patient characteristics (demographic and clinical), illness perceptions (illness representations and perceived risk), and coping style would be associated to the level of fear of cancer recurrence.

Lastly, coping styles were further explored as both a mediator or moderator between illness perceptions and fear of cancer recurrence in an attempt to help clarify all aspects, even minor ones, of their relationships. In conclusion, this midrange model guides the exploration of the many potential relationships among, between, and within the identified variables in an attempt to uncover their association to fear of cancer recurrence.

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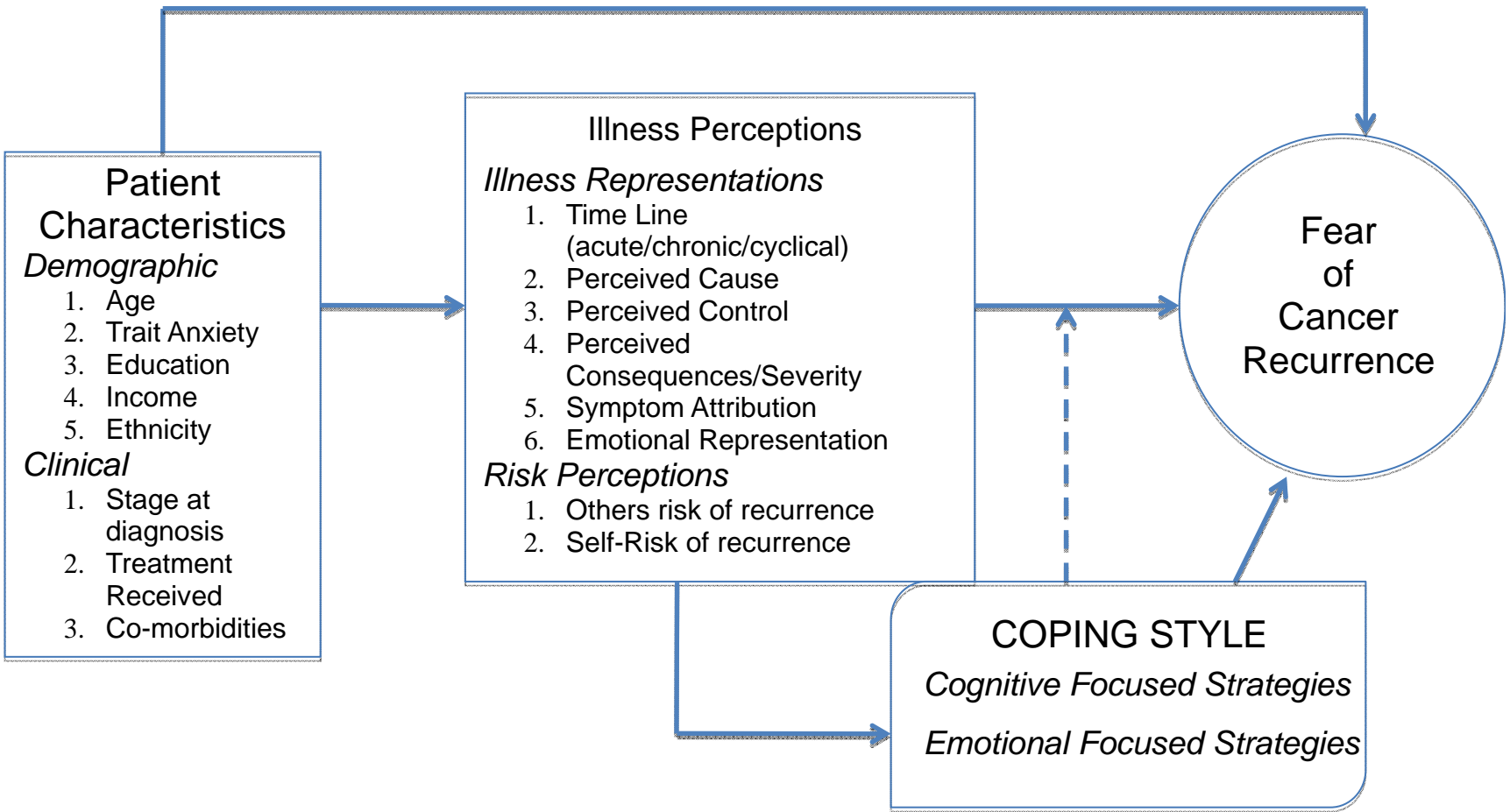


Figure 1.1
Breast Cancer Survivorship Model of Predictors of Fear of Cancer Recurrence

CHAPTER II

FEAR OF CANCER RECURRENCE: WHERE DID THIS CONSTRUCT COME FROM? A HISTORICAL LITERATURE REVIEW

INTRODUCTION

Currently it is estimated that over 192,000 women in the United States will be diagnosed with invasive breast cancer this year, with an additional 62,000 diagnosed with in situ breast cancer (American Cancer Society, (ACS), 2011-2012). Many of these women (with treatment) will join the ranks of the over 2.5 million American women who are living today with a history of breast cancer (ACS, 2011-2012). Breast cancer survivors need of follow-up care to monitor for latent physical effects of treatment, breast cancer recurrence, and evaluation/treatment of psychological needs (Alder & Page, 2008).

Fear of cancer recurrence has been identified as a universal non-physical consequence that breast cancer patients face to varying degrees in their survivorship trajectory (Bartelink, van Dam, & van Dongen, 1985; Lee-Jones, Humphris, Dixon, & Hatcher, 1997; Miedema, Tatemichi, & MacDonald, 2004; Northouse, 1981; Vickberg, 2001, 2003; Ziner, 2008). Fear of cancer recurrence in survivorship has been associated with increased anxiety, depression, death, and decreased quality of life (Lee-Jones et al., 1997; Ray, 1977; Simard & Savard, 2009; Van den Beuken-van Everdingen et al., 2008a; Vickberg, 2001). Research to identify and intervene with women who are suffering

negative effects from fear of cancer recurrence have been thwarted by inconsistent use of conceptual frameworks and limited research to help us understand factors associated with it as an independent construct.

The purpose of this article was to uncover and discuss the origins of the construct of fear of cancer recurrence, examine how it has been defined differently over the decades, and investigate the direction of current scientific inquiry. This retrospective historical literature review examined original scientific cancer related articles published from 1970 to the spring of 2011.

METHODS

An exhaustive selective review of the literature was conducted by the author using CancerLit®, CINHAL®, Medline®, Proquest®, and Pub Med® databases. The keywords and terms used were cancer, breast cancer, recurrence, fear, stress, worry, distress, survival, survivor, survivorship, return, progression, uncertainty, psychological, and psychosocial. These keywords and terms were used independently and in multiple combinations to identify the articles analyzed for this literature review. A vast number of citations were found and then systematically reduced by combining initial searches with various combinations of key words and terms (refer to Figure 1). A research assistant then independently repeated the search using the outlined parameters to ensure no significant articles were overlooked. One hundred and sixty two article citations and abstracts were further reviewed by the first author who searched for terms related to breast cancer survivorship with any mention of fear, distress, uncertainty or recurrence. Citations and abstracts were excluded that did not have a group of breast cancer patients included in the sample, if the main subjects had a breast cancer recurrence, if the study

focused on caregivers only, if they were an intervention study, or if they were a laboratory, cellular, or pure science study with no human subjects. A final group of 53 articles were chosen and retrieved for inclusion. Further evaluation of these retrieved articles uncovered a new group of repeatedly cited historic references and book chapters that were not found within the set search criteria. These articles and book chapters were also retrieved. A final group of 82 articles, 3 book chapters, 1 unpublished doctoral dissertation, and 1 Masters Thesis were retrieved and included in this review. All materials (except one salient article) retrieved included breast cancer patients and concerns about survivorship or the survivorship phase post-treatment. Current articles retrieved from the 2000's were principally on breast cancer patients, as the literature with breast cancer patients during this time was quite extensive. All of the retrieved articles were then sorted by decade and examined for common themes and conclusions.

1970-1979

A review of studies during this time indicated that cancer survivors had ongoing concerns, even though the term “fear of cancer recurrence” was not extensively used in this earlier literature. Clinical descriptions of survivors concerns often used the term emotional distress. Weisman (1979a) believed that the scope of psychosocial distress was far greater than initially recognized. Even people who were regarded as well-adjusted exhibited subclinical problems and this emotional distress persisted over time. Coping with the fear of cancer returning was a seemingly inescapable issue, and was found in this early literature to be a concern for all cancer survivors regardless of the type of cancer (Weisman & Worden, 1976). Many of these cancer survivors were left wondering if the treatment they had truly eradicated their disease or if they were just given a temporary

reprieve before the cancer's inevitable return and their ultimate untimely death (Weisman, 1979a; Weisman & Worden, 1976; Worden & Proctor, 1976). Emotional distress in this early literature was strongly associated with the trajectory towards dying, the ultimate outcome linked with pain, loss of control, physical disability, and being alone (Abeloff & Derogatis, 1977; Greer, 1979; Weisman & Worden, 1976; Worden & Proctor, 1976).

Cancer and death were intimately linked in the literature published in the 1970's (Craig, Comstock, & Geiser, 1974; Greer, 1979). Greer (1979) articulated this link well stating that, "cancer is still widely regarded as an incurable disease which usually ends in painful death" (p.174). This statement was supported by findings from a comparative study, which found a three-fold increase in mortality of breast cancer survivors versus controls, in a quality of survival comparison study (Craig et al., 1974). Weisman (1972) along with Worden and Proctor (1976) reported that cancer was often viewed as a fatal illness and noted that physicians rarely pronounced cancer patients as cured. They reported that cancer patients had ongoing concerns with life and death and used the term "death awareness." Death awareness was described as the ability to be aware that one may die from a health condition such as cancer without fear of this outcome. Worden and Proctor alleged if a person with cancer ultimately feared death and suppressed this fear that this would open the patient to other psychological issues such as increased anxiety and depression. Furthermore, they speculated that a cancer patient who had a high level of death awareness would cope better than a patient with a low level. At this point in the literature, a possible link between fear of cancer return and other psychological consequences was initially postulated.

Physical wellness or a return to physical functionality was also a major focus in this early literature. Schottnefeld and Robbins (1970) studied breast cancer survivors

quality of survival from radical mastectomy in the terms of their ability to return to pre-cancer activities. The investigators found that 84% of their sample had resumed their activities five years post-therapy. They linked advanced stage of disease with more excessive surgical interventions and significantly inferior performance status over time. Quality of survival did not include psychological outcomes in this early study of breast cancer patients. Craig et al. (1974) expanded on this early survivorship literature by defining quality of survival as linked with physical and psychosocial criteria. They found no significant differences between breast cancer survivors and a matched control group of women without breast cancer with respect to levels of happiness, future orientation, and depression.

Weisman and Worden (1975) continued to evaluate the psychosocial aspects of cancer survival. They conducted a study with 46 cancer patients, with various types of cancer, in an attempt to predict their length of survival by examining psychosocial considerations. They found that longer survival in patients could be predicted in patients based on the quality of their relationships, level of depression, death wishes, and level of apathy. Weisman (Weisman, 1979a; 1976) then attempted to identify an index of distress (vulnerability) and coping to predict which patients in the future were more likely to have poorer survival outcomes. Weisman felt that vulnerability would vary in its manifestation, extent, and degree across each cancer patient. This exploration into the degree and effects of vulnerability was an early attempt to determine which patients were more likely to experience distress after completion of cancer treatment. Weisman introduced the terms *resilience* and *adaptability* in this work suggesting that cancer patients may have unstable levels of these constructs prior to diagnosis and that patients'

earlier levels of resilience and adaptability may affect their future ability to adjust over time.

Along with the concept of vulnerability coping was introduced by Weisman and Sobel (1979) as an area associated with distress during the survivorship phase. The authors related a case study of a woman with breast cancer and multiple other life stressors. She was characterized as a person able to address her cancer and life stressors but still considered to be vulnerable to emotional distress, conflicts, and neurotic symptoms. Coping, in this case study, was defined as “an active problem-solving process (wherein one) assimilates new information, corrects as necessary and then accommodates to a revised situation” (p. 4). This article began to link distress with post treatment coping strategies.

Along with these early works, three other studies evaluated adjustment and psychological/psychiatric implications of having a mastectomy (Maguire et al., 1978; Morris, Greer, & White, 1977; Ray, 1977). Ray (1977) found that breast cancer patients who were more depressed and anxious, reported lower self-esteem, and were more introverted in their behavior than matched controls who had undergone a cholecystectomy. Fear of cancer returning was, for the first time in this decade, reported in the interview portion of this study by mastectomy patients. Ray believed this fear could be an alternative reason for the higher level of anxiety in this group and noted that women who did not state a fear of cancer returning were probably attempting to minimize or deny their fear of breast cancer recurrence. Morris, Greer and White (1977) found higher levels of depression in breast cancer patients when compared to women who had benign breast disease. They found that one fourth of the breast cancer patients in their study had not adjusted to mastectomy at one year after their surgery, and continued to be

stressed by having had this operation. A small portion (11%) of their sample considered themselves as actively ill or dying and reported that their ongoing fear was disrupting their lives. Morris and colleagues concluded that breast cancer patients need a forum in which to be able to voice their fears, allowing for a continued assessment of patients psychological and social adjustment to cancer, with the intent of early intervention when warranted. A direct association of adjustment to fear of cancer returning was suggested but not directly made in this early study.

Maguire et al. (1978) also found that women one year post mastectomy had statistically higher levels of anxiety, depression, and sexual difficulty when compared to women who had surgery for benign breast disease. The investigators believed that these higher levels of distress were related to women's perceived threats to self-esteem, role, health, loss of femininity, and loss of life. These findings suggest that women were concerned over future issues with breast cancer, but again a direct link to fear of cancer recurrence was not made. Greer (1979) recounted a poignant case study in his article on the psychological consequences of cancer. The subject, a breast cancer patient, stated that she became hypochondriacal to the point where everything that happened in her life became a cause for her to think that her cancer had returned. She stated that although this was an irrational fear, she continued to worry regardless of this revelation.

Weisman (1979b) continued his work with vulnerability, and suggested a model for psychosocial phasing in cancer. He felt that any type of cancer had ramifications and repercussions beyond the physical realm. He discussed variations in vulnerability levels and how some cancer patients contend with doubts and reminders more than others. He also discussed that some patients are never told that they were cured thus limiting their ability to put their cancer behind them. Weisman did not use the term "fear of

recurrence” but rather referred to his observations as “worries about survival.” Many of his descriptions are in keeping with uncertainty about the future and how uncertainty, and survival worries were causing ongoing psychosocial problems in cancer patients.

Perceptions of psychological symptoms were also explored by Derogatis, Abeloff and McBeth (1976). They found that increased psychological symptoms were linked with thoughts of poor prognosis in patients with breast as well as other types of cancer. Healthcare providers in their study underestimated the extent of distress cancer patients were experiencing and the authors stressed the importance of evaluating patients for physical as well as psychological issues.

In conclusion, these early studies were the first efforts to describe how depression, anxiety, coping, vulnerability, physical functioning, uncertainty, worry, adjustment and fear of death were ongoing psychosocial issues for cancer patients. These studies were also among the first to describe clinical observations of ongoing psychosocial issues that were previously not documented in breast and other types of cancer survivors. This early research laid the groundwork for further study of psychosocial issues and the discovery of fear of cancer recurrence as an independent construct.

1980-1989

Psychosocial problems remained a research focus for patients with all types of cancer and continued as a theme in the 1980’s literature. Once more, the use of the exact term “fear of recurrence”, or an exact definition of this phenomenon, was scarce.

Freidenbergs, Gordon, Hibbard and Diller (1980) suggested that cancer patients that were distressed needed psychosocial assessment and interventions. They acknowledge that fear of cancer return is a concern for all cancer patients. In their included case study they

discussed a female patient diagnosed with malignant melanoma. They stated that she began to view every mole or freckle change as having the potential for disease return, and suggested that this ongoing worry appeared to be within the limits of realistic vigilance. An ongoing longer-term assessment of this patient was not done to determine if this distress persisted in the ensuing years and when and if this preoccupation with disease return began to expand beyond their definition of realistic vigilance.

Holland and Mastrovito (1980) presented a beginning model of psychological adaptation, suggesting there were two main factors in adaptation, the psychosocial and the medical. Psychosocial factors included cultural context, life cycle tasks and disruptions, coping patterns, and interpersonal relationships. Medical factors included symptoms, site and stage of disease, treatment requirements, rehabilitation, and psychological management by staff. They suggested that when a patient completes treatment, it causes increased anxiety and thoughts that the disease could recur.

Worden (1983) developed an instrument to screen cancer patients for emotional distress after cancer treatment. Worden suggested that some patients coped well initially but then later suffered from psychosocial problems. Worden thought that identifying patients prior to developing obvious emotional distress and deterioration of coping skills would prevent severe emotional issues and preserve their mental health. Coping and emotional distress were consistent themes carried over from the seventies. The association of fear of recurrence to distress was suggested but not firmly established in this early study.

Northouse (1981) identified, in mastectomy patients, that the level of fear of recurrence was lessened in breast cancer survivors who had significant others with whom to discuss post treatment concerns. Northouse found that social support levels were

inversely related to level of fear of recurrence. This was the first study to develop and use a Likert-type instrument to evaluate a level of fear of recurrence. Northouse also provided the first definition of the term fear of recurrence as the “degree of concern reported by subjects about the chances of cancer returning at a future time” (p. 215).

Bartelink, van Dam, and van Dongen (1985) further explored the relationship of the psychological to physical consequences/outcomes of type of surgery for breast cancer patients. They found that patients, one to two years post treatment, who had a radical mastectomy were significantly more bothered by thoughts of cancer recurrence than women who had breast-conserving therapy. It is to be noted that only one Likert-type question was used to assess fear of recurrence in this study.

Two similar studies by de Haes and Welvaart (1985) and de Haes, van Oostrom, and Welvaart (1986) explored the effects of type of surgical intervention and quality of life for breast cancer patients. Fear of recurrence was measured using three Likert-type questions in a scale that they developed for their studies. In both studies, no difference was found in fear of recurrence levels with respect to type of surgical intervention for breast cancer treatment. Younger women had more fear of cancer recurrence and death as compared to older women. No direct association between fear of cancer recurrence and quality of life was reported.

Meyer and Asperen (1989) evaluated fear of cancer recurrence using a new subscale of an instrument they developed for their study of breast cancer patients with stage I disease, who were five to six years post-cancer treatment. They found no difference in level of fear reported by type of surgical intervention. Therefore, surgical intervention was not as significant a predictor of fear of cancer return as age was beginning to become in the literature.

The concept of “worry about cancer” was introduced by Easterling and Leventhal (1989) who compared breast cancer survivors (greater than five years post treatment) to matched controls without breast cancer. Breast cancer survivors, who perceived themselves at high risk for cancer, had more worry about cancer, which was frequently precipitated by ongoing physical and environmental cues. The authors did not specifically examine fear of cancer recurrence, but instead developed a ‘worry about cancer’ scale.

Late in the 1980’s researchers began to explore if there were other predictors related to fear of recurrence outside of the treatment modalities used. Hilton (1988) explored relationships between coping and fear of recurrence in 227 breast cancer survivors. Finding that level of fear of recurrence was related to planful problem solving, positive reappraisal, extent of cancer at diagnosis, time since diagnosis, uncertainty, and age. Younger women and women with more extensive cancers were found to have higher levels of fear. Welch-McCaffery’s et. al. (1989) comprehensive review of the literature found that adult survivors of various types of cancer had a common theme of fear of cancer recurrence and death. Unexpectedly, they found that time since diagnosis did not predict level of fear and that feeling vulnerable with a lack of control appeared to be a more central theme in predicting a level of fear of cancer recurrence and death.

In conclusion, the literature in the eighties expanded fear of recurrence as an issue for cancer survivors; further more themes of worry, along with relationships between type of surgical interventions, psychological states, and coping were explored among cancer survivors. The literature also suggested that age might be associated with level of fear of cancer recurrence however, associations between fear of recurrence and quality of life, although suggested, were unevaluated during this decade. The development of

quantitative instruments or items to measure fear of recurrence also began during this decade.

1990-1999

The 1990's research continued to focus on surgical interventions used for cancer treatments, adjustment to cancer, psychological effects of cancer on survival, age, and coping. The concepts of uncertainty, triggers, and a focus on quality of life associated with fear of recurrence in cancer survivors were common in this decade.

Several investigators examined if patients' fear of cancer recurrence was associated with extent of surgical intervention. These studies often only used one item to measure fear of recurrence. Lasry and Margolese (1992) investigated the trade off hypothesis which suggested that having more surgery initially should result in less fear of recurrence in the future. The authors speculated that breast conserving therapy would be associated with more fear of recurrence (measured using a two question scale developed for this study) than having a mastectomy. Results indicated that type of surgical intervention did not affect level of fear of recurrence, but having to have multiple surgical interventions did. Noguchi et al. (1993; 1993) found similar results in their studies of women in Japan. They found no significant differences in level of fear of cancer recurrence based on type of surgery or stage of breast cancer at diagnosis. In both studies only one question was used to assess level of fear of recurrence even though a few valid instruments had been developed to measure this construct. Curran et al. (1998), also found that type of surgical intervention did not determine the level of fear of recurrence (measured by a new three item scale developed for this study). Psychological adjustment by type and extent of surgical intervention in a group of breast cancer survivors was

explored also by Dorval, Maunsell, Dechenes and Brisson (1998) who found that that type of surgical intervention did not affect psychological adjustment to breast cancer. Pistrang and Barker (1992) as well found that surgery had no effect on level of uncertainty about recurrence or concerns over death and dying. In summary, type of surgical intervention alone was not associated with level of fear of recurrence and many different ways to assess level of fear were employed in this early literature.

Being diagnosed with breast cancer at a younger age added to the level of fear of cancer recurrence in the 1990's literature. Dorval et al. (1998) found that younger women who had a complete mastectomy had increased psychological distress verses older women. Mast (1998), Walker (1997), and Curran et al. (1998) established that younger age was consistently related to a higher level of fear of cancer recurrence in breast cancer survivors.

Kiebert, Welvaart, and Kievit (1993) found that women, regardless of cancer site, had more psychological complaints than men. Breast cancer patients had more psychological complaints than people with other types of cancer, suggesting that continued study of breast cancer patients was needed, as they appear to be more distressed than survivors of other cancer types. The authors also found that routine follow-up decreased patients' level of fear of recurrence (assessed by a newly developed three question Likert-type scale). Similar to other studies conducted during this time period, this group did not define or use an exact definition of fear of recurrence.

Uncertainty also became a topic linked with fear of recurrence in the 1990's. Pistrang and Barker (1992) explored communication patterns and disclosure of concerns of breast cancer survivors. In their sample of breast cancer survivors (2 years post diagnosis) women's greatest concerns included uncertainty about recurrence and the

effect of their illness on other people. The next highest concerns were about death and dying along with physical issues due to re-treatment.

Nelsons' (1996) qualitative study of nine women who were 2-6 years post-treatment, found that an uncertain future and fear of possible recurrence of disease was a common theme in breast cancer survivors. The author noted that uncertainty decreased over time but that there were triggers; such as a return visit to the hospital or clinic that increased fear levels and feelings of vulnerability. Pelusi (1997) did not call these concerns triggers but reported that hearing about other women's recurrence or death increased level of fear. The media was also identified as a source that had the potential to increase level of fear among the women in her study. Mast (1998) found that the level of uncertainty did not decrease over time in her quantitative study of breast cancer survivors who were six years post treatment. For these women level of uncertainty remained moderately high over time and was positively correlated with fear of recurrence and emotional distress.

Coping reemerged in this decade of literature in a qualitative study by Fredette (1995), exploring different coping strategies reported by breast cancer survivors 8-30 years after their diagnosis and treatment. Whereas most of the women studied coped well they continued to fear that their cancer would return and experienced uncertainty about the future.

Fear of recurrence was also examined in significant others during this decade. Walker (1997) modified the Fear of Recurrence Questionnaire (Northouse,1981), to study couples level of distress and evaluate adaptation in both members of dyads. It was found that the more the couples discussed the illness, the higher their level of fear of recurrence went especially in the significant other, suggesting that as fear of recurrence increased so

did communication. The couples also exhibited an increase in perceived emotional distress levels.

Fear of cancer recurrence in the nineties was found to be an ongoing issue that did not lessen as time passed. Carter's (1993) qualitative study of breast cancer survivors found that women pass through six stages of the survival process and some may not move to a stage of acceptance or adjustment after treatment has ended. Women reported that they never forgot that they had cancer and they expressed fear that their cancer may come back. Her final phase of "Flashing Back" is consistent with an ongoing need by women to adjust to their cancer diagnosis/treatment by reevaluating, re-working, and reintegrating their experience into their lives. Ferrell et al.'s (1997) qualitative study also assessed fear of recurrence within the section of psychological well-being component of quality of life. Women had an awareness of death and accepted that this may be an outcome regardless of the treatment they received. These survivors along with the women in Ganz, Coscarelli, Fred, Khan, Polinsky and Petersen (1996) were found to fear recurrence of their cancers, in varying degrees, for the rest of their lives. Other studies in this decade also attempted to link prior aspects of a person's personality such as coping style with survival outcomes, and levels of ongoing psychological distress (Tross et al., 1996; Watson, Haviland, Greer, Davidson, & Bliss, 1999)

In conclusion, the literature of the nineties continued to associate fear of cancer recurrence with younger age, death, gender, and coping. Researchers also reported on varying degrees of fear of recurrence. Prior to this decade many researchers added single items or a few questions to their studies to assess fear of recurrence. Within this decade instruments were being developed that measured fear of recurrence. Lee- Jones et al. (1997) reported that there remained no clearly accepted definition of fear of recurrence in

the ninety's. Studies of fear of recurrence as a separate entity were sparse in this decade and lacked a commonly used instrument by the majority of researchers to measure the level of fear of recurrence. Findings from these studies did however; begin to identify fear of recurrence as a common concern needing further in-depth study.

2000-Present Literature

The research literature in the 2000's continued with many of the same themes identified in earlier research highlighting that fear of cancer recurrence was now consistently being found in even long-term cancer survivors. Wolff et al. (2005) reported that 53% of the subjects in their research found their emotional needs were harder to meet than their physical needs and 70% of respondents suffered depression due to having had cancer. In a qualitative study of Canadian cancer survivors of various types, Maiedema, Tatemichi, and MacDonald (2004) were surprised at the intensity of fear of recurrence and how this seemed to pervade and saturate every aspect of survivors' lives regardless of time since diagnosis or type of cancer. Cappiello, Cunningham, Knobf, and Erdos (2007) also found that 65% of their sample of breast cancer survivors reported (one open-ended question) that fear of recurrence was a common ongoing concern regardless of how far they were out from their initial treatment. Diemling et al. (2006) found that even long-term survivors (greater than 5 years) continued to worry about their cancer returning (one of four items on another newly developed Cancer Related Health Worries Scale), getting a new type of cancer, or that a current symptom may indicate that their cancer has indeed returned. In a cross sectional study, breast cancer subjects, regardless of age, had moderate fears of disease recurrence (measured by an item on fear of recurrence within

the QOL-CS) and of developing a second cancer (Cimprich, Ronis, & Martinez-Ramos, 2002).

Psychological distress and adjustment continued to be a focus as researchers attempted to explain why some women, post treatment, exhibited more psychological issues than other women after treatment ended (Baider et al., 2003; Bleiker, Pouwer, van der Ploeg, Leer, & Ader, 2000; Hack & Degner, 2004; Kiss & Meryn, 2001; Kornblith & Ligibel, 2003). Researchers found that women with perceived increased stress at diagnosis, regardless of the cause, were more likely to have increased anxiety and exhibit depressive symptoms after treatment had ended. The impact of a breast cancer diagnosis was related to more depression and anxiety and carried through from initial treatment into the survivorship phase (Allen, Savadatti, & Levy, 2009; Edwards & Clark, 2004; Golden-Kreutz & Andersen, 2004; Kissane et al., 2004; Reddick, Nanda, Campbell, Ryman, & Gaston-Johansson, 2005; Sumerset, Stout, Miller, & Musselman, 2004; Wong-Kim & Bloom, 2005).

Death was a theme that reemerged in various studies (Little & Sayers, 2004; Vickberg, 2001; Wolff et al., 2005). Death awareness was found by Little and Sayers (2004) to permeate the lives of multiple types of cancer patients in their qualitative study of 15 cancer survivors and 3 partners of cancer survivors. This awareness had variable effects on survivors depending on where they were in their cancer journey. Recently treated survivors had more vivid fears of death than those who were long-term survivors. Many of the participants in this study however, regardless of time since diagnosis, reported having a fear that they may eventually die from their cancer. This is in keeping with research done by Vickburg (2001) and with an online survivorship survey of the Lance Armstrong Foundation (Wolff et al., 2005) in which 59% of respondents with

various types of cancer diagnosis felt that they would die from something other than cancer suggesting that the remaining respondents felt that they would die from their cancer.

One newer area in the cancer literature in the late 1990's, early to mid 2000's was the concept of cancer related traumatic stress, intrusive thoughts and how these concepts link to fear of recurrence. Initial studies indicated that breast cancer survivors and breast cancer patients with metastatic disease had high fear of cancer and psychological distress but few women actually met DSM-IV criteria for Posttraumatic Stress Disorder (PTSD)(Butler, Koopman, Classen, & Spiegel, 1999; Hampton & Frombach, 2000; Palmer, Kagee, Coyne, & DeMichele, 2004). Intrusive thoughts, sense of a foreshortened future, and assessment of triggers are all factors used to assess for PTSD. They are thought to be a part of normal vigilance in cancer patients as these threats are real and it is acknowledged that breast cancer has the potential to return in the future (Brewster et al., 2008; Palmer et al., 2004). However, Black and White (2005) who examined haematological cancer survivors disagreed with these findings. They found that survivors with greater levels of fear had symptoms of posttraumatic distress. They suggested that a higher fear score may indicate a "sense of serious current threat" affecting appraisal and memory of the patient and increasing symptoms consistent with posttraumatic distress. Currently the exact level of fear of recurrence considered to be normal vigilance versus an indicator of psychosocial distress is still under-investigated.

Uncertainty or the inability to structure meaning from illness-related events (Mishel, 1988) has circulated in the literature for several decades linked with adjustment to breast cancer. Uncertainty and fear of cancer recurrence have become a focus of research (Andersson & Albertsson, 2000; Ashing-Giwa et al., 2004; Gil et al., 2004;

Sammarco, 2001; Schnipper, 2003). Illness uncertainty was found to persist long after diagnosis of breast cancer and was linked with the notion of ‘triggers’ that cause an increase in fear of breast cancer recurrence (Gil et al., 2004).

Younger age, lower education level, and having had adjuvant chemotherapy continue to be factors related to higher levels of uncertainty, poorer adjustment, greater reported distress and more fear of cancer recurrence (Clayton, Mishel, & Belyea, 2006; Costanzo et al., 2007; Hainstock, 2003; King, Kenny, Shiell, Hall, & Boyages, 2000; Kornblith et al., 2007; Stanton, Danoff-Burg, & Huggins, 2002; Van den Beuken-van Everdingen et al., 2008b). Younger breast cancer survivors seem to need a much larger social support network in order to adjust to living life with the unpredictability of the effects of cancer treatment and the threat of cancer recurrence (Sammarco, 2001).

The presence of physical symptoms has been linked with decreased quality of life and also continues to be linked to fear of cancer recurrence (Bennett, Winters-Stone, & Nail, 2006; Costanzo et al., 2007; Deimling, Sterns, Bowman, & Kahana, 2005; Hainstock, 2003; Kuehn et al., 2000; Mrozek & Shapiro, 2005; Rabin, Ward, Leventhal, & Schmitz, 2001). Research has shown that breast cancer survivors who report ongoing symptoms after treatment is completed, such as fatigue, pain, and arm concerns, have an increased fear of cancer recurrence, and report a lower perceived quality of life (Bell, Ziner, & Champion, 2009; Deimling et al., 2006; Kuehn et al., 2000).

Current research in this decade has shown that there are several ongoing consequences (i.e., depression, pain, fatigue, anxiety, etc.) in multiple domains of quality of life associated with having survived breast cancer and that fear of recurrence is at least in part associated with many of them (Clayton et al., 2006; Costanzo et al., 2007; Gil et al., 2004; Kuehn et al., 2000). Strong associations appear to be difficult to find between

these many factors, and fear of recurrence, suggesting that fear of recurrence may indeed need to be studied more thoroughly as an individual construct rather than just as one of many contributory factors that affects quality of life in breast cancer patients (Black & White, 2005; Costanzo et al., 2007). In summary research on fear of recurrence, as a standalone distressing consequence in cancer survivorship, has just begun to emerge and further in-depth investigation into this phenomena is needed.

Discussion

Findings from this review indicate that a diagnosis of cancer is a life-altering event that does not conclude when treatment ends, but rather extends into the survivorship phase for many cancer patients. Researchers found, as early as the 1970's, troubling clinical manifestations in surviving cancer patients such as fear of cancer returning and fear of an ultimate untimely death (Weisman, 1979a; Weisman & Worden, 1976). These clinical observations prompted further research spanning over three decades that investigated the effects of many different factors such as surgical interventions; return to physical functioning, coping, age, gender, level of education, stage at diagnosis and quality of life, to name just a few, and how these were related to adjustment in the survivorship phase of cancer care (Clayton et al., 2006; Dorval et al., 1998; Ferrell et al., 1997; Hilton, 1988; King et al., 2000; Kornblith & Ligibel, 2003; Kornblith et al., 2007; Tross et al., 1996; Watson et al., 1999).

Current research has attempted to identify the cause of and treat ongoing psychosocial distress in cancer survivors with limited success (Cappiello et al., 2007; Knobf, 2011; Sherman et al., 2009). Fear of cancer recurrence has emerged from this literature as a potential contributor to ongoing distress for cancer survivors requiring

concentrated attention on it separate from other causes of distress. The relationship of fear of recurrence to other psychosocial issues in survivorship such as anxiety, depression, uncertainty, worry, personal and disease characteristics, and coping needs further research.

Findings from this review also indicate a lack of refined well-developed instruments to accurately measure and identify cancer survivors who experience fear of cancer recurrence. These concerns have prompted a new trend toward instrument development and more focused attention on the relationship of fear of recurrence to psychosocial distress in cancer survivors. New instrument development appears to be focused on how to accurately measure the multi-dimensional aspects of fear of recurrence, including triggers, fear responses, coping skills used and outcomes (Simard & Savard, 2009).

Methodological trends observed, such as smaller sample sizes (Andersson & Albertsson, 2000; Hack & Degner, 2004; Miedema et al., 2004; Vickberg, 2001), no uniform measurements of fear of recurrence consistently used (Andersson & Albertsson, 2000; Cappiello et al., 2007; Cimprich et al., 2002; King et al., 2000; Kornblith et al., 2007; Lasry & Margolese, 1992; Miedema et al., 2004; Ziner, 2008), rarely viewing fear of recurrence as a separate or endpoint entity (Ziner, 2008) and lack of in-depth study of fear of cancer recurrence as contributing to survivorship distress suggests that future research with more rigor may be warranted.

In summary fear of cancer recurrence has been emerging as a psychosocial concern for over 40 years in the cancer literature yet it remains in the infancy of its development. Concentrated research exclusive to this construct must become a focus for us to truly understand its impact and effect on the cancer survivorship group as a whole.

Conclusion

This historical review has discovered that many factors such as young age, ongoing persistent physical symptoms, triggers, lower education level, having to have multiple surgeries, history of psychological issues, lack of social support, decreased quality of life, and adjuvant treatments, have been associated with moderate to high levels of fear of recurrence. Conversely, other factors initially thought to be associated with fear of recurrence were found to be unrelated; for example, type of surgical intervention, stage of disease at diagnosis, type of adjuvant treatment, marital status, time since surgery, and time since last treatment.

The increasing number of cancer survivors and these initial findings appear to have sparked a trend, in the mid to late 2000 literature, toward further instrument development. Researchers are just now beginning to examine if there is a level where fear of recurrence should no longer be considered normal vigilance and are attempting to identify those with high levels who may be in need of clinical intervention (Black & White, 2005; Simard & Savard, 2009; Vickberg, 2001, 2003). Once this has been established clinical interventions must be implemented and evaluated to ensure ongoing quality of life in the survivorship phase of cancer care.

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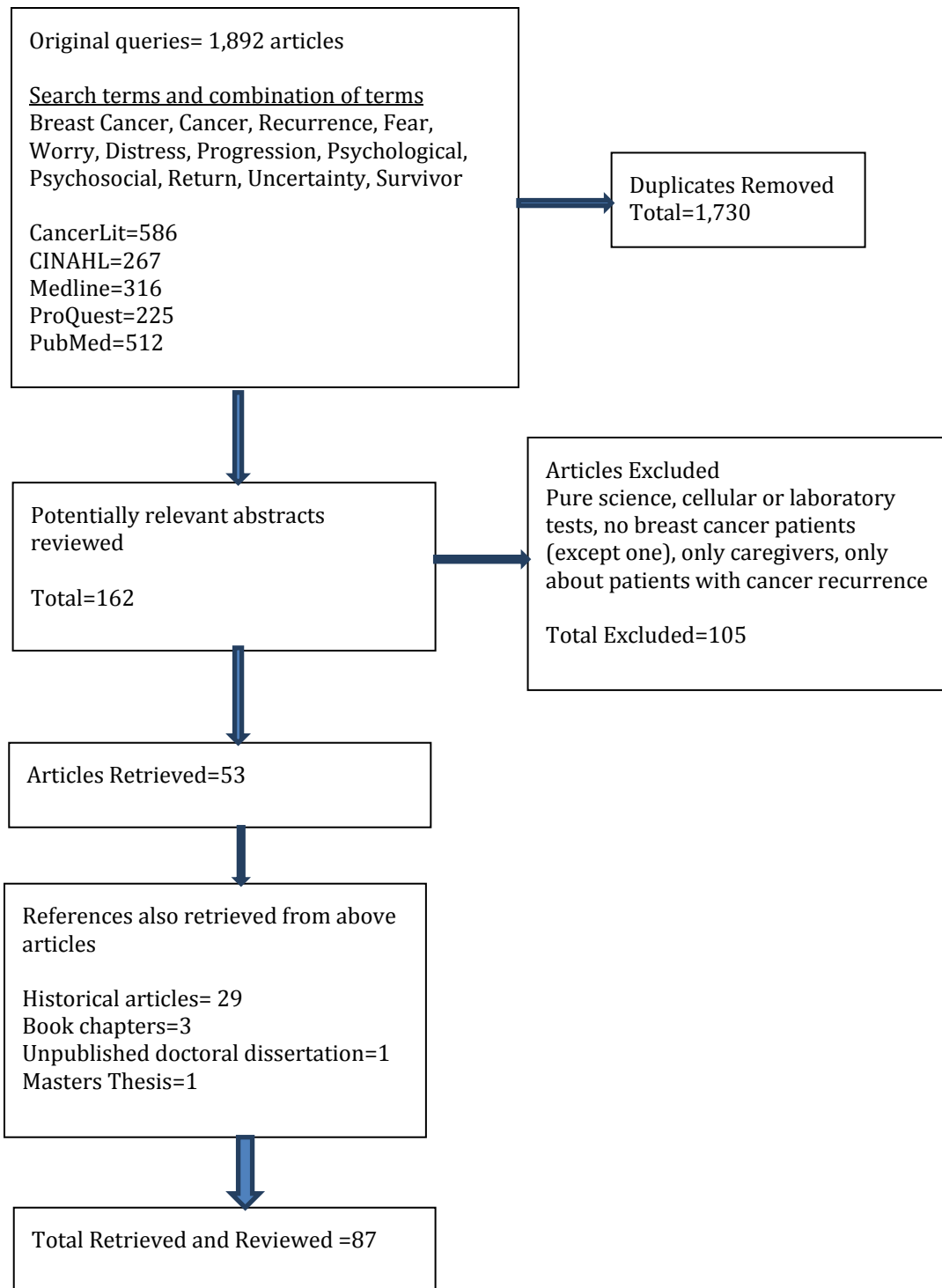
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Figure 1.2
Article Literature Search



CHAPTER III
THE RELATIONSHIP OF ILLNESS REPRESENTATIONS AND COPING TO
FEAR OF CANCER RECURRENCE

INTRODUCTION

There currently are over 2.6 million women alive in the United States who have survived a breast cancer diagnosis (National Cancer Institute [NCI], 2011). Breast cancer survivors are in need of follow-up care to monitor for latent physical effects of treatment, breast cancer recurrence, and evaluation/treatment of psychological needs (Alder & Page, 2008). Given this large growing pool of survivors' research and follow-up care needs to shift from acute to long term with more concentration on issues specific to survivorship especially within the realm of breast cancer research.

Post-treatment distress, a term coined by the National Comprehensive Cancer Network (NCCN), describes the non-physical consequences of cancer treatment that are a major concern for all cancer survivors (Vachon, 2006). Post treatment distress, manifested in psychological concern has been reported by many cancer survivors to be greater and more troublesome than physical consequences (Wolff et al., 2005). Psychological issues such as levels of anxiety, depression, worry, and uncertainty are as commonly reported as physical functioning issues (Maguire et al., 1978; Morris, Greer, & White, 1977; Ray, 1977). Fear of cancer recurrence has emerged from the literature as a

universal ongoing concern that breast cancer patients face to varying degrees in their survivorship trajectory (Bartelink, van Dam, & van Dongen, 1985; Black & White, 2005; Janz, Hawley, Mujahid, Giggs, Alderman, Hamilton, Graff, Jagsi, Katz, 2011; Lee-Jones, Humphris, Dixon, & Hatcher, 1997; Miedema, Tatemichi, & MacDonald, 2004; Northouse, 1981; Van den Beuken-van Everdingen et al., 2008; Vickberg, 2001; Ziner, 2008). However, most breast cancer survivorship research has not explored fear of cancer recurrence and its impact on survivorship.

The purpose of this study was to more fully explore the construct fear of cancer recurrence during survivorship in a post-treatment breast cancer population. This study was designed to specifically examine the relationships between a) patient characteristics (demographic and clinical), b) illness perceptions (illness representations and risk perceptions), c) coping styles (cognitive and emotional focused strategies), and d) fear of cancer recurrence as the outcome variable among cancer survivors.

THEORETICAL FRAMEWORK

A Breast Cancer Survivorship Model of Predictors of Fear of Cancer Recurrence (see Figure 1) deduced from Leventhal, Brissette and Leventhal's (2003) *Common Sense Model of Illness Representations* guided this study. Leventhal's work postulates that each individual will form illness representations based on one's past experience with any illness event (Leventhal, Nerenz, & Steele, 1984). These illness representations, as dynamic encoded memory structures, are then recalled to assist the individual in understanding and coping with current illness threats (Cameron & Leventhal, 2003; Leventhal et al., 1984; Rozema, Völlink, & Lechner, 2009). Illness representations guide individuals in interpreting new illness threats and allows for both cognitive and emotional reactions along with potential coping strategies to assist in dealing with the health threat.

Illness representations are fluid and change as new information is fed back into the representation. This then allows for the use of different coping strategies and the development of new representations when illness threats are reencountered (Anagnostopoulous & Spanea, 2005; Leventhal et al., 1984).

Cognitive and emotional representations are separate yet related components of illness representations. Emotional representations were overlooked in the initial instrument development to measure illness representations and were not clearly defined (Moss-Morris et al., 2002). Emotional representations are responses to the illness that grab the attention of one's unconscious and cause an unwanted reaction. Emotional representations consist of feelings of depression, upset, anger, anxiousness, worry and fear (Moss-Morris et al., 2002). Emotional reactions expressed, such as fear and/or anger to symptoms and other extraneous events were found to be separate motivators for seeking healthcare. These motivators were found to be unrelated to the perceived seriousness of the disease and are an alternative way to regulate ones emotional reactions to an illness situation (Moss-Morris et al., 2002).

Figure 1 illustrates the midrange model that guided this study, after an in-depth review of the Common Sense Model. The model postulates that patient characteristics (demographic and clinical), illness representations, perceived risk, and coping styles are associated with fear of cancer recurrence. The model expands on the original Common Sense Model to include the emotional representations suggested by Moss-Morris et al. (2002) and perceived risk as components of illness perception development with fear of cancer recurrence becoming the primary outcome. It also postulates a connection between the independent variables of patient characteristics (demographic and clinical), illness perceptions (illness representations and perceived risk), and coping style with the

associated level of fear of cancer recurrence. This modified model suggests that self-regulation is relevant to understanding fear of cancer recurrence.

Initial exploration of the relationship between self-regulation and the fear of cancer recurrence needs to be conducted to examine if illness representations of breast cancer, a component of self-regulation, are related to level of fear of cancer recurrence. Multiple authors have also supported that patient characteristics (demographic and clinical), illness representations, and coping styles are related in cancer patients, however, the extent of these relationships and their association to fear of cancer recurrence remain unknown (Anagnostopoulous & Spanea, 2005; Costanzo, Lutgendorf, & Roeder, 2010; Millar, Purushotham, McLatchie, George, & Murraray, 2005; Royer, Phelan, & Heidrich, 2009; Rozema et al., 2009; Stewart et al., 2001).

LITERATURE REVIEW

This literature review focuses on the main components of the modified model derived from the Common Sense Model (see Figure 1). Each subsection explored here refers to a key component of the modified model. It also introduces the main construct of fear of cancer recurrence and its potential relationship to the other model components of patient characteristics, illness representations, and coping styles.

Fear of Recurrence and Breast Cancer Patients

Fear of cancer recurrence is not a new phenomenon. As early as the 1970's researchers have reported clinical observations of seemingly well-adjusted cancer survivors experiencing subclinical issues and distress long after their cancer had been treated and deemed in control (Abeloff & Derogatis, 1977; Greer, 1979; Weisman, 1976; Worden & Proctor, 1976). This clinically observed distress linked fear of cancer returning with the potential subsequent outcomes of recurrence associated with ongoing

pain, infirmity, loss of control, being alone, and ultimately death (Abeloff & Derogatis, 1977; Greer, 1979; Worden & Proctor, 1976). Several researchers have studied breast cancer survivors who had mastectomies and found that psychological issues such as levels of anxiety, depression, worry, and uncertainty were commonly reported along with physical functioning issues (Maguire et al., 1978; Morris et al., 1977; Ray, 1977). Fear of cancer recurrence research expanded from these earlier studies and has been identified as a distinct construct different than anxiety, depression, or Post Traumatic Stress Disorder (PTSD) (Black & White, 2005; Costanzo et al., 2007; Mast, 1998; Palmer, Kagee, Coyne, & DeMichele, 2004; Simard & Savard, 2009; Simard, Savard, & Ivers, 2010; Stanton, Danoff-Burg, & Huggins, 2002; Van den Beuken-van Everdingen et al., 2008; Vickberg, 2003; Walker, 1997; Ziner, 2008)

Presently, level of fear of recurrence is not used as a measure of distress in the clinical setting although clinical anecdotes suggest that breast cancer and other types of cancer survivors may be suffering from its unknown chronic effects. Researchers acknowledging this gap in clinical care continue to attempt to distinctively categorize and measure fear of cancer recurrence so that it can be assessed and interventions developed to address it. Fear of cancer recurrence may be one significant unmeasured source of ongoing psychological distress in breast cancer survivors and consequently further research is warranted (Costanzo et al., 2007; Simard & Savard, 2009).

Patient Characteristics

Demographics

Fear of cancer recurrence in breast cancer survivors has been shown to cross all ethnic lines and be stable over time with little drop in intensity from time of diagnosis (Ashing-Giwa et al., 2004; Costanzo et al., 2007; Ferrell, Grant, Funk, Otis-Green, &

Garcia, 1997; Ganz et al., 1996; Gil et al., 2004; Mehnert, Berg, Henrich, & Herschbach, 2009; Miedema et al., 2004; Stanton et al., 2002; Van den Beuken-van Everdingen et al., 2008; Van Gestel et al., 2007). Younger age, one of the most commonly accepted objective predictors of breast cancer recurrence, has consistently been related to an increase in fear of cancer recurrence (Costanzo et al., 2007; Curran et al., 1998; J. deHaes, vanOostrom, & Welvaart, 1986; J. deHaes & Welvaart, 1985; Kornblith et al., 2007; Mast, 1998; Mehnert et al., 2009; Stanton et al., 2002; Walker, 1997; Ziner, 2008). Having ongoing symptoms or pain (Abeloff & Derogatis, 1977; Greer, 1979; Worden & Proctor, 1976) a higher level of anxiety (Ashing-Giwa et al., 2004; Bleiker, Pouwer, van der Ploeg, Leer, & Ader, 2000; Nelson, 1996; Ray, 1977) and having a lower income (McVea, Minier, & Johnson Palensky, 2001) have also been associated with a higher level of fear, even though these characteristics are not objectively connected to a higher risk of cancer recurrence. Education level, however, has been inconsistently related to level of fear of cancer recurrence, with some studies reporting more fear in less educated women while others suggest better educated women have more fear (Costanzo et al., 2007; Kiebert, Welvaart, & Kievit, 1993; King, Kenny, Shiell, Hall, & Boyages, 2000; Mehnert et al., 2009).

Clinical Characteristics

Objective medical predictors of cancer recurrence, such as surgical intervention type or amount of surgical interventions (Bartelink et al., 1985; Curran et al., 1998; J. deHaes et al., 1986; J. deHaes & Welvaart, 1985; Lasry & Margolese, 1992; Noguchi, Kitagawa, et al., 1993; Noguchi, Saito, et al., 1993; Northouse, 1981; Pistrang & Barker, 1992; Walker, 1997) and stage at diagnosis (Balch & Jacobs, 2009; Hilton, 1988; Northouse, 1981; Worden & Proctor, 1976), have shown only inconsistent associations

with fear of cancer recurrence. Time since diagnosis, has only been weakly linked with changes in level of fear of recurrence, with some studies showing a slight decrease in fear the further the breast cancer survivor is away from the initial cancer diagnosis (Cappiello, Cunningham, Knobf, & Erdos, 2007; J. deHaes et al., 1986; J. deHaes & Welvaart, 1985; Gil et al., 2004; King et al., 2000; Mehnert et al., 2009; Miedema et al., 2004; Northouse, 1981; Stanton et al., 2002; Van den Beuken-van Everdingen et al., 2008). Women who have had adjuvant chemotherapy report more fear of cancer recurrence unassociated with other more objective predictors of recurrence such as stage at diagnosis (Costanzo et al., 2007; King et al., 2000; Lasry & Margolese, 1992; Little & Sayers, 2004).

These findings suggest that fear of cancer recurrence is an ongoing issue for breast cancer survivors and seemingly remains unrelated to many objective disease predictors of recurrence. Currently it is unclear when normal vigilance (for example, attention or watchfulness for a breast cancer recurrence) changes to a persistent cause of distress unrelated to objectively appropriate concern. Nor is it clear how this distress is expressed cognitively, somatically, and affectively as fear of cancer recurrence in breast cancer survivors (Lee-Jones et al., 1997).

Illness Representations

Many aspects of the Common Sense Model and its six content domains of *timeline, cause, control, consequences, symptom attribution* and *emotional representations* have been found to be useful when exploring patients' perceptions of breast cancer in the few studies that used this model. Findings from these studies have produced mixed results, using a variety of different instruments to measure illness representations and when assessing a multitude of different constructs and endpoints, none of which were fear of cancer recurrence.

Rozema, Völlinkj and Lechner's (2009) research on breast cancer survivors found that illness representations vary for each person yet play an important role in perceived health. They also found that illness representations were weakly related to choice of coping strategies used by the breast cancer survivors. Anagnostopoulos and Spanea (2005) found that the content domains of *cause*, *control/cure*, and *consequence* beliefs differed in the illness representations of women who have never had breast cancer as compared to women who have had the disease. Nonmalignant women's representations indicated a weaker belief in curability/control of breast cancer and more serious physical, emotional, and economic consequences than the representations of breast cancer survivors who were studied. The authors suggest that the breast cancer illness representations changed as women, who experienced the disease, incorporated into their schema a cognitive reassessment of the meaning of breast cancer.

Millar et al. (2005) found that within one year of surgical treatment, distress, at the one-year post-operative mark was associated with perception of the content domains of *timeline and illness identity (symptom attribution)*. Women who believed that their illness had a shorter time line had a greater tendency to associate all symptoms to breast cancer, and also had more overall distress. Breast cancer survivors who felt that cancer had more serious *consequences*, or attributed the *cause* of their breast cancer to be associated with health behaviors or stress, were more likely to report improvement in their diet, increased physical activity, decreased alcohol use, and attempts to decrease stressors (Costanzo et al., 2010). Stewart and colleagues (2001) also found that many breast cancer survivors attributed their breast cancer to the specific content domain of *causes* such as stress, genetics or environmental factors. Sixty percent of survivors believed that keeping a positive attitude protected them from a cancer recurrence

suggesting that personal beliefs about cancer's *cause* and recurrence need further investigation.

Other factors that can influence illness representation have also been reported. Royer et al. (2009) found that older breast cancer survivors represented symptoms they were experiencing after treatment as age related within the content domains of *chronicity*, *cause* and lacking in *control*. As a result, women may underreport potential symptoms related to breast cancer recurrence to health care providers. Cameron, Leventhal, and Love (1998) also found that trait anxiety was related to illness representation in breast cancer survivors taking tamoxifen.

Many of these studies have found only single domains or parts of the six domains of illness representations to be relevant to breast cancer patients. Few have examined the six content domains simultaneously as a coherent whole. As a result, although micro components of the theory are clearly useful, integrative research is needed to produce a clearer picture of the model's usefulness as a whole.

Research on illness representation in other types of cancer found that illness representation was associated with fear of recurrence. Llewellyn and colleagues (2008) reported, in head and neck cancer patients, that perceptions of more severe *consequences* and stronger *emotional representations* of illness were associated with greater fear of cancer recurrence. Predictors of ongoing fear and increased distress in this population were found to be unrelated to any demographic or objective medical factors; for example, stage of disease, type of treatment, or ongoing symptoms suggesting that illness representations combined with other unknown factors may be better predictors of distress in this population.

In summary *timeline*, *illness cause*, *potential for cure or control*, *consequences*, *emotional representations*, and *symptom attribution* have not thoroughly been addressed in the literature. Consequently, a study that explores if these content domains of illness representations are related to fear of cancer recurrence in breast cancer survivorship was warranted.

Perceived Risk

Perceived risk of a health issue is the “risk judgment about the probability that the health issue will be experienced” (Katapodi, Dodd, Lee, & Facione, 2009, p. 307). Risk perceptions about breast cancer recurrence derive from a complex multi-dimensional process. Risk perceptions or perceived risk has been shown to be associated with “health behavior, medical decision making, and the processing of health information” (Klein & Stefanek, 2007, p. 148). It has also been postulated to contribute to illness representation formation (Liu et al., 2010; Partridge et al., 2008; Rakovitch et al., 2003). This attributed risk level as a part of illness representation, whether high or low, spurs on behaviors to minimize the potential outcomes from an illness threat (Lee-Jones et al., 1997).

Perceived risk of breast cancer recurrence has mainly been assessed in women with ductal carcinoma in situ (DCIS) and early stage breast cancer. Women in these studies were unable to accurately predict their risk of recurrence in comparison to their actual medically determined risk levels (Liu et al., 2010; Partridge et al., 2008; Rakovitch et al., 2003). Van Gestel and colleagues (2007) found no differences between DCIS and early stage invasive breast cancer groups when asked about their perceived risk of their cancer returning, although the actual risks of a recurrence in the DCIS group were substantially lower than the early stage invasive group. To date, no research can be found examining the relationship of risk perception, within the context of illness representation,

to coping strategies and fear of breast cancer recurrence in survivors with all stages of breast cancer.

Coping Styles

According to Lazarus (1993) “coping consists of cognitive and behavioral efforts to manage psychological stress” (p. 237). Each individual employs a variety of coping strategies depending on the context of the issue causing the distress and the circumstances surrounding the issue. Coping strategies used by various types of cancer patients are a frequent source of study in the cancer literature (Coyne & Racioppo, 2000). In the realm of breast cancer, problem-focused coping strategies as a type of cognitively focused strategy, such as reframing or acceptance, are associated with decreased anxiety, decreased depression and less psychological distress (Bussell & Naus, 2010; Fredette, 1995; Northouse, 1981; Reddick, Nanda, Campbell, Ryman, & Gaston-Johansson, 2005; Stanton et al., 2002; Vickberg, 2001). Conversely emotion-focused coping strategies, such as escape-avoidance or disengagement, are associated with a heightened threat of cancer recurrence, a higher stage of disease at diagnosis, Posttraumatic Stress Disorder (PTSD) and a younger age (Bussell & Naus, 2010; Hampton & Frombach, 2000; Hilton, 1988; Ray, 1977; Stanton et al., 2002).

Coping styles, which are often explored in association with illness representation in various chronic diseases, are less commonly explored in breast cancer research. Rozma, Völlink and Lecher’s (2009) study on the relationship of illness representation and coping to mental and physical health in breast cancer patients found only weak relationships between coping strategies used and illness representations. Belief that breast cancer would have a chronic timeline was strongly related to the use of cognitive avoidance and behavioral avoidance coping strategies. In addition, a belief that the

disease would have major consequences was associated with less use of cognitive problem focused coping strategies.

Coping, in chronic illness studies, was found to partially mediate a link between illness perceptions and psychological distress (Evans & Norman, 2009) but not found to be a mediator between illness appraisal and depression (Walker, 1997). Coping was also not a mediator between illness representations and mental or physical health in breast cancer patients (Rozema et al., 2009). Coping has, however, not been explored as a moderator between illness representations and psychological distress in any current research on chronic illnesses, cancer or breast cancer survivorship.

It remains unknown how illness perceptions are related to the use of cognitive and emotional coping strategies, and fear of cancer recurrence in breast cancer survivorship. Also it is not known how or if illness perceptions and/or coping strategies have any effect on level of fear of cancer recurrence. The aims of this study therefore are to: 1) examine whether patient characteristics influence illness perceptions of breast cancer; 2) examine how much variance patient characteristics, illness perceptions, and coping styles, account for in fear of breast cancer recurrence, and 3) examine if coping strategies mediate or moderate the relationship between illness perceptions and fear of cancer recurrence

METHODS

Research Design

This study used a cross-sectional descriptive correlational design with data obtained using a web-based survey. A priori power analysis using G*power 3.1 (Faul, Erdfelder, Buchner, & Lang, 2009) indicated that a sample of at least 119 participants would be required to detect a relatively small effect size ($ES=.3$; Cohen 1992), using 80%

power and an α of .05 assuming that the regression model will include 10 independent variables from the model.

Sample

One hundred and sixty eight women from three breast cancer Internet discussion boards followed the link provided to the web-based survey. Of these women 113 subjects finished the survey (response rate of 68%). However, during data screening six further cases were excluded due to an exorbitant amount of missing data. A final sample size of 107 subjects was used for this data analysis.

Eligibility Criteria

Criteria for inclusion were a diagnosis and treatment for any stage of breast cancer (Stage 0-IV). Cases were excluded if the subject was currently in treatment for their primary diagnosis of breast cancer or if they entered the study but did not complete the fear of recurrence questionnaire.

Measures

The measures selected for this study explored all concepts in the *Breast Cancer Survivorship Model of Predictors of Fear of Cancer Recurrence* (see Figure 1 and Table 1 and 2). All of the instruments used in this study were entered into Qualtrics Survey Software® for ease of Internet distribution. Permission from all authors of the instruments was obtained prior to the conversion of their instruments into the Internet survey used.

Patient Characteristics (Demographic and Clinical)

Selected demographic and clinical information was obtained from subjects enrolled in this study. Basic demographic information included: 1) age; 2) race; 3) marital status; 4) education level; 5) employment status and 6) income level. Clinical information consisted of: 1) type and stage of breast cancer at diagnosis; 2) how many and what type of surgical interventions were undergone; 3) if women received adjuvant chemotherapy; 4) if women received radiation therapy; 5) time since diagnosis; 6) if women had adjuvant estrogen depriving therapy, and 7) the presence and effect of co-morbidities.

The State Trait Anxiety Inventory-Trait (STAI-T)© form Y-2 for adults was used to measure trait anxiety. This scale has been used widely to measure the trait of anxiety in many different patient populations (Spielberger, 1983). It consists of 20 self-rating statements on a Likert type scale with 1=almost never to 4=almost always. Nine items of the twenty are reversed scored. This scale has longstanding documented test-retest reliability, validity, with an internal consistency $\alpha=.90$ (Spielberger, 1983). Permission for online use of 200 copies of this scale was acquired prior to its use. In the current study the Cronbach alpha coefficient was .92.

Illness Perceptions

This was addressed using two instruments. The first was the Illness Perception Questionnaire-Revised (IPQ-R), a widely used quantitative measure of illness representations (Moss-Morris et al., 2002). The IPQ-R is comprised of three sections. The first section measures identity (symptom attribution) and consists of a self-report 19-item symptom checklist. The subjects answer yes or no if they have had the symptom

and yes or no if they think the symptom is related to their breast cancer. Only the section where the subjects' state if they believe the symptom is related to their breast cancer is used to determine symptom attribution for this study. This section of the instrument has been modified, as suggested by the originators, to be more applicable to breast cancer rather than other illnesses (Moss-Morris et al., 2002).

The second section consists of 38 statements that measure timeline (cyclical, acute/chronic), control, consequences and emotional representation on a 5 point Likert type scale ranging from strongly disagree to strongly agree. The third section measures perception of cause and consists of 18 items using the same Likert type scale as above. High scores on the identity (symptom attribution), timeline (acute, chronic and cyclical), and consequences represent strongly held beliefs about the number of symptoms attributed to the illness, the chronicity and or cyclical nature of the condition, and the negative consequences of the illness. High scores on the personal and treatment control represent positive beliefs about the controllability of the illness and a personal understanding of the condition. This instrument has a documented internal consistency ranging from $\alpha = 0.79-0.89$ for all subscales, with good reliability and validity with all domains being scored as continuous variables (Moss-Morris et al., 2002). The six subscales for this study ranged from $\alpha = .72 - .87$.

Risk Perception

The Risk Perception Questionnaire is a four-item questionnaire adapted from the work of Katapodi, Dodd, Lee and Facione (2009) and Katapodi, Dodd, Facione, Humphreys and Lee (2010). The first item asks the subjects how much control they feel they have over the possibility of a breast cancer recurrence it is rated on a 5-point Likert

type scale ranging from not at all to a great deal. The next two items have subjects' rate how likely they feel that other women will have a breast cancer recurrence and to estimate how likely they are to have one. It uses a 10-point Likert type scale ranging from definitely will not to definitely will. The last item asks what percent (0-100%) chance do they think they possess of having breast cancer recurrence. It is a fill in the blank numerical response question. Katapodi et al. (2009) previously validated the written scale that was modified for this study. The alpha for the three Likert scaled items within this study was .54 so each individual item was entered as a stand-alone item rather than using the scale as a whole in this study.

Coping Style

The Brief COPE is a 28 item self-report survey consisting of 14 subscales (two items each) using a four point Likert type scale (Carver, 1997). The scale has participants select how much they have been doing the stated coping behavior ranging from not at all to doing it a lot. This instrument had documented internal consistencies ranging from $\alpha = .60-.90$ for all subscales, with good reliability, and validity (Carver, 1997; Carver et al., 1993). In the current study the Cronbach alpha coefficient for all of the 14 subscales ranged from .49-.98 suggesting a low reliability of some subscales. Correlations with each subscale and fear of recurrence had significant results for eight of the fourteen subscales however, four of them had very low Cronbach alpha coefficients therefore factor analysis was undertaken to seek a better fit of this scale to this sample.

Assessment of the pattern of relationships between each of the coping strategies assessed by the Brief COPE was initially done in order to assign each coping strategy to either the category of a cognitive strategy or an emotional strategy prior to hypothesis

testing. Factor analysis, however, uncovered a four-factor solution (see Table 3). These new factors, named Cognitive coping strategies (e.g. seeking emotional support and comfort from others), Self-Blame coping strategies (e.g. refusing to believe this is real, self-criticism, self-blame), Avoidance coping strategies (e.g. extra work to keep mind off of it and increased alcohol and drug use) and Positive Reframing coping strategies (joking about it, looking for the good in it) now had improved $\alpha=.53-.82$ and were used in the regression model rather than the 14 subscales originally suggested by Carver as this was a better fit with the data collected.

Fear of Cancer Recurrence

The Fear of Recurrence Questionnaire a 22-item questionnaire that uses a 5-point Likert type scale from strongly agree to strongly disagree. The questionnaire was specifically designed for use with breast cancer survivors to measure fear of cancer recurrence. Participant scores on the 22 item scale were summed to equal one overall score. It has been used with samples of breast cancer survivors in multiple studies with reported internal consistency $\alpha= .92-.95$ (Black & White, 2005; Hilton, 1988; Mast, 1998; Northouse, 1981; Stanton et al., 2002; Walker, 1997). In the current study the Cronbach alpha coefficient was .90.

Procedures

Women were recruited from the following three Internet breast cancer sites discussion boards: 1) Komen for the Cure™, 2) Young Survival Coalition™ and 3) Network of Strength™. Prior to recruiting subjects the IRB at the University of Michigan approved the study. Permission was then gained from each site to post a web-link to the survey or to allow the investigator be active on the discussion boards and personally

invite members to participate. Once the woman chose to participate in the study she either clicked on the provided link or was emailed the link by the PI. Participants signified consent by proceeding into the survey and completing the questionnaires after reading the introduction page of the survey. Women who completed the survey were also encouraged, at completion, to invite friends and acquaintances to participate in the study to create a snowball recruitment effect.

Data Analysis

Statistical analysis of the data collected was done using PASW 19 (formerly SPSS 19). After completion of all data collection procedures the raw survey material was uploaded into PASW 19 for analysis. Individual variables were examined for out-of-range values, and plausibility of means and standard deviations. When the data was screened for missingness, there were missing data primarily for the demographic variables of *age* and *years since treatment*. Initial descriptive analysis of patient characteristics and other variables (e.g. mean, standard deviations, etc.) was completed (see Table 1 and 2).

Prior to testing the main hypotheses of this study, data screening took place using mean substitution for missing data as the proportion of missing data was very small (< .05%) and of a random nature (Tabachnick & Fidell, 2007). Age, race and question number four on risk perception (typed in value of 0-100%) were excluded from the data set. Race was excluded because of its severe uneven data split, as Non-Hispanic Whites comprised 95.3% of the subjects while the remaining 4.7% of the subjects were spread among three other categories of the variables. Dichotomizing the variable into two levels (Non-Hispanic White and other) would not have resolved this uneven split therefore it was deleted from the database as recommended by Tabachnick and Fidell (2007). Age

had 36.4% missing data and it was felt that mean substitution was not acceptable even though initial testing including missing data found that the results were not substantially changed when dummy coding and mean substitution was used. Risk perception, designed to be a numerical response, also had greater than 30% missing data with some women typing in qualitative comments rather than a number so this item was removed from the data analysis. Time since treatment had 18.3% missing data however; when pattern of missingness was checked it revealed complete randomness in the missing data therefore the missing values were imputed using mean substitution. When general frequency testing was completed no out of range values were detected.

Preliminary analyses of the demographic data and fear of cancer recurrence (e.g. t-test and one way analysis of variance [ANOVA]) to explore the crude/unadjusted relationships among these study variables were completed prior to hypothesis testing. Correlation of all of the other study variables with fear of cancer recurrence was undertaken prior model testing (see Table 5).

Model testing was then undertaken in three steps. The first step was a complete assessment of the correlations between all study variables and fear of cancer recurrence to identify the nature of relationships and variable entry into the standard regression equation. The second step was stepwise multiple regression to determine the amount of variance in model selected predictor variables. The final step was to evaluate if coping was a mediator and or a moderator between illness perceptions and fear of cancer recurrence. Tests for multicollinearity and similarity were also completed and were not present in this data set.

RESULTS

Sample Characteristics

The final analyses were based on 107 breast cancer survivors who completed the online survey. Table 1 demonstrates that the majority of women were between 46-55 years of age, Caucasian (95%), resided in the United States of America (81%), were partnered (74%), highly educated with a bachelors or higher degree (55%), and middle to upper class with an average house hold income of > \$80.000 (49%). About one-half of the sample was employed full time (47%).

Disease characteristics identified that most women had invasive cancer (75%), underwent mastectomies (68%), adjuvant chemotherapy (79%), and radiation therapy (69%). The sample was evenly split between those who had one (46%) or more surgeries (54%), and those treated with adjuvant estrogen therapy (44%). Ten women (9%) self disclosed that they had a breast cancer recurrence. Preliminary investigations indicated that there was not a significant difference between women with or without a recurrence on any of the study variables and therefore these women were retained in the final analysis.

Correlational Data

Prior to model testing the predictor variables, demographic and medical characteristics, illness representations, risk perception, and coping factors were analyzed for their relationship to fear of cancer recurrence (see Table 4 and Table 5). Demographic variables and fear of cancer recurrence (as measured by the Fear of Recurrence Questionnaire [FOR]) were investigated using person product–moment correlation coefficient (see Table 4). Only three demographic variables were retained for the

regression model to evaluate fear of cancer recurrence. Years since treatment, $r = -.324$, $p < .01$, and having had radiation therapy, $r = -.203$, $p < .05$ were negatively related to FOR: woman, who were multiple years out from treatment and/or added radiation therapy, had lower levels of fear of cancer recurrence. The third variable trait anxiety (as measured by STAI-T, see Table 6), had a positive correlation with FOR. High levels of trait anxiety were associated with high levels of fear of cancer recurrence ($r = .410$, $p < .01$). The subsample of age that was collected was also negatively related to fear of cancer recurrence ($r = .320$, $p < .01$) however, it was excluded from the regression analysis due to substantial missing data issues. These three patient characteristics were retained for the standard regression analyses.

FOR was found to be correlated with Illness representations and risk assessment (see Table 5). Timeline, consequences of treatment, emotional representation, symptom attribution, and self-risk of recurrence were correlated. All were strongly positively correlated; as woman felt that as the timeline extended ($r = .421$, $p < .001$), there were more perceived consequences/severity to having had breast cancer ($r = .514$, $p < .01$), attributed more symptoms to her breast cancer ($r = .473$, $p < .01$), and had more of an emotional representation of her breast cancer ($r = .602$, $p < .01$) resulted in an increased level of fear of recurrence. Lastly, if women felt that they had more self-risk of a recurrence ($r = .370$, $p < .01$) than they also had an increased level of fear of recurrence. These five additional variables were also retained for the standard regression analyses.

Lastly two of the new coping scales, Cognitive coping and Self Blame coping, were positively correlated with FOR (see Table 5). As more Cognitive coping strategies ($r = .333$, $p < .01$) were used there was a higher level of FOR. The same was true for use of

Self Blame coping strategies ($r=.200$, $p<.05$). These two variables were the last independent variables retained for the standard regression analyses.

Regression Analysis

Testing of the model was then undertaken using initially standard regression analysis followed by Stepwise and then Hierarchical stepwise regression analysis. This was used to assess the ability of patient characteristics, trait anxiety (STAI-T), illness representations (IPQ-R and Risk Perceptions), and coping styles to predict levels of fear of recurrence (FOR). Preliminary analyses were conducted to ensure no violation of assumptions of normality, linearity, multicollinearity, and homoscedasticity. Tables 4 and 5 identified the predictor variables that had a moderately or higher significant relationship ($p \geq .25$) with fear of cancer recurrence and were included in the regression analysis.

The entered variables explained a total of 63% of the variance ($F(10, 96)=16.04$, $p<.001$) in fear of recurrence. Only three of the ten retained variables, emotional representations ($\beta=.348$, $p<.001$), symptom attribution ($\beta=.172$, $p<.026$) and cognitive coping ($\beta=.268$, $p<.003$) made a significant contribution. Two others nearly reached significance and five were non-significant contributors (see Table 6). Considering these results, Stepwise regression analysis with all ten variables was undertaken. This analysis produced a model that accounted for 60% of the variance ($F(5, 101)=29.92$, $p<.001$) in fear of recurrence and had five variables that made a significant contribution. Emotional representations ($\beta=.415$, $p<.001$), symptom attribution ($\beta=.246$, $p<.001$), cognitive coping ($\beta=.200$, $p<.004$), self- risk of recurrence ($\beta=.187$, $p<.009$), and consequences/severity ($\beta=.179$, $p<.017$) all became significant when controlling for the other five variables in

this equation (see Table 7 and Figure 2). The last step undertaken was to examine how much each of the five remaining variables uniquely contributed to the total variance in the proposed model. Therefore Hierarchical-Stepwise regression analysis was used (see Table 8) finding that emotional representations contributed the largest amount (36%), followed by symptom attributions (14%), self-risk of recurrence (4%), cognitive coping (3%) and Consequences/severity (2%). This suggests that emotional representations and symptom attribution alone account for at least 50% of the variance in fear of cancer recurrence. Interactions between coping, illness representations and fear of recurrence were also explored. Final analysis determined that none existed and therefore coping style was determined to not be moderator between illness representations and fear of cancer recurrence. Baron and Kenny's (1986) four step approach to examine mediation was also used and there were no full or partial mediation found to support that coping is a mediator between illness representations and fear of cancer recurrence.

DISCUSSION

The findings indicate that while there are strong relationships between illness representations, coping strategies, and fear of cancer recurrence, an association with patient/disease characteristics in breast cancer survivors was not present. These findings are consistent with the work of Llewellyn et al. (2008), in head and neck cancer patients, where demographic and medical factors were unrelated to fear of cancer recurrence, but emotional representations and belief in consequences from having cancer were related to fear of cancer recurrence. The results from this study suggest that other aspects such as symptom attribution, and self-risk of recurrence are unique contributors to fear of cancer recurrence and have been overlooked in past research on fear of cancer recurrence. Taken

alone each of the predictor variables contribute a small amount of variance however when combined together a significant picture emerges.

It is readily apparent that the highest correlation of personal characteristics with fear of recurrence in this study was trait anxiety. Women who have elevated trait anxiety when diagnosed with breast cancer will have a higher level of fear of cancer recurrence than women who score lower on this dimension. Our samples mean scores in trait anxiety were no different than the findings of Harrison et al. (2011) suggesting that these women's scores were normative for cancer survivors. Also, in the final analysis, trait anxiety was not retained in the regression analysis suggesting that there are no significant patient/disease variables that were good predictors of fear of cancer recurrence in this study.

Four of the seven main components of illness representations in our model emotional representations, symptom attribution, consequences of having cancer, and perceived self-risk of recurrence were found to significantly contribute to fear of cancer recurrence. These findings are similar to those of Anagnostopoulous and Spanea (2005) and Miller et al. (2005), who found that cause, control/cure, consequences and symptom attribution were related to increased levels of distress in cancer survivors. Emotional representation, which was unfortunately unmeasured in their study, was very strongly associated with fear of recurrence, a form of distress, in ours. It would appear that the strongest predictor of fear of cancer recurrence is an emotional representation of breast cancer. Emotional representations consist of feelings of depression, upset, anger, anxiousness, worry and fear (Moss-Morris et al., 2002). Fear that cancer may return will likely evoke similar feelings of distress and it was not surprising that this component of illness representation was so strongly related to fear of cancer recurrence. This finding

however, may be specific to frequent users of discussion boards alone. Emerging from treatment of breast cancer with more of an emotional representation may prompt these women to seek support on the Internet whereas those who have a different representation may not participate in this activity.

The strength of the relationships found in these study variables suggests that level of fear of cancer recurrence may also be a good indicator of distress. The relationship of symptom attribution or the labeling of bodily symptoms to a past illness, to fear of cancer recurrence suggests that women with heightened bodily awareness have more concern about cancer recurrence. This is a double-edged finding; on one hand being vigilant and reporting concerning symptoms could contribute to earlier and more successful treatment of a recurrence, or could compel women to be seen more frequently than needed (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006). Health care providers also have an opportunity, at the end of cancer treatment, to provide breast cancer survivors with clear examples of what symptoms are specific to a breast cancer recurrence. This type of intervention may decrease fear in survivors that every symptom felt is an indication of disease return.

Being diagnosed with cancer has been reported to have consequences that affect a person and their family personally, emotionally, financially, and physically (Wolff et al., 2005). Women who have experienced breast cancer already know how it disrupted their lives with their initial diagnosis. It was not surprising in our sample that the more women felt that their initial diagnosis of cancer caused consequences in their lives, the more they would be afraid of their cancer coming back to disrupt their lives once more.

An increased self-risk perception of recurrence in women breast cancer survivors was directly related to increased fear of cancer recurrence. It was suggested by Klien and

Stefanek (2007) that this elevated risk perception could motivate women to practice risk reduction behaviors. The most common risk reduction behavior would be to engage in close follow-up care, however, this behavior itself may be triggering more fear of cancer recurrence (Allen, Savadatti, & Levy, 2009; Lee-Jones et al., 1997; Nelson, 1996; Simard et al., 2010). Consequently this may be the reason for the strong connection in this study. Another possibility for this heightened self-perception of increased risk of recurrence in this Internet sample could be that these forum members are continuing to have consequences from their breast cancer (e.g. ongoing symptoms, post treatment side effects). This may in turn persuade them to frequent web sites looking for assistance. It is unknown if this creates an inflated risk perception, specific to this group, that would not be present in women who do not have ongoing issues and potentially were not included in this sample.

Surprisingly, only one coping strategy of four was related to fear of cancer recurrence. Cognitive coping or positive coping strategies such as seeking help, seeking advice, asking for emotional support, praying or meditating, suggest that potentially these women are continuously actively thinking about their breast cancer and the ways which they can cope. If one constantly has breast cancer at the forefront of one's mind it may keep one overly vigilant to a potential recurrence and thus increase the fear of cancer recurrence. This finding is similar to that reported by Walker (1997) where couples who communicated frequently about breast cancer also reported more fear of recurrence. It is almost as if by keeping the cancer diagnosis in the forefront of one's mind and discussions one is more likely to ruminate on it resulting in a heightened fear of recurrence. The other possibility is that this sample of women may have had higher levels of fear of cancer recurrence to begin with which lead them to employ more

cognitive coping strategies in an attempt to lessen their fear (Simard et al., 2010). These findings as well may be specific only to this Internet sample suggesting that they are seeking social support from other forum members because they are lacking it in their personal lives. This is consistent with Bender et al. (2012) who found that survivors of testicular cancer who frequented internet cancer sites had more unmet needs than those who felt their needs were being met.

The current study has several limitations, the sample was very selective and of a homogenous nature with the majority of women being Caucasian, well educated and upper middle class. The findings from this study preclude generalizing them to other breast cancer populations as it was drawn from a self-selected group of women who participate in online discussion forums. This group may have unique characteristics that are not found in the general population of breast cancer survivors. Sample bias may have occurred considering that the sample was exclusively recruited from online and other supportive type breast cancer networks thus excluding women who do not participate in these activities or have access to the Internet (financial constraints).

CLINICAL IMPLICATIONS

This research suggests that breast cancer survivors have ongoing fears that their cancer will return. Fear of cancer recurrence is a legitimate concern that appears to be associated with the development of negative illness representations of breast cancer during treatment. If this is the case, health care providers have the ability to intervene with focused psychological counseling and support during treatment to attempt to offset these fears and other emotional concerns, of an unknown future, and improve the overall wellbeing of patients once treatment is complete. Currently such support is limited as the full dimensions of fear of cancer recurrence and its implications for survivorship remain

in the formative years. By not providing needed support and tools at the clinic level to manage this fear we may be inadvertently driving women to seek support through frequenting Internet support sites. As valuable as the Internet may be it can also be a source of misinformation and may even contribute to a higher level of fear, as many triggers are found online that could bombard frequent users, increasing rather than alleviating their distress (Simard et al., 2010).

CONCLUSION

In conclusion, despite the notable limitations of this study we believe that it extends the literature on breast cancer survivorship and fear of cancer recurrence. Fear of cancer recurrence is significantly related to the development of emotional representations at the end of treatment, increased symptom attribution prior to diagnosis, increased self-risk perceptions of recurrence, and a fear of negative consequences in survivors who frequent internet forums. To a lesser degree the use of cognitive coping strategies are also related to fear of cancer recurrence. Future research should investigate if the reported results in this study can be used to identify and then intervene with cancer patients, while still in treatment, who may be at risk for developing increased distress in survivorship from an increased level of fear of cancer recurrence. Further research should investigate if this model of cancer survivorship holds for other types of cancer survivors and breast cancer survivors who do not participate in online discussion boards/forums. An examination of the influence of frequenting online supportive sites impact, if any, on patients' quality of life in survivorship and if frequent internet use impacts on patient provider relationships is also warranted. Lastly, a closer examination of potential relationships between fear of cancer recurrence, social support, Internet usage, and

utilization of resources may shed some light on how practice during treatment can be altered to support women as they transition into survivorship.

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Table 3.1

Demographic Variables (N=107)
Characteristics of Sample

<i>Variable</i>	<i>M±SD</i>	<i>Variable</i>	<i>M±SD</i>
Age* 26-75 yo 26-45 (43%) 46-55 (38%) 56 and older (27%)	1.85 ± .79	Breast Cancer Type DCIS (24%) Invasive (76%)	1.24 ± .43
Ethnicity Caucasian (96%) Others (4%)	1.04 ± .21	Stage Early Stage (DCIS-Stage 2)(62%) Later Stage (Stage 3 & 4) (38%)	1.38 ± .49
Residence USA (82%) Other (18%)	1.19 ± .39	Surgery Type Lumpectomy (32%) Mastectomy (68%)	1.32 ± .47
Marital Status Partnered (75%) Other (25%)	1.25 ± .44	Years since Treatment One Year (62%) >One Year (38%)	1.38 ± .49
Education High School or less (8%) Some College or Trade (36%) Bachelor's Degree (30%) Professional Degree or Higher (25%)	2.72± .94	Chemotherapy Yes (79%) No (21%)	1.21 ± .41
		Radiation Therapy Yes (69%) No (31%)	1.31 ± .46
Employment Full Time (48%) Other (52%)	1.52 ± .50	Adjuvant Estrogen Yes (45%) No (55%)	1.55 ± .50
Income <\$20,000-\$60,000 (23%) \$61,000-\$80,000 (27%) \$81,000->120,000 (50%)	2.26 ± .82	Recurrence Yes (9%) No (91%)	1.09 ± .29
		Treatment for Recurrence Yes (6%) No (94%)	1.06 ± .23
		Comorbid Conditions Affect Yes (21%) No (79%)	1.20 ± .41

*n=68 age excluded from final analysis

Table 3.2
Descriptive Data on Major Study Variables

<i>Variable</i>			<i>Mean ± Standard Deviation</i>
<i>Scale</i>	<i>Items</i>	<i>Range</i>	<i>M ± SD</i>
FOR	22 (1-5 Likert type scale)	22-110	83.7 ± 14.1
Trait Anxiety	20 (1-4 Likert type scale)	20-80	35.5 ± 10.5
Timeline	6 (1-5 Likert type scale)	6-30	17.5 ± 5.7
Time Cyclical	4 (1-5 Likert type scale)	4-20	10.2 ± 3.4
Consequences	6 (1-5 Likert type scale)	6-30	24.2 ± 4.2
Personal Consequences	6 (1-5 Likert type scale)	6-30	20.8 ± 4.8
Treatment Consequences	5 (1-5 Likert type scale)	5-25	18.9 ± 3.3
Illness Cohesion	5 (1-5 Likert type scale)	5-25	19.3 ± 4.3
Emotional Representation	6 (1-5 Likert type scale)	6-30	20.5 ± 4.7
Symptom Attribution	20 (yes/no -Sum of yes)	0-20	8.3 ± 4.3
Cognitive Coping	12 (1-4 Likert type scale)	12-48	32.6 ± 7.0
Self-Blame Coping	5 (1-4 Likert type scale)	5-20	6.38 ± 1.9
Avoidance Coping	4 (1-4 Likert type scale)	4-16	5.00 ± 1.7
Positive Reframing	3 (1-4 Likert type scale)	3-12	10.47 ± 2.8
Control over own risk of recurrence	1 (1-5 Sliding scale)	1-5	2.69 ± 1.2
Perceived others risk of recurrence	1 (1-10 Sliding scale)	1-10	5.2 ± 1.5
Perceived self-risk of recurrence	1 (1-10 Sliding scale)	1-10	5.0 ± 2.1

Table 3.3
 Psychometric Properties of the Brief COPE for Breast Cancer Survivors (BC-CBS)
 Factor Analysis and Internal Consistency Results

<i>Cognitive Coping</i>			<i>Self Blame Coping</i>		<i>Avoidance Coping</i>		<i>Positive Reframing Coping</i>	
	<i>Item</i>	<i>Loading</i>	<i>Item</i>	<i>Loading</i>	<i>Item</i>	<i>Loading</i>	<i>Item</i>	<i>Loading</i>
	1	.765	13	.763	18	.942	22	.875
	2	.764	14	.670	19	.940	23	.817
	3	.704	15	.605	20	.327	24	.472
	4	.703	16	.573	21	.308		
	5	.696	17	.550				
	6	.662						
	7	.628						
	8	.603						
	9	.597						
	10	.587						
	11	.542						
	12	.422						
<i>Eigenvalue</i>	5.43		2.91		2.09		1.97	
<i>Variance</i>	22.65%		12.15%		8.74%		8.227%	
<i>Cronbach α^*</i>	.82		.70		.53		.67	

Table 3.4
Correlation Matrix for Fear of Cancer Recurrence (FOR) and demographics

	Measure	FOR	AGE	Ethnicity	Marital Status	Education	Employment	Income	Breast Cancer Type	Stage	Surgery Type	Number of Surgeries	Years since Treatment	Chemo	Radiation	Adjuvant Estrogen
1	FOR	1														
2	Age	-.320**	1													
3	Ethnicity	.051	.099	1												
4	Marital Status	.092	-.029	.075	1											
5	Education	.147	.019	-.109	-.100	1										
6	Employment	-.056	.116	-.055	-.264**	.178	1									
7	Income	-.103	.048	-.017	-.293**	-.039	-.176	1								
8	Breast Cancer Type	-.179	.078	.081	.072	.022	-.114	-.022	1							
9	Stage	.083	-.029	.008	-.015	-.106	.175	-.183	-.178	1						
10	Surgery Type	.070	.248*	.134	-.073	.097	-.072	.077	.035	-.208*	1					
11	Number of Surgeries	.126	-.021	.115	.016	-.130	-.051	-.004	-.048	-.124	-.058	1				
12	Years since Treatment	-.324**	.134	.099	-.015	-.072	.059	-.065	.136	.091	-.042	-.047	1			
13	Chemotherapy	-.024	.121	-.116	-.042	-.061	-.184	.083	.446**	-.225*	-.015	.024	.009	1		
14	Radiation Therapy	-.203*	-.016	-.052	.125	-.049	-.092	-.016	.188	-.235*	-.412**	.005	-.027	.291**	1	
15	Adjuvant Estrogen	-.031	-.139	.022	-.038	.054	.005	-.056	.248**	-.101	-.151	.001	.131	.106	.114	1

** . Correlation is significant at the 0.01 level (2-tailed). * . Correlation is significant at the 0.05 level (2-tailed).

Table 3.5
Correlation Matrix for Fear of Cancer Recurrence (FOR) and other main study variables

		FOR	Trait Anxiety	Timeline	Time cyclical	Conseq.	Personal Conseq.	Treatment Conseq.	Illness Cohesion	Emotional Representations	Symptom Attribution	Control Risk	Others Risk	Self-Risk	Cognitive	Self-Blame	Avoidance	Positive RF
1	FOR	1																
2	Trait Anxiety	.410**	1															
3	Timeline	.421**	.250*	1														
4	Time cyclical	.187	.044	.387**	1													
5	Consequences	.514**	.284**	.329**	.177	1												
6	Personal Consequences	-.116	-.291**	-.280**	-.130	-.072	1											
7	Treatment Consequences	-.168	-.175	-.501**	-.267**	-.190*	.422**	1										
8	Illness Cohesion	.007	-.213*	.033	-.245*	-.013	.032	-.032	1									
9	Emotional Representations	.602**	.539**	.242*	.237*	.443**	-.242*	-.163	-.209*	1								
10	Symptom Attribution	.473**	.184	.389**	.192*	.271**	-.130	-.393**	-.010	.167	1							
11	Control Risk	-.017	-.082	-.051	.180	.159	.310**	.256**	.006	-.034	-.137	1						
12	Others Risk recurrence	.085	.072	-.167	-.151	.000	-.130	.193*	.001	.107	.104	-.149	1					
13	Self-Risk recurrence	.370**	.161	.511**	.207*	.265**	-.236*	-.406**	-.006	.150	.358**	-.059	-.316**	1				
14	Cognitive Coping	.333**	-.059	.018	.081	.174	.127	.070	.066	.197*	.213*	.072	.016	-.074	1			
15	Self-Blame Coping	.200*	.467**	.102	.145	.255**	-.087	-.125	-.219*	.360**	-.005	-.024	.042	.011	.069	1		
16	Avoidance Coping	.158	.237*	-.026	-.036	.073	.007	-.070	-.069	.147	.127	-.080	-.017	.117	.174	.059	1	
17	Positive RF	-.001	-.044	.036	.160	.038	.097	.064	.004	-.204*	.173	.106	-.107	-.099	.281**	-.033	.115	1

** . Correlation is significant at the 0.01 level (2-tailed). * . Correlation is significant at the 0.05 level (2-tailed).

Table 3.6

Standard Multiple Regression of all significant independent variables (N=107)

<i>Variable</i>	<i>B</i>	<i>SE</i>	<i>β</i>	<i>t</i>	<i>P</i>
Years since Treatment	-1.189	1.067	-.076	-1.114	.268
Radiation Therapy	-.557	.367	-.103	-1.516	.133
Trait Anxiety	.165	.111	.123	1.488	.140
Time Line	.246	.195	.099	1.260	.211
Consequences	.503	.256	.149	1.967	.052
Emotional Representations	1.040	.245	.348	4.242	.000
Symptom Attribution	.567	.250	.172	2.268	.026
Self-Risk of recurrence	.946	.511	.140	1.851	.067
Cognitive Coping	6.17	1.978	.268	3.121	.003
Self-Blame Coping	-.501	.535	-.071	-.936	.351

Linear regression of all correlations $>p=.25$; $R^2 = .626$ (62.6%); constant=22.45

Table 3.7

Stepwise Regression analysis (N=107)

<i>Variable</i>	<i>B</i>	<i>SE</i>	<i>β</i>	<i>t</i>	<i>P</i>
Emotional Representations	1.23	.213	.415	5.81	.001
Symptom Attribution	.810	.233	.246	3.46	.001
Consequences	.604	.249	.179	2.42	.017
Cognitive Coping	.402	.135	.200	2.98	.004
Self-Risk of Recurrence	1.26	.474	.187	2.65	.009

Linear regression of all correlations $>p=.25$; $R^2 = .597$ (60%); constant=17.51

Table 3.8
Hierarchical-Stepwise Regression analysis of only significant variables

<i>Model</i>	<i>R²</i>	<i>R² change</i>	<i>P</i>
Model Emotional Representations	.363		.001
Model Emotional Representations & Symptom Attribution	.505	.143	.001
Model Emotional Representations, Symptom Attribution & Cognitive Coping	.534	.029	.013
Model Emotional Representations, Symptom Attribution, Cognitive Coping & Self Risk of recurrence	.573	.039	.003
Model Emotional Representations, Symptom Attribution, Cognitive Coping, Self-Risk of recurrence, & Consequences	.597	.024	.017

R² = .597 (60%) Constant = 17.51

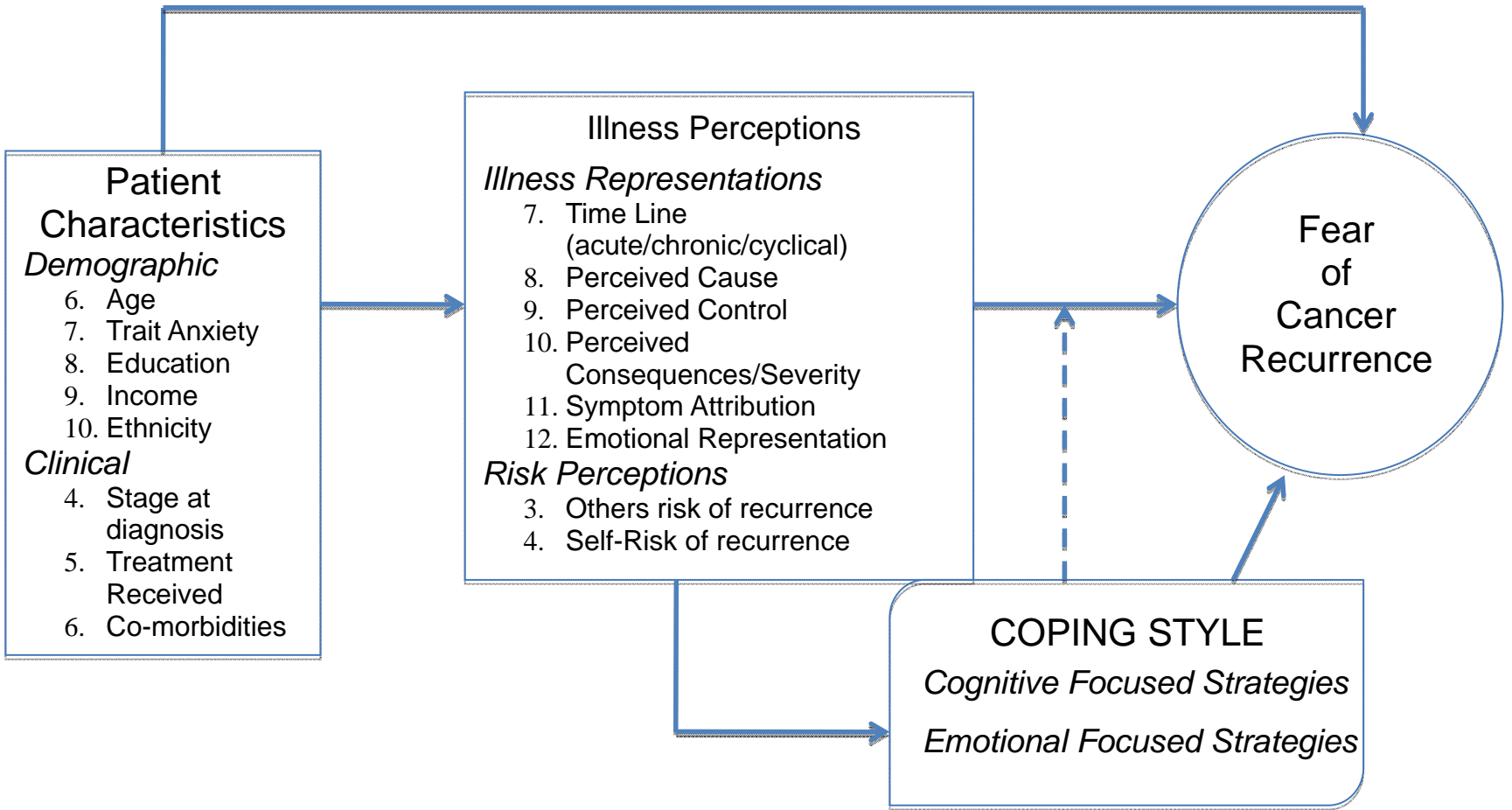
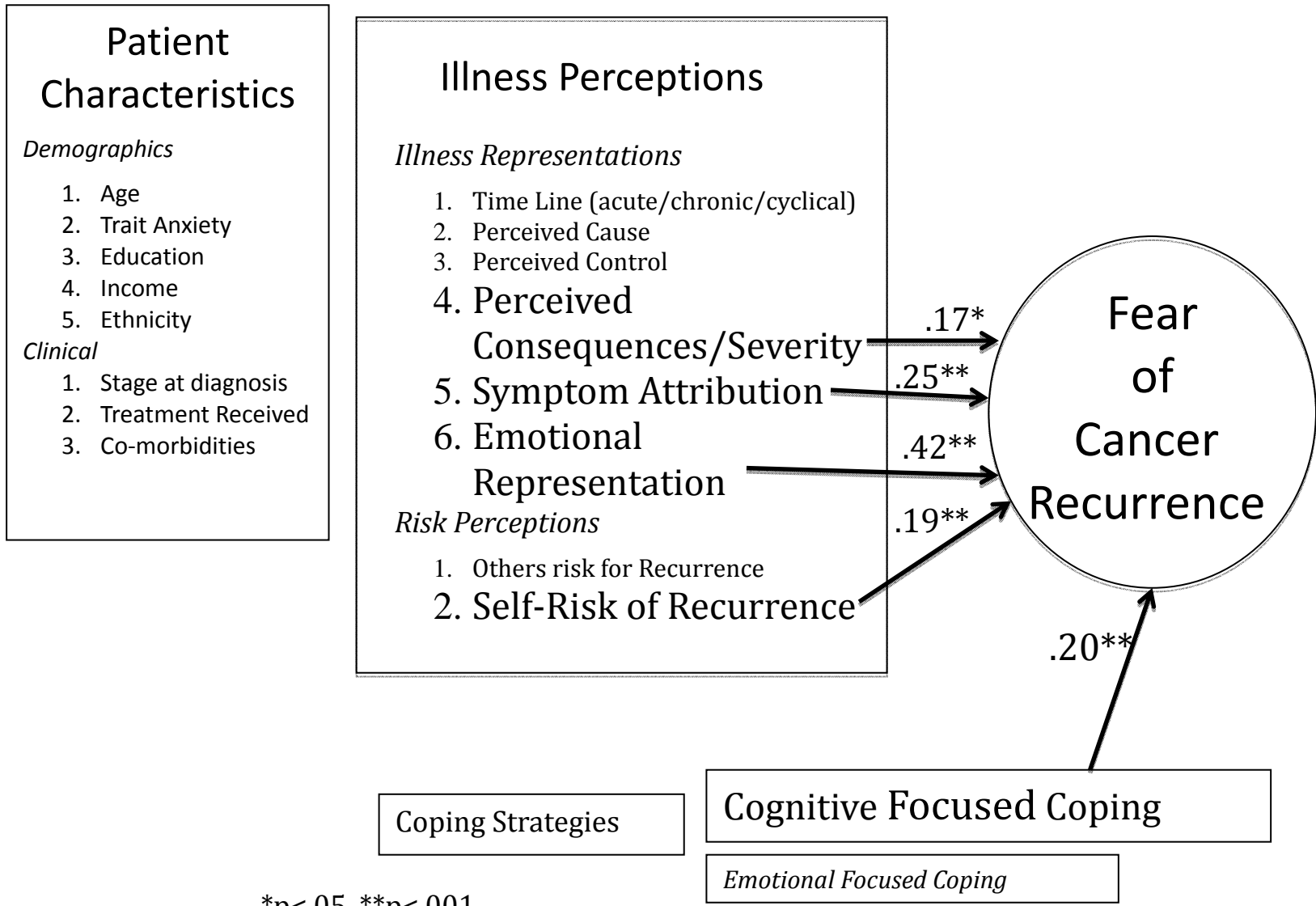


Figure 3.1
Breast Cancer Survivorship Model of Predictors of Fear of Cancer

Figure 3.2
Model Testing-Breast Cancer Survivorship Model of Predictors of Fear of Cancer Recurrence



*p<.05, **p<.001

CHAPTER IV
RECRUITMENT OF BREAST CANCER SURVIVORS FROM ON-LINE
COMMUNITIES: SUCCESSES AND PITFALLS.

INTRODUCTION

Recruitment into all types of health related research studies has become more challenging and costly due to regulations (for example the Health Insurance Portability and Accountability Act (HIPAA)) and the public's increasing concerns over the legitimacy of survey requests (Dillman, Smyth, & Christian, 2009; Fenner et al., 2012; H.H.S, 2003; Morton, Cahill, & Hartge, 2005). The traditional methods of recruitment with the use of standardized paper and pencil surveys has changed dramatically with the explosion of use of the World Wide Web (Das, Ester, & Kaczmirek, 2011; Dillman et al., 2009). It is estimated that greater than 74% of all persons living in the U.S. have broadband access to the Internet making this medium a potentially rich source of recruitment for health related surveys (International Union on Telecommunications, 2011). Historically, however, concerns have been raised over the legitimacy of Internet data, methods used in its collection, and if it is truly an accurate representation of the general public (Das et al., 2011).

Breast cancer survivors are a large and growing population (American Cancer Society, 2011-2012). Once their treatment for cancer has concluded many survivors leave oncology specific clinics and are followed in primary care settings (Ganz, 2009;

Hewitt, Greenfield, & Stovall, 2006). The movement of survivors back into mainstream care makes it more challenging to locate and recruit these women into survivorship studies (Ganz et al., 2009).

One potentially rich site for recruitment of breast cancer survivors may be within Internet cancer specific groups or communities. Bender, O'Grady, and Jadad (2008) report that many cancer survivors frequent online supportive environments to reduce stress, depression, and reactions to pain. They found that these sites provide social support systems and aid in post-traumatic growth once treatment had ended for participants. However, little is known about the level of fear of cancer recurrence or anxiety in survivors that frequent these sites. Consequently, it is increasingly important to assess and understand the concerns of these Internet populations in relationship to the survivorship phase of their disease trajectory (Alder & Page, 2008).

As use of the Internet to recruit cancer patients for studies increases, it is imperative that we understand the characteristics of cancer survivors who participate in research via Internet surveys as well as the viability of using various cancer communities for survivorship data collection. There is also need to understand how tailored surveys used on the Internet may impact on the type of data obtained.

The aims of this study were to describe: 1) who frequents Internet communities of breast cancer survivors; 2) the successes and pitfalls of recruitment from Internet discussion boards and/or forums; 3) the issues and successes of using a strictly Internet based survey for data collection with this population, and 4) the level of anxiety and fear of cancer recurrence reported by this sample drawn from breast cancer specific internet communities. This portion of the study was exploratory in nature and consequently no a priori hypotheses were stated.

LITERATURE REVIEW

Internet Communities

Internet cancer communities or any virtual space where people can come together with others to converse, exchange information and resources, learn, or just to be together provide a rich service to those with cancer or those affected by it (Kraut & Resnick, Under contract). Internet communities provide ongoing information and support while allowing for the telling of personal stories that can be accessed at any time of the day or night making these sites easily accessible to anyone in the world with access to the World Wide Web (Klemm et al., 2003; Kraut & Resnick, Under contract). Developing a community and sustaining it can be a challenge with many competing sites seeking new members with similar needs. Sites in general must actively seek and integrate newcomers, encourage commitment, regulate behavior, and coordinate work and activities within the site to maximize benefits for its members or the site will not be sustainable (Kraut & Resnick, Under contract).

Oncology specific online communities have flourished (Squiers et al., 2006) and continue to do so with many breast cancer organizations such as Komen for the Cure®, Young Survival Coalition™ and Y-Me© using the internet to support their members. They all provide, in one way or another, online information, personal and professional support, fundraising, research, patient advocacy and allow space for shared experiences through the use of discussion boards or forums (Klemm et al., 2003; Rodgers & Chen, 2005). Discussion boards or forums (referred to from here on as discussion boards) can be used by any registered participants to post topics of interest to themselves, other members or for members to seek answers to questions or concerns that they have during

their cancer journey. These discussion boards can vary in size from under 1,000 to over 24,000 registered members (Komen, 2012). Online recruitment techniques are considered either a good (Ip, Barnett, Tenerowicz, & Perry, 2010) or a poor (Im & Chee, 2004) way to recruit subjects for participation in research. No studies were found on the viability of the use of discussion boards to recruit breast cancer survivors into an Internet-based research project.

Internet Research

The Internet in general is considered a low cost effective method to recruit participants for online research (Eysenbach & Wyatt, 2002; Ip et al., 2010; Perry, Lund, Deninger, Kutscher, & Schneider, 2005; Rhodes, Bowie, & Hergenrather, 2003). Invitations to Internet group participants via discussion boards have been successfully used for past research recruitment and thus are a viable alternative to other forms used for recruitment for example: clinic, phone, mail requests or advertisements in local or national newspapers (Das et al., 2011; Ip et al., 2010; Lieberman, 2008; Perry et al., 2005; Rhodes et al., 2003). Recruitment however, appears to not be as easy as it may appear and one complaint has been low response rates (Im & Chee, 2004), whereas others have reported excellent response rates in a short period of time (Fenner et al., 2012; Lieberman, 2008; Perry et al., 2005; Sullivan et al., 2011). How subjects are recruited from the Internet varies greatly from study to study; for example some studies used advertisements on social networking sites (Fenner et al., 2012; Sullivan et al., 2011), paid for links as a type of advertisement on sites frequented by their desired subjects (Perry et al., 2005), or used email to send study links to potential participants for recruitment (Im & Chee, 2004). Other researchers outside of oncology have used discussion boards as sources for qualitative research using posted statements and comments for their research

(Eysenbach & Wyatt, 2002). How one recruits from a discussion board can lead to success or failure when one attempts to recruit in this way. Ip et al.'s (2010) guide on how to successfully recruit from discussion boards guided this studies data collection as there are limited studies in the literature that have used this recruitment methodology.

Online Surveys

The use of online surveys has exploded over the last few decades as easy to use software packages such as Qualtrics™, SurveyMonkey®, KeySurvey™, Zoomerang™, and Surveygizmo® have become more readily available for use by all members of the general public (Das et al., 2011). The appeal of using online surveys are multifaceted in that they: are cost effective, easy to develop, offer timely data return, can decrease participant response burden with the use of skip patterns, allow for randomization of options and questions, decrease issues with human errors when processing raw data, survey large geographical areas with no increase in cost, decrease socially desirable responses, and allow investigators the ability to correct errors in the survey while it is still being run (Das et al., 2011; Dillman et al., 2009; Groves et al., 2009). It must be noted that developing an online survey is not as simple as taking a paper and pencil survey and converting it into an online format (Dillman et al., 2009; Groves et al., 2009). Proper construction of questions, sequencing, and time required to finish the survey may impact on response and completion rates (Dillman et al., 2009). Researchers, however, have found no real difference in response patterns or changes in the validity of instruments from the traditional paper and pencil styles to those converted to a web based platform (Rhodes et al., 2003; van den Berg et al., 2011). Currently, no one way to construct an online survey for maximum results exists. Researchers report that the length of the

survey, sensitivity of questions asked, and sequencing can impact significantly or not on results obtained (Deutskens, De Ruyter, Wetzels, & Oosterveld, 2004; McCambridge et al., 2011; Morton et al., 2005; van den Berg et al., 2011).

Fear of Cancer Recurrence and Anxiety

Fear of cancer recurrence has been identified as a universal non-physical consequence that breast cancer patients face to varying degrees in their survivorship trajectory (Bartelink, van Dam, & van Dongen, 1985; Lee-Jones, Humphris, Dixon, & Hatcher, 1997; Miedema, Tatemichi, & MacDonald, 2004; Northouse, 1981; Vickberg, 2001; Ziner, 2008). Fear of cancer recurrence has emerged from the literature as a potential contributor to ongoing distress for cancer survivors requiring concentrated attention on it separate from other causes of distress (Lee-Jones et al., 1997; Van den Beuken-van Everdingen et al., 2008). The relationship of fear of recurrence to other psychosocial issues in survivorship such as anxiety remains unknown and is in need of further research (Ziner, 2008). Investigation in to the level of fear of recurrence and its' relationship to anxiety in online breast cancer communities is lacking in the current literature.

Therefore the objectives in this exploratory study were to explore: who frequents Internet communities of breast cancer survivors; the successes and pitfalls of recruitment from Internet discussion boards and/or forums; the issues and successes of using a strictly Internet based survey for data collection, and the level of anxiety and fear of cancer recurrence reported by this sample drawn from breast cancer specific internet communities.

METHODS

Study Procedures

The results presented here were collected as part of a larger Internet survey conducted from November 2010 to August 2011 in which fear of cancer recurrence was the primary endpoint. Three open community discussion boards were used for recruitment into this study, 1) Susan G. Komen for the Cure®; 2) Young Survival Coalition™, and 3) Y-Me ®. Prior to recruiting subjects, study approval was obtained from the IRB at the University of Michigan. Permission was then gained from each site to post a web-link to the survey or to be active on the discussion boards and personally invite members to participate. Once a woman chose to participate in the study she either clicked on the provided link or was emailed the link by the PI. Participants signified consent by proceeding into the survey and completing the questionnaires after reading the introduction page of the survey. The introductory page assured anonymity to participants and stated that this survey was interested in breast cancer survivorship concerns allowing for women to exit at this point if they felt that they did not fit the study objectives. Women who completed the survey were also encouraged, at the end of the survey, to invite friends and acquaintances to participate in the study to create a snowball recruitment effect. Criteria for inclusion were a diagnosis and treatment for any stage of breast cancer (Stage 0-IV). Cases were excluded if the subject was currently in treatment for their primary diagnosis of breast cancer or if they entered the study but did not complete the fear of recurrence questionnaire. The intent of the original study was to gather information on fear of recurrence among breast cancer survivors. Additional

questions were included to explore the characteristics of women who participate in these online discussion boards.

Recruitment Procedures

The Principal Investigator (PI) joined all of the Internet community discussion boards as a member. The profile section was completed and a signature line was used on all postings. This information enabled the PI to be identified as an oncology nurse practitioner and doctoral student so that she would not be mistaken for a breast cancer patient, survivor, or family member. Participants on these sites typically do not use their proper name and opt for user names; however, they consistently include substantial information on their breast cancer journey from date and type of diagnosis, all treatments including surgical interventions, adjuvant chemotherapy and radiation therapy and any issues or recurrence of disease. Many also post pictures of themselves and their families. Two of the sites had an initial screening process that the PI completed prior to being able to post the study link as a standalone topic area, with a note that the link was evaluated by web administrators and deemed a 'legitimate' posting. The last site used did not have this procedure and no topic area about the study was allowed. Initial recruitment was slow using only these two-posted links so the PI became an active member on all sites responding to topic areas with medical information and educational resources. The PI also sent invitations to individual members on the boards that were active participants. Lastly, a few women on the discussion boards asked permission to send out the link via email to groups that they were involved in (e.g. Dragon Boats). The PI for this type of recruitment gave permission as well. No other methods of recruitment were used, restricting this study to strictly online recruitment.

Online Survey

All of the instruments used in the initial study were entered into Qualtrics Survey Software® for ease of Internet distribution. No questions, in any part of the survey, forced an answer in order for the participant to proceed. This software also, ensures that a person does not take the survey multiple times. Qualtrics® uses a browser based cookie system to mark when a participant has entered the survey therefore stopping potential ‘*ballot stuffing*’ (the ability to access the survey again after one has completed it). If a participant attempted to access the survey a second time from the same browser or the same computer, the program would deny re-entry. While this is a good system reentering the survey from another computer or removing the cookies from ones browser history can circumvent it. However, given that participants were not offered any form of payment for study participation they have little to gain from redoing the study. Permission from all authors of the instruments was obtained prior to the conversion of their instruments into the Internet survey used. Five standardized instruments were converted and used along with a demographic section that asked for patient, clinical and Internet usage information. The Illness Perception Questionnaire-Revised (IPQ-R), The State Trait Anxiety Inventory-Trait (STAI-T)©, Risk Perception Questionnaire, Fear of Recurrence Questionnaire, and Brief COPE were presented to participants, followed by questions that sought patient characteristics. The majority of the questions asked in this survey used a Likert type click to select the appropriate response button or a fill in the blank option (see Figure 1). Patient characteristics consisting of selected demographic, clinical, and Internet usage questions were obtained. Data from the Fear of Recurrence questionnaire and the State Trait Anxiety Inventory-Trait (STAI-T)© was also examined. All of this

data along with qualitative data extracted from study participants emails sent to the PI will be used in this study.

Patient Characteristics

The basic demographic information in this study included: 1) age; 2) race; 3) marital status; 4) education level; 5) employment status, and 6) income level. Clinical information consisted of: 1) type and stage of breast cancer at diagnosis; 2) how many and what type of surgical interventions were obtained; 3) if women received adjuvant chemotherapy; 4) if women received radiation therapy; 5) time since diagnosis; 6) if women had adjuvant estrogen depriving therapy, and 7) the presence and effect on day to day life of co-morbidities. Internet usage information included the frequency of use of in-person and online support groups and how women found out about the current study.

Trait Anxiety

The State Trait Anxiety Inventory-Trait (STAI-T)© form Y-2 for adults was used to measure trait anxiety. This scale has been used widely to measure the trait of anxiety in many different patient populations (Spielberger, 1983). It consists of 20 self-rating statements on a Likert type scale with 1=almost never to 4=almost always. Nine items of the twenty are reversed scored. This scale has longstanding documented test-retest reliability, validity, with an internal consistency $\alpha=.90$ (Spielberger, 1983). Permission for online use of 200 copies of this scale was acquired prior to its use. In the current study the Cronbach alpha coefficient was .92.

Fear of Recurrence

The Fear of Recurrence Questionnaire, a 22-item questionnaire, uses a 5-point Likert type scale from strongly agree to strongly disagree. The questionnaire was

specifically designed for use with breast cancer survivors to measure fear of cancer recurrence. Participant scores were summed to equal one overall score. It has been used with samples of breast cancer survivors in multiple studies with reported internal consistency $\alpha = .92-.95$ (Black & White, 2005; Hilton, 1988; Mast, 1998; Northouse, 1981; Stanton, Danoff-Burg, & Huggins, 2002; Walker, 1997). In the current study the Cronbach alpha coefficient was .90.

The qualitative data included in this study was acquired by the PI through unsolicited personal emails sent to the PI by study participants after their completion of the survey.

Statistical Methods

Statistical analysis of the data collected was done using PASW 19 (formerly SPSS 19). After completion of all data collection procedures the raw survey material was uploaded into PASW 19 for analysis. Qualitative common themes from the emails received emerged and will also be reported.

RESULTS

Recruitment

Initial recruitment that used a posting of the link on two sites had 42 participants who entered the study of which 28 (66%) completing the study over the first month that the study was open. Enrollment then dropped the next month with only 13 entering the study and 7 (53%) completing the surveys. To increase enrollment the PI became an active member on the boards and over the next three months an additional 65 participants were recruited, with an 84% completion rate of these participants. Overall on average 16.8 persons entered the study per month with a 69% completion rate. Shortly after the

PI went on the discussion boards as an active site member there was an observed increase in the number of women entering and completing the study. The PI issued a total of 40 personal invitations to the study to site members, via the messaging email system on the site. In addition to these personal invitations the PI also entered each site twice a week for a total of 1.5-3 hours. Since many of the questions or discussion topics posted were in the area of the PI's clinical expertise they were briefly answered with postings by the PI. Email notification of comments made to any of the PI's postings were set to automatically notify the PI, who would then periodically return to the site, and post a response. The PI's postings on the sites mainly centered around giving some educational information on chemotherapy symptom management, vaginal dryness, and how to deal with menopausal symptoms. These postings were informal and did not mention recruitment into the survey. On the two sites that allowed posting of the study link the PI routinely posted updates to site members on enrollment. The PI also sent a personal thank-you to anyone who informed the PI that they had completed the survey. Over 200 comments and responses to various topic areas on all three discussion boards unrelated to recruitment into the study were made. A total of 168 persons entered the study over ten months of these 107 women completed the surveys and were retained for analysis with minimal missing data.

Patient Characteristics

The final analyses were based on 107 breast cancer survivors who completed the online survey. The majority of women were between 46-55 years of age, Caucasian (95.3%), resided in the United States of America (81.3%), were partnered (74.8%), highly educated with a bachelors or higher degree (55.1%), and middle to upper class with an

average household income of > \$80,000 (49.5%) (see Table 1). About one-half of the sample was employed full time (47.7%).

Most women had invasive cancer (75.7%), were diagnosed at stage III or IV (61.7%), under went mastectomies (68.2%), adjuvant chemotherapy (78.5%), and radiation therapy (69.2%). The sample was evenly split between those who were treated with adjuvant estrogen therapy (44.9%) and those who were not (55.1%). Ten women (9%) self disclosed that they had a breast cancer recurrence.

Internet usage questions found that about one-third of this group (36.4%) occasionally or frequently participated in-person in a support group of some type. The majority of the group (68.2%) reported participation in online support groups and most women (81.3%) reported that they found out about this study through the discussion boards that they frequented.

In order to evaluate this Internet sample more thoroughly, the level of fear or recurrence and trait anxiety were examined using the Fear of Recurrence questionnaire and the State Trait Anxiety Inventory-Trait (STAI-T)©. The mean score on the Fear of Recurrence questionnaire was 83.7 (SD 14.1) and Trait Anxiety was 35.3 (SD 10.5). Additional analyses explored if there was a relationship between women's participation in support groups (online and in-person), fear of cancer recurrence and trait anxiety (see Table 2). Only two significant relationships were found. Participation in online support groups ($r=.327$, $p<.01$) was positively correlated with level of fear of cancer recurrence suggesting that women with higher levels of fear of recurrence participate in online support groups. The relationship between participants' trait anxiety and fear of recurrence was also examined and found to be significant ($r=.410$, $p<.01$). No

relationship was found between trait anxiety and Internet support group usage. There was also no relationship between participants' trait anxiety, level of fear of recurrence and how they were recruited into the study.

Survey Completion

Completion of each of the sections of the survey was consistent with less than 5% missingness for the main five survey instruments. Completion time for this survey was approximately 30 to 35 minutes. Missing data was found to be greater than 5% in some of the patient characteristics section with age having the least completed responses of any data collected. Age was initially collected as a numerical number, typed in by the participant. It was noted that a substantial number of women were skipping this age question, so it was changed to a 'click the range' question (e.g. 25-29, 30-35 etc.). Unfortunately, this change did not improve collection of data for this variable with only a little over half of the participants reporting their age range (58.8%). The only other variables with missing data though to a lesser extent were use of Internet support groups (12.1%), and in-person support groups (9.3%); however, these variables were checked and revealed complete randomness in the missing data so they were retained for evaluation. The majority of women who completed the survey completed all items in each section.

Qualitative Comments

At the beginning of data collection a survey password was used to allow entry into the survey. Five women contacted the PI as they were unable to gain entrance with the provided password and consequently the password was removed. Sixteen women contacted the PI via personal messages through the discussion boards or via email. The following three themes emerged; 1) willingness to participate; 2) anxiety or concern over

the wording of the survey questions, and 3) sharing of more information and suggestions for future research.

Theme One: Willingness to Participate

Women responded in a positive manner when personally approached on the discussion sites or via a personal message. The following are comments received from some of them;

“Thanks for having me participate in the study”

“I just took the survey!! It was great! Good luck”

“I would love to participate! Last year we did one for a woman from CA”

“Would be glad to help with your study. Please let me know what to do.”

“I completed the survey. As I'm 2 1/2 years out, some questions didn't seem as pertinent as they may have just after diagnosis, but I did my best!”

“Done 😊”

“Found the link and completed the survey. I would love to see the findings!!!!!!!!!!!!!!”

Others encouraged participation:

“I did a survey the Administrators had recommended and trust it was yours. For all you gals on the board, it is an easy survey and should collect some information that will help other patients going through what we all have done. So if you have the time, please do it.”

Theme Two: Anxiety or Concern over the wording of the survey questions

Some participants felt that they knew the PI personally from her involvement on the discussion boards and were willing to share concerns about the research study.

“I had a bilateral mastectomy for that. As you know, DCIS is not a threat to my life so the questions about "coping" with "it" do not apply as there is no "it". So, I answered all of those as "never". “My husband and I participated in a study for couples diagnosed with BC, and each portion of the study contained about 30 pages of questions each, so this was much easier”

“Some of the wording is a little uncomfortable for me. A lot of questions describe “your” breast cancer. If we refer to it as “my” or “your” breast cancer, it is like we still have it, as if it is still part of us. When we describe it as “the” breast cancer, it is not ours, we do not own it, and it is now a thing that is gone..... Words can be very powerful and change the way we perceive things, so staying as positive as possible is so important.”

“I had a hard time with each question saying ‘your breast cancer’. I try not to think of the “Big Bad” I am just trying to get on with my life and forget about it”

One participant had many comments about the survey questions.

“I go through cycles in which my breast cancer gets better and worse- Are you referring here to someone with a recurrence? the only way for it to get better and worse, or to behave in a cyclic manner is if you are discussing recurrence. Otherwise, what exactly is getting better or worse? the Cancer? or perhaps how someone is feeling day today during initial treatment? That certainly is cyclic, but not the cancer itself”

“I expect to have breast cancer for the rest of my life-Uh, didn't you just ask if this would be permanent?”

“If you would like please take a stretch break and then continue with the survey-don't you think this is a bit condescending and patronizing, telling a grown woman when they can take a break? Are you giving ME permission? Did you pat me on the head...What the?”

Theme Three: Sharing and Future Research Ideas

One woman felt that we required more information, in case she was not answering the survey questions as expected.

“More data on the (fear of recurrence) topic (about me). I thought about recurrence on a daily basis for the first five years. It wasn't a destructive obsession, but there wasn't a day that went by for the first five years that I didn't think about it. After that, only before checkups.”

Others made suggestions on what we could add into the survey next time.

“Have you considered chemo-brain?”(4 comments on this topic area)

“You did not have anything on sexual issues in survivorship, I'd like to see more on this” (6 comments on this topic area)

“What about lymphadema and other physical long term consequences”(2 comments to this effect)

DISCUSSION

The demographic findings of this study are very consistent with other studies that have used the Internet for study recruitment. Our sample was predominantly Caucasian, middle class and well educated as has been previously found in the literature (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Klemm et al., 2003; McCambridge et al., 2011; Sullivan et al., 2011), suggesting that there is an under representation of poorer, less educated and minority groups when recruiting data through the internet and from discussion boards. On average these women were diagnosed at an earlier stage and

underwent mastectomies rather than breast conserving surgeries suggesting that women who undergo mastectomies may seek added support from Internet sites. However, stage and type of surgery were not significantly related to level of fear of cancer recurrence or other study variables. Age of subjects however, could not be used in the data analysis as a result of missing data. Age was the first demographic question and even though women did not answer this question they did proceed to complete the majority of the other demographic questions. This may be a comment on our society's views that age is very personal and private, especially for women, and should not be divulged even when assured anonymity. In conjunction with this, participants did not know the value of the variable age to the end results of this study. If value of the variable of age was somehow expressed to participants one wonders if accrual of this information could have been improved.

The women in this study were found to have a higher level of fear of cancer recurrence than those previously reported in the breast cancer literature (Northouse, 1981; Walker, 1997). It is possible that women who frequent discussion boards may be more distressed about the potential for a cancer recurrence which draws them to these sites for support, or that just being an active member of a discussion board itself, elevates ones level of fear. It is also possible that through participation women are exposed to triggers (e.g. persons on the board having a recurrence or dying from one), which increase their own feelings of vulnerability leaving them with a higher level of fear than women who do not frequent these sites. In contrast, our samples mean scores on trait anxiety were no different than the findings of Harrison et al. (2011) suggesting that these women scores were normative for cancer survivors when it comes to anxiety.

This experience with recruiting study participants from an internet breast cancer community site was consistent with the findings of Kraut and Resnick (Under contract) and Ip et al. (2010) who found that to recruit successfully from these informal sites one must become a trusted committed member of the community. It is not possible to just 'post' your study link and 'they will come'; you must become an active member of some value. If one is to use this method for recruitment, they must be prepared to spend hours becoming a valued member. Potentially, the employment of a research assistant to spend more time consistently visiting these sites and becoming a very active 'valued' member could have improved recruitment. Given that many of the subject recruited in to this study were not personally invited by the PI, suggests that members on the boards investigate other members (like the PI) and if they feel that another member is a valuable contributor they will assist in things that that member is participating in. For example an active member may write a book or blog. Members of the community will purchase the book or visit the blog site and recommend it to other site members as a good choice. It may also be that members who frequent these sites are encouraged to be supportive and helpful and therefore are more willing than women who do not use these sites to participate in research that may help others. Conversely, by becoming a member of the discussion boards you could become attached to other members, this has the potential to introduce researcher bias into the recruitment process if one only selects those that you like for the research project. Becoming a participant on these discussion boards also opens your research methodology and study materials up for scrutiny, discussion and unsolicited good or bad comments. Recruitment from these boards took less than ten months to gain a sufficient sample size making this a much faster more cost effective way

to collect data than the traditional paper and pencil method using other forms of recruitment (Das et al., 2011).

Survey assembly, format, and time to completion did not seem to deter or invite women to participate in this study. The only feedback on study design was that it was not “too long”. The majority of women who started the survey completed it suggesting that a survey that takes greater than 30 minutes may or may not affect completion rates. This is consistent with other research found on this topic (Das et al., 2011; McCambridge et al., 2011). One possible way to acquire a more heterogeneous sample would be to limit the number of participants of a particular group allowed to complete the survey. Currently, online survey software programs, such as Qualtrics®, have the ability to exclude participants from a survey if a set quota has been met. For example, if demographics were placed first in the survey and you only desired 50 Caucasians you could exclude further participants from completing the survey if they click on that race type after the quota has been filled. Including an “*if this answer is checked then take them to the end of the survey*” command would have this type of effect. However, doing this may increase your data collection time and it also does not assure that the first 50 participants have completed the survey with usable data. This type of restriction should be used cautiously or it may have untoward effects on study results.

Where to place questions to gather demographic information remains a quandary (Dillman et al., 2009; Groves et al., 2009). Given that this survey did not start with demographic information made it impossible to evaluate if there was a difference between those who did and those who did not complete the survey. Where one places demographic questions should be driven by the study’s theoretical underpinnings and

prior knowledge of what type of data is absolutely required to ensure as complete an analysis of the data as possible. Given that previous research on fear of cancer recurrence, in breast cancer patients, has found limited relationships between demographic/disease variables and level of fear of recurrence (Costanzo et al., 2007; Kiebert, Welvaart, & Kievit, 1993; King, Kenny, Shiell, Hall, & Boyages, 2000; Mehnert, Berg, Henrich, & Herschbach, 2009) suggested that collection of this data was of lesser importance than completion of the other survey instruments used. Consideration of what will be lost must be done prior to setting up the survey as it may affect end results due to missing important variables upon completion of data collection. However, by not forcing a response to move forward in the survey it may have made it easier to complete this survey and therefore, fortunately, not disrupt the findings with too many missing results even with the demographic/disease section slated at the end.

The current study has several limitations. The sample was very selective and of a homogenous nature with the majority of women being Caucasian, well educated and upper middle class. This study is limited in its generalizability in that it was restricted to those who frequent discussion boards from only three of many online breast cancer communities and there were non-response errors (not getting everyone who could have potentially been sampled to respond to the survey request) (Dillman et al., 2009). This could have been decreased if a more systematic recruitment method was employed, for example mass email messaging to all users of the sites, or employing some type of paid advertising to recruit members off of many sites at once. Sullivan et al. (2011) suggest that advertisements using pictures of desired participants from different races could help attract minority groups into online studies. Also the use of some type of payment or reward may have changed participation. Bias may have occurred as this sample was

exclusively recruited from online and other supportive type breast cancer networks thus excluding women who do not participate in these activities. Lastly, by becoming an active member of the site and projecting an opinion the PI could have inadvertently influenced the responses of subjects to survey questions.

CONCLUSION

Recruitment to an online survey from breast cancer discussion boards is a viable, cost effective method to acquire study participants, but can be labor intensive. Further research on how to attract a more heterogeneous sample with increased representation from minority groups is needed. Qualitative comments gathered during study recruitment can be a rich source of data to direct future research within the patient population of interest. The finding of a higher level of fear of recurrence in this group warrants closer examination to evaluate exactly what role discussion boards are serving in the breast cancer survivorship community. Replication of these results should also be considered using other types of cancer discussion boards, to see if these results are consistent within other groups of cancer survivors.

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Table 4.1 Demographic Variables (N=107)
Characteristics of Sample

Variable	N (%)	Variable	N (%)
Age*		Breast Cancer Type	
26-35	12(11.2%)	DCIS	26(24.3%)
36-45	15(14%)	Invasive	81(75.7%)
46-55	24(22.4%)		
56-65	10(9.3%)		
66-75	7(6.5%)		
Ethnicity		Stage	
Caucasian	102(95.3%)	Early Stage (DCIS- Stage 2)	66(61.7%)
Others	5(4.7%)	Later Stage (Stage 3 & 4)	41(38.3%)
Residence		Surgery Type	
USA	87 (81.3%)	Lumpectomy	34(31.8%)
Other	20 (18.7%)	Mastectomy	73(68.2%)
Marital Status		Years since Treatment	
Partnered	80 (74.8%)	One Year	66 (61.7%)
Other	27 (25.2%)	>One Year	41 (38.3%)
Education		Chemotherapy	
High School or less	7 (7.4%)	Yes	84 (78.5%)
Some College or Trade	39 (36.4)	No	23(21.5%)
Bachelor's Degree	32(29.9%)		
Professional Degree > Higher	27(25.2)	Radiation Therapy	
		Yes	74 (69.2%)
		No	33(30.8%)
Employment		Adjuvant Estrogen	
Full Time	51(47.7%)	Yes	48 (44.9%)
Other	56 (52%)	No	59 (55.1%)
Income		Learn about the Study**	
<\$20,000-\$60,000	25(23.4%)	Internet Discussion	87 (81.3%)
\$61,000-\$80,000	29(27.1%)	Board	12(11.2%)
\$81,000->120,000	53(49.5)	Referred by a Friend	8(7.5%)
		Other	
Support Group Participation (In- person)**		Support Group Participation (Online)***	
Never	42(39.3%)	Never	13(12.1%)
Once or Twice	16(15%)	Once or Twice	8(7.5%)
Occasionally	18(16.8%)	Occasionally	29(27.1%)
Frequently	21(19.6%)	Frequently	44(41.1%)

*N=63 **N=97, ***N=94

Figure 4.1

Survey Format

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I get depressed when I think about my breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I think about my breast cancer I get upset	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My breast cancer makes me feel angry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My breast cancer does not worry me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having breast cancer makes me feel anxious	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Breast cancer makes me feel afraid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the boxes below, please list in rank-order the **THREE** most important factors that you now believe caused **YOUR** breast cancer.

You may use any of the items from the box above, or you may have additional ideas of your own.

Cause 1

Cause 2

Cause 3

Table 4.2
Correlation Matrix for Fear of Recurrence (FOR), and other study variables

		1	2	3	4	5
1	FOR	1	.410**			
2	Trait Anxiety	.410**	1			
3	In-person support	.112	-.135	1		
4	Online support	.327**	.108	.089	1	
5	Learn about study	-.090	-.081	.275**	-.471**	1

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

CHAPTER V

CONCLUSIONS

The purposes of this dissertation were to: 1) build the scientific understanding of fear of cancer recurrence, as an independent construct, this study explored the relationships of patient characteristics (demographics and disease), illness representations, risk perceptions and coping to fear of cancer recurrence in women survivors of breast cancer, and 2) gain further understand of the impact of the Internet on study design and recruitment, along with exploring demographics and other pertinent characteristics of women recruited from breast cancer specific Internet sites. The following section summarizes the research results from this study, provides practice implications for health care providers, and suggests directions for future research.

RESEARCH RESULTS

Sample Characteristics

The findings of this research indicated that women recruited from breast cancer specific Internet discussion boards/forum were predominantly Caucasian, middle class, well educated and partnered. The majority of these survivors had mastectomies, adjuvant chemotherapy, and radiation therapy. While on average they reported a similar level of trait anxiety, that was comparable to other cancer survivor studies, they reported a higher level of fear of cancer recurrence. Emotional representations, symptom attribution, perceived self-risk of recurrence, and consequence/severity were the only variables within the six illness perceptions studied that were significantly related to level

of fear of cancer recurrence. The use of cognitive coping strategies was also related to a higher level of fear of cancer recurrence. The majority of women were involved in online support groups and had limited difficulty or issues completing the online survey.

Predictors of Fear of Cancer Recurrence

Results from regression analysis indicated that while there are strong relationships between illness representations, coping strategies, and fear of cancer recurrence, an association with patient/disease characteristics in breast cancer survivors was not present. Specifically, women who have increased emotional representation of breast cancer, more concerns over the consequences of having cancer, greater symptom attribution, more perceived self-risk for a recurrence, and reported more cognitive coping strategies accounted for 59% of the variance in fear of cancer recurrence. No other illness representations or coping strategies contributed to the variance in the proposed model. Furthermore coping, as speculated, did not mediate or moderate the relationship between illness representations and fear of cancer recurrence. These findings suggest that women who have completed treatment for breast cancer and who possess a strong emotional representation of breast cancer are at risk for developing a higher level of fear of cancer recurrence in survivorship. While past research has found that use of cognitive coping strategies either decreases or are unrelated to distress, it did not hold true for this study on fear of cancer recurrence. This suggests that Internet frequenters may have unique characteristics that we are unaware of and breast cancer survivors who use these services are in need of further evaluation.

Internet Research

Use of breast cancer specific discussion boards/forums was a viable, cost effective, yet time-consuming method of recruitment for this study. Researchers who choose this form of recruitment must be cognizant of that fact that the sample will be homogenous in nature and results will not be generalizable to other random samples drawn from the general population. Becoming a member of an Internet community to do online research takes perseverance and commitment. Internet surveys must be thoughtfully designed and guided by the theoretical underpinnings of the study. Researchers must have knowledge of sequencing and how questions are presented to subjects as this can influence response rates to certain items. Utilization of a mixed method design may be a better approach than a single methodology when doing Internet research in order to get a larger sample size with more diversity. For example, along with recruiting from discussion boards researchers could use: advertisements on social media sites showcasing different ethnicities; mass recruiting emails sent to all members of internet sites, or combine traditional clinical site recruitment strategies with online ones.

Practice Implications

This research highlighted that breast cancer survivors have ongoing fears that their cancer will return. Fear of cancer recurrence as a legitimate concern appeared to be associated with the development of negative illness representations of breast cancer during treatment. The women in this study were young active users of the internet for information and support. Health care providers need to be aware that breast cancer survivors, who frequent the internet, have increased fear of recurrence and that these women are in need of regular assessments in follow-up to provide early intervention and

support for this increased fear. The use of focused psychological counseling and support during treatment may also help to offset these fears and other emotional concerns about an unknown future and improve the overall wellbeing of patients once treatment is completed (Ganz, 2009; Hewitt, Greenfield, & Stovall, 2006). Currently, such support is limited as the full dimensions of fear of cancer recurrence and its implications for survivorship remain in the formative years (Hewitt et al., 2006). By not providing desired support and tools that are needed during survivorship to manage this fear, health care providers may be inadvertently driving breast cancer and other cancer survivors to seek support through frequenting Internet support sites. As valuable as the Internet may be, it can also be a source of misinformation and may even further contribute to a higher level of fear. Many triggers are found online that could bombard frequent users and rather than alleviating distress among survivors, it may lead to an increase in survivorship distress (Armes et al., 2009).

The use of online recruitment and surveys is a viable way to get information on cancer patients and survivors but may have limited generalizability. Consequently, findings from these types of studies should be viewed cautiously. As online interventions and support groups for cancer patients and survivors expand it is imperative that quality research initiatives accompany their development to evaluate any outcomes and effects on participants.

Directions for Future Research

Future research should investigate if the reported results in this study can be used to identify and then intervene with cancer patients, while still in treatment, who may be at risk for developing increased distress in survivorship from an increased level of fear of

cancer recurrence. Further research needs to investigate if this model of cancer survivorship holds for other types of cancer survivors, and for breast cancer survivors who do not participate in online discussion boards/forums. An examination of the influence of frequenting online supportive sites, if any, on patients' quality of life in survivorship is warranted. Research is also needed that explores the influence of frequent Internet use on patient provider relationships. A closer examination of potential relationships between fear of cancer recurrence, social support, Internet usage, and utilization of resources may shed some light on how practice during treatment can be altered to support women as they transition into survivorship.

A mixed methods approach to survey design and recruitment may assist in attracting a more heterogeneous sample with increased representation from minority groups (Dillman, Smyth, & Christian, 2009). By expanding recruitment to different areas and using multiple different recruitment modalities, a more representative sample could be attained making future results more generalizable (Dillman et al., 2009; Groves et al., 2009). Qualitative comments gathered during study recruitment can be a rich source of data to direct future research within the patient population of interest and should be considered in mixed-model designs (Dillman et al., 2009). A closer look at post treatment symptoms and long-term consequences of treatment could also yield other variables that are related to fear of cancer recurrence that have not yet been extensively studied. The finding of a higher level of fear of recurrence in this group and the connection between cognitive coping and fear also warrant closer examination to evaluate the specific role discussion boards are serving in the breast cancer survivorship community. Replication of these results should also be considered using other types of

cancer discussion boards, to see if these results are consistent within other groups of cancer survivors.

In summary, this study examined the relationships of multiple study variables and fear of cancer recurrence finding that illness representations and coping strategies should be considered when caring for breast cancer patients. It also suggests that fear of cancer recurrence, as a complex multifactorial issue for breast cancer survivors, is in need of continued examination. Lastly, it was found that the Internet is a rich source for recruitment into health related research studies and that with careful design and different approaches to recruitment more expanded generalizable results are possible.

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