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Rebecca J. Donatelle

More women than ever before survive breast cancer with 89% of those diagnosed becoming survivors (NCI, 2008). However, according to the National Cancer Institute (2005) some groups of women bear a greater burden of difficulty in survivorship. Sexual minority women (SMW), or women who partner with other women in romantic and spousal relationships, experience a higher prevalence of breast cancer and little is known about the unique factors that influence their breast cancer survivorship as compared to heterosexual women. This cross-sectional study investigated the influence of sexual identity/orientation, perceived social support, perceived stress, perceived discrimination and years since diagnosis status on breast cancer survivor's quality of life and affect. Two-hundred-eleven (143 heterosexual and 68 sexual minority) female breast cancer survivors completed online, electronic surveys regarding their breast cancer survivorship. Survivorship was assessed in this purposeful sample with quality of life and affect/mood scales. Statistical analyses including linear regression and t-tests indicated few statistically significant differences between heterosexual and sexual minority breast cancer survivor's scores on quality of life and affect. Significant differences in women's report of perceived stress were determined. Findings also pointed to perceived discrimination as an important factor

in understanding the influence of sexual orientation and identity on the quality of SMW’s breast cancer survivorship.

Breast Cancer Survivorship: Contributing Factors for Special Populations

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Jennifer M. Jabson

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APPROVED:

Major Professor, representing Public Health

Chair of the Department of Public Health

Dean of the Graduate School

I understand that my dissertation will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my dissertation to any reader upon request.

Jennifer M. Jabson, Author

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CHAPTER I

BREAST CANCER SURVIVORSHIP: CONTRIBUTING FACTORS FOR SPECIAL POPUATIONS

Introduction

Today nearly 89% of those diagnosed with breast cancer will live far beyond the five year, cancer free, mark (NCI, 2008). In 2007 alone, more than 2 million breast cancer survivors were reported in the United States (NCI, 2008). As the population of breast cancer survivors grows, cancer survivorship, and its associated unique health and quality of life issues and influences, are increasingly important. Although researchers once viewed survivorship in limited terms of years 'cancer free' or a finite number of years to be achieved; experts now recognize that the nuances of successful survivorship are characterized by quality of life, emotional wellbeing, and coping strategies that include support from others. Accordingly the Institute of Medicine (IOM, 2006) and the National Cancer Institute (NCI) (2008) have redefined 'cancer survivorship' to include the multifaceted and interrelated "physical, psychological, and economic issues of cancer from diagnosis until the end of life".

The new definition of survivorship provided by NCI's Office of Cancer Survivorship (OCS) is a dramatic improvement from prior definitions of 'survival'. However the newer definition still fails to account for the varied and unique experiences that culminate as women's survivorship. For many women breast cancer is a traumatic and disabling disease that can have devastating effects on quality of life including interpersonal relationships, economic stability, romantic and spousal relationships, as well as employment (NCI, 2008; Mullan and Hoffman, 1990; Stanton, Revenson and Tennen, 2006). For others, survivorship is characterized by a sense of *thriving or successful adaptations* that appear to cultivate a renewed, recharged version of their pre-breast cancer selves (Sabiston, McDonough, and Crocker, 2007; Parry, 2007; Parry, 2008; Culos-Reed, Shields, Brawley, 2005; Mitchell, Nielsen, 2002). Understanding the factors that enable, reinforce and facilitate high quality survivorship is critical for optimizing survivorship opportunities for all women diagnosed with breast cancer. Quality of life, affect/mood, perceived social support, stress, perceived discrimination and years since diagnosis are the foci of this work.

There is accumulating evidence indicating that the quality of women's breast cancer survivorship varies along a continuum with some women reporting very positive outcomes and others experiencing poor health and quality of life (Ganz et al., 1998; Ganz et al., 2002). Some suggest that the psychosocial domains of survivorship, such as affect/mood and quality of life, including spiritual, social and emotional wellbeing, are among the most important outcomes if we are to extend our understanding of survivorship (Aaronson, et al., 1985; Cella, Tusky, 1990; Ferrel, Dow, 1997) and to enhance the quality of survivorship for all women surviving breast cancer. For breast cancer survivors, the variance in quality of life is influenced by a constellation of important factors including social support, stress, age, sexual identity, and years since diagnosis (Aaronson, et al., 1985; Cella, Tusky, 1990; Ferrel, Dow, 1997). Although clear indicators that influence quality of life and survivorship have been identified, there are many unanswered questions about how selected subgroups of the breast cancer survivor population survive, and thrive.

Breast Cancer Survivorship and Sexual Identity

According to reports by the IOM (1999; 2010) and NCI (2008) social determinants of health lead some groups of women to experience more difficult survivorship than others. A few qualitative studies point to the influence of sexual identity as a possible key factor in understanding breast cancer survivorship experienced by sexual minority women (Boehmer, et al., 2005; Fobair et al., 2002). Sexual minority women (SMW), women who partner with women in spousal and romantic relationships, may be at greater risk for less favorable short and long-term outcomes in overall successful breast cancer survivorship (NCI, 2008). In particular there is a dearth of quantitative studies regarding breast cancer survivorship among SMW and even less information on the factors that may uniquely influence the quality of breast cancer survivorship among them. Consequently little is known about the experiences of breast cancer survivorship among SMW.

The NCI (2008) indicates that hundreds of thousands of women are surviving breast cancer annually, and it is unknown how many of these survivors also identify as sexual minority women. Population-based studies indicate that SMW have a significantly higher prevalence of breast cancer than the heterosexual population (Valanis, et al., 2000; IOM, 1999; Dean et al., 2000; Bradford and White, 2001). Given this elevated breast cancer prevalence, it is possible that many breast cancer survivors are SMW. However experts in the field of population-based methodologies indicate that locating this population has historically been difficult (Brogan et al., 2000; Dean et al., 2000; IOM, 1999). Despite the difficulty inherent to the study of sexual minority breast cancer survivors, the elevated risks and prevalence of breast cancer among this population make it vital that the factors influencing breast cancer survivorship among SMW be investigated. Despite the large and growing population of breast cancer survivors little is known about sexual minority breast cancer survivors or the role that psychosocial factors play in the complex, multifaceted and interrelated components of breast cancer survivorship among SMW.

In what follows we explore how the influences of heterosexism, discrimination, stress, and stigma could significantly diminish SMW breast cancer survivors' quality of life. Studying this population is important for three reasons: 1) Because of the unique influences of stress, stigma and marginalization on health and cancer survivorship, 2) Because SMW have 2-3 times higher rates of cancer compared to other groups (Valanis, et al., 2000; Solarez, 1999; Dean et al., 2000), and 3) Because there have been few studies that have quantitatively examined the influence of psychosocial factors, including perceived social support, perceived stress, and perceived discrimination, on SMW breast cancer survivorship (defined as quality of life and affect/mood).

SMW, Heterosexism and Stigma

Historically SMW have been stigmatized and marginalized in the United States (Berkman, Zinberg, 1997; Rich, 1986; Frye, 1983; Pharr, 1988). Some have suggested that the stigma experienced by SMW results in their being viewed as inferior and abnormal compared to heterosexual women (Barbara, Quandt, and Anderson, 2001; Pagelow, 1980). Others suggest that heterosexism, or far-reaching sociopolitical expectations that all people are biologically destined to be oriented towards the opposite sex (Frye, 1983; Pharr, 1988; Rich, 1986), is the root of discrimination and stigma against SMW. It understood that heterosexism and stigma results in higher rates of stress, compromised levels of perceived and actual social support from biological families and families of origin, in addition to strained experiences in health care settings among sexual minorities (Stevens, Hall, 1988; O'Hanlan, 1995; Rankow, 1995; Bradford, Ryan, 1998). The stress caused by living in these strained contexts and experienced by minority people is referred to as *minority stress*. Minority stress has been shown to have a negative impact on health status, wellbeing, and medical outcomes in virtually all minority populations. However, the impact of minority stress on SMW has not been clearly elucidated.

Minority Stress

SMW are thought to be at greater risk for poorer breast cancer survivorship because of the unique ways that their minority status positions them socially. It is increasingly understood that living outside of the dominant social expectations of heterosexuality results in negative stress and compromises in mental and physical health outcomes (Dean et al., 2000; IOM, 1999; Meyer, 1995; Meyer et al., 2002; Meyer, 2003). Meyer (1995) defines minority stress as "psychosocial stress derived from minority status" and is applied here to explain how SMW may engage health behaviors and coping differently compared to heterosexual women who are, in this case, the majority.

Meyer and colleagues (Meyer, 1995; Meyer et al., 2002; Meyer, 2003) document the risk for excess mental and social stress experienced by gay and lesbian individuals caused by their societal position as minorities. This social position can lead to compromised coping resources such as the quality and presence of social support (Wethington, Kessler, 1986; Cohen, Sheldon, Ashby, 1985; Pelushi, 1997; Bloom, 1982) and therefore influence the quality of life and psychological outcomes experienced by SMW who are surviving breast cancer. The combination of minority stress and compromised social support could result in greater risk for poorer quality breast cancer survivorship in the form of lower quality of life, depression and/or negative affect/mood.

Sexual minority women may face discrimination in many areas of life, including health care settings (Fields and Scout, 2001; IOM 1999); however, little research has been conducted on perceived discrimination among sexual minority breast cancer survivors at the time of this writing. Prior studies have documented women’s experiences with race-based discrimination in health care settings (Thorburn, Bogart, 2005; Mays, Coleman, Jackson, 1996; Bird, Bogart; 2003), and socioeconomic status-based discrimination (Bird, Bogart, 2001). These perceptions of discrimination have also been linked with health outcomes (Bird, Bogart, Delahanty, 2004) where HIV positive individuals who experiencing either race or economic-based discrimination were more likely to be depressed and have more psychological disturbances. However currently there is no documentation of sexuality-based perceived discrimination reported by SMW undergoing breast cancer treatments. The combined influence of stress and perceived discrimination could have an important influence on SMW's breast cancer survivorship and quality of life.

Quality of Life and Survivorship

Quality of life (QOL) is a broad umbrella term that typically includes four specific domains of well being: spiritual, physical, psychological and social. QOL has been an important and guiding theme in the literature pertaining to breast cancer survivorship because it represents a possible measure for the long and short term implications of breast cancer. Breast cancer survivor's QOL has been shown to be influenced by cancer treatment course (Meyer and Aspergren, 1989; Omne-Ponten, Homber, and Sjoden, 1994; Ganz and Horning, 2004), by the length of time since diagnosis (Vinokur, et al., 1989), and by survivor's level of social support (Sorensen, 1994; Lee, 1997).

Social Support, Perceptions of Social Support and Survivorship

Some have suggested that social support, and particularly perceptions of social support, is crucial to individual's adjustment to stressful and traumatic life events and experiences (Wethington, Kessler, 1986; Cohen, Sheldon, Ashby, 1985) such as those involved in breast cancer survivorship (Pelushi, 1997; Bloom, 1982). Theorists have explored the many forms of social support and social support mechanisms in an effort to harness the health benefits of perceived and actual social support. However, the literature does not specifically address how perceptions of social support impact breast cancer survivorship in diverse populations. In fact very little literature to date has explored the role of women’s perceptions of social support on their QOL in breast cancer survivorship, particularly among SMW.

There is minimal literature to date published regarding the unique experiences of SMW and the role that sexual identity plays in influencing women’s perceptions of social support. Fobair and colleagues (2001) found that SMW were more likely than heterosexual women to draw actual social support from romantic partners and a network of close friends. Heterosexual women on the other hand drew more social support from ‘relatives’ and were more likely to draw social support from families of origin (Fobair, et al., 2001). The perception of social support was not assessed in this study nor was it made clear what particular role social support played in the quality of women’s breast cancer survivorship and their quality of life.

Perceived Stress

Perceptions of stress are also important to measure when assessing the influence of social support. Wetherington and Kessel (1986) as well as Cohen, Sheldon and Ashby (1986) remind researchers that examination of perceived social support also required measures of stress and life stressors; as a result this model also contains measures of stress and psychological distress.

Stress has been shown to have powerful and influential affects on physical and mental health outcomes (Kasl, 1984; Arnetz, Ekman, 2006; Seyle, 1976). Having a breast cancer diagnosis has itself been found to be a stressful life experience, as are some of the experiences involved in survivorship (Mullan, 1990; IOM, 2006; NCI, 2008). Sexual minority breast cancer survivors may experience a magnified version of this stress that includes the stress associated with being a sexual minority.

Affect and Breast Cancer Survivorship

In addition to QOL, affect/mood is an important variable in breast cancer survivorship research. Breast cancer diagnoses can be traumatic and emotionally distressing. This psychological distress can, for some, be a relatively short phenomenon while others experience longer term distress that colors their long term survivorship experience (Kemeny, et al, 1988).

It has also been suggested that measures of affect/mood be assessed in conjunction with measures of QOL to enhance our understanding of breast cancer survivorship quality (Stanton et al., 2007). When used in combination with measures of QOL, assessments affect/mood may help to provide a more complete picture of breast cancer survivorship outcomes.

Purpose

This dissertation research is intended to extend the literature regarding the factors that contribute to breast cancer survivorship, particularly among SMW. There is no literature to date that examines the direct and indirect influences of perceived discrimination, perceived social support, and perceived stress on quality of life among sexual minorities surviving breast cancer. Measures of sexual identity, perceived social support, QOL, perceived stress, and affect/mood were used together to develop a model of survivorship and to extend our understanding of the factors that contribute to cancer survivorship. As depicted by the conceptual model in Figure 1, it is hypothesized that perceptions of social support influence survivorship outcomes such as quality of life (defined as physical, emotional and spiritual wellbeing), and affect/mood. The following overarching research questions support the study's hypotheses:

1. Are there differences in survivorship (as assessed by measures of affect and quality of life) between SMW and heterosexual women?
2. If so, what are the differences in survivorship between SWM and heterosexual women?
3. Do perceptions of social support differ between SWM and heterosexual women?
4. If there are differences in perceptions of social support, how do these perceptions differ between SMW and heterosexual women?
5. Does perceived social support influence breast cancer survivorship?
6. What role does perceived discrimination play in breast cancer survivorship among SMW?

Hypotheses to Be Analyzed

1. SMW will report lower perceived social support scores than heterosexual women.
    - Ho: Measured perceptions of social support will not vary based on women's sexual identity.
    - Ha: Measured perceptions of social support will be lower for SMW.
2. SMW will report higher perceived stress scores than heterosexual women.

  - Ho: Measured perceptions of stress will not vary based on women's sexual identity.
  - Ha: Measured perceptions of stress will be higher for SMW.

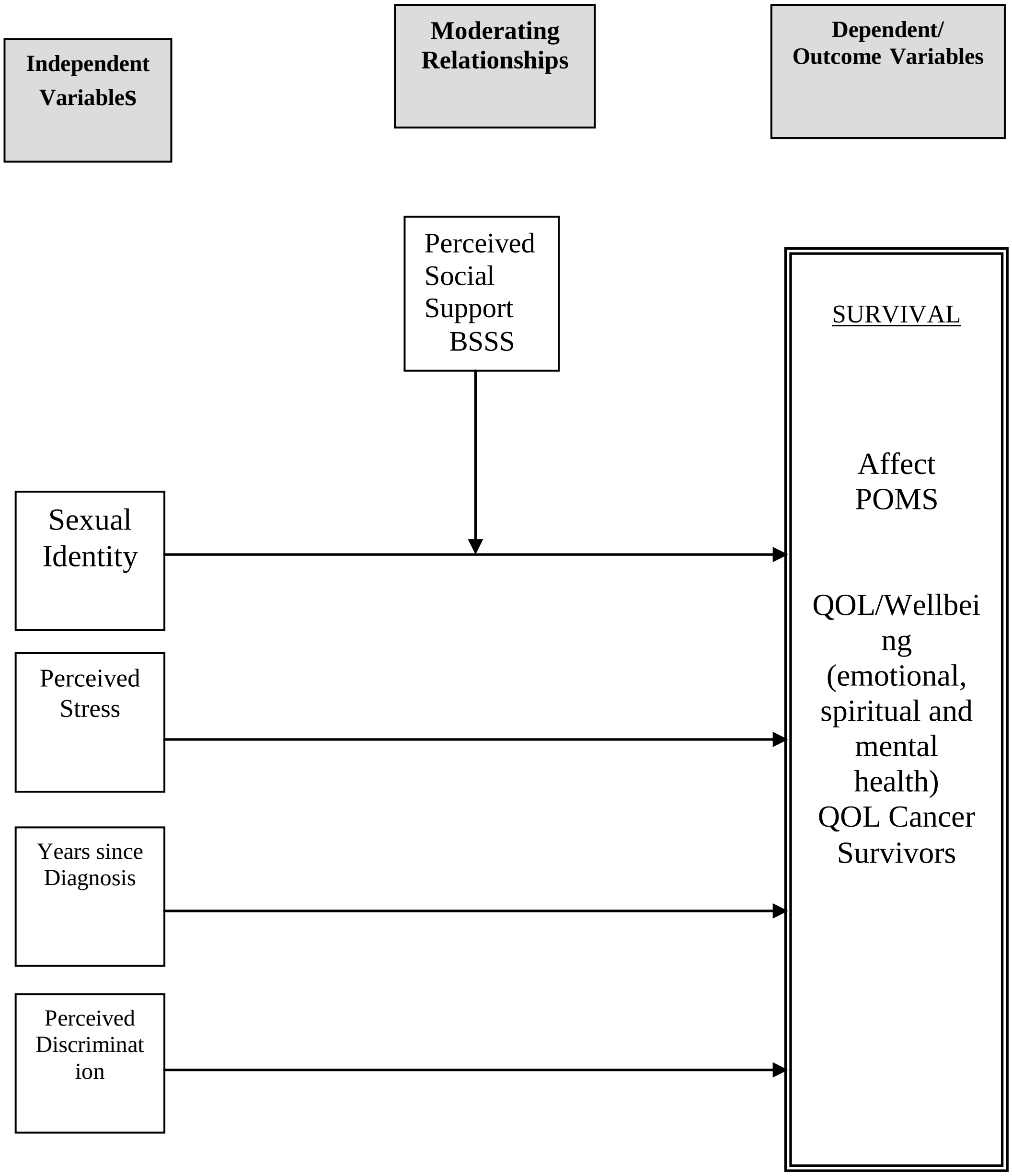
3. Survivorship (defined as quality of life and affect) will differ significantly according to women's sexual identity. SMW will report lower QOL scores and negative emotional affect/mood.
   - Ho: There will be no significant differences in quality of life and affect/mood scores according to sexual identity.
   - Ha: Quality of life and mood/affect scores will vary according to sexual identity. SMW will have lower scores of quality of life and mood/affect.
4. The variance in quality of life and affect/mood will be predicted from perceived social support, years since diagnosis, perceived stress and sexual identity.
   - Ho: The variance in quality of life and affect/mood will not be predicted from perceived social support, years since diagnosis, perceived stress and sexual identity.
   - Ha: A significant portion of the variance in quality of life and mood/affect will be predicted from perceived social support, years since diagnosis, perceived stress and sexual identity.
5. Measures of social support perceptions will moderate the influence of sexual identity for sexual minority breast cancer survivors. That is to say that women's perception of social support will modify the influence of sexual identity on

positive survivorship outcomes: quality of life (well being) and positive affect/mood.

- Ho: Perceptions of social support will not moderate survivorship measures.
- Ha: Perceptions of social support will moderate survivorship measures.

The following sections provide a review of breast cancer survivorship literature as it pertains to SMW. This includes definitions and classifications of survivorship as related to the experiences of SMW. A review of literature pertaining to social support and its role in disease adjustment among SMW segues into a discussion of the role of perceived social support as a moderator in breast cancer survivorship among SMW.

Figure 1. Research Model



CHAPTER II

THEORETICAL BACKGROUND: LITERATURE REVIEW

Defining Survivorship

Cancer survivorship is defined by the National Institute of Cancer (2008) as the “physical, psychosocial and economic issues of cancer, from diagnosis until the end of life. It includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life.” Mullan (1990) suggests three distinct phases of cancer survival, each characterized by different behavioral, physical and emotional disruptions. According to Mullan (1990) the first phase, *acute survival*, accompanies diagnosis and continues through the first year, which is often highlighted by cancer treatments. The second phase of survivorship is defined as *extended survival* and begins at the end of the first year after diagnosis and lasts until three years after diagnosis. A survivor is said to enter the third phase of survivorship, *permanent survival*, after the first three years since diagnosis pass without a recurrence of cancer.

Each phase of survivorship is characterized by differences in quality of life, wellbeing, affect, and depression. For example, Bloom (2002) reports that individuals in the acute survival phase report emotional distress and depression related to diagnosis and treatments, but that these symptoms abate near the end of the first year. Extended survival is characterized by physical disruptions similar to the first phase including low levels of physical energy and compromises in physical functioning. Additionally, during the second stage of survivorship or extended survival, some individuals experience difficulty returning to employment and engaging previously rewarding interpersonal relationships. These disturbances are expected during the second phase given that it is also the period when most survivors have the highest probability of cancer recurrence; a stressful reality for many survivors. The third, and final phase, or permanent survival, is characterized, in some cases, by permanent loss of physical energy and problems with interpersonal relationships. Although some survivors experience this phase of cancer survival with minimal negative outcomes, many other survivors in this phase of survival report continuing problems with social reintegration including close friendships, employment, and leisure activities. It is the sustained social disruption in the form of disrupted friendships and social reintegration that leads to questions about how social support issues differ as a function of women's sexual identity.

Although Mullan's (1990) categorical 'stages of cancer survival' is useful in characterizing the stages of cancer survivorship and in the development of treatment interventions and support efforts, we must be mindful of the need to tailor such work to the diverse and changing needs of cancer survivors. Mullan's model has limitations. It remains unclear from Mullan's (1990) survival categories, how women across the spectrum of social difference such as social class, race, economic stability, and particularly germane here, sexual identity, pass through these phases of survivorship. For instance, how do women with substantial and positive social support experience these phases differently than women who have compromised sources of social support? Does perceived social support moderate phases of survivorship? Importantly Mullan's (1990) survivor phases do not illuminate the specific factors that contribute to more or less physical, emotional, social and behavioral disruptions characterizing the described phases experienced by women surviving breast cancer. Investigating the factors that contribute to women's breast cancer survivorship is essential to extend our understanding of long term survivorship and if we are to diminish what can be devastating consequences of breast cancer for all survivors.

The complexity of quantifying the multi-factorial qualities and characteristics of cancer survivorship is enormous. Very generally, and based on the current definition of survivorship, measuring the quality of one's survivorship results in two broadly defined categories of cancer survivorship, physical health and psychosocial health (Rowland, 2007; Fobair, 2007). Physical health includes factors such as physiologic reactions to treatments, health consequences of cancer treatment, physical functioning, and physical health. Psychosocial health, and the focus of the current study, includes factors such as quality of life, stress, wellness, mental health, social support, mood/affect, and others that are influenced by the experience of breast cancer diagnosis, treatment and survivorship.

Quality of life and mood, in particular, have been, and are currently, routinely used as outcome indicators of breast cancer survivorship. Factors such as social support, years since diagnosis, stress and individual's demographic characteristics, such as sexual identity and income, have been, and are included here, as indicators that influence and predict the characteristics of quality of life and affect/mood among breast cancer survivors. In the following sections quality of life, and affect/mood, perceived stress and perceived social support, are discussed as they are related to breast cancer survivorship among sexual minority women.

Sexual Identity and Breast Cancer Survivorship

One group of breast cancer survivors is all too frequently considered an ‘invisible’ population (Frye, 1983). Sexual minority women (SMW), or women who partner in romantic and spousal relationships with other women, may be at increased risk for poor survivorship outcomes because of the minority stress, stigma, discrimination and marginalization faced on a daily basis. The influence of sexual identity has only rarely been explored in terms of health behavior, disease risk, and disease prevalence (Boehmer, et al., 2007; Valanis, et al., 2000; Bowen, et al., 2004; Committee on Lesbian Health Research Priorities, 1999). In terms of breast cancer survivorship, it is possible, and highly probable, that much of the extant research and literature pertaining to breast cancer survivors and survivorship unknowingly includes SMW. But because sexual identity information is either not asked, not analyzed, or not reported, the factors that uniquely contribute to breast cancer survivorship among SMW remains veritably unknown.

Population based studies indicate that SMW have 2-3 times the prevalence for breast cancer (Valanais, et al., 2000; Solarz, 1999), yet documentation of their survivorship experiences remains limited. It is suggested that their social invisibility, resulting from the heterosexist arrangements of the health care system positioned by and within the wider heterosexist social contexts, dramatically and uniquely influences their survivorship from the moment of their cancer diagnosis (Barbara, Quandt, Anderson, 2001; IOM, 1999; Boehmer et al., 2005). Before reviewing the literature that pertains specifically to breast cancer survivorship among SMW it is important to explore the theoretical concepts ‘lesbian invisibility’ and ‘heterosexism’ that serve as the theoretical backdrop for this work. This discussion is intended to provide a conceptual framework for the coming discussion of disparities in survivorship among SMW.

“Heterosexism”

Heterosexism is a system of oppression based on the systematic assumption that all people are heterosexual; an assumption embodied by the design and implementation of all U.S. social, political and economic systems (Frye, 1983; Rich, 1986; Pharr, 1988). This heteronormative assumption is rooted in compulsory heterosexuality; the notion that the only ‘natural’ form of sexuality is that of women being innately oriented sexually and relationally toward men (Rich, 1986). Heteronormative social, political, and economic principles are and have been historically established based upon compulsory heterosexuality thereby promoting and securing the illusion of a single, hetero-‘normative’ identity for all women. In this way compulsory heterosexuality functions as a mechanism to maintain control over women by securing their social and relational bondage to men and male-identified systems of power and social conduct.

Fundamentally, compulsory heterosexuality creates a social climate that funnels individuals toward a prescribed, singular expectation of sexual expression and identification. The result of this systematic funneling is not only the expectation that all women are heterosexual, but it also narrows socio-political frameworks from which other systems, such as the health care system, evolve and are codified (Sherwin, 1998; Pauley-Morgan, 1998).

The influence of heterosexism and compulsory heterosexuality dovetail with one another exerting a profound and overarching influence in shaping women's lives (Frye, 1983; Pharr, 1988; Rich, 1986), their health (Bradford, et al., 1996; Dean et al., 2000) and in this case, the quality of life, and breast cancer survivorship of SMW (Fobair, et al., 2002; Matthews, et al., 2002).

Feminist theorist Marilyn Frye (1983) describes how the social invisibility of SMW is perpetuated by 'heteropatriarchal' sociopolitical and economic systems, including the system that delivers and provides health care. The fundamental design of the health care system and its systematic implementation of health promotion materials, intake forms, health behavior modification and education programs, as well as available health care and support services, systematically omit the veritable experience and existence of SMW. In this way the invisibility of SMW is reinforced.

The social invisibility of SMW, resulting from compulsory heterosexuality, is an example of how oppression is operationalized in a social system; oppression operates systematically to press or mold individuals into a form that restricts and immobilizes opportunity and experience (Frye, 1983). Barbara and colleagues (2001) provide an example of how SMW become restricted in their survivorship because of their sexual identity. Qualitative interviews with sexual minority breast cancer survivors revealed that SMW felt unsafe attending breast cancer support groups and survivor activities for fear of rejection by group members because of their minority sexual identity (Matthews, et al., 2002; Fobair, et al., 2002). Women reported that their fear of 'coming out' in the survivor setting undermined their perception of safety and willingness to attend social groups and activities. These restrictions, anchored in heterosexism, acted as a 'cage' (Frye, 1983). Frye's theory, that systems of inequality act as a cage limiting women's lives, could explain the unique experiences of sexual minority breast cancer survivors. The 'cage' restricted SMW from engaging in opportunities that could have enhanced their survivorship and possibly their long term health outcomes.

Frye (1983) describes the accumulation of single and intersecting oppressions as a 'cage' that confines individuals. It is arguable that the metaphorical cage created by the intersecting systems of oppression not only confine women's experiences, but also restricts the likelihood of participation in protective and health enhancing activities, and in this case, activities associated with positive breast cancer survivorship. This may include, but is not limited to women's adoption of health protective behaviors that reduce the risk for comorbidities and access to the most appropriate forms of care and support for sexual minority breast cancer survivors.

Rich's (1986) analysis of compulsory heterosexuality articulates essential components of heterosexism, and Frye's (1983) discussion of 'lesbian invisibility', or the invisibility of SMW, illustrates how heterosexism operates over women's lives. Conceptual models can also be useful in understanding how heterosexism and stigma operate in women’s lives. In the following section Meyer’s (2007) conceptual model for sexuality-based minority stress explains how stigma and heterosexism generate stress that influences sexual minority women’s health uniquely from the stress caused by daily living.

Minority Stress and Sexual Minority Women

Sexuality-based minority stress is an important and negative consequence of heterosexism. In a series of articles and book chapters Ilan Meyer and colleagues (2003; 2007; 1998; 1995) have developed a conceptual model of sexuality-based minority stress that explains the unique forces and characteristics of sexuality based discrimination and heterosexism on the health of sexual minority individuals.

According to Meyer (2007) minority stress is distinct from ‘regular’ stress experienced in everyday living and is distinguished by three specific characteristics. First, minority stress is additive. The sexuality-based stressors experienced by sexual minority people occur *in addition* to the ‘regular’ daily living and life stressors experienced by all people. The overlay of minority stress occurs on top of the stressors experienced in daily living and requires sexual minorities to develop and utilize additional coping strategies or resources above and beyond those required for successfully coping with everyday life. Second, minority stress is chronic. This means that minority stress is constant. The constancy or chronicity occurs because sexuality-based minority stress is supported by socio-cultural frameworks and traditions that undergird institutions and society. The third characteristic that sets minority stress apart from ‘regular’ stress is that it is socially based. This means that minority stress stems from sources beyond individual control such as institutions and social processes.

When we apply the conceptual model of sexuality-based minority stress to sexual minority women we can conceive of how heterosexism, sexuality-based prejudice and discrimination can influence women's health adversely. For example, Dibble and Roberts (2002) found that SMW undergoing treatment for breast cancer experienced poorer symptom management and control than did heterosexual women undergoing breast cancer treatment. This disparity could be due to any one of the three characteristics identified in Meyer's model of minority stress, and more likely, all three characteristics working in concert.

Standpoint Theory

As is the case for women of varying and overlapping social difference, the social experiences of SMW influences their world view, their social position, and the opportunities that they are presented and experience. Standpoint theory suggests that how women view the world and what they deem as worthy of their attention is determined by their socio-political position. Patricia Hill Collin's (2001) seminal work in standpoint theory illustrates the way that intersecting oppressions position Black women differently from White women or men. From standpoint, or identity theory, heterosexism is then examined from the intersecting oppressions of SMW living in a hetero-androcentric social system. The reality created by these systemic intersections shapes the lives of SMW by influencing their ways of knowing and experiencing the world. The molding effect of these intersections is not suspended when women are diagnosed with breast cancer; rather, in the presence of a traumatic health experience such as breast cancer diagnosis and treatment, the powerful influences of systemic oppressions become magnified, strengthening their impact on SMW's lives and breast cancer survivorship. If we transfer Hill Collin's (2001) standpoint theory to health, it can be interpreted that SMW may react to and internalize knowledge about treatment, support and survival in a substantially different way from that of heterosexual women. Their access to knowledge or the applicability of knowledge to their health is arguably altered by their 'standpoint', their identity, and position in the world. Using the feminist theories of identity and heterosexism as the contextual backdrop of our discussion, we will next explore the literature pertaining to breast cancer survivorship among SMW.

Breast Cancer Survivorship and Social Support among Sexual Minority Women

All women bear the burdensome and varying negative consequences of gender inequalities (Sherwin, 1998; Hill-Collins, 1996; WHO, 2010). SMW bear the additional encumbrance of discrimination, social stigma, rejection, and alienation in a society that promotes their invisibility based on their sexuality (Rich, 1986; Frye, 1983; Fields, et al., 2001). Population based and regional surveys of SMW health indicate that these women specifically are at elevated risks for obesity (Aaron, et al., 2001; Valanis, et al., 2000; Roberts, 2001; Cochran, et al., 2001; O'Hanlan, et al., 2004; Solarz, 1999), heart disease (Markovich, et al., 2009; Roberts et al., 2003), all forms of cancer (Roberts, 2001; Cochran, et al., 2001; Marrazzo, et al., 2001), substance use and abuse (Aaron, et al., 2001; Valanis, et al., 2000; Roberts, 2001;

Cochran, et al., 2001; O'Hanlan, et al., 2004; Solarz, 1999), mental illness (Roberts, 2001), and economic instability. SMW are also more likely to report fewer contacts with and support from 'traditional' family members (Barnoff, et al., 2005; Fobair et al., 2002; Boehmer, et al., 2005; Arena et al., 2006; Sinding et al., 2006). The risk for and prevalence of disease among SMW combined with their elevated risk for social rejection, social invisibility, alienation and stigma make them a primary concern in studying the impact of social support on breast cancer survivorship.

Social support has long been thought to improve the health of individuals (Kaplan, Thoshima, 1990; Hobfoll, & Stephens, 1990; Sarason, Sarason, Pierce, 1990; Uchino, 2004; Cohen & Syme, 1985; Berkman, 1985; Wortman & Conway, 1985). Theorists have explored its many forms and mechanisms in an effort to harness the health benefits observed among those individuals who seem to be protected by the presence, and perceptions of social support (Cohen and Syme, 1985; Berkman, 1985; Wortman, and Conway, 1985; Uchino, 2004). Investigations of support have resulted in a plethora of theories and models that depict the role of social support in individual's lives. The vast majority of the literature points to an individual's *perception* of support as the most important for buffering, or managing, the negative effects of stressors caused by disease and disease adjustment (Uchino, 2004; Cohen and Syme, 1985; Perlin, 1985; Willis, 1985; Swann and Brown, 1990). However this literature does not specify how *diverse* populations, particularly sexual minorities, may utilize social support differently in the adjustment and survivorship of chronic conditions such as breast cancer. The heteronormativity of science and social values has resulted in limited writings and investigations concerning the specific ways that social support mechanisms and their utility differ for SMW surviving chronic diseases such as breast cancer.

With the theories of heterosexism as a guide, Barnoff, Sinding, and Grassau (2005) developed a qualitative, participatory action research study of sexual minority breast cancer survivors. Their call to action highlights the voices of 26 breast cancer survivors. Three distinct themes emerged from their interviews: 1. a need for treatment and breast cancer information that includes and reflects the reality of SMW diagnosed with breast cancer; 2. a need for breast cancer support services and activities designed and tailored for SMW and their families and; 3. a need for medical service providers who are conscious of, and sensitive to, the reality and experiences of SMW diagnosed with breast cancer. These themes underscore the previously discussed defining features of heterosexism and their limiting effects on SMW in the health care setting and on breast cancer survivorship experiences.

In a cross-sectional study of 64 SMW Boehmer, Linde and Freund (2005) explored SMW's coping and psychological adjustment after a breast cancer diagnosis. Participants were recruited through targeted community sampling methodology used to enhance snowball sampling, a technique commonly utilized for work with difficult to identify and/or seemingly 'rare' populations (Meyer, Rossano, Ellis, Bradford, 2002). Participation eligibility included women's self-identification as a sexual minority (a woman who partners with women), having a breast cancer diagnosis and fluency in English.

Women participating in the Boehmer and colleagues' (2005) study completed an audio-taped interview and self-administered questionnaire regarding their breast cancer experiences and survivorship. The questionnaire was comprised of the Profile of Mood States (POMS), and the abbreviated Mental Adjustment to Cancer scale (mini-MAC). The POMS was used to assess women's mood disturbances with higher scores indicating more mood disturbances (Cella et al, 1987). The mini-MAC includes five subscales measuring coping responses to cancer diagnosis (Watson et al., 1994): fighting spirit, helplessness-hopelessness, anxious preoccupation, fatalism, and cognitive avoidance. Breast cancer survivors who score high on fighting spirit are thought to have a more "positive reaction" to the cancer diagnosis where high scores on helplessness-hopelessness, anxious preoccupation, fatalism and cognitive avoidance are all interpreted as characteristics of maladaptive coping styles. This is important when we discuss the findings and implications of this study with sexual minority breast cancer survivors.

Demographic and descriptive analyses of the Boehmer and colleagues' (2005) data revealed that the participant's mean age was 50 years, 92% of the sample was White, 5% Latina and 3% African American. The sample was educated with 48% having attended college and 48% having attended graduate school. The majority of the sample indicated economic security and health insurance coverage.

Initially the data from the Boehmer and colleagues' (2005) study suggest that SMW do not differ significantly from heterosexual breast cancer survivors in their psychological and coping responses to breast cancer diagnoses. However when researchers took a closer look it became clearer that SMW had lower scores on fighting spirit, a valuable and protective coping style as indicated by Watson and colleagues (1994). It is possible that by increasing their fighting spirit, their long-term survivorship and perceptions of social support could have been enhanced.

This study is limited by its small, convenience sample of predominately White women. These factors restrict any ability to generalize to other SMW surviving breast cancer or to detect important relationships among variables under study. Additionally the absence of a comparison group makes it unclear if heterosexual women would perform differently on the measures of interest and in overall breast cancer survivorship than SMW. Furthermore it is unclear from Boehmer and colleagues' (2005) work how perceived social support is related to fighting spirit or other measures of coping and overall breast cancer survivorship. Finally, this work was principally focused on the 'adjustment' to cancer, the process by which women adapt to having a cancer diagnosis, rather than on overall breast cancer survivorship assessed by measures of the dimensions of quality of life. The distinction between 'adjustment' and survivorship is an important distinction to make. Adjustment is the psychological adaptations made to acclimate to the presence of disease in one's life (Stanton, Revenson, Tennen, 2007) and can be thought of as another aspect of survivorship. Survivorship is an overarching term including one's enduring physical, psychosocial, and economic issues that occur from the moment of diagnosis until the end of life (NCI, 2008).

Fobair and colleagues (2001) were also interested in the comparative responses of SMW and heterosexual women after being newly diagnoses with breast cancer. These investigators compared 29 SMW with 246 heterosexual women. Self-report measures completed by participants included demographic questionnaires and measures that assessed the following domains: Distress, Body Image and Sexuality, Relational Issues, Social Support, Medical Care and Coping. It was hypothesized that SMW would score higher on measures of distress, score higher on measures of cohesiveness (in the relational domain), and would have higher scores of social support from partners and friends than heterosexual women. Additionally these investigators hypothesized that SMW too would have fewer disturbances with body image and fewer problems with sexual activity as related to their breast cancer diagnosis than heterosexual women.

Analyses of the Fobair and colleagues (2001) study revealed that despite elevated mood disturbances (measured by the Profile of Mood States (POMS)) among SMW, there were no statistically significant differences between SMW and heterosexual women on mood disturbance and distress (Fobair et al, 2001). SMW did have fewer body image and sexually related problems associated with their breast cancer compared to heterosexual women. There were no statistically significant differences between women on relational issues (as in the expression of feelings), though SMW were statistically more likely to obtain more social support from partners and friends than from biological family compared to heterosexual women.

These findings point to the differences in women’s responses to breast cancer diagnosis between SMW and heterosexual women. However this study has significant limitations. Only 29 SMW were included in this work undermining statistical conclusion validity making it very difficult to statistically detect real response differences. SMW and heterosexual women were not matched according to specific demographic characteristics thereby compromising statistical power and adding to the difficulty in being able to detect important and substantive differences. The SMW represented a convenience sample recruited through newspapers, bulletin boards, advertisements and brochures. This too weakens the external validity and the ability to generalize the findings. External validity is further weakened by the introduction of self selection bias into the data. It is also significant that these investigators are again focused on the *response* to breast cancer diagnosis and not on the long term *survivorship* with breast cancer experienced by these survivors. Although it is important to explore the presence of differences between breast cancer survivors, too it is important to begin exploring the specific constellation of factors that contribute to survivorship and how survivorship is moderated by factors such as perceived social support.

In response to the Fobair and colleagues’ (2001) study, Arena, Carver and colleagues (2006) conducted a study with 39 self-identified SMW and 39 women heterosexual women, all of whom had recently been diagnosed and treated for early stage breast cancer. Measures completed for this study assessed three broad categories: 1) measures of emotional well-being, 2) relationship-related measures and

3) social support and coping measures. For full details pertaining to this study's measurement protocol please see Arena, Carver and colleagues (2006; p.86-90).

Arena, Carver and colleagues' (2006) results suggest that SMW breast cancer survivors reported embracing and allowing themselves to have thoughts about their breast cancer compared to heterosexual women who reported actively avoiding thoughts about breast cancer. Heterosexual women in this study were *more likely* to identify and cite the specific *benefits* inspired by their breast cancer diagnosis than were SMW. SMW did not significantly differ from heterosexual women on their scores of perceived available social support. However, heterosexual women had a seemingly *larger* social network and reported having accessed it more *recently* than SMW. Heterosexual women were significantly more likely than SMW to report a large number of family members whom they felt close to and at ease with. On the contrary SMW reported more social contact with friends than heterosexual women, though the size of these networks was still not as large as those of the heterosexual women. This difference in source of social support embodies the structural and institutionalized stigma associated with identification as a sexual minority and could be a key influence in the quality of one's breast cancer survivorship.

The study published by Arena, Carve and colleagues (2006) suggests that there were subtle but distinct differences between the heterosexual women compared to the SMW. This study also has notable limitations; namely the sample is a convenience sample and although this is the customary methodology for working with "invisible" populations, it does not protect against selection bias or allow for broad generalization.

This sample was not a large sample (N= 39) making differences between groups, if differences existed, difficult to detect thereby weakening this study's statistical validity. This study also did not explore how perceptions of social support moderate breast cancer survival among SMW or how such moderation may or may not differ for heterosexual women. This is an important point because if we can better understand the specific *role* of social support in breast cancer survivorship, we can develop programs tailored to enhance social support specifically as a survivorship moderator.

In a qualitative study of sexual minority breast cancer survivors, Barbara, Quandt, and Anderson (2001) conducted focus groups to determine women's perceptions of social support. Their work determined that SMW were less likely to participate in breast cancer support groups for fear of marginalization and stigma related to their sexual identity. This suggests that the perceived and anticipated stigma and marginalization experienced by SMW may significantly impact their perceptions of social support. This could have meaningful effects on their ability to engage positive aspects and outcomes associated with high quality breast cancer survivorship. Quantitative assessments of women's perceptions of social support were not measured or provided by Barbara and colleagues (2001).

Understanding the benefits of social support among breast cancer survivors Fobair and colleagues (2002) designed an intervention that provided a support group for SMW diagnosed with breast cancer. A convenience sample of 20 women consented to participate in a 12-week group support intervention program. The women were assessed at baseline, 3, 6, and 12 months after the group intervention to detect changes in coping, adjustment to disease, and social support. Results revealed an unexpected finding: group participants demonstrated *reduced* levels of instrumental and informational support. However, family conflict also declined and trends toward increased cohesiveness and expressiveness were evident. The increases in cohesiveness and expressiveness, paired with a decline in family conflict lead one to think that the reports of instrumental and informational support declined because of the reduced need for these forms of support. Consequently it appears that a SMW-specific breast cancer support group may be beneficial to SMW who are surviving breast cancer.

The studies reviewed here highlight the distinct differences between women, differences that become particularly important when surviving breast cancer. The literature indicates that SMW respond to breast cancer differently from heterosexual women. It remains unknown scientifically, but these differences may impact the factors that culminate as women's breast cancer survivorship. Unfortunately this literature is plagued by issues with convenience sampling and an 'invisible' population, self-selection bias, and small sample sizes inherent to studying a minority population (Brogan et al., 2000; Bowen et al., 2007). These initial works are intended to serve as a foundation for understanding some of the important and influential differences between women and how these differences may impact breast cancer survivorship and the growing numbers of breast cancer survivors. There remains a general lack of literature that pursues a deeper understanding of how these differences fit together to contribute to women's breast cancer survivorship.

As we have read from the prior work provided here pertaining to SMW and breast cancer responses, SMW and heterosexual breast cancer survivors report noteworthy differences in perceived and actual social support (Boehmer et al., 2005; Boehmer, et al., 2007; Forbiar, et al., 2002; Arena et al., 2006). We argue then that social support plays a significant role in these differences and in overall breast cancer survivorship for SMW.

Studies concerned with the beneficial influence of social support on health and adjustment to chronic disease are largely focused on sexual *majorities*. The few publications available for review indicate that SMW are significantly different from heterosexual women in their coping, support engagement and use of support. Given the limitations of few articles available, further work about the mechanisms of support among SMW is required. Similarly if interventions are to be developed towards enhancing the quality of life and survivorship among sexual minorities, social support theories must be considered in-line with knowledge about the oppressions of sexism and heterosexism. Only then can we proceed with more thorough investigations and interventions for sexual minority women adjusting to breast cancer, and ultimately, all forms of chronic disease.

Breast cancer survivorship is often measured in terms of women's quality of life and mood/affect, in which social support is thought to play a key role. In what follows, quality of life, as it is related to breast cancer survivorship will be discussed.

Quality of Life and Survivorship

In the field of breast cancer survivorship, quality of life has received much attention as a reliable measure of survivorship characteristics. Measures of quality of life are of particular utility in assessing cancer survivorship because they quantify one's wellbeing in the multiple domains of life including psychological wellbeing, physical wellbeing, social wellbeing and spiritual wellbeing.

Several studies of breast cancer survivorship have used quality of life to assess breast cancer survivor's survivorship and adjustment (Ganz, et al., 1996; Dow et al., 1996; Weitzner et al., 1997; Tomich et al., 2002; Cimprich, et al., 2002; Ganz et al., 2002). Quality of life indicators have been used as a dependent variable to determine the status of breast cancer survivorship generally, but they have also been used to discern differences among older versus younger women (Cimprich et al., 2002; Robb, et al., 2006), women who have opted for surgery or not (Rowland, et al., 2000; Nissen, et al., 2001), who are going through menopause (Durna, et al., 2002; Biglia et al., 2003; Holmberg, 2004), and who are experiencing cognitive dysfunction (Lemieux, et al., 2007). For example, in Cimprich and colleagues' (2002) study, quality of life indicators are used to determine the differences in breast cancer survivorship by age. In their study of 105 long term breast cancer survivors Cimprich, Ronis and Martinez-Ramos (2002) determined that women diagnosed with breast cancer at an older age (greater than 65) had worse physical quality of life scores than women diagnosed at younger ages (27-44 years). However, the younger age group showed worse social quality of life scores than the older survivors. Women diagnosed at midlife were the most likely to have positive physical quality of life scores as well as a positive overall quality of life, compared to the younger and older survivors.

Very few quality of life, breast cancer survivorship studies have included and/or focused on sexual minorities (Fobair, et al., 2002; Matthews, et al., 2002). The few that have used quality of life measures as an indicator of survivorship are limited by small sample sizes and methodological limitations. Matthews and colleges (2002) conducted a qualitative study using quality of life as a primary outcome for heterosexual and sexual minority women dealing with breast cancer. Interviews with 13 sexual minority women and 28 heterosexual women revealed similarities in quality of life in both groups. However, sexual minority women reported significantly more stress and greater dissatisfaction with provider care than did heterosexual breast cancer survivors. These findings are underscored by Meyer's (2007) conceptual model of sexuality-based minority stress in two ways. First, sexual minorities experience additive stress due to their sexual identity, as presented by the Matthews and colleagues study. Second, the conceptual model of sexuality-based minority stress posits that this stress is anchored in social systems and institutions, resulting in poorer treatment and care (in the health care system), as found by Matthews and colleagues' (2002). Although this study did not find significant differences in quality of life between groups of women, it is notable that the differences in stress and provider care could result in decreased quality of life later in life.

The majority of studies pertaining to quality of life either assumes women's heterosexuality or does not consider the role of sexual identity in quality of life as an outcome of survivorship. The minimal inclusion of SMW in studies pertaining to quality of life restricts our knowledge of sexual minority breast cancer survivorship as measured by quality of life.

In order to attain the most complete view of the psychosocial elements of breast cancer survivorship Stanton and colleagues (2007) suggest that measures of affect/mood be used in conjunction with measures of QOL to better our understanding of breast cancer survivorship quality. When used in combination with measures of QOL, assessments affect/mood may help to provide a more complete understanding of breast cancer survivorship outcomes. In the next section affect/mood is discussed as it relates to breast cancer survivorship with special focus on findings related to breast cancer survivorship among sexual minorities.

Affect/Mood and Survivorship

Breast cancer diagnosis, treatment and survivorship have all been shown to stimulate distress and mood disturbance in the form of depression, anger, apathy, and other emotions (Mullan, 1990; IOM, 2006; NCI, 2008). Assessing moods and affect provides an indicator for the quality of a women’s breast cancer survivorship. For example, a woman who reports low levels of distress, depression, anger and anxiety and high levels of friendliness, activity and vigor, would be demonstrating a positive degree of survivorship and might be characterized as thriving. Another woman who reports high levels of stress, distress, anger and low levels of friendliness and vigor would be demonstrating a compromised survivorship experience.

There is a preponderance of studies of mood disturbance and affect among heterosexual breast cancer survivors and a paucity of studies that address the experiences of sexual minority breast cancer survivorship. The few studies that do investigate the experiences of SMW surviving breast cancer indicate that this population experiences more stress and distress than heterosexual breast cancer survivors (Boehmer, et al., 2005; Matthews, et al., 2002; Fobair, et al., 2002). The ability to generalize the findings resulting from these studies is limited due to methodological constraints, qualitative approaches and small sample sizes.

Due to the dearth of research concerning sexual minority breast cancer survivor's affect/mood the field is left with an incomplete understanding of the characteristics and quality of affect/mood among sexual minority breast cancer survivors. The current research aims to assess sexual minority breast cancer survivor's affect/mood and to determine how and if SMW differ from heterosexual breast cancer survivors. This effort will extend the field's understanding of breast cancer survivorship among SMW.

Perceived Stress

Perceived stress is important to the current research for several reasons. As stated earlier in this work, perceptions of stress are important in the study of breast cancer survivorship due to the stress that is stimulated by experiences of cancer diagnosis, treatment and survivorship (Mullan, 1990; IOM, 2006; NCI, 2008). In addition, and more broadly, it has also been shown that among cancer-free populations perceived stress has a powerful influence on mental and physical health (Kasl, 1984;

Arnetz, Ekman, 2006; Seyle, 1976), where those who perceive a high level of stress report poorer mental and physical health. The importance of measuring perceived stress has also been emphasized by scholars in the field of social support. Wethington and Kesseler (1986) as well as Cohen, Sheldon and Ashby (1986) remind researchers that examination of perceived social support also requires measures of stress and life stressors, in order to account for the presence of a buffering effect.

Growing evidence from multiple studies suggests that SMW surviving breast cancer report higher levels of stress than heterosexual breast cancer survivors (Matthews, et al., 2002; Boehmer,et al., 2005; Fobair, et al., 2002). This provides important evidence for the inclusion of measures of perceived stress in this work. Earlier discussions of minority stress and heterosexism presented here also make it unmistakable that sexual minority breast cancer survivors may experience additional or elevated levels of stress, above and beyond the stress caused by a breast cancer diagnosis, treatment and survivorship, compared to heterosexual breast cancer survivors. Understanding the influence of perceived stress on breast cancer survivorship is essential to a complete conceptual understanding of SMW's breast cancer survivorship.

Years since Diagnosis

The factors reviewed up to this point are all important in discussions related to breast cancer survivorship. Additionally they are, in many cases modifiable (with the exception of heterosexism and discrimination). However, the length of time that has passed since a women's breast cancer diagnosis, or the duration of 'survivorship' is unmodifiable, and may play an important role in the quality of life and affect of breast cancer survivors. There is some disagreement in the literature pertaining to the influence of the years since diagnosis. Some research has found quality of life and life satisfaction improves with a longer post-diagnosis period (Kessler, et al., 2002). In a study of breast cancer survivors Kessler and colleagues' (2002) found that both the greater the time since diagnosis and the severity of disease, were associated with improvements in quality of life and health related quality of life. Kessler's work did also find that treatment related issues and concerns persisted long term among breast cancer survivors. Others have found that health and quality of life diminish over time (Ganz et al., 1996; Ganz et al., 2002). Ganz and colleagues (1996) found that women's health, affect/mood, quality of life and functional status improved the most between 1 month and 1 year post-diagnosis without subsequent improvements in later years. In a later study of women 1-5 years post-diagnosis Ganz and colleagues (2002) found that women's quality of life and functional status had diminished since diagnosis rather than improved.

Although it remains unclear how the duration of time since breast cancer diagnosis influences survivorship outcomes such as quality of life and affect, it is clear that time since diagnosis does influence survivorship. Additionally, studies concerning breast cancer survivorship have historically not included or analyzed data as they pertain to SMW. In fact there were no studies available that specified the influence of years since diagnosis in this special population of breast cancer survivors.

Concluding Statements

The evidence reviewed here underscores the complexity of breast cancer survivorship. The quality of women’s breast cancer survivorship is subject to a mixture of influential forces including perceived stress and perceived social support, in addition to societal influences such as minority stress and discrimination. Sexual minority breast cancer survivors have received minimal attention in the cancer survivorship literature. A few small and qualitative studies have begun to investigate the influence of sexual identity on breast cancer survivorship, but much remains to be known. At this time it is unclear how perceived discrimination and perceived stress influence sexual minority breast cancer survivor’s survivorship outcomes as assessed by measures of quality of life and affect/mood. It is also unclear how or if quality of life and affect/mood varies quantitatively according to women’s sexual identity. Finally, the role of social support as a factor in breast cancer survivorship is unknown among sexual minorities. This study seeks to investigate these areas in a cross-sectional, anonymous survey of heterosexual and sexual minority breast cancer survivors.

CHAPTER III

Methods

A cross-sectional comparison of breast cancer survivorship factors between SMW and heterosexual women is the focus of this work. The primary goal was to explore the factors thought to influence SMW's breast cancer survivorship. Using electronic data collection via an online survey, perceived discrimination, perceived stress, perceived social support, affect/mood, QOL and sexual identity are investigated. Specific methodological details, including sample size and power estimates, are provided following a detailed explanation of the measures used in this study.

Prior to formalizing the measures to be used in this online, quantitative study, focus groups were conducted with six breast cancer survivors. Focus group volunteers were recruited via advertisements posted in women's clinics, breast cancer survivors groups and online advertisement in breast cancer support discussion boards. Volunteering women self-selected into either the sexual minority breast cancer survivor focus group or the heterosexual breast cancer survivor focus group. One, 90-minute focus group was conducted with each group. Both groups were comprised of three volunteers who had experienced a breast cancer diagnosis and subsequent treatment.

During the focus groups women discussed their experiences feelings about breast cancer, breast cancer treatments and health care interactions, social support and support sources, as well as the influence that breast cancer had on their lives. The focus group discussions also included time for the volunteers to review the questionnaire and to provide feedback about the survey items.

The content of the focus group discussions were transcribed in person at the time of the focus groups by two research assistants using portable, laptop computers. Transcripts were later reviewed for important themes and information pertaining to the survey and breast cancer survivorship. Feedback from volunteers about survey items and survey design were integrated into the survey prior to the onset of data collection.

The central theme that emerged from these two focus groups was the need for social support. The heterosexual breast cancer survivors were all actively engaged in breast cancer survivors support groups and activities. They reported that support groups were essential to positive, high quality breast cancer survivorship. The sexual minority breast cancer survivors too reported on the importance of social support in high quality breast cancer survivorship. However, the sexual minority women also reported that there were no available support groups that reflected their intersecting identities as older, breast cancer surviving, lesbians. Consequently none of the sexual minority breast cancer survivors reported participation in support groups or support group activities.

Both focus groups indicated the need to include and focus on the role of social support in studying breast cancer survivorship. The sexual minority breast cancer survivors also requested that the survey reflect the fear of discrimination and the absence of social support resources for sexual minority breast cancer survivors. The results from these focus groups shaped the quantitative measure and the items selected.

The independent predictor variables in this study include: women's scores on measures of perceived discrimination, perceived social support, perceived stress, length of time since breast cancer diagnosis and self-reported sexual identity. Women participating in this study self-described their sexual identity as either: a) being a SMW (lesbian, queer, or homosexual) or b) being heterosexual (woman who pairs with the opposite sex). It is expected that the influence of sexual identity has a significant relationship with survivorship measures of quality of life and affect/mood. Social support is measured by the Berlin Social Support Scale (BSSS; Schwarzer, Schulz, 2000). It is expected that perceptions of social support moderate the predicted relationship between the influence of sexual identity and measures of breast cancer survivorship, quality of life and affect/mood.

The dependent outcome variables include: 1) quality of life (including physical wellbeing, psychological wellbeing, social wellbeing and spiritual wellbeing) measured with the Quality of Life—Cancer Survivors (Ferrell, et al., 1997) and 2) affect/mood measured by the Profile of Mood States (POMS) (Mcnair, Lorr, 1964). The following sections include specific details pertaining to the proposed measures, specific research questions and hypotheses, followed by a detailed discussion of the proposed online methodology.

Research Questions and Hypotheses

1. Are there differences in survivorship (as assessed by measures of affect and quality of life) between SMW and heterosexual women?
2. What are the differences in survivorship between SWM and heterosexual women?
3. Do perceptions of social support differ between SWM and heterosexual women?
4. If there are differences in perceptions of social support, how do these perceptions differ between SMW and heterosexual women?
5. Does perceived social support influence breast cancer survivorship?
6. What role does perceived discrimination play in breast cancer survivorship among SMW?

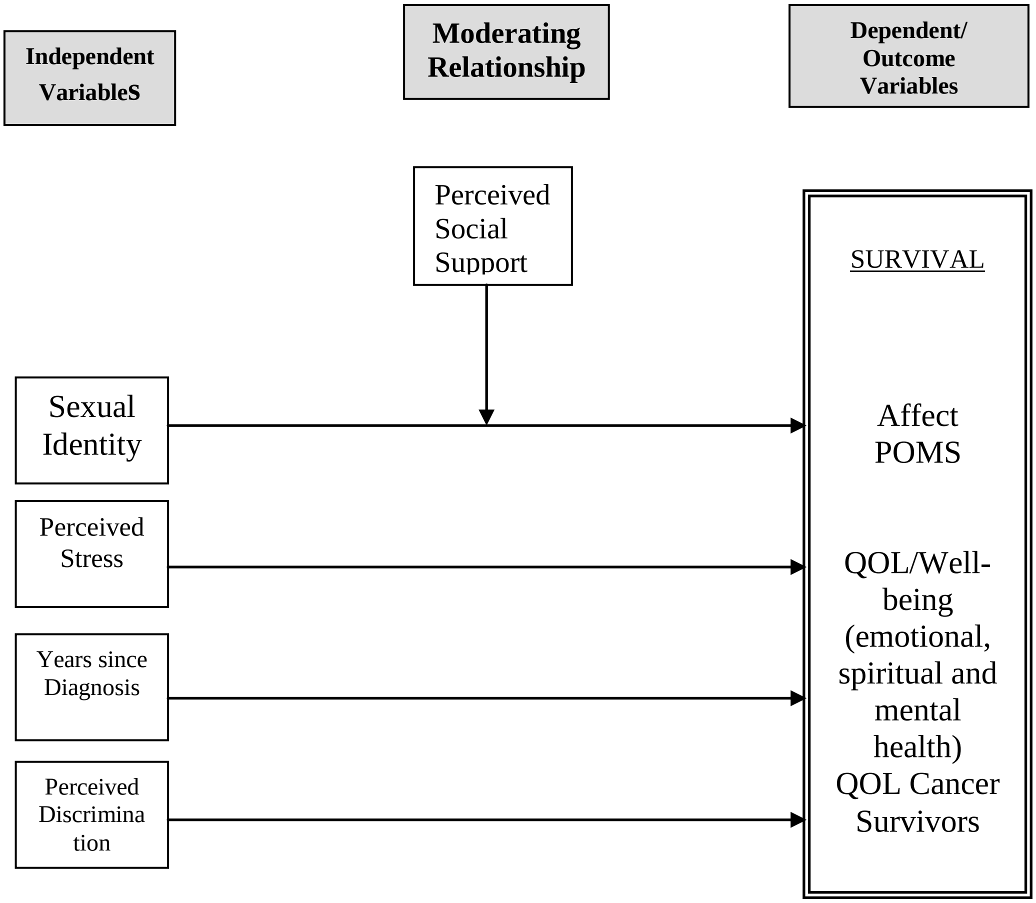
Hypotheses to Be Tested

1. SMW will report lower perceived social support scores than heterosexual women.
    a. Ho: Measured perceptions of social support will not vary based on women's sexual identity.
    b. Ha: Measured perceptions of social support will be lower for SMW.
2. SMW will report higher perceived stress scores than heterosexual women.
    a. Ho: Measured perceptions of stress will not vary based on women's sexual identity.
    b. Ha: Measured perceptions of stress will be higher for SMW.

3. Survivorship (defined as quality of life and affect) will differ significantly according to women's sexual identity. SMW will report lower QOL scores and negative emotional affect/mood.
    a. Ho: There will be no significant differences in quality of life and affect/mood scores according to sexual identity.
    b. Ha: Quality of life and mood/affect scores will vary according to sexual identity. SMW will have lower scores of quality of life and mood/affect.
4. The variance in quality of life and affect/mood will be predicted from perceived social support, years since diagnosis, perceived stress and sexual identity.
    a. Ho: The variance in quality of life and affect/mood will not be predicted from perceived social support, years since diagnosis, perceived stress and sexual identity.
    b. Ha: A significant portion of the variance in quality of life and mood/affect will be predicted from perceived social support, years since diagnosis, perceived stress and sexual identity.
5. Measures of social support perceptions will moderate the influence of sexual identity for sexual minority breast cancer survivors. That is to say that women's perception of social support will modify the influence of sexual identity on positive survivorship outcomes: quality of life (well being) and positive affect/mood.

- Ho: Perceptions of social support will not moderate survivorship measures.
- Ha: Perceptions of social support will moderate survivorship measures.

Figure 1. Research Model



Participants

Two hundred eleven women (68 SMW, 143 heterosexual women) participated in this study. Advertisement for this survey occurred through community newspapers, newsletters, postings at cancer treatment clinics, electronic mediums such as craigslist, and social networking sites such as Facebook, 'MySpace', as well as through advertisement at women-focused gathering places, groups and community outreach.

Inclusion Criteria

To participate in this study respondents had to be English speaking, have had a breast cancer diagnosis, have access to the internet to complete the online survey, and able to read and operate a computer to the extent necessary to complete the survey. There was no age restriction and women at any stage in their breast cancer survivorship were invited to participate.

Exclusion Criteria

Participants were excluded from the study if they did not indicate their sexual identity. If a respondent did not want to complete the survey after reading the electronic consent form, she was provided the opportunity to indicate this and was directed to a page that thanked her for her time. At this point the survey then closed.

Instrumentation

Perceived Social Support

The Berlin Social Support Scale (BSSS; Schwarzer, Schultz, 2000) was used to measure the four specific domains of perceived social support of interest to this work. The BSSS measured perceived support, provided and received support, need for support, and support seeking on four point Likert scales. Endorsements range from ‘strongly disagree’, ‘somewhat disagree’, ‘somewhat agree’, and ‘strongly agree’. All negative items were reverse scored during analysis preparation.

Profile of Mood States (POMS)

The POMS measures six dimensions of affect/mood including tension-anxiety, depression-dejection, anger-hostility, vigor-activity, fatigue-inertia, and confusion-bewilderment. The measure includes 65 adjectives that respondents endorse on a five point intensity scale specific to how they have been feeling in the past week. The POMS has been widely used to assess the affect and mood in cancer patients and survivors, including many of the studies reviewed in this work (Fobair, et al., 2002; Fobair et al., 2001; Boehmer, et al., 2005). McNair and colleagues (1971) and Cella and colleagues (1989) report extensively on the validity and reliability of the POMS.

Quality of Life—Cancer Survivors

The Quality of Life—Cancer survivors (QOL-Cancer Survivors; Ferrell et al., 1997) survey measures quality of life factors concerning long term survivors of cancer. The measure is comprised of 41 items that are endorsed on an eleven point Likert scale ranging from ‘0 worst outcome’ to ’10 best outcome’ that measure four domains of quality of life: psychological wellbeing, physical wellbeing, social wellbeing and spiritual wellbeing. Scores for each of the items are averaged to obtain a total raw score and then an average score for each of the four domains is also calculated. Reliability for overall test-retest is r=.89; subscales include: psychological, r=.88, physical, r= .88, social, r= .81, spiritual, r =.90 (Ferrell, et al., 1997). Internal consistency/reliability include Cronbach's alpha coefficient for this sample, overall score, r= .93; subscale scores are, psychological, r=.89, physical, r=.77, social, r= .81, and spiritual, r=.71 (Ferrell, et al., 1997).

Sexual Identity

Sexual identity was collected by asking women to self-report their sexual identity. The question states:

Please mark the description that best describes your sexual orientation or identity

1. ___ Heterosexual/Straight
2. ___ Lesbian
3. ___ Bisexual
4. ___ Woman who partners with women
5. ___ Not Sure
6. ___ Other (Please feel free to explain):

The measure also asks women to self-report their marital status:

What is your **current** marital or partner status?

____ 1. Married or living with an opposite sex partner
_____2. Married or living with a same sex partner
_____3. In a committed relationship with an opposite sex partner- not living together
_____4. In a committed relationship with a same sex partner- not living together
_____5. widowed
_____6. Divorced or separated
_____7. Single, never married
_____8. Involved with multiple partners
_____9. Other (Please specify)______________________________

Perceived Discrimination

To date there are no population-based, validated measures of perceived discrimination available to be used with sexual minority people. Therefore the measurement of SMW's perceived discrimination was translated from prior research involving perceived discrimination in health care settings among economically disadvantaged women and women of color seeking HIV treatment (Thorburn, et al., 2004; Mays, et al., 1993; Thorburn, et al., 2001). Participants who self-identified as sexual minority breast cancer survivors in the current study responded to the following questions on a five-point Likert scale: Based on your sexual identity, please rate the following according to your experiences during breast cancer treatments and meeting with doctors and nurses: a) You were treated with less courtesy than other people, b) You were treated with less respect than other people, c) You received poorer services than other people, d) You felt like a doctor or nurse was not listening to what you were saying, e) A doctor or nurse assumed you were heterosexual, f) A doctor or nurse assumed you were lesbian, g) A doctor or nurse assumed you had multiple sexual partners. Descriptive statistics for each item are calculated and an overall score is generated. The overall score is calculated by averaging across items and dividing by the total value by the number of scale items.

Perceived Stress

Wethington, and Kessler (1985), as well as Cohen, Sheldon and Ashby (1985) strongly recommend the measurement of individual’s perceptions of stress when assessing perceptions of social support. It is also indicated by Meyer (2002; 1995; 2003) and others that due to their position as sexual minorities that SMW experience a significant degree of stress that could be harmful physically and mentally (Stevens, Hall, 1988; O’Hanlan, 1995; Rankow, 1995; Bradford, Ryan, 1994; Meyer, 1995; Meyer et al., 2002; Meyer, 2003). Here Cohen’s four-item Perceived Stress Scale

(PSS) was used to assess women's perceived levels of stress (Cohen, et al., 1983; Cohen and Williamson, 1988). The four item scale is designed to be used with samples with at least a middle school level of education. Questions are designed to be easily understood and answered on a four-point Likert scale ranging from 0-never to 4-very often.

Demographic Characteristics

Demographic characteristics were collected with a short series of questions and included participant's current age, age at first breast cancer diagnosis, number of years since first breast cancer diagnosis, marital status and number of years of completed education, income, insurance coverage and contact with biological family.

Data Collection

Data collection occurred via an online, electronic survey. Advertisement for this survey occurred through newspapers, newsletters, postings at cancer treatment clinics, through electronic mediums such as craigslist and social networking sites such as Facebook and 'MySpace'. Hard-copy advertisements for this study were posted at woman-focused gathering spaces, activity groups and community organizations.

To detect differences in survivorship measures at a moderate level of effect (d =.10), with power set at .95, and .05 alpha, multiple regression with three predictors (perceived social support, sexual identity and SES), a total sample size of 200 women was needed. We successfully acquired data from 211 women; 68 SMW and 143 heterosexual women and determined that this was an adequate sample size to detect the predicted differences in this sample. These calculations were determined with the use of Gpower 3.0.05 (Gpower, 2008).

Women interested in participating in this study were directed to the specified website to complete the survey. Before beginning the online survey women read an electronic, voluntary informed consent page indicating the purpose of the study and what their involvement would entail. It also conveyed that participation was entirely voluntary and anonymous. Additionally it was clearly stated that by advancing from the consent page to the survey and completing the contents of the survey they were providing their voluntary consent for study participation. The survey took approximately 25 minutes to complete and was entirely anonymous. The data collection window lasted approximately 10 months, from November 2008- September 2009 at which time the sample size needed to conduct analyses was achieved.

CHAPTER IV

MANUSCRIPT I

BREAST CANCER SURVIVORSHIP:

FACTORS THAT INFLUENCE SURVIVOR QUALITY OF LIFE AND AFFECT

Abstract

The National Cancer Institute and Office (2008) of Cancer Survivorship indicate that 89% of women diagnosed with breast cancer will become survivors. However, some groups of women bear a greater burden of difficulty in survivorship (NCI, 2005). Sexual minority women (SMW), or women who partner with other women in romantic and spousal relationships, experience a higher prevalence of breast cancer and little is known about the unique factors that influence their breast cancer survivorship as compared to heterosexual women. This cross-sectional study investigated the influence of sexual identity/orientation, perceived social support, perceived stress, and years since diagnosis status on breast cancer survivor’s quality of life and affect. Two-hundred-eleven (143 heterosexual women and 68 sexual minority women) breast cancer survivors completed online, electronic surveys regarding their breast cancer survivorship. Survivorship was assessed in this convenience sample with quality of life and affect/mood scales. Statistical analyses including linear regression and t-tests did not indicate statistically significant differences between heterosexual and sexual minority breast cancer survivor’s scores on quality of life and affect. There were no differences detected between heterosexual and sexual minority breast cancer survivor’s scores on perceived social support, years since diagnosis, or demographic variables. However, analyses did reveal significant differences in women’s report of perceived stress. Significant differences in women’s perceived stress points to a need for future work to include a focus on perceived stress among SMW breast cancer survivors.

Introduction

Breast cancer survivorship is receiving increasing attention as more than 89% of women diagnosed with breast cancer go on to surpass the five-year cancer survival mark (NCI, 2008). Prior definitions of survivorship focused on cancer 'survival', or living past a cancer diagnosis and achieving the five-year cancer free mark. New definitions of survivorship have been modified to include the complex and multifaceted process, experience and varied issues related to living life with a history of cancer. Survivorship, is now defined by the National Cancer Institute (NCI) as the health, physical, psychological, and economic issues related to cancer arising any point from the moment of diagnosis on to the end of life (NCI, 2008), rather than their mortality or 5-year rate of survival.

Scientists in the field of cancer and cancer survivorship are accumulating evidence indicating that social differences linked with health disparities among women may also negatively impact breast cancer prevalence (Valanis et al., 2000; IOM, 1999; Dean et al. 2000) and breast cancer survivorship (Boehmer et al., 2007; Boehmer et al., 2005; Fobair et al., 2001; Fobair et al., 2005). Sexual minority women (SMW), women who partner in romantic and spousal relationships with other women, have a 2-3 times greater prevalence of breast cancer than heterosexual women (Valanis et al., 2000; Kavanaugh-Lynch et al., 2002). The issues presented by the elevated prevalence of breast cancer among SMW and the growing rate of survivorship among all breast cancer survivors are propelling forces in examining the influence of sexual identity on breast cancer survivorship.

Historically SMW have been discriminated against, stigmatized and marginalized in the United States (Berkman, Zinberg, 1997; Rich, 1986; Frye, 1983; Pharr, 1988) and some have suggested that the stigma experienced by SMW results from their being viewed as inferior and abnormal in a heteronormative culture (Barbara, Quandt, and Anderson, 2001; Pagelow, 1980). Others suggest that heterosexism, or far-reaching sociopolitical expectations that all people are biologically destined to be oriented towards the opposite sex (Frye, 1983; Pharr, 1988; Rich, 1986), is the root of discrimination and stigma against SMW. Heterosexism leads to higher rates of stress, compromises in levels of perceived and actual social support from biological families and families of origin, in addition to strained experiences in health care settings (Stevens, Hall, 1988; O'Hanlan, 1995; Rankow, 1995; Bradford, Ryan, 1994; Meyer, 1995; Meyer et al., 2002; Meyer, 2003). These influences of heterosexism, discrimination and stigma, could significantly diminish SMW's quality of life, and in this case, breast cancer survivorship. Meyer and others (Stevens, Hall, 1988; O'Hanlan, 1995; Rankow, 1995; Bradford, Ryan, 1994; Meyer, 1995; Meyer et al., 2002; Meyer, 2003) refer to the intersecting influences of discrimination, stigma and heterosexism on the lives of sexual minorities as minority stress. This stress is caused by living in strained socio-cultural contexts and is thought to have an impact on the health and wellbeing of sexual minority people.

Meyer's (1995) theory of minority stress provides a theoretical framework that explains how sexuality-based minority stress could result in survivorship disparities between SMW and heterosexual breast cancer survivors. Sexual minority breast cancer survivors may be at greater risk for poorer survivorship outcomes because of the unique ways that their minority status positions them socially. For example, Meyer and colleagues (Meyer, 1995; Meyer et al., 2002; Meyer, 2003) document the risk for excess mental and social stress experienced by gay and lesbian individuals caused by their societal position as sexual minorities. They (Meyer, 1995; Meyer et al., 2002; Meyer, 2003) claim that excess mental and social stress results in compromised coping resources, such as the quality of and presence of social support (Wethington, Kessler, 1986; Cohen, Wills, 1985; Pelusi, 1997; Bloom, 1982). Therefore, compromises in the quality and presence of social support could reduce the likelihood that SMW will engage in supportive and quality of life enhancing breast cancer survivor activities. This combination of minority stress and compromised quality of social support elevates SMW's risk for poorer survivorship outcomes.

Currently the small, but growing, literature pertaining to SMW breast cancer survivorship is largely characterized by qualitative methodologies (Barnoff et al., 2005; Boehmer et al., 2005) and a focus on adjustment to breast cancer (Boehmer, et al., 2005, Fobair, et al., 2001) rather than breast cancer *survivorship*. Prior breast cancer survivorship studies have found differences in social support between SMW and heterosexual women (Boehmer, et al., 2005; Fobair, et al., 2001), but these studies have not examined how perceptions of social support influence survivorship outcomes such as women's quality of life and affect.

Our study contributes uniquely to breast cancer survivorship literature in two ways. First, using prior qualitative findings as a foundation we examined breast cancer survivorship among SMW quantitatively and online. Second, we tested the combined and individual influences of social support, stress and years since diagnosis on quality of life and affect measures among SMW and heterosexual breast cancer survivors.

This work was guided by five specific hypotheses. First, we hypothesized that SWM would report lower perceived social support scores than heterosexual women, due to their unique social position as sexual minorities. Second, we hypothesized that sexual minority breast cancer survivors would report higher scores of perceived stress than heterosexual breast cancer survivors. Third, we hypothesized that dependent measures of breast cancer survivorship (including self-reported quality of life and mood/affect) would differ significantly according to women's sexual identity where heterosexual breast cancer survivors would report higher quality of life and affect/mood scores than SMW.   Fourth, we hypothesized that we would predict significant variance in quality of life and affect/mood from breast cancer survivors perceived social support, perceived stress, years since diagnosis and sexual identity. Finally, we hypothesized that measures of perceived social support would moderate the influence of sexual identity on measures of survivorship. In this case the presence of social support would reduce or eliminate the influence of sexual identity on survivorship outcomes, quality of life and affect/mood.

Methods

Participants

Two hundred and eleven women (68 SMW, 143 heterosexual women) participated in this study. Advertisement for this survey occurred through community newspapers, newsletters, postings at cancer treatment clinics, electronic mediums such as craigslist, and social networking sites such as Facebook, ‘MySpace’, as well as through breast cancer survivor chat rooms, discussion boards, activity groups and woman-focused gathering places, including women’s support groups and community outreach (i.e., Komen Foundation). Women were also recruited from community-focused events such as women’s dances, via national lesbian health newsletters (Mautner Project) and Gay Pride festivals. Women who voluntarily agreed to participate in our study were directed to a survey website (surveyconsole.com) where they completed the informed consent and electronic survey.

Inclusion Criteria

To participate in this study respondents had to be English speaking, have had a breast cancer diagnosis, have access to the internet to complete the online survey, and be able to read and operate a computer to the extent necessary to complete the survey. There was no age restriction and women at any stage in their breast cancer survivorship were invited to participate.

Exclusion Criteria

Participants were excluded from the study if they did not indicate their sexual identity. If a respondent did not want to complete the survey after reading the electronic consent form, she was provided the opportunity to indicate this and was directed to a page that thanked her for her time and logged her out of the survey window.

Data Collection

Data were collected electronically and online from female breast cancer survivors. Women answered survey questions regarding their perceptions of social support, affect/mood, QOL, sexual-identity, and stress.

Measures

The measures used for this study were selected based on their use in prior breast cancer survivorship research and assembled as a unified survey for participant completion. Measures of independent variables included the Berlin Social Support Scale, Cohen’s Perceived Stress scale and women’s report of years since diagnosis. Measures of dependent variables assessed participant’s quality of life and mood/affect. Quality of life was measured with the Quality of Life—Cancer Survivors and mood/affect was measured using the Profile of Mood States (POMS). In what follows each measure is described in detail and reliability statistics are provided.

Perceived Social Support

The Berlin Social Support Scale (BSSS; Schwarzer, Schultz, 2000) was used to measure the four specific domains of social support of interest to this work. The BSSS measures perceived support, provided and received support, need for support, and support seeking on five point Likert scales. All negative items were reverse scored during analysis preparation. In this sample of breast cancer survivors the BSSS scale reliability coefficient, r = .88 indicated that this was a reliable measure of social support in this sample. Alpha levels, means and standard deviations for each the measure's sub scales are presented in table 1.1.

Table 1.1: BSSS Descriptive Statistics

Scale N = 211	Mean	SD	Alphas
Perceived Emotional Support	4.10	0.92	0.83
Perceived Instrumental Support	4.10	1.0	0.82
Social Support Needs	3.03	0.80	0.90
Social Support Seeking	3.20	0.92	0.85

Profile of Mood States (POMS)

The Profile of Mood States (POMS) measures seven dimensions of affect including tension-anxiety, depression-dejection, anger-hostility, vigor-activity, fatigue-inertia, friendliness and confusion-bewilderment. The measure includes 65 adjectives that respondents endorse on a five point intensity scale that reflects respondent's feelings for the past week. The POMS has been widely used to assess affect and mood in cancer patients and survivors, including many of the studies reviewed in this work (Fobair, et al., 2002; Fobair et al., 2001; Boehmer, et al., 2005). McNair and colleagues (1971) and Cella and colleagues (1989) report extensively on the validity and reliability of the POMS. In this sample of breast cancer survivors the measure's internal consistency/reliability include Cronbach's alpha coefficient, overall score, r =.93 indicating that the subscales all held together in measuring the affect/mood of participants in this sample. The POMS individual subscale Cronbach alpha scores also indicate that the subscales reliably measured the affect/mood in the participants in this sample. The subscales and alpha scores are provided in table 1.2 with means, standard deviations and response ranges on the POMS for this sample of breast cancer survivors.

Table 1.2: POMS Descriptive Statistics

Scale N = 139	Mean	SD	Alpha	Range
Anger-Hostility	0.87	0.76	0.93	0-3.0
Depression-Dejection	0.94	0.85	0.93	0-3.6
Fatigue-Inertia	1.12	1.12	0.93	0-4.12
Vigor-Activity	1.84	1.61	0.94	0-5.0
Tension-Anxiety	1.27	1.04	0.92	0-4.3
Friendliness	2.27	1.85	0.93	0-5.0
Confusion-Bewilderment	1.21	1.14	0.92	0-4.3

Quality of Life—Cancer Survivors

The Quality of Life—Cancer survivors (QOL-Cancer Survivors; Ferrell et al., 1997) survey measures factors that influence quality of life among long term cancer survivors. The measure is comprised of 41 items that are endorsed on an eleven point Likert scale ranging from ‘0 worst outcome’ to ’10 best outcome’ on four domains of quality of life; psychological wellbeing, physical wellbeing, social wellbeing and spiritual wellbeing. Scores for each of the items is averaged to obtain a total raw score and an average score for each of the five domains is also provided. In this sample of breast cancer survivors the measure’s internal consistency/reliability include Cronbach’s alpha coefficient, overall score, r = .78 indicating that the overall quality of life measure reliably measured participant’s quality of life. Cronbach’s alpha was also used to assess the reliability of the measure’s subscales where spiritual wellbeing, r = .78, social wellbeing, r = .69, physical wellbeing, r = .73 and psychological wellbeing, r = .75. These alpha scores suggest that the subscales were reliable in assessing quality of life. However, it is also important to be cautious when interpreting values below .70. The social wellbeing subscale's value (r = .69) may indicate a weaknesses in the assessment of social wellbeing in this sample. Means, standard deviations, and ranges of participant's quality of life are listed in table 1.3.

Table 1.3: QOL Cancer Survivors Descriptive Statistics

Scale N = 207	Mean	SD	Alpha
Overall Quality of Life	4.6	1.19	0.8
Physical quality of life	4.8	1.2	0.73
Distress	5.6	1.9	0.71
Fears	5.2	2.8	0.78
Social	4.3	1.8	0.69
Spiritual Wellbeing	3.6	1.1	0.78

Sexual Identity and Partnering

The measurement of sexual identity was obtained by asking women to self-report their sexual identity or orientation. The survey question asks women to mark the description that best describes their sexual orientation or identity: 1) Heterosexual/Straight, 2) Lesbian 3) Bisexual 4) Woman who partners with women 5) Not Sure 6) Other. In our sample (N=211), 32% self identified as sexual minority, and 78% self identified as heterosexual.

The survey also asked women to self report their marital status: What is your **current** marital or partner status? 1) Married or living with an opposite sex partner, 2) Married or living with a same sex partner, 3) In a committed relationship with an opposite sex partner- not living together, 4) In a committed relationship with a same sex partner- not living together, 5) widowed 6) Divorced or separated, 7) Single, never married, 8) Involved with multiple partners, 9) Other. Table 1.4 provides the marital and partnered status of the participants included in this sample. Seventy percent of the respondents in this sample identified as partnered or married.

Table 1.4: Marital Status

		Total Sample (N = 211)	Heterosexual Women (n=143)	SMW (n=68)
Marital Status, % (n) (n=202)				
	Single	5.45 (11)	2.90 (4)	10 (7)
	Married Same Sex	18.32 (37)	0	54 (37)
	Partnered Same Sex	1.98 (4)	0	5 (4)
	Married Opposite Sex	52.97 (107)	78.26 (108)	.1 (1)
	Partnered Opposite Sex	3.47 (7)	4.35 (6)	.1 (1)
	Divorced/Separated	12.87 (26)	11.59 (16)	13 (9)
	Widowed	1.98 (4)	2.17 (3)	.1 (1)

Perceived Stress

The measurement of perceived stress is important to the present study for two reasons. First, prior research in the field of stress and social support strongly recommends measuring participant’s perception of stress when assessing social support. For example, scholars including Wethington and Kessler (1985) and Cohen and Wills (1985) strongly recommend determining individual’s perceptions of stress when assessing perceptions of social support in order to determine a buffering effect that social support may have on stress. The growing and important literature on the role of minority stress in the lives of sexual minorities provides the second rationale for including perceived stress in this study of breast cancer survivorship. This literature outlines the influence of minority stress on the health and health outcomes of

SMW (Meyer, 1995; Dean et al., 2000). Due to the absence of validated measures of minority stress, a global measure of perceived stress (Cohen's Perceived Stress Scale) was used in this study.

Cohen's four-item Perceived Stress Scale (PSS) was used to assess women's perceived levels of stress (Cohen, et al., 1983; Cohen and Williamson, 1988). The four item scale is designed to be used with samples with at least a middle school level of education. Questions are designed to be easily understood and answered on a four-point Likert scale ranging from 0-never to 4-very often. Table 1.5 provides inter-item correlation for each of the perceived stress questions. Each of the four perceived stress items were highly correlated at the p < .01 level. This indicates that the items were measuring similar aspects of perceived stress for the participants included in this sample. Table 1.6 provides perceived stress descriptive statistics for participants in this sample. Overall participants did not report high levels of perceived stress (mean score = 2.05). Women did report higher than average scores on two items, sense of confidence and things going my way.

Table 1.5: Perceived Stress Inter Item Correlations

Item N= 213	Control	Confidence	Way	Overwhelm
Sense of Control	1.00			
Sense of Confidence	0.17**	1.00		
Things Going Your Way	0.30**	0.63**	1.00	
Overwhelmed	0.60**	-0.25**	-0.40**	1.00

*** = p <.01*

Table 1.6: Perceived Stress Descriptive Statistics

Scale and Items N= 213	Mean	SD	Alpha
Perceived Stress	2.05	0.34	0.72
Sense of Control	1.80	1.11	
Sense of Confidence	3.02	1.04	
Things Going Your Way	2.70	1.05	
Overwhelmed	1.30	1.08	

Demographic Characteristics

Demographic characteristics were collected with a short series of questions including participant's current age, number of years since first breast cancer diagnosis, and number of years of completed education, income, insurance coverage and contact with biological family. Table 1.7 provides demographic details and differences in demographic details according to sexual identity.

Analysis

Analyses were conducted using STATA 10.0 (StataCorp, 2007). We generated frequency distributions and descriptive statistics for all variables of interest. Means and standard deviations were calculated for demographic and independent variables including perceived social support and perceived stress, as well as outcome measures of quality of life and affect/mood. Linear regression models were used to determine the influence of perceived social support, sexual identity and perceived stress on quality of life and mood/affect. Moderation of the outcome variables by social support were to be tested according to Baron and Kenny's (1986) guidelines for testing moderation.

Results

Five primary hypotheses guide the following analyses: 1) SMW will report lower perceived social support scores than heterosexual women; 2) SMW will report higher perceived stress scores than heterosexual women; 3) Measures of survivorship, (including self-reported quality of life and mood/affect) will differ significantly according to women's sexual identity where SMW would report lower quality of life and mood/affect scores; 4) Quality of life and affect/mood will be predicted from perceived social support, years since diagnosis, perceived stress and sexual identity indicators; 5) Measures of social support perceptions will moderate the influence of sexual identity for sexual minority breast cancer survivors. That is to say that women's perception of social support will modify the influence of sexual identity on survivorship outcomes: quality of life (well being) and positive affect/mood.

General Summary of Findings

Initially it appeared that there were minimal differences in participant's quality of life and mood/affect based on sexual identity, perceived social support and years since diagnosis. There were statistically significant differences found in women's perceived stress by sexual identity where SMW reported higher levels of stress than heterosexual breast cancer survivors. SMW and heterosexual women reported significantly different perceived stress but did not report significantly different scores on years since diagnosis, social support, quality of life scores, mood/affect. SMW reported higher stress than heterosexual women, and both groups reported moderate levels of social support, quality of life and positive mood/affect. Our regression model of survivorship did not predict a significant amount of the variance in quality of life or mood/affect in this sample of breast cancer survivors. In the following sections we will provide detailed summaries of the sample's characteristics and the statistical findings that emerged from this study. The results section is organized in the following way: participant characteristics are presented first, followed by the presentation of the independent variables including years since diagnosis, perceived social support and perceived stress and any differences according to sexual identity, followed by the dependent variables (quality of life and affect/mood) and finally regression models are presented last.

Power Analysis

Using G*Power (G Power, 2001) power analysis was conducted to determine the ability to detect differences in dependent measures from predictor measures in our sample. Effect size was calculated from the inter-indicator correlations between years since diagnosis, social support and perceived stress on quality of life and affect. Effect size for this analysis is considered large, $f^2 = .39$. Calculations conducted via G*Power (G Power, 2001) based on the sample size of this study, analytic approach (linear regression), and predictor variables used, the power to detect differences if differences exist equals .99, alpha =.05.

Participant Characteristics

Of the 211 participating breast cancer survivors, 143 women self identified as heterosexual and 68 identified as sexual minority. See table 1.7 for the sample's demographic details by sexual identity. Generally this sample is characterized as being white (90%), middle aged (mean age = 54 years, range = 30-79), partnered/married (71%), having attained high levels of education (57% having earned a Bachelors or Graduate degree), economically stable (69% have money left over at the end of the month sometimes or always), and having health insurance (96%).

Control Variable

As recommended by senior scholars in the field of sexual minority women's health (D. Bowen, personal communication February 4, 2010) income was included in the following analyses as a control variable. Due to consideration for analytic issues related to power and risking type I error, control variables were limited to the recommended income variable.

Table 1.7: Participant Characteristics

Characteristic		Total Sample (N = 211)	Heterosexual Women (n=143)	SMW (n=68)	t	*p*-value
Age in years, mean (range) (n = 211)		54.5 (30-79)	54 (38-74)	55.5 (38-74)	-1.05	.291
Ethnicity, frequency (n = 140)						
	White	127	86	41		
	Black/African American	1	0	1		
	Latina	6	4	2		
	American Indian/Alaska Native	4	4	0		
	Asian American/ Pacific Islander	2	2	0		
Education, % (n) (n= 204)						
	Secondary Ed (9-11 years)	6.86 (14)	8.63 (12)	10.4 (5)		
	Trade or Technical	2.94 (6)	4.32 (6)	8.3 (4)		
	Junior College or Some College	23.53 (48)	24.26 (34)	18.9 (9)		
	Bachelors Degree	24.02 (49)	23.02 (32)	14.6 (7)		
	Graduate Degree	33.33 (68)	33.09 (46)	44.0 (21)		
	Professional Training	7.35 (15)	5.04 (7)	4.2 (2)		
Income, % (n) (n=140)						
	Can't make ends meet	11.43 (16)	12.37 (12)	10.6 (5)	-0.3	.342
	I have just enough money, no more	14.29 (20)	12.37 (12)	21.3 (10)		
	Other	5.0 (7)	3.09 (3)	6.4 (3)		
Has health insurance, % (n) (n=139)					0.15,	.879
	No	96 (133)	96 (92)	4.8 (2)		
	Yes	4.32 (6)	4.17 (4)	95.2 (40)		
Payment for health insurance, % (n) (n= 138)						
	Paid for by employer	31.88 (44)	33 (31)	29 (12)		
	Paid for through spouse/partner employer	19.57 (27)	20(19)	19 (8)		
	Paid for through state/national insurance	11.59 (16)	11.6 (11)	12 (5)		
	I pay for insurance myself	21.74 (30)	22.1 (21)	21 (9)		
	I do not have insurance	2.90 (4)	3.16 (3)	2 (1)		
	Other	12.32 (17)	10.53 (10)	17 (7)		

Independent Variables

Years since Diagnosis

Eighty-six percent (n = 181) of the women in this sample answered the survey question about the length of time since their breast cancer diagnosis. Of these women the mean length of years since diagnosis was 5.8 years ranging from 0-28 years with 60% of these participants having a diagnosis of breast cancer within the past five years. Thirty-three percent of women had been diagnosed with the past 5-10 years and 7% of the women had been diagnosed 11-28 years prior to participation in this study. As illustrated in table 1.8, a t-test examining potential differences between sexual minority and heterosexual breast cancer survivors revealed no significant differences in years since diagnosis, $t = 1.65$, $p = 0.101$.

Social Support

The Berlin Social Support Scale (BSSS; Schwarzer, Schultz, 2000) was used to measure the four specific domains of social support of interest to this work; perceived available emotional support, perceived available instrumental support, need for support and support seeking behavior on a 5-point Likert scale. Participants in this study reported high levels of social support where each of the subscales approached the maximum value in each of the measure's sub-categories. Means, standard deviations, alpha levels and reliability scores for the social support subscales, including perceived emotional support, perceived instrumental support, support needs and support seeking, are provided in table 1.2.

Our first hypothesis that sexual minority breast cancer survivors would report significantly less social support than heterosexual breast cancer survivors was not supported. A two-sample t-test examining potential differences between sexual minority breast cancer survivors and heterosexual breast cancer survivors total social support scores revealed non-significant statistical differences, $t = .17$, $p = 0.865$. Although there were no differences between SMW and heterosexual women in this sample both groups reported elevated levels of social support. Illustrated in table 1.8, two-sample t-tests were also conducted on each of the social support sub-scales by sexual identity, also revealing no statistically significant differences in social support by sexual identity. Heterosexual and sexual minority breast cancer survivors reported very similar scores of total perceived social support and sub scales of perceived social support.

Table 1.8: Breast Cancer Survivors Perceived Social Support, Stress and Years since Diagnosis

Variable	Hetero-sexual Mean	SMW Mean	*t*	p value
Social Support (n = 208)	3.5	3.5	0.17	. 865
Perceived Emotional Support	4.09	4.12	-0.19	.845
Perceived Instrumental Support	4.10	4.13	-0.21	.829
Social Support Needs	3.02	3.06	-0.35	.727
Social Support Seeking	3.16	3.33	-1.26	.210
Stress (n = 213)	**2**	**2.13**	**-2.22**	**<.05***
Years Since Diagnosis (n=171)	6.3	4.8	1.64	0.101
Income (n = 130)	3.14	2.96	0.97	0.332

Perceived Stress

Cohen’s four-item Perceived Stress Scale (PSS) was used to assess women’s perceived levels of stress (Cohen, et al., 1983; Cohen and Williamson, 1988). Table 1.8 illustrates the two-sample t-test conducted on perceived stress between sexual minority and heterosexual breast cancer survivors. Findings reveal statistically significant differences in perceived stress between SMW and heterosexual women, $t = -2.22$, $p < .05$ where SMW reported higher levels of perceived stress than heterosexual women. This finding is consistent with our hypotheses and prior literature (Bradford, Ryan, 1994; Meyer, 1995; Meyer et al., 2002; Meyer, 2003) stating that sexual minorities experience a higher and different level of stress than do heterosexual people.

Dependent Variables

The dependent variables for this study, quality of life and mood/affect, were both non-normally distributed due to missing data. Non-normally distributed dependent variables violate one of the primary assumptions of linear regression which states that dependent variables must be normally distributed (Cohen, et al., 2003). In order to appropriately conduct linear regression with these data, two-part models were employed to model the relationships between predictor variables (income, social support, perceived stress, years since diagnosis, and sexual identity) on survivorship outcomes, quality of life and mood/affect. The details of this technique are included in the next section with the presentation of the inferential statistics for each regression model. First we present the descriptive statistics as they relate to each hypothesis.

Quality of Life

The Quality of Life—Cancer Survivors (QOL-Cancer Survivors; Ferrell et al., 1997) survey measures quality of life factors concerning long term survivors of cancer. As stated previously, the data were non-normally distributed due to missing data.

In this sample participant's quality of life scores ranged from 0-7.3 with a total possible score of 10. As previously stated, these data are non-normally distributed, kurtosis = 8.4, and skewness = -1.57. See table 1.4 for quality of life means, standard deviations and alphas. Inter-scale correlations are presented in table 1.9, quality of life scale reliability alpha = .78.

Table 1.9: Quality of Life Inter-Item Correlations

Scale (N= 207)	P	D	F	S	SW
Physical quality of life	1.00				
Distress	0.56	1.00			
Fears	0.42	0.50	1.00		
Social	0.63	0.57	0.56	1.00	
Spiritual Wellbeing	0.59	0.35	0.25	0.35	1.00

Our hypothesis, that SWM would report lower scores on quality of life than heterosexual breast cancer survivors was not confirmed. Table 1.10 of dependent outcomes illustrates the two-sample t-test reveals no statistically significant differences between groups, *t* = .834, *p* = 0.403. Sexual minority and heterosexual breast cancer survivors reported similar and moderate (mean = 4.68) values of quality of life.

Table 1.10: T-tests of Quality of Life and Affect

Variable	Heterosexual Mean	SMW Mean	*t*	p value
Quality of Life	4.68	4.53	0.84	0.403
Affect	1.25	1.23	0.16	0.870

Affect: Profile of Mood States (POMS)

The Profile of Mood States (POMS) measures seven dimensions of affect/mood including tension-anxiety, depression-dejection, anger-hostility, vigor-activity, fatigue-inertia, friendliness and confusion-bewilderment. This measure of moods/affect has been widely used to assess the affect and mood in cancer patients and survivors (Fobair, et al., 2002; Fobair et al., 2001; Boehmer, et al., 2005). McNair and colleagues (1971) and Cella and colleagues (1989) report extensively on the validity and reliability of the POMS measure.

The correlations among the POMS scales are presented in table 1.11. The scale means, standard deviations and alpha coefficients are calculated and presented in table 1.3. In this sample of breast cancer survivors POMS scores ranged from 0-3.25. The mean score for women in this sample was 1.25, standard deviation .98. This indicates that the women in this sample are scoring very low in negative moods/affect. These data are non-normally distributed, skewness = -.23 and kurtosis = 1.56. The non normal distribution is addressed when regression models are discussed.

Table 1.11: POMS Inter-Item Correlations

Scale (N=139)	A-H	D-D	F-I	V-A	T-A	FR	C-B
Anger-Hostility	1.00						
Depression-Dejection	0.95	1.00					
Fatigue-Inertia	0.87	0.90	1.00				
Vigor-Activity	0.65	0.58	0.48	1.00			
Tension-Anxiety	0.88	0.86	0.80	0.74	1.00		
Friendliness	0.74	0.71	0.66	0.91	0.82	1.00	
Confusion-Bewilderment	0.84	0.90	0.86	0.58	0.81	0.71	1.00

Our hypothesis, that SWM would report lower scores on mood/affect, than heterosexual breast cancer survivors was rejected. As illustrated in table 1.10, the two-sample t-test reveals no statistically significant differences between groups, $t = .16$, $p = 0.870$. These findings suggest that sexual minority and heterosexual breast cancer survivors in our sample are not experiencing statistically significant differences in their mood/affect and that both groups are not reporting elevated levels of negative mood/affect.

Statistical Modeling and Inferential Statistics

We hypothesized that years since diagnosis, social support, stress, and sexual identity would predict a statistically significant portion of the variance in quality of life and affect. Income was included as a control variable in these regression models. To account for considerable missing data in our outcome measures of quality of life (2.9% missing) and affect (34% missing), two-part models were employed for modeling the relationships between predictor variables, income, social support, perceived stress, years since diagnosis, and sexual identity, on survivorship outcomes quality of life and affect/mood.

Addressing Missing Data

As previously stated, the dependent variables, quality of life and affect/mood, were non-normally distributed. This non-normal distribution was caused by a large amount of missing data (quality of life = 2.9% missing, affect/mood = 34% missing). In order to accurately use linear regression analysis techniques it is necessary to use a two step modeling process. The first step in this process logistic regression was used to determine if a significant relationship existed between predictors and missing outcome variables. The relationship between missing outcome variables and indicator variables needed to be determined. If a significant statistical relationship existed between any of the predictor variables and the outcome variable, in this first phase of the analysis, we would know that the mechanism for missingness was not at random and linear regression techniques cannot be used. If there was no statistical relationship (non-significant χ^2), meaning that we could not predict missingness from our indicators, the missingness is not related to the indicator variables and data are missing at random. The second step in the two part modeling process then employs linear regression to model the relationship between predictor variables and the non-missing outcome variables.

In the first step of the two-part modeling process logistic regression was used to model the relationship between predictors and missing data for each outcome separately and then linear regression was employed to model the relationship between predictor and non-missing outcome variables.

Affect/mood was modeled first. The logistic regression did not predict a statistically significant relationship between indicator variables and missing affect data, χ^2= 3.44, *p* = 0.633. This suggests that the data are missing at random and that the missingness was not related to any specific predictor in our model.

Quality of life was modeled next. The logistic regression did not predict a statistically significant relationship between indicator variables and missing quality of life data, χ^2 = 1.38, *p* = .848. This means that income, social support, stress and sexual identity did not predict missing quality of life data. In the next step linear regression was used to develop models of breast cancer survivorship using quality of life and affect/mood as outcome variables.

Linear Regression and Statistical Models of Breast Cancer Survivorship

In the second step, linear regression was employed to model the relationship between affect and predictor variables. In this case affect was regressed on perceived social support, perceived stress, years since diagnosis, sexual identity and income. Table 1.12 provides regression coefficients and r-squared values for affect. The model did not predict survivors affect, *F* (5,71) = 1.04, *p* = .62, *r-squared* = 0.06. In this sample of breast cancer survivor's women's income, stress, social support, years since diagnosis and sexual identity were not predictive of their mood/affect. The small r-squared value (value less than .1 are considered weak) indicates that these indicators did not predict a significant amount of the variance in affect/mood among these sexual minority breast cancer survivors.

Table 1.12: Quality of Life and Affect Regression Models

Independent Variables		Affect F (5,71) = 1.04, *p* = .40, *n.s.*	Quality of Life F (5, 109) = 1.2, *p* = .31, *n.s.*
		b/se	b/se
Income (control)		-1.809	-4.671
		-2.39	-3.67
	P > |*t*|	0.452	-0.206
Stress		-0.194	-3.458
		-1.76	-2.49
	P > |*t*|	0.913	0.168
Social Support		-0.291	0.357
		-0.21	-0.44
	P > |*t*|	0.175	0.419
Years of Survivorship		-0.833	0.61
		-0.5	-0.71
	P > |*t*|	0.099	0.39
Sexual Identity		0.847	10.379
		-4.17	-7.03
	P > |*t*|	0.84	0.143
Survivorship Model	R-sqr	0.069	0.052

** $p<0.05$, **$p<0.01$, *** $p<0.001$*

Second, linear regression was used to model the relationship between quality of life and predictor variables. In this case quality of life was regressed on perceived social support, perceived stress, years since diagnosis, sexual identity and income. Table 1.12 provides regression coefficients and r-squared values for quality of life. The model did not predict survivor's quality of life, F (5,109) = 1.20, $p = 0.31$, *r-squared* = .05. In this sample of breast cancer survivors, women's income, stress, social support, years since diagnosis and sexual identity did not explain the variance in quality of life.

Our hypothesis was that perceived social support would moderate the influence of sexual identity on survivorship outcomes measured here as quality of life and affect. However sexual identity is not statistically significantly related to quality of life ($t = 1.13$, $p = .403$) or affect/mood ($t = .28$, $p = .870$) in either of the models analyzed here. Consequently there is no indication that additional analyses to test for moderating effects will provide any additional information. The non-significant contribution of sexual identity to both models of survivorship does not support further analysis regarding the moderating effects of social support on sexual identity.

Discussion

Our analyses resulted in rejecting several of our hypotheses. However the null findings presented here are important when considering influences in breast cancer survivorship. The findings from this work suggest that sexual identity is not playing a significant role in breast cancer survivorship of the survivors who participated in this study. The women in this sample reported positive mood/affect, high levels of perceived social support and moderate levels of quality of life. These findings did not appear to be influenced by women's sexual identity in this study. However, it should also be noted that the sample was demographically homogenous as the participants in this study were all quite similar. Participants in this study were economically affluent and there is very little variability in participant age, ethnicity, level of education, income, and insurance coverage. The findings reported here cannot be generalized to a more diverse, less affluent sample that may indeed experience the difficulties that we set out to examine.

The purpose of this work was to examine the role of perceived social support, perceived stress, sexual identity and years since cancer diagnosis on breast cancer survivorship outcomes; namely, quality of life and affect/mood by sexual identity/orientation. Our hypotheses were not confirmed by our analyses.

Our hypothesis that SMW would report lower levels of social support than heterosexual breast cancer survivors due to the presence of heterosexism in our culture and health care settings was not confirmed. Contrary to our hypothesis, we did not find variation in measures of social support by sexual identity. In fact, all women reported relatively high levels of social support within and across all of the sub-categories of social support. Our understanding of the positive influence of social support on health, quality of life, risk for disease and disease survivorship leads us to interpret this as a positive finding.

Literature on social support recommends measuring perceived stress in concert with social support, as was done in this study. It is notable that although perceived social support did not vary by sexual identity, perceived stress did vary significantly by sexual identity. In our sample SMW reported higher levels of stress than did heterosexual women. This is consistent with prior research indicating that higher levels of stress are found in sexual minorities forced to live in a heteronomorative socio-political environments (Bradford, Ryan, 1994; Meyer, 1995; Meyer et al., 2002; Meyer, 2003). This finding suggests that, despite our unconfirmed hypotheses, minority stress may be playing a role in the health and lives of the sexual minority breast cancer survivors who participated in our study. It is possible that the stress reported by sexual minorities had little to do with their breast cancer, or breast cancer treatments, but rather could reflect broader social issues. Additional research is required to enhance our understanding of the role of minority stress among sexual minority breast cancer survivors.

Our hypothesis that there would be significant differences in women's quality of life and affect/mood by sexual identity was rejected. Women's quality of life and affect/mood were remarkably similar in this sample. Again, it is thought that the affluence and demographic similarity of this sample has a strong influence over women's quality of life and affect/mood. This too can be thought of as an encouraging finding. It is heartening that at least in this sample, it appears that sexual identity is having minimal influence in breast cancer survivors overall quality of life and affect/mood as we did not find significant differences in either outcome. Instead, the women in this sample reported positive mood and high levels of quality of life with no differences by sexual identity.

Our hypothesis that perceived social support would moderate the influence of sexual identity in predicting the variance in survivorship outcomes, quality of life and affect/mood was also rejected. Our regression models did not significantly predict the variance in quality of life or affect/mood, nor did sexual identity contribute significantly to either model of breast cancer survivorship. Because sexual identity did not contribute to either of the regression models it was not appropriate to test for the moderating effects of social support on sexual identity.

Limitations

The results from this study are limited by notable factors. First, this study is limited by its small sample size which reduces the ability to detect possible additional influences in survivorship and the ability to conduct more advanced inferential statistics.

This study is also limited by recruitment bias in a variety of ways. This study was conducted entirely online. This methodology, although convenient and affordable, may have excluded breast cancer survivors who do not have computer access or computer literacy. This limitation is confirmed by the relative degree of affluence as indicated by participant income, education and health insurance characteristics.

Recruitment was also limited by the unique issues related to recruiting a minority population, or in this case, recruiting breast cancer survivors from a minority population. In this study we found that locating a rare population (cancer survivors) within a minority population (sexual minority women), presented several difficult challenges. These challenges include locating sexual minority breast cancer survivors to recruit them for participation, and overcoming a history of distrust in order to gain the trust of willing participants via an online survey.   First, traditional sources of breast cancer survivor participants, including but not limited to well-known breast cancer survivorship organizations and breast cancer survivor support groups and activities, did not yield the expected numbers of sexual minority breast cancer survivors. Rather it became clear early in the data collection phase of this project that locating the minority population required recruiting efforts in unexpected locations such as sexual minority focused quilting groups, choirs, motorcycle clubs, sports teams and other groups. Because these groups were not necessarily ‘breast cancer’ focused they often yielded few, if any, willing participants. This recruiting strategy did produce the minimum number of participants necessary to conduct the analyses presented here; however it did not result in a heterogeneous sample or a larger number of participants that could add strength to this study. These significantly limit the findings of our study.

Finally this study was also limited by the extent of missing data. Quality of life and affect/mood outcome variables both had extensive missing data. This increases the risk of a type II error where we accept the null hypothesis when there may have been undetected effects present in these data.

Conclusions

Two lessons emerged from this research. First, in this sample the participating breast cancer survivors report that they are well in that they report positive mood and encouraging scores on their quality of life. Additionally our analyses did not reveal any negative influence of sexual identity on these outcomes.

Research in the area of breast cancer survivorship has begun to focus on issues of thriving versus surviving, and in this study it seems that the participating breast cancer survivors appear to be thriving. Women reported moderate levels of quality of life, high levels of social support and positive mood despite their experiences with breast cancer. Although our a priori hypotheses were unconfirmed by the analyses conducted here, the encouraging findings regarding the positive outcomes may reflect advances made in breast cancer survivor support and resources.

The second lesson that we have learned from this research is that there is still work to be done in uncovering the influence of stress and heterosexism in the experiences of sexual minority breast cancer survivors. Although overall this study did not support the a priori hypotheses, we did find that the levels of stress reported by sexual minority breast cancer survivors were significantly higher than the stress reported by heterosexual breast cancer survivors. This finding is in line with minority stress theories (Meyer, 1995; Meyer et al., 2002; Meyer, 2003) that suggest that sexual minority people experience a notable and harmful degree of stress resulting from living in a heterocentric world that disregards and rejects the experiences and identities that are alternative to the heteronormative culture. Future research might examine the specific role of minority stress on sexual minority’s breast cancer survivorship and health outcomes and aim to develop measures that are sensitive to the unique influences presented by minority populations.

This study was conducted in response to a small but growing stream of literature pertaining to the factors that contribute to and influence quality breast cancer survivorship. Prior qualitative research pointed to the influences of sexual identity in women's breast cancer survivorship experiences, support resources and quality of life outcomes. Though this study did not find these differences quantitatively we acknowledge that the significant limitations of our study are likely influencing the findings presented here. Our findings lead us to suggest that future research could pursue three distinct directions. First, future research on sexual minority breast cancer survivors should examine the meanings, sources and influences of stress. Second, methodologies to enhance researcher ability to recruit this rare population should be pursued. It is well documented (Meyer, 1995; Meyer et al., 2002; Meyer, 2003; Dean et al., 2000; Bowen et al., 2004) that working with disparate populations, including sexual minority breast cancer survivors, is necessary and methodologically difficult given socio-cultural history and structural limitations. Third, although we used the best measures we could find for this study it is possible that the scales used here were not ideal for detecting important differences among sexual minority breast cancer survivors. Research concerning measurement sensitivity among this minority population could enhance our ability to detect differences and unique influences for minority groups experiencing health disparities. Some of these limitations might be alleviated by including questions about sexual identity on population-based surveys and cancer surveillance systems.

Female breast cancer survivors are the largest cancer survivor group in the United States, making this an important area of research. The literature to date has contributed to our knowledge regarding important issues for quality breast cancer survivorship. However, much of what we know continues to be based on a heterocentric norm that excludes the unique experiences of sexual minority breast cancer survivors. Previous research largely ignores the influence of sexual identity in breast cancer survivorship outcomes by including only heterosexual participants or assuming the heterosexuality of participants. The research presented here contributes to a movement aimed at the deliberate inclusion of sexual minority breast cancer survivors in cancer survivorship research. We accomplish this by focusing on SMW and their unique experiences and factors that influence survivorship differently from majority groups. Namely our focus on sexuality based minority stress adds to the growing understanding about disparities in breast cancer survivorship between SMW and heterosexual women by highlighting the influence of perceived stress. Continued research in the area of breast cancer survivorship should extend our findings by specifically including sexual minorities, and measuring the influence of the perceived minority stress to determine its influence on quality of life and emotional outcomes. Extending this work will ultimately result in our ability to develop interventions that could close gaps in health disparities observed in sexual minority groups.

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CHAPTER IV

MANUSCRIPT II

BREAST CANCER SURVIVORSHIP:

THE ROLE OF PERCEIVED DISCRIMINATION AND SEXUAL IDENTITY

Abstract

As more and more breast cancer survivors reach and live past the five-year cancer ‘survival’ mark, it is clear that breast cancer *survivorship* is a multi-factorial process that lasts, in many cases, long past breast cancer diagnosis and treatment. Accumulated evidence makes clear that the process of breast cancer survivorship is influenced by a constellation of important factors, among these is sexual identity. Breast cancer disproportionately affects sexual minority women (SMW) compared to heterosexual women and a small but growing literature indicates that SMW may have diminished survivorship outcomes, and outcomes that are measurably and importantly different from heterosexual breast cancer survivors. However, it remains unknown how sexual-identity influences breast cancer survivorship outcomes such as quality of life and affect/mood. One possible route of influence is SMW’s perceived discrimination in the health care setting. Our cross-sectional study examines SMW perceptions of discrimination as one of the multiple facets of the breast cancer survivorship process. This study assessed SMW breast cancer survivor’s perceptions of discrimination during their breast cancer treatment experience and secondarily, examined the role of this perceived discrimination on SMW’s survivorship outcomes measured by quality of life, and mood/affect. Sixty-eight, purposeful sampled sexual minority breast cancer survivors completed assessments of quality of life, affect/mood, perceived discrimination, perceived social support and perceived stress via an online survey. Statistical analyses point to perceived discrimination and perceived social support as important indicators for predicting SMW’s quality of life. Future research

on SMW's breast cancer survivorship should include measures of perceived discrimination.

Introduction

The National Cancer Institute's (NCI) Office of Cancer Survivorship (OCS) reports that as of 2006 there were an estimated 11.4 million cancer survivors residing in the United States. The largest group of cancer survivors, approximately 40%, is comprised of breast cancer survivors. According to the NCI, 89% of women diagnosed with breast cancer go on to surpass the five-year survival mark (NCI, 2008). Survivorship, defined by the Office of Cancer Survivorship of the National Cancer Institute, includes the health, physical, psychological, and economic issues related to cancer that may arise at any point from the moment of diagnosis on to the end of life (NCI, 2008). Survivorship is defined by the characteristics of individual's morbidity rather than one's mortality, or 5-year rate of survival, as previously defined. Survivorship has become an independent, large-scale research domain concerned with the multifaceted and complex factors that influence one's life after a cancer diagnosis (Rowland, 2007; NCI, 2008; Ganz and Horning, 2004).

Some groups of women bear a greater burden of difficulty in survivorship than others (NCI, 2008). Important differences underpin women's quality of breast cancer survivorship including where women live (rural versus urban), women's age at diagnosis, women's economic status, and women's ethnicity (NCI, 2008). There is also a growing literature on the role of sexual identity as a factor in women's health and cancer survivorship. Some qualitative research suggests that sexual minority women (SMW), or women who partner romantically and in spousal relationships with other women, are at greater risk for less favorable short and long-term outcomes in successful breast cancer survivorship (NCI, 2008; Boehmer et al, 2005; Arena et al., ; 2006; Fobair et al., 2002; Fobair et al., 2001). Potential reasons why SMWs have a poorer prognosis for successful survivorship are many, and include such factors as: (1) the influence of perceived discrimination during cancer treatment, (2) the impact of added stress burden caused by minority status (Meyer, 1995; Meyer et al., 2002; Meyer, 2003), and/or (3) the result of living in a heterosexist context that may influence coping resources such as social support and survivor support activities (Bradford, Ryan, 1994; Meyer, 1995; Meyer et al., 2002; Meyer, 2003).

Perceived Discrimination

One possible route to understanding the experiences of sexual minority breast cancer survivors is to examine their perceptions of discrimination in the health care setting (Stevens and Hall, 1988) during their breast cancer treatments. Prior research among other groups of social difference such ethnic minorities, HIV positive individuals, the poor, and women, point to the influence of perceived discrimination in health care settings (Thorburn, Bogart, 2005; Mays, Coleman, Jackson, 1996; Bird, Bogart; 2003).

Sexual minority women may face discrimination in many areas of life, including health care settings; however little research has been conducted examining these areas. Prior studies have documented women’s experiences with race-based discrimination in health care settings (Thorburn, Bogart, 2005; Mays, Coleman, Jackson, 1996; Bird, Bogart; 2003), and socioeconomic status-based discrimination (Bird, Bogart, 2001). Perceptions of discrimination have also been linked with health outcomes (Bird, Bogart, Delahanty, 2004) where HIV positive individuals experiencing either race or economic-based discrimination were more likely to be depressed and to have more psychological disturbances.

At the time of this writing we are unaware of any specific research documenting sexuality-based perceived discrimination among SMW undergoing breast cancer treatments. However the documented existence of race-based (Thorburn, Bogart, 2005; Mays, Coleman, Jackson, 1996; Bird, Bogart; 2003) and socioeconomic-based (Bird, Bogart, 2001) perceived discrimination in the health care setting make it possible that sexuality-based perceived discrimination may also occur in the health care setting. It is possible that the combined influence of perceived stress and perceived discrimination could have an important influence on SMW's breast cancer survivorship and quality of life.

Our study examined the role of SMW's perceived levels of stress, social support and discrimination on commonly used measures of survivorship, including quality of life and affect/mood. The primary aims of this work were 1) to assess sexual minority breast cancer survivor's perceptions of discrimination in the health care setting, and; 2) to test for the influence of perceived discrimination on sexual minority breast cancer survivor quality of life and affect/mood. Our first hypothesis was that measures of sexual minority breast cancer survivor's perceived social support and stress would explain a statistically significant amount of the variance in quality of life and affect/mood. Second we hypothesized that the inclusion of perceived discrimination in our statistical model of breast cancer survivorship would significantly increase the amount of statistical variance explained in survivor's quality of life and affect/mood.

Methods

Participants

Sixty-eight sexual minority breast cancer survivors participated in this cross-sectional study. Advertisement for this survey occurred through multiple venues, including community newspapers, newsletters, postings at cancer treatment clinics, electronic mediums such as craigslist, and social networking sites such as Facebook, and 'MySpace.' In addition, participants were recruited via advertisements distributed at key gathering places for women, including women's groups, women's-community focused events such as women's dances and Gay Pride festivals.

Data Collection

Data were collected electronically and online from sexual minority breast cancer survivors. Women answered survey questions regarding their perceptions of discrimination, perceived social support, and perceived stress, in addition to affect/mood and quality of life.

Inclusion Criteria

To participate in this portion of the study respondents had to be English speaking, have had a breast cancer diagnosis, have access to the internet to complete the online survey, and be able to read and operate a computer to the extent necessary to complete the survey. There was no age restriction and women at any stage in their breast cancer survivorship were invited to participate.

Exclusion Criteria

Participants were excluded from the study if they did not indicate their sexual identity. If a respondent did not want to complete the survey after reading the electronic consent form, she was provided the opportunity to indicate this and was directed to a page that thanked her for her time.

Measures

Perceived Social Support

The Berlin Social Support Scale (BSSS; Schwarzer, Schultz, 2000) was used to measure the four specific domains of social support of interest to this work. The BSSS measures perceived emotional support, perceived instrumental support, support seeking and support provided on a five point Likert scale. All negative items were reversed during analysis preparation. In this sample of sexual minority breast cancer survivors, the BSSS's reliability coefficient was r = .83. Table 2.3 provides sub scale means, standard deviations and alphas.

Profile of Mood States (POMS)

The POMS measures seven dimensions of affect including tension-anxiety, depression-dejection, anger-hostility, vigor-activity, fatigue-inertia, friendliness and confusion-bewilderment. The measure includes 65 adjectives that respondents endorse on a five point intensity scale specific to how they have been feeling in the past week. The POMS has been widely used to assess affect and mood in cancer patients and survivors, including many of the studies reviewed in this work (Fobair, et al., 2002; Fobair et al., 2001; Boehmer, et al., 2005). McNair and colleagues (1971) and Cella and colleagues (1989) report extensively on the validity and reliability of the POMS. In this sample of sexual minority breast cancer survivors the measure's internal consistency/reliability include Cronbach's alpha coefficient, overall score, r =.96. The measures subscales include anger-hostility, r = .94, depression-dejection, r = .95, fatigue-inertia, r = .95, vigor-activity, r =.96, tension-anxiety, r = .95, friendliness, r =.96, and confusion-bewilderment, r = .95.

Quality of Life—Cancer Survivors

The Quality of Life—Cancer survivors (QOL-Cancer Survivors; Ferrell et al., 1997) survey measures quality of life factors concerning long term survivors of cancer. The measure is comprised of 41 items that are endorsed on an eleven point Likert scale ranging from '0 worst outcome' to '10 best outcome' that measure four domains of quality of life, psychological wellbeing, physical wellbeing, social wellbeing and spiritual wellbeing. Scores for each of the items are averaged to obtain a total raw score and then an average score for each of the five domains is also provided. In this sample of sexual minority breast cancer survivors the measure's internal consistency/reliability was measured with Cronbach's alpha coefficient. The scale's overall score was r = .83. Subscale alpha coefficients include, spiritual wellbeing, r = .83, social wellbeing, r = .77, physical wellbeing, r = .77, and psychological wellbeing, r = .81.

Sexual Identity and Partnering

Sexual identity was measured by asking women to self-report their sexual identity or orientation. The survey question asks women to mark the description that best describes their sexual orientation or identity: 1) Heterosexual/Straight, 2) Lesbian 3) Bisexual 4) Woman who partners with women 5) Not Sure 6) Other. In this study 68 women self-identified as a sexual minority and 143 women self-identified as heterosexual. Only those women who identified as a sexual minority were included in the analyses presented here.

The survey also asked women to self-report their marital status: What is your **current** marital or partner status? 1) Married or living with an opposite sex partner, 2) Married or living with a same sex partner, 3) In a committed relationship with an opposite sex partner- not living together, 4) In a committed relationship with a same sex partner- not living together, 5) widowed 6) Divorced or separated, 7) Single, never married, 8) Involved with multiple partners, 9) Other. As seen in table 2.1, some women endorsed multiple categories, and at the time of data collection the majority of women (60%) reported *currently* being coupled or in partnered relationships.

Table 2.1: Relationship Status of SMW

Marital Status, % (n) (N=68)	SMW (n=68)
Single	10 (7)
Married Same Sex	54 (37)
Partnered Same Sex	5 (4)
Married Opposite Sex	.1 (1)
Partnered Opposite Sex	.1 (1)
Divorced/Separated	13 (9)
Widowed	.1 (1)

Perceived Stress

The measurement of perceived stress is important to the present study for two reasons. First, scholars in the field of stress and social support make strong recommendations regarding the measurement of social support indicating the necessity to measure participant's perception of stress when assessing social support. Wethington and Kessler (1985) as well as Cohen, Sheldon and Ashby (1985) strongly recommend determining individual's perceptions of stress when assessing perceptions of social support. Second there is a growing and important body of literature that outlines the influence of minority stress on the health and health outcomes of SMW (Meyer, 1995; Dean et al., 2000). Due to the absence of validated measures of minority stress a global measure of perceived stress was used in this study.

Cohen's four-item Perceived Stress Scale (PSS) was used to assess women's perceived levels of stress (Cohen, et al., 1983; Cohen and Williamson, 1988). The four item scale is designed to be used with samples with at least a middle school level of education. Questions are designed to be easily understood and answered on a five-point Likert scale ranging from 0-never to 4-very often. Table 2.2 provides inter-item correlation for each of the perceived stress questions. Three of the four perceived stress items were highly correlated at the $p < .05$ level. Table 2.3 provides perceived stress descriptive statistics for participants in this sample. Overall participants perceived moderate levels of stress with levels of perceived stress reported around the mean (mean score = 2.13). Women did report higher than average scores on two items, sense of confidence (mean score = 2.87) and things going my way (mean score

= 2.66). This means that women in this sample reported that they felt confident and that things were going their way in the past 30 days.

Table 2.2: Perceived Stress Inter Sub-Scale Reliability

Item (n=68)	Control	Confidence	Way	Overwhelm
Sense of Control	1.00			
Sense of Confidence	0.01	1.00		
Things Going Your Way	-0.23*	0.55**	1.00	
Overwhelmed	0.59**	-0.02**	-0.40**	1.00

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

Table 2.3: SMW Perceived Stress Descriptive Statistics

Scale and Items (n=68)	Mean	SD	Alpha
Perceived Stress	2.13	0.37	0.62
Sense of Control	1.83	1.13	
Sense of Confidence	2.87	1.15	
Things Going Your Way	2.66	1.17	
Overwhelmed	1.29	1.04	

Perceived Discrimination

To date we are not aware of validated measures of perceived discrimination available for use with sexual minority people. Perceived discrimination has been measured by scholars investigating the role of race-based perceived discrimination in health care settings (Thorburn, et al., 2004; Mays, et al., 1993; Thorburn et al., 2001). Therefore perceived discrimination was measured in this study through the adaptation of survey questions designed to measure perceived discrimination in health care settings among economically disadvantaged women and women of color seeking HIV treatment (Thorburn, et al., 2004; Mays, et al., 1993; Thorburn, et al., 2001).

Participants who self-identified as sexual minority breast cancer survivors, were asked to respond to the following questions on a five-point Likert scale: Based on your sexual identity, please rate the following according to your experiences during breast cancer treatments and meeting with doctors and nurses: a) You were treated with less courtesy than other people, b) You were treated with less respect than other people, c) You received poorer services than other people, d) You felt like a doctor or nurse was not listening to what you were saying, e) A doctor or nurse assumed you were heterosexual, f) A doctor or nurse assumed you were lesbian, g) A doctor or nurse assumed you had multiple sexual partners. In this sample of sexual minority breast cancer survivors the measure's internal consistency/reliability includes Cronbach's alpha coefficient, overall score, r = .75. We use Cronbach's alpha here as a coefficient of reliability, an indicator of how well these items measure the latent construct perceived discrimination.

Demographic Characteristics

Demographic characteristics were collected with a short series of questions including participant's current age, number of years since first breast cancer diagnosis, and number of years of completed education, income, insurance coverage, marital/partnered status and contact with biological family.

Analytic Approach

We generated frequency distributions and descriptive statistics for all variables of interest. Mean values for each of the perceived discrimination items were calculated and an overall score of perceived discrimination was generated. Means and standard deviations were calculated for demographic and independent variables including social support, perceived stress, and perceived discrimination as well as outcome measures of quality of life and affect. Two linear regression models were tested to determine the role of perceived social support, perceived stress and perceived discrimination on quality life and mood/affect among sexual minority breast cancer survivors. The likelihood ratio test was conducted to determine the presence of differences between the two regression models, the model that included perceived discrimination (table 2.12) and the model that did not include perceived discrimination (table 2.11).

Results

The primary aims of this work were to assess sexual minority breast cancer survivor's perceptions of discrimination in the health care setting, and to test for the influence of perceived discrimination on sexual minority breast cancer survivor quality of life and affect. We hypothesized that indicators of perceived social support and perceived stress would explain a statistically significant amount of the variance in survivorship measures, quality of life and affect/mood, among sexual minority breast cancer survivors. Second we hypothesized that including perceived discrimination as an indicator in our statistical model of breast cancer survivorship would significantly improve the amount of variance explained in survivor's quality of life and affect.

General Summary of Findings

Our findings suggest that sexual minority breast cancer survivors do perceive discrimination in health care settings. Additionally the analysis indicates that perceived discrimination significantly contributes to the survivorship model for quality of life, but not for mood/affect. We also found that adding perceived discrimination indicators to our statistical models statistically significantly improved our ability to model outcomes in survivorship.

Power Analysis

Using G*Power (G Power, 2001) power analysis was conducted to determine the ability to detect differences in dependent measures (quality of life and affect/mood) from predictor measures (perceived stress, perceived discrimination, perceived social support) in our sample. Effect size was calculated from the inter-indicator correlations between perceived stress, social support, perceived discrimination and quality of life and affect/mood. Effect size for this analysis was considered large, $f^2 = .54$ calculated from the inter-indicator correlations between perceived discrimination, social support and perceived stress on quality of life and affect. This study had adequate power, .81, alpha = .05, to detect differences if differences were present.

Participant Characteristics

This sample of SMW is largely characterized as being highly educated (63% college or graduate degree n = 28), middle aged (mean age = 55.5), insured (56%), in partnered relationships, and of non-Hispanic Caucasian ethnicity (table 2.4). Sixty-two percent (n = 29) of these participants indicate that they sometimes or always have money left over at the end of the month.

Table 2.4: Participant Characteristics

Characteristic		Total Sample (N = 68)
Age in years, mean (range) (N = 65)		55.5 (38-74)
Education, % (n) (N= 48)		
	Secondary Ed (9-11 years)	10.4 (5)
	Trade or Technical	8.3 (4)
	Junior College or Some College	18.9 (9)
	Bachelors Degree	14.6 (7)
	Graduate Degree	44.0 (21)
	Professional Training	4.2 (2)
Income, % (n)(N=47)		
	Can't make ends meet	10.6 (5)
	I have just enough money, no more	21.3 (10)
	I have enough with a little left over	36.2 (17)
	I always have money left over	26.0 (12)
	Other	6.4 (3)
Has health insurance, % (n) (N=42)		
	No	4.8 (2)
	Yes	95.2 (40)
Payment for health insurance, % (n) (N= 42)		
	Paid for by employer	29 (12)
	Paid for through spouse/partner employer	19 (8)
	Paid for through state/national insurance	12 (5)
	I pay for insurance myself	21 (9)
	I do not have insurance	2 (1)
	Other	17 (7)

We asked women to define their relationship status. It should be noted that women could endorse more than one category. For example, a woman may have been divorced and also in a partnered relationship. Eighty-four percent (n = 57) of the women defined the characteristics of their relationship status. Of these women, 59% (n = 40) self-identified as partnered or as being in a same-sex ‘marriage’ (legal marital status was not confirmed or asked). Ten percent (n = 7) identified as single, 13% (n =

9) identified as being divorced (though it was not indicated if the divorce was from a same sex or opposite sex partner), one woman identified as widowed, and one woman identified as being married to an opposite sex partner. Eighty-seven percent (n = 59) of the women answered our question about the time since their breast cancer diagnosis. Of the women who answered, the mean length of years since diagnosis was 4.9 years ranging from 0-23 years since diagnosis. The largest portion of this sample, sixty-eight percent, of the participant's breast cancer diagnosis occurred within the past 5 years. Seventeen percent of women had been diagnosed with the past 6-10 years and 15% of the women had been diagnosed 11-23 years prior to participation in this study.

Independent Variables

Perceived Discrimination

The total possible score on the perceived discrimination measure was calculated by summing the rating of individual items and dividing this by seven, the number of items in the scale. This provided a total perceived discrimination (in the health care setting) score for each participant (see table 2.5 for individual items). In this sample of sexual minority breast cancer survivors the range of scores was 0-3.4 where a score of 5 represents the highest possible score of perceived discrimination. The mean score for perceived discrimination was 1.8, with a standard deviation of .66. Table 2.5 indicates individual item mean scores and percentages.

Twenty-five percent of sexual minority women in this sample rated their total perceived discrimination in the health care setting a 1.4, indicating a low degree of perceived discrimination. The greatest number of participants, 39% of women (n =

27), rated "being perceived by doctors and nurses as heterosexually-identified" (mean = 2.97, out of possible 5) and 27% (n = 18) reported being undecided. In this sample of sexual minority breast cancer survivors 21% (n = 14) reported that doctors and nurses assumed that they were lesbian (mean = 2.63, out of possible 5). Largely this sample of sexual minority breast cancer survivors reported low perceptions of discrimination in health care settings. Ninety-two percent of these participants were not treated with less courtesy compared to other people based on their sexual identity or orientation and 91% (n = 62) report that they were not treated with less respect compared to other people. Eighty-four percent of participants (n = 57) indicate that they did not receive poorer services compared to others based on their sexual identity.

Table 2.5: Perceived Discrimination Descriptive Statistics

Experiences during breast cancer treatments and meetings with doctors and nurses		
Individual Item (n = 65)	Mean	SD
Treated with less courtesy	1.48	0.64
Treated with less respect	1.49	0.71
Received poorer services	1.40	0.60
Dr or nurse didn't listen	1.67	1.00
Dr or nurse assumed heterosexuality	2.97	1.25
Dr or nurse assumed lesbian	2.63	1.14
Dr or nurse assumed multiple sex partners	1.66	0.82

Social Support

The total possible score for social support on the Berlin Social Support Scale is 5 where larger scores indicate a higher degree of social support. In this sample of sexual minority breast cancer survivors overall social support scores ranged from 0-4.8 with a mean score of 3.5, and a standard deviation of .77. Individual social support sub-scales means, standard deviations and alphas are listed in table 2.6. SMW reported notably high scores of perceived instrumental (mean = 4.1) and perceived emotional support (mean = 4.1).

Table 2.5: SMW Social Support Descriptive Statistics

	Mean	SD	Alphas
Total Social Support (n= 67)	3.5	0.79	--
Perceived Emotional Support	4.1	0.84	0.73
Perceived Instrumental Support	4.1	0.95	0.74
Social Support Needs	3.0	0.71	0.87
Social Support Seeking	3.3	0.79	0.77

Perceived Stress

The total possible score for perceived stress on Cohen's scale of perceived stress is 16. In this sample women's perception of stress was low and ranged from 1.5-3.25, mean 2.13, standard deviation, .37, individual item means and standard deviations are provided in table 2.3.

Dependent Variables

Quality of Life

The quality of life data were non-normally distributed. Scores of quality of life were strongly skewed due to missing data. Quality of life scores ranged from 0-7.3 with a totally possible score of 10 mean 4.5, standard deviation 1.26. These data are non-normally distributed, kurtosis = 8.17, and skewness = -1.7. Table 2.7 provides quality of life descriptive statistics. SMW in this sample rated two dimensions of quality of life higher than the others: distress (mean = 5.98) and fears (mean = 5.2). Inter-scale correlations are presented in table 2.8.

Table 2.6: SMW Quality of Life Descriptive Statistics

Scale (n= 67)	Mean	SD	Alpha
Total QOL	4.65	1.19	
Physical quality of life	4.83	1.19	0.75
Distress	5.98	1.87	0.75
Fears	5.20	1.89	0.78
Social	4.29	1.80	0.72
Spiritual Wellbeing	3.50	1.11	0.80

Table 2.7: SMW Quality of Life Inter Scale Correlations

Scale (n=67)	P	D	F	S	SW
Physical quality of life	1.00				
Distress	0.60	1.00			
Fears	0.40	0.50	1.00		
Social	0.69	0.63	0.55	1.00	
Spiritual Wellbeing	0.60	0.43	0.30	0.40	1.00

Affect: Profile of Mood States (POMS)

The inter-item correlations among the POMS scales are presented in table 2.9. The scale means, standard deviations and alpha coefficients are calculated and presented in table 2.10. In this sample of women, the range of POMS scores was 0-3.25 (out of a total possible score of 5). The mean score for women in this sample was 1.23 (total possible score = 5), standard deviation 1.0. These data were normally distributed, skewness = -.20 and kurtosis = 1.57. Women reported the highest scores for the two positive mood domains measured by the POMS; vigor-activity and friendliness. This sample of women reported the highest scores for friendliness (mean = 2.11) indicating that this sample felt ‘friendly’ above all other moods. The second highest score was reported for vigor-activity (mean = 1.68) suggesting that these women were feeling positive, ‘cheerful’, ‘full of pep’ and ‘active’.

Table 2.8: SMW Affect/Mood (POMS) Inter Sub Scale Correlations

Scale (n=43)	A-H	D-D	F-I	V-A	T-A	FR	C-B
Anger-Hostility	1.00						
Depression-Dejection	0.94	1.00					
Fatigue-Inertia	0.88	0.94	1.00				
Vigor-Activity	0.61	0.56	0.46	1.00			
Tension-Anxiety	0.88	0.87	0.81	0.78	1.00		
Friendliness	0.70	0.67	0.62	0.93	0.84	1.00	
Confusion-Bewilderment	0.84	0.91	0.86	0.58	0.83	0.66	1.00

All were significant, p < .001

Table 2.9: POMS Descriptive Statistics

Scale (n=43)	Mean	SD	Alpha
Anger-Hostility	0.88	0.80	0.95
Depression-Dejection	0.97	0.90	0.95
Fatigue-Inertia	1.14	1.10	0.95
Vigor-Activity	1.68	1.55	0.96
Tension-Anxiety	1.24	1.03	0.95
Friendliness	2.11	1.79	0.96
Confusion-Bewilderment	1.25	1.21	0.95

Statistical Modeling and Inferential Statistics

We hypothesized that our indicators of perceived social support and stress would explain a statistically significant amount of the variance in survivorship measures, quality of life, and affect/mood among sexual minority breast cancer survivors. The relationship between perceived social support, perceived stress and perceived discrimination on quality of life and affect/mood were modeled with linear regression models using Stata 10.0 (StataCorp, 2007). In the first regression model quality of life and affect/mood were regressed on perceived social support and perceived stress (see coefficients in table 2.11).

Table 2.10: QOL and Affect Regression Model without Perceived Discrimination

		Dependent Variables	
Independent Variables		Affect F (2, 65) = 1.08, *p* = .34, *n.s.*	Quality of Life F (2, 65) = 13.55, *p* < .001
		b/t	**b/t**
Stress		-3.15	1.25
	t	-.75	.32
	P > |*t*|	0.453	0.75
Social Support		0.600	2.335
	t	1.27	5.20
	P > |*t*|	.210	0.001 ***
Survivorship Model	**R-sqr**	**0.032**	**0.29**

* p<0.05, **p<0.01, *** p<0.001

The model significantly predicted quality of life, *F* (2, 65) = 13.55, *p* < .001. In this model, social support significantly contributed to the variance in women’s quality of life, *t* = 5.20, *p* < .001. If other variables were held constant, every unit increase in social support resulted in 2.3 unit increase in quality of life in this sample of sexual minority breast cancer survivors. This finding suggests that scores on quality life increase in the presence of social support among these sexual minority breast cancer survivors. This model accounted for 29% of the variance in quality of life among sexual minority breast cancer survivors, *r-squared* = .29. This finding indicates that among these sexual minority breast cancer survivors nearly 30% of the variance in their quality of life was explained by social support, and perceived stress included in this survivorship model.

The first regression model did not significantly predict women's variance in affect/mood, *F* (2, 65) = 1.08, *p* = .344. This finding indicates that perceptions of social support and stress did not individually contribute significantly to sexual minority breast cancer survivor's mood/affect. Nor did these indictors explain a significant amount of the overall variance in breast cancer survivor's report of mood/affect.

Second, we hypothesized that including perceived discrimination, as an indicator in our statistical model of breast cancer survivorship, would significantly improve the amount of variance explained in survivor's quality of life and affect/mood. In the second multivariate linear model we regressed quality of life and affect/mood on perceived social support, perceived stress and perceived discrimination. As illustrated in table 2.11, this second model significantly predicted quality of life, *F* (3, 64) = 15.29, *p* < .001. Perceived social support significantly contributes to the variance in quality of life, *t* = 4.79, *p* < .001. When all other variables are held constant, for every unit increase in social support quality of life also increases 2 units. As predicted, perceived discrimination also significantly contributed to the model and explaining the variance in quality of life, *t* = 3.68, *p* < .001. Unexpectedly, when all other variables are held constant, for every unit increase in perceived discrimination, quality of life also increases 4 units. Forty-two percent (*r-squared* = .42) of the variance in quality of life among sexual minority breast cancer survivors was accounted for by social support, perceived stress, and perceived discrimination. Social support was an important indicator in this model but perceived discrimination seems to have had an even larger influence on survivor's quality of life than social support. Quality of life increases twice as much for every unit increase in perceived discrimination than social support.

Table 2.11: QOL and Affect Regression Model With Perceived Discrimination

		Dependent Variables	
Independent Variables		Affect F (3, 65) = .982, *p* = .41, *n.s.*	Quality of Life F (3, 65) = 15.29, *p* < .001
Stress		**b/t**	**b/t**
		-3.23	1.55
	t	-0.77	.430
	P > |*t*|	0.442	0.67
Social Support		.69	2.01
	t	1.42	4.79
	P > |*t*|	.160	0.001 ***
Perceived Discrimination		-1.21	4.36
	t	-0.89	3.58
	P > |*t*|	.378	0.001***
Survivorship Model	**R-sqr**	**0.04**	**0.42**

* p<0.05, **p<0.01, *** p<0.001

This second regression model that regressed perceived social support, perceived discrimination and perceived stress on affect/mood did not significantly contribute to the variance in survivor's affect/mood, *F* (2, 65) =.98, *p* = .407. In this sample, of sexual minority breast cancer survivors, perceived social support, discrimination and stress did not predict the variance in survivor's mood/affect.

To determine if there was a significant difference between the survivorship models (the second model included perceived discrimination and the first did not) a ratio likelihood test of the two models was conducted. Ratio likelihood tests indicate the presence of a significant difference between regression models. The likelihood ratio test indicated that the quality of life models were significantly different from one another, chi-square = 13.05, *p* < .01. In this sample of sexual minority breast cancer survivors, perceived discrimination increased our ability to predict more of the variance in quality of life compared to the model that excluded perceived discrimination. Adding measures of perceived discrimination improved the amount of explained variance in breast cancer survivor's quality of life in this sample. This suggests that in the assessment of quality of life among sexual minority breast cancer survivors, measuring perceptions of discrimination expands our understanding about the factors influencing breast cancer survivorship.

Discussion

The purpose of this research was to assess sexual minority breast cancer survivor's perceptions of discrimination in the health care setting, and to test for the influence of stress, social support and perceived discrimination on sexual minority breast cancer survivor quality of life and affect. We did this by asking sexual minority women to report their perceptions of discrimination during their breast cancer treatment and in interactions with health care providers. This allowed us to determine and describe the presence and characteristics of perceived discrimination among sexual minorities. Results suggest that sexual minority breast cancer survivor study participants did not perceive significant amounts of discrimination during their breast cancer treatment. Ninety-two percent (n = 63) of these participants reported that they were not treated with less courtesy compared to other people based on their sexual identity or orientation and 91% (n = 62) reported that there were not treated with less respect compared to other people. Eighty-four percent (n = 57) of participants indicate that they did not receive poorer services compared to others based on their sexual identity. In other words, sexual minority breast cancer survivors felt that they are being treated as well any other breast cancer survivor by their health care providers.

The largest proportion of participants, 39% of women (n = 27), rated "being perceived by doctors and nurses as heterosexually-identified" (mean = 2.97). This is noteworthy because the assumption of heterosexuality or 'passing' as a heterosexual could lessen opportunity for tailored support services offered to sexual minority breast cancer survivors. Some have also suggested that the assumption of heterosexuality may also lead to inadequate symptom management among sexual minority breast cancer survivors (Dibble and Roberts, 2002) thereby reducing the quality of their survivorship experiences. It is also possible that 'passing' as heterosexual could offer protective benefits, in terms of perceived discrimination, for sexual minority women undergoing breast cancer treatments.

We hypothesized that indicators of perceived social support and perceived stress would explain a significant amount of the variance in survivorship measures quality of life and affect among sexual minority breast cancer survivors. We generated a pair of linear regression models of survivorship by regressing quality of life and mood/affect on perceived social support and perceived stress indicators. The first model in the pair of survivorship models calculated, partially confirmed our hypothesis. The regression model (table 2.11) significantly predicted quality of life from sexual minority breast cancer survivor's perceived social support and perceived stress. The social support indicator significantly contributed to the breast cancer survivorship model of quality of life. This means that among this study's participants, perceived social support explained the degree of quality of life that women reported. In our models social support increased women's scores on quality of life measures. This confirms our hypothesis, as well as prior research, underscoring the importance of social support as a factor in positive breast cancer survivorship. Several studies have highlighted the importance of social support in quality of life among breast cancer survivors (Pelushi, 1997; Bloom, 1982; Fobair, 2001; Boehmer, et al., 2005). However SMW's breast cancer survivorship experiences are rarely reported, as prior studies of survivorship often focus exclusively on heterosexual, or assumed heterosexual, breast cancer survivors. Establishing that social support is also important for sexual minority breast cancer survivors is an important key step. Based on this knowledge we can advocate for social support programs tailored specifically to the needs of sexual minorities surviving breast cancer.

Our hypothesis that social support and stress would account for a significant portion of the variance in survivor's mood/affect was rejected. Measures of perceived stress and perceived social support did not explain sexual minority breast cancer survivor's mood/affect at the time that participants completed the survey. It is possible that the POMS measure was validated based on heterosexual norms and does not accurately measure the experiences of sexual minority breast cancer survivors. It is also plausible that our analyses lacked necessary power due to the small sample size to detect relationships between perceived social support, perceived stress and affect/mood.

We also hypothesized that including perceived discrimination as in indicator in our statistical model of breast cancer survivorship would significantly improve the amount of variance explained in survivor's quality of life and mood/affect. We conducted a second pair of linear regression models of survivorship (table 2.12) that included perceived discrimination as an indicator. In the second pair of regression models quality of life and mood/affect were regressed on perceived social support, perceived stress and perceived discrimination. Our second hypothesis was partially supported by this analysis and also produced unexpected results. As hypothesized, the inclusion of perceived discrimination in the modified regression model of survivorship accounted for a significant portion of the variance in survivor's quality of life. Additionally, and as hypothesized, this modified model also explained a larger portion of the variance in quality of life. However the way in which perceived discrimination modified the model was unexpected and contrary to our hypothesis. The results suggest that perceptions of discrimination *increased* the quality of life reported by sexual minority breast cancer survivors.

Initially this result may be interpreted as problematic. After all, we would certainly never make a recommendation to subject breast cancer survivors to discrimination. Upon closer review, it appears that the most influential item in our measure of perceived discrimination asked respondents to rate whether or not providers assumed that they (survivors) were heterosexual (mean score = 2.97, table 2.5). In this case, our model suggests that breast cancer survivor's provider assumption of patient heterosexuality was related to higher quality of life. This is logical given the heterocentric nature of U.S. culture and the medical field. If providers assume that all women are heterosexual, or if SMW 'pass' as heterosexual, SMW would not experience the difficulties of discrimination. This is problematic however in that the assumption of heterosexuality may keep SMW from discussing the intimacies of their experiences with breast cancer treatments and symptom management for fear of revealing their concealed minority identity (Dibble and Roberts, 2002; Sinding, et al., 2004).

There are several possibilities that could explain our findings that women were assumed to be heterosexual. For example, it is not uncommon for SMW to 'pass' as heterosexual if their appearance is not in-line with the stereotypical appearance of SMW that is promoted by society. This 'passing' as heterosexual could result in practitioner's erroneous assumption of SMW's heterosexuality. Additionally, practitioner's assumption that all women are heterosexual, unless they 'look' otherwise, also reflects societal norms and stereotypes of women’s assumed heterosexuality. Clearly these are important and real issues that are likely to be influencing this data. The measurement technique used to assess SMW’s perceived discrimination may also be influencing our findings in an important way. Our measure of perceived discrimination asked SMW to rate their breast cancer treatment provider’s perceptions about their sexuality retrospectively. This approach may have introduced error in two ways. First, women may have incorrectly assessed their provider’s perceptions. Second women may not remember accurately their perceptions of discrimination or provider interactions. Both of these issues could have increased the report of perceived discrimination and the assumption of heterosexuality. It is likely that our findings regarding perceived discrimination have been dually influenced by measurement technique and social factors. The development of measures that more accurately assess perceptions of discrimination in the health care setting would strengthen the ability of researchers to determine the influence of discrimination on breast cancer survivorship.

Future research concerning breast cancer survivorship among sexual minorities should address the ways in which women respond to and cope with breast cancer treatments and discrimination. Such research may involve a larger study that delves more deeply into the perceived discrimination experienced by sexual minority women during and after breast cancer treatments. Such work may utilize cancer and tumor registries in order to enhance scientific rigor and to gather a larger and more diverse sample of cancer survivors.

Our findings are important because they indicate a need to more deeply explore sexual minority breast cancer survivor's perceptions of discrimination when assessing their overall cancer survivorship. This assessment must also be conducted via unique formats alternative to convenience sampling. This may include the use of population-based surveys, which are with increasing frequency including sexual-identity questions, as well as tumor and cancer registries.

Social support and perceived discrimination contributed significantly to quality of life in the modified model of survivorship. Although social support remained statistically significant in the second survivorship model, the contribution of social support to the model's explanation of the variance in quality of life was lessened with the inclusion of the perceived discrimination indicator. This suggests that among sexual minority breast cancer survivors, social support *and* perceived experiences of discrimination are important to positive survivorship. Additionally it is important to note that the role of discrimination in breast cancer survivorship pathways is complex.

The modified model of survivorship did not significantly improve our ability to predict the variance in survivor's mood/affect. This portion of our hypothesis is not supported by this analysis.

Finally, we determined that the improvement in the second regression model's predication of quality of life was significantly different from the first model. Our findings indicate that the models were significantly different; suggesting that including sexual minority breast cancer survivor's perceptions of discrimination enhances our understanding of their survivorship. This is a notable finding and could also be used to help providers become sensitive to the unique factors that influence the quality of sexual minority breast cancer survivorship.

Limitations

This study is limited by important factors. First, this study is limited by its small sample size. Sample size limits the ability to detect possible additional influences in survivorship and our ability to conduct more advanced inferential statistics.

This study is also limited by recruitment bias as the study was conducted entirely online. This methodology, although convenient and affordable, may have excluded sexual minority breast cancer survivors who do not have computer access or computer literacy. Additionally this study did not have a comparison group. A comparison group who may have also experienced some form of discrimination in the health care setting while undergoing cancer treatments would strengthen our findings.

There are also several threats to external validity and our ability to generalize to sexual minority breast cancer survivors outside this study. First, this is homogenous sample and lacks varied representation from diverse ethnic groups, people of varied economic status and varied stage of cancer at the time of diagnosis. Our findings provide important contributions for future research but cannot make broad generalizations about all sexual minority breast cancer survivors or survivors at any specific stage of cancer at time of diagnosis.

Finally, our study suffers from missing data. This results in a bias toward the null and inflates the risk of conducting a type II error in which we could falsely accept the null hypothesis when there are indeed effects present in the data. Future research involving electronic surveys will require safeguards to prevent against missing data.

Conclusions

Two important messages emerge from this study. First, sexual minority breast cancer survivors perceived some, however limited, discrimination in the health care setting during their breast cancer treatment. This is important for two reasons. First, if we can assess the types of discrimination being experienced we can develop training protocols that may enhance the sensitivity of health care providers and reduce the negative consequences to sexual minority breast cancer survivors. Second, our evidence of unique factors influencing sexual minority's breast cancer survivorship contributes to the growing body of literature that justifies the continued study of the unique and not well understood forces that compromise survivorship outcomes for this population.

The second important message that emerges from this work is that sexual minority's perception of discrimination in the health care setting significantly enhances the ability to statistically predict the variance in quality of life, a common and well established indicator of breast cancer survivorship. Adding perceived discrimination as an indicator significantly increased our ability to predict quality of life (from $r^2 = .29$ to $r^2 = .42$, $\chi^2 = 13.05$, $p < .01$). This is useful for future studies of breast cancer survivorship as it provides additional information about the unique factors that influence women's social support and quality of life when surviving breast cancer.

The findings presented here may also be useful to providers interested in maximizing women's positive survivorship experiences. In this study sexual minority breast cancer survivors reported minimal levels of perceived discrimination; it is important to remember the small sample size and that these reports may vary with a more diverse sample. Additionally, these perceptions, however limited, did enhance our ability to predict survivor's quality of life. By understanding the influence of perceptions of discrimination on sexual minority women's survivorship, it is possible for providers to reduce unintended discriminatory protocols and behaviors. This knowledge may also support providers as they guide breast cancer survivors toward best possible support options and activities available as they begin and continue their survivorship. This might include, but certainly should not be limited to, support groups tailored to sexual minority breast cancer survivors or support services sensitive to the norms and differences that may characterize sexual minority experiences in dealing with breast cancer.

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CHAPTER V
CONCLUSION

Rapidly advancing cancer treatments and technologies have resulted in enhanced cancer survival for millions of individuals. This has also lead to a growing body of research focused on the unique ways in which women survive cancer and factors that influence successful cancer survivorship. As an increasing number of individuals diagnosed with cancer live long past the ‘five year survival’ mark, it is evident that they face unique and important psychosocial and quality of life challenges that must be understood and studied. The NCI and the Office of Cancer Survivorship jointly point to the need for scientific examination of the psychosocial elements of cancer survivorship and the survivorship outcomes among underserved and disparate populations. The current study’s findings add to a developing literature pertaining to the psychosocial factors that influence sexual minority women’s breast cancer survivorship.

The health disparities literature on sexual minorities indicates that sexual minorities are at greater risk for poorer physical and mental health outcomes compared to heterosexual populations (Bradford et al., 1994; Dean et al., 2000; Meyer 1995; Meyer et al., 2001). Population-based research on women’s health also highlights a higher prevalence of all forms of cancer including breast cancer among SMW (Valanis, et al., 2000; Dean et al., 2000, Solarz, 1999). Additionally, although the NCI and OCS indicate that women diagnosed with breast cancer are living, in many cases, long past the five-year survival mark, we do not have good estimates pertaining to the breast cancer survivorship of SMW. Perhaps more importantly there is a dearth of knowledge pertaining to the unique challenges that SMW face in breast cancer survivorship and the factors affecting their successful survivorship. In fact prior empirical research on breast cancer survivorship has largely ignored the experiences of sexual minority breast cancer survivors. The few studies that have been conducted prior to the current research have been largely qualitative and have not quantitatively addressed factors that uniquely influence sexual minority breast cancer survivorship.

Based on limitations of previous research, this study sought to contribute to the growing literature pertaining to SMW breast cancer survivorship in the following ways: First, this work broadly aimed to quantify the differences in social support, stress, years of survival, and perceived discrimination between sexual minority and heterosexual breast cancer survivors. Second, this study examined the influence of perceived discrimination on sexual minority breast cancer survivor’s quality of life and mood/affect. Lastly, this study was designed as a first step in the preliminary conceptualization and development of a breast cancer survivorship model. Such a model should account for the influence of sexual identity, social support, stress, perceived discrimination and years of survival that would predict women’s quality of life and affect/mood. The current study included these components of survivorship and assessed their relationship for sexual minority and heterosexual women.

Hypothesis 1: SMW will report lower perceived social support scores than heterosexual women.

The first hypothesis is rejected because the analysis conducted and presented here revealed no differences in social support according to women’s sexual identity.

Sexual minority and heterosexual women reported similar total scores on social support as well as on the social support sub-scales.

Hypothesis 2: SMW will report higher perceived stress scores than heterosexual women.

The second hypothesis is not rejected. The analysis indicates that there are significant differences in perceived stress according to breast cancer survivor's sexual identity. SMW reported more perceived stress than heterosexual women. This is consistent with the literature pertaining to theories of minority stress and the effects of being a sexual minority living in a heterocentric culture (Meyer, 1995; Meyer et al., 2002; Meyer, 2003; Bradford, et al., 1994). Stress, including minority stress, has long been understood as a pathway to physical and mental health disparities (Dean et al., 2000; Meyer et al, 2001). Our findings add to the literature uniquely by providing evidence of minority stress experienced by sexual minority breast cancer survivors specifically.

Hypothesis 3: Survivorship (defined as quality of life and affect) will differ significantly according to women's sexual identity. SMW will report lower QOL scores and negative emotional affect/mood.

This hypothesis was rejected. Quality of life and affect/mood did not vary according to sexual identity. Sexual minority and heterosexual breast cancer survivors reported statistically similar scores of quality of life and mood/affect.

Hypothesis 4: Quality of life and affect will be predicted from perceived social support, years since diagnosis, perceived stress and sexual identity.

This hypothesis was rejected. Our statistical models of breast cancer survivorship did not predict significant variance in survivor’s quality of life or affect/mood from perceived social support, perceived stress, years of survival and sexual identity indicators. This finding is contrary to the extant literature on breast cancer survivorship as prior research has successfully predicted quality of life from measures of social support (Arena et al., 2006; Fobair et al., 2001). The findings from the current research may be partially explained by the homogeneity of the sample, small sample size and the influence of recruiting bias.

Hypothesis 5: Measures of social support perceptions will moderate the influence of sexual identity for sexual minority breast cancer survivors. That is to say that women’s perception of social support will modify the influence of sexual identity on survivorship outcomes: quality of life (wellbeing) and positive affect/mood.

The fifth hypothesis was rejected based on this study’s findings. The statistical models of breast cancer survivorship tested in this work did not reveal significant differences between the two groups of survivors based on women’s sexual identity. Additionally, there was no statistically significant relationship determined between women’s sexual identity and measures of quality of life or affect/mood. Consequently, assessment of the moderating relationship of social support on the influence of sexual identity was inappropriate.

The final overarching objective of this study was to assess the presence of perceived discrimination among sexual minority breast cancer survivors and to determine its influence on quality of life and affect/mood. The participating breast cancer survivors reported relatively minimal perceived discrimination in their breast cancer treatment experiences. This could be interpreted as a positive finding in that reducing the presence of discrimination in the health care setting has obvious positive implications for the health of patients. Our findings could also indicate that our perceived discrimination measure was not sensitive enough to the nuances experienced by sexual minority breast cancer survivors. Or, these results could be an indication of sexual minority women's lack of awareness about the presence of discriminatory behavior.

This project aimed to determine if the additional measure of perceived discrimination would enhance the ability to predict quality of life and mood/affect among sexual minority breast cancer survivors. In this study adding perceived discrimination to the model improved our ability to predict women's quality of life; however, it did so in an unexpected manner. Women who rated experiencing perceived discrimination in their breast cancer treatment had better quality of life than women who did not perceive discrimination. Superficially the interpretation of this is tricky as it is difficult to determine if it is an artifact or a meaningful finding. The survey asked women to retrospectively rate the discrimination that they experienced during breast cancer treatment. This is problematic in that recall bias likely influenced their report of discrimination as the average length of time since cancer diagnosis among these participants was nearly six years (mean = 5.8 years). This considerable length of time could have had a significant influence on their memory of discrimination. It is also notable that the sexual minority participants in this study were highly educated, financially secure and White. It is possible that these characteristics had a positive impact on their treatment experiences and protected them from the negative consequences of discrimination. Being economically secure and highly educated may have allowed women to learn about and pursue more expensive treatments or health care settings where providers were accepting of their minority identities.

Perceiving discrimination in the health care setting was significantly related to higher quality of life. Looking more closely at the data it appeared that of those who answered the perceived discrimination questions, most SMW indicated that their treatment providers assumed they were heterosexual. This is an important finding when considering the influence of discrimination. Provider's assumptions of patient heterosexuality are evidence of the presence of heterosexism in the health care setting. It is possible that provider's general assumption of women's heterosexuality systematically limited sexual minority's exposure to discriminatory behavior and women's awareness of heterosexist policy during their breast cancer treatments. This suggests that the assumption of heterosexuality may have acted 'protectively' and enhanced women's quality of life in this model of breast cancer survivorship. Other alternative factors that could explain this finding include recall bias and tselection bias. There are many possible explanations for our unexpected finding and it is possible that the currently methodologies and measures do not offer a valid assessment of perceived discrimination among sexual minority breast cancer survivors. It may be impossible for us to speculate accurately about these unexpected findings.

Despite the numerous null findings discussed here, this research provides an important first step in quantitatively examining specific factors that define and influence sexual minority's breast cancer survivorship. This work contributes to the literature by identifying the importance of asking SMW about discriminatory experiences as contributing to their survivorship outcomes, and by underscoring the importance of recruiting as diverse a sample as possible to maximize the field's ability to better understand the qualities of breast cancer survivorship among SMW.

The null findings presented here are also important. The absence of significant differences in social support, quality of life and affect/mood according to sexual identity challenges our a priori assumptions and prior literature on this topic. Prior studies have indicated that sexual identity influences the quality and availability of social support, quality of life and affect/mood among sexual minority breast cancer survivors. However, we did not detect any differences in women's perceptions of social support, quality of life and affect/mood according to sexual identity. This challenges the assumptions upon which the current research was developed and leads us to speculate about the experiences of sexual minority breast cancer survivors. Is it possible that there is something unique about the *fighting spirit* of sexual minority breast cancer survivors that shields them from the hetero-androcentric nature of the health care setting? Or perhaps these women have developed an arsenal of coping behaviors that help them to survive in spite of potential and real difficulties identified in other studies. It is possible that the consequence of living a lifetime as a sexual minority results in resilience to factors such as discrimination or unequal treatment.

These unanswered questions suggest that additional research must be conducted to extend and deepen the understanding of breast cancer survivorship among SMW.

Limitations

The results from this study are limited by notable factors. This study is limited by its small sample size. Sample size limits the ability to detect possible additional survivorship influences and our ability to conduct more advanced inferential statistics.

This study is also limited by recruitment bias in a variety of ways. This study was conducted entirely online. This methodology, although convenient and affordable, may have excluded breast cancer survivors who do not have computer access or computer literacy. This limitation is underscored by the relative affluence of the participants as indicated by their demographic characteristics.

We experienced recruitment difficulties reported by prior studies on SMW health related to recruiting a minority population, or in this case, recruiting breast cancer survivors from a minority population (Meyer, et al., 2002; Bradford et al., 2001; Brogan et al., 2001). In this study we found that locating a rare population (heterosexual women’s lifetime risk of breast cancer is 1 in 8) within a minority population (sexual minority women), presented several difficult challenges. These challenges include locating sexual minority breast cancer survivors to recruit them for participation, and overcoming a history of distrust in order to gain the trust of willing participants via an online survey. Traditional sources of breast cancer survivor participants, including but not limited to well-known breast cancer survivorship organizations and breast cancer survivor support groups and activities, did not yield the expected numbers of sexual minority breast cancer survivors. Rather it became clear early in the data collection that locating the minority population required recruiting efforts in unexpected locations such as sexual minority focused quilting groups, choirs, motorcycle clubs, sports teams and other such groups. Because these groups were not necessarily ‘breast cancer’ focused they often yielded few, if any, willing participants. This recruiting strategy did produce the minimum number of participants necessary to conduct the analyses presented here; however it did not result in a heterogeneous sample or in a larger number of participants that could add strength to this study. These important factors significantly limit the findings of our study.

This study is also limited by missing data points. Missing data in this study has biased our findings toward the null and inflated the likelihood of producing a type II error in which we accept the null hypothesis when indeed effects were present. Online, electronic data collection, as discussed previously, has limitations including the preponderance and risk for missing data. Future research that utilizes internet based data collection will need to be strengthened by safeguards that reduce the presence and risk of missing data.

Future Directions

Continued research pertaining to the survivorship outcomes among SMW is needed. This was the first study, at the time of this writing, to quantitatively examine the influence of sexual identity, social support, stress, and years of survival on quality of life and affect/mood. Future research along these lines should strengthen recruitment procedures to include a larger sample of SMW as well as a more demographically and ethnically diverse sample of participants overall. This will allow for an enhanced examination of the factors that contribute to survivorship. Future research in survivorship should also use multiple measures of stress and social support to more comprehensively assess types of stress and social support in addition to the broad measures of these variables.

This was also the first study of its kind to measure the role of perceived discrimination among sexual minority breast cancer survivors. Future sexual minority breast cancer survivor research should include measures of perceived discrimination and these measures should also assess the influence and presence of alternate forms of perceived discrimination such as economic and race-based discrimination. This would strengthen the field’s understanding about the influence of discrimination by providing a much needed comparison for the differences between the experiences of sexuality-based discrimination and other forms of discrimination in the health care setting among breast cancer survivors.

Finally future research with sexual minority breast cancer survivors should include multi-modal data collection and recruitment techniques to increase access among the hardest to reach sexual minority breast cancer survivors. Although online data collection and recruitment was an affordable technique to acquire data, it undoubtedly introduced bias. Future recruitment techniques that could augment an online approach include utilizing local and national cancer registries and working closely with cancer treatment clinics and cancer survivor support groups to identify and locate cancer survivors who may be at risk for the poorest quality survivorship.

Additionally, augmenting the online data collection technique used in the current study with face-to-face data collection option may improve sample selection and increase what we know about breast cancer survivorship among SMW. Used together these modifications to data collection and participant recruitment could have a powerful impact on the quality and characteristics of the data generated and inferences made about breast cancer survivorship among SMW.

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APPENDIX

INFORMED CONSENT

Project Title: Factors that Contribute to Breast Cancer Survivorship: The Role of Perceived Social Support and Sexual Identity

Principal Investigator: Rebecca J. Donatelle, PhD, Public Health
Co-Investigator(s): Jennifer M. Jabson, MPH, Public Health

WHAT IS THE PURPOSE OF THIS STUDY? Thank you for your interest in this survey. You are being invited to take part in a research study because you are a breast cancer survivor. This study is designed to understand the social factors that contribute to women's breast cancer survivorship. The survey is comprised of questions about your experiences with breast cancer, including but not limited to social support, time since diagnosis, sexuality, marital status and quality of life. The data from this survey will be used for the completion of a PhD thesis at Oregon State University in the Department of Public Health, and will be submitted for publication.

WHAT IS THE PURPOSE OF THIS FORM? This consent form gives you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask any questions about the research, the possible risks and benefits, your rights as a volunteer, and anything else that is not clear. When all of your questions have been answered, you can decide if you want to be in this study or not.

WHY AM I BEING INVITED TO TAKE PART IN THIS STUDY? You are being invited to take part in this study because you self identify as a breast cancer survivor.

WHAT WILL HAPPEN DURING THIS STUDY AND HOW LONG WILL IT TAKE? If you agree to participate in this study your participation will take approximately 30-45 minutes. Should you continue with this survey you will answer questions about your breast cancer survival, your health, your sexual identity and your sources of support. This survey will be completed only ONCE and you will NOT be contacted in the future for any further information or participation.

WHAT ARE THE RISKS OF THIS STUDY? The possible risks and/or discomforts associated with the procedures described in this study include: possible emotional discomfort recalling your breast cancer experiences. There is minimal risk for violation to your confidentiality because we will not be collecting any identifying information, including your email address.

WHAT ARE THE BENEFITS OF THIS STUDY? We do not know if you will benefit from being in this study. However, by sharing your experience you are helping us to develop a more complete understanding of breast cancer survivorship. This will ultimately help us to design better tailored treatments and survivorship programs in the future.

WILL I BE PAID FOR PARTICIPATING? You will not be paid for being in this research study.
WHO WILL SEE THE INFORMATION I GIVE? The information you provide during this research study will be kept confidential to the extent permitted by law. To help protect your confidentiality, we will not be requesting any identifying information from you during the survey. Additionally the online survey company will not provide the researchers with email addresses or URL information. Data from this study will be maintained under password protection and will be destroyed at the end of the project. If the results of this project are published your identity will not be made public.

DO I HAVE A CHOICE TO BE IN THE STUDY? If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering. You will not be treated differently if you decide to stop taking part in the study. If you are uncomfortable or choose not to answer questions, you may skip to the next question on the survey or you may end your participation. If you choose to withdraw from this project before it ends, the researchers may keep information collected about you and this information may be included in study reports.

WHAT IF I HAVE QUESTIONS? If you have any questions about this research project, please contact: Rebecca J. Donatelle, PhD (541) 737-3839 or by email at Becky.Donatelle@oregonstate.edu or Jennifer M. Jabson, MPH by email at jjabson@onid.orst.edu.If you have questions about your rights as a participant, please contact the Oregon State University Institutional Review Board (IRB) Human Protections Administrator, at (541) 737-4933 or by email at IRB@oregonstate.edu.By clicking “ CONTINUE” you are indicating that you choose to voluntarily participate in the completion of the survey. You may print this screen for your records. By exiting your participation in the survey will be concluded.

What was the date of your first diagnosis (month/date/year)?

When you were first diagnosed with breast cancer, what STAGE of cancer did you have?

1. Stage 0
2. Stage 1
3. Stage 2
4. Stage 3
5. Stage 4
6. Dont Know

Have you had a recurrence of breast cancer?

1. Yes, current recurrence now
2. Yes, one past recurrence
3. Yes, more than one past recurrence
4. No, I have not had any recurrences

Have you had reconstructive surgery?

1. Yes
2. No
3. Other

If you had reconstruction, please describe why you decided to pursue reconstruction (please write as much as you like).

Do you participate in any breast cancer survivor support activities (such as support groups, dragon boating, walk for the cure etc)?

1. Yes
2. No

If you participate in breast cancer survivor activities, please indicate which activities you participate in:

1. Support Groups
2. Race For the Cure
3. Dragon Boating
4. Team in Training
5. Survivor Cycling
6. Avon Five-Day Walk For the Cure
7. Do not Participate
8. Other

If you DO NOT, or DID NOT, participate in survivor activities, please indicate the top three reasons why you dont or didnt participate:

1. Not interested
2. None in my area
3. Not healthy enough
4. Not a joiner
5. No groups or activities that match who I am
6. Fear
7. Too expensive
8. Didnt know these activities existed
9. No time
10. No transportation
11. Not a priority
12. I did participate
13. Other

Did you attend support groups that (check all that apply):

1. Included only heterosexual women
2. Included heterosexual women and lesbian women
3. Included only lesbian women
4. I dont know the sexuality of those who attended
5. I did not attend support groups
6. Other

Please indicate which of the following support groups were available to you and/or advertised in your area (mark all that apply):

1. heterosexual breast cancer support groups
2. lesbian breast cancer support groups
3. young woman breast cancer support groups
4. older woman breast cancer support groups
5. mixed breast cancer support groups (inclusive of all ages and sexual identities)
6. mixed cancer survivor support groups (groups for all and any cancer survivor)
7. Other

If you were partnered or married at the time of your diagnosis, did your partner or spouse attend any treatments or meetings with doctors or your treatment team?

1. Yes
2. No
3. Was not partnered or married at the time

Did your spouse or partner want to attend doctors visits and treatment sessions with you?

1. Yes
2. No
3. Was not partnered or married at the time

Did your partner or spouse attend any breast cancer support activities with you?

1. Yes
2. No
3. Was not partnered or married at the time

Did YOU want your partner or spouse to attend breast cancer support activities with you?

1. Yes
2. No
3. Was not partnered or married at the time

Did you partner or spouse attend any breast cancer support groups for spouses/partners of survivors?

1. Yes
2. No
3. Was not partnered or married at the time

Did you want your partner or spouse to attend breast cancer support groups for spouses and partners?

1. Yes
2. No
3. Was not partnered or married at the time

In the next section please tell us about your life since being diagnosed with breast cancer.

Since being diagnosed with breast cancer:

Friends have rejected me

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

	☐	☐	☐	☐	☐

I have pulled away from my friends

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

My partner or spouse has been faithful to me and our relationship

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	N/A
	☐	☐	☐	☐	☐	☐

I have become closer to my spouse or partner

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	N/A
	☐	☐	☐	☐	☐	☐

My spouse or partner and I have divorced or separated

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	N/A
	☐	☐	☐	☐	☐	☐

My relationships with friends has become more fulfilling since my breast cancer diagnosis

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

My relationships with friends has become less fulfilling since my breast cancer diagnosis

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

I feel my breast cancer has had a greater purpose in my life

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

What purpose, if any, has breast cancer had in your life?

How many months since your most recent breast cancer diagnosis?

How many months have you been cancer free?

Now we would like to know a bit about your social support.

There are some people who truly like me

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

Whenever I am not feeling well, other people show me that they are fond of me.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

Whenever I am sad, there are people who cheer me up.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

There is always someone there for me when I need comforting.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

I know some people upon whom I can always rely.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

When I am worried, there is someone who helps me.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

There are people who offer me help when I need it.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

When everything becomes too much for me to handle, others are there to help me.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

When I am down, I need someone who boosts my spirits.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

	☐	☐	☐	☐	☐

It is important for me always to have someone who listens to me.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

Before making any important decisions, I absolutely need a second opinion.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

I get along best without any outside help.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

In critical situations, I prefer to ask others for their advice.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

Whenever I am down, I look for someone to cheer me up again.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

When I am worried, I reach out to someone to talk to.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

If I do not know how to handle a situation, I ask others what they would do.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

Whenever I need help, I ask for it.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

We are interested in knowing how your experience of having cancer affects your Quality of Life. Please answer all of the following questions based on your life at this time. Please circle the number from 1 - 10 that best describe your experiences.

To what extent are the following a problem for you?

Fatigue

	1 not a problem	2	3	4	5	6	7	8	9	10 Severe problem
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Appetite Change

	1 not a problem	2	3	4	5	6	7	8	9	10 Severe problem
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Aches or Pain

	1 not a problem	2	3	4	5	6	7	8	9	10 Severe problem
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Sleep Changes

	1 not a problem	2	3	4	5	6	7	8	9	10 Severe problem
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Constipation

	1 not a problem	2	3	4	5	6	7	8	9	10 Severe problem
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Nausea

	1 not a problem	2	3	4	5	6	7	8	9	10 Severe problem
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Menstrual Changes or Infertility

	1 not a problem	2	3	4	5	6	7	8	9	10 Severe problem
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Rate your overall physical health

	1 extremely poor	2	3	4	5	6	7	8	9	10 excellent
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How difficult is it for you to cope today as a result of your disease?

	1 not difficult	2	3	4	5	6	7	8	9	10 very difficult
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How difficult is it for you to cope today as a result of your treatment

	1 not difficult	2	3	4	5	6	7	8	9	10 very difficult
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How good is your quality of life

	1 poor	2	3	4	5	6	7	8	9	10 excellent
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How much happiness do you feel

	1 none at all	2	3	4	5	6	7	8	9	10 a great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

To what degree do you feel like you are in control of things in your life

	1 not at all	2	3	4	5	6	7	8	9	10 completely
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How satisfying is your life?

	1 not at all	2	3	4	5	6	7	8	9	10 completely
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How is your present ability to concentrate or to remember things?

	1 poor	2	3	4	5	6	7	8	9	10 excellent
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How useful do you feel?

	1 not at all	2	3	4	5	6	7	8	9	10 extremely
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Has your illness or treatment caused changes in your appearance?

	1 not at all	2	3	4	5	6	7	8	9	10 extremely
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Has your illness or treatment caused changes in your self concept (the way you see yourself)?

	1 not at all	2	3	4	5	6	7	8	9	10 extremely
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How distressing were the following aspects of your illness and treatment?

Initial diagnosis

	1 not distressing	2	3	4	5	6	7	8	9	10 very distressing
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Cancer chemotherapy

	1 not distressing	2	3	4	5	6	7	8	9	10 very distressing	NA
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Cancer radiation

	1 not distressing	2	3	4	5	6	7	8	9	10 very distressing	NA
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Cancer surgery

	1 not distressing	2	3	4	5	6	7	8	9	10 very distressing	NA
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Completion of treatment

	1 not distressing	2	3	4	5	6	7	8	9	10 very distressing
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How much anxiety do you have?

	1 none	2	3	4	5	6	7	8	9	10 a great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How much depression do you have?

	1 none	2	3	4	5	6	7	8	9	10 a great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

To what extent are you fearful of:

Future diagnostic tests

	1 no fear	2	3	4	5	6	7	8	9	10 extreme fear
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

A second cancer

	1 no fear	2	3	4	5	6	7	8	9	10 extreme fear
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Recurrence of your cancer

	1 no fear	2	3	4	5	6	7	8	9	10 extreme fear
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Spreading (metastasis) of your cancer

	1 no fear	2	3	4	5	6	7	8	9	10 extreme fear
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Regarding your social concerns:

How distressing has your illness been for your family?

	1 not at all	2	3	4	5	6	7	8	9	10 a great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Is the amount of support you receive from others sufficient to meet your needs?

	1 not at all	2	3	4	5	6	7	8	9	10 a great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Is your continuing health care interfering with your personal relationships?

	1 not at all	2	3	4	5	6	7	8	9	10 a great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Is your sexuality impacted by your illness?

	1 not at all	2	3	4	5	6	7	8	9	10 a great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

To what degree has your illness and treatment interfered with your employment?

	1 not at all	2	3	4	5	6	7	8	9	10 a great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

To what degree has your illness and treatment interfered with your activities at home?

	1 not at all	2	3	4	5	6	7	8	9	10 a great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How much isolation do you feel is caused by your illness?

	1 none	2	3	4	5	6	7	8	9	10 a great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How much financial burden have you incurred as a result of your illness and treatment?

	1 none	2	3	4	5	6	7	8	9	10 a great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

The next questions are about your spiritual wellbeing.

How important to you is your participation in religious activities such as praying, going to church?

	1 not at all	2	3	4	5	6	7	8	9	10 very important
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How important to you are other spiritual activities such as meditation?

	1 not at all	2	3	4	5	6	7	8	9	10 very important
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How much has your spiritual life changed as a result of cancer diagnosis?

	1 not at all	2	3	4	5	6	7	8	9	10 very much
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How much uncertainty to you feel about your future?

	1 none at all	2	3	4	5	6	7	8	9	10 a great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

To what extent has your illness made positive changes in your life?

	1 none at all	2	3	4	5	6	7	8	9	10 a great deal
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Do you sense a purpose/mission for your life or a reason for being alive?

	1 not at all	2	3	4	5	6	7	8	9	10 very much
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How hopeful do you feel?

	1 not at all	2	3	4	5	6	7	8	9	10 very hopeful
	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

In the next section please tell us about your stress.

In the last month, how often have you felt that you were unable to control the important things in your life?

0 never	☐
1 almost never	☐
2 sometimes	☐
3 fairly often	☐
4 very ofetn	☐

In the last month, how often have you felt confident about your ability to handle your personal problems?

0 never	☐
1 almost never	☐
2 sometimes	☐
3 fairly often	☐
4 very often	☐

In the last month, how often have you felt that things were going your way?

0 never	☐
1 almost never	☐

2 sometimes	☐
3 fairly often	☐
4 very often	☐

In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

0 never	☐
1 almost never	☐
2 sometimes	☐
3 fairly often	☐
4 very often	☐

In this next section please tell us a little about your living situation.

State of your primary residence

Do you live in a region that is:

1. rural
2. urban
3. suburban
4. Other

Year of Birth

Month and Day of Birth

What is your current marital or partner status?

1. Married or living with an opposite sex partner
2. Married or living with a same sex partner
3. In a committed relationship with an opposite sex partner- not living together
4. In a committed relationship with a same sex partner- not living together
5. Widowed
6. Divorced or separated
7. Single, never married
8. Involved with multiple partners
9. Other

What is the highest level of education that you have earned?

1. Primary education (1-8 years of education)
2. Secondary education (9-12 years of education)
3. Trade or technical school
4. Junior College, or some College
5. Bachelor’s degree
6. Graduate degree
7. Professional
8. Other

What is your current employment status?

1. Working full time (35 or more hours per week)
2. Working part time (34 or fewer hours per week)
3. Homemaker
4. Unemployed or laid off
5. Looking for work
6. Retired
7. Disabled
8. Other

Do you currently smoke?

	Yes	No
	☐	☐

How many cigarettes a day do you smoke on the average (0 if none)?

Please indicate how old you were when you first began smoking (na if never smoked)

During your entire life have you consumed 12 drinks of any kind of alcoholic beverage

	Yes	No
	☐	☐

Do you still drink alcohol?

	Yes	No	NA
	☐	☐	☐

Please mark your living situation

1. Live alone
2. Live with spouse or partner
3. Live with roommate(s)
4. Live with parents or other adult family members
5. Live with children
6. Other

Generally where in the US do you live?

1. West Coast
2. MidWest
3. Southwest
4. East Coast
5. The South

Please mark the description that best describes your sexual orientation or identity

1. Heterosexual
2. Lesbian, woman who partners with women
3. Bisexual
4. Not Sure
5. Other

If you marked ‘lesbian, or woman who partners with women’ please answer the following. Based on your sexual identity, please rate the following according to your experiences during breast cancer treatments and meeting with doctors and nurses:

You were treated with less courtesy than other people.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

You were treated with less respect than other people.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

You received poorer services than other people.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

You felt like a doctor or nurse was not listening to what you were saying.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

A doctor or nurse assumed you were heterosexual.

	Strongly	Disagree	Undecide	Agree	Strongly

	Disagree		d		Agree
	☐	☐	☐	☐	☐

A doctor or nurse assumed you were lesbian.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

A doctor or nurse assumed you had multiple sexual partners.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
	☐	☐	☐	☐	☐

Use the following rating scale to indicate how open you are about your sexual orientation to the people listed below. Try to respond to all of the items, but leave items blank if they do not apply to you. 1 = person definitely does NOT know about your sexual orientation status2 = person might know about your sexual orientation status, but it is NEVER talked about3 = person probably knows about your sexual orientation status, but it is NEVER talked about4 = person probably knows about your sexual orientation status, but it is RARELY talked about5 = person definitely knows about your sexual orientation status, but it is RARELY talked about6 = person definitely knows about your sexual orientation status, and it is SOMETIMES talked about7 = person definitely knows about your sexual orientation status, and it is OPENLY talked about0 = not applicable to your situation; there is no such person or group of people in your life

	1	2	3	4	5	6	7	0
mother	☐	☐	☐	☐	☐	☐	☐	☐
father	☐	☐	☐	☐	☐	☐	☐	☐
siblings (sisters, brothers)	☐	☐	☐	☐	☐	☐	☐	☐
extended family/relatives	☐	☐	☐	☐	☐	☐	☐	☐
my new straight friends	☐	☐	☐	☐	☐	☐	☐	☐
my work peers	☐	☐	☐	☐	☐	☐	☐	☐
my work supervisor(s)	☐	☐	☐	☐	☐	☐	☐	☐
members of my religious community (e.g., church, temple)	☐	☐	☐	☐	☐	☐	☐	☐
leaders of my religious community (e.g., church, temple)	☐	☐	☐	☐	☐	☐	☐	☐
strangers, new acquaintances	☐	☐	☐	☐	☐	☐	☐	☐
my old heterosexual friends	☐	☐	☐	☐	☐	☐	☐	☐

Which of the following best describes your ability to get along on your income?

1. 1 I can’t make ends meet
2. 2 I have just enough; no more
3. 3 I have enough with a little extra sometimes
4. 4 I always have money left over
5. Other

Do you have health insurance?

	Yes	No
	☐	☐

If YES, who pays for it?

1. 1 Paid by my Employer?
2. 2 Through your spouse or partner’s employer?
3. 2 State/National Funded health insurance/subsidized plan (In the U.S.A, this could include Medicare
4. 4 I pay for it myself
5. 5 I do not have health insurance.
6. Other

To what primary race/ethnic group do you belong (please mark all that apply)?

1. 1 Asian, or Pacific Islander
2. 2 Black or African Descent
3. 3 Hispanic or Latino
4. 4 White, Caucasian, European, not Hispanic
5. 5 Native American or Alaskan Native, Native Aboriginal
6. Other

What is your current height in feet and inches?

What is your current weight?

How did you learn about this survey?

1. 1 online advertisement
2. 2 email/list serve

3. 3 friend
4. 4 word of mouth
5. 5 community event
6. 6 flier
7. 7 newspaper
8. Other

What would enhance or improve your experience as a breast cancer survivor experience?

Please describe how you feel RIGHT NOW by clicking one space after the words listed below.

	1 not at all	2 a little	3 moderate	4 quite a bit	5 extremely
Friendly	☐	☐	☐	☐	☐
Tense	☐	☐	☐	☐	☐
Angry	☐	☐	☐	☐	☐
Worn out	☐	☐	☐	☐	☐
Unhappy	☐	☐	☐	☐	☐
Clear-Headed	☐	☐	☐	☐	☐
Lively	☐	☐	☐	☐	☐
Confused	☐	☐	☐	☐	☐
Sorry for things done	☐	☐	☐	☐	☐
Shaky	☐	☐	☐	☐	☐
Listless	☐	☐	☐	☐	☐
Peeved	☐	☐	☐	☐	☐
Considerate	☐	☐	☐	☐	☐
Sad	☐	☐	☐	☐	☐

Active	☐	☐	☐	☐	☐
On edge	☐	☐	☐	☐	☐
Grouchy	☐	☐	☐	☐	☐
Blue	☐	☐	☐	☐	☐
Energetic	☐	☐	☐	☐	☐
Panicky	☐	☐	☐	☐	☐
Hopeless	☐	☐	☐	☐	☐
Relaxed	☐	☐	☐	☐	☐
Unworthy	☐	☐	☐	☐	☐
Spiteful	☐	☐	☐	☐	☐
Sympathetic	☐	☐	☐	☐	☐
Uneasy	☐	☐	☐	☐	☐
Restless	☐	☐	☐	☐	☐
Unable to concentrate	☐	☐	☐	☐	☐
Fatigued	☐	☐	☐	☐	☐
Helpful	☐	☐	☐	☐	☐
Annoyed	☐	☐	☐	☐	☐
Discouraged	☐	☐	☐	☐	☐
Resentful	☐	☐	☐	☐	☐
Nervous	☐	☐	☐	☐	☐
Lonely	☐	☐	☐	☐	☐
Miserable	☐	☐	☐	☐	☐
Muddled	☐	☐	☐	☐	☐
Cheerful	☐	☐	☐	☐	☐
Bitter	☐	☐	☐	☐	☐

Exhausted	☐	☐	☐	☐	☐
Anxious	☐	☐	☐	☐	☐
Ready to fight	☐	☐	☐	☐	☐
Good-Natured	☐	☐	☐	☐	☐
Gloomy	☐	☐	☐	☐	☐
Desperate	☐	☐	☐	☐	☐
Sluggish	☐	☐	☐	☐	☐
Rebellious	☐	☐	☐	☐	☐
Helpless	☐	☐	☐	☐	☐
Weary	☐	☐	☐	☐	☐
Bewildered	☐	☐	☐	☐	☐
Alert	☐	☐	☐	☐	☐
Deceived	☐	☐	☐	☐	☐
Furious	☐	☐	☐	☐	☐
Efficacious	☐	☐	☐	☐	☐
Trusting	☐	☐	☐	☐	☐
Full of pep	☐	☐	☐	☐	☐
Bad-Tempered	☐	☐	☐	☐	☐
Worthless	☐	☐	☐	☐	☐
Forgetful	☐	☐	☐	☐	☐
Carefree	☐	☐	☐	☐	☐
Terrified	☐	☐	☐	☐	☐
Guilty	☐	☐	☐	☐	☐
Vigorous	☐	☐	☐	☐	☐
Uncertain about things	☐	☐	☐	☐	☐

Bushed	☐	☐	☐	☐	☐