

ABSTRACT

Title of dissertation: BREAST CANCER NARRATIVES OF WOMEN
WITHOUT PARTNERS

Amanda Christine Ginter, Doctor of Philosophy, 2013

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This qualitative study examined the experiences of female breast cancer patients without partners through the theoretical perspectives of ecological systems and health promotion. Family science literature addresses the importance of social support to quality of life. Women with breast cancer, the second most common cancer among women, often report that their main social support comes from intimate partners. If so, women without intimate partners may experience a health disparity that affects how they cope with their diagnosis and treatment. Although some studies indicate differences in the utilization of detection services between breast cancer patients with and without partners, there is a gap in the literature concerning the lived experience of patients without partners.

Qualitative data were collected from 20 participants who did not have partners during diagnosis and treatment. Participants took part in one-time interviews conducted by the researcher. Phenomenology informed the methodology and thematic analysis. Findings included how breast cancer patients without partners adapted supportive networks to cope with the fears and frustrations of diagnosis and treatment; how these women sought health information and interacted with their medical teams; and how they made meaning of their relationship status within the context of their cancer experience. Based on findings from this study, family scientists and public health professionals and

oncology care providers may have a better understanding of the specific concerns and experiences of breast cancer patients without partners. Additional implications of these findings for patients, practice, policy, and research will be discussed.

BREAST CANCER NARRATIVES OF WOMEN WITHOUT PARTNERS

by

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*Dedicated to my parents,
David and Stephanie Ginter*

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Table of Contents

	Page Number
List of Tables	viii
List of Figures	ix
Chapter I: Introduction	1
Chapter II: Literature Review	5
Health Disparities and Diversity of Population	5
Relationship Status as a Health Disparity	7
Support During Diagnosis	8
Interpersonal Resources	8
Intrapersonal Resources	15
Access to Health Care and Health Information	17
Lymphedema	23
Making Meaning of Relationship Status	23
Theoretical Framework	25
Epistemology	25
Paradigm	25
Theory: Ecological Systems Framework	26
Theory: Health Promotion Perspective	31
Rationale for This Study	35
Research Questions	37
Chapter III: Method	38
Participants	38
Interviews	40
Descriptive Analysis	40
Methodology	41
The Researcher's Reflections and Personal Motivations	45
Data Quality	46

Chapter IV: Results	50
Initial Reactions to Diagnosis	50
Stressful Personal Backgrounds	52
Relationships Within Social Networks	53
Support from Social Networks: Needed and Received	66
Medical Treatment	73
Relationship Status in the Context of Treatment	79
Resources for Coping	89
Meditative and Holistic Care	101
Barriers to Care and Treatment	104
Advice for Other Single Breast Cancer Patients	108
Summary	113
Chapter V: Discussion	114
Research Questions and Answers	114
Major Conclusions	116
Utility of Theoretical Frameworks	122
Implications	125
Limitations	129
Transferability	130
Contribution and Conclusion	131
Appendix A: Study Flier	133
Appendix B: Written Consent Form	134
Appendix C: Interview Protocol	136
Appendix D: Demographic Survey	141
Appendix E: Codebook	142
Appendix F: Descriptive Statistics	148
References	152

List of Tables

1. Breast Cancer Statistics	6
2. Types and Characteristics of Social Networks and Social Support	33
3. Data Analysis Plan	44
4. Descriptive Statistics	148

List of Figures

1. Ecological Systems and Social Support Model	35
2. Ecological Systems and Social Support Model with Themes	125

Chapter I: Introduction

Breast cancer is an uncontrolled growth, or malignant tumor, of breast cells. Approximately one in eight women in the United States (between 12% and 13%) will develop invasive breast cancer sometime in her life (National Cancer Institute, 2012). In 2013, an estimated 232,340 new cases of invasive breast cancer will be diagnosed in women in the U.S., along with 64,640 new cases of non-invasive (*in situ*, those cancerous cells that do not metastasize) breast cancer (American Cancer Society, 2013). For women in the U.S., breast cancer death rates are higher than those for any other cancer besides lung cancer. After skin cancer, breast cancer is the most commonly diagnosed cancer among U.S. women (American Cancer Society, 2013; National Cancer Institute, 2013).

In the last few decades, many breast cancer cases have transitioned from guaranteed death sentences to manageable chronic diseases. More and more individuals are surviving longer, and thus there are more issues surrounding survivorship, including the family's impact on the patient's well-being. The study of the quality of life post-cancer treatment is a relatively new phenomenon (Mellon & Northouse, 2001). There is extensive literature about grieving for family members who died from cancer, but not nearly as much about how patients' social environments change during the course of treatment and how patients' perspective on the future changes.

Health status is not based solely on physiological state. There are multiple contextual factors that determine health and well-being, including social environment. The social environment comprises interpersonal relationships including family, friends and associates, work, neighborhood, faith organizations, and support groups (Schmidt & Andrykowski, 2004). The impact of social environment on health has been established

(Hawe & Shiell, 2000; Seeman, 1996; Yen & Syme, 1999). However, the direction of that relationship varies depending on whether the social environment is offering support or stress (Remmers, Holtgrawe, & Pinkert, 2010). Having social support is linked to higher quality of life (Helgeson, 2003). In contrast, stress can diminish quality of life. Stress can result from unsupportive individuals or family, friends, and co-workers who require more time and energy than an individual can give (Frieswijk & Hagedoorn, 2009; Remmers, Holtgrawe, & Pinkert, 2010). Therefore, the social environment must be examined for the extent to which it is a help or a hindrance to an individual's well-being.

There is also a relationship between social environment and cancer.

Understanding the social environments of patients can reveal their cancer-coping processes, which may include benefit finding and positive thinking (Dunn, Occhipinti, Campbell, Ferguson, & Chambers, 2011; Knott, Turnbull, Olver, & Winefield, 2012). Cancer patients who are well connected to their social environment possess more personal resiliency (Denz-Penhey & Murdoch, 2008). Additionally, social environments can help explain or predict choices to engage in healthy breast behaviors, such as self-examination or regular mammograms (Kearney, 2006). The social environment can also impact how patients cope with a breast cancer diagnosis (Schmidt & Andrykowski, 2004). Care providers need to be aware of their patients' social environment and whether members of that environment are a source of stress or are providing enough support to the patients (Den Oudsten, Van Heck, Van der Steeg, Roukema, & De Vries, 2010).

Just as the social environment explains the impact of interpersonal relationships and resources on patients' well-being, it is also necessary to consider the quality and quantity of health information that patients have and how that affects their health. One

social determinant of health is health literacy (Guimaraes, Silva, & Noronha, 2011). To reduce health disparities, it is necessary for individuals to be health literate. That is, they must know how to access information, be able to make sense of the information and take appropriate action based on the information (HealthyPeople 2020, 2012). Individuals must also believe they can take action, such as accessing information, that will positively impact their personal health (HealthyPeople 2020, 2012). Another component of health literacy is that professional care providers acknowledge their patients' trouble accessing or understanding information and work to ensure that their oral directions and printed materials are clear (Koch-Weser, Rudd, & DeJong, 2010). The estimated cost of limited health literacy in the United States is \$1.6 trillion to \$3.6 trillion annually (Vernon, Trujillo, Rosenbaum, & DeBuono, 2007).

Professional care providers must be cognizant of patients' cultural background and health literacy and their access to and use of health information. However, positive health outcomes cannot be achieved simply by distributing information: there is no guarantee that distributing information will result in change (Glanz, Lewis, & Rimer, 1997). Change occurs when the behavior of patients is activated or modified. Patients' behavior can be influenced through providers' understanding of theories of behavior change infused with their acknowledgment of patients' social environment (Glanz, Lewis, & Rimer, 1997).

When a woman is diagnosed with breast cancer, she may interact with many different types of professional care providers, including her general practitioner, oncologist, surgeons, radiologists, nurses, and administrative personnel (Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birenbaum, Heggan, & Martin, 1993). The quality of

interaction with each professional care provider may vary. The patient's oncologist may be aware of health literacy issues, whereas the surgeon is not (or vice-versa). Therefore, the phrase "medical team" was used to refer to the patient's professional care providers. Women with breast cancer might have had positive or negative experiences with any member of the team.

The following chapter is a literature review on breast cancer patients' forms of social support, interpersonal relationships that can alleviate or contribute to stress, health disparities, and challenges that breast cancer patients face post-diagnosis. This chapter builds the case that breast cancer patients in general require social support in order to cope with the fears and frustrations of diagnosis and treatment. The chapter discusses intimate partners as part of the social environment and, more specifically, lays the groundwork for additional information on breast cancer patients without partners.

Chapter II: Review of the Literature

Breast cancer patients require ample social support to cope with their diagnoses, treatment, and all the surrounding challenges (Schmidt & Andrykowski, 2004). Among all racial, ethnic, and socioeconomic groups, patients that perceive having adequate social support experience less psychological distress post-diagnosis (Buki, Garcés, Hinestrosa, Kogan, Carrillo, & French, 2008; Galván, Buki, & Garcés, 2009).

The following sections explore the literature on social support and stress for breast cancer patients. The literature review is divided into sections on the diversity of the population; forms of interpersonal and intrapersonal support needed by breast cancer patients; how breast cancer patients seek and utilize health information; and how women without partners make sense of their relationship status, particularly in poor health contexts.

Health Disparities and Diversity of Population

Documented health disparities include race, ethnicity, sex, socioeconomic status and health literacy (Clark, Anderson, Clark, & Williams, 1999; Cooper, Hill, & Powe, 2002; Kreps & Sparks, 2008). Breast cancer incidence and mortality rates vary among racial and ethnic groups (CDC, 2012). Racial and ethnic minorities and women from lower socioeconomic backgrounds are more likely to be diagnosed with breast cancer at later stages and they are more likely to die from breast cancer than white women or women from higher socioeconomic backgrounds (CDC, 2012; Joseph, Kaplan, Luce, Lee, Stewart, Guerra, & Pasick, 2012). Explanations for these racial/ethnic mortality differences and disparities include that minority women may not use screening services as frequently as white women, and thus when they are diagnosed with breast cancer, it is

at later stages, which means that the disease has progressed further and is less likely to be treatable (Banegas, Matthew & Li, 2012). Breast cancer incidence rates are higher among white women than African American women, but African Americans are more likely to die from the disease (National Cancer Institute, 2012).

Table 1

Breast Cancer Statistics

	Incidence Rates by Race	Mortality Rates by Race
All Races	124.3 per 100,000 women	23.0 per 100,000 women
White	127.3 per 100,000 women	22.4 per 100,000 women
Black	121.2 per 100,000 women	31.6 per 100,000 women
Latina	92.7 per 100,000 women	14.9 per 100,000 women

Table 1
2012

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Knowing that socioeconomic status (SES) and racial/ethnic groups have different incidence and mortality rates for cancer leads to the question whether they have varied breast cancer *experiences* as well. Ethnic minority cancer patients are more likely to experience depression, distress, and lower quality of life than cancer patients from majority groups (Luckett, Goldstein, Butow, Gebski, Aldridge, McGrane, Ng, et al., 2011). Additionally, racial and ethnic minorities are more likely to stop being employed after a breast cancer diagnosis (Mujahid, Janz, Hawley, Griggs, Hamilton, & Katz, 2010). Not being employed significantly affects a patient's ability to afford treatment and

contributes to added stress and a more negative experience overall (Janz, Hawley, Mujahid, Griggs, Alderman, Hamilton, Graff, et al., 2011; Mujahid, Janz, Hawley, Griggs, Hamilton, Graff, & Katz, 2011).

Socioeconomic status also contributes to health disparities. Uninsured women are more likely to have metastasized breast cancer and larger breast tumors than privately insured women (DeSantis, Jemal, & Ward, 2010). Lower-income women are also more likely to be diagnosed at later stages than higher-income women (Barry, Breen, & Barrett, 2012). Finally, lower-income breast cancer patients are less likely to experience the immunological benefits of social support than higher-income breast cancer patients (Fagundes, Bennett, Alfano, Glaser, Povoski, Lipari, Agnese, et al., 2012).

Socioeconomic status is a mediator of racial differences in breast cancer treatment outcomes (Berz, Johnston, Backus, Doros, Rose, Pierre, & Battaglia, 2009). In the United States, and much of the world, minority racial groups simply have less wealth (Burton, Bonilla-Silva, Ray, Buckelew, & Freeman, 2010; Gregg, 2009).

The following sections will examine women's general breast cancer experiences, as well as the breast cancer experiences of African Americans and women from lower socioeconomic backgrounds.

Relationship Status as a Health Disparity

Relationship status may be added to the list of health disparities. Unmarried women are more likely to be diagnosed with breast cancer at later stages than married women (Kuo, Mobley, & Anselin, 2011). Between 1970 and 2007, excess mortality of never-married cancer patients compared with married patients has increased (Kravdal & Syse, 2011). Married individuals tend to have better overall health than never-married

individuals and they are more likely to go to a physician when they experience suspicious symptoms (Kravdal & Syse, 2011; Nayeri, Pitaro, & Feldman, 1992; Osbourne, Ostir, Du, Peek, & Goodwin, 2005). Marital status and the presence of a partner are predictors of breast cancer patients' quality of life and functioning (Taira, Shimosuma, Shiroya, Ohsumi, Kuroi, Saji, Saito, et al., 2011). One study found that among breast cancer patients, being single or unpartnered is associated with fewer depression symptoms over time as compared to being partnered or married (Wittenberg, Yutsis, Taylor, Giese-Davis, Bliss-Isberg, Star, & Spiegel, 2010).

Support During Diagnosis

Both interpersonal and intrapersonal resources are crucial for coping with disability and disease (McColl & Skinner, 1995). Interpersonal resources are those that come from other people (including family, friends, and colleagues); types of support include instrumental, informational, emotional, and appraisal (Glanz, Lewis, & Rimer, 1997). Intrapersonal resources are intrinsic to individuals. For breast cancer patients, intrapersonal resources include having faith, finding something to live for, gaining insight about their lives and health, and actively working to get better, as well as activities such as meditation and yoga (Jensen, Back-Petterson, & Segesten, 2000; Trinkaus, Burman, Barmala, Rodin, Jones, Lo, & Zimmermann, 2011). Another intrapersonal resource is health literacy. The following section outlines types of interpersonal and intrapersonal resources for breast cancer patients.

Interpersonal Resources

Family. A woman's breast cancer diagnosis is likely to create the need for new family roles, because her focus shifts to treatment and recuperation (Rolland, 1987). Her

family members may need to adjust their roles and handle more household responsibilities. It is important to understand how her family adjusts because that may determine how supportive they can be (Raveis & Pretter, 2005; Rolland, 1987). Two common categories of family supporters are first degree female relatives and intimate partners (Raveis & Pretter, 2005; Fobair & Spiegel, 2009). (Intimate partners will be discussed in the following section).

First Degree Female Relatives (FDFRs) of breast cancer patients are genetically related sisters, daughters, and mothers of women who have been diagnosed with breast cancer (Raveis & Pretter, 2005). Because of their genetic tie, these women encounter many issues that relatives of patients with other illnesses do not face. When an FDFR learns of a relative's diagnosis, she is also learning of her increased susceptibility. At the same time she must be a comfort and support to the patient and cope with the knowledge that she is now at risk (Raveis & Pretter, 2005).

At the time of diagnosis and treatment, families are challenged to reconcile the present and the future (Rolland, 1987). While they are assisting the ill family member and possibly living from one day to the next, they must also consider the future – their fears, their expectations, and their goals. Looking ahead is made especially difficult if the family member's illness is severe, chronic, or unlikely to improve (Rolland, 1987). It may be further confusing if it is difficult to ascertain how soon, or if, the patient will recover, and whether the family needs to change their plans temporarily or permanently. Even if the changes are temporary, it may be hard for family members to restore their initial plans, before their relative was diagnosed. It is essential that health care

professionals offer psychoeducation to their patients' families, so that families are better prepared for the stress and chaos that may accompany a relative's illness (Rolland, 1987).

Regardless of the patient's prognosis, his or her family members will rely on previous multigenerational experiences with similar situations, as well as their family's values, to navigate such tribulations (Rolland 1987). How the family has reacted to illness in the past suggests how family members will respond now. For the purpose of this study, I asked participants whether they considered asking family members to help them, and whether that decision was based on previous experiences.

Other factors include the family's personal style of functioning, as well as their resources, such as outside help, doctors, clergy, or counselors they may speak to (Rolland, 1987). Much also depends on where individual family members are in their life cycles when illness strikes the family – an adolescent preparing to leave for college will react to, and be affected by, a parent's illness differently from a middle-aged adult child whose aging parents had expected news of illness (Rolland, 1987).

Perceived social support from family and friends is an important contributor in the adjustment to breast cancer (Shelby, Crespin, Gregorio, Lamdan, Siegel, & Taylor, 2008). African American patients have reported higher emotional well-being than white patients post-diagnosis (Janz, Mujahid, Hawley, Griggs, Alderman, Hamilton, Graff, et al., 2009). This discrepancy is especially interesting given that African Americans' dissatisfaction with care providers is commonly reported, and negative patient-physician relationships are often tied to patients' decreased quality of life (Davey, Kissil, Nino, & Tubbs, 2010; Gregg, 2009). Recognizing that African American families are often tightly connected and contain supportive networks may help us consider how the general support

of extended family members might apply to African American breast cancer patients' higher levels of well-being (Stewart, 2007). The emotional and social support from African American breast cancer patients' families may buffer any negative impact from the perceived discrimination (Hamilton, Agarwal, Carter, & Crandell, 2011; Hamilton & Sandelowski, 2004). These synergistic female family relationships may even empower women to engage their relatives in healthy behaviors, including self-detection and preventive care; the family's increased awareness of breast cancer improves informational support for the patient (Williams, Mullan, & Todem, 2009). At the same time, because African American women are often called upon to be the caregivers in their family, they may not feel sufficiently supported when they need care (Ashing-Giwa & Ganz, 1997). Additional studies must examine how the typical caregivers receive support when it is their turn to be cared for.

Intimate partners. Breast cancer can alter the female patient's body and thus her self-perception and sexuality (Fobair & Spiegel, 2009). As a result, breast cancer can have effects on her intimate relationship unique from other cancers. Treatments such as chemotherapy may also negatively affect her sexual desire and functioning. These changes often stress intimate relationships (Fobair & Spiegel, 2009). Yang and Schuler (2009) found that marital stress was also associated with slower recoveries and poor results. Spousal stress is more likely caused by patient distress; spousal stress often leads to marital stress (Fang, Manne, & Pape, 2001).

At least one study found that being single may be a protective factor against depression among breast cancer patients (Vahdaninia, Omidvari, & Montazeri, 2010). Theories for this association between relationship status and depression include that

married/partnered women may experience relationship dysfunction or dissolution following diagnosis (Fang, Manne, and Pape, 2001; Fobair & Spiegel, 2009; Vahdaninia, Omidvari, & Montazeri, 2010). In fact, a partnership or marriage need not end in dissolution or divorce before the breast cancer patient is negatively affected by her partner: simply being unaccompanied by one's spouse for hospital follow-ups is associated with higher levels of depression and anxiety (Karakoyun-Celik, Gorken, Sahin, Orcin, Alanyali, & Kinay, 2010).

Do breast cancer diagnoses directly cause intimate relationship dysfunction and even partner abandonment (Kneece, 1995)? Research suggests that relationships and marriages that do not survive the breast cancer experience had preexisting problems that ultimately caused the dissolution, and relationships in which someone is diagnosed with breast cancer are no more likely to end than other relationships (Dorval, Maunsell, Taylor-Brown, & Kilpatrick, 1999; Taylor-Brown, Kilpatrick, Maunsell, & Dorval, 2000). Not all of these studies were racially or ethnically diverse, which is a significant limitation.

Among a sample of African American breast cancer patients, those with intimate partners felt emotionally supported by them, although the partners did not assist them in making health decisions (Ashing-Giwa & Ganz, 1997). Female partners play a critical role in sexual minority women's¹ breast cancer treatment experiences, taking on additional household roles and offering verbal support and encouragement (White & Boehmer, 2012; Boehmer, Freund, & Linde, 2005). Their role stands in contrast to previous literature on different-sex partners' reactions to women's breast cancer

¹ Lesbian, bisexual, or women who partner with women (SMW).

diagnoses and treatment – namely, avoidance and withdrawal strategies that caused distress to the patient (Fergus & Gray, 2009; Manne, Ostroff, Winkel, Grana, & Fox, 2005). At the same time, female partners who are caregivers of cancer patients generally report more anxiety and care burden than male partners (Perz, Ussher, Butow, & Wain, 2011). Among a sample diverse in relationship status, breast cancer patients who got a new partner post-diagnosis were more sexually satisfied than patients who retained the same partner (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998).

Both qualitative and quantitative articles examine how intimate partners provide support. There is also information to suggest that single women are protected from the simultaneous stress of illness and dysfunctional relationships (Vahdaninia, Omidvari, & Montazeri, 2010). It is possible that single women will reflect on past relationships or their peers' relationships in an effort to explain how their lives might be different if they had had partners during their diagnoses and treatment (Legg, Occhipinti, Ferguson, Dunn, & Chambers, 2011).

Friends. Increased contact with friends post-diagnosis is associated with lower risk of death for breast cancer patients (Chou, Stewart, Wild, & Bloom, 2012). Simply having someone to share one's problems with improves breast cancer patients' quality of life (Karakoyun-Celik, Gorken, Sahin, Orcin, Alanyali, & Kinay, 2010). Benefits of contact with friends post-diagnosis include improving one's coping skills, receiving emotional and instrumental support, and increased opportunities for sharing health information (Chou, Stewart, Wild, & Bloom, 2012).

Formal support groups. Breast cancer support groups offer a very specific form of social support: being surrounded by individuals who understand the breast cancer

experience because they are also living through it (Park, Bae, Jung, & Kim, 2012). In a longitudinal study of newly diagnosed breast cancer patients, those who took part in a seven-day support group were more likely to have lower levels of anxiety at the two-month follow-up as compared with the control group (Bjorneklett, Lindemalm, Rosenblad, Ojutkangas, Letocha, Strang, Bergkvist, 2012). Support groups traditionally last longer than a week; additional studies might look at breast cancer patients' mental health after several weeks or months of support group participation. Another study examined breast cancer survivors' mental health following a year of psychoeducational support group participation (consisting of individual face-to-face education, health-coaching sessions via telephone, and small-group meetings). Those who took part in the program reported both a higher quality of life overall and higher emotional well-being (Park, Bae, Jung, & Kim, 2012). Additional studies that focus on such programs for patients receiving treatment would also be informative.

Papers that discussed group art therapy interventions for cancer patients listed such patient outcomes as self-expression, decreased anxiety, increased coping skills, and social intervention (Geue, Goetze, Buttstaedt, Kleinert, Richter, & Singer, 2010). Among cancer patients on chemotherapy who attended group watercolor painting classes, those who attended four or more classes had significantly lower levels of depression post-intervention (Bar-Sela, Atid, Danos, Gabay, & Epelbaum, 2007). Conversely, among a sample of newly diagnosed Stage I and Stage II breast cancer patients, taking part in creative arts therapy (pencils, pastels, acrylic paints and drawing/painting tablets) was not effective in increasing participants' emotional expression. However, it was effective in enhancing psychological well-being (Puig, Lee, Goodwin, & Sherrard, 2006).

Intrapersonal Resources

Spirituality. Spirituality is key in helping breast cancer patients cope with their diagnosis and treatment (Matthews, Tejada, Johnson, Berbaum, & Manfredi, 2012). The benefits of spirituality are numerous, including less mood disturbance and higher quality of life (Friedman, Barber, Chang, Tham, Kalidas, Rimawi, Dulay, & Elledge, 2010). Spiritual activities include prayer and attending church (Ashing-Giwa, Padilla, Bohorquez, Tejero, & Garcia, 2006; Levine, Aviv, Yoo, Ewing, & Au, 2009). Spirituality is a protective factor against anxiety among breast cancer patients (Janiszewska, Buss, de Walden-Galuszko, Majkowicz, Lichodziejewska-Niemierko, Modlinska, 2008) and against depression in general (Braun & Marghi, 2003).

African American breast cancer patients and survivors especially report spirituality as a coping mechanism (Gregg, 2011; Lewis, Sheng, Rhodes, Jackson, & Schover, 2012; Sheppard, Adams, Lamdan, & Taylor, 2011). Specifically, spirituality helps patients overcome their fear of death immediately following diagnosis (Ashing-Giwa & Ganz, 1997).

Complementary and alternative medicine. Breast cancer patients require care for the mental and emotional turbulence that they may experience during and following treatment (Dyson, Thompson, Palmer, Thomas, & Schofield, 2012; Seeman, Williams, & Simms, 2012). A growing movement toward integrative oncology incorporates mind-body therapy into traditional medical treatment (Elkins, Fisher, & Johnson, 2010). Complementary and alternative medicine (CAM) offers patients the opportunity to “go within” and bolster their intrapersonal resources, which leads to improved mental health (Beatty, Adams, Sibbritt, & Wade, 2012). Previous research has analyzed CAM therapies

for advanced cancer patients, including massage, acupuncture, meditation, yoga, spiritual healing, and prayer (Trinkaus, Burman, Barmala, Rodin, Jones, Lo, & Zimmermann, 2011, p. 747). CAM may even help individuals in their identity construction as cancer patients, as they make decisions about their biomedical treatment (Spadacio & Barros, 2008).

In a meta-analysis of 10 articles that examined health of yoga groups for cancer patients compared with waitlist control groups of cancer patients, the yoga groups showed significant improvement in psychological health (Lin, Hu, Chang, Lin, & Tsauo, 2011). Similarly, among a pilot study of female breast cancer patients and survivors, those in yoga groups were more likely to report improved mental health, positive affect, spirituality, and diminished depression, as compared with the waitlist control group (Danhauer, Mihalko, Russell, Campbell, Felder, Daley, & Levine, 2009). Both articles' results reflect that of a multiethnic sample of breast cancer patients who engaged in yoga classes: patients who did yoga reported a higher quality of life than patients who were in the waitlist control group (Moadel, Shah, Wylie-Rosett, Harris, Patel, Hall, & Sparano, 2007).

Health literacy. Health literacy is an intrapersonal resource because it is a measure of the individual's capacity to access, understand, and act upon health information. The Institution of Medicine (2004) defined health literacy as "[t]he degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (p. 1). Common threats to the patient's access to, and comprehension of, health information include inability to understand medical forms, perceptions about treatment, and not using the

same language as the medical team or forms (Hendren, Chin, Fisher, Winters, Griggs, Mohile, & Fiscella, 2011). While these threats are embedded in multiple social systems (as will be discussed in the theoretical framework, p. 26), they also lie in the patient's individual experience.

Health literacy is affected by the culture in which an individual is embedded (Williams, Mullan, & Todem, 2009). Culture includes the values, norms and behaviors of social systems including families, communities, and societies (Hofstede, 1997). A woman's culture impacts her search and receipt of health information, in that the culture shapes her "knowledge, attitudes, and personal practices, which affects [her] responses to health information" (Guidry, Fagan, & Walker, 1998, p. 166).

Health literacy is a key tool in reducing cancer disparities (Sulik, Cameron, & Chamberlain, 2012). Health literacy may also explain some breast cancer disparities (Polacek, Ramos, & Ferrer, 2007). For example, breast cancer outcomes are influenced by choice of treatment, types of treatment, level of understanding of treatment options, and emotions surrounding decision-making; health literacy is a determinant of these factors (Polacek, Ramos, & Ferrer, 2007).

Access to Health Care and Health Information

Many barriers potentially obstruct access to and use of detection and treatment services. Having prior negative experiences with professional care providers, lacking leave time from work or the ability to afford treatment, and not being able to travel to health care facilities all impact the likelihood of receiving medical treatment (Eng, Maxfield, Patrick, Deering, Ratzan, & Gustafson, 1998). This is true of health care in general and breast cancer specifically (Eng, Maxfield, Patrick, Deering, Ratzan, &

Gustafson, 1998; Scoggins, Fedorenko, Donahue, Buchwald, Blough, & Ramsey, 2012; Shinagawa, 2000). Physician-patient communication, perceptions of discrimination, patients' employment status, and geography all relate to patients' ability to access adequate health care and health information (Hutchinson, Thompson, & Cederbaum, 2006; Jackson, Davis, Waldron, McNeel, Pfeiffer, & Breen, 2009; Tamminga, de Boer, Verbeek, & Frings-Dresen, 2012). People who are less health literate have less access to adequate health care and health information (U.S. Department of Health and Human Services, 2010). Many of the determinants of health literacy also determine the quality of medical team-patient encounters (Rudd, 2010).

Physician-patient communication. Communication with physicians is critical to patients' well-being (Boehmer, Glickman, Milton, & Winter, 2012; Hutchinson, Thompson, & Cederbaum, 2006; Mravcak, 2006). Ability to communicate is especially necessary when making decisions about chemotherapy and surgery (Radina, Ginter, Brandt, Swaney, & Longo, 2011). Breast cancer patients report desiring more holistic conversations with their oncologists about the impact of the disease on other areas of their lives (Peate, Meiser, Hickey, & Friedlander, 2009).

African American breast cancer patients report receiving insufficient information about cancer terminology, their diagnoses, and subsequent treatment; they attributed this dearth to their medical teams failing to provide them with relevant information (Ashing-Giwa & Ganz, 1997). African American breast cancer patients have attributed their unhappiness with physicians to their own race or ethnicity, lack of health insurance, and the physicians' insensitivity (Ashing-Giwa & Ganz, 1997). African American breast

cancer patients reported severe displeasure with their surgeons, regardless of the surgeons' race or ethnicity (Ashing-Giwa & Ganz, 1997).

Perceptions of discrimination. Breast cancer patients have reported feeling discrimination because of their race, ethnicity, and sexual orientation (Ashing-Giwa & Ganz, 1997; Boehmer, Glickman, Milton, & Winter, 2012). Many African American breast cancer patients are concerned about racism within the health care system (Ashing-Giwa & Ganz, 1997; Ashing-Giwa, Padilla, Tejero, Kraemer, Wright, Coscarelli, Clayton, et al., 2004). Experienced discrimination includes internalized discrimination and group discrimination (Quach, Nuru-Jeter, Morris, Allen, Sherna, Winters, Le, et al., 2012). At the same time, African American breast cancer patients often feel it is safer to follow the oncologist's medical advice rather than researching their options independently (Ashing-Giwa & Ganz, 1997).

There is an association between discrimination experiences and SMW patients' worse physical health (Boehmer, Glickman, Milton, & Winter, 2012). These sexual orientation-based forms of discrimination include lack of medicolegal rights, the oncologist's uncertainty or discomfort acknowledging the patient's sexual orientation, and the intentional or unintentional exclusion of the patient's partner (Hutchinson, Thompson, & Cederbaum, 2006; Mravcak, 2006).

One systemic barrier to health care is the fear of disclosure about sexual orientation to physicians and oncologists (Brown & Tracy, 2008; DeHart, 2008). Having a good oncologist-patient relationship is key to feeling secure about disclosure and including one's partner in conversations with the oncologist (Boehmer & Case, 2006; Lauver, Karon, Egan, Jacobson, Nugent, Settersten, & Shaw, 1999).

Health information: seeking, processing, using. African American breast cancer patients report receiving insufficient health information, and young African American patients report a particular deficit in the receipt of information about infertility post-diagnosis (Lewis, Sheng, Rhodes, Jackson, & Schover, 2012). A diagnosis of cancer may feel like a death sentence, especially among individuals with lower incomes and less education who know people that had late or end-stage cancer and died soon after being diagnosed (Ashing-Giwa & Ganz, 1997). This fatalism is associated with less likelihood of early detection and pursuit of medical opinions for suspicious symptoms, which perpetuates the cycle of lower-SES women being diagnosed with breast cancer at later stages (Beeken, Simon, von Wagner, Whitaker, & Wardle, 2011). Other contributing factors to later-stage diagnoses among lower-SES women include affordability and accessibility, even among samples with full mammogram coverage (Halliday, Taira, Davis, & Chan, 2007). Based on this literature, it is possible that some lower SES women may be less likely to envision their lives as survivors because they believe they will probably die from breast cancer.

Socioeconomic status also plays a role in information-seeking behaviors. Cancer patients with low SES are less likely to seek health information or independently research their options (Protiere, Moumjid, Bouhnik, Soriano, & Moatti, 2012). If they are unhappy with their oncologists and do not feel capable of seeking health information independently, such a lack of self-efficacy may lead to decreased well-being (Bandura, 1998; Bandura, 2004; Deno, Tashiro, Miyashita, Asakage, Takahashi, Saito, Busujima, et al., 2012).

The principles of plain language dictate that patients must fully understand their medical team's directions (Kimble, 2002). This means that oral and written instructions should be unaffected, exclude any unnecessary details, and use comprehensible words (Kimble, 2002; Rudd, 2011). This corresponds with the fact of different types of health literacy. Among a sample of breast cancer patients, the majority were able to read written medical instructions provided to them, but fewer were able to understand and act upon the information (Cox, Bowmer, & Ring, 2011).

Employment during treatment. A thorough review of the literature yielded no articles on the social support that co-workers might offer breast cancer patients; existing literature regarding breast cancer patients' employers suggests that support from employers is a protective factor against concerns about continuing to work post-diagnosis and during treatment (Tamminga, de Boer, Verbeek, & Frings-Dresen, 2012). Most breast cancer patients, if employed, continue working during treatment or anticipate going back to work post-treatment, but they may face obstacles relating to their physical health (fatigue, nausea, and "chemo brain") or their work-related expectations post-diagnosis (Gallardo, Rey, & Peretti-Watel, 2012; Tamminga, de Boer, Verbeek, Frings-Dresen, & 2012). Support from supervisors and co-workers greatly impacts breast cancer patients' return-to-work process (Tamminga, de Boer, Verbeek, & Frings-Dresen, 2012). Employment status is linked to poorer quality of life among breast cancer patients (Salonen, Tarkka, Kellokumpu-Lehtinen, Koivisto, Astedt-Kurki, & Kaunonen, 2011).

Some patients choose not to disclose their diagnosis to supervisors or colleagues for fear of discrimination (Gallardo, Rey, & Peretti-Watel, 2012). In one study of African American breast cancer patients, participants had enough sick leave and vacation days

that they perceived no need in telling their employers about their diagnoses and thus risk discrimination (Ashing-Giwa & Ganz, 1997).

Geography. Geographic proximity to health care facilities indicates the likelihood of using preventive and detection services, such as mammography. Women in urban areas are more likely to get mammograms than women in rural areas (Jackson, Davis, Waldron, McNeel, Pfeiffer, & Breen, 2009). Thus it follows that women in rural areas are more likely to be diagnosed at later stages than women in urban areas (Baade, Turrell, & Aitken, 2011). Census tracts with predominantly African American populations have longer travel time to mammography facilities than tracts with other racial/ethnic populations (Peipins, Graham, Young, Lewis, Foster, Flanagan, & Dent, 2011). This association confirms that African American women are more likely to be diagnosed at later stages than white women (CDC, 2012; Joseph, Kaplan, Luce, Lee, Stewart, Guerra, & Pasick, 2012). Census tracts with low and middle SES families are more likely to illustrate African American health disparities in terms of later-stage breast cancer diagnoses and mortality rates (Tian, Wilson, & Zhan, 2011). Later stage at diagnosis for Medicaid breast cancer patients is associated with travel burden (Scoggins, Fedorenko, Donahue, Buchwald, Blough, & Ramsey, 2012).

Travel time to health facilities is associated with type of treatment; women who live farther away from facilities are more likely to select mastectomy over a breast-conserving surgery (Onega, Cook, Kirlin, Shi, Alford-Teaster, Tuzzio, & Buist, 2011). This suggests that if travel time is a concern, women might opt for services requiring fewer visits (Onega, Cook, Kirlin, Shi, Alford-Teaster, Tuzzio, & Buist, 2011).

Lymphedema

When women undergo mastectomies and surgical removal of underarm lymph tissue, they may experience lymphedema, the blockage of lymph passages (U.S. National Library of Medicine, 2010). This results in chronic and often painful swelling of the arm as well as skin breakdown (U.S. National Library of Medicine, 2010). Lymphedema is a source of pain and can limit one's daily activities; it is a known contributor to decreased well-being for breast cancer patients (Heiney, McWayne, Cunningham, Hazlett, Parrish, Bryant, Vitoc, et al., 2007). Arm symptoms – including lymphedema – are associated with higher levels of depression and anxiety among breast cancer patients (Karakoyun-Celik, Gorken, Sahin, Orcin, Alanyali, & Kinay, 2010). Lymphedema can discourage patients from participating in family leisure activities (Radina, 2009). African American breast cancer patients and survivors experience lymphedema more than white breast cancer patients and survivors (Morehead-Gee, Pfalzer, Levy, McGarvey, Springer, Soballe, Gerber, et al., 2012).

Making Meaning of Relationship Status

Although “single” is frequently used as an umbrella term to describe people without partners, there are in fact several types of single: ever-single, divorced, and widowed (Lahad, 2012). These variations of relationship status invite different contextual explanations for women's current life experiences (Lahad, 2012). The experience of singlehood differs by race, ethnicity, age, and gender (Lahad, 2012).

Among a sample of single women, white women were more likely to explain their relationship status by personal fault rather than structural issues as compared with African American women (Tucker & Mitchell-Kernan, 1998). As single women age, they

report an increased awareness of their changing social world (including the diminished pool of eligible partners) and acknowledge feeling displaced in their families, particularly if other relatives their age are married (Sharp & Ganong, 2011). While they may still hope for a long-term partner, ever-single women simultaneously grieve for the absence of a partner and children and the fact that their families have decreased interest in their romantic lives (Sharp & Ganong, 2011). Older and divorced women are more likely to adjust to their single status as compared with younger or ever-single women (Allen, 1989; Lewis & Moon, 1997).

These feelings may be indicative of *singlism*, which is a form of discrimination against single people (DePaulo & Morris, 2005). Singlism is a reflection of our society's ideology that promotes couples and marriage over singles "in everyday thoughts, interactions, laws, and social policies" (Sharp & Ganong, 2011, p. 957). Upon reviewing recent U.S. Census data as well as literature on single women, Sharp and Ganong (2011) posit:

The demographic shifts in women's marital and childbearing patterns suggest that individual life pathways are acceptable but, at the same time, women remain restricted (and face stigma and discrimination) in a society that promotes marriage and motherhood as central to women's identities. (p. 958)

Thus, despite growing numbers of women without partners in the United States (U.S. Census Bureau, 2012), these women may still face covert discrimination owing to their single status.

Theoretical Framework

We can think about the process of shaping a research project like a cascading stream.... Epistemology is the source that ultimately gives direction to the path of inquiry. The second level of the cascade is to consider the way that scientific paradigms steer the course of the flow. Third, assumptions and concepts from theories give direction to the movement of ideas. At the fourth level, methodology outlines the procedural assumptions as they are determined by epistemology, paradigms, and theory. Methods are the most specific and tangible level of the cascade and refer to the techniques we use in data collection. The stream ultimately spills into a collected pool that we can think of as the data that come together as a result of this process. (Daly, 2007, p. 21-22).

Epistemology

Of the two epistemological positions, objectivism and subjectivism, the former stipulates that there is one known reality, and it is the scientist's responsibility to "explain that reality without influencing it" (Daly, 2007, p. 23). This is also known as science through the one-way mirror (Guba & Lincoln, 1994). The latter, subjectivism, is based on the concept that there are multiple realities and no objectivity, because the researcher is constantly "shaping the direction and outcome of the inquiry" (Daly, 2007, p. 23). For the purpose of this dissertation, I used a subjective epistemological position. The participants and I possess multiple realities, and I acknowledge that I impacted the investigation.

Paradigm

I employed a social constructivist approach for this study. This approach acknowledges that there are multiple realities: those created by the participants and those

created by the researchers. There is no one reality. Social constructionism lends itself well to subjectivism. Daly (2007) states:

When the object of discovery is human action in social contexts, interpretive induction is concerned with two layers of meaning: the meanings that are held and communicated to researchers by their subjects concerning their everyday lives, experiences, and perceptions, and the meanings that researchers bring to these meanings as they endeavor to understand, explain, and theorize about these everyday realities. (p. 49)

As I will explain in my section on reflexivity, as the researcher, I possess my own reality through which I filtered my participants' words and explanations. I needed to be cognizant of this filter and frequently acknowledge that my own beliefs as a researcher and experiences with cancer might have impacted how I heard my participants. I was interested in learning how my participants made sense of the events in their lives. This "making sense" is part of social constructionism (Daly, 2007), and because it is a different process for each participant, it contributes to the multiple realities. Health promotion and education theoretical frameworks are derived chiefly from constructivist paradigms, as is phenomenology (Glanz, Lewis, & Rimer, 1997). Social constructionism is one of the leading paradigms for studying health communication, as it focuses on the lived experience of patients (Sharf & Vanderford, 2003).

Theory: Ecological Systems Framework

Theories are helpful when trying to understand the phenomena of social interactions because they offer a larger explanation for individuals' actions and rationalizations, and when a topic has little existing information, theories may be used to

supplement what is already known. This is especially true in the present case in which no empirical attention has thus far been paid to this phenomenon. A family theory that may offer a broad understanding of the impact of the social environment on the breast cancer patient is ecological systems theory. This framework is based on the concept that individuals live in four types of nested environmental systems and that there are bidirectional influences within and between systems (Bronfenbrenner, 1979). Additional assumptions of ecological systems theory include: humans are social and need to interact with other humans, we can understand human behavior on multiple levels, and when the environment is no longer supportive, humans must adapt (White & Klein, 2008). Ecological systems theory requires us to consider family factors and contextual factors simultaneously (Bengston, Acock, Allen, Dilworth-Anderson, & Klein, 2005). Ecological systems theory and phenomenology (the guiding methodology) may work together to explain participants' lived experiences within their nested systems (Spencer, 2007).

Nested systems. Individuals do not live in isolation; rather they are constantly interacting with their microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 1979). The *microsystem* consists of individuals and institutions that either directly affect the breast cancer patient or with which she is directly associated. (These include the patient's family, friends and associates, her job and co-workers, religious institution, and her medical team [oncologist, surgeon, radiologist, and nurses]). The size of the microsystem changes as people take up and end life roles (Berk, 2007). Thus, an individual's microsystem might expand post-diagnosis, because it will include hospitals and new medical teams. The *mesosystem* is made up of the relationships between microsystems. The mesosystem includes relationships between family

experiences and job experiences, church experiences and hospital experiences, and hospital experiences and job experiences, and so forth. For example, if the patient's family had bad experiences with physicians, those experiences are likely to influence how a woman in that family interacted with her medical care providers. Likewise, if chemotherapy treatments leave the patient feeling fatigued, then she might have had to take time off work. That time off might affect her work environment or her relationships with colleagues.

The *exosystem* refers to links between social settings in which the patient is and is not directly a part. For example, hospital policy (which is created by administrators and policymakers) might dictate that the medical team asks whether the patient has a supportive family that can accompany her to treatments. In asking this question, the medical team might learn that the patient does not have anyone to accompany her, and so they will put her in contact with Nurse Navigators for additional support. Hospital administration is not a setting that the patient is part of, but she has been impacted by the administration's policies.

The *macrosystem* is the culture in which the patient resides. The cultural context includes the socioeconomic status, race, and ethnicity of its members; federal policies on health insurance; and groups' tendencies to watch out for their members.

Interpersonal relationships. Another assumption of ecological systems theory is that there are bidirectional influences between people and their systems (White & Klein, 2008). This is very evident in the breast cancer patient's experience. The patient relies on her medical team to provide her with the best medical care possible. Exceptional care includes achieving social concordance with one's patients (Thornton, Powe, Roter, &

Cooper, 2011). The patient must also rely on her social environment (family, friends, and co-workers) to provide her with emotional and instrumental support during her diagnosis and treatment (Kroenke, Michael, Tindle, Gage, Chlebowski, Garcia, Messina, et al., 2012). Emotional support includes words of encouragement, listening to the patient talk about her concerns and fears, and validating the patient's thoughts. Instrumental support includes driving the patient to and from treatment, making meals for the patient and her family, and (for the co-worker) taking on a project so that the patient's workload is lessened (Bloom, Stewart, Johnston, Banks, & Fobair, 2011).

When a woman is diagnosed with breast cancer, this disease and the treatment for it will become very much a part of her environment: hospital visits, doctor's appointments, medical jargon, and discussions of recovery and survivorship will permeate her life (Pereira, Brito, & Smith, 2012). As stated earlier in the literature review, a breast cancer diagnosis has a large impact on a woman's interpersonal relationships. For example, she may seek deeper connections with her family and friends, or she may find that negative reactions to her diagnosis lead to faltering relationships. Requiring time off from work for surgical and medical procedures may impact her relationships with supervisors and co-workers. In turn, the woman's interpersonal relationships will likely affect those appointments and medical discussions. There is a constant give-and-take between individuals or families and their surrounding systems. Bronfenbrenner (1979) explained: "When one member of a dyad undergoes developmental change, the other member will also undergo change" (p. 65). The necessity of change is another form of adaptation.

Adaptation. Adaptation is a critical component of the ecological systems framework (White & Klein, 2008). When the system is perceived to be inadequate, then the individual or family must adapt (Radina, Ginter, Brandt, Swaney, & Longo, 2011). Methods of patient adaptation include changing and enhancing personal environments (i.e., eliminating unsupportive individuals or including new individuals or groups of people that are supportive, such as a cancer support group) (Erci, 2007). In turn, members of those environments must respond to the adaptations. Another example of bi-directional influences occurs when oncologists receive feedback from patients about their needs; oncologists must adapt their behavior in order to adequately communicate with them (Rottmann, Helmes, & Vogel, 2010).

Ecological systems theory also applies to this study because previous research indicates that members of the medical team, which becomes an important component of the patient's microsystem, must be vigilant in talking with their breast cancer patients about the patient's relationships; otherwise they may make incorrect assumptions about the patient's support systems (NCI, 2012). Thus, although the medical team's primary concern is treating the patient's breast cancer, it would also be extremely beneficial to inquire about the patient's ability to rely on family and friends for instrumental and emotional support, because these things could in turn affect the patient's ability to understand and act on the information that the medical team is providing. Similarly, members of the medical team may inadvertently ignore the patient's personal life goals and values in their focus on the patient's breast health. Aspects of the patient's psychological and interpersonal life must also be acknowledged.

By fully understanding the patient's perspective on her illness, the medical team will be better equipped to offer additional information and resources that will improve the patient's health and overall quality of life (Thornton, Powe, Roter, & Cooper, 2011). However, many health care providers are not having these important conversations with their patients, and for one overarching reason: it is not considered a priority by the larger health care system. "Since individual health care practitioners are trained within the existing health care system, the culture, norms, and biases of the traditional health care system are major influences across all levels" (Hutchinson, Thompson, & Cederbaum, 2006, p. 394). Moreover, the health care system is influenced by societal contexts. This exemplifies the impact of the exosystem and the macrosystem on the breast cancer patient.

Theory: Health Promotion Perspective

Another perspective that may help explain the impact of the social environment on breast cancer patients is health promotion and education. This discipline uses multiple theoretical frameworks that explain and predict individuals' health behavior and attempt "to transform knowledge about behavior into useful strategies for health enhancement" (Glanz, Lewis, & Rimer, 1997, p. 20). This behavioral perspective, similar to the family science perspective of ecological systems, highlights the significance of the social environment (Glanz, Lewis, & Rimer, 1997; Stokols, 1992). There are four primary assumptions in the integration of ecological systems and health promotion (Glanz, Lewis, & Rimer, 1997):

1. Health is likely to be influenced by multiple facets of the physical and social environments but that the role of personal attributes is also acknowledged

2. Environments are complex, and efforts to understand environmental effects on health must take into consideration environments' multiple dimensions
3. Participants in environments can be described at varying levels of aggregation: individuals, families, organizations, communities, and populations
4. There are multiple levels of feedback across different levels of environments and aggregates of persons (Glanz, Lewis, & Rimer, 1997, p. 409)

For the purpose of this study, the two disciplinary approaches to all four levels of environments or systems will be examined. The microsystem and mesosystem will be examined in the most detail.

Health promotion and education is interested in the social environment, which comprises individuals' social networks and social support. Different network members will provide varying levels of support, with family members more likely to provide long-term assistance and friends and neighbors more likely to provide short-term assistance (Glanz, Lewis, & Rimer, 1997). Developing new social network linkages may be necessary when "the existing network is small, overburdened, or unable to mobilize for the provision of effective support" (Glanz, Lewis, & Rimer, 1997, p. 193). Well-known examples include Alcoholics Anonymous, but this is also evident in breast cancer patients' need to interact with other patients (Bjorneklett, Lindemalm, Rosenblad, Ojutkangas, Letocha, Strang, Bergkvist, 2012). Patients can relate to each other's frustrations and concerns better than non-patients ("empathetic understanding," Thoits, 1986).

Health promotion and education contains the following concepts for social network and social support. These are similar to the family science perspective on ecological systems:

Table 2. Types and Characteristics of Social Networks and Social Support
Glanz, Lewis, & Rimer (1997)

Concepts	Definitions
Social network	A person-centered web of social relationships
<i>Selected social network characteristics:</i>	
Reciprocity	Extent to which resources and support are both given and received in a relationship
Intensity	Extent to which social relationships offer emotional closeness
Complexity	Extent to which social relationships serve many functions
Density	Extent to which network members know and interact with each other
Social support	Aid and assistance exchanged through social relationships and interpersonal transactions
<i>Types of social support:</i>	
Emotional support	Expressions of empathy, love, trust and caring
Instrumental support	Tangible aid and service
Informational support	Advice, suggestions, and information
Appraisal support	Information that is useful for self-evaluation

Ecological systems theory is applicable to several social science and public health fields. Simultaneously applying the family science and health promotion and education perspectives provides an opportunity to bridge the gap between family science and public health, which is necessary if we want to fully understand the lived experience of breast

cancer patients without partners. The selected social network characteristics in Table 2 helped guide creation of research and protocol questions about the support that participants did or did not receive from their social environment.

Figure 1 depicts the researcher's model of ecological systems theory and social support. Participants' lived experiences were impacted by four nested models: the *microsystem*, which comprises patients, characteristics of their social networks, and the patients' intrapersonal resources; the *mesosystem*, which includes patients' interpersonal resources as well as their families' previous health experiences; the *exosystem*, which consists of hospital policies and work policies; and finally the *macrosystem*, which frames patients' access to health information and health disparities. The research questions and protocol questions were framed to yield more information about participants' perspectives on their lived experiences within these systems.

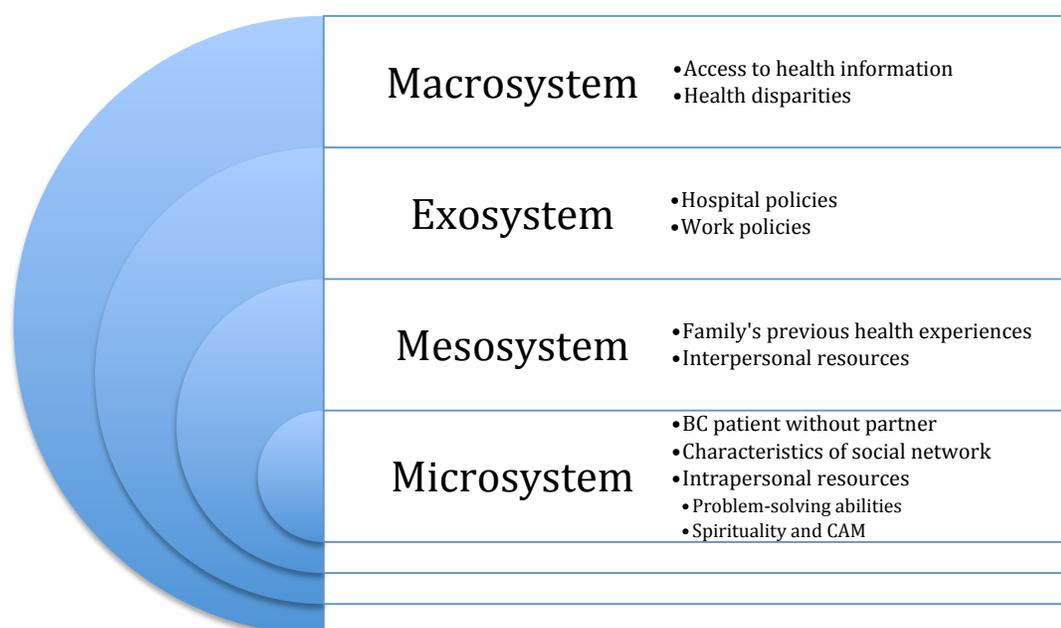


Figure 1 Ecological Systems and Social Support Model

Rationale for This Study

This study examined the experiences of breast cancer patients without partners through the perspectives of ecological systems theory and health promotion. To date, academic literature concerning breast cancer and the family has primarily focused on patients with partners. Although some studies indicate differences in utilization of detection services between breast cancer patients with and without partners, there is a gap in the literature concerning the lived experience of patients without partners. Likewise, although there are no data on how breast cancer patients without partners access health information, relationship status health disparities exist among breast cancer patients. The next step is to understand what created those disparities; this was made possible by asking patients how they obtained and used health information and what barriers they might have perceived to getting that information. Previously there was no empirical understanding of how patients without partners access existing supportive networks or create new networks, how they obtain and use health information, or how they make meaning of their relationship status within the context of their illness.

The purpose of this qualitative dissertation was to examine how women without partners navigated their breast cancer diagnoses, treatment, recovery, and survivorship. By developing an understanding of interpersonal relationships these women rely on (immediate or extended family members, breast cancer support organizations, friends), family and health professionals will have a better concept of the coping mechanisms employed by patients without partners. By learning how these women made meaning of their relationship status within the context of their cancer experience, family scientists

will have a more comprehensive understanding of the role of relationship status – including any meaning attributed to it – by people facing serious health issues. This study was designed to provide missing information needed to improve understanding by patients’ medical teams.

Research Questions

1. Do breast cancer patients adapt or create social networks to cope with the fears and frustrations of diagnosis and treatment? If so, how?
2. What types of social support (informational, emotional, instrumental, appraisal) do breast cancer patients desire?
3. Do breast cancer patients perceive difficulty in accessing health information?
4. Do breast cancer patients perceive difficulty in communicating with their professional care providers? If so, how?
5. What does it mean to breast cancer patients to not have partners during diagnosis and treatment?
6. How do the experiences of breast cancer patients without partners vary qualitatively by race, ethnicity, socioeconomic status, and health literacy?

Chapter 3: Method

Participants

Twenty participants were recruited for this study. This was the number at which saturation was reached. Saturation occurs when enough data have been collected that more data do not shed additional light on the topic under investigation (Glaser & Strauss, 1967). In one popular sampling technique, *sampling for range*, the researcher identifies the sample's sub-groups and attempts to collect data evenly from individuals that belong to those groups (Small, 2009). The subgroups for this study included 10 Caucasians, nine African Americans, and one Indian American woman. The former two groups are the largest racial/ethnic groups in the United States.

To be eligible for participation, individuals must have been over the age of 18, unpartnered at the time of diagnosis and treatment, and have been treated for breast cancer in the last five years. The rationale for these inclusion criteria was that individuals who had not been treated for breast cancer recently might have forgotten some of their experiences. Not only was sampling done for range, but snowball sampling was also used within those groups. Snowballing expands the sample by asking participants to recommend other potential participants that share the same racial, ethnic, or socioeconomic background (Small, 2009).

Recruitment. Breast cancer patients without partners were recruited through electronic mailing lists and by posting announcements (Appendix A) on discussion boards on internet-based support groups for breast cancer patients. Such online organizations include breastcancer.org and the Susan G. Komen page on Facebook. Permission was obtained from website hosts before posting announcements about the

study. Liaisons from the Montgomery County and Regional Breast Health Initiatives, the Breast Health Quality Consortium, and the Primary Care Coalition of Montgomery County (all located in Maryland) distributed the announcement to their listservs. Finally, the researcher recruited from among participants in a spring 2012 study of breast cancer patients using CAM; this study was also conducted by the researcher. These patients were contacted with information about this study to determine whether they were willing and able to participate. The researcher's contact information appeared on all study announcements and fliers. The University of Maryland IRB granted approval for this study (373050-1).

Initial recruitment efforts procured several Caucasian participants and one Indian American participant. To ensure even numbers of African American and Caucasian participants, I also recruited from African American-specific breast cancer support organizations (both local and national). After explaining the purpose of this study and my reasoning for recruiting African American participants, organization leaders agreed to share my study information. From those organizations, I recruited all nine African American participants.

Potential participants who contacted the researcher completed a short screening survey to ensure that they were eligible for the study (over the age of 18, were treated for breast cancer within the last five years, and did not have partners at the time of diagnosis and treatment). They were asked to self-identify their race/ethnicity, education level, age, year of breast cancer diagnosis, partnership status at the time of diagnosis and treatment, and income using a standardized range. Participants were entered into a raffle for a \$50 gift card to Target. After all interviews were conducted, a winner was drawn.

Interviews

Participants took part in face-to-face or telephone interviews conducted by the researcher. The interviews lasted approximately 75 minutes. The interviews were semi-structured and included measures of health literacy, health status, spirituality, and demographic information. The protocol was constructed using principles of plain language to increase the likelihood that the sample participants would understand the words and meaning of the questions. The interviews were conversational in nature, allowing the participant to guide the interview. If a participant did not initiate all topics outlined in the interview guide, the interviewer asked questions in the protocol to ensure that these topics were addressed and probed. Each interview was digitally recorded and transcribed by the researcher prior to data analysis.

Pilot study. The instrument and interview protocol were pilot-tested with three women to determine adequacy of instruments, assess whether the protocol questions made sense to participants, and gain participants' feedback about the structure and organization of the instruments and protocol questions. After conducting the pilot study, the researcher made revisions as necessary to instruments and protocol before sample interviewing began. The only major revision was to include questions about participants' pets.

Descriptive Analysis

Quantitative data regarding participants' age, years since diagnosis, education, income, and measures of spirituality, health literacy, and satisfaction with the medical team were collected and analyzed using SPSS (Appendix F). Only range, central tendency, and dispersion were analyzed and reported, as the sample size did not contain enough power to conduct bivariate analyses.

Methodology

Phenomenology is a method for investigating the “lived experience” of people in a study “from the standpoint of a concept or phenomenon” (Schram, 2006, p. 98). This study used phenomenology as the method for understanding how women without partners navigate their breast cancer diagnoses, treatment, and recovery. The concept of lived experience comes from the German word *erlebnis*: “experience as we live through it and recognize it as a particular type of experience” (Adams & van Manen, 2008, p. 616). Phenomenology focuses on how humans explore their world. Phenomenology lends itself to qualitative methods because the researcher is gathering experiential material (Adams & van Manen, 2008, p. 618). Although the lived experience is unique to every individual, the researcher ought to be able to “convey a meaning that is fundamental to the experience no matter which specific individual has had that experience” (Schram, 2008, p. 99). There should be an essential structure of the concept (breast cancer experiences of women without partners) that allows for individuals’ varying perspectives (Creswell, 1998).

Phenomenology includes two primary concepts:

Epoché— the researcher’s ability to bracket all judgments and preconceptions about the participants’ world until he has a better understanding of their world (Schram, 2008). This corresponds to social constructionism (Daly, 2007).

Life-world— the participants’ conscious experience of daily living, common activities, and interpersonal relationships. Phenomenologists are interested in describing participants’ life-worlds (Schram, 2008).

As discussed in the recruitment section, when potential participants contacted the researcher, a short screening took place. Screening for relationship status and breast cancer diagnosis was especially important, as phenomenology dictates that participants must have experienced the phenomenon under focus (being a breast cancer patient without a partner) and be able to discuss their experiences (Creswell, 1998).

Interviews were conducted with participants to determine how they faced, have been affected by, and discuss their breast cancer experiences and what those experiences have meant in the context of their relationship status. The research questions asked participants to describe their lived experiences (Creswell, 1998). Through analysis of the interview, the researcher sought meaning in the participants' experiences. The researcher's actions constitute the "basic tenets" of phenomenology (meeting, learning, discussing and understanding; Schram, 2006, p. 100). First the researcher entered the participants' field of perceptions; next the researcher learned how participants "experience, live, and describe" the phenomenon (p. 100); and then the researcher uncovered the meaning of these experiences and descriptions (Creswell, 1998). The process of meaning-making is described below.

Thematic analysis. After transcribing an interview, the researcher read it in its entirety and made note of participants' statements about experiencing the phenomenon (Table 3, Stage 1-IP). This inductive thematic analysis is often used in phenomenological research to find common threads indicated by the data (Creswell, 1998). Braun and Clark (2006) define thematic analysis as "a method for identifying, analyzing and reporting patterns (themes) within data. It minimally organizes and describes your data set in (rich) detail. However, frequently it goes further than this, and interprets various aspects of the

research topic” (p. 79). The researcher reviewed the transcripts multiple times for a deeper understanding of the data (Stage 2-IP).

After reading these responses several times, the researcher noted identifiable themes or “meaning units” (Creswell, 1998, p. 150) (Stage 1-CC). Braun and Clarke (2006) state that “an account of themes ‘emerging’ or being ‘discovered’ is a passive account of the process of analysis, and it denies the *active* role the researcher always plays in identifying patterns/themes, selecting which are of interest, and reporting them to the readers” (p. 82). These themes did not appear suddenly; it took time and studying the data sets to understand the patterns that were found. It was crucial to recognize the varying nuances in every participant’s voice, the words she chooses to explain her interpersonal relationships (“best friend,” “very close,” “more than a mom”), and what she herself deemed important.

For a pattern to constitute a theme, there had to be substantial data from multiple participants. Word repetition, similarity in descriptions of experiences, and noting what participants did *not* say all contributed to the thematic analysis. In qualitative methodology, it is accepted that a theme does not have to be present among *all* participants, but there should be multiple pieces of rich data across the sample (Braun & Clarke, 2006). (Rich data offers a “deep and detailed picture” that fully describes the lived experience; Wood & Welch, 2010, p. 56.)

After the researcher cataloged patterns into themes, they were shared with peer debriefers. The peer debriefers were three doctoral students trained in qualitative methodology, social science, and public health. The peer debriefers read the sections of transcripts and the analysis to offer alternative interpretations (Stage 2-CC). Then the

researcher conducted member checks with some participants (Stage 3-CC).² In this way both depth and breadth of analysis of themes were achieved (Lincoln & Guba, 1985). After verifying with participants that these themes represented their descriptions of their lived experiences, the researcher developed a final codebook (Stage 4-CC).

After creating the final codebook, the researcher read literature related to the patterns (Stage 1-BA) and then formed an overall description of the concept and the essence of the phenomenon (Creswell, 1998) (Stage 2-BA). The phenomenon under investigation was the experiences of female breast cancer patients without partners. Ultimately, readers of this study should be able to say, “I understand better what it is like for someone to experience that” (Polkinghorne, 1989, p. 46). Table 3 describes these stages.

Table 3
Data Analysis Plan

Initial Patterns (IP)

Stage 1-IP: Create initial codebook using participants’ statements about their experiences

Stage 2-IP: Identify data that relate to these patterns

Combine and Catalog (CC)

Stage 1-CC: Catalog patterns into sub-themes

Stage 2-CC: Share patterns with peer debriefers

Stage 3-CC: Conduct member checks

Stage 4-CC: Develop final codebook

Build Argument (BA)

Stage 1-BA: Read related literature

Stage 2-BA: Develop storyline

² Member check criteria included being representative of race and cancer stage, having developed rapport with that participant during the interview, the participant’s interview containing rich data, and the participant agreeing to participate in a member check.

Researcher's Personal Motivations and Reflections

This dissertation research focuses on female breast cancer patients without partners living in the United States. For the past five years I have conducted qualitative research on breast cancer patients' experiences during their diagnoses, treatment, and recovery stages. I have also researched the lived experiences of patients' partners and family members. In the spring of 2012, I researched how breast cancer patients utilize complementary and alternative medicine in conjunction with their biomedical treatment. During that time I formed partnerships with the directors of two cancer support organizations in the Washington, D.C., metropolis. From that study, I unexpectedly discovered new information about the experiences of unpartnered patients (e.g., divorced or single at the time of the diagnosis and treatment). My intent was to further explore what it means to be a breast cancer patient without a partner.

In the following section, I will discuss my personal reflections and intent to acknowledge my values. I will discuss potential threats to the trustworthiness of my findings as well as procedures that I employed to ensure these data and findings meet appropriate standards of quality and rigor as a way of acknowledging that no research is value free (Morrow, 2005). These standards are considered equivalent in many ways to the standards set out in quantitative research: objectivity, internal and external validity, and reliability (Guba & Lincoln, 1994).

Personal reflections. It is imperative in qualitative research that the researcher recognizes any personal biases that may be relevant to the work and acknowledges that the researcher is the research instrument in the collection and analysis of data. Thus, I

have provided a brief description of my personal experiences with issues related to breast cancer and family illness so that I may best represent myself as the research instrument.

My paternal grandmother was diagnosed with breast cancer when I was thirteen years old. I am aware of my slightly heightened risk for developing breast cancer, and since beginning my breast cancer research I have thought more about my grandmother's experience and the need to be open to those personal thoughts. Second, within the last four years, I have been made aware of two other family members' cancer diagnoses (not breast cancer). Having researched how an individual's chronic illness affects family members, I am aware of decisions and changes I have made based on this information.

Data Quality

The first criterion of trustworthiness is confirmability or objectivity. This criterion is associated with the view that while research is never objective, the research findings should convey adequate measures to attempt neutrality. When working with qualitative data, the researcher must maintain as much objectivity as possible. As the principal investigator, I inherently filtered all data through my experiences, and I had to remain aware that this research project was subjective and that my personal experiences might have influenced my participants and findings (Morrow, 2005). To keep my personal experiences from unduly influencing my research and, specifically, my analyses of my interviews, I maintained several memos during my data collection and analyses processes. It was a way to acknowledge how I was feeling and to track those feelings. I was open to the possibility that I might become subjective and I was prepared to talk with my dissertation chair to devise ways of maintaining objectivity.

Credibility or internal validity is ensuring that the researcher has portrayed the multiple realities of the participants' experiences (Morrow, 2005). Morrow stated: "Credibility can be achieved by prolonged engagement with participants; persistent observation in the field; the use of peer debriefers or peer researchers; negative case analysis; researcher reflexivity; and participant checks, validation, or coanalysis" (Morrow, 2005, p. 252). I achieved credibility by establishing rapport with the participants prior to the interview, by keeping a journal of my experiences and thoughts throughout the collection and analysis of my data (researcher reflexivity), by conducting member checks, and finally by sharing my experiences, perceptions, and concerns with my dissertation chair and peer debriefers.

Dependability or reliability refers to the consistency with which the data are collected throughout the study (Morrow, 2005). To demonstrate this I maintained journals, logs, and auditable records so that the specific research processes could be scrutinized. The journal of experiences and thoughts regarding data collection and analysis served as a record of my research procedures. I also met regularly with my dissertation chair, who served as auditor regarding the dependability of my research processes. If any ethical issues had arisen, I would have met with her.

Transferability or external validity refers to the extent that the findings are generalizable from one study to other contexts or situations by the reader (Morrow, 2005). Unlike more positivist standards of rigor that focus on the researchers having offered generalizations from their findings (Hoepfl, 1997), transferability in qualitative research refers to the reader's ability to make generalizations from the findings. According to qualitative research philosophy, it is not the researcher's role in qualitative

studies to tell future researchers whether the findings could transfer to their own research. Thus, in qualitative research, the goal of transferability is to provide a description detailed enough so that others may decide for themselves. At the same time, the description cannot be so detailed that it breaches confidentiality. I provided a rich description of research procedures and participants and presented sufficient evidence of themes and subthemes through exemplar quotes found within the data.

There are five questions about data quality that must be asked of phenomenological studies specifically:

1. Did the interviewer influence the contents of the subjects' descriptions in such a way that the descriptions do not truly reflect the subjects' actual experience?
2. Is the transcription accurate, and does it convey the meaning of the oral presentation in the interview?
3. In the analysis of the transcriptions, were there conclusions other than those offered by the researcher that could have been derived? Has the researcher identified these alternatives?
4. Is it possible to go from the general structure description to the transcriptions and to account for the specific contents and connections in the original examples of the experience?
5. Is the structural description specific, or does it hold in general for the experience in other situations? (Moustakas, 1994, p. 57)

By using member checks and peer debriefing, I ensured that my conclusions were well-founded (Lincoln & Guba, 1985). After conducting interviews, I asked participants if I might later contact them with my analysis of their words. After sharing the analysis

with them, they confirmed that what I had written clearly reflected their lived experiences. Member checks are the “most critical technique for establishing credibility” (Lincoln & Guba, 1985, p. 314). I also shared sections of transcripts and analysis with three peer debriefers. They helped determine whether my conclusions were plausible. The peer debriefers and I maintained written accounts of our sessions. The peer debriefers offered useful feedback concerning my thematic analysis.

Chapter IV: Results

Twenty women were interviewed for this study. The age range was 36 to 70, with the average age being 52.15 (SD = 8.1). Ten participants self-reported as Caucasian; nine as African American, and one as Indian American. Nineteen self-identified as heterosexual; one as bisexual. At the time of the interviews, eleven had never been married or in a domestic partnership; nine were divorced; and one was in a relationship. All twenty participants were single and had health insurance throughout treatment. The sample was well-educated, with 75% possessing college degrees and 50% possessing graduate degrees. Time since diagnosis ranged from 7 to 92 months, with the median time being 24 months ($\mu = 32.1$, $SD = 21.9$). Eight participants experienced lymphedema; twelve did not. (See Appendix F for more information.)

Ten predominant themes emerged from the interviews: initial reaction to diagnosis, stressful personal backgrounds, relationships within social networks, support from social networks, medical treatment, relationship status in the context of breast cancer, resources for coping, meditative and holistic care, barriers to care and treatment, and advice for patients and providers. This chapter will explore these themes in depth. To protect the participants, all names were changed to pseudonyms.

Initial Reaction to Diagnosis

Participants talked about being initially very surprised by their diagnoses, since they were otherwise healthy. Six women explained that they had known they had fibrocystic breasts and had found suspicious lumps in the past; because the lumps had never been cancerous before, they were surprised to be diagnosed now. Paula said: “I was frankly shocked to find out that it was breast cancer. I had had two biopsies previously and they were fibrocystic... so I was very, very surprised.”

After being diagnosed, Margaret questioned some medical information she had received ten years prior:

I said, "Hey!" On the same breast, in the same area, maybe about ten years ago, I had a biopsy done, and a mammogram, and they saw something light on the x-ray, and they did a biopsy, and it wasn't – it was not cancerous. So I still had to take the medication Tamoxifen for five years, and I started seeing the oncologist. And when I started seeing him, I started to think back, because when I had the biopsy, the tissue biopsy, and I kind of connected the two, and I said, "Wow. I had a tissue biopsy of the same area ten years ago, but it wasn't cancer. I had cancer in that same spot." So you know, you think about those things.

Elizabeth tied her diagnosis to her relationship status: "I found the lump myself, actually about four months before I ended up going to the doctor, and I do think that's relevant to being single, because I felt like I didn't pick up on what the lump was for a really long time, because how could I – how could I figure it out?"

Difficulty processing information. Participants described the initial hours and days following their diagnoses as fog-like. They were stunned to learn that they had breast cancer. Phyllis said: "After you hear 'cancer,' you almost go kind of brain dead. Like, 'What? Can you say that again? Really? Is this real?'"

It was also difficult to understand all of the medical information and terminology used by their medical teams. Elaine recalled: "I needed to try to understand it, because the medical people were just pushing everything so fast, their words were so fast, so fear-based: 'Well, you have to do this!'" Camille admitted, "You're sort of like, body there, but mind/soul somewhere else, and when you get all the information, you kind of miss a

lot of things. I'm catching my breath now, but this is after the fact." Louise simply stated: "When [you get the news], you don't really hear anything, you're still sitting there oblivious."

Stressful Personal Backgrounds

Half of the women were going through divorces or break-ups at the time of diagnosis. Fourteen women discussed how stressed they had felt even prior to their diagnoses (generally attributing that stress to their intimate relationships or their jobs); some wondered if stress had caused their breast cancer. Participants often referred to feeling "burnt out" at work prior to their diagnoses. Kara remembered: "I was under a lot of stress. I had finished a masters in public health in 11 months while working full time... And I worked a lot. So part of me wonders if that triggered something, because I was under a lo-o-o-o-t of stress."

Ten participants were divorced at the time of their diagnoses. Phyllis said about the dissolution of her marriage:

I had gone through a divorce. We were already separated, but I decided to initiate and go ahead and file the papers and all that stuff. I had quite a bit [laughing] going on. ... We got that done and it's like, soon after that I was divorced and I went to the doctor and had breast cancer. [Laughs] So it was weird.

Some participants talked about the amalgamation of problems they had faced pre-diagnosis. Mira had experienced multiple stressors at work and in her personal life: "I had kind of burnt out at work and I just decided to take a personal leave of absence, um, for a year, and I was just overworked and I just ended a relationship – I kind of got left at the altar."

Other medical concerns. Along with intimate relationships ending and job stress, nine women reported experiencing other acute and chronic health concerns pre-diagnosis and sometimes alongside their breast cancer. These health concerns included fibromyalgia, chronic fatigue, thyroid cancer, shingles, diabetes, MRSA, and hip and shoulder surgeries.

Of the women who reported other health concerns, several stated that those concerns were far worse than their breast cancer. Carolyn said about her case of the shingles: “The cancer part was pretty easy to go through, but I got one of the worst cases of shingles they’ve ever seen right as I was starting my radiation, so the shingles put me right under. That one had me down on my knees for several months.” She concluded, “I have to tell you, it’s worse than natural childbirth. Telling anybody – I’ve been telling my friends about the shingles vaccination. I mean, it put me down. The cancer was nothing compared to the shingles. Nothing.” Similarly, Tara stated that her experience with MRSA³ was “even worse than the breast cancer.”

Relationships Within Social Networks

When asked to describe their social networks, participants primarily named their siblings, female friends, and other extended family members. Women who attended religious services often referred to their congregations. Some referred to their co-workers. Frequently social networks changed after the diagnosis: some people left or were excused from the network because they could not handle the news, were unsupportive, or offered unwanted advice. The people most likely to leave participants’ social networks were friends or casual acquaintances, followed by relatives. Participants generally referred to

³ Methicillin-resistant staphylococcus aureus.

these experiences as necessary and had forgiven people who had hurt them. However, new people also entered the network (and participants were often surprised by who did enter). Joy commented, “Since I was diagnosed, I’ve had more friends than I had before.”

Family systems.

Vulnerable parents. Participants were concerned about sharing their news with their parents: they perceived their parents as not being able to handle the information. This often resulted in waiting to tell their parents. Kim explained: “I waited until after I had the surgery before I told my mother... because my mother is a worrier. OMG... My stepfather has Alzheimer’s. So, she has to deal with that. So I didn’t want her to be stressing and worried. She worries about everything; I didn’t want her to be worried about the fact that I was diagnosed with breast cancer.”

After sharing the news, mothers were either very supportive or unable to cope. Participants whose mothers were unable to cope were often confused and hurt. Mira recalled:

My mom just could not spend a lot of time with me while I was going through treatment, and I was – for a couple years, actually, I was very upset with her. I was like, “You couldn’t even care to spend time with me.” I find out later it was because I had told them they couldn’t cry in front of me. She just couldn’t handle watching me go through this.

Kara acknowledged that although she was familiar with cancer because she was a nurse, her mother did not have nearly as much understanding: “Initially when I got diagnosed, my mom had a very hard time. I think I was more blunt. You know, I had already seen it. I had worked in the OR and dealt with a lot of cancer patients before.”

Although participants generally understood the reasons why their mothers were less involved, they also commented that the lack of presence was hurtful. At the time of the interviews, most participants had forgiven their mothers for not being there.

Relationships with children. Half of the participants had children. Children's ages ranged from three years old to early 50s at the time of diagnosis. There were three categories of children: 1) Those under the age of 18 and still living with their mothers; 2) "emerging adults" that may live away from home, but still are financially dependent on their mothers (Arnett, 2000); and 3) Adults who lived away from home and supported themselves. This section will reveal how mothers disclosed their diagnoses to their children in age-appropriate ways, how they relied on their children during treatment for informational and emotional support, and how relationships with their children changed during treatment and recovery.

Participants had age-appropriate conversations with their children, often limiting the amount of information they shared with them. Participants with older children discussed their children's difficulty coping with the information. Josephine said about her children (ages 11, 15, 18, and 19 at the time of diagnosis): "Yeah, I did sit down and tell them, and they were... nonresponsive. Which in retrospect makes sense, because what do you say to that? I remember – my father died of cancer – I remember my mom telling me – telling us – when I was twelve years old... just thinking, 'Whatever. It's your problem.'" Jenny's son was three years old when she was diagnosed. Thus she employed a simple approach: "It was minimal. Real minimal. I didn't tell him much. But he knew I was going to the doctor and he got a little envious. He demanded to go to the doctor. I

was kind of like, ‘Okay, I’ll take you to the doctor!’ I think he was feeling like, I don’t know, I was getting a lot of attention because I was always going to the doctor.”

Patricia’s son was 10 at the time of her diagnosis. She said about their conversations:

I started off by telling him the positives, um, about – one thing I asked him was “What do you know about cancer?” He was ten years old at the time. He said, “Nothing!” I told him that I was going to be okay. I think I overdid it in terms of being positive, which I wanted to do, because he was totally unprepared for my response to chemo, the way I’d laze around, and the exhaustion, um – so I did keep it positive and I tried to minimize the disruption as much as possible. We go on a week-long vacation, we do that every summer, and I was going to be dead in the middle of chemotherapy. So we went away for a weekend before I started chemo, and that helped him understand that some things were going to change, um, but it’s going to be okay. It’s going to be all right.

The second group of children was the emerging adults (ages 18 – mid-20s). Often participants chose when, how, and how much to disclose based on what was happening in their children’s lives concurrently and whether the children lived nearby. Denise said: “I got the call from my doctor to let me know that I had – that it was positive ... I hung up, and I just repented to the Lord that, you know, ‘I’m worried. How do I do this? How do I tell my daughter when she comes out of this class?’” After Denise told her eldest daughter, she had to tell her younger daughter, who was in college several states away:

We Skyped her. And by that time, I think I had taken control of hair removal and chemo and stuff and I was like, “Well, I’m going to get my hair cut short now so I

won't have to go through all that drama," so I called my daughter – she's away at [university]. She looked at me on Skype and she's like, "What's wrong?" And she was like "It's short. You cut your hair. What's wrong?" And so I just told her, "I was diagnosed with breast cancer, I'm Stage II, I have surgery coming up."

Phyllis, whose ex-husband had become a quadriplegic as a result of a serious car accident during Phyllis's treatment, felt that both her son and daughter (in their early twenties) had been greatly impacted by both events, but that her son was suffering more. "I think [my son is] having the hardest time. My daughter is more – you know, she's in school, working, you know, she's the type that if there's something going on, she's like, 'Okay, what can I do to help?' Where my son's personality is more, 'I just want to run and hide. This is too much.'"

Mothers with young adult children living away (usually at school) did not initially realize how difficult it was for those children to cope. Louise said about her daughter: "She really took it harder than I knew or had any idea. Because she did not share with me. It wasn't until just last year that she explained to me that she really had, um, I'm not going to say a breakdown, but it really took a toll on her."

The third category of participants was those with adult children who lived away from them. Carolyn, who had always sustained a very good relationship with her son, said about his response:

Oh, my son was right there. He went with me for my consultations. He was probably the toughest one to tell, because he and I are very, very close, but he's kind of like me. We're very pragmatic: we'll go get our information, then we'll

get our consultations, then we'll figure out what to do. You know, he was there when I had my surgery, and he'd be over to check on me.

Elaine's daughter reacted differently. Elaine attributed this to the fact that she had recently moved to be closer to her daughter and help care for her grandchildren. The diagnosis had thrown a wrench into those plans. "My daughter said at one point, 'I knew I'd need to be taking care of you, not physical care but doing stuff with appointments, but I didn't expect it so soon.' I'd just moved here and she had a four-month-old baby, a third kid. Three children is a lot of work [laughs]." Even older adult children were not always sure how to react or support their mothers; participants acknowledged this as understandable and did not harbor hurt feelings.

Relationships with siblings. Within family systems, siblings provided the bulk of support for participants. This included emotional and instrumental support. Elizabeth found that for the first time in their lives, her younger brother became the caretaker and protector. This role reversal ultimately enhanced their relationship. "We got to know each other quite a lot better.... So probably, in some ways, our relationship could have broken down, but really it improved, because he was in charge."

Mira described the instrumental and emotional support her sister gave her:

I would stay at her house and she would take care of me. After I had my mastectomy, I couldn't even shower; I didn't have the range of motion in my arms. So... she would get in the shower with me and wash my back and all that stuff. I mean, not too many sisters would do that. Just... when I'm feeling like crap, and just bawling my eyes out in the middle of the night, you know, she was the one who was there.

Where a lot of parents – particularly mothers – could not grasp their daughters’ diagnoses and as a result turned away from them, siblings could still step in and provide emotional support. Camille said: “My sister was there for me as far as listening, whereas my mom couldn’t [laughs]. ‘Cause I think my mom was more in shock that [her] baby was going through this and, um, my sister was there to listen more.”

Relationships with friends. Friends were the group most likely to enter and leave participants’ social networks post-diagnosis. Sometimes this was because they could not relate to having breast cancer; other times they were able to offer only one type of support. As Susan said, “People that I thought were my friends have now pretty much gone by the wayside, and strangers have become friends.” Josephine found that some of her friends were able to offer support at the onset of her diagnosis and treatment, but later did not know how to support her.

Actually, my network was also a group of women that were all recently divorced. I knew a couple – I knew like two of them through my kids. The other ones I hadn’t met until literally a week before I was diagnosed, and they rallied, totally, as far as meals. And we had a party before I went into surgery, the night before, and they dyed my hair purple. Um, they brought all this food and we were drinking wine and we were laughing. They were great, but as I got better, they fell away. ‘Cause I didn’t really know them.

Josephine’s friends were able to support her initially with instrumental and some emotional support, but following her treatment they could not relate to each other enough to sustain a relationship.

Like most participants, Camille's friends fell into several different groups: "Some seemed like, 'Oh, such-and-such happened, you'll be fine,' you know, sort of brushing it off. Some of them were kind of like – colleagues were like – acting like I had the plague.... And some of them could relate."

Cancer diagnoses and treatment often tested friendships. Participants attributed the test to individuals' reactions and participants' inability or disinterest in joining the same activities as before diagnosis. Patricia commented,

Woowww! That's one thing about diagnosis. It really shows you who's in your corner. And I've got four of the most amazing girlfriends... who have just really been there through it all. Um, even the day of my surgery, you know, I had four people waiting for a while. Waiting outside the recovery room for me. I didn't just drive to appointments by myself. I didn't go to one chemotherapy session by myself. ... There were a couple of people that I thought that if something of this magnitude had occurred in my life, they would be there. But they weren't. But it's okay, I'm not even angry.

Kara drew parallels between how friends and spouses react to breast cancer:

A lot of people could not handle [my] cancer treatment. Like with marriages, most people can't handle it. Some friends – I think people don't know what to do, so some people try to rescue you. Some people can't handle it. Um, my two best friends, they – we used to do a lot of social stuff, and when I suddenly didn't want to go out and drink and do things like that, I think who I was in my thirties in my life changed. It changed our relationships and it's just never come back.

Relationships with co-workers. Among participants who continued to work throughout treatment, co-workers and supervisors tended to offer them emotional and instrumental support. Participants reported co-workers calling and visiting post-diagnosis and post-treatment. This was especially true for Phyllis, who learned that she had breast cancer while at work:

I saw the [hospital] number pop up on my cell phone, and I almost – I was just so, you know, oh my goodness. I didn't even want to talk to the doctor. I didn't even know, but my heart was just racing. When I took the call, I went out to the car and talked to them and they told me it was cancerous. And that whole thing – when I came back, I was kind of in the twilight zone, 'cause I was at work, and I had a dear friend at work, too. Me and her always talked. I told her, "They just told me that it's cancerous," and she just looked at me and she said, "It's going to be okay."

Phyllis found that once she returned to work after several months, her co-workers were still very supportive:

When I started back, the things that I noticed the most though, and I heard other people talk about it, the term called "chemo brain," where you're very – where you forget stuff. And you know, at that point I'd been working for about ten years. And there was basic stuff that I had to like, re-train all over again. ... When they'd be training me, I'd be like, "Look, um, you guys are gonna have to bear with me, because I need you to say that again, because I don't understand what you just said." ... I made a joke about it, but I'm serious. They understood that.

Co-workers devised several methods of instrumental support for patients. These ranged from donating sick days to creating gift baskets to taking over certain tasks. Jenny said about her fellow teachers: “They got together and went to the union leader to see if they could donate their sick days to me. Actually in [state of residence], they have an official sick bank. They tried to create one, which was very sweet. I didn’t end up needing it, but just the thought that they did that was very powerful for me.” At the time of her diagnosis Kim worked two different jobs. Co-workers from both jobs were supportive: “[They] gave me a care package. They gave me movies, they gave me movies to rent, they’d come over and visit – both jobs, would come over and visit. They’d call, they’d email.”

Along with co-workers, direct supervisors were also generally supportive. Patricia’s manager removed her from “a very time-intensive project” after Patricia did not recover from her surgery as quickly as anticipated. Similarly, Tara reported about her supervisors: “They just said, ‘Hey, do what you need to to get it done.’ But yeah, they were really excellent through that whole time. My employer gave me free time, which was also awesome.”

Managing social networks. In the midst of diagnoses, treatment, and sometimes changing prognoses, participants had to make decisions about who remained, entered, or left social networks; how to disclose the initial news to people; and how much information to share over time.

Ending toxic relationships. Participants realized that people in their social networks were not necessarily going to be supportive. Sometimes people made selfish, insensitive comments, while others retreated. Tara reminisced:

I got to the point where I didn't want people who were toxic and took energy out of life, so I did end some friendships and family relationships.... Making the cancer about themselves or being very hurtful about it. I had one brother tell me, as I was going into surgery – or coming out of surgery, that it was only cancer; why was I making such a big deal out of it? ... And I don't think people meant to be hurtful per se – or maybe they did. But it doesn't matter to me. I wanted people that were very toxic to be out. So I said, "Okay, that's fine. I learned my lesson." Life is too short to be with certain people, and I chose not to be around them as I ended relationships.

In the time between her divorce and diagnosis Josephine had grown close to a group of women. Although they had been very supportive of her during her divorce and all the subsequent family fall-out, she learned that they did not know how to be supportive once she had breast cancer.

One woman in particular was a therapist and she shocked me, because she said to me one time – I was telling her about a conversation – oh, I had an allergic reaction to chemo, and I couldn't walk, and I was so upset, and she was giving me this lecture: "I think it's important for you to stay positive." She based this lecture on the fact that she had surgery on her breasts. Cosmetic surgery on her breasts... "I know what you're going through. I had both my breasts" – "Yeah, but that was your choice." So that shocked me. That kind of shocked me into silence.

Jenny said about her brother's wife: "She doesn't really mean it, but she would just say stupid things like, 'I'd just get my breasts cut off! I'd just take them off!' It's just like really insensitive. Shut up." Susan explained: "When someone calls on the phone and

says, ‘Oh, I just heard about you... I thought my life was crap but you got me beat.’ Like, ‘Well, thank you. I’m glad I made you feel better.’ It put a strain on the friendships.”

Kara said about her mother: “My mom was in denial and she had such a hard time dealing with it. I actually did not talk to her for... gosh, 10 months? She felt very bad for herself, and I made the decision that I can’t cheer you up and cheer me up, and there were times that were really tough, and I just stepped away from it. And it is what it is. She still is – I think – upset about it, but at the time it was the right thing to do.”

Disclosing information and talking about their experiences. Approximately 75% of the women really wanted to talk about their breast cancer experience with others, but they also wanted to disclose the information on their terms and be judicious with whom they shared their stories. Mira recalled:

I was actually very open about it. I blogged about it, so I had my little soapbox where I could talk ad nauseam about all that was going on... um, just be able to vent about it. For a while there, it felt like every conversation I was having was a cancer-status conversation, talking about what the latest was and what I was doing next, and I was almost at the point where I was boring myself... but I did need to talk about it.

Jenny was glad that she had told as many people as she did about her diagnosis: “I’m a teacher, so there’s a good chance I’m going to be bald and all that, so people are really going to notice, and it’s a small school.” She reported only positive experiences from sharing her news. “I learned you should just instantly tell everybody.”

Kara found that over time the amount of information she wanted to share, and with whom, differed:

If I was having a pissy moment – “I need to let you know I have breast cancer.” In the beginning I used it as a crutch. ... Sometimes when I was in a bad mood, I think I used it as an excuse. ... But more so now, as the years go by, I don’t really talk about it as much. I pretty much only talk about it when I need to help somebody else out or ask somebody a question about it.

Carolyn learned that although she wanted to talk about her experience with some people, it had to be on her terms or not at all:

I was kind of – as a matter of fact, I have a couple of friends – female friends who wanted to get very emotional about it, and I was like, “Okay. Stop. No. I am not going to go there with you. If you want to help me, then you can’t fall apart, and I’m not going to deal with your emotional response to this.” ... I decided to take control of this and said, “Look. All of you care about me, but there are gonna be days when I don’t want to talk. I’m going to put all of you on an email distribution, I’m telling you all when I care to talk.”

Due to some bad experiences confiding in unsupportive family members, Denise was very cautious about disclosing her health status: “I don’t even think I even went into detail with friends. I didn’t have the – I got to a point where I just wanted to get through it and survive, and no one was in front of me.”

Limiting information shared at work. Participants were often judicious about whom they confided to at work. Sometimes this was because they were concerned about potential fall-out from supervisors and corporate, but more often they just did not want people to gossip about them. As Susan put it, “my boobs are no one’s business.” Louise said:

And when I was at work, I didn't tell anybody about my diagnosis. I told my co-workers that I was going to be out for a couple weeks because I was going to have a tummy tuck. Because I remember when I went through a divorce – it wasn't painful for me, it was more painful for the people around me: “Ohhh, no!” and I was like, “Calm down.” So it was like, how would they react to breast cancer? So I told them I was getting a tummy tuck. And that was the story until I came back to work.

Camille was grateful to have a supervisor and some close friends that shielded her from her co-workers' speculation about her extended absence:

I really didn't want to talk about it at work. Um, there was a lot of people inquiring about it while I was gone... my little birds told me that. “Oh, they were asking all about you and they want to know what happened, and they – they think cancer,” and I was like, “Okay.” But um, I do believe my supervisor did say, “It's up to Camille. It's none of your business. If she wants to talk about it, she'll talk about it when she gets back.”

Support From Social Networks: Needed and Received

Support needed. Participants needed informational, instrumental, and emotional support: informational support from medical professionals, and instrumental and emotional support from their social networks. As outlined in the following sections, there were occasional discrepancies between what support was needed and what was actually offered.

Informational support. Participants who surrounded themselves with other breast cancer patients often found that fellow patients could offer more informational support

than members of the medical team. Additionally, whereas an individual patient might only talk to two or three physicians about treatment options, all of whom agreed on a particular course of treatment, a support group yielded a more diverse array of opinions and suggestions. Cora recalled being pushed by her doctors to get a lumpectomy versus a mastectomy: “I would have liked the option of talking about it. And I would talk about it with friends... they supported me, and a number of them did have mastectomies.”

Along with not being told about various treatment options, some participants were surprised by the side effects they experienced. Camille was unaware that she could get lymphedema:

I feel that lymphedema popped up out of nowhere, and if I'd discussed this earlier with the nurse practitioner, and she'd told me this was normal, that was it. And then when I cried bloody murder, “This hurts,” and the swelling under the arm, and “This is normal?” ... So I never knew that I could get lymphedema.

Participants' first source for informational support was the medical team. When members were rude or degrading, participants felt devastated. Jenny said about a negative experience with her gynecologist, post-diagnosis:

She was so incredibly rude to me. And I ended up leaving the office sobbing and I was like, “God, why are you this upset? Like, she's a bitch and you're never going to her again. Why are you sobbing?” And I just couldn't stop crying. And I kind of sat in the car analyzing it, and it was like, two things: One, you're relying on your doctor to take care of you, and she was not taking care of me. And the other thing was, I have so much confidence – my only go-to place is that I am pro-active, you know, that's my comfort. I've had cancer a couple times, but I'm

really pro-active. I always go to the doctor. If I see a lump, I'm always there.

That's all I have is my proactiveness. And she tore it down.

Instrumental support. Participants frequently talked about the need for help with household tasks, especially immediately after surgery and during chemotherapy. Tara said: "In retrospect, I would have had somebody coming in and cleaning the house. That was a big mistake. When my sister finally came to visit, she goes, 'Well, let me clean the house for you.' I said, 'No, no, no,' and she said, 'Yes, yes, yes,' and it made the biggest difference." Paula had cancer survivor friends who advised her to "Never go to an appointment by yourself.' ... I started lining up people to go with me to appointments."

Emotional support. Participants needed emotional support from their family and close friends, but they differed in what that support looked like. Some participants needed to be surrounded by loved ones, while others needed people to give them space. Tara said about her first diagnosis:

I was very inward. I looked to family for the support. I had to explain to them and they finally got it, I said: "Okay, this is happening to me, so I need you to support me in terms of how much support I need or not. If I need to be by myself, or you don't hear from me for a week, I know you're concerned, but don't be. I know you're there and I will reach out to you." That was harder for all of them than it was for me.

Tara went on: "And I totally understand. I think it's worse for the caregivers, I really do. The person going through it. Because they want to be there and they want to help so much, but they're not going through it, so they don't know." This incongruity between what patients needed and what loved ones thought patients needed could be

stressful. Often participants had to remind their friends and family of their wishes, but there were no reports of resentment from friends and family concerning participants' wishes.

Support received. The support that participants actually received from friends and family did not always match what they reported having needed. However, the assistance received still fell into the categories of informational, instrumental, and emotional support, including some from surprising sources.

Informational support. Informational support from friends and family differed slightly from the informational support from the medical team. From the former group it also included helping obtain and process information; the latter group was expected to supply relevant medical information. Phyllis said: "I'd have my daughter go with me to many of the appointments and stuff, because she had more of a level head. ... she's more grounded and could hear better than me in terms of not being too emotional, but just listening to what was being told to me." Margaret's daughter, a radiation technologist, "was with me for all of my appointments, and I was really glad I had her because she asked questions that I couldn't even imagine. You know, as far as chemo and lab work and what have you. Her concern was, 'Who's going to protect my mom's kidneys and liver because of all this stuff that she's taking?'"

Instrumental support. Instrumental support included homemade and catered meals brought to the house, gift cards to favorite restaurants, help with bathing (especially after surgeries), and help cleaning one's home. Elaine remarked, "To have my half-brother here was amazing, because his wife had had breast cancer about twenty years ago. Um, because I was totally a basket case at that point. I couldn't cook, I couldn't

clean. Basically I could lie down.” Elaine concluded that because her sister-in-law had had breast cancer, her brother had special insight into her own needs. Often participants underestimated how much help they would need after surgery and during chemotherapy .

Emotional support. Emotional support included having friends and family encouraging patients, spending time with patients, and making them feel loved. Mira’s sister set up a “chemo buddy” schedule: “I had a different friend take me to each chemo appointment, which made it more exciting – we celebrated every single event.” Several other participants talked about having “chemo buddies,” which usually included siblings, friends, and occasionally co-workers.

Prayer. Several participants disclosed that people prayed for them and what solace that brought them. Some of the prayer groups were from the participants’ own churches; others had siblings’ and friends’ church prayer circles praying for them. Tara said:

My sister was in a prayer group... and they had prayed over a shawl and sent that to me for when I went to the hospital. And when I was going through it, she was talking to me and their prayer group was praying for me. And somehow, you know, I felt something. I wear that shawl all the time, with the chemo and everything. It just felt reenergizing.

Help from unexpected sources. Although participants talked about the sting of people being surprisingly unsupportive, they also talked about people that unexpectedly helped. Some of these people even became close friends with the participants. Patricia explained:

One of [my son's] friends – his mom had been treated for breast cancer ... and she was one of the ones who helped. She'd do pick-ups for karate. ... I'd see her there, I'd see her husband there – “Hi, how are you,” and that it was it. We'd once gone away, the karate group, gone away on a long weekend, and shared a cocktail or something, but it was nothing – she wasn't my best friend. She wasn't on my speed dial of my cell phone. When I got a good report from the surgeon, she was one of the people who were on that list to tell.

Participants commented that, at the time, it was surprising how certain people would be there for them. In retrospect they often found it wonderfully beneficial, but not unusual.

Therapy. Approximately one-quarter of participants were seeing therapists prior to and during diagnosis and treatment. Elizabeth, who had been seeing a psychotherapist prior to her diagnosis, found that during treatment there was a shift in focus from self-improvement to support. She pointed out, “They have social workers you can talk to about what you've gone through... You can talk about your feelings about dating again.” Josephine went to an oncology counselor during her treatment. She found a therapist who specialized in cancer was especially helpful:

Well as I said I was going through a divorce and I was seeing a counselor, but she really didn't know anything about cancer. Not just the physical ramification, but what it's like to be a woman and to be bald. What it's like to be a woman and lose a breast. Those are huge differences. I felt disfigured by the surgery and I wanted to show somebody, other than the doctors who kept saying, “Wow, she did a good job! Wow, she did a good job!” and I'm sure she did, um, but compared to what it

was before, it was a nightmare. The regular counselor was not comfortable with that. She would not look. She did not want – one of my friends – only one of my friends would look, and the oncology counselor... sometimes we sit in those groups and somebody says, “I gotta show you this, this nipple that I got,” and in that way, they are light years ahead of anybody else.

Benefits of pets. Several participants talked about how helpful their pets, particularly cats and dogs, were throughout their cancer experience. Kara said about her dog:

I can't even state how much my dog meant to me. As a single person, my pets meant the world to me. ... You know, that was the most important thing to me, because that was my support system. My best friends really downplayed how much my dog meant to me, and, um, I can tell you our friendship pretty much ended because they kind of told me how to live my life and didn't understand that I dealt with things in a certain way and they dealt with another. And when it came down to it, I walked away from the friendships because they weren't supportive. In the beginning, if something had happened to my dog, I probably would have been suicidal, if that makes sense, because I would be losing everything. ... I think at the time, if I would have lost her, I don't know if I would have made it.

Pets' metaphysical perceptions. Among participants who had cats and dogs at the time of their diagnosis, many felt that their pets possessed metaphysical perceptions about their owners' health. Alma stated about her cat: “She knew I was sick. She knew.” Margaret theorized:

There's something about cats. They can sense if there's something wrong with you. Because when I was staying in bed, she nuzzled with me and always kind of laid next to me. But, it was like our little special time. You know, I talked to her, she would look at me and meow. I'm glad I had her, rather than my ex-husband.

Phyllis said something similar about her dog:

It's almost like she knew cancer was in my body before I even realized it. I can't even explain that either, but she would – when she was near me, it's like she would always come near my breast and sniff. ... It's almost like she was trying to tell me something. I've heard that animals can smell – not that I have an odor or anything, but they can smell something, I don't know, where they can sniff out certain illnesses before you even realize that you have it. And she's just very gentle and very tender around me.

Medical Treatment

Treatment decision-making. Participants generally made their treatment decisions independently; in many cases their doctors outlined only one reasonable course of treatment, and participants agreed to it. Only two of the participants reported differing viewpoints.⁴ The most common course of treatment was a mastectomy followed by chemotherapy.

Kim explained, “Like I said, I put my faith in God and I – whatever, you know, what the doctors told me I need to do. I did what they told me I need to do. It wasn't – I assumed they knew, so I didn't question it too much.” Louise recalled, “Out of all the

⁴ The two exceptions were Tara and Patricia. The first time she was diagnosed with breast cancer, Tara elected not to have chemotherapy, against her physicians' recommendations. When the cancer returned, she and her medical team agreed she needed to have chemotherapy. Patricia was diagnosed with multifocal breast cancer. It took time to find a surgeon that would perform a lumpectomy instead of a mastectomy, but she did find one.

doctors that I spoke with, none of them told me what I needed to do. All of them gave me options.” This is representative of most patients, who consistently felt in concordance with their medical team.

Friends’ and families’ influence on treatment decision-making. In selecting various treatments, some participants admitted being influenced by their families. Influences included family members who could speak from a professional standpoint. Josephine recalled her physician uncle advising her, ““Go to the younger people. They stay abreast of the journals; they’re not so cynical yet. They’re usually empathetic.”” Other relatives in the medical field knew what questions patients should ask at doctor appointments.

Participants also referred to their observations – past or recent – of friends’ and relatives’ experiences with cancer. This impacted their concerns about types of chemotherapy as well as surgeries. Josephine explained:

Initially when I got the diagnosis, I wasn’t going to do chemo. Especially since it was the same medication my father had, and he died anyway.

Adriamycin/Cytosan. And he had a terrible time with chemo. And you know, as a kid I didn’t know what was going on, but he was so deathly ill. And prior to that he just had a sore throat.

Josephine’s oncologist was able to assure her that in the decades since her father’s death the medical profession had learned more about Adriamycin/Cytosan (correct dosage amounts, how to administer it). This enabled Josephine to feel comfortable about starting chemotherapy.

Louise made a last-minute decision to have a mastectomy instead of a lumpectomy. Her explanation:

And the night before they gave me the anesthesia, I talked to the nurse and changed my mind about the mastectomy because with the lumpectomy, you have to have radiation. And I saw what my mom went through with radiation – having to be hooked up to the machines repeatedly, every day. I didn't want to do that.

Breast cancer survivor friends also influenced participants. Patricia said about her friend:

My one friend, who was a Stage 0 survivor, opted for a mastectomy, but that was based on her family history and her experiences that she had seen. She was [the] one who helped me make the decision not to have a mastectomy. Or she was the one who helped me not go see her surgeon. Because I figured if her surgeon was encouraging her, or at least talking to her, particularly about having a mastectomy at Stage 0, my coming in there with multifocal, she would probably say the same thing to me.

The Internet is a scary place. Generally, participants found searching the Internet for breast cancer information to be frustrating and even scary, owing to inaccurate statements or bad prognoses. Kara said: “I would look at things on the computer sometimes. People send you the craziest things, and I'd bring it in to the docs and they'd poo-poo stuff like, ‘Okay, that doesn't work. It's only done on dogs.’” Josephine was advised by her doctors not to look up information on the Internet: “‘Don't get on the internet. There's a lot of stuff, and you don't necessarily know that it's true.’” Mira said: “I guess I found books to be a little more pessimistic – if I read something I didn't like,

I'd literally rip it up and either burn it or trash it or destroy it. [Laughs] I mean you read a lot statistics and stuff like that, statistics about women with my stage.”

Relationship with medical team. Participants' relationships with their medical team varied. Half the participants reported good relationships; those who did not often replaced members of their medical team (including oncologists and surgeons).

It meant a lot to participants to have medical professionals acknowledge how awful the overall breast cancer experience was. Josephine reflected:

Everybody seemed to have a shadow of grief that helped me. You know, it felt to me like they were so sad for me. And I wasn't sad yet. I was just shocked. I particularly remember those folks at the MUGA scan⁵ because they were super, super nice. And they were – the woman was upset. And she said, “It seems to me there's an epidemic. We've seen so many women lately.” And that was just her opinion anyway. It really resonated with me.

Participants often developed complex relationships with their oncologists and surgeons. These medical professionals primarily counseled them about treatment and performed operations on them, and thus patients viewed them as the gatekeepers to their health. Elizabeth commented, “Your relationship with your medical oncologist ... can be very emotional, I think.” Paula referred to her medical team as “partners in the healing process.” Participants sometimes felt vulnerable, particularly if they had an unexpectedly negative experience, or if they felt their doctors could not relate to them. Margaret was frustrated by the discrepancy between what treatment was supposed to be and what it actually was:

⁵ Multigated acquisition scan. Identifies preexisting heart conditions. People receiving chemotherapy may need this test (American Society of Clinical Oncology, 2012).

These doctors, they want you in and out. The chemo treatments – going there was really difficult, you're just in and out. Reading these articles about how you're in the comfort of pleasure and music. You're paying what your medical benefits are, and that's all you hear about.

Some participants talked about how they perceived their medical teams' practices to be factory-like, that is, treating many patients quickly rather than valuing individual patients' needs. Denise referred to her plastic surgeon's practice as "a titty factory." Patricia said about her surgeon: "And then when he told me it would be easier for him to do implants, because – well, 'It's not about what's easier for you. This is about my health and what I want to do.'"

Many patients had very positive experiences with their doctors. This generally occurred when doctors considered the patient's holistic health and really asked about her overall well-being. Bonus points were given to doctors who took more time than necessary to check up on patients. When asked why she had rated her surgeon a 10, Mira said:

"Because of his bedside manner. I have very vivid memories of being there – I was having a bad day... I'd be bawling for no apparent reason. He had a waiting room full of patients – and he did this several times – you know, a waiting room full of patients, and he'd just sit there with me and talk to me for a half hour until I calmed down and felt better about life and just, you know, everything. Very, very, amazingly caring person.

Kara, who had Stage IV breast cancer, had difficulty getting her medical team to help her battle the weight she had gained during treatment: "They consider me a success

because I'm alive. But for me, being a success is being able to do what I want to do in order to keep me happy and to keep me active. So that's been my big, big battle." Kara continued: "A lot of times I feel like they're, 'Yay, you're alive,' um, and so that's been the hardest part of... I think I realized that at Stage IV, they don't necessarily know what to do with you. They don't know why it works for one person and doesn't work for another."

Teaching the doctor. Sometimes participants were surprised to realize they knew more than their doctors did. This happened if the patient researched a type of treatment or risk factor. It was disconcerting to realize they might know more than their oncologist or surgeon. However, in all reported instances the medical professionals met the patients' perspective or newfound information with interest and respect. Denise said about an encounter with her oncologist:

[My surgeon] didn't know that Tamoxifen, when I was telling you about finding it on the computer, and then I read the book Knockout by Suzanne Somers and read that Tamoxifen for African American women – after you take that, have a higher level of getting cervical cancer. And so I would talk to him about that, because I knew outside of my oncologist, this doctor, my surgeon – he would talk to me more about experiments and he's a researcher and he's on the board and he knows surgeon teams."

Medical professionals' assumptions about patients' wants. Occasionally participants felt that their doctors encouraged a particular treatment or surgery because they assumed that all single women would want to keep their breasts or get reconstructive surgery, since they would be dating eventually. Cora reflected:

In retrospect, I would have liked the option of a mastectomy. A bilateral mastectomy. Instead of going through chemo, you know? But because it was such an early cancer, and small, and I guess they just assume you want to keep your breasts. You know, that was never really an option nor presented as an option.... Because most women are tied up with the way they look and their breasts.

Relationship Status in the Context of Treatment

Relationship history. Prior to diagnosis ten of the participants were divorced or in the middle of divorce proceedings. Several characterized their previous partners as being abusive (emotionally and verbally). Josephine said about her former husband: “The divorce was my idea. Um, I had been pretty sick for ten years with fibromyalgia and chronic fatigue, and he didn’t do illness. And just night and day, he was an angry person and very abusive. Emotionally abusive to me, because I wasn’t pulling my weight.” She didn’t file for divorce until, according to Josephine, her therapist said, “You need to get out of that relationship, or you’re going to die there.” Margaret, who was in the middle of divorce proceedings when she was diagnosed, said: “My marriage was very stressful for me. I’m really glad that we did split up, because it gave me peace of mind and ... he was a very stressful man. He was very stressful and very, um, verbal-abusive. So ... I didn’t need that with my surgery.”

A few women were dating men casually but stopped seeing the men as soon as they were diagnosed, believing the men would not be supportive during treatment. Tara reminisced: “So the second time I was actually dating somebody, um, not all that serious but we were dating up until the time of diagnosis, and, um, his response to my diagnosis

weirded me out, so I ended that right away. Because when you go through this, you need to focus on you.” As Paula explained about her recent breakup, “I didn’t want to be in a relationship that wasn’t headed some place.”

Thoughts on being single pre-diagnosis. While some expressed sorrow for the end of previous intimate relationships, all said they were better off single than if they had stayed with their exes, regardless of their health status. Participants that were not dating in the months preceding their diagnoses expressed interest but also felt that their lives were full even without intimate partners. When asked what it meant to her to be single prior to her diagnosis, Kim said, “It meant I was single. Nothing thrilling, just single. Nothing thrilling. Me and my own life, don’t question it. Don’t have to answer to anyone.” She continued, “I was working two jobs, sometimes 60 hours, you know, 50 hours a week, so I didn’t really have that much time. So yeah, if it came up, I was good.” Similarly, Carolyn explained:

I’m not averse to having a relationship, but it would have to be something so significantly added to my life, because I consider my life very good. I dated briefly when I moved here, but when I saw that I resented having to carve out time, and I said, “This really isn’t what you want to be doing.” I was like, “Well, do you think we could meet from 2 to 4 [laughs] but I don’t know if I want any more time.” I think it was more that social norm that I should want to do it.

What if you’d had a partner during treatment? There were four categories of responses to this question, reflecting participants’ varying beliefs about such relationships under the stress of a health crisis.

First, many said that their experiences would have been easier if they had had a partner, but emphatically not one of their previous partners. When asked how might her breast cancer experience been different with a partner, Josephine immediately countered, “Do you mean a real partner?” Mira said: “It really depends on the partner. If it was the guy I was going to marry, so much worse. Just – oh my God, just infinitely worse.”

Second, other participants conveyed that if they had had a partner during treatment, they would have felt more emotionally supported. Alma said, “I think I might not have felt so alone throughout my journey. Like I said, I have people that love me and that I love and they were there for me, but I still felt – I still felt alone.” Denise said:

My treatment would have been different because I would have had a partner, I would have had a husband and somebody that really loved me, that was there. It really hit me, the women that are married going through this.... I mean, man. To have a husband to know you, he’s there for you. I can’t imagine how wonderful that would have been. The love. He knows if you have a left breast or not, to help you make decisions: “Honey, get the breast or whatever makes you feel good, I’m okay with you.” That would have just been the ultimate.

The third category of participants suspected that a having a partner would have been nice, but it was not critical to one’s overall health and well-being. These participants acknowledged the strain that cancer places on relationships. Susan reflected:

It’s nice to have a partner, but it’s not necessary. ... Somebody once told me that if you’re with someone, and there’s an illness... if you can stay with them through that, then you’re in pretty good shape. Because that will test everything within a relationship. And I believe there’s some truth to that. You know, the focus has to

be on your health, and what you need to do to be healthy. And depending on what type of relationship you're in – if you're with someone that's needy, and now you're the one that's going to be needy, it's not going to work. And that will make you more devastated than anything.

Kara said:

I've heard so many horror stories. Would they be with me because they have to be, because why would you break up with somebody when they're going through cancer? I'd feel guilty – would they really want to be with me? Um, I think personally for me in the long run, it was probably better that I was by myself. It taught me to just see what I was fighting for and what was worth fighting for.

In the fourth category, participants were grateful not to have partners during treatment. They perceived partners (sometimes from speculation, sometimes from observing their friends' partners) as being a drain on one's energy and focus. Carolyn said:

I think that if I'd had a partner, I would have been more concerned about how my partner was doing than how I was doing. I think in some ways – for me, anyway – it was easier, because I could make all the decisions for myself. Focus on myself. Do what I wanted to do or not do, and if I wanted to lock myself in the house for a week and not get out of my pajamas or talk to anybody, then I didn't have to. Versus if I were in a relationship, I'd still have to support that relationship at some level.

Comparing relationship status to other breast cancer patients. Participants often drew comparisons with breast cancer patients that did have partners during

treatment. Even within one participant's social network of breast cancer patients, there were notable differences among their friends with partners. Tara commented:

I think what that all comes down to is how your life could be different if you were in a marriage or not. You know, you have friends that have very supportive partners who were a total part of it and were there and had the other person's back. You had other partners who were totally the opposite and were a drain on energy instead of any kind of caregiving, loving support, and then you have those in the middle who still need their demands met but help you out. It kind of goes all ways, and I've only seen one or two of my friends in that first category with supportive spouses who, once they were diagnosed, were there for them. More than that, [friends] who ended up divorced because of the cancer.

Elizabeth noted that women with families of their own had more built-in motivation than women like her: "The other thing about being single is that a lot of the 'inspirational' stories about women going through treatment is how they did it for their children or grandchildren. People without children or grandchildren have to find their own motivation, which I think is harder."

Several participants talked about how patients without partners needed to be more proactive in seeking support. Jenny explained, "I would imagine that women who didn't have partners are more like me, in that you're out there, like telling everybody, you're on the message boards, not isolated at home with your husband, relying on him. You know, you're relying on everybody."

Sometimes participants forgot that patients with partners could have very different experiences than them. Patricia recalled:

So one of my friends who was in the process of getting a diagnosis, when I told her, “Oh, you need to go see Dr. Butler, she’s fabulous.” I said, “Well, here’s her number, call her and make an appointment.” I told her, “Well, do you want me to go with you?” And she basically – she didn’t take me up on it. She was like, “Why would I want you to go with me? My husband will go with me.” [Laughs] Yeah, it was a little different, but I guess I wasn’t accustomed to the role that your husband would play.

Thoughts on being single post-treatment. Most participants were interested in dating again, even if they were not immediately prepared for those next steps. A lot of participants admitted to feeling lonely. Although Alma felt the support of loved ones, she still felt something was missing: “And I had sooo much support from my co-workers, all of my family, my friends – I had plenty of support. But I still felt alone.”

Many expressed interest in dating in the future, but were nervous about getting back into the dating game. Mira said:

I have a hard time with just trying to figure out the rules and that kind of stuff. I actually have a friend that’s kind of helping me out with that a little bit – helping me interpret somebody that I was seeing a couple – a couple months ago – just got back in touch, and I was having a hard time interpreting what he was saying to me, um, maybe because I just don’t understand guyspeak completely, um, so having a guy translate that for me was very helpful. So yes, it’s like I really would like to be in a relationship. At some point, I’d love to get married. But I don’t know that that’s necessarily going to happen.

Other participants expressed interest in dating, but for now, wanted to focus on themselves. As Camille explained, “Right now I’m still trying to get back to Camille. I know I’ll never be the old me, but I’m still trying to get myself back to where I feel comfortable ... I am afraid to show my scar, talk about my situation... this is personal. I don’t think I want to share that right now with anyone.” Because she was not ready to show her scar, which represented her overall breast cancer experience, she knew she was not ready to date and disclose such a recent and big part of her life.

Disclosing health status to potential partners. At the time of the interviews, all but one participant were still single. Many talked about how they have or would disclose their health status to potential partners, and what it might be like to show their post-treatment bodies to those partners. Mira said:

I didn’t know what to say about the cancer, when to say it. And even now I really don’t know, five years out. Even now I feel I try nonchalantly to bring it up, and that’s pretty much the end of me seeing whoever that is, because most guys just don’t know how to deal with it. Usually I make sure I’ve done something kind of active before I bring it up, just so that they know, “Okay, you’re not going to drop dead on me!” [Laughs] ... I’ve done a lot of online dating, so when you tell somebody that you’re a cancer survivor, they construct images of you being really sickly, the idea that you’re walking around bald throwing up all over the place. Definitely not somebody anybody would want to date! [Laughs] So if you tell somebody after you’ve gone running or gone for a hike or whatever it is, it’s like, okay, they definitely know that you’re not sick anymore, that you’re fine, but still, hearing that that thirty-one-year-old had cancer, it’s pretty scary for most guys.

And then the fact that I can't have kids – I guess that's another deal-breaker for my age group.

Among participants who had shared their health status with men they were dating or wanted to start dating, many found that those men were never to be heard from again.

Jenny recalled:

The first guy I dated, I think he hesitated and didn't want to get involved with me in case I was going to die. [Laughs] And then the second one – eh, he's kind of like – it's like he's a real avoider of stuff like that. Like of course I told them, I was real casual. And there was another time he was like, "One day I'd like to hear more about that," and I was like, "Okay," and he never – that day never seemed to come. I think that's how he is. . . . He knows he should want to hear it, but he doesn't.

Margaret, the one participant who was dating someone at the time of the interview, was also the only participant who had had a positive experience disclosing her health status to a potential partner. She said:

I told him, about the mastectomy, the scars I had, and how uncomfortable I was exposing those. So he told me, "Don't worry," when I felt comfortable and wanted to talk about it some more, we would! And one evening he came to visit me and we were talking about things in general and he asked me if I felt comfortable enough to let him see where I had the mastectomy and, you know, he wanted to see the scars I wanted to hide so bad. So I showed him. I was a little apprehensive, but I showed him, because I cared a lot about him for all those years - I had feelings for him and he had feelings for me. And he told me, he said, "There's

nothing wrong with those scars." He said, "No. Girl, don't feel ashamed." He said, "No. Those are good, because that's what helped keep you alive, so that you and I could go see each other." So it's like, "Oh, okay! I'll look at it that way."

Impact of treatment on the body and sex drive. Several participants talked about how much their bodies changed from surgery and chemotherapy: scars, missing breasts⁶, baldness, and extreme weight loss or weight gain. Participants framed these changes in the context of their relationship status and how it might affect their ability to meet potential partners. Mira, who gained 70 pounds after her diagnosis, commented:

The weight has been a big thing. I don't feel very attractive, so it's like I already – the first thing that people would notice – the first thing that guys would notice about me is that yes, I am overweight. And then, if they can get beyond that, then it's like when you get to the bedroom, you know, it's like to have to be, "Oh, by the way, my boobs aren't real and I don't feel anything on my chest." I don't know, I feel like it's just too many strikes against me at this point.

Mira summarized, "Face it, most of us don't want to be alone forever. We want to be social. We want to date, but this is just another thing that makes you feel like you can't."

Patricia wondered aloud, "What are my breasts going to look like, um, post-radiation? And one of my friends who's been through it says, 'They're going to look like a fried rib!' [Laughs] You know, how distorted will I be, and will I be attractive to someone. But anybody who comes into my life, to share that kind of intimacy with, will have to love you, not just on a physical level." Kara said something similar, that is, whomever she met now would have to be attracted to her on multiple levels: "I'm like,

⁶ Not everyone had reconstructive surgery, and of those who did, they did not get the surgery immediately following their mastectomies.

‘Dear God, I couldn’t get a man when I was really pretty, and now, how the hell am I going to attract...’ But in the long run I thought, ‘Well, you know, maybe I didn’t meet the right guy before because of my looks or being superficial. And now I might meet somebody who really loves me for who I really am.’” Several other participants said that if they started dating someone now with their post-treatment bodies, then they would know that person was interested in them on all levels, and not due solely to physical attraction.

Participants also talked about the impact that treatment had on their hormones. Some participants stated that sex wasn’t as important to them as it was pre-diagnosis and that taking Tamoxifen had shut down any sexual desire. Others felt that chemotherapy had forced their bodies into premature menopause, which also lessened their sex drive. In contrast, Jenny described a quite opposite result:

The weirdest thing about all that was it was during radiation treatment, like suddenly, I had a sex drive again out of nowhere. Like, how – I felt certain that it was chemical or there was something bodily about it, because who wants to have sexual feelings during radiation when you’re working all day and running to the hospital every single day. It’s like the worst time. Why would I be suddenly interested?

Choosing treatment in the context of relationship status. Most participants, when describing how they selected their treatment, explained that it was the course most recommended by their medical team or which they had chosen based on their own research. Only three participants framed the decision in the context of their relationship status. Josephine commented:

I think if I had had a partner, the decisions would have been different....Because my thinking was, “Hey, I can’t walk around with one boob. I’m going to start dating again and hopefully fall in love.” You know, I’m sorry to say, but my first thought was, who’s going to go out with someone with one breast? Um, and I see it time and time again the support groups where women say, you know, “I’m going to start dating again, when I have reconstruction” – you never, it never seems to be about us. It seems to be about them. So yeah, it would be different.

Carolyn stated, “I don’t have a partner, so therefore, what my breasts looked like or didn’t look like wasn’t as primary to me, probably, as some other people.”

Although single, Kim speculated that a couple might negotiate another alternative:

For me, it was going to be a mastectomy. But if it’s a husband and wife, you know, some wives prefer to do the lumpectomy because they still have part of their breast to make – you know, because their husbands prefer that. But, I mean – but that’s about the only choice, because they have to – that’s a choice they both have to make. With me, it was no choice. Me, myself, and I, and that’s the choice I chose.

Resources for Coping

Participants’ methods of coping fell into two categories: intrapersonal and interpersonal resources. There were notable differences in the support from participants’ social networks and the support and solace they found from interpersonal resources. Family, friends, co-workers, and congregation members were already part of the

participant's social network prior to the diagnosis.⁷ Individuals in the formal breast cancer support groups became part of one's social network, but that happened post-diagnosis: the participant received her diagnosis, eventually joined the support group (or the team or the website), and then met other breast cancer patients. The following sections outline participants' intrapersonal and interpersonal resources.

Intrapersonal resources. Intrapersonal resources were those resources within an individual or under her control—her beliefs, values, and self-efficacy. They included being proactive (seeking additional information or refusing to accept misinformation or bad service); maintaining a grateful attitude; having faith in a higher power; and knowing when to shut others out and simply focus on themselves. Participants with higher incomes and more financial stability often acknowledged they had more resources and were more advantaged than other patients, and they wondered how others fared.

Proactive behaviors. Fourteen participants referred to themselves as proactive or described proactive health behaviors. They sought health information beyond that received from their medical teams, they made sure all their questions were answered by reputable sources, and when there were problems obtaining information or communicating with members of the medical team, participants tried to find better resources or doctors. Carolyn described her belief:

If I did not have a rapport with someone medically, I would have found someone else that I did. Because I believe that there has to be that communication and trust relationship, and I'm always kind of amazed when people don't expect that from their physicians. It's what I consider old school: where doctors got, you know,

⁷A social network includes all the people an individual knows, either directly or indirectly.

and it's not a partnership. I believe in having a partnership where I feel very comfortable asking and telling them what I think I need.

Phyllis stated, "You realize that you got to be your own advocate." And Jenny: "I'm real quick to, you know, go on the Internet. I will never accept not understanding it. I'll gather information and then maybe I'll go back to the doctor, say, 'This is how I understand this,' and usually I'm correct."

Transformative changes. Participants talked about huge, transformative changes they experienced as a result of their breast cancer. These changes fell into two categories: behaviors and perspectives.

Behavioral change consisted of deciding to either include or exclude people from their social networks, traveling more often, and more readily accepting help from others. Several women discussed the importance of being accessible. Tara admitted, "I'm just more open to people that I'd never interacted with before. I'm going out with people at work, which I'd never done much of. That kind of thing." Kim reflected, "I'm just more open and willing to be upfront with people and talk to people more than I used to be."

Still others began to fortify the boundaries of their social networks and inner circles, as Kara described:

I'm still nice to everybody and I'll help out a stranger because I know what it's like to go through cancer, but I'm very cautious about who I let in my inner circle. I don't think I'm out there as much as I used to be. I'm pretty cautious.

Throughout her interview, Kara referred to a number of people that were either not as supportive or were distinctly unsupportive as she went through her diagnosis and treatment. She said, "I think the biggest thing I have learned from this entire process is to

do the things I wanted, to live my life, to make peace with people and let them know I love them, and just to go, go, go. I've been to Australia and New Zealand this past year. I'm getting ready to go to Tibet. I travel all the time, so I don't put things off anymore."

After being diagnosed, Phyllis found she could not tolerate people's negative attitudes: "I don't have tolerance for [negativity] anymore. Because I know life really – you have what you have today. Tomorrow is not promised. So I don't even want to spend my time with people who are just full of negativity and nonsense."

Several participants recalled wanting to do things on their own during treatment but eventually recognizing that was not always possible. Cora said, "It's hard for me to accept help from people, I know that. Um, [rowing teammates] helped me do that."

After her breast cancer diagnosis, Patricia framed certain choices in the context of her survivor status: practicing safe sex, for instance, and no longer talking on her cell phone while driving: "That's why I wear a headset. 'You survived breast cancer. You cannot die in a car accident.'"

Perspectives also changed throughout this process. New perspectives included recognizing oneself as a cancer patient, that life goes on after cancer, and that other people also struggle. Although no participant admitted to being in denial at diagnosis or throughout treatment, Josephine explained her transformation from viewing cancer patients as "other" to now belonging to such a group. While deliberating over her options for transportation to treatment, she was told: "You can contact the American Cancer Society; they can get you a ride to treatment." Josephine went on to say, "Um, I never did. I didn't want to ride to treatment with strangers. In retrospect, those strangers would have been like me. Um, they were people going through it." Phyllis had a similar

realization at her first support group meeting: “I thought to myself, this is one group I don’t want to belong to.... Because who wants to be part of a cancer group? ... I realized that you know what, no one wants to be here!”

Despite being diagnosed with a later-stage breast cancer, Mira realized that good things were still ahead of her:

This is not the end of the road for me, this is not the end of my life. I’m going to have a great life after this. And it’s like, it’s kind of all about how I deal with it. I mean, if I want to be depressed and convalescent all my life, then I can do that, or, I can get out there and be positive and live it.

Like many participants after being diagnosed, Phyllis wondered why she was singled out:

So you start to go there and think, “Why does this have to happen to me?” Um, it will take you down to a deep depression. And you start saying, “Well, why not you?” This is your deal, and you just have to make the best of it. That’s my mentality now. But I went through that phase for a minute, where I was [mimics crying] “Why is this happening to me?” You know? And then you start to meet other people and go through, or start to understand what they go through, which is way worse than anything you could ever imagine, and then you start to realize, “You know what? It is what it is. That’s just part of life.”

Attitude of gratitude. Even in the midst of stress, discomfort, and confusion, participants often maintained gratitude. They were grateful for good prognoses, the love and support they received from friends and family, and being able to afford their treatment. Cora, a lifelong rower, said, “My spiritual and religious activities take place on

the river, and I do pray while I'm out there. If I'm by myself it's obviously easier. I try to maintain an attitude of gratitude, and thank God for what I can do and what I've been able to do and to keep doing it and to be strong for my family.... I look at the stars if it's dark and be grateful.”

Kara said, “I feel very blessed because I don't have to struggle with money. And that's the other thing too, probably with the docs trying to help other patients. You never know what people can afford and not. Um, I luckily could afford everything.” Phyllis frequently talked about using her breast cancer experience for a higher purpose.

When you start ... going through stuff, people connect more to you because, like, “Oh wow, I thought you had it all together and you're dealing with all this stuff,” and it's like, “Well, yeah!” And it helps you to help yourself and to help them.

Faith in a higher power. The majority of participants talked about having faith in a higher power, which often increased after their diagnosis. African American participants reported higher levels of religiosity than other participants. Only one participant remarked that her faith had probably decreased since she had been diagnosed. Participants who went to church frequently pre-diagnosis reported trusting God's plan for them.⁸

Carolyn said, “I can remember the thing that just really bothered me the most was when they told me they'd have to put the wire in the breast in the surgery. And I really started praying about that, and I really felt such a sense of peace throughout the whole time I was in getting those procedures. The whole time – in fact, I can almost say I enjoyed my whole surgical experience, so I mean, I definitely felt the presence of God.”

⁸ With the exception of one person, all participants previously or currently self-identified as Christian. (Mira came from a Hindu background.) As an adult, Jenny began practicing Buddhism.

Other participants also referred to praying or meditating during treatment, and seeking comfort through that ritual.

Several participants clarified the difference between religiosity and spirituality. Caucasian participants were the most likely to differentiate between the two. Participants not practicing religion before diagnosis often found religious services to be stifling, yet they still sought a strong connection to a higher power. Tara pointed out, “There’s a big difference between religious, which is manmade, and spiritual, which is a connection to God. And while I enjoy – I was raised Catholic, so I enjoy the mass, but when I want to go to God, I go to my meditation and spirituality. So it’s two distinct things for me. And many people look to religion for that social community, and I don’t do that. It’s just not something that I do.”

Kim relied on God in making her treatment decisions:

There’s a reason why God does everything to us, and there’s no use in questioning why he does it, because it’s not for us to question it. It’s just for us to do as He asked us to do. So therefore, there was no question as to why it happened to me. The only thing for me was what I needed to do. And therefore, I just put it in His hands and let it, you know, and do what He wanted me to do, which was go ahead and have the mastectomy and do my chemo.

Phyllis felt that her breast cancer diagnosis was part of God’s plan and, as such, offered her greater clarity. “I always believed in God, but I just felt like this brought me closer in terms of understanding that the big picture, and how we’re all connected, and how for me, the way I look at it is ... when I was diagnosed with this, it helped me to understand other people.” Phyllis also believed that God had a direct message for her:

“God – I felt like He led me to, ‘You need to reach out. You need to allow people to help you.’” Other participants did not understand why they had been diagnosed or why they had survived, but still attributed it to God. Alma said, “I’m just very thankful to God that I am alive and I am just thankful that I’m – that the cancer has not come back. I don’t know why I’m here, but I’m thankful I am.”

Some participants talked about feeling “tested” by a higher power. Sometimes they said this earnestly, sometimes with humor like Susan:

Every day that you’re alive there’s a challenge. Every challenge you face is a test of your convictions, of your faith and your morals... your character. One of these days I’m going to find out who’s been testing me and just slap them, because I know I’ve passed the test. [laughs] And it’s how you go about it... some people feel like they have a black cloud over their head constantly. And things happen. Call it faith, karma – whatever you want to call it. It just happens. It’s not just somebody singling you out, although sometimes it does feel that way. I don’t... I’m not going to say, “Oh God, why me? Oh God, why me?” It’s like, “God, help me through this. Show me the way.”

Perspectives on death and dying. Only three participants referred to their own death and dying. Most of them had received positive prognoses; only one participant was diagnosed with Stage IV breast cancer⁹ (as Kara put it, “I’ll be in treatment for the rest of my life”). There was a difference between considering the prospect of having to go through treatment again and one’s acknowledgement of mortality. Alma compared an acquaintance’s perspective with her own:

⁹ Stage IV breast cancer is characterized by cancer cells that have spread to other parts of the body. At that point, it is unlikely the cancer will be eradicated. Women diagnosed with Stage IV have a 15% chance of survival over five years (American Cancer Society, 2013).

One of my co-worker friends, she just finished her chemo treatment, and hers was much longer than mine. Um, you know, and she would just talk about how she doesn't know if she can do it any more. And that's how I felt. And I also felt that if I ever had to go through this again, I don't know if I could. Or want to. So now the question is, do I want to live or don't I want to live?

Tara said:

What I'm afraid of is that process I have to go through, what my breast cancer friends – not many, but a handful – have gone through, is that awfulness, when you get to the end. You know, I just had a friend pass a couple weeks ago.... She was told it was her end time. She just couldn't embrace it. I could just see the bewilderedness in her eye, and I totally got it.

Interpersonal resources. Interpersonal resources included the women's support groups (in-person and online) and breast cancer-specific sports teams. Some support groups were specific to race or cancer stage. Participants talked about how beneficial it was to meet people with similar experiences and stories as theirs. Fellow support group members and teammates also able offered practical advice.

Cancer support/social organizations – in-person and online. Participants emphasized that while other breast cancer patients in general were more likely to understand them, it was especially helpful to surround oneself with patients who had had a similar experience (stage-status) or had shared interests (i.e., water sports). Tara said about her rowing team of breast cancer patients and survivors:

But the difference with [breast cancer rowing team] is that everybody in the boat came up, whether it's Stage I or Stage IV, everybody has a common thread there.

The other thing about that organization is the women are there to row. In support groups everybody wants to keep rehashing the problem. I don't want to rehash problems, I want to do something. In the course of hanging out together – “Hey, I have a lump in my breast again, what do you think about that?” – there's a conversation about it, but it's a healthy conversation.

Elizabeth said about her breast cancer rowing team: “When you're rowing... you're not thinking about your poor little self anymore. You're thinking about your team.” This was similar to other participants who belonged to breast cancer-specific sporting organizations. The practices and races allowed them opportunities to focus on something important aside from their health.

In-person support groups. There were many similarities between in-person and online support groups. In-person support groups offered emotional, informational, and some appraisal support; online groups offered informational and emotional support. Participants were more likely to develop relationships with directors and members of in-person support groups. Joy repeated the encouraging words she received from the director of a local African American breast cancer support group:

“If you're not ready to go back, then don't do it. Stay on disability. You can always go back when you're ready,” and she just really helped me to understand that. ‘Cause in this society it's like, you know, people don't care that you have cancer. They just want you to produce. So she really helped me to understand that I deserve to take care of myself in every way, and she really helped me.

Another benefit of support groups was finding and receiving affirmation for treatment choices. Participants also learned about alternative treatment options. Denise

said: “When I was going to the group meetings – who was handling Tamoxifen, who was handling all these different therapies and who wasn’t and who was. At some point you kind of realize that I did have choices that I could make and didn’t have to go totally according to what these doctors were saying to do, um, so it was very helpful.”

Sometimes women talked about intimate relationships at support group meetings. Margaret, the only participant that had an intimate partner at the time of the interview, relayed the encouragement she had been able to offer: “One woman was saying she needed to tell men she had cancer, because she – well, with one young man, she talked about it with him, and she said that she hadn’t heard from him since. And we all said, ‘Yeah, that’s going to happen, but there are some good men out there like’ – and I told her about mine.”

Support groups: Finding the right fit. In finding support groups, participants explained that it could be difficult to find the right fit. The primary example was stage status: it was hard for women with later-stage cancer to relate to women diagnosed with Stage 0 or I. Mira said about her first support group experience:

Walking in there as a thirty-one-year-old who, you know, had Stage IIIC cancer and having to listen to a sixty-five-year-old woman who was, you know, Stage IB or something like that, bawling and crying about how her life is over, um, even though she’s got kids and grandkids – you know, that’s something that I don’t get to have.... I had a really hard time dealing with that, and that was the point that I just swore off support groups. But then I found an under-forty support group.... And that was a freaking godsend ... we’re all around the same age and run at the same pace.

Kara likewise had difficulty finding the right support group, owing to her stage status:

I went once and realized everyone was Stage I, Stage II. It's different when you're Stage IV because you're what everybody doesn't want to be, and so instead of having a support group where everyone looks at me with support, they looked at me with pity.

Camille went to a general support group once, but for several reasons she could not relate to the members. "The one time I did go, I did – I felt, you know, I felt a little connection, but then I felt way, way, way different from everyone because one, I was the youngest, two, a lot of them had mastectomies and chemo, and three, I think I might have been the only black one there. [Laughs]"

The other African American participants in this study belonged to support groups created specifically for African American women. Thus, they did not report being unable to relate to members of other races in these support group settings.

Online support groups. One of the best things about online support groups was the constant availability, as Jenny recalled:

I was on the Komen Breast Guide – the message board... They were amazing. Particularly wonderful: I'd freak out about something late at night, and I'd put a message out there, and within fifteen minutes, someone would answer me. And it was so incredibly helpful.

Patricia was extremely grateful for the conversation she had with a member of an online support group who had the same unusual kind of breast cancer that she had:

"There was one woman ... who told me she also had multifocal breast disease, but she had a lumpectomy. And she said, 'This is a phone call – we can't do this by computer'."

Giving back. Many participants wanted to return the favors they received by helping other breast cancer patients or individuals impacted by cancer. They often selected groups that had offered services to them. These groups included the American Cancer Society; Look Good, Feel Better; Survivors Offering Support; and Y-Me.¹⁰ Mira said about Survivors Offering Support,

When they have somebody that's diagnosed that's kind of... serious, they usually send them my way... I felt like I got a lot of support when I was going through treatment, um, like the Cancer to 5K group was just so [sighs] – I used to laugh and joke and call it my therapy session. Um, because it was just amazing being around these people who have been through something similar and dealing with it in such a positive way.... And some of these people are just so inspiring and if I can help people in that way, it just makes me feel like, okay, something good came out of this whole experience.

Josephine spoke about her volunteer work: “I got involved volunteering at [cancer support organization], working with the kids who had lost a parent to cancer, which was a great experience, um, because I had lost a parent and had nobody to talk to. I also worked with the kids that had cancer for a while. It was great. They were amazing little soldiers, yeah, so it was all, um, positive and healing to me.”

Meditative and Holistic Care

Participants used meditative and holistic care throughout their breast cancer experience. This included massage, yoga, Pilates, prayer, and some art therapy. Two

¹⁰ These are all large national organizations; naming them does not compromise participants' confidentiality.

participants had wellness coaches during treatment. Sometimes the medical team contributed to participants' meditative experiences. When asked if she engaged in meditation during treatment, Jenny recalled:

After radiation, when I went to the hospital – and it's real quick, you know you travel all the way there and you lie down and they zap you, but then they send you back into this room where there'd be a nurse and they have these like big fans, like big, hand-held fans. She would – that was just part of their treatment – she would just fan you. They didn't want you to get burned, but it was so – and I pretty much had the same nurse, I just loved this woman. I swear, I would just go into this meditative trance there. She'd be fanning me, and just kind of telling me, talking to me, telling me stories about her life, and it was just ... I didn't want to leave! It was fabulous. I just looked forward to going – I don't think she had any idea how much I looked forward to lying there and having her fan me and talk to me.

Between the connection to the nurse and the physical comfort derived from the fanning, Jenny was able to relax.

Radiation staff also helped Camille find peace during treatment:

The radiation part was another where I kind of lost my mind, because the machine is intimidating and, uh – it's scary.... To me it's like – it's like it's medication, but I don't see it that way. I didn't see it that way at that time. I saw it as going into my body, and it's going to make me worse, and I was there every single day. But I had a wonderful staff. They talked to me and they played music and we

finally got into a ritual where I was almost in tears laughing coming in out of there. So yeah, that helped. That helped a whole lot.

Participants varied in what they derived from yoga. Some, like Cora and Mira, used it more for physical exercise than mental or spiritual peace. As Mira explained, “The yoga was kind of also my physical activity. Like the sun salutation – for me at the time, that would be a workout in itself.... Whereas the meditation was just... kind of quiet my mind and those five billion thoughts that were constantly running through my head, kind of just pause them, relax, and just decompress.”

Some participants referred to the healing benefits of massage, acupuncture, and reiki during and post-treatment. Joy was glad to experience positive physical touch during treatment:

There’s this organization called Healing Touch. [They] put their hands on people with diseases. Because I didn’t have a partner, and my family was so disoriented. It just really helped to have someone touch my body, touch my head – all of that really helped me to feel... “loved” is a strong word... but, um, “supported,” I guess. It helped me feel less alone.

Patricia valued the concept of “positive energy,” which she discussed with her Pilates instructor, reiki practitioner, and acupuncturist. Both Camille and Phyllis found that reading scriptures or books on peace was soothing. Phyllis said, “[The book] talks about acquiring peace no matter what the circumstances are that are swirling all around you. You have to find that place where you let go of that worry. That’s what peace is to me.”

Wellness coaches. Two participants engaged wellness coaches and both described their experiences as informal and unstructured, yet teeming with informational support. To a lesser extent the coaches offered emotional support as well. The participants referred to these people as “health coach” and “spiritual advisor.”

Barriers to Care and Treatment

Participants frequently talked about barriers to care and treatment. Sometimes they had personally experienced these barriers; other times they had observed discrepant access to care or could imagine it. These barriers included race, socioeconomic status, education, red-tape at work, and paperwork problems. Several participants acknowledged their own resources and juxtaposed those with the experiences of others without those same resources (education, health insurance, and transportation).

Race. Race as a barrier to treatment fell into two categories: participants who felt that their own medical teams did not know how breast cancer impacts African American women distinctly, and then at a societal level how African Americans are at a disadvantage concerning accurate medical information. Denise said: “I feel like I was that experiment of black women with my surgeon.” Joy, who wanted to create a documentary for African American breast cancer patients, said:

I think a lot more has to be revealed and said about African American women and men going through breast cancer. ... I think more information about our major lifestyle choices may contribute to breast cancer, and the fact that African American men and women don't participate in clinical trials ... the statistics for dying are higher for African American women than they are for Caucasian

women. ... Why is that? Is that really true? What's going on? This needs to be addressed.

Socioeconomic status. Several participants were stressed about having to work during treatment; they could not afford to quit their jobs. Others reported observing patients under the stress of employment constraints. Carolyn, a former insurance agent, said:

I was sitting there one day, waiting for my radiation, and there's a mother and daughter sitting over there, and they were really talking about how they didn't know how they were going to do this every day – transportation – they had to take several buses to get here, and this, that, and the other. I went through my treatment and it really bothered me, so I found the social worker, and I said, "So what's the deal?" She said, "Well, we can give them bus tickets and taxi fare or whatever, but right now [funds are] low." So I decided I'd start contributing to that fund. ... Because you know, I'm very fortunate. This was not an economic hardship on me. I have excellent insurance from retirement, I mean... I can't imagine having to go through that when you're working. When you're economically challenged, trying to get treatment.

Red-tape at work. Sometimes there were red-tape issues that hindered patients' reentry (e.g., sick days, inflexible schedules). Camille recalled:

I'll talk about trying to go back to normal with my employer, which hasn't happened [laughs]. I – I work as a manufacturer. I worked – work on a press. It's very physical. It requires lifting and standing and washing and – you know, it's just a lot. It's like working on a car. And the days, you know, they're – we're

there nine hours and it's hot, it's cold, it's greasy, it's dirty, you know, it's all the above. It's kind of hard for a female... It's hard for me, and then have to try to get back to the way I was working. So... it's – to me it's not happening, because I'm still feeling a little pain... I've taken off a lot of time. Um, during the time I had surgery I had approximately six months away on the – from the job... I was sort of bullied to come back to work. And I will use that word, "bullied." I didn't get paid, I ran out of leave, and it's a situation, you know, where I feel I'll lose my job.

Camille went on to describe the breakdown in communication with her primary medical caregiver that ultimately led to her going back to work prematurely:

[My nurse practitioner] took me off my job-modified work duty. She took me off. She told me, you know, that I had the compression, I got the sleeves, she said, "I'm putting you back to work," and I looked at her like, "You know what that means? That means they're going to make me go full duty," and she goes, "I think you're ready to go back to work." And I'm not, and she didn't hear me. I told her, "Well, if you're going to do that, then you need to put somewhere in print that I need to take breaks. Because I'm on Tamoxifen... and, um, I'm tired, and I hurt very easily. My bones and muscles hurt a lot." And she wrote that down, but that was the end of that.

Alma's post-diagnosis frustrations at work went beyond the scope of her personal experience. At the time of her interview, she was one of several female firefighters who had been diagnosed with breast cancer. Attributing the multiple diagnoses to their work environment, Alma took part in a class action lawsuit.

Because of the percentage of women in our department with cancer, that's where we had a lot of outside agencies investigating this whole thing, and they're finding that all the exposures and stuff that we're exposed to are causing this. Uh, so it's hard when you're trying to get well, and you're stressing, because you don't know, you know, how you're going to pay your mortgage. Um, it was really hard. That was really difficult for me.

Two participants addressed the Susan G. Komen controversy and how lower-income patients were affected when the Komen Foundation withdrew funding that supported Planned Parenthood's breast cancer screening for poor women. Josephine, who had previously remarked on the power of online breast cancer support systems, stated emphatically:

And something that had a huge impact on all survivors was what happened with that Susan Komen thing.... That lit up the Internet... people were outraged. And I've done quite a few walks in Making Strides and everything, and there are a huge amount of low-income families, women, with cancer. And how could they do that? ... I mean, they've done amazing work ... but they fucked it up big time.

Education and health literacy. Several participants commented on the difficulty of understanding medical information and forms. Josephine said about selecting treatment, "I don't know how people that aren't at least a little bit educated could go through something like this, because they're perfectly willing to – it seems to me that they don't want the weight of that decision, so they give you all this information. What if you don't understand it?"

Reflecting on a recent exchange with her health insurance company, Carolyn explained how long it had taken to convince the carrier that because she had a referral, she should not have to pay \$24,000. It took several conversations with several employees before they realized she was correct, and the error was on their part. She concluded from the experience that:

I feel bad and I've often thought that maybe one of the things I could do is figure out a way to provide as a volunteer service to people who are having issues with trying to resolve – because at some point, your medical provider says, “We can't resolve it. You're going to have to get with your insurance provider to resolve it,” and generally people are less able to resolve it than their providers are.

Along with the frustrations of reconciling incorrect charges, Carolyn acknowledged the difficulty of patients who have no health insurance: “Cause I have to tell you, if you don't have insurance, and you're having to worry about getting medical care, that has to be daunting.”

Advice For Patients and Providers

Advice for other single breast cancer patients. When asked to offer advice to other single breast cancer patients, participants recommended determining who would be most supportive and relying on those people, being careful about whom to disclose personal information to, and taking time to focus on oneself.

Josephine said, “Find an oncology counselor. I didn't even know there was such a thing. And my career – I was a therapist... and I had no idea that there were social workers that focused just on cancer.”

Cora advised, “Reach out more to other people. I don't know what else to say. I did that to somebody who was getting a mammogram at the same time I was. I gave her my number and she called me and talked to me before she told her family, and she had a pretty big family. But it was nice – I think she appreciated me giving her my number and then talking to her on the phone, even if it was just a couple of times. You know, to reach out and don't be too proud.”

Carolyn cautioned other patients to “[b]e... very selfish and discerning about friends or family, um, that you kind of allow to be in your inner-circle. Particularly if you are a ... pleaser or a caretaker. Because you need your energy and your focus to be on discerning what treatment you need to be doing and to take care of yourself. And also allowing others, when appropriate, to take care of you.” Phyllis also recognized that predetermined roles could impact individuals' actions during treatment, although she encouraged patients to talk with someone: “People need to talk. Especially women, because we think we just have to hold it all together, and a lot of times we're doing so much that we don't realize that we need to take the time to do the preventative care. Get in there and don't wait for something to happen. Get in there.”

Kim recommended perseverance:

Don't let the disease make you – don't let it depress you into doing something that's not you. Continue on living your life. You just got to cope. You got to keep continuing forward. You can't let someone bring you down. This is just something that happened to me. This doesn't define who I am ... I'll tease people and say, “I have breast cancer you guys, can I go first? Can I do this?” But I just

do it as a joke. I'm proud of it, I have no shame in it, and most of the time I'm walking around with no hair on – no hat on. I don't care.

Speaking from her own experiences, Margaret said, "If you are a member of a church, stay in touch with your church, talk with your pastor. Um, see if there is other women at your church that have gone through it. Not everybody is just going to announce it. You don't know who they are."

Joy pointed out the risks of isolation:

Just because you don't have a partner doesn't mean that there are things that you cannot achieve throughout the treatment – [the] entire process. Being alone is the worst thing I could have done to myself. There are people out there going through the exact same thing that I'm going through and it just reminds me to get out there. If you spend too much time alone you start believing things about yourself and beating yourself up where you would probably die.... Get some type of support as you go through this process.

Kara advised single breast cancer patients to be self-protective:

Don't feel the need to tell everybody what you have going on. Be selective. You know, protect yourself. Just like you would if you didn't have cancer, 'cause again, I feel like people feel like they have to tell everybody about their cancer. It does scare people away, but a lot of people get to know you. And again, just really take care of yourself. I think it's a time – to some extent – to soul-search what is important to you, whether you're Stage 0 or Stage IV, to really think about what you want out of life. And I think it's also a kick in the butt to not put things off tomorrow that you can do today. So, you know, if it's important for you

to meet somebody, then put yourself in the state of mind to meet somebody. If it's important to spend time with your family, spend time with your family, but do what you love and don't feel pressured.

Phyllis also encouraged women to date if they wanted to date:

Life goes on. You gotta grab it. If you sit back and say, "Oh, I'm not going to date or anything until I feel 100 percent." There may never be 100 percent. You know, each day is a process, and if someone wants to hang out with you... You – you still feel vulnerable, but you feel like, "Okay, I could really get hurt now, this person doesn't want to deal with me or whatever." I could see how that would be very difficult. But you also realize, you know, you have to live your life.

Advice for medical professionals. When asked to offer advice to the doctors of single breast cancer patients, participants recommended that they learn whether patients have supportive networks and encourage them to bring someone with them to treatment. Jenny said, "It would be good to check in and see, 'Who will be coming in with you?' That kind of thing, and if the person didn't know, let them know that it's really important to have some rational people. Like, check in – 'Who's the rational person you're going to be working with?'"

Carolyn pointed out that there are questions that doctors should ask all patients, regardless of whether the doctors know anything about the patients' relationship status.

None of them knew if I really had any support or not. Or if I needed any or not.

So I think maybe not just even for single people, maybe for people in general, that they need to kind of have some dialogue about "How are you dealing with things or not dealing with things." My perception was going through this – and maybe

this was a misperception on my part – was that they wanted me to be diligent about living my life normally, whatever normally means. So there wasn't a lot of what I'd consider a lot of, um, coddling, “do you need help driving or getting meals” – there were none of those conversations.

Denise also felt it was important for physicians to be aware of patients' support systems. “To make inquiries into – ‘Would you like to invite your partner or whoever, your family member to the next visit?’ Give the doctor some kind of idea whether they're alone or not ... really noticing, tracking who comes to the visits. You know, asking ‘Where is your daughter?’”

Besides awareness of patients' lives and overall needs, participants thought that physicians should be judicious in which support groups they recommended. Mira recalled:

So my doctors definitely recommended the support groups, but I think understanding that – that finding a support group that matches the needs of your patient is really, really key. Because having a – I know that – I met a bunch of women that were 26, 27 and going through treatment right now. So sending them to a support group with mothers and grandmothers – it's not – it's not relatable. It's not really going to help them as much. Sending them to a younger women's support group, um, or just even a general cancer support group where there's a bunch of twenty-year-olds, it's like, that's going to be relevant to their lives. Um, I think that would have made a really big difference. Because if I had gone there earlier, I think that would have really helped me out.

Several participants talked about the need for attending to patients fully. Camille said, “I mean, I know time is the essence [laughs] but I think that each patient is different and just a moment of their time to actually listen to what they’re saying or trying to say.”

Kara urged empathy:

I think one of the biggest things for them – not necessarily my oncologist, but the entire team – is to not treat you like you’re a triple-positive, Stage IV, thirty-six-year-old. I’m Kara, and I have a life, and to treat me like I’m a human being and to maybe put themselves in that situation, lest we forget there’s a person there, and not just a diagnosis.

Many participants expressed interest in using alternative treatment, but they commented that their medical teams either knew nothing about these other forms of treatment or discouraged them. Kara said, “The other thing I wish they could encourage was alternative treatment, because they would push different meds. It seems like the doctors were kind of scared of that and didn’t – they wanted to stay away from it.” Elaine declared, “The doctor should be concerned with the whole person, and I’d say that a couple of them aren’t.”

Summary

Ten themes emerged from the interviews: initial reaction to diagnosis, stressful personal backgrounds, relationships within social networks, support from social networks, medical treatment, relationship status in the context of breast cancer, resources for coping, meditative and holistic care, barriers to care and treatment, and advice for patients and providers. The following chapter will discuss major conclusions and implications based on the data.

Chapter V: Discussion

The purpose of this study was to explore how breast cancer patients without partners adapt or create supportive networks, seek health information, and make meaning of their relationship status within the context of their breast cancer experience. This chapter examines answers to the research questions; presents major conclusions, implications, and limitations; and offers directions for future research, policy, and practice. The practical implications of this study apply to many types of family and medical professionals.

Research Questions and Answers

This study asked six research questions. Listed below are the answers to each research question.

1. *Do breast cancer patients adapt or create social networks to cope with the fears and frustrations of diagnosis and treatment? If so, how?*

Breast cancer patients often adapted their social networks to ensure that the people surrounding them throughout treatment were supportive. Sometimes this meant temporarily cutting ties to relatives who could not cope; other times it meant dissolving friendships. Participants told well-meaning friends and family what exactly they needed, including time to themselves.

2. *What types of social support (informational, emotional, instrumental, appraisal) do breast cancer patients desire?*

Participants talked about needing informational support from their medical team and emotional and instrumental support from their social networks. When members of their medical team did not offer this support, participants often

switched to different providers. When members of their social networks did not offer emotional support, participants often distanced themselves from those individuals. Patients did not discuss wanting or receiving appraisal support.

3. *Do breast cancer patients perceive difficulty in accessing health information?*

Participants often knew how and where to obtain health information, but they expressed dismay with the potentially confusing, pessimistic, and inaccurate information they found on the Internet. The majority of participants discussed practicing proactive health behaviors.

4. *Do breast cancer patients perceive difficulty in communicating with their medical care providers? If so, how?*

Communication issues arose when providers had different goals or measures of success than patients did. Participants who reported continual difficulty in communicating with their medical care providers usually replaced those individuals with different providers.

5. *What does it mean to breast cancer patients to not have partners during diagnosis and treatment?*

Overwhelmingly, participants stated that they were better off single than with their former partners and spouses. They also admitted that a supportive partner would have been desirable. Most felt that their experiences would have been different with the presence of partners; responses varied in terms of whether their experience would have been enhanced or worsened.

6. *How do the experiences of breast cancer patients without partners vary qualitatively by race, ethnicity, socioeconomic status, and health literacy?*

Participants discussed how patients' experiences might differ based on the above variables, but they were not necessarily describing their own experiences. Instead, these participants acknowledged their own financial and informational resources and wondered how women without those resources accessed treatment and health information. Some African American participants talked about feeling their physicians did not know enough about the association between race and breast cancer rates. Several participants felt pressured to return to work too soon. On average, African American women are diagnosed later and with more aggressive forms of breast cancer (National Cancer Institute, 2012). This may lead to different experiences among various racial groups.

Major Conclusions

From my analysis that produced 10 themes has come several conclusions for family scientists, health care providers, therapists, policymakers, and other patients. These conclusions will be discussed for the remainder of the chapter.

No built-in support. When a person is diagnosed with cancer, his or her intimate partner is most likely the primary caregiver (Colgrove, Kim, & Thompson, 2007; Ockerby, Livingston, O'Connell, & Gaskin, 2013). If there is no partner, then who is the primary caregiver? This study illustrated that caregivers vary among women without partners, and that they really have no *primary* caregiver. Their caregivers included siblings, children, and occasionally parents, but no built-in support system as would be expected from a spouse or intimate partner. Children still living at home were either too young to be supportive or they were preoccupied with other family matters. Women otherwise lived alone. These findings confirm that common clinical assumptions about

breast cancer patients' support systems are often mistaken (Gass, Weitzen, Clark, & Dizon, 2007).

Families and breast cancer. Family members are greatly impacted by breast cancer diagnoses. In this study participants reported their mothers and young adult daughters as having particular difficulty dealing with their relatives' diagnoses. Siblings provided the most support. This is consistent with previous findings that first-degree female relatives are the most impacted by a breast cancer diagnosis within the family (Raveis & Pretter, 2005).

Mothers' reactions to diagnosis. Although participants' families in general were supportive, participants talked about needing to shield their parents – especially their mothers – from the diagnosis. Once mothers were told, they were often unable to cope with the knowledge that their daughters had breast cancer. In turn, mothers' reactions hurt participants, whether or not they understood why their mothers were avoiding them. Family members sometimes have unanticipated or undesired reactions to an individual's breast cancer diagnosis (Figueiredo, Fries, & Ingram, 2004). These reactions can hurt patients when they are already stressed. The more that patients prepare for this possibility, the sooner they surround themselves with more supportive people.

Telling the children. Participants with children had difficulty sharing news about their cancer, particularly if the children were very young, living away from home (usually at college), or otherwise preoccupied. Disclosing such news to children could be very difficult, as participants had to guess how their children would handle the information and whether the children would inform their mothers if they had questions or concerns. Participants reported that young adult children living away from home were particularly

affected, even if participants did not know about their children's reactions until months or years later. This is consistent with previous findings: parental cancer can have adverse effects on children's well-being (Krauel, Simon, Krause-Hebecker, Czimbalmos, Bottomley, & Fletchner, 2012; Visser, Huizinga, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2004). Patients who are parents need to be alert to their children's potential reactions, which may or may not be discernible.

Finding worthy partners post-diagnosis. There was a residual grief in participants' stories: women pointed out that while they could get by on their own during diagnosis and treatment, it would have benefited them to have a supportive partner throughout that process. Although participants often had supportive friends and family, there was still a deficit. This was compounded by their uncertainty about dating after being diagnosed. Nineteen of the twenty participants reported not having positive experiences with dating post-diagnosis. They attributed this to potential partners (in all cases, men) not feeling comfortable with their health status – especially if the participant was in her thirties or early forties when diagnosed.

Despite a lack of research on the experiences of breast cancer patients without partners, a literature search found one article on the experiences of young women with breast cancer mutations (BRCA) (Hamilton & Hurley, 2010). Those women talked about difficulty disclosing this information to potential partners. However, participants in that study could only speculate whether they would be diagnosed with breast cancer, whereas participants in this study had already been diagnosed and were undergoing or had recently been treated. Findings from this study on dating post-diagnosis may have implications for other cancer patients and survivors.

Disclosing information: when, where, and to whom. Participants talked about needing to limit how much information they shared and with whom. They discussed well-meaning friends and family who wanted to drop by or be kept up to date on their health status; this could be overwhelming and unwanted. Participants appreciated the concern but sometimes needed time for themselves. Other breast cancer patients understood this best. Earlier research acknowledges that disclosing one's cancer diagnosis usually results in "emotion work," which includes managing and protecting the emotions of others (Yoo, Aviv, Levine, Ewing, & Au, 2010). Emotion work is stressful to patients and should be minimized even if it means limiting how much patients share with friends and family (Yoo, Aviv, Levine, Ewing, & Au, 2010). This is an important message for friends and family, who may have difficulty understanding why their presence is not always wanted or needed. Families need instruction in communicating with patients throughout treatment.

Relevant support groups. Participants' experiences with support groups varied, depending on how closely they identified with other members of the group. Participants were more likely to connect to members if they were the same age or at the same point in their lives, if they had similar prognoses, or if they enjoyed the same activities (as in the case of the breast cancer rowing team members). Conversely, participants discussed how frustrating support groups were if they could not relate to the other members, or if they were reminded of their own more serious prognoses. One existing study found similar results that suggest stage-specific support groups are more beneficial to later-stage patients than mixed-stage support groups (Vilhauer, 2011). The purpose of support groups is to help breast cancer patients connect with other people having similar

experiences (Park, Bae, Jung, & Kim, 2012). However, this study found that women need more than just breast cancer to connect with each other. Otherwise, there is a dearth of support, and in some cases more harm than good is done.

Benefits of pets. Pets were tremendous sources of support to participants. They brought comfort and humor to participants when they needed it most. Two participants pointed out that their dogs were the most important form of support for them, even above any former or potential partners. Pets or companion animals (especially cats and dogs) can contribute to humans' health and well-being (Wells, 2009). Cancer patients specifically may benefit from pet therapy, as it reduces rates of depression (Larson, Looker, Herrera, Creagan, Hayman, Kaur, & Jatoi, 2010; Orlandi, Trangeled, Mambrini, Tagliani, Ferrarini, Zanetti, Tartarini, et al., 2007).

Although not all cancer patients can have pets (possible limitations include affordability, ability to exercise animals, and household members' allergies), there are other ways to interact with animals. Hospitals that use animal-facilitated therapy (AFT) have found that patients' vital signs improve and that patients have increased pleasure and decreased emotional distress (Urbanski & Lazenby, 2012). This information should be further disseminated to hospitals, medical teams, and cancer support organizations.

Complementary and alternative medicine. Participants expressed interest in complementary and alternative medicine (CAM) and even engaged in it, but usually they did this independently of their medical teams. Some participants lamented that their doctors seemed unfamiliar with CAM or even discouraged it. Integrative oncology (which may include elements of CAM) is gaining support from some medical providers (Geffen, 2010). Integrative oncology involves the medical team being more fully

involved in offering CAM to patients, whereas CAM may occur as part of or separate from the medical team's services. Examples of integrative oncology include guided imagery, massage, and nutrition counseling (Hart, Freel, Haylock, & Lutgendorf, 2012; Seely, Weeks, & Young, 2009; Serra, Parris, Carper, Homel, Fleishman, Harrison, & Chadha, 2012). However, conversations about CAM tend to be patient-driven and often result in moderate-minimal encouragement from physicians (Juraskova, Hegedus, Butow, Smith, & Schofield, 2010). Studies on CAM and integrative oncology have found that these soothing and relaxing techniques bring peace to patients (Beatty, Adams, Sibbritt, & Wade, 2012). As treatment for breast cancer can be harsh and invasive, it is important that medical teams consider what they can do to provide comfort to patients – or at the minimum, be able to refer patients to programs and services that can offer them some solace.

Being proactive is critical. Fourteen participants referred to themselves as proactive or described proactive health behaviors. They knew where to find accurate health information, asked questions of their medical team, and made changes to the team if they could not develop rapport with one of the doctors. These findings are encouraging because they suggest that many breast cancer patients know what they need to do for the best treatment experience possible. Having good patient-medical team relationships are critical, because the quality of the patient-provider relationship may determine whether the patient regularly goes to doctor appointments and is vigilant about her health (Eng, Maxfield, Patrick, Deering, Ratzan, & Gustafson, 1998). Findings from this study are similar to previous research that reports breast cancer patients as being proactive in their search for health information (Radina, Ginter, Brandt, Swaney, & Longo, 2011). These

health behaviors are indicative of health literacy, a public health concept that has significant ramifications for cancer screening, prognosis, and comprehension of health information (Polacek, Ramos, & Ferrer, 2007; Sulik, Cameron, & Chamberlain, 2012).

Transformative changes. Participants talked about feeling grateful for still being alive, for having relatively positive prognoses, and for experiencing personal transformations post-diagnosis. This echoes earlier work on cancer patients making meaning of their diagnoses and developing subsequent positive attitudes on survivorship (Kahana, Kahana, Deimling, Sterns, & VanGunten, 2011; Zebrack, 2000).

Although many forms of cancer are not as life-threatening as they were in previous decades, cancer of any type is still a very serious diagnosis. Given the relation to previous literature, it would be sensible to suggest that the issues discussed by participants are part of a wider experience among cancer patients of all types and prognoses. In an editorial on studying disease through a more holistic perspective, Senzon (2010) commented, “Disease, then, can be viewed as a catalyst to develop a new sense of a person’s role in his or her own life; a new connection to the body, emotions, spirit, family, community” (p. 1240). Participants described transformative changes to their religiosity, philosophies, and life perspectives that they attributed to their cancer experiences.

Utility of Theoretical Frameworks

This study used ecological systems theory and the health promotion perspective as frameworks for understanding the lived experiences of breast cancer patients without intimate partners (Figure 2). Ecological systems theory posits that individual experiences occur within integrated systems of family and contextual factors. Thus, a single woman

who is facing a breast cancer diagnosis is surrounded by multiple systems of factors that will influence her reaction to the diagnosis, treatment, and holistic experience. Her family, friends, co-workers, and medical team are part of her microsystem.

Participants discussed the positive and negative reactions and relationships they sustained with these groups throughout their diagnosis and treatment experience. The mesosystem – the interaction of two microsystems – was evident in participants' descriptions of family members' previous medical experiences that impacted choices they made during their own crises. It was also evident in participants' descriptions of interactions between relatives who were health professionals and participants' doctors. The exosystem included hospital and work policies. Some participants felt forced to return to work before they were truly ready; because of their employers' specific work policies, these participants could not take more time off work without risk of being fired. The macrosystem includes cultural influences. Participants talked about the impact of race and socioeconomic status on the timeline and quality of treatment.

Another premise of ecological systems theory is that individuals learn how to adapt. If the system is inadequate, than people will make the necessary changes to survive. This was very apparent in the study. Participants talked frequently about unsupportive members of their networks whom they cut ties with, as needed. Toxic people included relatives and friends. Adaptation also refers to the bidirectional influences of patients and the medical team. Participants talked about sharing their own breast cancer research with their doctors; sometimes they described their doctors as learning something new. In one case, a doctor even joined a group for African American

breast cancer patients in order to learn more about how this group might be uniquely impacted by breast cancer.

A second lens for viewing the study's findings is that of the health promotion perspective, which also considers the social environment and multiple contexts of patients. The health promotion perspective refers to four types of support that patients may need: emotional, instrumental, informational, and appraisal. Participants most frequently referred to receiving instrumental support from friends, family, and co-workers in the forms of meals, rides to surgery and treatment, and cleaning their houses. Participants did not discuss needing or receiving appraisal support.

According to this perspective, developing new social network linkages may be necessary when "the existing network is small, overburdened, or unable to mobilize for the provision of effective support" (Glanz, Lewis, & Rimer, 1997, p. 193). Participants who were involved in breast cancer groups (either traditional support groups or sports teams specifically for breast cancer patients) talked about how helpful it was to meet with people who knew what they were going through because they too had experienced it. Shared experiences included tumor type, selecting treatment, the aftermath of mastectomies, and dating during and post-treatment. However, some participants in this study went further to explain that general support groups were not enough: stage-specific groups would be more beneficial.

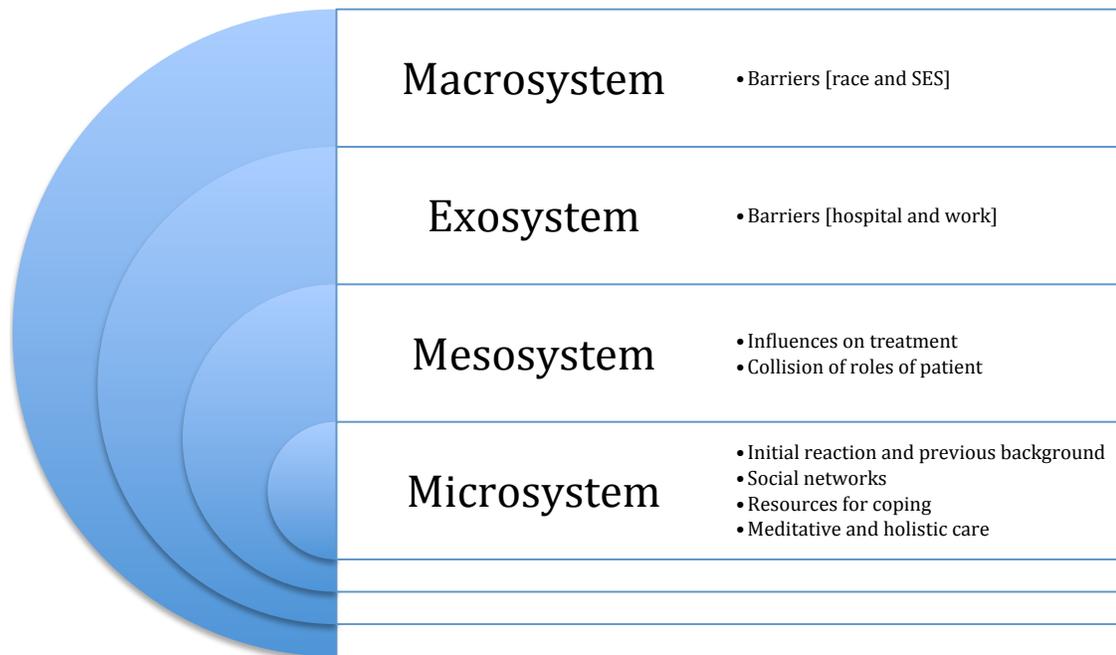


Figure 2 Ecological Systems and Social Support Model with Themes

Implications

Although previous studies on breast cancer patients have included relationship status as a variable, to date there are no studies on breast cancer patients without partners. This is the first study to examine the lived experiences of breast cancer patients without partners. There are several implications for the results of this study; the following section discusses the implications for research, therapy, policy, and practice.

Directions for future research. This exploratory study uncovered important themes that should be explored further. Many women were interested in dating – often to find a serious partner, not a casual fling – but either feared or had experienced potential partners’ loss of interest once they disclosed their health status. This was particularly true of younger participants (under age 45). Future research should look at how breast cancer

patients seek intimate partners and when they choose to disclose their health status. Some of these results might be generalized to other cancer diagnoses and chronic health issues.

This study had no age parameters except a minimum age of 18. Women at 36 and 55 likewise talked about being interested in dating. However, there were notable differences between women who had never had children and those who had. Future studies might examine age, cancer stage and prognosis, and parity as factors in expectations for dating post-diagnosis. Although saturation was reached in this exploratory study, future researchers might usefully consider larger samples stratified by age. Participants' comments about their age being a factor in diagnosis, treatment, and overall experience led me to this conclusion.

Policy. Participants discussed how race, socioeconomic status (SES), transportation accessibility, and education level might hinder obtaining relevant medical information and care. Race, SES, and education are all factors related to breast cancer health disparities and barriers to care and treatment. Several free and low-cost programs exist for breast cancer detection and treatment, as well as meal and housekeeping services during treatment, but not everyone is aware of these programs. Participants lamented that they had not known about some programs until it was too late to use the services. Additionally, many of these national programs serve heavily populated areas, but not rural areas. More publicity for these programs is critical, but it must be targeted and based on best practices that address health literacy.

Health literacy levels have implications for when people are diagnosed in relation to the progression of illness and whether and how patients access treatment and seek health information (Sulik, Cameron, & Chamberlain, 2012). Public health campaigns and

policies must target demographic groups that are less likely to get mammograms or that may be unable to access or afford treatment (Sulik, Cameron, & Chamberlain, 2012). In this way we may lessen the cost of limited health literacy in the United States (Huber, Shapiro, & Gillaspay, 2012).

Therapy. Participants discussed varying experiences with mental health professionals prior to, during, and after treatment for breast cancer. They met with therapists, psychotherapists, counselors, social workers, and even one oncology counselor. Participants' mental health professionals usually did not work in conjunction with their medical teams, and participants occasionally reported that the professionals did not understand what clients needed from them. It is clear that cancer patients have specific needs and interests, which raises questions about the training for mental health professionals that work with them. The results of this study suggest that patients without partners may need to explore issues unique to their relationship status. This is something for mental health professionals to consider if they work with cancer patients and for those in training to study.

Patients. The results of this study have implications for patients without partners and what they can do to ensure support as they navigate their diagnoses and treatment. Participants offered useful suggestions related to interacting with medical teams and families, taking time for oneself, and maintaining a positive outlook. When asked about the sources of health information they sought, participants referred primarily to websites and some books.

Following approval of this dissertation, the author and major advisor will create a guidebook for breast cancer patients without partners that medical teams will be able to

distribute to patients following diagnosis. The guidebook will be grounded in plain language and be accessible for patients of varying educational attainment (Kimble, 2002). Ideally, this will help raise awareness for patients and put into context issues they may encounter throughout their breast cancer experience.

Practice. There are several findings that have important ramifications for medical practices. First, participants talked about the need for stage-specific support groups. There is a big difference between Stage 0 and Stage IV breast cancer; concerns and experiences differ greatly based on one's prognosis. If doctors recommend that patients attend support groups, it would be highly beneficial if they recommended appropriate and relevant groups. A poorly fitting support group may be more damaging than not going to a support group at all.

Second, doctors and other members of the medical team must take into account the racial or ethnic differences among breast cancer patients. Several African American participants talked about how their physicians were unaware of race-based differences in terms of detection, diagnosis, and prognosis. For participants to feel comfortable with their medical teams, these medical providers must be up-to-date on racial health disparities.

Third, some participants conveyed interest in using complementary and alternative medicine (CAM) but lamented that their doctors did not know much about CAM. Because integrative oncology is becoming increasingly popular, physicians and other members of the medical team should learn more about these supplemental treatment options and share the information with patients. A next step would be to consider including integrative oncology programs in hospitals and clinics.

Fourth, participants recommended that doctors and other members of the medical team ask whether patients have a supportive network of friends and family members that could offer emotional and instrumental support following their diagnoses. Some participants commented that their doctors never asked if they had anyone to talk to or attend appointments with them. Physicians should discuss this with their patients at the initial intake appointments. If patients do not have a supportive network, physicians should make recommendations concerning Nurse Navigators or other systematic support options.

Additionally, patients referred to several members of their medical team (oncologists, radiologists, surgeons, nurses, oncology therapists, and Nurse Navigators) separately and sometimes as a whole. All members of oncology medical teams should be trained in how to communicate and work with patients, as they all could have impacts on patients' well-being.

Limitations

There were limitations to this exploratory study. Because there were no reported studies, the researcher had to create an interview protocol based on the review of literature. The protocol might not have been effective in eliciting all aspects of participants' experiences. Each interview was a single snapshot into participants' lives and was based on recall. This is a limitation of cross-sectional research, because unlike longitudinal studies, there was no opportunity for follow-up. There was the potential for recall bias, when a participant does not fully or accurately recall past events or perceptions (Coughlin, 1990).

Another potential limitation is the process of recruitment and participant self-selection: Nineteen of the twenty participants reported having no positive experiences dating post-diagnosis, raising the possibility that still-single women were more likely to volunteer for this study. Likewise, the majority of participants had already completed treatment. One of the criteria for recruitment was that participants had completed treatment within the last five years, but they could still be going through treatment. As treatment for breast cancer is physically and emotionally invasive, it is possible that breast cancer patients still going through treatment would report different experiences than people who had recently completed treatment. Similarly, there was a range of stage at diagnosis, which might also have influenced participants' experiences (Appendix F).

Additionally, most participants reported higher incomes. Income might be indicative of access to breast cancer support organizations (both in-person and online), and thus those with lower incomes might not have had access to the places where recruitment information was distributed. Finally, most participants described practices that suggest they were or became health literate in relation to breast cancer. Health literacy correlates with higher incomes; people who are not health literate might not be using the community resources that could have led them to this study.

Transferability

In qualitative research, transferability refers to two applications of data: assigning results of the study to a larger population and assigning the results to different populations (Lincoln & Guba, 1985). Use of the first application occurs when a researcher examines the sample to determine how well it reflects a larger population from which the sample is drawn. One transferability question for this study is: Does the

sample of African Americans, Caucasians and one Indian American reflect the greater female population of those racial groups? This question may be answered by examining the sample and how well it reflects the population. In this study, the sample is reflective of the largest racial groups in the United States (African Americans and Caucasians), but it does not reflect other racial groups (Latinas and Asian Americans in particular)

Another question is whether the ages and sexual identities of the sample reflect the greater population of women? This sample reflects some of the age groups most likely to be diagnosed with breast cancer, but it is not reflective in terms of sexual orientation (nineteen of the 20 participants identified as heterosexual; one person identified as bisexual). Thusly, the results of this study likely have the most meaning for other single heterosexual breast cancer patients in their 40s and 50s.

Use of the second application occurs when a researcher examines the sample to determine if the results can be interpreted as true for a different population. In this case, the missing racial/ethnic populations were Latinas and Asian Americans. Readers of this study must determine whether their theoretical framework is similar to the one used for this study (Daly, 2007; Kennedy, 1979). If it is, then they may transfer the results of this study to another population of interest – for example, Latinas and Asian Americans, or even patients of other cancers (for example, prostate or colon cancer patients).

Contributions and Conclusions

This study makes several contributions to the family science body of literature on breast cancer and family relations. This study illuminates a special group in the breast cancer community: women without partners. This group was previously unrecognized in the literature. The purpose of this qualitative dissertation was to examine how women

without partners navigate their breast cancer diagnoses, treatment, recovery, and survivorship. By developing an understanding of interpersonal relationships that these women rely on (immediate family members, breast cancer support organizations, friends, and even pets), family and health professionals will have a better concept of the coping mechanisms employed by patients without partners. By learning how these women made meaning of their relationship status within the context of their cancer experience, family scientists will have a more comprehensive understanding of the role of relationship status – including the meaning attributed to it – by people facing serious health issues.

Women without partners in this study reported unique breast cancer experiences. Participants drew comparisons between themselves and patients with partners. They discussed what it meant to have less built-in support – and what it meant to not be burdened by unsupportive partners. They speculated on dating as patients and survivors, and they pondered how their experiences would have been different with partners. Participants described interactions with their medical teams and outlined what they might have benefitted from. They talked about the challenges and strengths that their social networks provided, and what changes they had to make to those networks in order to endure treatment.

This exploratory study yielded new insight into how women without partners manage their social networks, seek and use health information, and think about their relationship status in the context of breast cancer. The implications for research, policy, practice and personal health care drawn from this study could improve care and well-being of cancer patients. By understanding the challenges and strengths of women

without partners going through breast cancer, medical teams and family scientists can improve support of those patients.

Appendix A.

Study Flier

Breast Cancer Study: Single Patients

Breast cancer patients often refer to their intimate partners and spouses when discussing who supported them during their diagnosis and treatment. **But what about the breast cancer patients that do not have partners?** Study participants will talk about their breast cancer experiences, family relationships, how they sought health information, and their forms of social support.

*Contact Amanda Ginter
at aginter@umd.edu to
take a one-time
face-to-face or
telephone interview!*

To participate, you must:

- Be 18 years or older
- Have been treated for breast cancer in the last five years
- Not have had a partner during diagnosis and treatment
- Be willing to talk for 60 minutes about your breast cancer experience

Amanda Ginter, M.S.
Doctoral Candidate

Family Science Department
1142 School of Public Health
College Park, MD 20742

Email: aginter@umd.edu
Under direction of Dr. Bonnie Braun
Univ. of MD IRB 373050-1



You will be entered
into a raffle for a \$50
Target gift card for
your participation in
this study!



Appendix B.

Page 1 of 2

Written Consent Form Initials ___ Date _____



Project Title	Breast Cancer Narratives of Women without Partners
Purpose of the Study	This research is being conducted by Amanda Ginter at the University of Maryland, College Park, under the direction of Dr. Bonnie Braun. You are invited to participate in this research project because you are over 18, have been treated for breast cancer in the last five years, and did not have a partner at the time of your diagnosis and treatment. The purpose of this research project is to learn how patients without partners alter or create supportive networks that help them cope with the challenges and fears of diagnosis and treatment.
Procedures	The procedures involve meeting one time with Amanda Ginter at a secure location of mutual choice or talking with Amanda Ginter on the telephone. Interviews will last approximately 60 minutes.
Potential Risks and Discomforts	You may risk unpleasant memories by discussing your breast cancer experience. A list of support resources will be available on request.
Potential Benefits	There are no direct benefits to participants. However, other women may benefit from this study through improved understanding of the specific experiences and needs of breast cancer patients without partners.
Confidentiality	Any potential loss of confidentiality will be minimized by storing data in a locked cabinet and password protected computer. If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park, or governmental authorities if you or someone else is in danger or if we are required to do so by law.
Medical Treatment	The University of Maryland, College Park, does not provide any medical, hospitalization or other insurance for participants in this research study, nor will the University provide any medical treatment or compensation for any injury sustained as a result of participation in this research study, except as required by law.

Written Consent Form Initials ___ Date _____



<p>Right to Withdraw and Questions</p>	<p>Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.</p> <p>If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the research, please contact the investigator:</p> <p>Amanda Ginter 1142 School of Public Health College Park, MD 20742 aginter@umd.edu</p>	
<p>Participant Rights</p>	<p><i>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</i></p> <p style="text-align: center;">University of Maryland College Park Institutional Review Board Office 1204 Marie Mount Hall College Park, Maryland, 20742 E-mail: irb@umd.edu Telephone: 301-405-0678</p> <p><i>This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</i></p>	
<p>Statement of Consent</p>	<p><i>Your signature indicates that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.</i></p> <p><i>If you agree to participate, please sign your name below.</i></p>	
<p>Signature and Date</p>	<p>Print your name here </p>	
	<p>Sign your name here </p>	
	<p>Put the date here </p>	

Appendix C.

Interview Protocol

Hello, _____. Thank you for being willing to talk with me as part of a research study involving breast cancer patients without partners. I want to learn more about how breast cancer patients use social networks, access health information, and talk about their relationship status within the context of their breast cancer experience so that I can find ways to help other women like you improve their experience.

Your Background

1. First of all, please share with me your breast cancer experience [e.g., staging, treatment, age at diagnosis, current health status, troubles/triumphs].
 - a) In thinking back to your health at the time of your breast cancer diagnosis, would you say it was excellent, very good, good, fair or poor?
 - b) Did you ever get mammograms or do self-exams?
 - c) Did you experience any lymphedema?
2. What was going on in your life at the time of your diagnosis? [E.g., school, moving, career change, parenthood.]

Your Coping

3. How would you describe your social network – the most important people in your life?
 - a) Has that network changed since your diagnosis?
 - 1) If yes, why?
4. What has helped you deal with your breast cancer the most? (Probe to get at the four levels of the systems)
 - a) Family, friends, co-workers, neighborhood, medical team?
 - b) Connections between family, friends, your job, and the medical team?
 - c) Certain hospital or work policies?
 - d) Your cultural background?
 - e) Pets?
5. Since learning of your breast cancer diagnosis, who was/were your supporter(s)?
 - a) How did that person or those people become your support?
 - b) Who gave you the most support to help cope with breast cancer?
6. Did you want or need to talk about your diagnosis or treatment with others?

- a) Why or why not?
7. What kind of support did you need from your medical team or others to deal with your breast cancer diagnosis and treatment? (informational, emotional, instrumental, appraisal)

Relationship History

8. Tell me about your relationship history.
- a) What was your relationship status at the time of your breast cancer diagnosis (single, divorced, separated, widowed)?
9. What did it mean to you to be [relationship status] prior to your diagnosis and treatment?
10. What did it mean to you to be [relationship status] after your diagnosis and treatment?
11. If you had had an intimate partner, how might your experience have been different?
- a) Do you think it would have been better, worse, or the same?

Health Information and Treatment Decision-Making

12. Describe for me how you selected treatment for your breast cancer.
- a) Did you check into your options?
 - b) Did you talk with more than one doctor?
 - c) Did you speak with friends/family about your decision-making process?
 - d) Did you get information from the medical team or others in a doctor's office?
 - 1) From the Internet? Other places?
 - 2) How easy was it to get this information?
 - 3) How helpful was the information you got?
 - 4) Did anyone help you get this information?
13. Some people have difficulty understanding health information.
- a) "How often do you have someone help you read hospital materials?" (HI 1)
 - 1) Never, occasionally, sometimes, often, always?
 - b) "How confident are you in filling out medical forms by yourself?" (HI 2)
 - 1) Extremely, quite a bit, somewhat, a little bit, not at all?
 - c) "How often do you have problems learning about your medical condition because of difficulty understanding written information?" (HI 3)
 - 1) Never, occasionally, sometimes, often, always?
14. Tell me about your relationship with your medical team.

- a) Did you feel comfortable asking them questions?
- b) Did you feel comfortable sharing with them what you've learned about breast cancer?
- c) On a scale of 1-10 how would you rate your doctor?
 - 1) How would you rate the rest of the medical team?
- d) On a scale of 1-10, did your doctor show respect for what you had to say?
 - 1) Why that number?
 - 2) Did this keep you from getting information or care that you needed?
- e) What did your doctor(s) or other provisional care providers tell you to do to get well?
 - 1) Did you agree with them?

15. Did you have any trouble getting to doctor appointments, treatment, or surgery?

- a) If yes, why did you have that trouble?
- b) What would have made things easier for you?

Family Systems

16. After your diagnosis, did relationships change between you and immediate/extended family members, etc? Please describe these.

17. Did you have children at the time of your diagnosis?

- a) How old were they?
- b) How did you discuss your breast cancer with them?
- c) How did you handle care for them during your treatment?

Friends and Associates

18. After your diagnosis, did relationships change between you and your friends? Please describe these.

19. Prior to your diagnosis, were you involved in any organizations or programs outside of work (church, volunteering, neighborhood activities)?

- a) Did these groups offer any support post-diagnosis?
- b) Were there any changes regarding your membership in these groups after your diagnosis?
- c) After your diagnosis, did you get involved in any new organizations or programs?
 - 1) Were they support organizations?
 - 2) Did they help you cope?

Job

20. Were you working at the time of your diagnosis?

- a) What type of support did you receive from your supervisor?
 - 1) Co-workers?
- b) Did you have to take any time off from work? If so, how did you talk about that with your supervisor?

Self-Care

21. I am going to read a list to you of self-care options. After I read the list, please tell me what you engaged in:

Yoga and/or Pilates Meditation Knitting/textile arts Spiritual/religious activities

- a) Did you notice any changes to your physical, mental, or emotional well-being after you began those methods of self-care?
- b) If you used more than one method, how did each method differ from other things you did to care for yourself?
 - 1) Were some methods more useful than others?
- c) How often do you attend church or other religious activities?
 - 1) Never, once a year or less, a few times a year, a few times a month, once a week, more than once a week
- d) How often do you spend time in private religious activities, such as prayer, meditation or Bible study?
 - 1) Rarely or never, a few times a month, once a week, two or more times a week, daily, more than once a day
- e) My religious beliefs are what really lie behind my whole approach to life.
 - 1) Definitely not true, tends not to be true, unsure, tends to be true, definitely true of me

Conclusion

22. How would you rate your mental or emotional health?

- a) Excellent, very good, good, fair, or poor?

23. How would you rate your physical health?

- b) Excellent, very good, good, fair, or poor?

24. Having gone through this, what advice would you give to other women without partners recently diagnosed with breast cancer?

- a) What advice would you give to the doctors and other professional caregivers who treat women without partners?

25. Is there anything else you would like to share with me?

Would you like to receive a summary of the findings of this study?

Thank you for your openness and willingness to assist me in this research study. I appreciate your time.

NOTE: Give at least 5 seconds for a response before prompting further.

Question 13 *a-c* (Chew, Bradley, & Boyko, 2004); 14 *c-d* & 22-23 (CAHPS, 2011); 21*c-e* (Koenig & Büssing, 2010)

Appendix D.
Demographic Survey

ID number:

Date:

About you:

What is your age? _____ years

How long ago were you diagnosed with breast cancer? _____ years _____ months

What was your relationship status during diagnosis/treatment? (circle one)

**Single
Relationship**

Divorced/Separated

Widowed

What is your *current* relationship status? (circle one)

**Single
Relationship**

Divorced/Separated

Widowed

How would you describe your racial/ethnic background? _____

**Non-Hispanic White Non-Hispanic Black Hispanic Asian Native American/Alaskan
Native**

How would you describe your sexual orientation? _____

**Heterosexual
Answer**

Bisexual

Lesbian

Questioning

Asexual

Refuse to

How many years of formal education do you have? _____ years

(12 = high school; 16 = graduated from college, etc.)

Did you have health insurance at the time of your diagnosis? _____

What is your annual income? (circle one) (U.S. Census Bureau Quintiles)

> \$25,000 \$25,000-\$50,000 \$50,000-\$75,000 \$75,000-\$100,000 \$100,000+

How many people are you financially responsible for? _____

Appendix E.

Codebook

Code Label (* = sub-code)	Code Description
Initial reactions	Diagnosis, initial meetings with physicians.
*Fibrocystic breasts	Previous breast cancer scares, aware of fibrocystic breasts. Therefore weren't especially concerned about biopsies/were surprised when they were diagnosed with breast cancer this time.
*Difficulty processing information	Initial diagnosis/cancer information goes through one ear and out the other. Often participants talked about bringing someone with them to appointments to be a second set of ears.
Stressful personal background	Going through separations/divorces immediately prior to diagnosis; many talked about experiencing a lot of stress prior to diagnosis (work, relationship stress), and attributing that as a possible cause of the cancer.
*Other medical concerns	Medical issues (disease, illness, and surgeries) generally unrelated to breast cancer, that patients encountered. These health issues occurred prior to, during, and post-diagnosis.
Social network	Who mattered the most pre-diagnosis. Sometimes changed a little post-diagnosis (often expanded to include other breast cancer patients/members of organizations).
*Family systems	Parents, children – to a lesser degree, siblings.
**Vulnerable parents	Parents – mothers especially – couldn't handle diagnoses. Sometimes this resulted in strained mother-daughter relationships. Sometimes participants decided not to tell parents right away because they didn't think the parents would be able to handle the news.
*Relationships with children	Comforting children; being supported by children; forgiving unsupportive children.
**Age-appropriate conversations	Disclosing diagnosis information to children in ways they could handle it. Being aware of children's previous exposure to friends/family with cancer.
*Relationships with siblings	Were generally good; siblings could stand in where parents could not
*Friends	Often shifted between pre- and post-diagnosis.

**Pre-diagnosis	Participant's friends and social groups prior to diagnosis.
**Post-diagnosis	Cancer's impact on relationships with friends. Participants learned who was and was not in their corner.
*Relationships with co-workers	Showed support in the form of offering their sick days, providing food/restaurant gift cards. Supervisors allowed participants to work from home; took them off stressful projects.
Managing social networks	
***Forgiveness	Understanding and forgiving people for not being there for them (often parents, siblings, and female friends).
***Cutting out toxic people	Participants learned to avoid/limit time with people that were selfish, rude, and/or unhelpful. Sometimes this included realizing that the bad behavior wasn't personal (the toxic person acted like that towards everyone, and cancer patients were not exempt).
***Unwanted advice	Friends sometimes offered bad advice or poorly worded statements.
*Talking about experience	Whether or not participants wanted to talk about their experience, fears, or concerns with others.
**Disclosing information on one's own terms	If participants are going to share information, it needs to be on their own terms – when, when, and how they talk about it.
**Limiting information shared at work	Had to be self-protective and judicious about disclosing health information to supervisors and co-workers.
Support needed	Instrumental, emotional, informational.
Support received	Instrumental, emotional, informational.
*Receiving help from unexpected sources	Just as participants learned they couldn't count on certain people, they also received unexpected help from co-workers, casual friends, and members of their children's social networks.
*Pets	Provided emotional comfort; sat next to participants more often than usual. Sometimes they were more protective.
**Metaphysical perceptions	Pets just seemed to know that participants were sick/not feeling well.
*Therapy	Received mental health support (usually in the form of a therapist) during/following treatment. Sometimes were receiving support prior to diagnosis.

Medical treatment	Lumpectomies, mastectomies, chemotherapy, and radiation.
*Treatment decision-making	Chose independently, with physicians' help, or not given a choice.
**Families' influence on treatment	Families' previous experiences with health care system, BC, that influenced patients' perspectives on treatment.
*Concordance with physicians	Whether or participants agree with physicians' [suggested] treatment plan.
*It is scary searching Internet for medical information	Full of contradictory and inaccurate information.
Relationship with medical team	Wide range of relationships. Good relationships included felt being heard and respected; if physicians took a lot of time to listen to them. Bad relationships included being ignored, mocked, misunderstood
*Empathetic acknowledgment	Having people acknowledge the significance and stress of patient's experience, as well as discussing how prevalent breast cancer is.
*Teaching the doctor	Doctors weren't always up to date on medical information/procedures. Patients were generally surprised by this. Also, patients introduced doctors to breast cancer support groups.
*Professionals' assumptions about patients' needs/wants	Assumed patients wanted to keep their breasts, thus didn't present mastectomies as options OR encouraged patients to get reconstruction.
Relationship history	50% divorced, 50% single – no one was widowed. Participants generally referred to their previous intimate relationships (especially the one most recent) as very stressful. This included references to emotional and verbal abuse.
*Thoughts on being single pre-diagnosis	Most were fine with this, many said they were too busy at that point to date. Some were dating casually (still considering themselves "single"), but stopped seeing that person because they knew they wouldn't be supportive during treatment.
Relationship status in BC Context	
*What if they hadn't been single	They would have received more instrumental and emotional support; they would have felt less alone.
*Difference between good and bad partners	Participants acknowledged that many of their previous partners would have been terribly unsupportive, and that they were better

	off alone than with someone who would be callous or selfish.
*Don't miss previous partners	No one reported regret at the previous relationship(s) ending. Many pointed out that that particular partner would have been very unsupportive throughout treatment, and thus it was a blessing that the relationship had ended.
*Comparing experience to patients with partners	They perceived patients with partners having more built-in support (especially instrumental support).
*Unique experiences of single BC patients	Since there isn't the [presumed] built-in support of a partner, you must rely on many, many more people – and probably many more people step up to the plate for you than if you'd had a partner.
*Thoughts on being single/dating now	Participants are generally hopeful/open to dating, but many admitted to feeling self-conscious since diagnosis/treatment. Some said they wanted to continue focusing on themselves, or that they relished not having to care for a [bad] partner.
*Disclosing health status to potential partners	After disclosing, participants often didn't hear back from potential partners (especially if the participants were younger – in their 30s). Many participants admitted being concerned about disclosing their health status, whether or not they'd already had a bad experience.
*Impact of treatment on sex drive/body	Chemo affected sex drive; treatment put participants' bodies into menopause, which impacted their sex drive; surgeries and radiation make them self-conscious (especially at the thought of showing their body to a potential partner).
*Choosing treatment in context of relationship status	Participants acknowledged that having an intimate partner or the prospect of an intimate partner would make them more likely to get reconstruction.
Resources for coping	
Intrapersonal resources	Intrinsic to individuals. Includes having faith, finding something to live for, gaining insight about their lives and health, and actively working to get better.
*Proactive	Taking the initiative to find out as much as possible about prognosis and treatment; refusing to settle for flimsy answers or information from professionals.
*Transformative changes	Participants' changes for the better – usually involved new, enlightened perspectives on being diagnosed with breast cancer, opening up and allowing others to help them.

**“That’s not me”	Not initially seeing oneself as a cancer patient; eventually realizing that they are part of that group.
*Attitude of gratitude	Grateful to have certain resources, generally good health now.
*Faith in a higher power	Trusted God/the universe regarding prognosis, reason for being diagnosed.
*How do people go through this if they don’t have xxxx?	Acknowledging that some patients lack certain resources, have barriers that impede them from getting the care that they need.
*Perspectives on death & dying	Knowing when it’s the end time.
*Focus on self	Do whatever it takes to make yourself feel better, including limiting how much information is shared with your social network, taking time before returning to work, and allowing time to really think about what you want.
Interpersonal: support organizations	
*In-person	Often participants belonged to a themed support organization – sports-oriented (rowing, paddling) or for African American patients in particular.
*Online	Swift feedback from other women that had experienced similar prognoses, innovative treatments.
*Support groups: finding the right fit	Contingent on being with women of the same age and prognosis; sometimes the same race.
**Stage-status	There’s a big difference between Stage 0 and Stage IV; often patients can’t relate to each other when they have different treatment plans, prognoses, and concerns/fears.
*Giving back	Volunteered for breast cancer support organizations post-treatment, often as mentors. Expressed interest in helping recent patients with make-up (Look Good, Feel Better) and finances.
Meditative/holistic care	Often unexpectedly, participants found things that offered them tactile comfort and psychological/emotional peace.
*Wellness coaches	Individuals that guided participants through holistic care (teas, meditation, spirituality).
Barriers to Care and Treatment	
*Education and health literacy	Being able to access, obtain, and understand accurate and relevant health information

*Race/ethnicity	Having medical team understand the qualitative and quantitative differences in African American breast cancer experiences
*Red tape	Had to fight workers comp; were allowed to work from home but then had poor performance assessments.
Advice	
*For other single BC patients	Take care of yourself, do whatever you need to do, find a supportive network. (Mixed response: tell people. Others said just tell them in your own time.)
*For medical care providers of single BC patients	Find out if patients have supportive networks and/or someone they can bring with them to treatment.
Miscellaneous	
*Susan G. Komen controversy	Participants remarked on displeasure with Susan G. Komen following the threat to take away affordable care from qualifying women.

Appendix F.
Descriptive Statistics

Table 4

Demographic Information

	Participants (N=20)	
	n <i>or</i> Mean(SD)	%
Individual Characteristics		
Age	52.15(8.1)	
Racial/Ethnic Background		
African American	9	45
Caucasian	10	50
Indian American	1	5
Relationship Status (at interview)		
Divorced	9	45
In a relationship	1	5
Single	11	55
Widowed	-	-
Sexual Orientation		
Asexual	-	-
Bisexual	1	5
Heterosexual	19	95
Lesbian	-	-

Education

High school graduate	1	5
Some college	4	20
College graduate	5	25
Some graduate school	1	5
Graduate degree	10	50

Income (\$)

Less than 25,000	-	-
25,000-50,000	6	30
50,000-75,000	3	15
75,000-100,000	4	20
Greater than 100,000	7	35

Health Insurance

Yes	20	100
No	-	-

Time Since Diagnosis 32.1(21.9)

Pre-Diagnosis Health

Poor	-	-
Fair	3	15
Good	7	35
Good-Very Good	1	5
Very Good	4	20
Very Good-Excellent	1	5
Excellent	4	20

Stage at Diagnosis

0	5	25
I	5	25
II	5	25
III	4	16
IV	1	5

Health at Interview

Mental and Emotional Health

Poor	1	5
Fair	2	10

Good	8	40
Very good	7	35
Very good/Excellent	1	5
Excellent	1	5
Physical Health		
Poor	-	-
Fair	2	10
Fair-good	2	10
Good	8	40
Good-very good	2	10
Very good	5	25
Excellent	1	5
Health Literacy		
Health Information 1		
Always	1	5
Often	1	5
Sometimes	7	35
Occasionally	2	10
Never	9	45
Health Information 2		
Not at all	-	-
A little bit	-	-
Somewhat	1	5
Quite a bit	6	30
Extremely	13	65
Health Information 3		
Always	-	-
Often	-	-
Sometimes	6	30
Occasionally	6	30
Never	8	40
Religiosity Measures		
Religiosity 1		
Never	2	10

Once a year or less	1	5
A few times a year	6	30
Once a month	1	5
A few times a month	4	20
Once a week	4	20
More than once a week	2	10

Religiosity 2

Rarely or never	3	15
Once a month	1	5
A few times a month	1	5
Once a week	1	5
Two or more times a week	4	20
Daily	8	40
More than once a day	2	10

Religiosity 3

Definitely not true	1	5
Tends not to be true	2	10
Unsure	3	15
Tends to be true	3	15
Tends to be true/definitely	1	5
Definitely true of me	10	50

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