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Journey of Decision-Making among a Sample of
Women Diagnosed with Breast Cancer and
Living with a Non-Supportive or Abusive Partner

A dissertation submitted in partial satisfaction of the requirements for the degree

Doctor of Philosophy in Nursing

by

Wendy Ann Johnson

2017

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ABSTRACT OF THE DISSERTATION

Journey of Decision-Making among a Sample of
Women Diagnosed with Breast Cancer and
Living with a Non-Supportive or Abusive Partner

by

Wendy Ann Johnson

Doctor of Philosophy in Nursing

University of California, Los Angeles, 2017

Professor MarySue V. Heilemann, Chair

In the US, breast cancer is one of the most common forms of cancer in women. When a woman is diagnosed with breast cancer it is often expected that she will receive support from her partner. However, this may not always be the case as some women find that their partners are either non-supportive or abusive. This can have a profound effect on the decisions women make regarding their treatment. The aim of this study was to explore and describe the journey of decision-making among women diagnosed with breast cancer while living with a non-supportive or abusive partner. Despite the highly-stigmatized topic, multiple recruitment sites were utilized

to recruit eight women who were diagnosed with breast cancer, who had non-supportive or abusive partners, and who were willing to be interviewed one to two times. Techniques from Grounded Theory methodology, informed by Symbolic Interactionism were used for analyzing data for this Qualitative Descriptive study. Results showed that the lack of support in the women's relationships proved to be stressful, confusing, and disheartening. It affected their sense of self and heightened their need to rely on other inner and outer sources of support in multiple ways that were unique to each woman's situation. However, despite a potentially fatal diagnosis and a non-supportive partner, participants were resourceful, found ways to stand up for themselves, and persevered. The women provided insight into how they utilized strategies that helped them work through a process to make decisions regarding treatment and to "move on" with their lives. Results are useful for clinicians' ability to understand how a non-supportive or abusive partner may impact decisions made by a woman diagnosed with breast cancer and how to help with their processes of "moving on" after treatment.

The dissertation of Wendy Ann Johnson is approved.

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Dedication

This dissertation is dedicated to my wonderful and loving family. Your love and encouragement has been the foundation on which I now build my future. To my ancestors who lived through their own set of struggles and on whose shoulders, I now stand, thank you for allowing me the honor of drawing on your strength. To future generations, I now give you my shoulders and inner strength to draw upon to accomplish all that you desire for your lives.

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Chapter 1: Background and Significance

Women face many challenges in our contemporary society including physical, psychological, emotional, and financial strain that may influence her ability to maintain the quality of life in which she feels empowered and satisfied (Kabeer, 1999, 2005). Areas of concern for women in their quest for self-empowerment are the experiences in their lives that place undue restrictions on their health and their sense of autonomy (Hadley, Brewis, & Pike, 2010). This proposed research will further our understanding of the challenges women face when diagnosed with breast cancer (BC) while living with a non-supportive or abusive partner and how deciding about treatment options is experienced from the women's perspective.

Background

An individual's personal and collective well-being depends partially on how well the person makes decisions. The process of decision making (DM) encompasses choosing between selective courses of action or inaction, which is based on information and psychosocial aspects (O'Connor, Jacobsen, & Stacey, 2002; Revenson & Pranikoff, 2005). The psychosocial processes of DM are bound in the multiple interdependent sociocultural, situational, interpersonal and temporal contexts of people's lives (Revenson & Pranikoff, 2005). Two key points to understanding DM from the viewpoint of the individual is a) the identification of reciprocal relationships between the individual within the contexts of their lives and b) the aspects of how family members interact and react to decisions in their role in the DM process (Revenson & Pranikoff, 2005).

Effective DM is the need to understand and identify available options and its implications on one's values and beliefs (Fischhoff, 2005). The array of options available to aid in the DM

process for clinical diagnoses can be both anxiety producing and hopeful (Blank, Graves, Sepucha, & Llewellyn-Thomas, 2006). The complexity of treatment DM varies and is often complicated by such factors as the timing of the decision, available options, amount and quality of information available, and the variety of patient's preferences (Blank et al., 2006). The need for information and the sources available which may include decision aids, the internet, and other individuals are intricate components of the DM process (Blank et al., 2006).

Understanding treatment DM can help to ascertain the patient's preferred level of involvement in their care, and can minimize patient's anxiety about being forced to participate to a degree in which they are uncomfortable with. In addition, understanding treatment DM can decrease patient's frustrations of not being able to participate at the level of involvement they desire and can help implement interventions according to patient preferences (Florin, Ehrenberg, & Ehnfors, 2006; Fried, Bradley, Towle, & Allore, 2002).

Patient involvement in treatment DM may include benefits such as an increased knowledge regarding treatment options, improved satisfaction with DM and/or the decisions made, and decreased levels of anxiety and decisional conflict (M. O'Brien et al., 2013). The shared approach to DM to increase personalized healthcare has grown significantly to include a number of common conditions (Sepucha, Fowler, & Mulley, 2004). Patient expectations for personalized care encompass a holistic approach to health care that incorporates the physical, mental, and spiritual concerns of the individual and is becoming increasingly important to provide quality treatment to individuals (Cornetta & Brown, 2013).

Decision aids have been developed to strengthen communication about treatment DM between individuals and healthcare providers. Decision aids are used to assist individuals in the process of making intentional and personalized choices regarding their treatment (O'Connor &

Edwards, 2009, p. 191). The focus of decision aids is on detailed, specific and personalized options and outcomes to assist individuals in informed DM (O'Connor et al., 2009). Decision aids are used as a supplements rather than a replacement for counseling and information provided by the healthcare provider (O'Connor et al., 2002).

Most individuals desire extensive and in-depth information regarding their diagnosis, yet the literature has shown that there is great variability in the purpose for the information and what is considered important by the individual (Feldman-Stewart, Brennenstuhl, & Brundage, 2007; Feldman-Stewart & Brundage, 2004). While correct information is important in effective DM, some individuals can make perfectly healthy decisions despite being misinformed regarding treatment options and outcomes (Pieters & Wiley, 2013). Therefore, it is important that healthcare providers understand treatment DM from the perspective of the individual.

Cancer treatment options vary and require clear recognition of both the potential benefits and risks before informed decisions can be made (Vogel, Bengel, & Helmes, 2008). Making decisions about cancer treatments are complex and can be especially challenging for individuals (Jones, Steeves, Ropka, & Hollen, 2013). Individuals who receive a cancer diagnosis are often faced with the need to obtain a large amount of information, learn a new lexicon and communicate with different healthcare providers to maximize positive health outcomes (Pieters, Heilemann, Maliski, Dornig, & Menten, 2012). Thus, the exchange of information and understanding treatment DM are essential in cancer care (Vogel et al., 2008). Understanding treatment DM from the patient's perspective is particularly vital for nurses to optimize nursing care processes and the resultant favorable outcomes of care for individuals faced with cancer (Florin et al., 2006).

Breast cancer (BC) is the most common cancer in women and the second most common cause of death worldwide (American Cancer Society, 2017). In the United States, approximately 1 in 8 women have been diagnosed with BC (American Cancer Society, 2017; Siegel, Naishadham, & Jemal, 2013). In 2017, an estimated 252,710 new cases of invasive BC were expected to be diagnosed among women and of those 63,410 additional cases of in situ breast cancer were expected to be identified (American Cancer Society, 2017). In addition, approximately 40,610 women are were expected to die from the disease (American Cancer Society, 2017). Death rates from BC have decreased from 1989 to 2007. However, since 2007, BC death rates have been steady in women younger than 50, but have continued to decrease in older women. The decreased rates in deaths are believed to be a result of finding breast cancer earlier through screening, increased awareness and better treatments (American Cancer Society, 2017).

Women who receive a diagnosis of BC are often challenged with the immediate need to make treatment decisions (Swainston, Campbell, Van Wersch, & Durning, 2012) while simultaneously maneuvering past barriers to receive care (Pieters, Heilemann, Grant, & Maly, 2011). Attempts to understand BC-treatment options, each with various short- and long-term risks and benefits, are particularly difficult when associated with a sense of urgency and a need to proceed quickly (Pieters et al., 2012). The need for a speedy decision regarding BC treatment is often done without further assessment of other factors that may influence a woman's treatment and health outcomes (Halkett, Arbon, Scutter, & Borg, 2005). Clinician's assessment of psychosocial aspects such as prior experiences with cancer, financial feasibility, access to care, physician preference and spousal support are insufficient (National Comprehensive Cancer

Network, 2014). These aspects have been identified as important factors a woman may use to consider her choice for treatment (Blank et al., 2006).

The need for support in making treatment decisions about BC vary according to patient preference. In some cases it is the support from the spouse or partner that can prove to be most instructional in the process of treatment DM (Fergus & Gray, 2009). Most women rely regularly on positive spousal support and found it to be a source of strength throughout their cancer trajectory (Bigatti, Brown, Steiner, & Miller, 2010; Fergus & Gray, 2009). However, there are times when the support that a woman receives is either lacking through omission or is present through the commission of abuse (Sawin, Laughon, Parker, & Steeves, 2009). Such lack of support and presence of abuse can result in additional distress for the woman (Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010). Levels of control and abuse from an abusive spouse or partner commonly infringe upon a woman's sense of empowerment and may result in internal conflicts about her ability to make well-informed decisions about treatment (Campbell, 2002). Thus, when the woman is living with IPV, the capacity to make concrete and appropriate decisions about BC-treatments can prove to be an additional challenge (Spittler, Pallikathayil, & Bott, 2012).

Intimate partner violence, also referred to as domestic violence, gender-based violence (Ellsberg & Heise, 2005), partner abuse (McLaughlin, O'Carroll, & O'Connor, 2012), or situational couple violence (Johnson, 2005) accounts for the approximately 1.3 million women who are physically assaulted by an intimate partner in the US each year (Tjaden & Thoennes, 2006). In the US, the prevalence of IPV results in approximately 1 in every 4 women experiencing some type of abuse within their lifetime (Tjaden & Thoennes, 2000). Equally devastating is the fact that IPV is evident across all age, ethnic, socioeconomic and social groups

worldwide (Tjaden & Thoennes, 2000). Intimate partner violence is present in various groups of individuals with specific health conditions including women with different types of cancer (Martino, Balar, Cragun, & Hoffman, 2005; Sawin, 2010, 2012; Sawin et al., 2009; Sawin & Parker, 2011). Although there has been a limited amount of research examining the presence of IPV in women with BC, the potential for a concurrent experience is plausible (Hara & Rose, 2006; Schmidt, Woods, & Stewart, 2006) .

Significance

With 1 in 4 women experiencing some form of IPV within their lifetime (Tjaden & Thoennes, 2000), and 1 in 8 women is expected to be diagnosed with BC (American Cancer Society, 2017), the potential impact of IPV in the process of treatment DM with a new diagnosis of early stage BC requires research. Given the high prevalence and incidence of BC and the cancer's potential impact on relationships, closer examination of relational factors is needed to help identify various psychosocial aspects that influence treatment DM. A diagnosis of BC is known to have a profound effect on emotional issues for both partners (Fergus & Gray, 2009) and can subsequently impact the quality of the relationship (Holmberg, Scott, Alexy, & Fife, 2001). Concerns regarding changes in body image, decreased sexual sensibility, side effects of treatment and loss of sexual desire may create challenges for the woman and her relationship with her partner (Defrank, Mehta, Stein, & Baker, 2007; Waldrop, O'Connor, & Trabold, 2011). Post diagnosis, approximately 61.1% of women with BC have reported that sexual relations with their husbands worsened after diagnosis (Bredat, Dolbeault, & Savignoni, 2011). In some cases a diagnosis of BC can be the catalyst for divorce in marriages that were characterized by long-term conflicts (Holmberg et al., 2001).

Appropriate spousal support provided to individuals with cancer is frequently studied (Shiozaki et al., 2011). However, the impact of a negative or abusive relationship is understudied. The proposed study will explore aspects of partner non-support and IPV among women with BC and its influence on treatment DM.

Intimate partner violence encompasses negative patterns of behavior, attitudes, and beliefs in which power and control are used by one partner over another through the use of psychological, physical, financial, emotional and/or sexual coercion (Tjaden & Thoennes, 2000). Members of vulnerable groups are at a greater risk for becoming victims of this type of abuse (Sokoloff & Dupont, 2005). Increased vulnerability in individuals with cancer is associated with greater dependency (Stovall & Young, 2006, pp. 177-178), financial challenges (Institute of Medicine (IOM), 2008), and the perpetuating potential adverse effects that can result from cancer treatments (Hassett, O'Malley, Pakes, Newhouse, & Earle, 2006). All of which can create situations in which relationships may be further strained and challenged. Relationships that were less supportive or abusive prior to a cancer diagnosis can become more abusive after the diagnosis (Watson, 2006). Thus, the psychological and physiological impact of personal concerns and situations in the lives of women diagnosed with BC with a concurrent history of non-support or IPV can have a profound effect on treatment DM.

Overall, the literature shows that IPV can escalate with a cancer diagnosis. This increased risk provides a unique opportunity to identify IPV that may have been previously undetected.

Implications

If clinicians are able to detect and understand partner non-support and IPV, they can provide additional support, education, safety planning, and referrals to domestic violence services (Owen-Smith et al., 2008). Thus, if we can identify effectively the presence of partner

non-support and IPV, it can provide an opportunity for intervention such as referral for specialist care. Implications of a greater understanding of treatment DM in the context of BC diagnosed among women living with non-supportive partners and IPV span three components of the nursing process: assessment, implementation and evaluation.

Nursing practice implications for understanding IPV apply to three contexts: when a history of IPV is unknown, in the immediate presence of known IPV, and in the longer-term or more extensive follow-up period in which women who have a known history of IPV seek assistance to change their lives (Ford-Gilboe, Varcoe, Wuest, & Merritt-Gray, 2011). The increased risk that a cancer diagnosis brings to the escalation of existing IPV or the introduction of violence provides a unique opportunity to identify a condition that often goes underreported and untreated. This unique window provides a valuable opportunity for nursing practice in the first context.

Guidelines for assessing and screening for IPV in patient populations have been developed to assist healthcare practitioners to identify victims of abuse (Ford-Gilboe et al., 2011). Specifically among women diagnosed with early stage BC, the detection of IPV can provide healthcare professionals with essential information to help direct and support clinical practice to meet the needs of these women (Mick, 2005). Furthermore, identifying the presence of IPV in BC can also provide plausible explanations for non-adherence to treatment and resultant poor health outcomes (Gandhi et al., 2010).

The nature of relationships between the patient and the oncology nursing staff often provide levels of trust in which the woman may find it easier to disclose the presence of abuse (Hara & Rose, 2006). The presence of these types of trusting relationships can make identification of patterns of abuse easier (Mick, 2005).

Oncology professionals often provide support to patients regarding complex situations that entail high levels of emotional, psychological and psychosocial stress, such as a cancer diagnosis, which can also be used as an avenue of support to victims of abuse (Mick, 2005). Oncology nursing practice facilitates the use of a holistic approach which incorporates both the physical and psychosocial needs of the patient (Mick, 2005). Oncology nurses are in an important position to assist patients and their families as they work through the demands of a cancer diagnosis (Pearson, 2006). As part of psychosocial care, identifying components of relational issues between patients and families are an essential aspect of nursing care (Traeger et al., 2013). Therefore, it is important that healthcare providers ask about the quality of marital relationships as it may identify particular challenges that have an impact on treatment decisions and health outcomes (Taylor-Brown, Kilpatrick, Maunsell, & Dorval, 2000).

Important immediate and future implications for this research proposal are as follows:

- (a) To understand the complex factors that women with concurrent non-supportive partners or IPV and early stage BC face that may influence their behaviors regarding their health and their treatment decisions;
- (b) To provide guidelines to help oncology nurses help with assessment and identification of the presence of IPV in their patient population;
- (c) To aid healthcare providers to assist breast cancer survivors and their spouses or intimate partners adapt to cancer survivorship (Canady et al., 2010);
- (d) To help clinicians understand the importance of offering appropriate referrals to victims of IPV;

- (e) To develop a training program for nursing professionals on how to communicate and help women who are living with IPV when they are diagnosed with early stage BC make informed treatment decisions.

Philosophical Framework and Methodology

The philosophical underpinnings of symbolic interactionism will guide this study (Blumer, 1969/1986). The research will proceed according to the methodology of constructivist grounded theory (Charmaz, 2006).

Research Purpose, Specific Aims and Research Questions

The overall purpose of this proposed research is to develop new knowledge and understanding of the experiences of treatment DM among women diagnosed with early stage BC while living with IPV. Grounded in the voices of women, the specific aims and research questions are as follows:

1. To identify, explore and describe how women diagnosed with early stage BC in the presence of non-supportive partners or IPV create meaning to their realities and act upon these meanings.
 - a. What are the perceptions of the quality of their relationships with their spouse or partner at the time of the BC diagnosis?
 - b. What does it mean for the woman to receive a diagnosis of BC while living in a non-supportive or abusive relationship?
 - c. How do women describe their interactions with their non-supportive or abusive spouse or partner in relation to making decisions about BC-related treatments?
2. To explore and describe what women diagnosed with early stage BC understand to be the interactions between non-support and/or IPV, BC and cancer-related DM.

- a. What situations (physical, emotional, social, and spiritual) about IPV was difficult or complicated treatment DM?
- b. What aspects of their relationships with their spouses or partners were helpful for the women in making decisions about their treatment?
- c. What other contributing relationships and factors were present that helped or complicated their choice of treatments?
- d. What conversations with clinicians and other individuals about health or cancer-related DM were helpful or less helpful?

In conclusion, the process of treatment DM often proves to be challenging for women diagnosed with BC. The presence of non-support and/or IPV concurrent with early stage BC may present additional challenges that can negatively impact treatment DM and resultant health outcomes. This proposed research will be the first study to explore these challenges by examining treatment DM among women living with a non-support and/or IPV at the time that they were diagnosed with early stage BC.

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Chapter 2: Review of Pertinent Literature

Cancer is the second leading cause of death worldwide with approximately 8.8 million deaths in 2015, resulting in nearly 1 in 6 deaths globally (World Health Organization, 2017). In 2017, the American Cancer Society (ACS) predicts that 1,688,780 new cases of cancer will be diagnosed in the United States (US) (American Cancer Society, 2017). Cancer is more common in older adults; 87% of all cancers in the United States are diagnosed in individuals 50 years of age or older (American Cancer Society, 2017). Among women, the three most common types of cancer are predicted to be breast, lung, and colorectal cancer, accounting for 50% of the total overall estimated cancer cases (American Cancer Society, 2017).

In addition to the well-documented emotional and physical suffering associated with cancer, the disease is financially costly (American Cancer Society, 2013). The Surveillance, Epidemiology, and End Results (SEER), a program of the National Cancer Institute (NCI), projected medical costs associated with all types of cancer in 2010 and 2020 to be \$124.6 and \$158 billion, respectively (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011). Relatively higher costs per capita were associated with breast cancer at \$16.5 and \$20.5 billion during the same projected period (Mariotto et al., 2011).

Breast Cancer

Breast cancer (BC) is the most common form of the disease in women worldwide, accounting for 1 out of every 3 new cases of all cancers diagnosed in women in the US (American Cancer Society, 2012). Nationwide 252,710 women are predicted to receive a first-time diagnosis of invasive BC in 2017 (American Cancer Society, 2017). In addition to invasive BC (the more advanced form of the disease), 63,410 new cases of in situ BC (a noninvasive form) are expected to occur (American Cancer Society, 2017). The number of women diagnosed with BC worldwide has rapidly increased from about 500,000 new cases in 1975 to 1.4 million in

2008, to an expected 2.1 million women in 2030 (Bray, Ren, Masuyer, & Ferlay, 2013). This represents about 11% of all new cancer cases and 23% of all female cases in 2008 (Bray et al., 2013). The increased probability for being diagnosed with BC has been attributed to various factors including longer life expectancy, increased incidences related to changes in reproductive patterns, menopausal hormone use, increased prevalence of obesity, and better detection through screening (American Cancer Society, 2011). At present, it is estimated that a woman in the US has a 1 in 8 chance of developing invasive BC during her lifetime, signifying an increase from 1 in 11 in 1975 (Siegel et al., 2013). Despite advances in treatments for BC, the disease continues to be the second most common cause of all cancer-related deaths, after lung cancer (American Cancer Society, 2017). In 2017, approximately 41,070 deaths in women are expected to occur from breast cancer (American Cancer Society, 2017).

The presence of BC is associated with aging. The median age for women in the US at the time of diagnosis is 61 years (Howlader, Noone, & Krapcho, 2011). However, BC has become the most common malignancy in adolescent and young adult women ages 15 to 39 years, accounting for approximately 14% of all cancers in men and women in this age group (Bleyer et al., 2008). In 2008, the individual average risk of a woman developing BC in the US was 1 in 173 by the age of 40 years (Anders, Johnson, Litton, Phillips, & Bleyer, 2009). Recent research has shown however, that about 1 out of 8 women younger than 45 years and 2 out of 3 women age 55 or older were found to have invasive BC (American Cancer Society, 2011).

Breast cancer is most frequently staged according to the tumor-nodes-metastasis (TNM) classification system, which evaluates the tumor size (T), involvement of regional lymph nodes (N), and distant spread of the disease or metastases (M) (American Cancer Society, 2013). This information is important in determining the choice of therapy, for close monitoring of response

to treatment, and for assessing prognosis (Langhorne, Fulton, & Otto, 2007). Once ascertained, a stage is designated and typically ranges from stage 0 through stage IV. Stage 0 is used to describe non-invasive breast cancers, such as DCIS (ductal carcinoma in situ), while stage IV is used to designate a more advanced level of the disease with evidence of its presence in distant parts of the body. BC that has not spread beyond the breast or the axillary lymph nodes is defined as early stage BC. This includes DCIS and stage I, stage IIA, stage IIB, and stage IIIA BC (Department of Health and Human Services, 2010). These early stages of BC are the focus of the proposed research.

The majority of women diagnosed with early stage BC can expect to live longer and disease-free as a result of advances in early detection and treatment (Chantler, Podbilewicz-Schuller, & Mortimer, 2006). The 5- and 10- year relative survival rates for invasive breast cancer are 90% and 83%, respectively (American Cancer Society, 2017). However, if the BC has spread to regional areas beyond the primary site to nearby lymph nodes or organs and tissues the 5-year survival rate decreases significantly, with a subsequent decline if the cancer has spread to distant organs or lymph nodes (American Cancer Society, 2013).

Effects of Breast Cancer

Breast cancer often produces changes in a woman's life that requires major adjustments (Bleiker, Pouwer, van der Ploeg, Leer, & Adèr, 2000). In addition to the physical stress of cancer treatments (Curtis, Groarke, McSharry, & Kerin, 2013; Schmid-Büchi, Halfens, Müller, Dassen, & Van den Borne, 2013), feelings of increased vulnerability, loss of control and uncertainty frequently result in emotional trauma for a woman facing a diagnosis and treatment for BC (Arman, Rehnsfeldt, Lindholm, & Hamrin, 2002). Upon learning of a BC diagnosis, women may

begin to experience new and various types of distress that they need to cope with (Shell & Kirsch, 2001).

These significant life changes related to a cancer diagnosis are best described by the term 'distress' because the word is less stigmatizing than like-terms such as psychiatric, psychosocial or emotional stress (National Comprehensive Cancer Network, 2014). Furthermore, distress is self-reported and may have a more conventional and accepting tone (National Comprehensive Cancer Network, 2014). Used in the context of BC, distress is a multidimensional concept composed of unpleasant emotional experiences that are comprised of psychological, social and/or spiritual attributes. Distress occurs across a continuum, ranging from sadness, fear, depression, anxiety, panic, and social isolation to concerns about one's existence and spiritual considerations (National Comprehensive Cancer Network, 2014). Most women experience some degree of distress associated with the physical and psychosocial effects associated with BC (Hewitt, Herdman, & Holland, 2004).

Physical side effects of BC-treatment from chemotherapy, radiation, surgery and hormone therapy can create distress (Waldrop et al., 2011). For example, breast surgery may involve partial or complete removal of one or both breasts, potentially resulting in breast asymmetry, extensive scarring, alteration to breast and/or nipple sensation, need for a prosthesis, limb changes that limit mobility, lymphedema and related body image concerns (Vadivelu, Schreck, Lopez, Kodumudi, & Narayan, 2008). Physical distress related to the chemotherapy, radiation and/or hormone treatments may include weight fluctuation, skin and fingernail discoloration, neurological changes, and signs of early menopause including hot flashes, vaginal dryness, and mood disturbances (Defrank et al., 2007). Rapid alterations in body image test a

woman's ability to cope with the multiple losses and physical changes (Przezdziecki et al., 2012).

Psychosocial distress can start at the time of diagnosis when some women are overcome with questions about why they have the disease and concerns regarding imminent death (Bertero & Chamberlain, 2007). A sentinel review from the Institute of Medicine (Institute of Medicine (IOM), 2008) states that the BC trajectory is associated with fears of cancer recurrence, presence of physical symptoms, body image disruptions, sexual dysfunctions, treatment-related anxieties, intrusive thoughts about illness/persistent anxiety, marital/partner communication issues, and fear of dying (Hewitt et al., 2004). Women can also face challenges in areas that may be comprised of family conflicts, social isolation, difficulties in decision making, quality-of-life issues, and domestic abuse and neglect (National Comprehensive Cancer Network, 2014). Furthermore, women diagnosed with BC have higher levels of distress, depression and anxiety (Edwards & Clarke, 2004).

Distress among women diagnosed with BC can be higher at specific points throughout their diagnosis and treatment: the time of diagnosis, while awaiting treatment, during and after completion of treatment, at follow-up visits, at the time of recurrence and at the time of treatment failure (Hewitt et al., 2004). Distress may occur even in the early stages of BC diagnosis and treatment among women with a relatively good prognosis (Bleiker et al., 2000). Distress can interfere with a woman's ability to cope with symptoms and the effects of treatment for BC and can place them at risk for non-adherence to treatment, especially with oral medications (Partridge, Wang, Winer, & Avom, 2003). Specifically, distress was associated with a 50% risk of premature discontinuation of tamoxifen in women with BC, placing them at risk for an inadequate clinical response (Partridge et al., 2003).

Adjustments to the potential physical and psychological distress of BC are not the same for all women (Schmid-Büchi et al., 2013). Some women adjust well to their challenges, while others demonstrate significant problems in their attempts to overcome the physical and psychological changes associated with the diagnosis (Helgeson, Snyder, & Seltman, 2004). Age-related consequences of having BC is key to understanding the unique challenges some women face (Baucom, Porter, Kirby, Gremore, & Keefe, 2005; Pieters et al., 2011; Pieters et al., 2012). Younger (premenopausal) women diagnosed with BC face challenges with specific concerns regarding fertility preservation, pregnancy, lactation, sexuality, body image, and active professional lives (Baucom et al., 2005; Cardoso & Harbeck, 2012). Effects of adjuvant treatments that result in premature menopause present an additional challenge to young women with BC (Brennan, French, Houssami, Kirk, & Boyages, 2005). Younger women also tend to have a poorer prognosis and a higher rate of recurrence and often present with a more aggressive disease process than their older counterparts (Anders et al., 2009; Mosher & Danoff-Burg, 2006). Challenges for older women diagnosed with BC is different from younger women regarding the presence of preexisting comorbid diseases, transportation issues, a sense of urgency to receive treatment and the drive to maintain independence throughout their experiences (Baucom et al., 2005; Pieters et al., 2011; Pieters et al., 2012).

Social Support

Social support is defined as an interpersonal process derived from the reciprocal exchange of contextual information in a social environment between individuals (Finfgeld-Connett, 2005; Helgeson, 2003). Measures of support are conceptualized as structural and functional in which social relationships and resources are utilized by people in their individual social networks (Helgeson, 2003). The three basic functions of social support are emotional,

informational and instrumental support (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007; Finfgeld-Connett, 2005; Helgeson, 2003). Emotional support consists of comforting gestures such as having people available to listen, to care, to sympathize, to provide reassurance, and to make one feel valued, loved and cared for (Finfgeld-Connett, 2005; Helgeson, 2003). Instrumental support includes tangible goods and services including child care supplies, food, help with household chores, money, transportation and running errands (Finfgeld-Connett, 2005; Helgeson, 2003). Informational support involves the provision of information and/or guidance (Helgeson, 2003).

Social Support for Breast Cancer

A woman's ability to adjust to the challenges of the BC trajectory relies on both her physical response to treatment and her emotional well-being (Bertero & Chamberlain, 2007). Adequacy of both social support and interactions are also related to variations in adjustment among women with BC (Curtis et al., 2013). Psychosocial support from relatives and health care professionals can help women manage the challenges of treatment and life adjustments (Landmark, Bøhler, Loberg, & Wahl, 2008). Medical professionals, family members and friends, other breast cancer survivors, support groups and the religious community are key sources of support for women with BC (Chantler et al., 2006). Members of a woman's social network play different roles to assist her with coping at different times across the cancer trajectory (Arora et al., 2007). The woman's experience of the support is influenced by the type of relationship and the setting in which the support is available and provided (Drageset, Lindstrom, Giske, & Underlid, 2012). Higher levels of emotional and informational support from family and health care providers occurred for women diagnosed with BC closer to the time of diagnosis (Arora et al., 2007). However, helpful support significantly decreased over time (Arora et al., 2007). This

reduction was related to a decrease in the availability of support as well as the perceived quality of available support (Arora et al., 2007).

Support from spouses or intimate partners has an especially influential effect on the psychological adjustment of women diagnosed with BC (Fergus & Gray, 2009) particularly during the treatment and recovery phase (Glantz et al., 2009; Wagner, Tanmoy Das, Bigatti, & Storniolo, 2011). Specifically, women who perceive their spouses' or partners' adaptation to their BC diagnosis as positive were more likely to report better psychosocial outcomes (Brusilovskiy, Mitstifer, & Salzer, 2009). While research has shown that positive spousal support can be a significant source for coping, it is the presence of negative or unsupportive behaviors from partners that presents a real concern (Badr et al., 2010).

This proposed research is focused on women living with intimate partner violence (IPV) when diagnosed with early stage with BC. In IPV, women will most likely not receive support. Thus, for the purposes of this literature review, the following section is devoted to non-supportive spouses or partners followed by a section on violence against women (VAW).

Non-supportive Spousal or Partner Behaviors

The positive and negative toll that a BC diagnosis and treatment can take on intimate relationships is well documented in the scientific literature (Fergus & Gray, 2009; Nasiri, Taleghani, & Irajpour, 2012; Shiozaki et al., 2011; Zalis & Lewis, 2010). Some couples adjust effectively to the demands and changes following a diagnosis of BC (Northouse, Templin, & Mood, 2001). Yet, even couples with relatively stable relationships may find their families significantly challenged as they attempt to deal with the demands of a BC diagnosis (Holmberg et al., 2001).

Non-supportive behaviors from partners or spouses can be perceived by the woman as ranging from overprotection (which can present as excessive engagement), problem avoidance, underestimation of the effects of the disease, minimizing the significance of the situation, forced cheerfulness, lack of partner's understanding, and insensitive comments (Gremore et al., 2011; Shiozaki et al., 2011; Wimberly, Carver, Laurenceau, Harris, & Antoni, 2005). In addition to these relatively covert behaviors, non-support can also present as overt negative responses which can take on many forms (Manne, Taylor, Dougherty, & Kemeny, 1997) including abusive behaviors from a partner (Sprung, Janotha, & Steckel, 2011). Also, while there are no definite numbers available, it was noted that in rare cases some family members may lose control and become physically violent (Watson, 2006). Researchers and clinicians agree that the time is ripe to closely examine the presence of non-supportive and negative spousal and partner behaviors among cancer patients (Canady et al., 2010).

Non-supportive behaviors from their partners or spouses can result in conflict and have negative effects on the women's psychological adjustment through the time of diagnosis, treatment and recovery from BC (Ballantyne, 2004). The introduction of a BC diagnosis in a couple's relationship that is characterized by long-term conflict may be the catalyst for divorce (Holmberg et al., 2001). In some cultures, women who seek care for an illness are faced with the fear of retribution from their partners (Chavez, 2008). As stated by woman of Mexican-descent, "It can mean divorce or losing your families because for a Hispanic man, a woman without a breast is not a woman"(Erwin et al., 2010, p. 697).

Cancer in general is conceptualized as a chronic disease (McCorkle et al., 2011) impacting the quality of life of families and communities (McCorkle et al., 2011; Phillips & Currow, 2010). Elevated rates of separation or divorce were found to occur more frequently in

married couples (N=515) with chronic illness (Glantz et al., 2009). Sentinel research focused on men (n=261) and women (n=254) with chronic illnesses including malignant primary brain tumors (n=214), general oncology (n=193), and multiple sclerosis (n=108). Women were the affected partner in 78% of the primary brain tumor cohort, 93% of the general oncology and 96% of the multiple sclerosis cohorts. Following the chronic disease, sixty (11.6%) of the marriages ended in either separation or divorce. Divorce was significantly correlated with gender: 20.8% of the relationships that ended occurred when the woman was the affected partner compared with only 2.9% when it was the man. The woman was the affected spouse in nearly 90% of separations that occurred among the patient population (Glantz et al., 2009).

Other researchers studied women (N=204) younger than 50 years to investigate the impact of BC (stage I, II or III) on relationships with their partners (Walsh, Manuel, & Avis, 2005). More than half of the participants (n=117) provided open-ended responses to questions regarding ways in which the BC diagnosis affected their relationships. Participants were predominately white (96%) between the ages of 25 and 30 (6.9%), 31-40 (31.4%) and 41-50 (61.7%). In 82% of the women their relationships were defined as either being married or being marriage-like.

Major themes that emerged included increased closeness and intimacy, communication avoidance, separation or termination of the relationship, and problems related to sexuality (Walsh et al., 2005). Responses to the open-ended questions showed that in 75% of the couples the women felt closer to their partners as a result of their BC diagnosis while 25% reported relationship strain due to a lack of communication and emotional withdrawal (Walsh et al., 2005). Additional data from the open-ended questions indicated that in 12% of the 117 women who responded separation or termination of their relationships with their partners occurred after

their diagnosis of BC. Most women noted that their partners initiated the separation or divorce as a result of the partners' perceived inability to cope with their diagnosis. In a few cases (6%), the women initiated leaving the relationship reporting that they did not receive emotional support from their partners, they did not have their needs met and saw that the presence of their diagnosis was an impetus for them to leave an already problematic relationship (Walsh et al., 2005).

In conclusion, findings show that spouses and partners play an important role in providing support to women diagnosed with BC (Shiozaki et al., 2011). However, these significant others do not always provide the type of support that a woman may desire or need (Shiozaki et al., 2011). Research has posited that unsupportive behaviors from partners or spouses towards women with BC may have a detrimental effect on a woman's ability to cope with their diagnosis (Manne, Winkel, Ostroff, Grana, & Fox, 2005). How a partner or spouse responds to a woman's BC diagnosis has implications for her level of distress and overall well-being (Brusilovskiy et al., 2009). In line with the purpose of the proposed research the following literature of the presence and impact of IPV on women diagnosed with early stage BC is reviewed in order to explore options of more effective clinical care.

Violence against Women

Universally agreed-upon definitions for VAW are lacking (Ellsberg & Heise, 2005). International consensus for VAW is that abuse towards women and girls should be considered gender-based violence (GBV) because it is largely derived from women's subordinate status in society relative to men (Ellsberg & Heise, 2005). In 1993, the United Nations defined GBV as any harmful behavior that is directed towards women and girls because of their sex, including wife abuse, sexual assault, dowry-related murder, marital rape, selective malnourishment of

female children, forced prostitution, female genital mutilation, and sexual abuse of female children (United Nations General Assembly, 1993).

The WHO has accentuated that worldwide VAW is a major contributor to adverse health conditions (World Health Organization, 2005). Of particular importance to this proposed research and the focus of the subsequent review is the type of violence that is perpetrated by a spouse or an intimate partner towards a woman, known as intimate partner violence (IPV).

Intimate Partner Violence

There is great variability in how IPV is defined and conceptualized. The WHO defines IPV as, “any act or omission by a current or former intimate partner which negatively affects the well-being, physical or psychological integrity, freedom, or right to full development of a woman” (Krug, Dahlberg, Mercy, Zwi, & Lozano, 2002 p. 24). The Centers for Disease Control and Prevention’s (CDC) definition for IPV is summarized as including threats or intentional use of physical and/or sexual violence with the potential for causing injury, disability, or death, or psychological/emotional abuse. and/or coercive tactics when there has been prior physical and/or sexual violence perpetrated by a current or former spouse or non-marital partner (Saltzman, Fanslow, McMahon, & Shelley, 2002). The National Crime Victimization Survey, a data collection source sponsored by The Bureau of Justice Statistics, defines IPV as any act of rape, sexual assault, robbery, aggravated assault, and simple assault committed by an individual who is the victim’s current or former spouse, boyfriend or girlfriend (Catalano, 2012). Another organization defines IPV as behaviors that consist of assaultive and coercive acts that include inflicting physical injury, psychological or sexual abuse, isolation, stalking, treats, intimidation and deprivation perpetrated by one intimate partner towards another partner (Family Violence Prevention Fund, 2010).

Intimate partner violence can occur in various types of intimate relationships, including marriage, cohabitating couples, committed relationships in opposite sex and same sex couples, and in dating relationships (U. A. Kelly, Gonzalez-Guarda, & Taylor, 2011). Abusive behaviors in a relationship can continue after the couple are no longer together (U. A. Kelly et al., 2011).

Forms of IPV often vary (Kelly et al., 2011). Abuse can present itself as either overt or covert behaviors (Evans, 2010). Intimate partner violence is sometimes comprised of a combination of physical violence, sexual violence, threat of physical or sexual violence, and psychological/emotional abuse. Some authors define IPV based on the combined presence of violence, while others treat each of these behaviors as discrete categories (Crawford, Liebling-Kalifani, & Hill, 2009; Saltzman et al., 2002). Examples of IPV-related behaviors include physical violence (slapping, hitting, kicking, and beating), sexual violence (forced sexual intercourse and other forms of sexual coercion), emotional/psychological abuse (insults, belittling, constant humiliation, intimidation for example destroying belongings), threats (to harm or take away children), and controlling behaviors (isolating a person from family and friends, monitoring their movements and restricting access to financial resources, employment, education or medical care) (Krug et al., 2002). Although physical abuse is the most visible and recognized form of IPV, it is important to note that other types of abuse can be just as detrimental to a woman's health (Campbell, 2002; Pico-Alfonso et al., 2006).

While some types of IPV are overt and easily recognizable, covert types of IPV may be difficult for women to recognize and respond to (Evans, 2010). Nonphysical abuse often presents as controlling, coercive behaviors, through the use of verbal abuse and threats (Gondolf, Heckert, & Kimmel, 2002). Coercive controlling behaviors are identified as patterns of physical violence that are often combined with emotion abuse in the form of intimidation, coercion and

control (J. B. Kelly & Johnson, 2008). Effects of coercive control are usually comprised of three primary characteristics: it is designed to punish, hurt, or control a victim; it has a cumulative effect and it frequently results in severe injury or death (Stark, 2007).

Psychological abuse may be labeled as such because it occurred in the company of others outside the relationship, it is judged as abusive from these outsiders or normative definitions suggested that the behavior was or was not abuse (DeHart, Follingstad, & Fields, 2010). Contexts, perceptions, motivations, intentions and outcomes of psychological abuse all affect whether a particular type of behavior is likely to be labeled as abusive at that time, except in cases of extreme pathological actions (Follingstad, 2011).

While frequency and duration of abuse is important to determine the potential long term effects, it is the sequence of actions between partners that is of most importance. This sequence could inform whether the psychological abuse was a one-time event, consisting of a pattern of abuse, results from a perpetrators response to an apparent provocation by the woman or is comprised of a “tit-for tat” response between the perpetrator and the woman (DeHart et al., 2010). Given that there are no precise definitions for IPV, for the purposes of this proposed research IPV will be defined as the acts of omission and/or commission from a spouse or partner that are harmful to the emotional, physical, sexual, psychological or financial health and well-being of another spouse or partner.

Prevalence of Intimate Partner Violence

Intimate partner violence is a serious public health problem affecting millions of individuals worldwide (Krug et al., 2002). Data regarding the precise magnitude of IPV is imperfect because it is a crime that is under-reported and unrecorded (Kapoor, 2000). The WHO reports that 15% to 71% of women interviewed from around the world (N=24,000) stated that

they had been physically or sexually assaulted by an intimate partner at some point in their lives (World Health Organization, 2005). Victims of abuse reported that ongoing psychological violence, such as emotional abuse and living under terror, is often more unbearable than the physical acts with mental stress sometimes leading to a higher incidence of suicide and suicide attempts (Kapoor, 2000; World Health Organization, 2005).

In the U.S. approximately 1.3 million women are physically assaulted (Tjaden & Thoennes, 2006) and 16,8000 are killed by an intimate partner each year (Centers for Disease Control and Prevention, 2003). Prevalence of IPV among women age 15-19 years, suggests that violence begins early in woman's relationships and peaks between the ages of 40-44 years (WHO, Department of Reproductive Health and Research, London School of Hygiene and Tropical Medicine, & South African Research Council, 2013). From 1994 to 2010, 4 in every 5 victims of IPV were among females between the ages of 18-34 years (Catalano, 2012). Females ages 35-49 years were the only age group to experience a statistically significant increase from 7.1/1,000 victimizations in 2005 to 9.6/1,000 victimizations in 2010 (Catalano, 2012). Furthermore, most female victims of IPV were previously victimized by the same offender, including 77% between the ages 18 to 24, 76% between 25-34 years, and 81% between 35-49 years of age (Catalano, 2012). There is evidence that IPV occurs across the life span including in older adults (Mouton, 2003; Rennison & Rand, 2003). In a study of 1,245 women between the ages of 50-79, 58.5% of the women reported being exposed to some type of IPV in their adult lifetime (Mouton, 2003). In this study 5.2% to 22.8% of the women experienced the abuse within the past 12 months prior to the interview from September 1997 and October 2001 (Mouton, 2003). In another study, researchers found that from 1993 to 2001, about 118,000 women 55 years and older were victims of IPV (Rennison & Rand, 2003).

In California, nearly 4 million or 17.2% of the adult population, report being victims of physical or sexual abuse by an intimate partner (Zahnd, Grant, Aydin, Chia, & Padilla-Frausto, 2010). According to the California Women's Health Survey, approximately 40% of women in California have experienced IPV in their lifetimes (Weinbaum, Stratton, Roberson, Takahashi, & Fatheree, 2006). While both men and women are victims of violence from their partners (Hamberger & Guse, 2002), in California women were found to be twice as likely to be victims of IPV (21.1%) as compared to men (11%) (Zahnd et al., 2010). Ethnic and racial diversity of IPV in California were found to be considerable (Zahnd et al., 2010). Indian/Alaska Natives report higher rates of IPV (33.9%) when compared to African Americans (24.4%), Whites (20.6%), Latinos (13.7%) and Asians (8.5%). Approximately 95,800 cases overall were reported to have occurred in the 12 months prior to 2007 and were noted to be higher in African Americans (30.6%), when compared to Latinos (28%), American Indian/Alaska Natives (26.1%), Asians (23.4%), and Whites (21.5%) (Zahnd et al., 2010).

An identifiable risk for women experiencing IPV is the risk of being killed by their partners or spouses when they attempt to leave the relationships (Campbell et al., 2003). Nationwide, female victims of IPV are substantially more likely to be killed by an intimate partner than male victims, with 2 out of every 5 female homicide victims killed by their partners (Cooper & Smith, 2011). In 1980, homicides committed by a spouse were 69.1% while 26.8% were committed by a boyfriend or girlfriend. By 2008, the proportion of homicides committed by a spouse decreased to 43.7% yet homicides committed by a boyfriend or girlfriend increased to 48.6% (Cooper & Smith, 2011).

Pregnancy is often a time when IPV begins or escalates (Bloom, Bullock, Sharps, Laughon, & Parker, 2011) placing both the woman and her fetus in jeopardy (Krug et al., 2002).

The WHO multi-country study found the prevalence of IPV in pregnancy range from 1% in Japan to 28% in Peru, with most sites ranging from 4% to 12% (Garcia-Moreno, Watts, Jansen, Ellsberg, & Heise, 2003). In the US, IPV during pregnancy range between 0.9% and 20.1%, with most estimates from 4% to 8%, translating into approximately 156,000 to 332,000 pregnant women experiencing IPV each year (Gazmararian et al., 2000). The first trimester is when most (77%) IPV occurs (Krulwich, Pierre-Louis, de Leon-Gomez, Guy, & Green, 2001).

Marginalized groups of women are also at an increased at risk for IPV. Such populations include women with disabilities (Curry, Hassouneh-Phillips, & Johnston-Silverberg, 2001; Hassouneh-Phillips & Curry, 2002; Hassouneh-Phillips & McNeff, 2005), immigrant women (Raj & Silverman, 2002; Riddell, Ford-Gilboe, & Leipert, 2009), elderly women (Band-Winsterstein & Eisikovits, 2009), and women with cancer (Schmidt et al., 2006).

Financial costs of Intimate Partner Violence

The financial cost of IPV is extraordinary high (National Center for Injury Prevention and Control, 2003). In the U.S. alone, IPV in the form of rape, physical assault and stalking exceeds \$5.8 billion each year, nearly \$4.1 billion for direct medical and mental health services (Centers for Disease Control, 2012). Ten years ago, the total medical and mental health care cost per victimization by an intimate partner was estimated to be \$838 per rape, \$816 per physical assault and \$294 per stalking (National Center for Injury Prevention and Control, 2003). Direct medical costs consist of mental health services and medical treatment (such as visits to an outpatient clinic or an emergency department, ambulance transport, physician, physical therapy, dental visits and inpatient hospitalization) (National Center for Injury Prevention and Control, 2003). Furthermore, the increased annual health care costs for victims of IPV can persist as long as 15 years after the cessation of abuse (Rivara et al., 2007).

The estimated lost productivity for victims of abuse is nearly 8 million days of paid work. This is equivalent to more than 32,000 full-time jobs and almost 5.6 million days of household productivity each year (National Center for Injury Prevention and Control, 2003).

Health Outcomes and Intimate Partner Violence

The detrimental effects of IPV on women's physical, psychological or sexual health have been well documented in the literature (American College of Obstetricians and Gynecologists, 2012; Breiding, Black, & Ryan, 2008; Coker, Smith, Bethea, King, & McKeown, 2000; WHO et al., 2013). Women who experience IPV often rate their health as lower than women were not abused (Lown & Vega, 2001; Wittenberg, Joshi, Thomas, & McCloskey, 2007).

Psychological and emotional health problems associated with IPV include depression (Dienemann, Campbell, Landenburger, & Curry, 2002), substance abuse (Walton-Moss et al., 2003), and posttraumatic stress disorder (PTSD) (Woods, Hall, Campbell, & Angott, 2008). IPV places women at greater risk for physical such as HIV infection (Silverman, Decker, Saggurti, Balaiah, & Raj, 2008; Wyatt et al., 2011; Wyatt et al., 2002), sexually transmitted diseases (Alvarez et al., 2009), and chronic pain, including back and neck pain, pelvic pain, and swollen, painful joints (Woods et al., 2008). Victims of IPV are prone to stress-related health problems, including headaches, seizures, and sleep problems, (Campbell, 2002; Coker et al., 2002; Garcia-Moreno et al., 2003; Woods et al., 2008). In addition, the presence of hostile marital relationships have been attributed to increased proinflammatory cytokine production and lower wound healing (Kiecolt-Glaser et al., 2005). Noncommunicable diseases such as hypertension, cardiovascular diseases and cancer has all been identified as possible consequences of IPV in a woman's life (WHO et al., 2013) (See Figure 1)

Cancer and Intimate Partner Violence

Women living with IPV are more likely to smoke, abuse alcohol, eat unhealthy diets and be obese (Hathaway et al., 2000; McNutt, Carlson, Persaud, & Postmus, 2002; Weinbaum et al., 2001). These lifestyles are linked with cancer. So, while IPV is common among the general population, it has been surmised that it also may be common among individuals diagnosed with various types of cancer (Schmidt et al., 2006). Thus IPV in the lives of women have been identified as a risk factor for cancer (Ackerson, 2012).

Associated with a cancer diagnosis and treatment are changes in health status, physical limitations, increased dependency on caregivers, and resulting disabilities. These changes may increase feelings of weakness and vulnerability (Curry et al., 2001; Hara & Rose, 2006). In and of themselves, BC and IPV constitute major stressors for women. It follows that a combination of the two phenomena can potentially overwhelm and harm women in a number of ways (Canady et al., 2010). Women diagnosed with BC may share similar characteristics with other marginalized groups that place them at a greater risk for abuse, and consequently make them members of a vulnerable population (Schmidt et al., 2006).

The presence of pre-existing vulnerabilities may increase an individual's susceptibility to certain types of coercive behaviors (Dutton & Goodman, 2005). Economic liabilities (Tolman & Rosen, 2001), illness or injury (Breiding et al., 2008), physical disability (Anderson, Leigh, & Samar, 2011), pregnancy (American College of Obstetricians and Gynecologists, 2012), motherhood (Patrice Erdmans & Black, 2008), and substance abuse or mental health problems (Kilpatrick, Acierno, Resnick, Saunders, & Best, 1997) can increase an individual's level of vulnerability to various types of abuse because these vulnerabilities may negatively affect the ability to act on her own behalf (Dutton & Goodman, 2005). Some women may initiate

relationships with partners while also dealing with pre-existing vulnerabilities. The presence of these vulnerabilities can then be used against them and exploited by their abusive partners. For example, in one case an abusive man exploited his partner who was diagnosed with BC by insisting that she continue in their relationship because no one else would want her (Dutton & Goodman, 2005). Although the author does not explicitly define the characteristics of the relationship and the onset of abuse, it can be surmised that multiple levels of vulnerabilities may exist within women who are subjected to abuse.

For the purpose of this proposal, four studies were found that investigated the association between IPV and cancer. These studies examined various types of cancer during different stages of the cancer trajectory, and used both quantitative and qualitative methodologies with different approaches (case studies, chart review, interviews). (Studies that focused specifically on decision-making for cancer treatment are discussed in a following section.)

The first study was purposed to explore the association between IPV and cancer screening for pre-invasive and invasive cervical cancer during clinic visits (Coker, Sanderson, Faden, & Pirisi, 2000). Women seeking medical care in two university-associated family practice clinics were interviewed (N=1152). The women were between the ages of 18 to 65 who were insured by either Medicaid or a managed care provider. The presence of IPV was characterized by (a) the timing of the violence (past or present), (b) the type of violence (physical, sexual, or psychological violence), and (c) frequency of the violence and injury. Women were asked if they had ever had cancer or if they had ever been treated for an abnormal Pap test. Cervical dysplasia was used to refer to women who had been treated for an abnormal Pap test but who did not have cervical cancer. The women were divided into groups comprised of those who reported a diagnosis of cervical cancer (n=14), cervical dysplasia (n=234), or no history of cervical

neoplasia or other cancer as controls were (n=847). A multivariate logistic regression was used to model the association between IPV by type and cervical neoplasia. To show the risk of cervical neoplasia associated with physical and sexual IPV, frequency-duration scores were given for history of sexually transmitted infections (STI).

The prevalence of IPV among this sample was high: 53.7% reported an experience some type of IPV. Among the women who reported a history of IPV, 77% experienced physical or sexual IPV and 23% experienced psychological violence without physical or sexual IPV. Higher IPV of the sexual type were associated with cervical cancer among women with and without a history of STI. Higher physical IPV scores were associated with cervical cancer only among women with no history of STI. Women with a history of IPV had an increased risk of with cervical dysplasia only among women who had never had a sexually transmitted disease. Physical and sexual IPV were noted to be higher in women with cervical cancer than among women both with and without a history of STI. The researchers concluded that IPV may be associated with cervical cancer indirectly through chronic stress and through having an STI. Another conclusion was that women who experienced IPV were at increased risk for cervical neoplasia (Coker, Sanderson, et al., 2000).

In another study researchers examined the prevalence of IPV among women recruited from a gynecologic and breast oncology clinic (Modesitt et al., 2006). The sample was comprised of women (N=101) with cancer of the breast (n=11), cervix (n=14), endometrium (n=11), or ovary (n=13). Almost half of the sample group (n=49; 48.5%) reported a history of violence. Of the women who experienced violence, 46.9% (n=23) reported a childhood history of violence and 75.5% (n=37) had experienced violence as an adult. Of the women who reported a history of violence 55% were sexually abused. The number of women who experienced a history

of both types of violence was not reported. Compared with the women without a history of violence, women who experienced violence were found to differ significantly with regard to being younger, divorced, smoked, and lacked commercial health insurance.

Advanced-stage cancers were diagnosed more frequently among women who disclosed a history of childhood or adult violence despite adherence to recommended screening protocols for breast, cervical, and colon cancer. Specifically, women with a history of violence had a 2.6-fold increased chance being diagnosed with a more advanced cancer. In addition, women who experienced violence were less likely to report either not seeing a physician or relied on emergency room visits in the year prior to their cancer diagnosis (Modesitt et al., 2006). Implications for future research included that detection of serious health problems, such as cancers, is vitally important in improving health outcomes for women with a history of violence.

In a more recent study, chart audits were used to research the association between IPV and screening rates for breast and cervical cancer among women from four urban family practices (Gandhi et al., 2010). The sample (N =382), were comprised of non-victims of violence (n=319), victims of emotional abuse only (n=37), and victims of physical and/or sexual abuse (n=26). The majority of victims (58.5%) reported emotional abuse only; 41.5% reported both physical and/or sexual abuse. Most of the women were younger than 40 years (63%), African American (77%), and unmarried (64%). Overall, 16.5% of the women were victims of IPV.

Age interacted with IPV to affect both breast and cervical cancer screening rates. While there was no significant difference in cervical cancer screening rates among victims and non-victims <40 years, older women were at increased risk for delays in screening (Gandhi et al., 2010). Type of abuse also played an important role in affecting cancer screening in women \geq 40 years. Women \geq 40 years (n=26) who reported physical and/or sexual abuse, had a lower

screening rate for breast cancer (15.4%) compared to those who experienced emotional abuse only (53.8%) and non-victims (34.5%) Screening rates for cervical cancer (36.4%) were significantly lower among women who reported emotionally abused only (76.9%) compared to non-victims (47.7%) Women who were married and who had “other” insurance had a significantly lower cervical cancer screening rate. Overall, the findings from this study reiterate the presence of IPV occurred across the adult life span. However, the delay to seek screening for breast and cervical cancer were more pronounced among women 40 years and older who had experience physical and/or sexual IPV.

Doctoral research from a psychological perspective was purposed to examine how the presence of a BC diagnosis, treatment, and recovery affect rates of abuse in a comparative sample involving physical and psychological abuse among ethnically-diverse women (Canady et al., 2010). The researcher hypothesized that rates of IPV would be comparable in two matched groups in the year before, during and the year after the cancer diagnosis. Ethnically-diverse BC survivors (BCS) (N=206) and age- and ethnicity-matched female cancer free control (CFC) peers (N=206) who had never been diagnosed with any type of cancer, were compared for perceived physical and emotional well-being. Participants was 30 years or older (mean age: BCS= 53.28 and CFC = 52.42). The BCS-group were diagnosed on average 5.77 years (SD=4.87) ago with BC staged as pre-cancer/ductal carcinoma in situ (n=27, 14.44%), Stage I (n=67, 35.83%), Stage 2 (n=60, 32.09%), Stage 3 (n=27, 14.44%), Stage 4 (n=3, 1.6%), and unknown (n=3, 1.6%).

When completing the questionnaire about their retrospective experiences at defined time points, the BCS-group was asked to refer to the cancer including the year before the BC diagnosis, the year following the diagnosis and the year preceding completing the questionnaire. The CFC-participants were asked to identify a stressful event and to use that event as the

reference point when completing the questionnaire. The CFC-group answered the questions for the year prior to this stressful event, the year following the stressful event and the past year.

Seven tools were used to assess perceived physical and emotional well-being. Three of the tools, the Dyadic Adjustment Scale, the Conflict Tactics Scale-2 and the Women's Experience with Battering Scale (WEB) were presented to the women at the time of the interview and were asked to retrospectively answer each questionnaire regarding the three designated time periods. The tools measured marital satisfaction (three questions based on the Dyadic Adjustment Scale), physical violence (Conflict Tactics Scale-2). The additional tools were used to assess for psychological abuse (WEB), relationship components (Gottman's Best to Work out Problems Alone Scale), depression (The Beck Depression Inventory), individual feelings at the present time and in general (State -Trait Inventory), and for frequency of common physical symptoms and sensations.

Repeated measures MANOVA compared the two groups for physical and psychological abuse at each of the three time points measured. Although physical and psychological abuse were low in both groups, results found that the two groups reported different patterns of physical ($p < 0.0129$), but not psychological ($p < .7023$) abuse across time. The BCS group reported lower levels of both types of abuse at all the time points. For psychological abuse, although both groups had similar patterns of change, the groups were different at all the time points ($p < .0074$) and both groups reported changes at different time points ($p < .0001$). Although the CFC group reported a decrease in physical violence at later time points, they never reached the same low level reported by the BCS group. In addition, the BCS group reported lower levels of psychological abuse at all the time points.

A strength of the study is that it explored the under-researched area of abuse in women diagnosed with BC, but the researchers also note limitations: the lack of focus on sexual abuse, the use of very brief measures of two types of abuse, and the reliance of retrospective reporting. Suggestions for future research include employing a prospective design, the use of multiple groups for generalizability, and methodological rigor to examine how the co-occurrence of cancer and IPV can affect overall well-being (Canady et al., 2010).

In conclusion, practitioners and researchers are beginning to explore the association between IPV and cancer in the lives of oncology patients. The limited research focused on the influence of IPV in the lives of cancer patients show that IPV can greatly impact care, health outcomes and decisions regarding treatment. For the purposes of this literature review, treatment decision making (DM) among women who living with IPV when diagnosed with early stage BC will be described in the following section.

Treatment Decision Making

Decision making (DM) is defined as the process of choosing between alternative courses of action or inaction (O'Connor et al., 2002) and is noted to be a deeply social event (Rapley & May, 2009). In recent years, the healthcare system in the US strongly encourages greater patient involvement in treatment DM (Stiggelbout et al., 2007) because collaborative DM enhances patients' control over their health, facilitates more patient-oriented decisions, and may lead to better health outcomes (Vogel et al., 2008). For males and females alike the majority of treatment DM in the healthcare setting often takes place within the context of the physician-patient relationship (Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2012). The use of a particular decision-making model will vary based on the patient's preference for autonomy and control in the DM process. Two common frameworks of treatment DM are the paternalistic

model and the shared DM model. The paternalistic model, known as ‘the doctor knows best’ framework, occurs when the patient is passive and dependent upon the ‘expert’ physician to make all the decisions regarding care (McKinstry, 1992). Decisions made by the physician are then communicated to the patient (Brown et al., 2012). This model is primarily used in situations of emergency where the patient’s critical condition takes precedence over patient involvement (Tariman et al., 2012). On the other hand, the shared DM model involves the two-way exchange of information and treatment preferences (Charles, Gafni, & Whelan, 1999). Both the patient and the clinician are involved in the treatment DM and agree on the plan of treatment (Tariman et al., 2012).

Decisional conflict occurs when individuals have opposing tendencies to either accept or reject a specific course of action (Janis & Mann, 1977). Conflict with DM is defined as a state of uncertainty when outcomes are unknown, when a higher degree of risk is involved, and/or when the benefits and risk of loss are not clearly defined (Spittler et al., 2012). Known factors which may contribute to decisional conflict include uncertainty regarding the difficulty of the choices available and other modifiable factors (O'Connor et al., 2002). The presence of modifiable factors can therefore have the propensity to make an essentially difficult decision even more challenging for individuals (O'Connor, 1995). Unclear perceptions of others, social pressure, lack of support, and lack of self-confidence can potentially influence treatment DM (O'Connor et al., 2002). Signs of decisional conflict include concerns regarding choices, fears of unknown or unwanted results, indecisiveness about treatment options and/or delay in making decisions regarding treatment (Spittler et al., 2012).

Decision making about cancer treatments has become increasingly complex over recent years for both patients and clinicians (Vogel et al., 2008). Treatment DM in oncology settings

are associated with key components of commonality (physician-patient interaction and desire for information) and diversity (age, family factors and social support) (Blank et al., 2006). The complexity of making decisions regarding cancer treatment can be especially challenging for some individuals (Blank et al., 2006). Variability in treatment options with the focus on potential benefits and side effects must be evaluated closely by the patient and the health care team before treatment starts (M. O'Brien, Whelan, T., Charles, C., Ellis, P., Gafni, A., Lovrics, P., Hasler, A., Dimitry, S., 2008). Interventions to increase collaborative cancer-related DM are effective in increasing patient's knowledge about treatments, improving patient satisfaction with treatment decisions and, in some cases, decreasing decisional conflict without increasing patient anxiety (M. O'Brien et al., 2013).

A woman's ability to make decisions regarding her treatment for BC results from several factors including the role she desires to play in the process, the role of her significant other, the treatment choices available, her quality of life, and the communication between herself and her health care providers (Nazareth et al., 2008). When diagnosed with BC, a woman is often confronted with the urgent need to make critical treatment decisions regarding types of surgery, chemotherapy agents, radiation treatment and even when and where to receive the treatments (Hewitt et al., 2004). Yet, despite the growing trend for more patient involvement in the DM process, there is great variability in a patients' desire to participate in the process (Duffy & Valentine, 2011).

Internal (patient-related) and external (physician or system-related) factors present in a woman's life may influence her ability to make decisions regarding her treatment for early stage BC (Mastaglia & Krisjanson, 2001; Tariman et al., 2012). Furthermore, a woman's personal confidence in the decisions that are made and her ability to participate in the process at the level

she desires can have a significant impact on her overall cancer experience and health (Blank et al., 2006).

Decisions for treatment are often made in a very short period of time after diagnosis of early stage BC (Swainston et al., 2012). That is, women meet with a number of specialists to explore the disease process and treatment options shortly after diagnosis. Even with early stage BC, there is usually a sense of urgency to make a decision and to receive treatment (Pieters et al., 2012). While women search for information to collaborate in DM process (Pieters et al., 2012), the overload of the new knowledge can prove to be overwhelming for her and may lead to information overload (Spittler et al., 2012). In some situations, the presence of increased stress and anxiety associated with the diagnosis of BC can lead women to make decisions regarding their treatment that they later regret (Spittler et al., 2012).

Decision Making in Domestic Violence

An abusive intimate relationship involves a continuous stream of decisions to be made, conflicting needs to be negotiated, and options and desires to be balanced (Bancroft, 2002). A woman's ability to participate in decisions pertaining to the needs of her household, her children and herself are all indications of the level of empowerment and control she has in her relationship (Kishor & Johnson, 2004). The decision to address the presence of IPV and its consequences in a woman's life is often mitigated by circumstances surrounding the history of other forms of violence sustained, her social isolation and the availability of services to assist her (Ford-Gilboe et al., 2011).

Violence from a partner or spouse may result from a woman's attempt to control some decisions which are not normally perceived to be in the realm of her control, such as economic or childrearing decisions (Kishor & Johnson, 2004). Furthermore, in some cases, behaviors that are

perceived to be violating specific gender roles may add fuel to the violence she may already be experiencing (Kishor & Johnson, 2004). Women are vulnerable to controlling behaviors in their private lives because of the subordinate position they hold in the larger social structure. For example, economic inequality (occupational segregation, a glass ceiling, and a wage gap) all make it difficult for women to make decisions about leaving an abusive relationship (Arnold, 2009).

Women in abusive relationships have made it clear that what is done to them is less important than what they are prevented from doing by their partners either through the limitation of their resources, by undermining their social support, by subverting their rights to privacy, self-respect and autonomy, or by depriving them of essential equality (Stark, 2007). A woman's response to the violence, including her ability to make decisions regarding disclosure or leaving, are influenced by her commitments to her partner, the community, and by the religious expectations of others (Ford-Gilboe et al., 2011). Male control of household DM is a clear predictor of partner violence (Levinson, 1989; Oropesa, 1997) so women living with abusive relationships may also be actively prevented from making decisions about what happens in their household through the controlling behaviors of their partners (Kishor & Johnson, 2004). The intention of controlling behaviors from a partner is to destroy the woman's autonomy, her ability to make decisions, and her ability to act on her own behalf (Arnold, 2009). Furthermore, the presence of DV contributes to lowering a woman's self-esteem and by eroding her mental health (Astbury, 2000; Ellsberg, Pena, Herrera, Liljestrand, & Winkvist, 1999; Fikree & Bhatti, 1999), thereby affecting her capacity and willingness to participate in DM (Kishor & Johnson, 2004).

Among the many decisions women face, arguably the most crucially important for her self-interest are decisions she makes about her body and healthcare. However, it is the general

consensus that in the majority of abusive relationships, it is the husband who is most likely to be the main decision-maker in all areas of a woman's life, including healthcare (Kishor & Johnson, 2004). For example, abusive relationships are associated with limited fertility control, unintended/unwanted pregnancies, and forced abortions contributing to a sense of disempowerment in women (Pallitto, Campbell, & O'Campo, 2005). Women experiencing IPV visit their healthcare providers more often than women without a history of violence (Plichta, 2007; Ulrich et al., 2003). However, significant socio-economic characteristics such as low socioeconomic status, racial and ethnic status, age of the woman and locale (urban vs. rural) may limit a woman's ability to make decisions regarding her need for care (Bloom et al., 2011). Thus, despite consulting with healthcare professionals, factors that often accompany abusive relationships can have a profound effect on treatment DM in women diagnosed with BC.

Focused Literature Review

To understand the impact of IPV partner or spousal behaviors among women diagnosed with early stage BC on treatment decision-making a systematic search of the databases MEDLINE, CINAHL, PubMed, and PsychoINFO was done. Inclusion criteria were purposefully broad to identify as many articles as possible. Key words used either individually and/or in combination included "breast cancer", "intimate partner violence", "domestic violence", "partner abuse", "spousal support", "decision-making", "cancer", "oncology", "negative support", "significant other", "unsupportive behavior", and "non-supportive spousal behavior". Following this electronic search, the references of the relevant papers were hand-searched for additional articles. Researchers (Sawin, 2010, 2012; Sawin et al., 2009; Sawin & Parker, 2011) in addition to oncology practitioners (Martino et al., 2005; Mick, 2005; Schmidt et al., 2006) examined the presence of various types of IPV and/or non-support from the partners or spouses

of women diagnosed with of cancer. Types of IPV and non-support included physical threats, intimidation, and various degrees of control regarding a woman's health situation and choice. A summative table of the research is presented in Table 1.

For the purposes of this review, seven articles were found that focused on the phenomenon of non-support or IPV and treatment DM among women with various kinds of cancer. Of these seven articles, the four with Sawin as first author resulted from one study (E. Sawin, personal communication June 01, 2011). Thus, only four studies were found that investigated the phenomenon of specific relevance to inform this research proposal. The first of these studies was published in 2005 (Martino et al., 2005; Mick, 2005; Schmidt et al., 2006) making this complex phenomenon a relatively new field of scientific inquiry in cancer survivorship literature.

The four studies used two qualitative methodologies: case studies with sample sizes between one and four women (Martino et al., 2005; Mick, 2005; Schmidt et al., 2006) and hermeneutic phenomenology with sample sizes ranging from seven to sixteen women (Sawin, 2010, 2012; Sawin et al., 2009; Sawin & Parker, 2011). The sample characteristics of the reviewed studies are limited in scope by sample size, the homogeneity of study participants, specific types of abuse, by treatment decision outcomes after the abuse was recognized, and by how the presence of abuse specifically altered or complied with the decision desired by the woman for treatment. For example all four studies were based on self-report (Martino et al., 2005; Mick, 2005; Sawin, 2010, 2012; Sawin et al., 2009; Sawin & Parker, 2011; Schmidt et al., 2006) and not all abuse experienced by the women were solely physical as some partners often used multiple types of abuse (Sawin et al., 2009; Schmidt et al., 2006). Furthermore, some women experienced abuse that was reported to have occurred accidentally by their abusive partners (Sawin et al., 2009).

The results of the reviewed studies provide consistent evidence that the many challenges that women face when they are diagnosed with cancer are further complicated when they are in abusive relationships that potentially interferes with their treatment DM. Physical, psychological and emotional concerns specific to BC diagnosis are difficult to overcome when women do not have the support they desire from their partners or spouses (Holmberg et al., 2001; Manne et al., 1997; Shiozaki et al., 2011; Walsh et al., 2005; Zahlis & Lewis, 2010). The extreme inequality in power and the social isolation associated with IPV and non-support are evidenced by the reviewed studies. The control inflicted upon the women by abusive partners can hinder treatment and lead to progression of a life-threatening disease (Martino et al., 2005).

In particular cases it was not simple for healthcare providers to identify non-support (Martino et al., 2005; Mick, 2005), abuse (Martino et al., 2005; Mick, 2005) or IPV (Mick, 2005). Outside of oncology settings, abuse (Queen, Brackley, & Williams, 2009; Stark, 2007) or IPV (Bhandari, Bullock, Anderson, Danis, & Sharps, 2011; Hegarty et al., 2013) are not solely of a physical nature. This review of similar phenomena in an oncology setting reflected that some partners used multiple types of abuse (Sawin et al., 2009; Schmidt et al., 2006). While not all patients with cancer will succumb to physical or psychological abuse at the hands of their partners, clinicians need to be more aware of the potential risk of its occurrence in their female population (Hara & Rose, 2006). For when a woman perceives a limited control over her body from the disease and/or from her partner or spouse, her view of life can often be greatly impacted (Clements & Sawhney, 2000; Gorman, 2006).

Based on the limited research available, a key dimension of IPV and non-support from partners or spouses is that women can experience either the introduction of abuse or an escalation in its level after their diagnosis of cancer (Sawin, 2010, 2012; Sawin et al., 2009;

Sawin & Parker, 2011; Schmidt et al., 2006). Although some women reported that they decided independently from their non-supportive partners on how they were going to proceed with their treatment (Sawin, 2012), others found their treatment to be withheld or delayed by the presence of their abusive partners because they were dependent upon their partners to provide transportation to treatment and partners refused (Sawin, 2010). Finally, the potential for partner abandonment was also noted to be a potential outcome after receiving a cancer diagnosis (Sawin et al., 2009; Sawin & Parker, 2011).

Limitations in the reviewed literature provide opportunities for future work. No study accommodated the essential nature of treatment DM as a process (Pieters et al., 2012; Pinney, 1991). Thus, no methodology in the existing literature was suited to reflect the underlying process of DM to construct a situation-specific theory to move cancer-survivorship science forward (Abbott, Johnson, Koziol-McLain, & Lowenstein, 1995; Im, 2005; Im & Meleis, 1999). The proposed research will fill this gap by using grounded theory methodology that is particularly suited to describe underlying processes of a phenomenon (Creswell, 2007).

Another limitation of the present state of the science relates to sampling. The findings reflect the experiences of women diagnosed with various types of cancer (breast, cervical, colon, lung and liver) across all phases of the cancer trajectory (from an undetermined time to 31 years post diagnosis) (Mick, 2005; Sawin, 2010, 2012; Sawin et al., 2009; Sawin & Parker, 2011). Only one study with a sample size greater than a single participant (Sawin, 2010, 2012; Sawin et al., 2009; Sawin & Parker, 2011), selected exclusively for one type of cancer. However, cancer-survivorship science underlines that different cancers are experienced differently (National Research Council, 2005). Furthermore, the time since diagnosis influences the cancer experience (Mullan, 1985). It stands to reason that future explorations of IPV among women who

experience cancer need to select for (a) specific cancer(s) and a specified time frame since diagnosis.

Summary

Despite major progress with early detection and treatment of BC, the prevalence, morbidity and mortality associated with the disease remains a major concern for the women themselves, our community, and healthcare providers. Breast cancer continues to produce long lasting psychological, emotional and physical ramifications. Younger women are also dealing with a disease that once was thought to occur almost exclusively in older women. Challenges and concerns for both younger and older women must be recognized and addressed in a way that promotes good health outcomes for women of all ages.

Treatment DM is a complicated process that often proves to be especially challenging for the women just diagnosed with BC. Values upheld by healthcare providers expect patients to have autonomy and accept responsibility for informed treatment choices. In the case of BC, collaborative DM requires that the woman make sense of extensive amounts of new information and make life and death decisions regarding her treatment and the resultant long-term effects which she feels that she can be satisfied with. Support for women diagnosed with BC is a vital key in the challenge to overcome the illness. While many women may have multiple resources available to assist them, it is important to note that the interaction and support she receives from her partner or spouse often hold special meaning during her cancer trajectory. Yet, not all relationships with partners or spouses have the capacity to provide the woman with the type of support she needs.

One in four women will experience some degree of abuse from their partners or spouses within their lifetime (Tjaden & Thoennes, 2006), and one in eight will develop BC (Howlader et

al., 2013). These statistics reflect the likelihood that women diagnosed with BC may also be dealing with relationships where partners or spouses are abusive to women in various ways. Identifying IPV among women diagnosed with early stage BC is essential particularly because such circumstances can have a negative impact on her health. Understanding this type of behavior towards women diagnosed with early stage BC is necessary to address their unique psychosocial needs, develop holistic care, and produce positive health outcomes.

Based on the state of existing literature, it is an assumption of the proposed research that women face unique challenges when diagnosed with early stage BC. These challenges can be further complicated when IPV exist when the woman is diagnosed with early stage BC. Making decisions about various BC treatments can prove to be difficult for some women in the context of their situations. The novel research proposed herein, will extend our knowledge with its focus on the interface between treatment DM among women living with IPV when they were diagnosed with early stage BC.

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Chapter 3: Theoretical Framework

The application of a theory in examining research phenomena is to help guide the research process, to aid in answering research questions, and to facilitate the process of describing and explaining the research findings (Meleis, 2007). Theories are available that describe the topics of breast cancer (BC) (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997), intimate partner violence (IPV) (Stark, 2007), and healthcare decision-making (DM) (Reyna, 2008) independently. However, there is no theoretical framework to guide the study of the concurrent experience of three phenomena: IPV among women diagnosed with BC and its influence in DM. The theoretical framework of symbolic interactionism (SI) will guide this proposed research.

Symbolic interactionism states that meaning refers to the nature of the perceived relation between an individual and their world, and is developed in the context of social interaction (Blumer, 1969/1986; Charon, 2010; Mead, 1934). Symbolic interactionism emphasizes the importance of both understanding and explaining society and the human world. Furthermore, SI acknowledges the importance of the subjective researcher, that is that the researcher brings assumptions to the study (Blumer, 1969/1986, p. 38).

Previous researchers have used SI to describe phenomena which are relevant to the proposed research: the experiences of battered women (Baker, 1997), comparisons among battered and non-battered women (Forte, Franks, Forte, & Rigsby, 1996), the batterer's identified view of self in domestic violence (Goodrum, Umberson, & Anderson, 2001), the experiences of older women with diagnosed with breast cancer (Crooks, 2001), the experiences of BC survivors (Collins, Nash, Round, & Newman, 2003), and the process of treatment decision making (Charles, Whelan, Gafni, Reyno, & Redko, 1998). This proposed research will be the first to use

SI as a framework for understanding treatment DM in the context of concurrent IPV and BC among women.

Symbolic Interactionism

Symbolic interaction is a broad perspective derived from sociology which is used to study, identify and understand the subjective or symbolic meanings people give to human interaction (Charon, 2010). This interaction takes place through the construction of self and the interaction with others within social and cultural contexts (Charon, 2010). Through the process of social interaction, meanings are derived which are then used to help describe how individuals plan and reason their actions and interactions with themselves and with others (Brinkerhoff, White, Ortega, & Weitz, 2008). One of the most important elements of SI is to understand how meanings emerge from human behavior through social interactions and social processes (Jeon, 2004). Also vital to the theory of SI is that the individual and the context in which that individual exists, are inseparable (Blumer, 1969/1986). Truth is tentative and never absolute because meanings change depending on the context for the individual (Pascale, 2011).

Symbolic interactionism originated from the Chicago School of Sociology founded in 1892. The primary focus of the department were social relations, qualitative methodology, and a demanding data analysis (Lutters & Ackerman, 1996). George Herbert Mead (1863-1931) originally constructed SI (Mead, 1934) and is known as the father of SI (Reynolds, 2003). Herbert Blumer (1900-1987) coined the term symbolic interactionism (Aksan, Kısac, Aydın, & Demirbuken, 2009) and expounded on Mead's work (Jeon, 2004).

Mead was a professor of philosophy at the University of Chicago School of Sociology, and was known as a pragmatist, philosopher, behaviorist and social psychologist (Charon, 2010; Mead, 1934). Key components of SI that were derived from the teachings of Mead were the

concepts of mind, society and self (Mead, 1934). (Relevant details about these core concepts are described in a later section of this chapter.) Mead posits that the self is a social structure that arises from social experiences, and involves communication with self and with others (Mead, 1934; Miller, 1973). He further theorized that humans have a mind and therefore can interpret the symbolic meanings of things or gestures around them (Musolf, 2003). Mead also noted that society consists of acting people (Blumer, 1969/1986).

Blumer was a student of Mead during his time at the Chicago School (Jeon, 2004). While Mead's contribution to sociology was more philosophical, Blumer was especially concerned with the development of SI as a sociological theory and as a research approach (Jeon, 2004). Blumer developed three key premises (described in a later section) in providing the foundation for SI: (a) humans act toward things based on the meaning that the things have for them, (b) the meaning of things is derived through social interaction with others, and (c) meanings are used and modified through an interpretative process (Blumer, 1969/1986). As individuals interact with themselves and others in relation to objects, meaning will result from that interaction and will guide how they will then act toward it (Blumer, 1969/1986). Therefore, Blumer notes that the meaning of an object is the outcome of the interaction between humans rather than something that is inherent to the object (Blumer, 1969/1986). Subsequently, it is the experiences of humans that form meaning rather than the objects themselves (Blumer, 1969/1986). The author's depiction of Blumer's three key premises of SI is presented in Figure 2.

Although Mead and Blumer are credited with the development of SI, they were strongly influenced by other key individuals. Charles Darwin (1809-1882) and his theory of natural selection which describe how species change over time, strongly influenced Mead's thinking (Charon, 2010). John Dewey (1859-1952), a colleague of Mead at the University of Chicago,

also greatly influenced SI. Dewey's primary contribution to the development of SI was pragmatism (Reynolds & Herman-Kinney, 2003). Dewey stressed the importance of humans adjusting to their world as they attempt to master it and found that the most unique aspect humans possessed is the ability to think. This thinking is a process that emerges from a human's effort to adjust to the environment. The process of the mind begins with the recognition of objects in the environment, followed by the contemplation of action towards the object and the envisioning of consequences as a result of that action, and then finally the adjustment of action to the object. Importantly, Dewey surmised that the mind is a process of adjustment rather than a specific thing or entity (Turner, 1991). Pragmatism holds four important ideas that Mead later incorporated into SI: humans interpret their environments instead of simply responding to what they see, humans act according to what is useful to them, humans notice selectively and respond accordingly, and humans are active beings (Charon, 2010). Pragmatists also support the idea that humans adapt continuously in an evolving social world because of the ability to contemplate and adjust to a situation (Jeon, 2004).

Charles Cooley (1864-1929) was another key person in the development of SI. Cooley's major focus was on the development of the human self (Aldiabat & Le Navenec, 2011). In SI, Cooley is best remembered for his development of the concept of the looking glass (Charon, 2010) which is described in a later section of this chapter.

Charon (2010), a contemporary expert on SI, states that the theory incorporates the following five central ideas in its view of human beings:

1. Humans are social beings who continuously interact with others in the development of action and of their world. Thus, the actions of individuals are based on their interaction with others.

2. Humans also interact with themselves through the process of thinking. The individual communicates with himself by indicating the social objects to which he is acting toward. The meaning of these things comes from the way others act toward the person in regards to the thing.
3. Environments of individuals are defined indirectly by the situation they are in.
4. An individual's present state of thinking, present level interaction and present definition of the situation will define their immediate situation.
5. Individuals are actively involved in relation to their environments.

Thus, according to Charon, humans' perspective of their world is based on how it is viewed by them. The development of their perspective is an active process that is derived from social interactions within that world. Human reality is translated to a world that is understood, explained, divided, unified, and established through the use of social objects. Once that world is understood and meaning is attached to it, then human beings are in the position to act upon it. Interaction which takes place in their social worlds is characterized by the use of symbols or social objects. It is through the interaction with others and through the use of symbols that rules, ideas, and values are established and utilized. We use the sharing of social objects within society to communicate with others, to bring us together and to formulate structure. On an individual level the development of naming, memory, categorizing, perceiving, problem solving, transcending space and time, self-directing and creating are used with social objects to provide the background for action (Charon, 2010). The author's adaptation of Charon's description of SI is presented in Figure 3.

There are many important components in SI which explain aspects relevant to the proposed research such as how individuals interact develop meaning and formulate plans of

action. For the purpose of this proposal, details of relevant key concepts for understanding how women diagnosed with BC while living with IPV make decisions about their treatment are described in more detail in the following section. The last part of this chapter is a description of how four key premises of SI, as outlined by Blumer (1969), apply to the proposed research.

Key Concepts of Symbolic Interactionism

Symbols/Social objects

Humans live in a social world that is comprised of social objects. A social objects (which are also referred to as a symbol) is anything that can be designated or referred to in a situation (Mead, 1934). Social objects are socially derived, intentionally used and understood by its user within their social world. Social objects often change based on the needs and actions of the individual towards them.

Types of social objects can include symbols, (such as words) language or perspectives. Furthermore, social objects can consist of other people, physical things, man-made things, a time, oneself or even an idea. Social objects are non-stationary objects throughout nature that change and are redefined by the individual's response and goals (Mead, 1934).

Thus, social objects are representation of something. The meaning of a social object is defined by an individual's proposed action toward it (Blumer, 1969/1986; Charon, 2010). Social objects are used as tools for communication. Its purpose and use are constantly being constructed by individuals according to their particular preference and action toward it (Blumer, 1969/1986).

Self

Mead posits that humans are different from other creations in that humans possess a self that is developed through a socially interactive process with others (Mead, 1934). The self is an

social object to itself (Mead, 1934; Miller, 1973). As objects, humans have perceptions of self, and communicate and act towards themselves in the process of self-interaction (Blumer, 1969/1986). Self-interaction is an ongoing process that individuals use by reflecting on the significance of the object and then determining the action they will take related to it (Blumer, 1969/1986). How a person views, defines and acts towards the self as a result of self-interaction is a product of the individual's encounters within a greater social setting (Mead, 1934).

Mead describes several stages that individuals go through in the development and creation of the self. The preparatory stage (a pre-symbolic period of self) is followed by the play stage (when the acquisition of language takes place and the perspective of other persons are introduced), the game stage (which represents organization and the perspectives of more than one individual), and the reference group stage (in which individuals interact with many different groups) (Charon, 2010; Mead, 1934).

Mead also introduced the concepts of the "I" and the "Me" as parts of a whole self (Mead, 1934). From this viewpoint, the "I" is the subjective portion of the self or how one sees oneself. The "I" is natural and spontaneous; unlimited by others. The "me" portion is the objective part of the self or how one imagines that one is seen by others. The "me" is a more reflective side that is seen when one looks back at themselves. The "I" and the "me" are in constant conversation with each other, prior to producing a specific action or behavior (Blumer, 1969/1986; Jeon, 2004; Mead, 1934). The presence of this internal conversation facilitates the process of reflexivity within the individual. This internal conversation also allows the individual to 'take the role of the other' in the contemplation of action.

Taking the role of the other

Role taking consists of imagining ourselves in the role of others in order to determine the criteria others will use to judge our behavior (Mead, 1934, p. 151). Another author describes role taking as covertly imagining to be in the other's role to predict his or her behavior (Forte et al., 1996).

Role taking is responsive to the perceived expectations of significant others – role players with whom the individual chooses to have personal relationships with. These perceptions are decisive in forming one's self-concept. Thus, self-perception and self-judgment follows when we view ourselves as we think others view us (Charon, 2010).

As the role is expanded to a larger network of others it further helps in understanding what society in general expects of individuals. Eventually, individuals begin to judge their behavior not only from the perspectives of significant others but from others as well. These "others" Mead calls the 'generalized other,' which is the composite expectation of the other players with who an individual interacts with (Blumer, 1969/1986). Mead argued that individuals learn social norms through the process of role taking since information is gathered and used as a guide for our individual behaviors. Role taking allows an individual to subtly control and coordinate his or her actions with the actions of others (Forte et al., 1996).

Looking-glass self

The looking-glass self was a concept first developed by Cooley (Charon, 2010) when he proposed that individuals see themselves as they think others see them. In this process of looking-glass formation, he noted that there are three steps that individuals take: (a) imagine how they appear to others; (b) imagine how others may judge their appearance, and (c) actively think about, internalize or reject these judgments (Brinkerhoff et al., 2008). Thus, an individual's self-

concept is not merely a mechanical reflection of others, but rather resides in the internal understanding of the perceived judgments of others judgments (Brinkerhoff et al., 2008). Individuals are actively engaged in defining their self-concept, choosing whose and what looking-glass they want to pay attention to and using past experiences to aid them in interpreting others' responses.

Meaning

Symbolic interactionism theorizes that the meaning of things develop through an interactive process between people (Blumer, 1969/1986; Charon, 2010; Mead, 1934). The individual derives meaning from the ways in which people act toward the individual in regards to an object. Any subsequent action to that object will then provide the definition of it for the person as a social product (Blumer, 1969/1986).

There are two interpretative processes that occur in the development of meaning of the object: the interaction with the self and the interpretation of its meaning. Once the self-interpretative process is completed, the individual begins the process of handling its interpretation. This interpretative process is completed by examining, checking, suspending or modifying the meaning of the object in light of the individual situation followed by directing the course of action based on its newly developed meaning (Blumer, 1969/1986).

Human action

Humans go through a process of interaction with self and with others in determining their plan of action (Blumer, 1969/1986; Charon, 2010). In order for individuals to act, they must note the presence of an issue, define the issue in terms of a need for action, construct their plan of action and then modify their created plan to produce the desired results (Blumer, 1969/1986).

Human actions follow the derived definition and meaning of the situation that is an outcome of interaction with the self and with others as each act is part of a greater picture of action that is constantly adjusted and realigned by the individual preparing for the action (Charon, 2010). It is in social interactions that an individual attempts to ascertain the intention or direction of the actions of others (Blumer, 1969/1986). By taking on the role of the other, individuals define the situation through the perspective of others to develop a plan of action or to examine a situation (Blumer, 1969/1986; Charon, 2010). Thus, human action consist of processes that alter and conform to the minds and established goals of individuals as they evaluate and interpret their situations and their subsequent plans for action (Charon, 2010).

Decision making is an ongoing process that is utilized to determine the expected outcomes of situations (Blumer, 1969/1986; Charon, 2010). For the symbolic interactionist, the end result of decision making is that choices made by an individual must be meaningful, understandable and manageable before a satisfactory action can be implemented (Charon, 2010).

Key Premises of SI as it Relates to This Research Proposal

Four key premises were chosen from Blumer's sentinel work on SI (Blumer, 1969/1986) to apply the theory to this proposed study. There are many components in SI that can be selected to give explanatory examples of how women create meaning in the context of their social interactions and how these meanings influence their subsequent actions. It is to the belief of this author that the four chosen premises will provide a broad and clear avenue to apply SI to DM about BC while living in a relationship of IPV. Each premise will be examined closely by citing a specific sentence from SI, followed by a relevant finding from existing research and then applied to the purpose of the proposal.

Premise #1: “People act toward things based on the meaning those things have for them, not on the basis of the meaning that these things have for the outside scholar” (Blumer, 1969/1986, p. 51). Women’s responses to the presence of abuse and neglect are often determined by the options available to them and by the circumstances surrounding the abuse (Ruiz-Perez et al., 2006).

When a woman receives a diagnosis of BC she will likely begin the process of interacting with herself and with others with the specific purpose of developing meaning for the presence of cancer in her life. She may also begin to contemplate what it all means to her in the context of her life and present relationship with a spouse or partner. As she interacts with herself and others regarding her options for treatment and the potential outcomes and adverse effects, she can then transition into the stage in which she will formulate a plan of action both for her healthcare and for her life. The decision to choose a particular treatment option over another will depend deeply on what BC in the context of her present abusive relationship means to her. It is at that point that she can determine the subsequent course of action to take.

Premise #2: “The meaning of things is derived from or arises out of, the social interaction that one has with one’s fellows” (Blumer, 1969/1986, p. 2). “The use of meanings by a person in his action involves an interpretative process” (Blumer, 1969/1986, p. 5). As a woman attempts to give meaning to the presence of IPV and subsequently decide to seek protection, the process is often mitigated by the intensity of the abuse and the availability of others outside the relationship (Dienemann et al., 2002).

The type of social interaction that takes place in the presence of IPV may require the woman to modify her interpretation of her situation and need for healthcare depending on how she sees the BC and the intimate relationship. Her need for support during this time may increase

causing her to reexamine her situation and to seek available options that will help her deal with her needs. Making decisions about treatment options may be modified as she interacts with her partner or spouse and determines the type of support that she needs.

Premise #3: “ The social action of the actor is constructed by him; it is not a mere release of activity brought about by the play of initiating factors on his organization” (Blumer, 1969/1986, p. 55). The woman’s self-concept, her beliefs regarding gender roles, identities, marriage and family, and her ideals of femininity as characteristically submissive and passive are all components of how she will respond to the presence of partner abuse and her subsequent decisions regarding her life (Boonzaier & De La Rey, 2003).

A woman diagnosed with BC is in a place in which she must create and partake in the type of world that is most conducive to her health and her situation. Whether she chooses to be an active participant in the decision-making process or not will be determined by her view of herself, her partner, and of her world. Even choosing to not be actively involved in making decisions regarding her care and treatment is a decision in itself. It is the woman who is in the position to create her world, a world that is derived from her willingness and desire to be active or not.

Premise #4: “In (taking the role of the other) humans seek to ascertain the intention or direction of the acts of others. He forms and aligns his own action on the basis of such interpretation of the acts of others” (Blumer, 1969/1986, p. 82). Control of others is not determined by who will have the control but rather on who decides who will have control, on what decisions will be controlled, and how control will be monitored and consequences of misaligned to control will be dealt with (Stark, 2007).

Living with IPV is a difficult and ongoing challenge. Incorporating a significant change such as a life-threatening diagnosis of BC into such a relationship creates additional challenges. It is without a doubt going to be challenging for a woman if her partner stands in the way of her attempts to survive cancer. Although the woman determines the true meaning of her situation, she may not always have the freedom to choose what to an outsider may seem to be the best for her. Thus, she may have to pragmatically adjust both her desires and needs to survive the abusive relationship and the BC according to what she perceives is determined for her by others. Although there are varying levels of both violence and non-support within these dysfunctional relationships, the woman may be on a continual spiral of internal conflict when faced with others who limit her freedom of choice.

In conclusion, SI provides a framework for examining how women diagnosed with BC make treatment decisions while living with IPV. Challenges faced by the women may hinder them from obtaining the desired results regarding treatment DM and completing treatment. The women will continually be placed in a position of adjustment and readjustment as they interact with themselves and with others. The author's position is that the use of SI will facilitate the understanding of action and meaning in the life worlds of these women and provide a solid foundation for the type of methodology that will allow the women to give voice to their worlds and capture the true essence of the purpose of the proposed research.

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Chapter 4: Research Design and Methods

Various grounded theory (GT) techniques informed by Symbolic Interactionism (SI) and constructivism were used in this Qualitative Descriptive (QD) Study (Sandelowski, 2000). The study aim was to explore and describe the journey of decision making among a sample of women diagnosed breast cancer (BC) while living with an non-unsupportive partner. Data obtained from personal interviews using semi-structured questions were coded and analyzed to describe the process of the journey. Incorporated throughout data collection and analysis was memo writing, the use of field notes, critical reflexivity and diagramming.

This chapter includes discussions of the following areas: (a) rationale for using a qualitative research approach, (b) rationale for using a Qualitative Descriptive research design, (c) research sample, (d) methods of data collection, (e) data analysis, (f) human subject's considerations, (g) considerations of trustworthiness, (h) limitations of the study, and (i) dissemination strategy.

Research Design

Rationale for Using a Qualitative Research Design

The overall purpose of qualitative methodologies is to explore a concept or phenomenon of which little is known, to identify, describe and generate hypotheses for future research (Maly, 2000), to develop a theory, and/or to examine a topic for which quantitative measurements is not best suited (Waltz, Strickland, & Lenz, 2010, pp. 225-226). Qualitative research encompasses a holistic worldview that is based on the singularity and diversity of reality for individuals in a given context or situation (Burns & Grove, 2009, p. 23). The intent of a qualitative methodology is to examine the sociocultural world of individuals from the internal perspectives of their experiences (Corbin & Strauss, 2008, p. 12).

Ontological aspects in qualitative studies accentuate a reality that is both subjective and varied according to individual perceptions (Creswell, 2007, p. 16). Epistemological perspectives of naturalistic paradigms point to the fact that participants and researchers are collaborators in the development of knowledge (Pascale, 2011, p. 29). Thus, the development of knowledge using a qualitative approach is associated with the naturalist paradigm and is best generated when the distance between the researcher and the research participant is reduced (Polit & Beck, 2008, p. 15). Axiological assumptions of qualitative research identify and take ownership of the researcher's values and biases that are present in the research process (Creswell, 2007, p. 18). Finally, qualitative research uses an inductive, logical approach in which the researcher builds concepts, categories, hypotheses, models, and theory from the data (Waltz et al., 2010, p. 226).

A qualitative research design was best suited for this research because it was an exploratory study about a topic that had not been studied. Furthermore, to study treatment decision-making (DM) among women diagnosed with BC living with the concurrent presence of intimate partner violence (IPV) and/or a non-supportive partner, the researcher assumes that there is no single reality and a qualitative methodology will allow the women to verbalize the realities of their situations as they deem them to be true and meaningful. The use of a qualitative methodology was effectively used in previous research to explore treatment DM for BC among women albeit unrelated to the presence of IPV (Pieters et al., 2012).

The diagnosis of BC can present multiple complex challenges for women in deciding appropriate forms of treatment (Maly, 2000). These challenges can be further complicated when the woman is living with IPV and/or a non-supportive partner. Sociocultural factors add further complexity to these challenges. Clinicians who make inaccurate assumptions about sociocultural factors subsequently provide misinformation to individuals that can result in poor health

outcomes. Sociocultural needs and concerns of individuals can be closely examined through the use of a qualitative methodology (Maly, 2000).

Rationale for A Qualitative Descriptive Study Using

Constructivist Grounded Theory Techniques

Qualitative descriptive (QD) research focuses on describing the lived experiences of individuals in the everyday life of their worlds (Magilvy & Thomas, 2009). The methodological aim of QD research is not to result in a theory (as in grounded theory), follow an interpretative approach (as in phenomenology), or provide a thick description of an experience (as in ethnography). Rather its primary purpose is to provide a straight forward description of an experience or process that is gathered from staying close to the data (Sandelowski, 2000). Researchers using QD methods seek both descriptive and interpretive validity in that the researcher is providing an accurate account of events that most researchers observing the same event would agree is accurate in its description. Interpretive validity which consists of an accurate account of the meanings participants attributed to the events are also agreed upon to be accurate (Sandelowski, 2000). Techniques from Grounded theory methodology, informed by Symbolic Interactionism (SI) (Charon, 2010) were useful for analyzing the qualitative data in this QD study.

The philosophical underpinnings of SI (as discussed in Chapter 3) hold that individuals create their realities through the meanings they attach to their particular situations (Burns & Grove, 2009, p. 56). As individuals respond to events or problems in the context of their situations, they often go through a process of adjustment or readjustment (Corbin & Strauss, 2008, p. 96). The qualitative data collected in the research interviews were used to examine the courses of action individuals took and that changed in response to their situations in the attempt

to obtain a goal (Corbin & Strauss, 2008, p. 98). Then, using a QD approach, the aim was to describe the courses of action taken. Therefore, we concentrated on the actions and the interactions of the participants through the close examination of the data.

Constructivism

Constructivism focuses on how and why humans construct meanings and actions in particular situations within multiple social realities (Charmaz, 2006, p. 130). In addition, constructivism postulates that how individuals make sense of their world is valid and worthy of respect (Crotty, 1998, p. 58). The purpose of this study was to understand the experiences of women living with IPV and/or non-support through the interactions they have with themselves and with others, including the researcher, as they relate IPV and/or non-support with their BC diagnosis and treatment DM. Elements of GT methodology, influenced by constructivism, that were used throughout data collection and analysis included reflexivity in memo writing, field notes and diagramming.

Reflexivity

The use of critical self-reflexivity throughout the research trajectory was vital in creating a greater understanding of the process for the researcher (Charmaz, 2006). Reflexivity required the researcher to be in the moment and remain aware of what was influencing their internal and external responses. At the same time the PI researcher sought to remain cognizant of her own relationship to each participant and to the topic throughout the process of data collection and analysis (Dowling, 2006).

Self-reflectivity served to minimize researcher bias and maximize a deeper understanding of the phenomenon. Specifically, the use of reflexivity in the form of memo-writing assisted the researcher to create an audit trail to help provide an understanding of how key components of the

study came to be (Watt, 2007). In addition, the PI applied reflexivity through memo-writing to help define ideas that best fit and interpret the data during the various stages of the research (Charmaz, 2006, p. 3). For this reason, the researcher created a book dedicated to memo-writing with the sole purpose of reflecting and writing on the processes, issues and concerns regarding the study during early stages of its development.

Research Methods

Research Sample

Recruitment

Recruitment took place in various sites in Southern California such as waiting areas at cancer centers where women were being treated or screened for breast cancer (UCLA Westwood), at cancer support agencies (Cancer Support Community; Women of Color Breast Cancer Survivors' Support Project), at women's health clinics (Los Angeles Center for Women's Health). Community areas for recruitment included local churches, and church organizations. Recruitment also occurred at domestic violence organizations (Women in Need of Gaining Strength (WINGS) - Domestic Violence Services); domestic violence intervention programs (Jenesse Center), and at domestic violence shelters (Sojourn). Furthermore, an organization where the PI received domestic violence training and volunteered (Peace over Violence) also served as a site for recruitment. Prior to initiating recruitment, the PI developed a sound working relationship with key personnel and/or gatekeepers at the sites. This was done by contacting and connecting with individuals on a regular basis through telephone conversations, emails and face to face meetings with the goal of allowing flyers (see Appendix A) to be placed at each of the designated sites (see Table 2).

Table 2: Recruitment Sites

Type of Site	Number	Number of Fliers	Emails	Telephone Calls	Talk about Study	Workshops	Presentations
Alcohol and Drug Programs <ul style="list-style-type: none"> Alcohol Program Education Program Residential Treatment Program 	1 1 1	10 10 20	X				
Breast Cancer <ul style="list-style-type: none"> BC Symposium Mammogram Screening BC Support Group BC Walk BC Boutique 	2 4 4 1 1	30 61 40 15 10	X X X	X			
Cancer – General <ul style="list-style-type: none"> Hematology Oncology Office Cancer Support Group 	1 1	15 10	X		X		
Clinics <ul style="list-style-type: none"> Free Clinic 	1	10					
Community Organizations <ul style="list-style-type: none"> Community Centers Self-help Groups 	1 2	30 20	X				
Churches <ul style="list-style-type: none"> BC Awareness Church Groups BC Church Support Group DV Awareness Church Group 	2 1 1	30 15 1	X X		X X		X
Domestic Violence <ul style="list-style-type: none"> DV Organizations DV Symposiums Workshops Rape Centers 	18 1 1 2	266 15 10 10	X X			X X	
Shelters	1	0	X	X			
Homeless Organizations	1	0	X				
Legal Assistance Organizations	2	25					
Mental Health Organizations	2	13					
Women’s Conferences	1	20			X		X
Social Workers	2	15			X		
Individual Contacts	2	10					
Libraries	2	20					
Total	60	741	12	2	5	2	2

Key:

Workshops: Worked with individual women dealing with domestic violence

Speeches: Limited opportunity to speak about the study

Presentations: Talk specifically about breast cancer and about the study

Recruitment flyers invited women who were interested to participate to call for additional information regarding the study. Words such as “abuse” or “violence” were not used in the flyer because some eligible participants may not define the type of actions committed by their spouse or partner as “abuse” or “violence.”

Recruitment methods consisted of several formats. In addition to passive recruitment where women responded to the flyer, another recruitment method was to ask clinicians and staff at oncology sites and domestic violence organizations to provide the flyer to potential participants whom they deem eligible for the study. Snowball sampling, also known as network sampling, in which participants refer other individuals who may be eligible to the study (Polit & Beck, 2008) was also utilized to recruit. That is, at the end of the interview, the participants were asked if she knows another woman who may be eligible. If so, and if she was willing, the participant was given a recruitment flyer to pass onto the other potential participant. Furthermore, flyers were displayed at organizations where the researcher was asked to present the research topic. Women who showed interest to participate in the research were invited to call the researcher to assess if they are eligible to participate in the study.

Sample size

Purposive sampling was used for the study. A purposive sampling approach initially selected women who met the selection criteria and who had different views and perspectives about the research topic (Polit & Beck, 2008, p. 355). The primary aim of purposive sampling was to select rich cases that produced insight and understanding of the phenomenon (Bloomberg & Volpe, 2012).

Eligibility Criteria

The researcher screened for eligibility at the time of the telephone call by asking questions from a screening script and algorithm that was purposefully created for the study (see Appendix D and Figure 4). Eligibility was determined from inclusion criteria questions and from questions focused on abuse that were derived from the Woman Abuse Screening Tool (WAST) (see Appendix E) and the Women Experiencing Battering (WEB) screening tools (see Appendix F). The use of the WAST and the WEB screening tools were used to assist in identifying both overt and covert type behaviors.

As the name indicates, the WAST was intentionally developed as a screening tool. The tool was standardized in a sample of White, African American and Latina women in a family practice (J. B. Brown, Lent, Brett, Sas, & Pederspm, 1996). In a pilot test of the WAST, a purposive sample of self-identified abused (n=24) women from shelters and non-abused women (n=24) were examined. The WAST was found to be a highly reliable measure with sensitivity at 47%, specificity at 96%; and a coefficient alpha estimated at 95%. The scale also demonstrated satisfactory construct and discriminant validity when compared with Abuse Risk Inventory (ARI) (J. B. Brown et al., 1996). The WAST was used to compare the validity of other screening tools such as the Hurt, Insult, Threaten, and Screen (HITS, sensitivity 30%-100%, specificity 86%-99%), the Partner Violence Screen (PVS, sensitivity 35%-71% specificity 80%-94%), and the Abuse Assessment Scale (AAS, sensitivity 93%-94%, specificity 55%-94%) (Rabin, Jennings, Campbell, & Bair-Merritt, 2009). Furthermore, the WAST has also been evaluated in Spanish-speaking patients (Fogarty & Brown, 2002), in family practice (J. B. Brown, Lent, Sas, & Schmidt, 2000), and in an emergency department (Halpern, Susarla, & Dodson, 2005).

The first two questions of the WAST, also referred to as the WAST-Short, is used to ask general questions about relationships and is an effective tool for initial screening of abuse (J. B. Brown et al., 1996; J. B. Brown et al., 2000; Punukollu, 2003). If scores on the first two questions identify the presence of tension or difficulty in the relationship, the remaining six questions are asked to screen specifically for verbal, emotional, physical, and sexual abuse. For the purposes of the proposed research, select questions from the WAST will be used to obtain additional information about the woman's experience of abuse.

The WEB is a screening tool for IPV that measures the experiences of women in abusive relationships rather than measuring the behaviors of abuse by their male spouses or partners. The primary focus of the WEB is emotional abuse by measuring a woman's perceptions of her vulnerability to physical danger and her sense of loss of power and control in her relationships. The WEB was found to be highly reliable with sensitivity at 86.0%, specificity at 91.0%; and a Cronbach's alpha at 95%. The scale was compared to the Index of Spouse Abuse (ISA) scale. The WEB was evaluated in family practice clinic (Coker, Smith, & Fadden, 2005), in a population based study (P.H. Smith, Thornton, DeVellis, Earp, & Coker, 2002) and in a longitudinal study (Coker et al., 2007).

There is no single screening tool that has been determined to best capture all of the aspects of IPV (Rabin et al., 2009). For the purposes of this study the WAST and the WEB were selected as screening tools because of their brevity, internal consistency, construct validity, and applicability to this research and population. The use of the WAST and the WEB had been discussed with selected committee members as to their feasibility for the study.

Inclusion criteria

- Women who are 18 years or older. Rationale: Women who were 18 years or older are considered adults capable of making their own decisions.
- Diagnosis of a first-time and early-stage BC (defined as Stages I – IIIA and ductal carcinoma in situ.) Rationale: Primary, early stage BC was the focus of this research based on the assumption that women who have experienced cancer before or were diagnosed with a primary but advanced tumor may see the BC as more serious and this can influence treatment DM in unique ways.
- Women who were living with IPV and/or a non-supportive partner prior to their diagnosis of early stage BC. Rationale: The focus of this study was DM among women who experienced the presence of IPV and/or a non-supportive partner at the time of their BC diagnosis. Even an one time occurrence of abuse can have an impact on a woman's decisions regarding treatment (WHO et al., 2013).
- Women who were in heterosexual relationships at the time of diagnosis. Rationale: Women who were in same-sex relationships may present unique challenges in the context of IPV and/or a non-supportive relationship and BC, including the fear of being “outed” if the abuse is reported (Balsam & Szymanski, 2005, p. 259).
- Participants had to be able to speak English. Rationale: Must be able to communicate fully with the researcher as the researcher is fluent in English only. Participants were able to participate in the interview without the presence of another adult. Rationale: To ensure and adhere to safety and confidentiality concerns for the study participants and the researcher, the interviews were done with only the woman and interviewer present.

Exclusion criteria

- Women who perceived that participation in the study will increase their risk for harm.

Rationale: The goal of this criterion was to minimize any additional risks for harm to the participants.

Human Subjects Considerations

Respondent burden is the subjective perception of a participant that the presence of psychological, physical, and/or economic hardships is associated with research participation (C. M. Ulrich, Wallen, Feister, & Grady, 2005). This perceived burden may vary depending upon several factors including the level of risk in the research, and the individual subject's condition, mental state and support systems (C. M. Ulrich et al., 2005). Respondent burden was a concern in the study and specific considerations were implemented during the entire process of the research.

Women who are living with IPV have been noted to be at an increased risk for depression (Devries et al., 2013; Stein & Kennedy, 2001). In addition, depression is also more prevalent in women diagnosed with BC (Burgess et al., 2005). Furthermore, some individuals who are living with depression commit suicide (Takahashi, 2001). Thus, participants in the study may have been at a heightened risk for the presence of depression and/or suicide. Therefore, the researcher incorporated a suicide protocol to address this potentially detrimental effect of depression (see Appendix K).

Safety protocol

It was important to minimize the risk for harm from abusive spouses/partners to women who participated in the study (Sullivan & Cain, 2004). To protect the safety and privacy of both the participants and the researcher explicit safety rules throughout all stages of contact with the

participants were closely followed to decrease the risk for harm (Parker & Ulrich, 1990). Safety considerations for the participants and the researcher were as follows:

Participant Contact Protocol

1. The PI purchased a prepaid cellphone with the capability of phone messaging specifically for the purpose of the study (Sullivan & Cain, 2004). A scripted message was placed on the telephone to provide initial information about the study (see Appendix C).
2. When the women called and the researcher was not available, the phone message asked her to leave a telephone number and time when it was safe to return her call (Langford, 2000).
3. Guidelines for leaving a message on the participant's answering machine about the study were included in the initial directions for contact on the PI's answering machine message. The message informed the participant that the study will be called "The Women's Health Program" to minimize the risk of an abusive spouse/partner from becoming aware of the sensitive nature of the study (Sullivan & Cain, 2004).
4. At the first conversation with the woman, the researcher introduced the discussion by asking if this was a safe time for the woman to talk (Sullivan & Cain, 2004).
5. Researcher-initiated contact for scheduling interview times were kept to a minimum.
6. While most participants were interviewed once, the informed consent included the possibility of a second interview to clarify elements of the first interview.
 - a. The second interview was conducted only after the initial interview had been analyzed and the aspects that need further clarification had been clearly identified.
 - b. The same safety considerations that were applied in the initial interview were also implemented in the subsequent interview with the participants.

Conducting the Interview

1. An introduction about the interview was given to the participant when she called in response to the recruitment flyer. (See Appendix G)
2. When the woman confirmed that this was a safe time to talk, the PI described the study and the nature of the participation requested.
3. During the consenting process, the researcher introduced the sensitivity of the research topic concerning living with IPV and/or a non-supportive partner.
4. The PI asked if the woman was currently in an abusive relationship or if she was currently being stalked by someone who had abused her in the past. The PI had a cell phone fully charged and available during the interviews.
5. The interviews were conducted privately between the women and the researcher.
6. Interviews were held in public places. No interview took place in the home of the woman to minimize the risk for harm from a perpetrator to the woman and/or the researcher. The interviews were conducted in a location that was well-lit and secure and only during daytime hours. Considerations were used in the planning of a safe interview site that included the ability to summon help or leave the site if the situation becomes dangerous.
7. Interviews did not exceed two hours.
8. The researcher remained for a minimum of five minutes after the conclusion of the interview so that there was no chance of being seen leaving with the participant.

Confidentiality

1. A signed copy of the informed consent form was made available to the participant with the opportunity to decline a copy. A cash honorarium (\$50) was given to each participant

at the end of the interview so that there will be no social security numbers or check requests that can be traced back to the participant (Langford, 2000).

Reporting Disclosed Abuse or Presence of Current Abuse

Participants were informed prior to the start of the interview of the investigator's duty to report disclosure of child or elder abuse.

Script: In the State of California the law requires that all nurses' report suspected child or elder abuse to protective services. Therefore, if you choose to talk about child or elder abuse during the interview, I am mandated to report it. If that happens, then I will talk to you further about the reporting process.

Assumptions of the PI

1. The PI did not assume that the woman was no longer being abused simply because she was currently not in a relationship with the perpetrator (Parker & Ulrich, 1990).
2. The PI did not assume that the quality of the relationship between the woman and her spouse or partner was the same as it was at a prior time (Parker & Ulrich, 1990).

Considerations for the Woman

1. The opportunity for debriefing was included after the conclusion of the interview. Women were provided with the opportunity to discuss any concerns they may have regarding participating in the study.
2. Contact details to agencies concerning IPV were given to the women (see Appendix M).
3. Time was allotted at the end of the interview to make sure that the women had the opportunity to self-regulate their ability to maintain a satisfactory mental state. This time was used to have the women talk about things other than that which was the focus of the

interview, and to encourage that the women talk with her support system about any other concerns she may have.

Considerations for the PI

Steps were taken to minimize negative reactions for the researcher to the research by limiting the number of interviews conducted during an allocated time, and to debrief after interviews with professionals who were familiar with women who are victims of IPV and/or non-supportive partners. Collaborative coding with other individuals such as the chair of the researcher's doctoral committee also took place. To prevent insomnia and/or nightmares the researcher deterred coding the data or interviewing late in the evening. Finally, the researcher socialized with a support network during the research process (McCosker, Barnard A., & Gerber, 2001).

Data Collection Procedures

Upon telephone contact with the participant, the PI explained the purpose of the study. The eligibility to participate in the study was determined using an eligibility questionnaire and algorithm developed by the researcher (see Figure 4). When a woman was found not to be eligible, the researcher informed her per a purposefully-designed script (see Appendix H). A script was also developed to inform women who were eligible to participate (see Appendix G).

The sensitive nature of the study, potential safety issues for both the participant and the researcher, and concerns regarding confidentiality were addressed at the time of the telephone call. A time and place that was mutually convenient, safe and public was arranged with the participant to conduct the interview. The participant was asked to select a place that felt comfortable for her and where the interview can be conducted privately and with minimal distractions.

Informed Consent

Approval from The Institutional Review Board (IRB) of UCLA was obtained prior to the start of research. Informed written was obtained from the participants prior to the start of the interviews.

For face-to-face interviews, a written informed consent was used and served as proof of the woman's participation in the study and provided an audit trail. The woman was asked to read the consent and ask any questions that she may had. When she was fully informed and wanted to participate, she was asked to sign two copies of the informed consent, one for the researcher and one for herself. However, to lessen the risk of a violent spouse or partner finding out about her participation in the study, the woman was given the opportunity to decline to sign and receive a personal copy or to discard her copy of the signed consent form. If the woman chose not to keep a personal copy of the informed consent, a business card with the information about the PI and the phone number that was dedicated to the research was made available to her.

Socio-Demographic and Clinical Information

Participants were asked to complete a form with questions about their demographic details, breast cancer diagnosis, forms of treatment and follow-up breast cancer care prior to the start of the interview (see Appendix I).

Interviews

The purpose of interviews in qualitative methods is to provide a deeper understanding of a phenomenon through the interactions with the participants (Rubin & Rubin, 2012). The focus of the study represented a sensitive topic, therefore, personal interviews were conducted. The interviews were audio-recorded with two digital recording devices simultaneously to ensure that

the interview was captured in its entirety. The participant was informed as to when the recording devices were turned on and off.

Interviews were guided by a purposefully designed interview guide that consisted of open-ended, neutral, sensitive and clear questions and prompts from all the key components of the research (see Appendix J). Through interaction with the participant, the interviewer developed a positive and collaborative relationship. Thus, the interview guide served as a tool to promote the exploration of the phenomenon rather than to interrogate the participant. Furthermore, the interview guide was a flexible tool so that the researcher did not adhere rigidly to the order of the questions, but instead supported the woman to speak freely allowing co-construction of the interview to take place and all the questions were discussed by the end of the interview.

The interview began with broad, open-ended, nonthreatening questions (DiCicco-Bloom & Crabtree, 2006; Rubin & Rubin, 2012) that the participants were likely expect to answer when speaking with a nurse about breast cancer. The interview proceeded with questions about her support, her relationship with her spouse or partner at the time of diagnosis and about her treatment DM. Questions were also asked about her expectations of the study and suggestions to other women who may be experiencing similar situations.

During the interview, attention was given to the participants' language and possible implicit meanings within the words that women spoke. The researcher was mindful of when it was necessary to probe the participant to elicit additional information or for clarification to better understand the participant's experience from her point of view (Charmaz, 2006, p. 32). Influenced by constructivism, the researcher especially focused on seeking information regarding personal definitions of terms, situations and events used by the participant throughout the

interview (Charmaz, 2006, p. 32). At the conclusion of the interview, the researcher focused on ending the interview on a positive note (Charmaz, 2006). The researcher made sure that all questions on the interview guide were responded to. Each interview concluded with the researcher's brief review of the participant's emotional state. While the length of time for the individual interviews varied, each interview last approximately 60-90 minutes. Participants received \$50.00 cash at the end of each interview as a token of appreciation for their time and sharing their experiences. Cash, instead of a gift card, was used to minimize the chances of harm for those participants who continued to live with IPV and/or a non-supportive partner because of the risk that an abusive spouse or partner might discover her participation in the research.

Field notes

Glaser postulated that “all is data” and that data is comprised of anything that assists the researcher to generate concepts that will advance theory development, such as field notes (Glaser, 2002, p. 145). Informed by the GT focus on the processes of action within data, fieldnotes were used to record observations before, during and after interviews with the participants. The PI took observational notes about anything that was noticed or happened in the field. The format used in the field notes led to a record of the time, date, and location of the interview; descriptions of the settings; and nonverbal details or observations of the participants from the interview. Specific information in the field notes also addressed how comfortable participants appeared when talking about their experiences; this included the presence of any changes noted in their nonverbal communication particularly when discussing sensitive issues in their relationships (e.g., body posture, gestures, tone of voice, affect, actions such as crying, etc.). The influence of the location and environment of the meeting places where the interviews were conducted was also addressed. This was particularly important as the need to interview in a

private, safe and public place was of utmost importance for the safety of both the participant and the PI. For the purposes of this study, library meeting rooms fit these criteria and were used often. Also, included in the field notes were observations about the participant's interactions with others in their immediate surroundings and the arrival of the participants – whether on time or late.

Data Analysis

In this QD study, GT techniques were used to engage in the concurrent process of data collection and analysis using a constant comparative method during each stage of analysis (Charmaz, 2006, p. 54). The constant comparative approach consisted of identifying processes of action and interaction in one data source with that of another. The practice of memo-writing was incorporated and used to clarify relationships and processes while helping to identify gaps in the data (Charmaz, 2006).

The PI transcribed the first two interviews verbatim to facilitate the initial process of becoming immersed in the data. Subsequent interviews were transcribed by a professional transcription service (Transcript Co-op). To enhance the credibility of the transcriptions, the PI checked each transcript for accuracy by listening to the interview while reading (and correcting) the verbatim transcribed report. All identifying information was removed during this check for accuracy. Field notes and memos were written by the researcher before and after the interviews; they were analyzed along with the data.

The transcribed interviews were coded using the systematic guidelines as defined by Charmaz (2006) including initial coding and focused coding. A constant comparison approach was used to take note of the similarities and differences across the data and to assist in establishing analytic distinctions throughout the coding process (Charmaz, 2006, p. 54).

Initial or cycle I coding explored and described what is happening in the data through a line-by-line analysis. Approaches to initial coding include line-by-line, word-by-word or incident-by-incident (Charmaz, 2006). For this study a line-by-line approach was used. The use of line-by-line coding helped in identifying implicit concerns and explicit statements from the participants. Initial coding identified processes throughout. (Charmaz, 2006). Line-by-line coding also provided insights into the types of data to be collected next (Charmaz, 2006, pp. 52-53).

Each line of the transcription was coded with the focus of remaining open to the data and to see nuances within it (Charmaz, 2006, p. 50). During the initial phase of coding, the data was broken into discrete parts by asking ‘what is happening in the data’ and ‘what does it mean?’ The researcher used gerunds to identify actions and processes in the data. During the line-by-line approach meticulous coding occurred without prior categories to facilitate the emergence of “in vivo” codes which are symbolic markers of participants speech and meanings (Charmaz, 2006, p. 50). This step in the process of analysis was also be used to make comparisons across the interviews.

In vivo codes were used to help preserve the meanings that participants gave to their experiences. The use of vivo codes helped in giving insight into the world of the participants. These in vivo codes or symbolic markers were examined for their implicit meanings and how they were constructed and acted upon (Charmaz, 2006, p. 55). Types of in vivo codes used by the participants were identified and examined including general well known terms, participant specific terms and insider shorthand terms that were identified within a specific group. Actions based on the meanings given to in vivo codes by the participants were closely identified and explored. During the aggregated level of coding the in vivo codes helped to look for

assumptions and actions with the goal of understanding what was happening and what it meant to the participants (Charmaz, 2006, pp. 56-57).

Focused or cycle II coding was the second phase of the coding process. Codes developed during this phase of analysis were used to synthesize larger portions of data (Charmaz, 2006, p. 57). With focused coding, the aim was to identify the most significant and/or frequent codes that emerged during initial coding (Charmaz, 2006, p. 57). For this study, focused codes were most productive for identifying the similar steps that women took while each woman was dealing with their unique situations on their individual journeys.

Collaborative analysis enhanced methodological rigor, accountability and depth of analysis as the PI co-coded all eight interviews with a faculty mentors. In addition, the researcher paired up with a peer collaborator to assist in an interactive data analysis and to act as a source of support throughout the process (Pieters & Dornig, 2013). This triangulation involved independent coding by the PI and another researcher followed by cross-comparison and discussion of the data with a reflexive stance to check the assumptions that were made.

Memo-writing

Memo-writing was used to identify particular areas of concerns that emerged in the data (Charmaz, 2006, p. 72). Used before, during and after completion of the research, the practice of memo-writing was an essential tool to keep an introspective record of the researcher's personal biases, feelings, and thoughts and to create an understanding of how these processes may have influenced all aspects of the research.

The PI used memo-writing to explore and address a variety of issues that surfaced throughout the development and implementation of the study. Memo-writing also provided opportunities in which significant areas were further explored. A few topics addressed in memo-

writing were ideas about how the potential sense of loss of control among women living with BC and a non-supportive partner may impact the decision-making process; the exploration of steps women take to regain or maintain a degree of control in their lives; the importance of social support, and its influence on decision-making; and how the women set goals for their lives moving forward.

Upon review of the data memo-writing was used to help identify components of SI that were related to the sense of self and the meaning of experiences to the women. Throughout coding and analysis, memo-writing was used to help develop themes and processes identified in the data, including the steps that women took throughout their overall journey. This use of memos continued throughout the development and completion of the study.

Diagrams and Charts

Diagramming throughout data collection and analysis served to provide concrete images of important ideas allowing for the conceptualization of data in various ways (Charmaz, 2006, p. 117). After the initial coding, individual diagrams were created for each woman to represent salient traits in the data. Individual diagrams were compared so similarities and differences between different participants could be identified and analyzed.

Various other charts were developed and used to compile different types of information about the sample, taking each participant into account but displaying the data together in a format that was helpful to identify patterns and processes across the entire sample. For example, one chart drew upon initial codes and was used to help find differences and commonalities that surfaced from coding. Another data chart was created to help identify major themes (and focused codes) across cases. Then, a specific focused code chart was used to further develop the themes and to identify the steps of the process women went through on their journeys. There was a

similarity in the steps that the women took on the paths even though findings from the data showed that each woman's experiences were unique. Thus, the women's steps taken on the journey became the central focus of this QD study.

A chart based on the results from the Woman Abuse Screening Tool (WAST) was created to help identify the presence of abuse or non-support in the women's' lives which were obtained during the screening process. Results from specific categories were identified for each participant and given a total WAST score. A brief description of the scoring process was also included on the chart. Another chart was created to clarify the types of abuse and/or non-support the women experienced before, during, and after their breast cancer diagnosis.

Looking back on the entire process of recruitment, a specific chart was developed to track and describe the efforts made for recruitment throughout the study. This chart included information about the type of sites visited for recruitment, number of sites, number of fliers dispersed, and the types of contact made to each site (emails, telephone calls, talks about the study, workshops and presentations). The chart organized information and identifies the results of the recruitment process.

Data Re-Presentation

To depict the steps the women took as they traveled on during their journey of BC treatment and diagnosis, a diagram was created. Sandelowski (2000) pointed out that data re-presentation can take on many forms. The format for arranging data can be compiled by summary of time; actual or reverse chronological order of events; most prevalent to least prevalent themes; progressive focusing (describing the broad context of an event to particular cases, or from particular cases to the broad context); a day, week, month or year in-life approach;

or the Rashomon effect, where the same event is described from the perspective of more than one participant.

For this study data re-presentation was found to be most effectively depicted as a diagram showing the chronological order of the steps the women took on their journey from BC to treatment and beyond. To develop this, several tentative diagrams were created and then revised to help understand and identify the lived experiences of the participants, the steps they took, and the processes they used throughout their cancer trajectory. Multiple diagrams were created in succession and refined through comparison across cases.

An initial diagram was created that focused on the transition to a place of regaining control after losing control when diagnosed with BC. Then, analysis of additional areas of experiences were incorporated and explored included how coping, treatment decision-making and support impacted the women on their journeys. The whole process was investigated in relation to characteristics of the abusive and/or non-supportive relationships to help understand how they influenced the women's decision-making processes. This led to an added analysis of the impact of the relationship, the sense of self, as well as internal and external support which helped shape the diagram further. The final diagram described an overall process the participants experienced on their journey from the time of breast cancer diagnosis and treatment to the time of being able to move on from BC.

Supporting Trustworthiness of Qualitative Data Analysis

In qualitative research the aspect of trustworthiness is comprised of credibility, dependability, and transferability. These constructs are the comparable to that of quantitative research: credibility vs. internal validity; dependability vs. reliability;; and transferability vs. generalizability (Guba, 1981).

Credibility refers to the confidence in the truth of the data and its interpretations (Polit & Beck, 2008). A special focus of the researcher (Guba) was to establish rapport to enhance an honest exchange during interviews. The researcher maintained and incorporated information from field notes into data analysis to ground the interpretation in the unique context for each individual woman. The interviews were transcribed verbatim and carefully checked for accuracy. The researcher incorporated relevant quotations directly from the interviews in the results section to provide verbal evidence of the findings and interpretation.

Dependability of the data over time was maintained by collaborative coding throughout the initial coding and focused coding processes. In addition, an audit trail was sustained to ensure the evolution of thinking and rationale for all choices and decisions made during the research process, as advised by Guba (1981).

This study was not intended to provide findings that can be generalized. However, a descriptive report of this will advance existing knowledge and maybe applicable to other contexts involving a woman's coping with non-supportive partners and chronic illness

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Chapter 5: Results

The focus of this study was to gain understanding of the experiences of women who were diagnosed with breast cancer while living with a non-supportive or abusive partner. While being interviewed, participants worked through a variety of emotions as they explored and articulated their lived experiences to the researcher. Their descriptions provided insight into how the women utilized strategies that helped them work through a process to overcome the challenges of a breast cancer diagnosis and the demands of their partnered relationships. Throughout the process the participants found their sense of self and the components of their relationships were intricate and intertwined at each phase.

This population was hard-to-reach, perhaps because women may have found it difficult to talk about living with a non-supportive partner or spouse when diagnosed with breast cancer. Following Institutional Review Board (IRB) approval from the University of California, Los Angeles, women were recruited from the Southern California area. Fliers were given out at over 60 recruitment sites that included breast cancer support groups, churches, domestic violence support groups, social worker's offices, physician's offices, community organizations, women's organizations, speaking engagements, libraries and through personal contacts. Recruitment lasted 24 months however, only 8 women were available, willing, and eligible to participate. We were not able to raise the data to a higher level of abstraction (such as would be done to build theory), but we were able to describe the process the women went through.

The women were screened prior to the interviews for the presence of non-support and/or abuse using the Women Abuse Screening Tool (WAST). This tool specifically screens for verbal, emotional, physical, and sexual abuse. The questions addressed the quality of their relationships in addition to the presence of abuse. The initial questions of the WAST assessed the degree of relationship tension and the amount of difficulty that women and their partners had in

working out arguments. The remaining questions were used to gain a more complete assessment of the abuse by asking the women to rate the frequency of various feelings and experiences on a scale from 1 (often) to 3 (never). Most of the women described their relationships with their partners as having “some tension” or “a lot of tension”. For the majority of the women, working out arguments with their partners were defined on the WAST as either “with the presence of some difficulty” or “with great difficulty” (See Table 1).

Sample Characteristics

A total of eleven women called about the study. Three women were deemed ineligible to participate either because they did not have a breast cancer diagnosis or they were not in a non-supportive or abusive relationship at the time of diagnosis. Eight of the women were qualified based on inclusion criteria, provided consent, and participated in the study. Two of the women had a second interview to clarify previous interviews. The eight participants ranged in age from 45-60 ($\bar{X} = 52$) at the time of the interviews. Four of the women were non-Hispanic white, one was Hispanic, one was Hispanic/White and two were African American. All the women were in relationships with men at the time of their breast cancer diagnosis, and the length of their relationships ranged from 3-35 years ($\bar{X} = 18$). Five of the women were no longer in their relationships at the time of the interview, while three of the women were still with their partners. Six of the women had children (range: 1-5 children).

Table 3: Sociodemographic Characteristics of Study Participants

Age	
40-45	1
46-50	2
51-55	3
54-60	2
Education	
Some College	4
College Graduate	2
Graduate School	2
Income	
Less than \$20000	2
\$21000 - \$40000	2
\$41000 - \$60000	1
\$61000 - \$80000	1
\$81000 - \$100000	2
Duration of Relationship	
0-5 years	1
5-10 years	3
10-20 years	0
20-30 years	3
More than 30 years	1
Racial Ethnic Group	
Black or African American	1
Hispanic	1
Hispanic/White	1
Non-Hispanic White	4
Black or African American/Native American	1
Stage at time of Diagnosis	
Stage I	2
Stage II	5
Stage III	1
Stage IV	0
Treatment Received	
Radiation	8
Chemotherapy	7
Lumpectomy	3
Mastectomy	4
Combination Therapy	7
Reconstructive Surgery	1

Participants Cancer Diagnosis

The diagnoses of cancer given to the women ranged from Stage I-III. Four of the women had lumpectomies and four had mastectomies; one woman had both. Six of the women received radiation therapy and seven received chemotherapy. Only one woman completed reconstructive surgery (see Table 2).

Participants Main Support Person

The main support person identified by the women in our sample was someone other than their partner. Four of the women named their mothers or parents as the main support; one identified her family (not including her husband), one identified her boss, and two identified both friends and sisters.

Traumatic and Difficult Experiences with Partners

The women described various traumatic experiences which occurred in relation to their partner during their cancer trajectory; these ranged from physical to psychological abuse. For example, one woman described how she was being abused by her husband so she delayed screening for cancer because she did not want to receive any “more bad news”, this delayed her diagnosis which was very difficult for her. Another woman faced the progression of her cancer from stage II to stage IV while having to deal with conflicting opinions from her mother and father. Another dealt with the recent death of her two sons (one from cancer) while she was simultaneously dealing with her own cancer diagnosis. Two of the women spoke of their husbands as having affairs and another dealt with physical abuse from her husband towards herself and her daughter. One woman dealt with her husband’s mental illness and the subsequent abuse she experienced at his hands. And finally, one participant dealt with a husband who

remained angry at her when she chose to have a mastectomy because he equated her breast with being a woman.

Overview of non-supportive relationships

Non-supportive relationships in the context of a breast cancer diagnosis and treatment proved to be stressful and disheartening for the women. The quality of the relationships affected their lived experiences throughout both diagnosis and treatment. Relational experiences often varied and ranged from the absence of support to the presence of abuse that transpired in a non-linear fashion. In some cases, receiving the breast cancer diagnosis was a catalyst for an undesirable shift in the direction of their relationships. In other cases, the presence of non-support or abuse was manifested before the diagnosis and often contributed to an escalation in its characteristics afterwards. The following will offer a summary of the relationships both before and after the breast cancer diagnosis.

Status of relationship before diagnosis

For some women, the quality of their relationships before or at the time of the breast cancer diagnosis were described as positive and supportive. For example, Joyner described her marriage as “pretty good” before her diagnosis. Although she noted that there were some concerns and conflicts in the marriage before diagnosis, they were able to work through their challenges resulting in her being “pretty happy with him.” She further noted that “there’s been fears through it kind of thing. But through these last two years, the way it has come out to be, I have felt more assured in the marriage.” Nicey described her experience as “right before cancer, we renewed our vows and we had a wonderful wedding again. We had a beautiful party, I looked perfect and we were very much in love and things couldn’t be better. I felt like it was perfect.”

At the other end of the spectrum, some women described their relationships before diagnosis as being negative and difficult. For example, Jaden spoke of being married to a registered sex offender and the quality of her relationship as “I was in a marriage with my husband and he was abusive for many years.” Even though she knew that her husband was a registered sex offender she still chose to marry him. Her thoughts about the marriage differed over time as she said that “I can’t believe, I never thought I’d marry a man like that. I should have given myself more time to think about it.” Grace experienced sexual abuse from her husband before her diagnosis when “he would come home and expect me to have sex with him, kind of be forceful. He would force himself, so in my eyes that is rape.”

At the extreme, some women reported their husbands to be violent. This was the case for Paula who said that she first experienced physical abuse from her husband prior to her diagnosis when she was pregnant and he pushed her down. She described her experience as “he liked pushing a lot and he liked putting his hands around my neck. He pulled my hair and he spit on me while I was breastfeeding.” Her husband told her on several occasions that he was “going to cut you up in pieces and throw you in the canal.” Paula’s husband also displayed abusive behaviors towards their daughter as she notes “he picks her up by her neck, puts her against the wall, and yells out three times really loud, are you stupid?” Jaden stated that she began experiencing abuse from her husband approximately 6 months into their marriage. During one incident, she was threatened by her husband when “he waved a cigarette lighter in my face.” Another incident occurred when he threw a telephone at her. Grace’s experiences with her husband’s violent behaviors included him killing her animals, and being raped by him.

Status of relationship at the time of diagnosis

At the time of diagnosis some women described their relationships as non-supportive. This lack of support was displayed in a variety of ways. For instance, Maria spoke of her husband's absence at the time of her diagnosis noting that she wanted him to be there with her. His absence had a profound effect on her as she described how she later broke down in the car when she was alone.

Others noted negative personality traits of their mates. For example, Sade described her husband as being narcissistic. At the time of diagnosis, she stated that her husband "was negative and he didn't want me to have chemo and didn't want me to have the surgery, because he didn't believe that I had cancer."

Paula described her relationship with her husband prior to the diagnosis as like a "wishy, washy roller coaster ride" and one in which she was "walking on eggshells." She often experienced verbal and physical abuse at the hands of her husband. One example of such abuse included statements made by him to the oncologist about her treatment. She pointed out that she was shocked and did not understand what he meant when he said to the oncologist "I want you to cure her. I don't care what it takes. I don't care if you have to amputate her arms and legs."

Status of the relationship after diagnosis

In some cases, the quality of the relationships changed dramatically after the breast cancer diagnosis. Several of the women felt alone throughout their cancer trajectory. Candice noted that her husband was reluctant to go to treatment sessions with her and seemed to value work above her. She explained he only attended one treatment session, saying "I asked him to come with me to others but he didn't want to stop working." Grace noted that her husband was not supportive and felt that he "really wasn't part of it," he did not talk to her about it, and she

concluded that, “he just didn’t care.” Nicey was not able to remember how her husband responded towards her after the news. Jaden spoke of how she did not want to tell her ex-husband about the diagnosis. She was separated from him at the time of diagnosis but still in communication with him. Nonetheless, she did not want him to know about the diagnosis, although he found out from someone else.

Spousal participation in the treatment decision process was often limited for the women. Nicey and Maria both had husbands who did not take an active role in terms of the decisions before them. Their husbands seemed to have no opinion on the topic, which felt like there was not much substance to their relationships. For example, Maria pointed out that her husband said, “You decide; it’s your decision.” She went on to explain that, “We didn’t discuss too much about it about things, he just left it up to me cause he said it was my decision. There’s no interrelationship, or relationship wise as far as discussing stuff.”

Two of the women spoke of dealing with infidelity on the part of their husbands. Nicey described her marriage as being perfect before the diagnosis, however she later found out he was having an affair. Her husband later filed for divorce and still she did not know about his affair. She said he “denied that he had a girlfriend even in the marriage counseling. We drove over to the art gallery and then this woman comes in and she was young and tall. I thought that’s his girlfriend. He has a girlfriend.” Finding this out while she being treated for breast cancer had a devastating effect on her sense of self. She described how she was lonely and wanted him to spend more time with her. He responded by telling her to get a job. She was undeniably hurt by his response.

Candice noted how her relationship with her husband became strained as she learned about his affair. She said, “because my husband had been having an affair. I knew about the

person. I didn't know how far it had gotten, supposedly a friend who lived out of town type of thing, I didn't know until after I was diagnosed." Her hopes and expectations for healing in the marriage after her diagnosis were dashed as she realized he had no intention of investing in their marriage; "so I get the diagnosis, okay we'll get through this. So, I figured, okay, so now, good, he's going to focus on us, he's going to leave all of that other mess alone because this is real serious now. The reality was it did not happen. It continued on and that's when I started finding out more and more things."

Overview of participants' sense of self

Many of the women described an emergent shift in how they viewed themselves during their journeys. The sense of self varied as women faced the challenges of their diagnosis and the complications in their relationships. While some relied on their strong sense of self to help determine the path they would take, others felt a need to be strong for their loved ones. In some cases, women noted that despite what they had gone through they did not feel a sense of renewed strength or empowerment. The fears and concerns regarding the possible outcomes from treatment also had a profound effect on how some women viewed themselves. The loss of their breasts and hair influenced how they saw themselves as women and their sense of femininity. It also played a role in how they perceived their spouses' or partners' view of them as women. The sense of self was a key component of how the women faced the challenges of breast cancer and a non-supportive relationship at each phase of the trajectory.

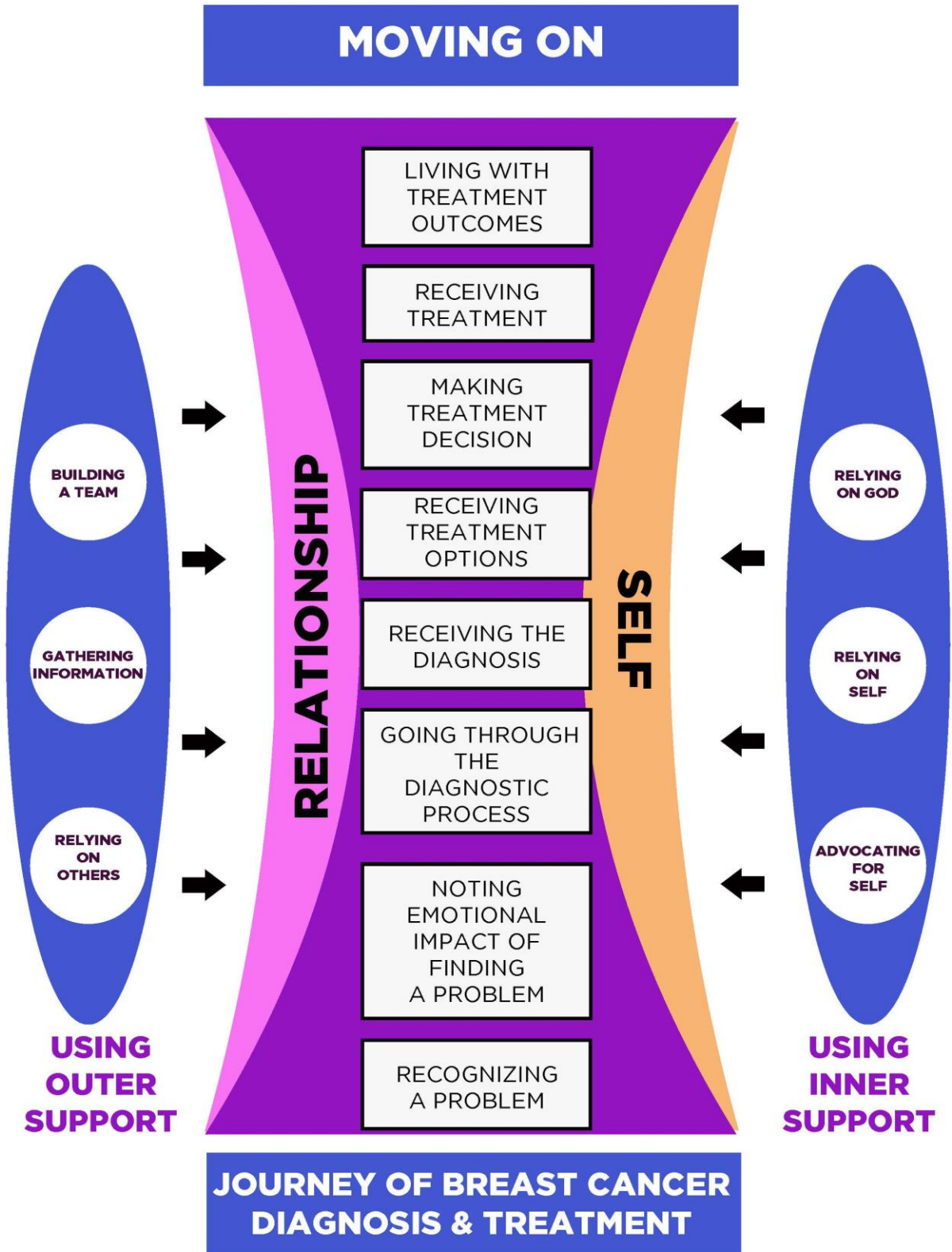
Journey of BC diagnosis and treatment

Making decisions about breast cancer treatment was often a varied, complicated and emotional task for the women. Some found the transition from diagnosis to treatment to be a

succinct and linear process. Others either spent a great deal of time contemplating what was ahead for them or chose to rely on the advice of others to help with the process. For some the burden of living with a non-supportive partner often added an additional dimension to their experiences which further complicated the treatment process. Receiving a breast cancer diagnosis in and of itself is a challenging experience, coupled with the lack of support from a partner or spouse women were now carrying a double load.

For the women, there were clear processes identified in making decisions about moving forward. Women first identified a problem, dealt with the emotional impact of the problem and prepared for the diagnostic process. Once the initial steps were completed women were then told of the findings and presented with treatment options. The women then needed to make decisions about their treatment. Finally, the women received the treatment. (see Figure 4)

Figure 4: Journey of Breast Cancer Diagnosis & Treatment



Recognizing a problem

The presence of a change in the women's breast was often the catalyst for exploring its ramifications on the sense of self and its potential impact on a woman's relationship. This change was often the first indication that an important occurrence was taking place and one that needed to be addressed quickly.

For our sample, the most common sign of a problem was finding a lump or having pain in the breast area. For example, Paula felt a lump while taking a shower. Others noticed a change in their breasts after performing their breast self-examinations (Maria and Grace).

Some women found the presence of pain as an indication of something wrong. For example, Candice, was always active and became concerned during her yoga class when she couldn't do her normal pose or clasp her hands behind her back. She noted that the area under her armpit was particularly painful. She "then started feeling around in that area and found a lump." Jaden, had a history of lumps in her breast. During one year, after having a biopsy her physician told her that it "may become cancerous later on down in life." At that time, she wasn't too concerned and delayed follow-up care for several years. It wasn't until she began to develop pain in the breast area that she sought medical attention. For Maria, it was the change in the color of her breast that indicated something was wrong. She described her symptoms as "it looked kinda funny, I didn't feel a lump, it was just a little warm to the touch."

Finally, a couple of the women realized there was a problem after going for their annual examinations or mammograms. It was Joyner's physician who noticed something amiss during her annual checkup. Another woman, Sade, had missed her previous yearly mammogram, so she made an appointment to have it done. She was later informed via the mail that something was wrong and that she needed to go back.

Noting Emotional Impact of Finding a Problem

The emotional impact of finding a problem or facing the possibility of a breast cancer diagnosis held different levels of significance for the women. Accordingly, the response to the news varied from woman to woman and ranged from lack of concern to fear.

Some of the women noted that they weren't initially concerned about finding something wrong nor about the possibility of a breast cancer diagnosis. For example, Paula noted that cancer was never in her mind after she noticed something wrong while showering. Maria pointed out that she didn't think anything of the discoloration in her breast. To her "it didn't even dawn on me that it was cancer." Others, Nicey and Joyner, simply pointed out that they weren't concerned about it. For example, Joyner said "I wasn't too worried really originally. It could be anything, such as I had a cyst on my breast awhile back – that kind of thing, and there was no real worries about it kind of thing. And I had no feeling that it could be cancer."

However, not everyone identified the presence a problem as a simple matter. For many fears of the unknown was the most pronounced emotion felt. Their fears were voiced with varying degrees of intensity. For example, Candice described feeling scared and nervous about finding a lump near her breast area. She even had her husband check out the area to make sure that she was not just "freaking herself out." He immediately suggested that she go to the doctor. Her conversation with the technician during her mammogram only compounded her fears. She informed the technician that "I'm not worried because breast cancer does not run in my family." The response was "you don't have to have a family history of breast cancer." It was at that point that it really hit her and she broke down crying.

Grace also recognized that finding a lump was something significant. She immediately acted on the discovery by going to her doctor to address what she found and to receive further

instructions. After testing and consulting with her physician she was then notified of the diagnosis.

Jaden went through a long process of finding problems in her breast and addressing them before she finally received a definitive diagnosis. Early on she found a lump and had a biopsy but couldn't recall the results. At a later date, she found another lump and had a second biopsy and was told that it may become cancerous in the future. It was the time when she started to developed pain in her breast that she finally received the diagnosis. Her response to the experience consisted of feeling overwhelmed, scared and worried. Throughout that time, Jaden hesitated addressing the changes in her breast because of several reasons which included the fact that she was living with an abusive partner and felt that she "had enough things going on my plate." In addition, she didn't want to go anywhere and get any tests done because of the marriage and because she felt that she couldn't "take any more bad news." Despite the varying degrees of concern the women experienced, they all proceeded to the next step down the path of receiving a diagnosis.

Going through the diagnostic process

Once the women identified a problem and dealt with its emotional impact, their next step was to receive information addressing their fears and concerns. This was often a difficult process in which women either chose to rely on their own inner strength and knowledge or to depend on the guidance from others. Regardless of the source of their strength the women now faced the challenge of formulating a plan for the initial steps to move forward.

Some women chose to begin the diagnostic process without their partner's input. For example, Maria wanted to be strong. She had a history of doing things by herself and this

included going to the doctor to receive the news alone. This was further complicated as she was at the same time dealing with the recent death of one son and the cancer diagnosis of another.

Jaden, also chose to move forward without help from her spouse. She described her marriage of many years as abusive which resulted in a subsequent separation and divorce. She made the decision to connect with others to help her enroll in a state program rather than seek assistance from her husband. The program was key in helping her move forward in the decision-making process when she was diagnosed with breast cancer.

Formulating a plan in seeking answers encompassed both facing fears and also taking a stand when necessary. For example, when Paula was diagnosed with breast cancer, she decided that she didn't want to hear data or statistics about breast cancer. She noted that "I'm not going to listen to any of that because they gave me initially like three to five years. Like I don't want to listen to any of that. I just want to beat this because I have a little girl to take care of." Nicey also was faced with hearing statistics regarding her prognosis. She found herself in a place in which she had to determine which treatment modality was most applicable to both her condition and to her life. After much contemplation and after receiving input from others whom she valued, she was able to create a plan for getting her diagnosis, that fit her needs.

Input received from others was just as important for Sade who, after receiving her diagnosis, sought out a second opinion from an oncologist before developing her plan. Candice was more direct in her decision to move forward. She said "I got to fight. That was my next step. Cause I didn't have time to get into the woe-is-me attitude. It was time to fight and I had to figure out my next step. I just went into survival mode."

Receiving the Diagnosis

All the women went through similar diagnostic processes that resulted in a definitive cancer diagnosis. Transitioning from the unknown to the known proved to be a challenging for the women. While some received assurances from their clinicians that it was “probably nothing,” all went down the path to receiving their diagnosis.

After the completion of mammograms, ultrasounds or biopsies, the women were then presented with the news of their diagnosis. The waiting time often varied. Maria, for example, pointed out that it wasn't until 2 or 3 weeks after her biopsy that she was told that she had cancer. Sade identified the word malignancy on her chart which she took as an indication that she had cancer. Nicey was sure it wasn't going to be anything, but was notified via telephone that it was indeed cancer. Candice had to wait over the weekend after her mammogram to receive a call from her physician to come in to the office, where she was told about the diagnosis. She remembers that they “weren't sure if it was esophageal, stomach or breast cancer. They had no clue what it was because the type I had was [something called] triple negative breast cancer.” She explained her understanding of the diagnosis as “triple negative breast cancer does not feed off of estrogen, progesterin or HER2. So, they don't know what it feeds off of and there's no after treatment like Herceptin or tamoxifen because they don't know what it's feeding from.” She was also informed that it was a very aggressive and fast growing cancer, and treatment decisions needed to be made quickly. Grace was told a day later after her biopsy that it was cancer. Regardless of the time span between testing and diagnosis the women now had to proceed to exploring treatment options.

Receiving treatment options

All the women were presented with a treatment plan that consisted of surgery, chemotherapy and/or radiation therapy. In addition, some were given the option to have reconstructive surgery. Most accepted the offered plan and continued moving forward without hesitation. Others went back and forth between choosing alternative treatment versus traditional. In the end, all the women chose to receive traditional therapies. In the case of Maria, she was concerned with the possibility that she would not live through her treatment, when she said "it was kind of late for alternative treatment" and she didn't want to "kill herself" by not accepting the treatments of chemotherapy and radiation therapy.

Others were concerned about the outcome of specific therapies. Jaden was presented with the option of getting a lumpectomy or a mastectomy. She was told that if she had the lumpectomy, she would be left with a dent in her breast that would not go away. For her a mastectomy was the more appealing choice. Joyner was also presented with the lumpectomy versus mastectomy option. The determining factor for her was with the lumpectomy she would need to have chemotherapy and radiation therapy afterwards. With the mastectomy, no chemotherapy or radiation therapy would be needed. She chose to get the mastectomy, to avoid the chemotherapy, radiation therapy and any worries about its spread to her other breast.

Sade was presented with the plan to receive a mastectomy with chemotherapy afterwards. This was very difficult for her as she stated "I didn't want to lose my hair and I didn't want to lose my boob." She also struggled with the information provided to her by the surgeon because as she says, she "did not hear what the surgeon said." She wanted the flap surgery and recalled him telling her that she had up until the day of surgery to decide. However, on the day of surgery

she was told that was not the case as they were not prepared to perform that type of surgery even though it was what she desired.

A couple of the women were given statistics along with their treatment plan. Grace was told that she had a good chance of “beating it” and was presented with a lumpectomy followed by chemotherapy and radiation therapy. Nicey was also given statistics to support the treatment plan. She had a lumpectomy followed by chemotherapy and radiation therapy. Candice who, despite being diagnosed with triple negative breast cancer, was also presented with a similar treatment plan that consisted of surgery, chemotherapy and radiation therapy.

Making treatment decisions

The women used various processes to help them make decisions about their treatment. Some were firm about what types of treatment they were willing to have, while others struggled with the process. Joyner decided early on what she was willing to have. She wanted to avoid receiving chemotherapy and radiation therapy. She also did not want to face the possibility of the cancer spreading into her other breast. It was at that point when she noted “when I thought it might something be growing in my right breast and everything, I decided I’m going to go for the bilateral mastectomy.”

Nicey, initially did not have a clear direction as to what she wanted to do. She “was really on the line for a while and went home and thought about it” before making any decisions. She utilized her inner support through relying on herself and utilized outer support by relying on the advice from others. Her interaction with her friend helped to her decide between traditional and alternative medicine. She pointed out that a conversation with this friend about treatment and the friend’s emphasis on Nicey’s desire to be there for her children effectively “gave me such a strong sales pitch that it pushed me over to do the regular conventional medicine.”

Other women also relied on advice from others. Sade sought additional professional advice before making any decisions regarding her treatment. She outlined the process as “so then he diagnosed me and then I went to the oncologist. I got a second opinion from an oncologist and then I [also] went to the oncologist through my medical group.”

While making decisions about treatment, contemplating the potential side effects that they would face played a role in how the women were willing to moving forward. The possibility of losing their hair, losing a breast and altering their sense of femininity all played a role in the decisions they made. Grace was very concerned about losing her hair. Her concern regarding hair loss was very important to her. She noted “I didn’t want to do it because of the hair. That’s how much it meant to me of losing my hair. I struggled, I really struggled.” She relied on the advice from others to help her move forward. It was the oncologist who helped her decide on the treatment. She also sought the advice from others including her girlfriend and a nurse who she asked, “if it were you, would you do it? The nurse said ‘Yes, I would,’ in a heartbeat, so I think that was what did it for me.”

Other women looked within themselves to help formulate a plan to get them through the process. For example, Jaden, who received assistance with her treatment through a state program, pointed out how she made up her mind when she told herself very clearly, “figure it out and deal with it!” She tearfully said, “it was like I’m just going to take whatever comes my way, and I’m going to do the best job I can at that time and at that moment [cries].” Candice took a stand, explaining that it was “time to fight” and that she just needed to figure out her next step. She called it going into “survival mode.” She stated that “I had to get things in order, I had to be strong, I had to do my research and I had to function normally until I had the next appointment with the oncologist to hear more about what was going on. I knew that I had to get my team

together. So, that was survival mode, just organizing how things were going to be implemented out, you know?” As already noted, Paula decided not to listen to certain information, specifically statistics. She said she needed to focus on being a mom to her little daughter. Maria on the other hand, took a less forceful role. Her reasoning was to “just listen to everything, what they say, all the instructions, and I can get through this.”

Receiving treatment

For the women in our sample, receiving treatment was not always an easy process to live through. Maria got sick a few times. Her experience with radiation therapy involved resisting; she did not want radiation therapy and fought against it the entire time she received it. She said she did give into the treatment because she “hated radiation.” Despite her feelings towards the radiation therapy she ultimately was pleased with the surgery because she felt that she was not mutilated by it.

Jaden was pleased with the trajectory of her treatment which began with chemotherapy followed by a mastectomy. She also felt comfortable with her health care provider and their expertise.

Joyner was adamant about not receiving chemotherapy because of her father’s experience during his bout with cancer. Treatment modalities had to be reevaluated for her as her disease progressed to Stage IV. She had had surgery on her femur, followed by 10 days of radiation therapy, so choices were limited to address the other cancerous areas in her body. Joyner made the decision to incorporate holistic therapies as a modality for her treatment with surprisingly good results; she emphasized that now (at the time of the interview) she had no active cancer present.

Sade had a great fear of needles and IVs. This fear had an impact on how she was willing to move forward. When she misunderstood how the surgeon was going to proceed to conduct her reconstructive surgery and how she could not decide on the type of surgery (i.e., she wanted the flap procedure as already noted) at the last minute, she was faced with deciding whether or not to delay the surgery.

Nicey noted that despite her initial concerns about receiving chemotherapy and its potential to make her sick, she found her experience to be tolerable with the help of additional medications. Her main concern was the physical changes that she experienced. There was a significant change in how she saw herself and how she looked physically, which she believed contributed to the change in her relationship with her husband.

Paula faced a recurrence less than a year after her mastectomy on her right breast. In hindsight, she wished that she had done a bilateral mastectomy with an immediate reconstructive surgery followed by chemotherapy instead of waiting three years. Instead, at the time of the first diagnosis, she received radiation therapy that resulted in her breast being badly burned and complicating the possibility for future reconstructive surgeries.

Candice experienced a frightening episode after her treatment. Despite being forewarned of possible side effects from the chemotherapy, she explained how her throat began to close one evening. She reached out to her husband to help her during this time but received no response. Instead she called the cancer center and received help via the telephone so she could work through the alarming episode.

Grace just wanted the cancer to be removed, however she had to wait two months before she could receive her surgery. After her surgery, she had to deal with the negative side effects of

painful constipation. She asked for help from her partner who refused to assist her. Instead her sister drove a great distance to help her in her time of need.

Living with treatment outcomes

Living with treatment outcomes proved to be very different for each of the women. Some dealt with ongoing treatment complications while others simply put the experience behind them. Maria described how "lopsided" she looked and how she was very uncomfortable because there were little balls of flesh that gouged her at her surgery site. Sade was also unhappy with the outcome of her treatment. In fact, she stated that she hated how her breast looked and didn't want to proceed with reconstructive surgery for fear that it would look worse.

Jaden described her experience with chemo as being "really bad." She had to deal with a bloody nose on several occasions and a rash that covered her entire body. Yet, despite her experience she was very satisfied with the outcome of her treatment, noting that the size of the tumor shrunk significantly, and even after examining her scars recently she noted that the surgeon "did a really good job."

Joyner was not as fortunate. After treatment, she was later diagnosed with Stage IV cancer and it had spread to her spine, pelvis and femur. She also faced the challenge of dealing with multiple infections at her surgical site. Paula also had to face multiple reoccurrences and the spread of her disease. She noted that the cancer had spread "throughout my spine, cervical, thoracic, right femur, pelvis and liver." Paula had 13 reconstructive surgeries on her right breast. This process was complicated as her skin was totally burned due to the radiation therapy she had received. Candice also had to deal with significant treatment side effects that included neuropathy, the perception of her throat closing in, black fingernails, changes in her eyesight and the loss of her hair. She also developed anxiety and weight gain.

A couple of the women were very pleased with the outcome of their treatment. For Grace, her only concern was that her breasts were now smaller, however, she was very pleased that she was not “mutilated.” Nicey also found the experience to be tolerable, in fact, during the interview she pointed out that “I would absolutely do it again.”

Support

Finding a problem, receiving a breast cancer diagnosis and going through treatment proved to be complicated in the presence of non-supportive partners. To compensate for the lack of support from their partner the women chose to rely on using either inner or outer support, singularly or as a combined method of coping. Inner and outer support were utilized at various points and in varying degrees. Inner support consisted of relying on God, relying on self and/or advocating for self. Outer support consisted of building a team, gathering information and/or relying on others.

Using Inner Support

Relying on God

Various women in our sample verbalized some level of connection with who and what God meant to them and described how this was a support in their lives. Either they participated in a formal setting in a place of worship or chose to connect with God on a more personal and private level. Regardless of how they engaged with God, it was evident that they relied on a power that gave them strength and hope throughout their journeys. One example was Maria who made firm statements about how she felt about God when she said “I so love God, He’s done so much for me. I bow down on my knees for my Lord.” Sade affirmed her belief and reliance on God when she said “yes my hope, yes my faith, yes my prayers helped. But if it wasn’t for the doctor and God I don’t feel like I did anything.” Joyner, also chose to “only depend on God. I

pretty much have tried to focus my thoughts on God every moment no matter what. I depend on God to lead me. God is my shepherd. I'll do my best. I know God is in control. To extend my life here on Earth in the body, I'll do what I can, as much as I can. But I try to emphasize that I belong with God.”

Another woman, Candice, admitted that she was angry with God because of her diagnosis. She stated, “so I was angry because I felt like why is God doing this to me? You know, and it wasn’t supposed to happen to me.” Her anger towards God eventually shifted as her faith began to grow and as she pointed out “I have faith, I knew God was working through these people. I believed it so. That’s what kept me going. God has blessed me to have that same network here. But I believe that God had me walk on this journey and I survived.”

Relying on Self to Make Decisions

For some women, the option to have their partners help in the decision-making process proved to be challenging. The women dealt with false assertions made by their partners that they would be there for them, only to be let down and left with the only option of relying on themselves or others. A few husbands offered some input regarding treatment decisions but ultimately it was the women who made the final decisions.

Maria wanted to be strong and wanted her husband to contribute to the decision-making process despite her always “doing things by myself.” Her husband’s input simply consisted of telling her to do “whatever I want to do, that was his role. You decide. It’s your decision. We didn’t discuss too much about it, he just left it up to me cause he said it was my decision.” Jaden was dealing with an abusive partner so she had to develop a plan in which she could rely on her own abilities. She talked of “dodging bullets” and figuring things out on her own. She described her self-talk saying, “It was like constantly, ‘Do and don’t think. Just ‘do what you need to do

and don't think. Dodge the bullets from your husband, and dodge the bullets from your family.' [I told myself] 'I just got to put it over here and deal with it later. You're going to have to figure it out and deal with it.'"

Joyner questioned the decisions she needed to make by asking "what's the right thing to do? What's going to happen to me?" She relied on her researching abilities to help her formulate a plan. She said,

"I, myself, am a researcher, so I went into doing research onto what's the right thing to do. Then I did my research. Then it was a big debate in my head on what should I do. Should I have reconstruction or not? And what kind of reconstruction and all that kind of stuff boiling in my head. So somewhere there I somewhat decided I should have reconstruction."

Sade previously relied on the advice from others to help with making decisions. However, it was the decision regarding her reconstructive surgery that she made on her own. "Yes, because in my mind all the other times with decisions to have the mastectomy, chemo, that was my husband and the doctors and everybody else talking. I went along because I felt they knew what was best. I didn't want the surgery. I didn't want the chemo. I didn't want to die. I don't feel like it was my power. I had no power. I feel like I was powerless the whole time. Until I finally made the decision not to have that second reconstruction."

Nicey received a great deal of input from others. She felt that she was "really on the line for a while" despite receiving input from doctors, neighbors and friends. Her husband gave her minimal input. He left the decisions for treatment entirely up to her and he offered no opinion either way. In the end, she relied on her own best judgment and decided to receive chemotherapy.

Paula made the decision not to listen to the statistics presented to her by her physician. She wanted to “beat the cancer” if not for herself, then for the purposes of being there as a mom to her young daughter. She ultimately made the decision for treatment alone. When presented with the option for a mastectomy, Paula weighed the opinions from several doctors and decided on which advice to eventually follow.

Candice knew right away that she wanted to fight the cancer and “win”. She alone chose whom to speak to about her treatment and whose advice to follow. Her final decision wasn’t made until after she spoke with her cousin who was also an oncologist. She pointed out that she listened to the advice given to her from her mother, her kids and even her husband, but the decision was made strictly by herself.

Grace defined herself as someone who was strong because of all that she endured in her life. It was this inner strength that helped her to remain calm and clear headed about having surgery. Her focus was on getting the tumor “out” and she created a vision in her head that she was going to be asleep during surgery so she reasoned with herself that there was no need to be afraid.

Advocating for Self

The women advocated for themselves by drawing on their own inner strength and taking a stand. Maria found it difficult to face the challenges of her treatment particularly without the support from her husband. Initially her husband would accompany her to her appointments but she noticed that he often sat in the corner and read a magazine. This caused her to take a stand and ask that he no longer come with her because he was not providing her with the support she needed.

Joyner noted how she struggled with the input from her husband and her mother because they were “opposite opinions.” To help her move forward she specifically asked them, “please don’t push me to your opinion. Don’t tell me what you want me to do. Only if I ask for your opinion. Otherwise, please let me make my own decisions, and please support me on my own decisions.” She also pointed out that she had received different pieces of information from various sources and chose to “listen and do my own research and then make my own decisions.” When it came time to decide on whether or not to take a study medication, she was firm in waiting until there was additional study data to support the use of the medication.

Sade had a difficult time working through the opinions of her husband. His suggestion was for her not to get the surgery and she noted that “he was mad at me ‘cause I was going to do it. Because then I did do it. He was mad the whole time. I felt like he was saying that I chose to have cancer or I chose to cut my boob off. And in a way, maybe I did choose, because I chose to save my life.”

Jaden had to face the difficult challenge of dealing with her mother who was very vocal with her opinion about the treatment. Her mother wanted to make decisions regarding her treatment for her, but Jaden took a stand and said that “we can talk about it and discuss it, but this is my body.”

Grace had a hard time with the loss of her hair. To her it was a major concern that was complicated when her husband would refer to her negatively in public. To compensate for the loss of her hair she would wear a wig or bandana in public. Family members told her that “it wasn't working for her” but it made her feel good about herself and she was able to leave the home and go out. She pointed out she used her own feelings to help her make decisions saying, “so I did what made me feel good.”

Using outer support

Using support from outside themselves, or outer support, helped the women to manage their cancer journey. Outer support included building a medical team and developing support systems. It involved information gathering done through the internet, books or organizations. Also, relying on others consisted of allowing others to be their eyes and ears, supporting the women during appointments, providing transportation for the women, and helping with their personal needs.

Building a team

Women built teams to support them. For most of the sample, the team members did not include their partners. Instead the women relied on the expertise and help from others to move them forward. Women saw themselves as building teams that included health care professionals and others. Candice noted “I went to the oncologist and I had my team which was, at that time, my best friend and my oldest daughter, and then a cousin who was an oncologist. Paula noted how she “had to build new doctors because I didn’t even have a general practitioner, all I had was the Ob/Gyn and then from there, I had an oncologist and a radiologist.”

Teams organized through social service agencies described as beneficial in various ways. For example, Sade found that connecting with a support group was helpful for her. “You can call them on the phone, you were matched with a survivor with the same cancer that you have, and that helped me a lot.” Grace received a great deal of help from a support group that allowed her to speak with someone "who's actually been through it and can tell you." Jaden signed up with the “Every Women Counts” program which helped her schedule an appointment with the surgeon. She was then referred to an oncologist that provided information, support and a sense of being cared for.

Gathering information

Women engaged in an ongoing process to obtain accurate and timely information regarding their breast cancer diagnosis and treatment. Most relied on taking direction from others to get information, while a few took on the burden of gathering information alone. One avenue several women used was that of researching on the internet. This did not always prove to be helpful as some found the information to be overwhelming.

Jaden was given a book by her physician that helped her. This book provided detailed information about breast cancer diagnoses and treatment. She was also instructed not to seek out information on the internet. Her physician told her that "what you find on the internet will just be general, and it will cover everybody." This information appeared to resonate with her as she noted how overwhelmed she felt and how difficult it was to understand the medical terminology used. Instead she relied on her conversations with her doctor and the book she received to help her understand what was happening.

Joyner used her researching background to help her as she mainly got her information via online research. She researched what was the right thing to do particularly as it pertained to reconstructive surgery. Sade initially did her research on the internet, but found it to be more harmful than good. She felt that the information only showed the bad side of her diagnosis.

Paula received information about her recurrence and treatment options through second opinions from physicians. Candice relied on the help from friends to conduct research and gather important information; she allowed them to be her "eyes and ears." One friend did a lot of the research prior to the first visit to the physician. She explained that she felt fine about the decisions that were being made because other people were doing the research for her. Another friend brought her several books, food plans and other information on how to stay healthy and

how to stay alive. Grace's partner offered his assistance in helping her find a breast cancer support group. When it came to gathering information, she chose not to search too much on the internet because she "didn't want to become a hypochondriac." So, she did minimal research.

Relying on Others

Many of the women relied on family members to provide the necessary support they needed. Family members included children, parents, friends and employers. In a limited number of cases, it was their partners who helped with providing supportive care. For example, Nicey's husband accompanied her to the doctor's appointments. She explained,

“He went with me to my chemotherapy appointments. And he went with me for most of them, not all of them. And he went with me to my doctor's appointments. For the first part of the doctor's appointments. He went with me to my chemotherapy treatments.”

However, when it was time to buy herself a wig, it was her friend who went with her. They did this before her hair fell out to make the transition easier. It was the same friend who also provided meals for her when she was too ill to cook.

For Joyner, both her husband and her mother provided support in that they provided her with transportation particularly to faraway places. When she had to go out of town for five days for a consultation, it was her husband who accompanied her. Locally, it was her mother who helped with transportation. Candice's husband would take her to get her injections on the weekends that he was home from work.

Paula found her husband to be somewhat supportive but this only lasted for one year. He went with her to the consultation visit and would make arrangements and schedule the appointments. She remembered that he would say, “‘What can I get for you? You're too tired. I don't want you driving. You don't have to do this. Give me the list.’ He'd go grocery shopping,

take me out for dinner. He was just – he was there." However, after the mastectomy, which was one year after diagnosis, her husband became less supportive often yelling and belittling her.

Other women got outer support from their mothers. For example, Jaden relied on help from her mother to drive her to her doctors' appointments and to help with constructing questions to present to her physician during the visits. For Paula despite her mother being very emotional and having a dramatic way of coping, which was not helpful, she did offer some level of emotional support throughout the process.

Another source of outside support for some women, was their supervisors at work. Sade relied heavily on her "boss" to help her in her time of need. "My boss, she was my support system even though I'm married." Her boss took her to the doctor's appointments and "she was the one that heard what I couldn't hear" and was her eyes and ears throughout the process. Coworkers offered to help with washing her clothes and preparing meals for her and her family; although she resisted initially she realized that she needed the help and gladly accepted their offer.

Some of the women relied on other family members to provide support such as their own children. Maria asked her children to step in where support from her partner was lacking. My daughter would have to help me and other people would have to cook for me. My sister came from Arizona, she was supportive she came and she was there for my surgery too and her kids and her grandkids, my family basically.

Sade received support from her children using the example of her middle child reminding her when it was time for her to take her medications. She jokingly called her "Nurse Ratchet." They would also help clean and prepare meals for her after her surgery.

Friends played an important role in providing support. Candice chose twelve women that she spoke to on a daily or weekly basis to be her support circle. These women made themselves available to her so she could call them at any time for support. She also chose six of her sorority sisters to be part of her circle. Grace noted that one of her female friends who was in the medical field was the main support person for her. She was assured that this friend would be there for her throughout the process. However, her sister was the one who helped her deal with a significant side effect from the treatment when her husband refused to help.

Moving on

All the women traveled the course of their breast cancer journeys and subsequently reached a point in which they were able to look back at their experiences, and look forward to their futures. This bidirectional viewpoint allowed the women to evaluate and compare their progress and to use their experiences to help develop a plan for moving forward. Their perceptions of the impact of their relationships, and their sense of self shaped how they viewed their diagnosis and treatment experiences. These newly defined perceptions were the building blocks for the development of new outlooks on life and the prospect of moving on.

Relationship

Despite challenges faced by the women in their interpersonal relationships they were still able to move forward. They did not allow their relational difficulties to stop them or to eliminate their possibilities. Instead they chose to take a practical approach that supported the idea that they could manage somehow to get through their experiences. Maria is one example of how women worked through their relational difficulties in the face of dealing with breast cancer. Maria had a difficult time with her husband after completion of her treatment. She dealt with his ongoing lack of support and felt that she no longer wanted to be in the relationship and told him

to leave. Her husband honored her wishes and left, however he was the one who initiated the divorce proceedings. This process ultimately led to financial instability as her husband refused to sign papers that would allow her access to her retirement funds. This both confused and devastated Maria. However, despite his lack of willingness to work with her on this matter, Maria was able to see some hope in her future that included dealing with the prospect of “being single” and making plans to make her life more comfortable by remodeling her home.

Jaden continued to have a difficult time with her husband even after their marriage ended. She noted that “my feelings, towards my husband before and after my breast cancer diagnosis haven’t changed, he’s hurt me, I’m angry with him, he’s abused me.” Jaden experienced emotional and verbal abuse throughout her marriage. This abuse had a lasting impact on her. She pointed out that “I think being married to my husband has caused me to cower down and to not say anything and now that I’m not with him and time has gone by and people say something hurtful, I’m writing it in a letter.” She recognized how the abuse negatively affected her. However, she was no longer willing to sit back and allow others to abuse or mistreat her. She notes that she feels embarrassed telling anyone about being married to a registered sex offender, because she is not sure what others will think of her. “It’s like these are things that you just want to hide and you don’t want anybody to know.” She was also hesitant to be in a new relationship with someone else explaining, “I don’t want to tell him that he abused me.” Her fear was that a new partner “might want to turn around and abuse me. Even if I know deep down in my heart that this man cares about me and wouldn’t do anything to hurt me, I still don’t feel comfortable. I still don’t feel I would be comfortable telling him, the man in my future.”

Sade also struggled with the state of her relationship throughout her journey. While she experienced varying degrees of non-support and abuse, she chose to remain in the relationship.

She noted that she will not discuss the abuse she experienced with others because “I choose not to until I am out of it, there’s no need to talk to people about it.” To her it made no sense to discuss what she was going through because she had chosen to stay with him. The outcome from her surgery also had an impact on how she viewed herself and in how she perceived others may view her. She gave an example of how the outcome of the surgery played a role in her present and potential future relationships. “I think that’s part of the reason since the cancer I’m still with my husband. It impacts if I wanted to divorce my husband and be with someone else, because I’d have to go through the explanations and then trying to be comfortable being naked and all of that.”

Joyner described her relationship as being stable throughout her journey. Despite facing times in which she struggled with decisions presented to her, she was able to work through that process to help complete her plan. In the end, she noticed a positive change in her relationship with her husband when she stated “I feel like maybe my husband has been sharing a little more positive love and caring since then. Before, I felt like I was maybe doing more of everything, while now he’s doing more of an even share of things.”

Nicey believed that her cancer diagnosis ruined her marriage and caused her to be “in a club I didn’t want to be in.” She pointed out that if “cancer hadn’t happened my relationship might be fine.” She described the relationship as being “severed” versus “damaged” in that damage is repairable but her marriage was not repairable. She also came to the realization that she needed to be prepared to take care of herself, because “he’s not going to take care of me like I always knew he would.” She faced fears of financial instability and homelessness as a result of the divorce but realized that it caused her to “get a life”.

Paula dealt with the introduction of drugs by her husband in the relationship. She defined that time as when “all hell broke loose.” Although she contemplated leaving the relationship on several occasions she often changed her mind as she wasn’t prepared to care for herself. She noted that “he managed to make my money disappear and he didn’t want me to work. He wanted me to rely on him.” Nonetheless, she eventually filed for divorce.

Candice dealt with her husbands’ infidelity and non-support throughout her cancer journey. She found that her husband wasn’t there for her when she needed him the most. She realized that with every affair it “took a piece” of her which caused her to feel that she was “never good enough.” She noted that it wasn’t until she put him out that she realized that she was not to be blamed for his affairs and that she didn’t have to put up with his behavior. At conclusion of data collection, Candice remained in the relationship with her husband. Although she felt like he would now listen and talk to her, she had not opened those lines of communication because she was “scarred from what happened previously.” She felt that “he just doesn’t have the control that he once had, that I gave him.” However, she reported that the biggest battle was letting go of what had been done to her in the past.

Grace was being physically abused by her partner throughout their relationship. She found that “he was making my life very miserable.” She was financially dependent on him and that decreased her ability to remove herself from the relationship. She eventually obtained a restraining order to ensure safety for herself and daughter; then she ended the relationship.

Self

The women described how their sense of self often changed after their treatment. While some found a renewed sense of empowerment, other women in the sample discovered that their experience with cancer did not have the impact on their lives that was expected. The women

evaluated who they were and what was important to them both during and after treatment. While not all the women recognized what the significance of living in a non-supportive relationship while dealing with breast cancer fully meant, they all were able to grasp some degree of autonomy to help them move forward in life. Some described themselves as fighters because they were able to survive. However, others struggled with that perception. Jaden grappled with seeing herself as a fighter because she didn't feel stronger after her experience, despite being told by friends or acquaintances that she was. She remembered thinking at one point, that "my only way out of this marriage was to commit suicide." She eventually felt that "now after going through all of this breast cancer, I'm a fighter." She felt that she was in a place where she would no longer allow others to take advantage of her and that she would stand up for herself.

Sade also struggled with how others saw her and her experience. She heard how the breast cancer experience had empowered and made other women feel stronger. That was not the case for her, she felt like she had gone on a road trip, kicking and screaming, and that she didn't learn anything from her experience. She knew that she didn't want to be defined by her diagnosis or by the effects from the treatment, and that she had to get past this; she couldn't let this beat her. She realized that "life is too short" and there is no guarantee about anything in the future. So, having cancer helped her to be less strict and rigid and to loosen up about life. Regardless, she remained firm to the fact that unlike most cancer survivors who are proud of having survived the experience, she did not share their perceptions and did not want to be reminded of it every day. Sade initially thought that she would not be classified as a woman after the loss of her breast and her hair, but later found that she wanted to teach her daughters that you have to be okay with who you are, no matter how you look. She eventually accepted the change in her body and "calmed down" and decided that she was going to do whatever it would take to live. To help

address the changes in how she looked without hair she explained she would be ok “as long as I have a big pair of earrings; I just want to make sure they know I’m not a boy.”

Several of the women said they struggled with depression throughout their cancer journeys. For Maria, the depression was a result of her diagnosis and treatment, and the loss of her two sons (for reasons unrelated to her cancer diagnosis). However, at the end of her journey she stated that she felt better now. She noted that “I see myself as coming close to what I used to be, not the same person because I’ll never be the same. But I see myself coming close, as close as I can.” Joyner was diagnosed with depression before her diagnosis and started therapy sessions that continued throughout her treatment. When she was initially diagnosed with depression, she was given the option to start on antidepressants. She decided against antidepressants and instead found her sessions with the therapist to be most helpful in dealing with her situation and moving forward in life. Candice spoke with her clinician about being depressed. She believed that the depression was more related to her husbands’ infidelity than to the breast cancer. At one point, she felt that she was going to die, not from the cancer but from a broken heart. After spending time trying to work through her feelings she decided that she wanted to live and that she was going to fight. She also decided to stay in her marriage but pointed out that “it took breast cancer to show me, you can make it.” She noted that her renewed sense of self came when the chains of control from her husband were broken. This new-found freedom had paved the way for her to help create a “new me.” She stated, “I think the new me is just learning to breath and staying more positive, more focused and not reverting back to my old ways.”

Nicey began to focus more on herself after the divorce, as she pointed out “I realized that life is about me; it’s not about anybody else.” She found that the divorce forced her to seek and

gain her own “life,” because she felt she had not really had “a life” before. Prior to the divorce her identity was wrapped up in others as she lived her life through the desires and needs of others. After she completed her treatment, she felt that she needed to live her life “faster” and with intention, rather than passively just letting it happen. She was now on the path to take steps in which she saw herself as a strong woman and capable of knowing what she wanted out of life with the ability to now stand up for herself.

Paula struggled with drug abuse during her treatment. This proved to be especially challenging as she overdosed on several occasions. Her self-esteem was at an all-time low as she had no one to turn to except her drug addicted partner. This was particularly difficult as she progressed to Stage IV breast cancer. At the time, she felt that she had no choice but to do drugs with him. She eventually ended the relationship and was able to move on. Then, she began a job in which she counseled other women going through similar situations. She said her advice for others was, “I know what it’s like to want to die. I know what it’s like to be in pain. I know what it’s like to be abused. I know what it’s like to feel powerless and helpless. But you’ve got to hold onto anything, whatever it is that makes you happy. Just hold onto that image and keep that image with you throughout the day. Be gentle on yourself and do things that are good for you.” Grace was looking forward to the future. She wanted to be happy and appreciated. She learned to take “baby steps” to rebuild herself and to move on. She knew that she couldn’t complete the journey alone and that she needed help. Now, she feels that she is being healed through the help and support she receives from the domestic violence center. She offers advice to other women going through similar situations. She said her advice is, “I know men intimidate us and they say, ‘Oh I’ll hurt you’ and you’re afraid they’re going to take your kids away. I felt all of those things, but you’ve got to conquer those fears and you got to move on.”

Chapter 6: Discussion

The aim of this study was to understand the experiences of women who made decisions regarding diagnosis and treatment while simultaneously living with breast cancer and a non-supportive or abusive partner. Eight women described how they went through the process of pre-diagnosis to treatment of breast cancer while factoring in their perceptions of self and their relationships. The women then worked through the decision-making process by considering their diagnosis, non-supportive partners and their sense of self.

For the women in our sample, dealing with a breast cancer diagnosis and treatment was perceived as a challenging experience. When the women identified a problem with their breast they began the process of interacting with themselves (e.g. thinking) and with others. The women then began to contemplate what the prospect of a breast cancer diagnosis meant in the context of their lives and their relationships.

The journey for the women began with identifying a potential breast problem and dealing with its emotional impact. The next step consisted of going through the diagnostic process to receive a definitive diagnosis. Once the women received their diagnosis they explored treatment options, made decisions about and received their treatment. In the end the women described how they were living with treatment outcomes and were able to move on in life. Throughout the process the women examined how their sense of self and their relationships and the use of inner and outer support helped them maneuver their journeys (See Diagram).

Need for Information

The need for information about treatment options and care was an important step in helping women move forward in the process of decision-making. Whether seeking information from clinicians, family members, partners, friends or loved ones, women sifted through the

information presented to them and made adjustments to fit their specific needs. Vivar and McQueen (2005) also found in their literature review that the informational and emotional needs after breast cancer treatment among long term survivors were often unmet by their oncology teams. This resulted in women seeking other resources for support, as was the case for the women in our sample. To help meet their informational needs our participants used both inner and outer resources for support. The women gathered information from a variety of sources that included the internet, books, conversations with others, or research they conducted on their own. While the sources and types of information often varied, the women needed to make sure that the information given to them fit their particular situations and had the potential to help move them forward in their decision-making processes before they made any final decisions.

Need for Emotional Support

Emotional support was also an important factor in the women's journey. For this, women relied on others or worked to build a team to help them cope. While some women expected their partners to be their primary source of support, this was not always the case as their expectations were often misaligned with the reality of their situations. Contributions from their partners regarding decision making about diagnosis or treatment were either minimal or non-existent. When support was provided by a partner or spouse, the women found that it often diminished over time. Due to this lack the women altered their reliance on support from their partners to best meet their needs by continually reassessing their situations and making changes accordingly. These research results are aligned with other studies that showed how partners of women diagnosed with breast cancer are not always supportive. In research with a sample of 28 breast cancer patients, Shiozaki et al. (2011) used exploratory and confirmatory factor analyses and found that the avoidance of addressing problems or an inappropriate attitude without the

intention of support by a spouse or partner, negatively affected the psychological adjustments of women. In another study, Walsh's research team used a mixed methods approach to identify the impact of breast cancer on younger women's relationships with their partner and children; they had a sample of 204 women diagnosed with Stage I-III breast cancer and found that a partner's inability to cope with a woman's breast cancer diagnosis sometimes served as the catalyst for termination of the relationship (Walsh et al., 2005). In our sample, the women noted that their husbands were often physically present but emotionally detached. Instead the women relied on other sources of social support to help meet their emotional needs. Family members, friends and the medical community were valuable substitutes for the lack of emotional support missing from the relationships with their partners.

Some of the women in our sample experienced an increase in the level abuse after their breast cancer diagnosis. This contrasts with the findings of Canady et al. (2010) in their study of women diagnosed with breast cancer (N=206) as compared to an ethnicity-match female cancer free control group (N=206). The authors found that rates of physical and psychological abuse among breast cancer survivors were low and did not change significantly at the time of diagnosis and treatment. However, for our sample, abuse sometimes escalated in intensity or transitioned from verbal to physical after the women were diagnosed with breast cancer. Some of our participants also dealt with levels of abuse that included infidelity and negative responses from partners to the physical changes women were experiencing. This was also the case in another study examining the experiences of women who were living with an abusive or non-supportive partner at the time of their breast cancer diagnosis (Sawin et al., 2009). The lack of support and abuse caused participants to reevaluate their sense of self and their relationships.

Sense of self

The philosophical theory of Symbolic interactionism (Blumer, 1969/1986; Charon, 2010; Mead, 1934) is helpful for understanding how the women in our sample seemed to develop meaning between themselves and others as it pertained to their breast cancer diagnosis. The women's thought processes affected how they viewed, defined and acted towards themselves and were informed by their encounters with their partners. These experiences led them to examine and modify the meaning of their breast cancer in the context of their non-supportive or abusive relationships. This new understanding seemed to contribute to their evolving definition of self and was key in helping the women to make choices that were meaningful, understandable and manageable for each of their unique situations. Over time, our data suggest that the women were developing a sense of self that helped them to either stand up for themselves, make decisions or end the relationship. The levels of abuse often varied but had the same definitive negative effect on both the women's sense of self and their relationships.

Stay or Go?

Despite challenges the women faced in their relationships, they were able to formulate a plan to transition from diagnosis to treatment and beyond. Even though the women expected but did not receive a more positive response from their partners, some chose to accept their situations as they were and stayed; however, others left the relationship. Recognizing that they were in fact in an abusive relationship was difficult for some of the women while they were in the midst of it. For them, it was only upon reflection that they realized their relationship was abusive and took action.

Commitment to a relationship, despite its negative features, appears to be particularly prominent for predicting a women's decision to stay in a violent relationship, according to Bell

and Naugle (2005). They studied various factors that influences a woman's decisions to remain in or leave an abusive relationship and their findings are insightful for understanding our results, not because our results are similar, but because they are so different. For women in our sample, the level of commitment they had to their male partners was not an issue and did not come up in the course of the qualitative interviews for this study. Rather, women reported that reasons for staying in their abusive relationships included not knowing what non-support or abuse looked like and therefore not realizing they had a reason to leave the relationship, staying for the sake of the children, or staying because they had no one else to turn to. In many cases women stayed because they had to survive and they did not see another alternative that would work.

Decision-making

Various research teams have investigated how participants maneuvered through the decision-making process after receiving a breast cancer diagnosis (Pieters et al., 2011; Polacek, Ramos, & Ferrer, 2007; Swainston et al., 2012). Furthermore, other researchers focused on women diagnosed with cancer living with abusive or non-supportive partners (Gandhi et al., 2010; Sawin, 2010, 2012; Speakman, Paris, Gioiella, & Hathaway, 2015). However, none of these studies have addressed the combined phenomenon of decision making after a breast cancer diagnosis while also being in a non-supportive partner relationship. Our sample and our study is unique from the others in that we focus on the combined phenomenon. Our participants dealt with partners who were non-supportive or abusive through the cancer trajectory. This further complicated decision-making as they had to rely on inner or outer sources of support to assist with the process.

Support

Social support is multidimensional and often varies from person to person, according to Drageset and colleagues (2012) who used a qualitative descriptive design with a convenience sample of 21 newly diagnosed breast cancer survivors awaiting surgery. Several themes identified in their study are useful in discussing our results. They found that available support included a wide assortment of beneficial resources that include advice, knowledge, counseling from health professionals, understanding, respect, comfort, and having someone to talk personally and intimately with. They noted that women needed to find the balance between being close but not too close to one's social network. Similarly, women in our sample found that different types of support were valuable to them. Furthermore, different resources were valuable to different women at different points that were unique to them and their particular cancer trajectory. There was no singular pattern or general path; each woman's situation was unique. For example, various combinations of inner and outer support helped the women work through the intricate facets of their relationship, their sense of self, and the decision-making process.

To help meet their emotional needs participants relied on others who could listen and care for them. This was particularly helpful as the women found that their partners were either unwilling or incapable of addressing their emotional needs. For instrumental support, which was comprised of tangible goods and services, the women found it very helpful to have others step in and assist them with the daily demands of their lives. Finally, when others provided informational support the women found that they were better prepared to make decisions about each step in the process.

The use of outer support helped participants maneuver the overall process of their diagnosis and treatment. Having input as to who would be on their team of friends and family

and who they could rely on, as in the case of team building, helped build a sense of control for some women. Therefore, some women relied on others to be their eyes and ears and help gain the necessary information throughout their journey. The women then sifted through the information and came to a decision that they felt best met their individual needs. The overarching component of outer support allowed women to rely on others despite having a non-supportive partner. However, the women did not solely rely on others to help get them through.

Inner support was just as important to the women as it allowed them to look within themselves and to use their voices to help formulate a plan for themselves, their treatment, and their lives. By using the internal aspects of support the women of our sample became empowered by gaining the strength and courage to make decisions that they could live with. Ultimately, it was a reliance on God and themselves that allowed our participants to take a stand and advocate for themselves despite their non-supportive relationships.

Participants incorporated aspects of both types of support (inner and outer) at particular points in their journey where and when they felt it would be most advantageous. There was no general pattern to this. Throughout the process, however, various women reexamined and reevaluated how much support they would need, identified their available options, and then formed a plan to implement how the support they had could be best used.

Moving on

The women of this sample confronted many different challenges in the diagnosis and treatment decision-making process but they all told stories of being able to move on after breast cancer. Some of the women initially struggled with making decisions, while others were very clear about what direction they were willing to take. Despite a potentially fatal diagnosis and

unsupportive partner, the women accessed services, developed new found strength, were resourceful, stood up for themselves, persevered and moved on.

Limitations

While this research added to the literature by bringing together the separate phenomena of breast cancer, having a non-supportive partner, and decision-making, the results cannot be generalized. In addition, there were important limitations that should be noted. First, despite a recruitment and data collection period that lasted 24 months, we were only able to attract and recruit a relatively small sample, which limited the nature and extent of our analysis. For this study eight women were willing to participate in the study and met the eligibility criteria. Ideally, in subsequent research a larger sample size would allow for more depth and breadth in data for analysis. Due to the limit to the data we could collect, analysis was limited to a description of the process the participants experienced; we were unable to move to a theoretical level. In addition, while women volunteered to be interviewed, there was some reluctance, hesitation, or uncertainty among some participants to identify their partners as non-supportive or abusive during their cancer journey during interviews. While the women's preferences were honored in terms of what they wanted to share and what they held back, this limited the depth of data collected.

In terms of the challenges we met with recruitment, we explored over 60 potential sites and 5 different recruitment methods to connect with women in this unique population. Potential sites for participants included breast cancer support groups and events, community organizations, churches and domestic violence organizations, alcohol and drug programs, among others (see Table 3). However, despite dispensing over 700 fliers, very few participants were either eligible or inquired about the study. This lack of response led to continual reassessment of recruitment

sites and methods. Research by Dutton and colleagues (2003) focused on recruitment and retention in intimate partner violence research. While they did not specifically address concerns with women diagnosed with breast cancer, they did find that collaboration with community organizations and agencies can be an effective recruitment strategy when seeking to gain participants for studies dealing with partner abuse. However, despite the enthusiasm of staff at such sites, this method was not found to be effective for recruitment for our study. In addition to staff, the community in general was interested in the overall topic of the study; still this method did not yield the desired results to gain a significant number of participants. Nonetheless, several key individuals in the community were contacted and engaged in passing out fliers; the PI conducted workshops and gave presentations in various community sites to make them aware of the study.

The suggestions from women who did participate in this study were taken into consideration for recruitment related to future research. For example, women acknowledged the complexity of talking about breast cancer and partner abuse as a combined phenomenon. When attending various types of support groups in the past, the women noted that each phenomenon always had been addressed as a separate entity so they had no experience talking about the combined phenomenon. Instead, women were directed to separate, respective groups to discuss intricate or personal details. Thus, future recruitment needs to overcome the obstacles due to the assumed separation of experiences.

Implications for Practice

Oncology clinicians can play a vital role in helping women diagnosed with breast cancer address sensitive issues surrounding their relationships and its impact on the treatment decision-making process. Similar to other research, findings from our study support the need for oncology

clinicians to incorporate questions about the presence of abuse and non-support during assessments with women diagnosed with cancer overall (W. A. Johnson & Pieters, 2016). Speakman and colleagues (2015) conducted a study using grounded theory techniques with 21 participants (20 women and 1 man) who reported being abused by a current or former spouse and who were diagnosed with various types of cancer (note: breast cancer was the most common cancer for their sample). The researchers found that it is important to help individuals with cancer identify possible red flags such as elevated anxiety and depression, problems with sleep, or their partner's lack of involvement in the treatment process (Speakman et al., 2015). This way, clinicians can facilitate conversations with patients about their relationships and support systems to help identify risky situations.

Understanding the steps that women take to reach a point in which they are able to move on after a breast cancer diagnosis is vitally important in helping to address their needs. While some women will have support from their partners, others will not and must rely on inner and outer support to help them through. How women use inner and outer support is crucially important in understanding the decision-making processes that women work through to make their journey as beneficial as possible. In addition, providing women with definitions of, or educational support about, abuse and non-support can help improve their lack of understanding regarding potentially harmful situations they may be in and to help them seek out necessary resources.

Implications for Research

Future research should focus on how the presence of a non-supportive or abusive partner among women diagnosed with other types of cancer can impact decision-making. Women diagnosed with breast cancer may face unique challenges that have an impact on their sense of

self, femininity, decision-making and relationships that other types of cancer may not necessarily encompass. By exploring its impact on women with other types of cancers their experiences can potentially address unique aspects otherwise not seen.

While recruitment for this sample proved to be challenging, future research can use other avenues to capture this hard-to-reach population. The use of social media, such as Facebook, chatrooms and websites, may allow the PI to reach a greater number of participants. In addition, the use of social media can possibly incorporate a level of anonymity that will help women feel more comfortable talking about such a sensitive topic.

Exploring the presence of a non-supportive or abusive partner in other populations including same-sex couples, underserved and minority women may address issues that are unique to this population. Additional research should include how the presence of non-support or abuse from a partner directly influences the delay of cancer screening or treatment.

Conclusion

Despite a potentially fatal diagnosis and unsupportive partner, the women in this sample were found to be resourceful, able to stand up for themselves, and persevere. Throughout their journey, the participants were able to make plans, evaluate the need for adjustments, and incorporate certain aspects that helped to support their decisions and move them forward. Though our data does not allow us to make firm conclusions regarding the unique challenges faced by women diagnosed with breast cancer who are also living with a non-supportive or abusive partner, it does lay the foundation for understanding their lived experiences.

Recruiting women for research that addresses sensitive topics can be especially difficult. It is important to provide avenues in which women can feel comfortable talking about sensitive matters that relates to their relationships and their cancer diagnosis. By exploring other avenues

to reach women, this may allow them an otherwise limited opportunity to face and talk about their specific challenges.

Helping clinicians become aware of the need to address such sensitive topics have a twofold effect on assisting women who are dealing with non-supportive partners and breast cancer. First, clinicians can be the avenue to allow conversations to take place regarding difficulties with decision-making. By providing opportunities to talk about challenges women may be facing in their relationships, clinicians can help women recognize the need to search out important resources to help them manage their situations. Second, helping clinicians to be aware of some of the challenges women diagnosed with breast cancer may be facing can be important in helping to educate themselves and their patients in the need to look at the decision-making process in its entirety.

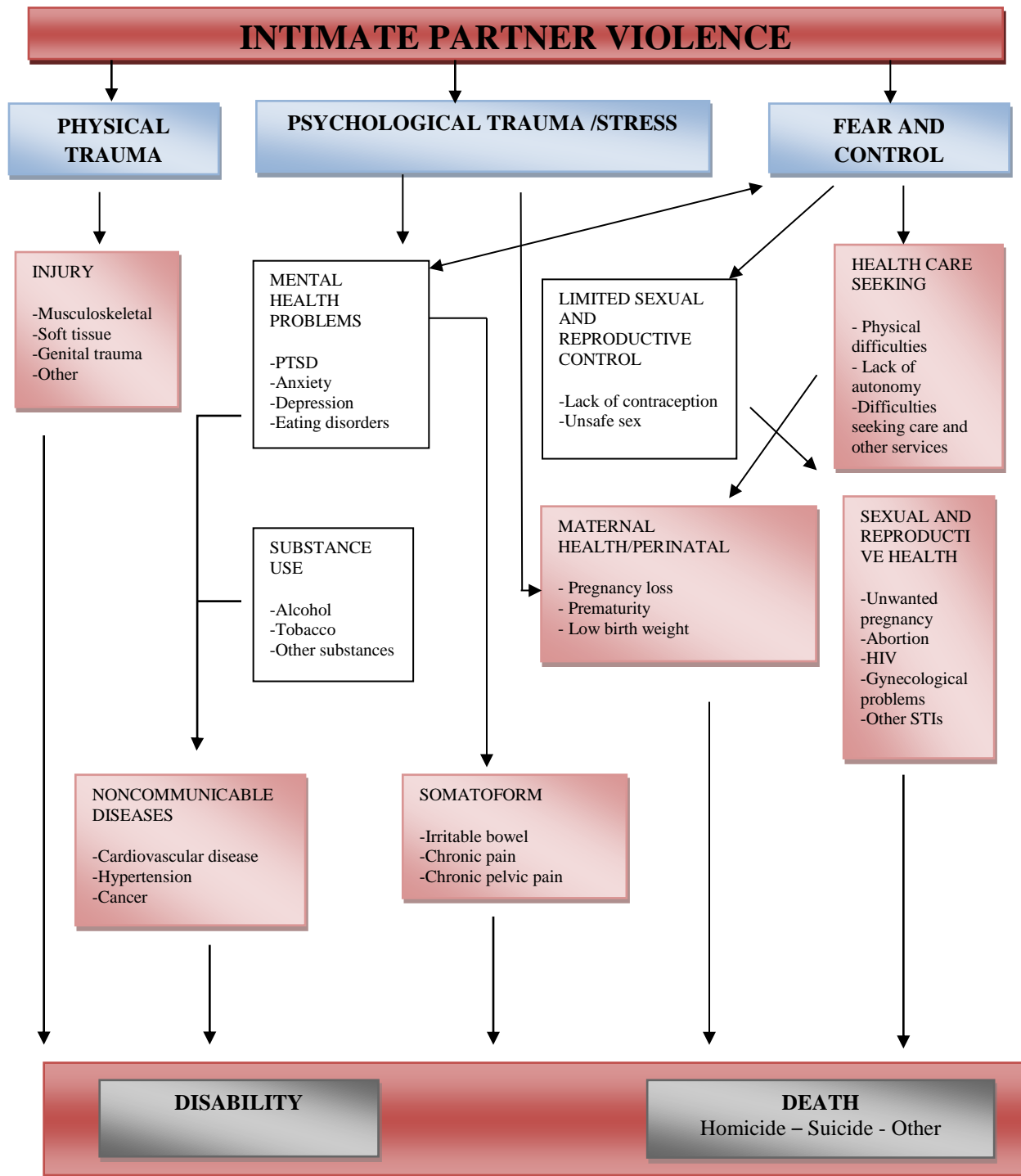
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Figure 1: Pathways and Health Effects on Intimate Partner Violence



There are multiple pathways through which intimate partner violence can lead to adverse health outcomes. This figure highlights three key mechanisms and pathways that can explain these outcomes. Mental health problems and substance use might result directly from any of the three mechanisms, which might, in turn, increase health risks. However, mental health problems and substance use are not necessarily preconditions for subsequent health effects, and will not always lie in the pathway to adverse health (WHO, Department of Reproductive Health and Research, London School of Hygiene and Tropical Medicine, & South African Research Council, 2013).

Table 1: Intimate Partner Violence and Non-Support in the Context of Cancer

Article	Research Design	Cancer Diagnosis	Spouse/partner Behavior	Treatment Received and Impact on Treatment	Implications
<p>Delay in treatment of invasive cervical cancer due to intimate partner violence</p> <p>(Martino et al., 2005)</p>	Case study (N=1)	41-year female, diagnosed with high-grade cervical dysplasia; progressed to stage IIB cervical carcinoma	Partner denied that anything was wrong with the patient; demanded that the patient leave the hospital with him and threatened hospital staff. In his absence, patient admitted to mental, physical and domestic abuse, but failed to report her partner to authorities.	<p>Received external radiation by a female radiation oncologist. The partner refused further treatment for his wife from a male oncologist.</p> <p>Impact: The patient developed advanced cervical cancer; never returned for follow-up treatment. Her current status is unknown.</p>	Treatment for significant illness may be denied appropriate care by an abusive partner. IPV often brings a complex interaction of psychosocial factors that may make it difficult to target IPV as an isolated causal factor.
<p>Identifying signs and symptoms of intimate partner violence in an oncology setting</p> <p>(Mick, 2005)</p>	Case study (N=4)	<p>1) 55-year female, diagnosed with breast cancer arrived in clinic for follow-up appointment after completing her second chemotherapy.</p> <p>2) 22-year female diagnosed with cervical cancer presented for her pre-operative assessment.</p> <p>3) 62-year female, with cervical cancer arrived for her six-month follow-up appointment with noticeable flat affect and statements about experiencing extreme fatigue.</p> <p>4) 43-year female, with breast cancer who was being battered from her same-sex partner.</p>	<p>1) Patient appeared fearful when spoken to by partner. Partner refused to leave examination room for patient to be examined alone and insisted that he remain with her during the examination.</p> <p>2) Several bruises and scratches on the woman's back and abdomen that were in various stages of healing. A similar pattern of bruising was observed on both sides of her neck. Patient denied abuse.</p> <p>3) Patient confided to staff that sometimes her husband's behavior "frightened her" (p. 511) but that he never was physically violent towards her.</p> <p>4) Patient presented with her partner Ms. O (same-sex couple). On previous visits patient requested information about IPV.</p>	<p>1) Completed second chemotherapy treatment. Impact: Unknown</p> <p>2) Unknown Impact: Unknown</p> <p>3) Unknown Impact: Unknown</p> <p>4) Unknown Impact: Unknown</p>	<p>Signs of abuse are not always obvious.</p> <p>Some people who are dealing with violent relationships do not define or interpret their situations as abuse or DV.</p> <p>Injuries caused by physical abuse commonly are found in areas covered by undergarments.</p> <p>Clinicians are encouraged to invite patients to discuss abuse, provide non-judgmental support and information about DV and local DV resources.</p> <p>Gather information about associated health problems to determine a plan of care for immediate and long-term health and safety needs.</p>

<p>Domestic violence against women with cancer: Example and review of the literature</p> <p>(Schmidt et al., 2006)</p>	<p>Case study (N=3)</p>	<p>1) 37-year female, diagnosed with stage III colon cancer</p> <p>2) 52-year female, recently diagnosed with early-stage lung cancer.</p> <p>3) 42-year female, diagnosed with metastatic hepatocellular carcinoma</p>	<p>1) In the initial visit with the psychologist, the patient described her husband as extremely controlling. Subsequent visits revealed an escalation in physical abuse by her husband that resulted in two broken ribs and an attempt to strangle her.</p> <p>2) States that the abuse began as emotional cruelty initially which later converted to physical abuse after the cancer diagnosis. Patient states that the abuse ranged from her husband's demand for total control over her activities to the occasional "punch or two" (p.25). Recently, her husband hit her with his fist in the area of her surgical scar. Abuse continued towards her even after he attended sessions with his wife and a therapist to discuss her mood.</p> <p>3) Patient stated there was a continual pattern of emotional abuse by her husband that was directed at their child. Patient states that the emotional abuse she was subjected to occurred throughout the 15-year marriage and increased as the cancer progressed. Her husband refused to provide food or water to her when she was physically unable to do so for herself. Once when in severe pain, her husband refused to call her an ambulance. Husband stated that the wife "wasn't dying fast enough" (p. 25)</p>	<p>1) Surgery and chemotherapy Impact: Unknown</p> <p>2) Tumor resection followed by chemotherapy Impact: Unknown</p> <p>3) Chemotherapy Impact: Unknown</p>	<p>Domestic violence is common among the general population of medical patients and also may be common among cancer patients.</p> <p>Some patients with cancer may develop increased dependency on others during their treatment and care thereby putting them at a greater risk for various types of abuse by their intimate partners.</p>
<p>"The body gives way, things happen": Older women describe breast cancer with a non-supportive partner</p> <p>(Sawin, 2012)</p>	<p>Qualitative research: Hermeneutic phenomenology</p>	<p>N=16 Age at time of interview: 50-84 years (avg. = 68.1) Age at time of diagnosis of breast cancer: 50-75 years (avg.= 60.7) Length of relationship: <1-60 years (avg.= 35.6) Time between interview and diagnosis: 1-31 years (avg.= 7.4) Breast cancer stage I-IV</p>	<p>One woman described that her boyfriend became emotionally and sexually unresponsive towards her following her lumpectomy.</p> <p>Another participant stated that "woman 65 and up are not likely to leave a non-supportive spouse, whereas the slightly younger women might say, 'I don't have that much time left.'" (p.3).</p> <p>One woman felt that her cancer diagnosis made her</p>	<p>Unknown</p> <p>Impact: Most women made treatment choices independent from their non-supportive partners. Age and age-related issues affected the way participants decided on treatment more than on their</p>	<p>Four themes emerged: At my age (participants reflect on aging and breast cancer); breast cancer itself, sexuality and aging, and silence</p> <p>Marriage is not necessarily supportive of the unique age-related needs of older women. Many women described</p>

			partner “angry, like it was an inconvenient annoyance” (p.4). She then deliberately eliminated him from her treatment decisions.	partner’s opinions.	functional relationships, despite the many challenges of poor health and aging in both themselves and their spouses.
<p>“If looks would kill then I would be dead”: Intimate partner abuse and breast cancer in older women</p> <p>(Sawin & Parker, 2011)</p>	Qualitative research: Hermeneutic phenomenology	<p>N=11</p> <p>Age at time of interview 51-84 years (avg. = 64.8)</p> <p>Age at time of diagnosis of breast cancer 50-65 (avg.= 56)</p> <p>Length of relationship (years) <1 to 52 (avg.= 27)</p> <p>Time between interview and dx 1 to 31yrs (avg.= 8.8, median =4)</p> <p>Breast cancer stages I-IV (3= unknown)</p>	<p>Participants described control in the context of their partner’s tightening control over them after the BC diagnosis. Many relationships already contained elements that the women described as controlling, but the BC diagnosis increased that control. Areas of control included: money: “He wanted to control the finances” (p.30) and insurance coverage: one woman explained how her husband told her that he might lose his job, “I felt like he was telling me that I couldn’t have my surgery” (p.30). One woman described her husband’s behavior as “trying to hold me as a captive” (p.30). Regarding her contact with family and friends, one woman said “over the years he has done a lot of things to isolate me” (p.31).</p>	<p>Unknown</p> <p>Impact:</p> <p>One husband believed he was a healer and tried his personal herbal treatments and did not want his wife to receive chemotherapy. He always went to her physician appointments and tried to prove them wrong. She described his behaviors as trying to hold her captive.</p> <p>Another woman said that her husband “did not want his money going to the doctors”.</p>	<p>Four themes emerged: Cancer and control; negative relationship changes; changes in intimacy; and moving on.</p> <p>The older women described that they were less likely to leave their abusive partner and/or experience physical abuse than the younger women in the study. For these women, they experienced that their advanced age and lack of job skills made them less employable. Difficulty coping with an angry partner was intensified by physical tiredness and weakness which can be exacerbated by increased age and cancer treatment.</p>
<p>“My husband would not help me, so I was driving over there”: Older rural women experiencing breast cancer with a non-supportive intimate partner</p> <p>(Sawin, 2010)</p>	Qualitative: Hermeneutic phenomenology	<p>N = 9</p> <p>Age at time of interview 55 to 84 years (avg.= 69);</p> <p>Age at time of diagnosis of breast cancer 53 to 71 years (avg. = 59.2).</p> <p>Length of relationship 1-55 years (avg. 28.5).</p> <p>Time between interview and diagnosis 1 to 31 years (avg. =9.8).</p> <p>Breast cancer stage I-III</p>	<p>Refusal of some husbands to drive their wives to their treatments. One woman believed that the abuse from her husband caused her to delay her mammogram. Another woman tried to avoid any conflict with her husband because she needed him for several things. Because “he was the one taking me to (urban medical center) all the time” (p.6). Lack of privacy was an issue for one woman who was living with her abusive husband. She described the difficulty in obtaining DV-related prosecution against her husband “because he had a lot of relatives down there” (p.6). One woman described how the relationship with her</p>	<p>Unknown</p> <p>Impact:</p> <p>Presence of non-supportive partners created increased difficulty for some women to get to treatment. In one case a partner was no longer available to be a woman’s driver after she ended their relationship when she found out that he was having an affair while she was in treatment. Another woman’s husband simply refused to drive</p>	<p>Themes emerged: Driving, gossip, rural location as therapeutic, and community support.</p> <p>Rural women operating without complete support of their intimate partner while dealing with BC, present for treatment with unique needs. A complete assessment of their social network, their community resources and intimate partner support is necessary for effective treatment to occur.</p>

			<p>husband created difficulty during treatment because she lost her husband as her driver.</p> <p>One woman felt that the abusive relationship caused her to delay her screening mammogram.</p>	his wife to her treatments.	
<p>Breast cancer in the context of intimate partner violence: A qualitative study</p> <p>(Sawin et al., 2009)</p>	<p>Qualitative: Hermeneutic phenomenology</p>	<p>N=7</p> <p>Age at time of interview 37 to 63 (avg.= 50)</p> <p>Age at time of diagnosis of breast cancer 36 to 58 (avg.= 46)</p> <p>Length of relationship 2 to 29 years (avg.= 12)</p> <p>Breast cancer stage I-III</p>	<p>One woman described “abuse by neglect” abuse by “acts of omission rather than commission” (p.688).</p> <p>Another was emotionally abused when her partner hid things and lied to her repeatedly. Another woman reported that her partner repeatedly knocked into her breast following her breast biopsy. Another partner became physically abusive towards the participant after they separated, pushing her down the stairs and kicking her. Another woman was verbally and sexually abused after her discharge from the hospital. One woman’s husband left her when he found out that she would have a mastectomy. Another woman’s husband left her because the cancer was in her breast. He said that he was a “breast man and felt like he couldn’t fully do his job as a man with one breast” (p. 690).</p>	<p>Unknown</p> <p>Impact: One woman stated that her partner abandoned her when she began chemotherapy.</p>	<p>Themes: reassessing life, believing that stress from the relationships caused the cancer, valuing support from others, and the significance of the breast.</p> <p>Women diagnosed with BC may also be experiencing IPV. IPV can take on many forms. Oncology professionals should be aware of the ways that IPV might affect a woman’s experience with BC and vice versa.</p>

Figure 2: Author's Depiction of Blumer's Three Key Premises of SI

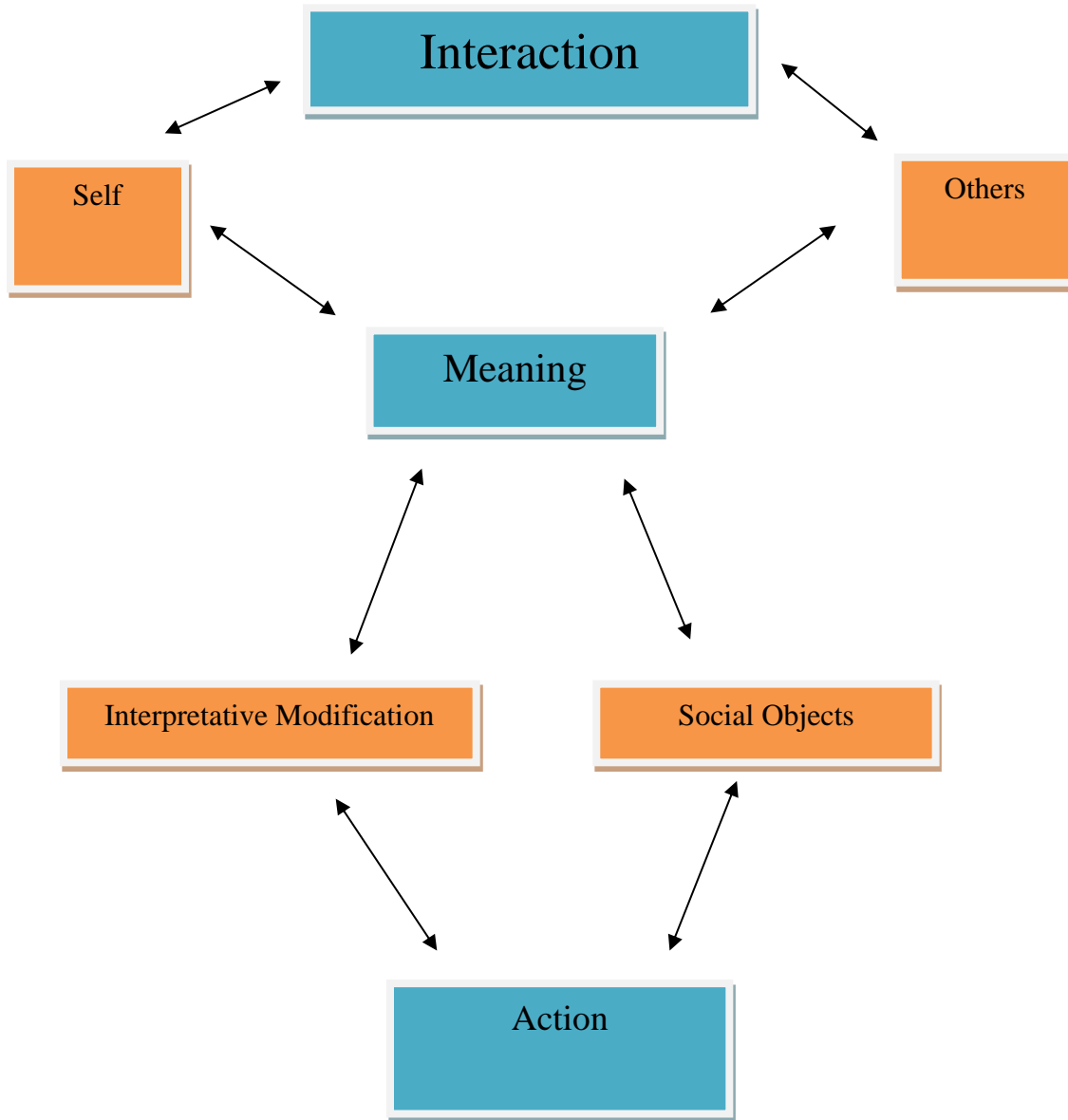
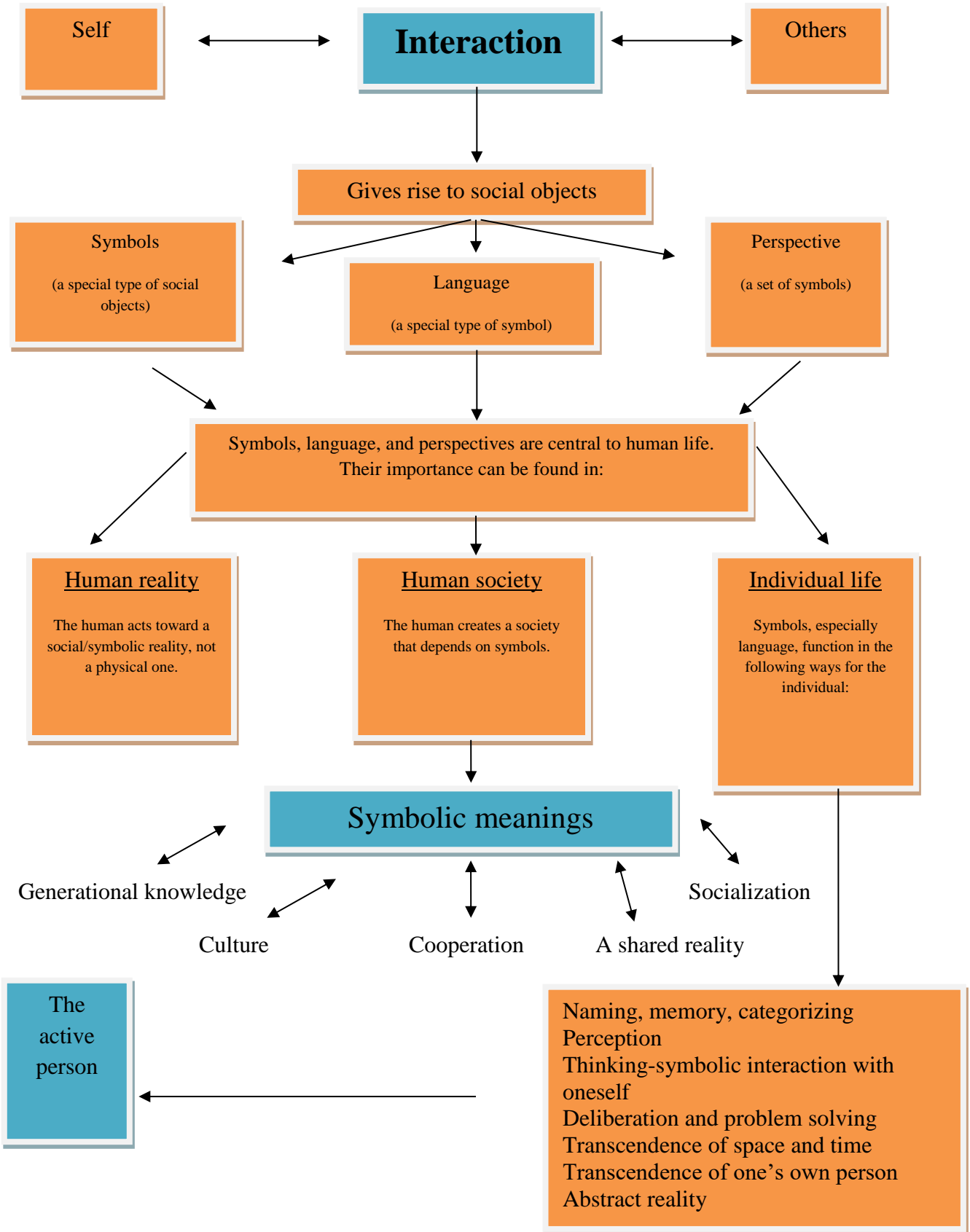


Figure 3: Symbolic Interactionism (Adapted from Charon, 2010 p.68)



Appendix A: Recruitment Flyer



ARE YOU A WOMAN WHO FELT YOU DID NOT HAVE THE SUPPORT OF YOUR SPOUSE OR PARTNER WHEN YOU MADE DECISIONS ABOUT YOUR BREAST CANCER TREATMENT?

YOU MAY BE ELIGIBLE TO PARTICIPATE IN THIS STUDY.



I am an oncology nurse and a doctoral candidate at the UCLA School of Nursing. The purpose of my research is to understand how women diagnosed with breast made decisions about their treatment when they did not feel they had the support of their spouse or partner.

I would like to personally interview you, either in person, or over the telephone or Skype. We can set up a time and place that is convenient to you.

YOU WILL RECEIVE \$50.00 FOR YOUR PARTICIPATION IN THIS STUDY

Wendy Johnson, RN, MSN, CNS, OCN, PhDc
Wajohnson@ucla.edu
(310) 293-6249

Appendix B: Introduction to Study Script

Thank you for your interest in this research. As you may have noticed from the flyer, this study is concerned with examining the experiences of women diagnosed with breast cancer who may not have had the support of their spouse or partner at the time of their diagnosis. Some women have experienced levels of nonsupport from their spouse or partner that they may identify as abusive. As well, some women have remained in their relationships with their spouse or partner and may be currently experiencing some degree of abuse. To ensure the safety of women who are interested in participating in this study I will begin by asking if this is a safe time for you to talk.

Appendix C: Script for Leaving a Message for Contact with Potential Participant

If a potential participant calls inquiring about the study and the researcher did not pick up at that time, a script will be used for calling the participant back and leaving a message. To minimize the risk of an abusive spouse/partner from becoming aware of the sensitive nature of the study, the study will be referred to as the Women's Health program. The details of calling the research such will be included in the message on the researchers' phone.

Hello (name),

This is Wendy calling from the Women's Health program. I am calling to ask you a few questions about your breast cancer treatment. This call will take just a few minutes of your time. Please call me back at your earliest convenience at the following number (310) 293-6249. If I am away from the phone, please leave a message and I will gladly call you back. When calling back I will refer to the call as from the Women's Health program to deter others from becoming aware of the sensitive nature of the study. Be sure to also let me know of a safe date and time to return you telephone call. Thank you.

Appendix D: Screening Script and Algorithm for Determination of Eligibility

Thank you for calling and being interested to participate in this study. May I begin by asking you a few general questions about yourself and the breast cancer?

1. What is your age? _____

Thank you, now I am going to ask you about the breast cancer.

Screening for Early Stage Breast Cancer

2. Do you know what stage of breast cancer you were diagnosed with?

[If the woman is uncertain about the stage of the BC, ask any or all of questions a to c]:

3. Have you ever had cancer before?
 - a. Yes _____ b. No _____
 - b. What type of treatment did you receive for that cancer?

4. Did the cancer appear in any other places in addition to the breast?
 - c. Yes _____ b. No _____
5. Did your doctor say that your cancer has “metastasized?”
 - d. Yes _____ b. No _____
6. When did you complete your treatment? _____

If the woman was diagnosed with advanced breast cancer or if answers to the previous questions indicate advanced disease, the woman will not be eligible for the study. The script for non-eligibility will then follow per Appendix K: Script when the woman is ineligible to participate in the study.

Screening for IPV:

The following questions are about your relationship with your spouse or partner at the time of your diagnosis.

- 7. Were you in a heterosexual relationship with your spouse or partner at the time of diagnosis?
a. Yes _____ b. No _____
- 8. After seeing the flyer about the research, please tell me what made you feel alone or non-supported and caused you distress when you were diagnosed with BC.

[Following the algorithm in Appendix G (Algorithm for Presence of Abuse Eligibility) screening will proceed as follows to continue to determine eligibility.]

For some women who call me, the relationship with their spouse or partner was especially challenging. The next few questions will focus on specific types of behaviors that you may have experienced in your relationship at the time of diagnosis. Please be advised that some of these questions may be difficult to answer but it is necessary for me to ask them to determine if you are eligible to participate in the research. Is it okay for me to ask these questions? Please remember that these questions relate to the time before your diagnosis with breast cancer.

[Ask questions from the WAST (see Appendix H) and/or the WEB (see Appendix I). If needed, the researcher will provide clarification of “physical or sexual harm”. Examples will include hitting, kicking, pushing, slapping, and being forced to preform sexual acts or participate in sex

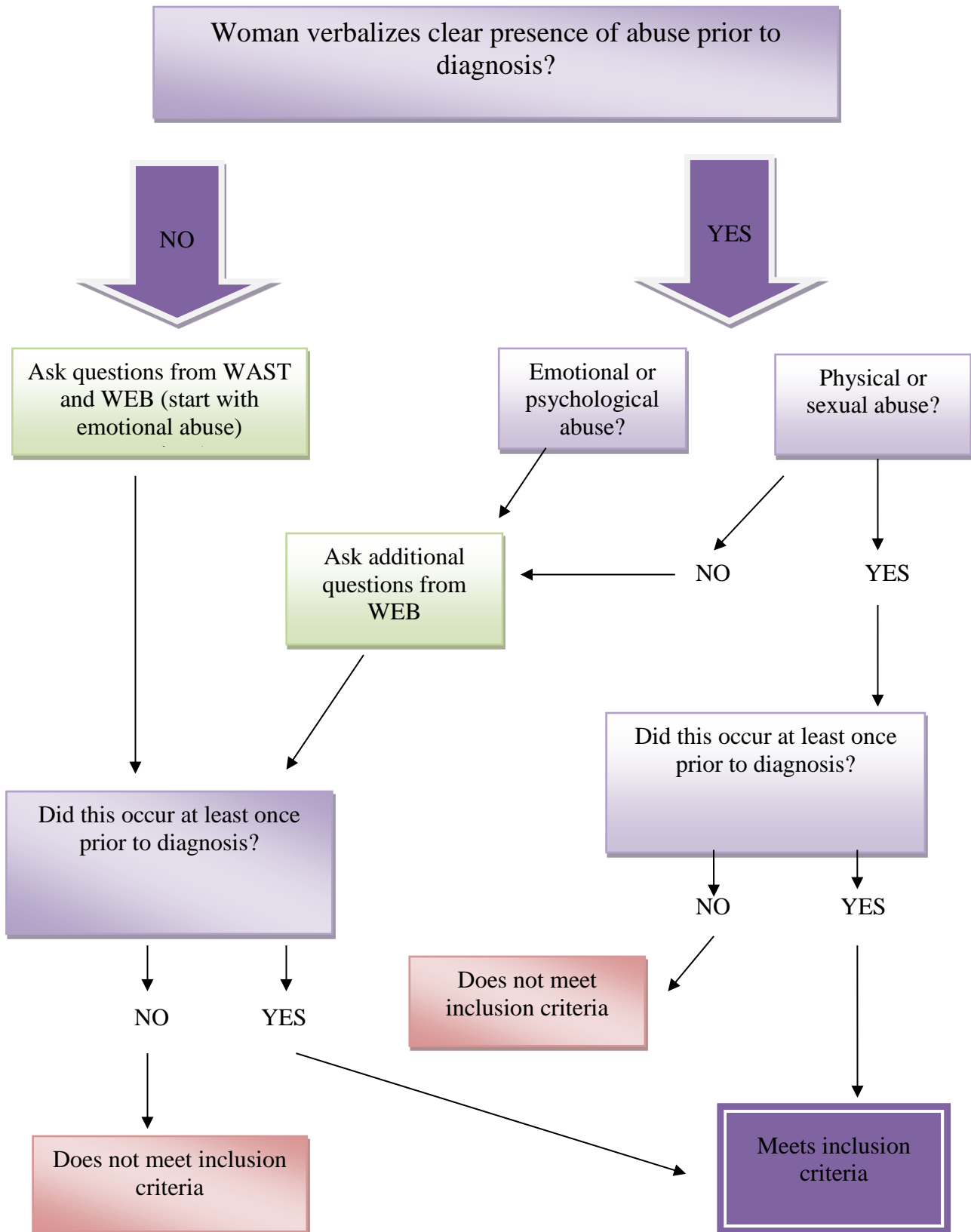
against her will]. Also, clarification of “emotional or psychological harm” will be provided if needed including: feeling frightened by what your partner does or says, preventing you from remaining in contact with family members, monitoring your daily activities closely.

Eligible Yes _____ No _____

[If the woman is eligible to participate in the study, a date will be set up for an interview following the Script for Acceptance to participate in the Study (see Appendix J).

[If woman is not eligible to participant in the study the script for non-eligibility will follow.] (See Appendix K: Script when the woman is ineligible to participate in the study.)

Figure 4: Algorithm for Presence of Abuse Eligibility



Appendix E: Women Abuse Screening Tool (WAST)

Today's Date _____ Participant no (to be assigned) _____

1. In general, how would you describe your relationship with your partner or spouse?
 - A lot of tension (1)
 - Some tension (1)
 - No tension (0)
2. Do you and your partner or spouse work out arguments with:
 - Great difficulty (1)
 - Some difficulty (1)
 - No difficulty (0)
3. Do arguments with your partner or spouse result in you feeling down or bad about yourself?
 - Often (1)
 - Sometimes (2)
 - Never (3)
4. Do arguments with your partner or spouse ever result in hitting, kicking or pushing?
 - Often (1)
 - Sometimes (2)
 - Never (3)
5. Do you ever feel frightened by what your partner does or says?
 - Often (1)
 - Sometimes (2)
 - Never (3)
6. Has your partner or spouse ever harmed or scared you physically?
 - Often (1)
 - Sometimes (2)
 - Never (3)
7. Has your partner or spouse ever harmed or scared you emotionally?
 - Often (1)
 - Sometimes (2)

- Never (3)
- 8. Has your partner or spouse ever harmed or scared you sexually?
 - Often (1)
 - Sometimes (2)
 - Never (3)

Score _____

Eligible Yes _____ No _____

Scoring procedures: A positive WAST – Short screen is present if questions 1 and 2 are answered as “a lot of tension” and “great difficulty.” A positive WAST – Short should be followed by the completion of questions 3 through 8 for the entire WAST. There is no fixed positive scoring assigned and interpretation is based on clinical judgment.

(J. B. Brown et al., 1996; J. B. Brown et al., 2000; Fogarty & Brown, 2002).

Appendix F: Women Experiencing Battering (WEB) Scale

1. He makes me feel unsafe even in my own home

- Often
- Sometimes
- Never

2. I feel ashamed of the things he does to me.

- Often
- Sometimes
- Never

3. I try not to rock the boat because I am afraid of what he might do.

- Often
- Sometimes
- Never

4. I feel like I am programmed to react in a certain way to him.

- Often
- Sometimes
- Never

5. I feel like he keeps me prisoner.

- Often
- Sometimes
- Never

6. He makes me feel like I have no control over my life, no power, no protection

- Often
- Sometimes
- Never

7. I hide the truth from others because I'm afraid not to.

- Often
- Sometimes
- Never

7. I feel owned and controlled by him.

- Often
- Sometimes
- Never

8. He can scare me without laying a hand on me.

- Often
- Sometimes
- Never

9. He has a look that goes straight through me and terrifies me.

- Often
- Sometimes
- Never

Eligible Yes _____ No _____

(P. H. Smith, Smith, & Earp, 1999; P.H. Smith, Tessaro, & Earp, 1995; P.H. Smith et al., 2002).

Appendix G: Script for Acceptance into the Study

Once again, thank you for calling about this study. You have met the eligibility requirements for this study.

As you may have gathered from the types of questions that I asked, this study will examine aspects of intimate partner violence or sometimes referred to as domestic violence. With which one of these terms are you more familiar with? I am looking at how women who were living with intimate partner violence (or domestic violence) at the time of their cancer diagnosis, made decisions about their treatments. While some women may feel comfortable with discussing aspects of intimate partner violence (or domestic violence) with others, there are other women who may feel challenged to share their story about such a sensitive topic. Therefore, I would like to let you know before we proceed that your level of comfort and safety is of utmost importance in to me. I am an oncology nurse and I have volunteered at a domestic violence organization in the past so I am very much aware of the potential challenges that this topic may produce.

I would like to schedule a time to meet with you to discuss your experiences with intimate partner violence (or domestic violence) and breast cancer and how it may or may not have influenced your treatment decisions. Sometimes research takes place in a woman's home, but for this study, your home setting will not be an option. We can arrange to meet at a public place that is both convenient and safe for our interview to take place. In addition, it is important because of the sensitive nature of the interview that you can meet with me without the presence of another person. The interview is up to you, but is likely to take between 60 to 90 minutes. I will give you a \$50 cash honorarium for your time at the end of our interview.

Now, that I have given you all the information, do you have any questions for me? If this study sounds like something you would be interested to join and if you can meet at a public place where we can talk privately, I would be happy to set up a time and place to interview you at your

earliest convenience. If you agree, would you like for me to call you to confirm the meeting 24 hours ahead of time? If, so what number can I call and leave a safe message regarding our meeting?

Appendix H: Script for Ineligibility to Participate in the Study

I would like to thank you again for your interest to participate in this study. I certainly appreciate you taking the time to speak with me today.

However, you have not met the eligibility requirements to be included in this research, once again, thank you for your time.

Appendix I: Sociodemographic and Clinical Data Sheet

Today's Date _____

Participant no. _____

1. What is your age? _____
2. How would you describe your race or ethnicity?
 - Black or African American
 - Non-Hispanic White
 - Asian American/Pacific Islander
 - Hispanic
 - Native American
 - Bi/multi-racial
 - Other_____
3. What is your highest level of education?
 - Some high school
 - High school graduate/GED
 - Some college
 - College graduate
 - Beyond undergraduate
 - Some graduate school
 - Graduate from graduate school
4. What is your current employment status?
 - Employed outside the home
 - Unemployed
 - Disabled/unemployed
 - Unpaid work in home
5. What is your occupation? _____
6. What is your annual household income?
 - Less than \$ 20,000
 - \$21,000 - \$40,000
 - \$41,000 - \$60,000
 - \$61,000 - \$80,000
 - \$81,000 - \$100,000
 - More than \$101,000
7. Did you have a spouse or a partner at the time of your breast cancer diagnosis?
 - Yes
 - No
8. What is your current marital status?
 - Single
 - Married

- Divorced
- Separated
- Living with partner
- Widowed

9. Are you currently living with this spouse or partner?

- Yes
- No

10. How many children do you have? _____

11. If you have children, how often do you see your children?

- Daily
- Several times a week
- Once a week
- Monthly
- Several times a month
- Less often
- Not at all

12. How often do you talk with your friends?

- Daily
- Several times a week
- Monthly
- Several times a month
- Less often
- Not at all

13. When were you diagnosed with breast cancer? _____

14. What stage was the cancer?

- Stage 1
- Stage 2
- Stage 3
- Stage 4
- Don't know

15. Have you ever been diagnosed with any other type of cancer?

- Yes
- No
- If yes, what type? _____

16. What treatments did you receive for the breast cancer?

- Chemotherapy
- Surgery

- i. Lateral Mastectomy
 - ii. Bilateral Mastectomy
 - iii. Lumpectomy
 - iv. Reconstruction
 - Radiation
 - Hormone therapy
 - Combination type?
-

17. Were there lymph nodes removed?

- Yes
- No

18. If “yes”, how many lymph nodes were removed?

19. If lymph nodes were removed, were they?

- Positive
- Negative
- Not sure

20. Where did you receive your treatment?

- Community hospital
 - Clinic
 - Private oncologist
 - County hospital
 - Cedars-Sinai Medical Center
 - Ronald Regan Medical Center
 - UCLA
 - Charles Drew Medical Center
 - Other
-

21. Who is providing your follow-up breast cancer care now?

- Oncologist
 - Health clinic
 - Primary care provider
 - Nurse practitioner
 - Physician’s assistant
 - No one
 - Other
-

22. What type(s) of health insurance do you have?

Appendix J: Interview Guide

Develop a relationship of reciprocity.

I would like to begin by saying that there is no right or wrong answer to the questions I will ask. I am interested in your story from the inside and what you have to say. So please know that I am not here to judge you.

If at any time you do not wish to discuss a question you can say so and I will move on.

[Ask if the participant has any questions.]

I will now turn on these two recorders and then we will begin our interview. [Begin the interview.]

Breast cancer

Can you tell me about your experience with breast cancer?

Prompt: How did you first learn that you had breast cancer diagnosis?

Prompt: What were you told about your breast cancer diagnosis?

Prompt: Who informed you of your diagnosis?

Breast cancer and culture

You identified your cultural heritage as _____ (culture). Can you tell me how breast cancer is seen in your _____ (particular) culture?

Prompt: What are some aspects of your culture you believe influence how you view breast cancer?

Prompt: Describe to me how you believe culture plays a role in how you see breast cancer.

Breast cancer and health

Can you tell me about your health prior to your breast cancer diagnosis?

Prompt: How was your health prior to your diagnosis?

Prompt: What were some of your health concerns prior to your diagnosis?

Feelings and concerns breast cancer

In your experience, what were your feelings after hearing of your diagnosis?

Prompt: What were your immediate thoughts regarding your diagnosis?

Prompt: What did you do to help you address your immediate concerns regarding the diagnosis?

Meaning of breast cancer

Can you describe to me what having a diagnosis of breast cancer means to you?

Prompt: What does having a diagnosis of breast cancer mean in your life?

Prompt: What do you base your meaning of breast cancer on? (Prior personal experience, others?)

Support

Can you tell me about your support system?

Prompt: Please describe the individuals in your life that you share your concerns with.

Prompt: Who are the individuals that you have most contact with you on a regular basis?

Prompt: Tell me about a time when you had to deal with a major problem about the cancer and you spoke with someone who you could trust.

Can you tell me about your relationship with your children?

Prompt: Describe the type of relationship that you have with your children.

Prompt: How did you share the information about your breast cancer diagnosis with your children?

How much support did you receive from your children after your diagnosis?

Prompt: Please give me an everyday example of something that your children did or said that showed you that there was support for you.

Prompt: Now can you give me an example of something that a child of yours did or said that was not supportive or helpful or could have been more supportive?

Prompt: How did you solve a problem like that?

Sharing about the breast cancer diagnosis

Can you tell me which individuals did you chose to tell about your diagnosis?

Prompt: Why did you choose to tell these specific individuals about your diagnosis?

Prompt: Did you have immediate concerns about telling others about your diagnosis? Can you give me an example?

What type of support did you receive from these individuals?

Prompt: What about the support that you received from others help you?

Prompt: In your experience, is there anything that could have been more helpful?

Relationship with spouse or partner at the time of your diagnosis

We will now be discussing your relationship with your spouse or partner at the time of your diagnosis.

Can you tell me about your relationship with your spouse/partner at the time of diagnosis?

Prompt: How did you and your spouse/partner meet?

Prompt: How long have you and your spouse/partner were/been together?

Prompt: Describe to me the type of relationship you have/had with your spouse/partner.

Now that you think back, what concerns or worries do/did you have regarding your relationship with your spouse/partner at the time of your diagnosis?

Prompt: Can you give me an example of anything about the relationship with your spouse/partner that caused you to be afraid?

Can you tell about communicating with your spouse/partner at the time of diagnosis?

Prompt: How comfortable are/were you with interacting with your spouse/partner?

Prompt: How do/did you and your spouse/partner communicate about matters that concerned you?

Prompt: Can you give me an example of something that was said or happened?

Relationship with spouse/partner and the breast cancer diagnosis

Can you tell me how did/do you tell your spouse/partner about the diagnosis?

Prompt: How did/do your spouse/partner react to the news of your diagnosis?

Prompt: What did his response mean to you?

Can you tell me about your relationship and your diagnosis?

Prompt: How was your relationship with your spouse/partner before your diagnosis?

Prompt: How was your relationship with your spouse/partner after your diagnosis?

Prompt: How did your breast cancer diagnosis impact your relationship with your spouse/partner?

Can you tell me how has your spouse/partner responded to you since your diagnosis?

Prompt: How would you describe the support you received from your spouse/partner after your diagnosis and during treatment?

Prompt: How did your spouse/partner interact with you when you were not feeling well?

Prompt: How did your spouse/partner react to the presence of any physical complications or changes you experienced during treatment?

In the time since your diagnosis, what is the most helpful thing that your spouse/partner has said or done to help you with your diagnosis?

Prompt: What about what he said or did was helpful for you?

Abuse or Non-support from partner

Sometimes people who are close to us may say or do things that make us feel bad. They may have had the best intentions, or maybe they just weren't thinking at the time.

In the time since your diagnosis, what has your spouse/partner said or done that you experienced as most annoying?

Prompt: What has your spouse/partner done that upset you, made you angry, or just somehow rubbed you the wrong way?

Prompt: How does your spouse/partner react towards you when he is angry or upset?

What have your spouse/partner said to you about your body after your diagnosis?

Prompt: How does your spouse/partner interact with you intimately since the time of your diagnosis?

Prompt: How does your spouse/partner make you feel about your body since your diagnosis?

What have you wished that your spouse/partner had done or said to help you with your breast cancer that he didn't do?

Prompt: What are some of the things that your spouse/partner said or did for you that you wish were different after your breast cancer diagnosis?

Treatment decision making

Can you tell about your decisions regarding your treatment for breast cancer?

Prompt: What treatment options were offered to you?

Prompt: Who told you about your treatment options?

Can you tell about how you made your decision about treatment?

Prompt: Some people weigh up pros and cons when they decided about treatments for breast cancer? How did that work for you?

Prompt: When did you make your particular decision for treatment?

Prompt: Describe how you came to make the particular decision for your treatment that you did.

Prompt: What influenced you to make the particular treatment decision that you made?

What sources did you use to obtain the information you needed that helped you make your decision about treatment?

Prompt: Please describe how you received information that helped you make your decision about treatment.

How confident are you in your ability to get a doctor or nurse to pay attention to what you have to say?

Prompt: Give me an example to illustrate how you would get a doctor or nurse to answer all your questions.

Tell me about your confidence to understand what a doctor or nurse says?

Prompt: Give me an everyday example where you did not understand something that was said and you asked for more explanation (or did not ask for an explanation.)

Describe how you felt regarding the treatment options offered to you.

Prompt: What was it like for you to decide about the treatments?

How much control did you want to have in making decisions regarding your treatment?

Prompt: Describe to me who you wanted to be primarily responsible for making decisions about your treatment.

Prompt: How much control did you feel that you had in making decisions about your treatment?

Prompt: Can you give me an everyday example about control when decisions were made about the breast cancer?

What role did/do your spouse/partner play in your treatment decision-making?

Prompt: How much influence did your spouse/partner have in your decisions about treatment?

Prompt: How much influence did you want your spouse/partner to have in your decisions about treatment?

Prompt: Describe to me how your spouse/partner contributed to your decisions regarding your treatment options.

Current situation

How do you feel since receiving your diagnosis and treatment?

Prompt: Have your thoughts about your life changed since your diagnosis?

Prompt: Has your diagnosis impacted your outlook on life? How so?

Do you have any regrets about the way you selected treatments?

Prompt: To what extent did you make the right decision for your unique circumstances? What about the choice was wise for you?

Prompt: To what extent would you now make different decisions? Tell me how you understand it now.

Can you tell me how you view yourself now?

Prompt: What type of person did you see yourself as when you received your diagnosis?

Prompt: Has your diagnosis impacted the way you see yourself now?

Can you tell me what your future goals in life are?

Prompt: Please describe what you would like your life to be like in the next year. Next five years?

Prompt: Describe for me any changes you would have like to have made at the time of diagnosis.

Prompt: Describe for me any changes you would like to make in your life now.

Conclusion

If you were to meet a woman just diagnosed with breast cancer and living in an abusive or non-supportive relationship what advice would you give her?

Prompt: What are some things you would like to share with other women who have experienced similar situations as yourself?

Prompt: How do you think others can help individuals who have experienced similar situations as yourself?

Were there any questions that I did not ask that you wanted me to ask or that you expected I would ask?

Prompt: Did I address those areas in your life that you felt were most significant regarding your breast cancer diagnosis, your relationship and deciding about treatment?

Prompt: Is there anything else that you would like to make sure that I address in this interview?

When we started, I explained to you that I looked forward to hearing about your experience. I am concerned about your feelings and the impact of telling your story may have on you.

I would like to know if any of the questions I asked you today leave you with an unpleasant feeling or has harmed you in anyway?

[If not] I will now turn the recorder off.

Appendix K: Suicide Protocol

If the woman makes statements about committing suicide, guidelines will be followed to identify and decrease the risk for suicide (Albright & Valente, 2006).

Guidelines that the interviewer will adhere to:

- Be aware. Learn the warning signs.
- Ask the woman if she is thinking about suicide.
- Be direct. Talk openly and freely about suicide.
- Be willing to listen and allow for expression of feelings. Accept the feelings.
- Express concern about woman's statement regarding suicide.
- Offer empathy.
- Take suicidal thoughts and feelings seriously.
- Be non-judgmental.
- The suicidal person will not be left alone.
- If possible, remove the means for suicide.
- Never agree to keep serious suicidal thoughts in confidence.
- Offer hope that alternatives are available.
- Get help from individuals or agencies specializing in crisis intervention and suicide prevention.

Lethality Assessment

The interviewer will ask all of these questions reflecting empathy throughout:

- Are you thinking of killing yourself?
 - "I'm really concerned for your safety. Are you thinking of killing yourself?"
- Do you have a plan?

- “You’ve told me you are thinking of killing yourself. You must be in a lot of pain. Have you thought of how you would do this?”
- “You’ve told me you will (method) _____ to kill yourself. Have you decided when you would kill yourself?”
- Have you done anything to hurt yourself already?
- Have you thought of suicide in the past 2 months?
- Have you ever attempted to kill yourself?
 - “When was the last time you attempted to kill yourself?”
 - “What about the first time?”
 - “And how many times between these two?”
- Do you have access to a firearm?
 - “You have told me you are going to (method) _____ to kill yourself. For your own safety, I need to ask; do you have access to a firearm?”

The important subject of suicide prevention will be included in the informed consent. If the woman is found to be suicidal, the interview will be terminated immediately. At that time the woman will be referred to emergency services at a local hospital and/or will be connected to a crisis intervention or suicide prevention hotline professional. The researcher will remain with the participant until assistance has arrived or the person is transported to the hospital. The chair of the committee will then be informed of the incident as soon as possible and no later than 24 hours. The IRB will also be notified of the incident as soon as possible.

Appendix L: Suicide Resources

The interview will provide resources for individual who are having suicide ideations

- 911 Emergency Services
- Suicide Prevention Hotline 1-877-727-4747 (Toll free: LA and Orange)
- National Suicide Prevention Lifeline 1-800-273-TALK (8255)

Appendix M: Resources for participants regarding IPV

I would like to thank you once again for taking the time to share your experiences with me. Your input has provided me with the opportunity to examine how women such as yourself deal with a breast cancer diagnosis.

I know that it may be difficult sometimes to talk about some of your experiences and I am concerned with your overall well-being after our conversation. If you would like to speak with someone who is an expert in the field of intimate partner violence, I can provide you with the names and phone numbers of local resources. This information is optional and you can decline if you wish. Would you like to have such a list?

All of the following resources are available 24 hours/7 days a week.

National Domestic Violence Hotline	1(800) 799- Safe (7233)
Peace over Violence	(213) 626-3393 Central LA (310) 392-8381 Southwest LA (626) 793-3385 West San Gabriel Valley
Sojourn/Ocean Park Community Center	(310) 264-6644
Jenesse Center	1 (800) 479-7328
LA County Referral Line	211

Table 2: Recruitment Sites

Type of Site	Number	Number of Fliers	Emails	Telephone Calls	Talk about Study	Workshops	Presentations
Alcohol and Drug Programs <ul style="list-style-type: none"> Alcohol Program Education Program Residential Treatment Program 	1 1 1	10 10 20	X				
Breast Cancer <ul style="list-style-type: none"> BC Symposium Mammogram Screening BC Support Group BC Walk BC Boutique 	2 4 4 1 1	30 61 40 15 10	X X X	X			
Cancer – General <ul style="list-style-type: none"> Hematology Oncology Office Cancer Support Group 	1 1	15 10	X		X		
Clinics <ul style="list-style-type: none"> Free Clinic 	1	10					
Community Organizations <ul style="list-style-type: none"> Community Centers Self-help Groups 	1 2	30 20	X				
Churches <ul style="list-style-type: none"> BC Awareness Church Groups BC Church Support Group DV Awareness Church Group 	2 1 1	30 15 1	X X		X X		X
Domestic Violence <ul style="list-style-type: none"> DV Organizations DV Symposiums Workshops Rape Centers 	18 1 1 2	266 15 10 10	X X			X X	
Shelters	1	0	X	X			
Homeless Organizations	1	0	X				
Legal Assistance Organizations	2	25					
Mental Health Organizations	2	13					
Women’s Conferences	1	20			X		X
Social Workers	2	15			X		
Individual Contacts	2	10					
Libraries	2	20					
Total	60	741	12	2	5	2	2

Key:

Workshops: Worked with individual women dealing with domestic violence

Speeches: Limited opportunity to speak about the study

Presentations: Talk specifically about breast cancer and about the study

Table 3: Socio-Demographic Characteristics of Study Participants

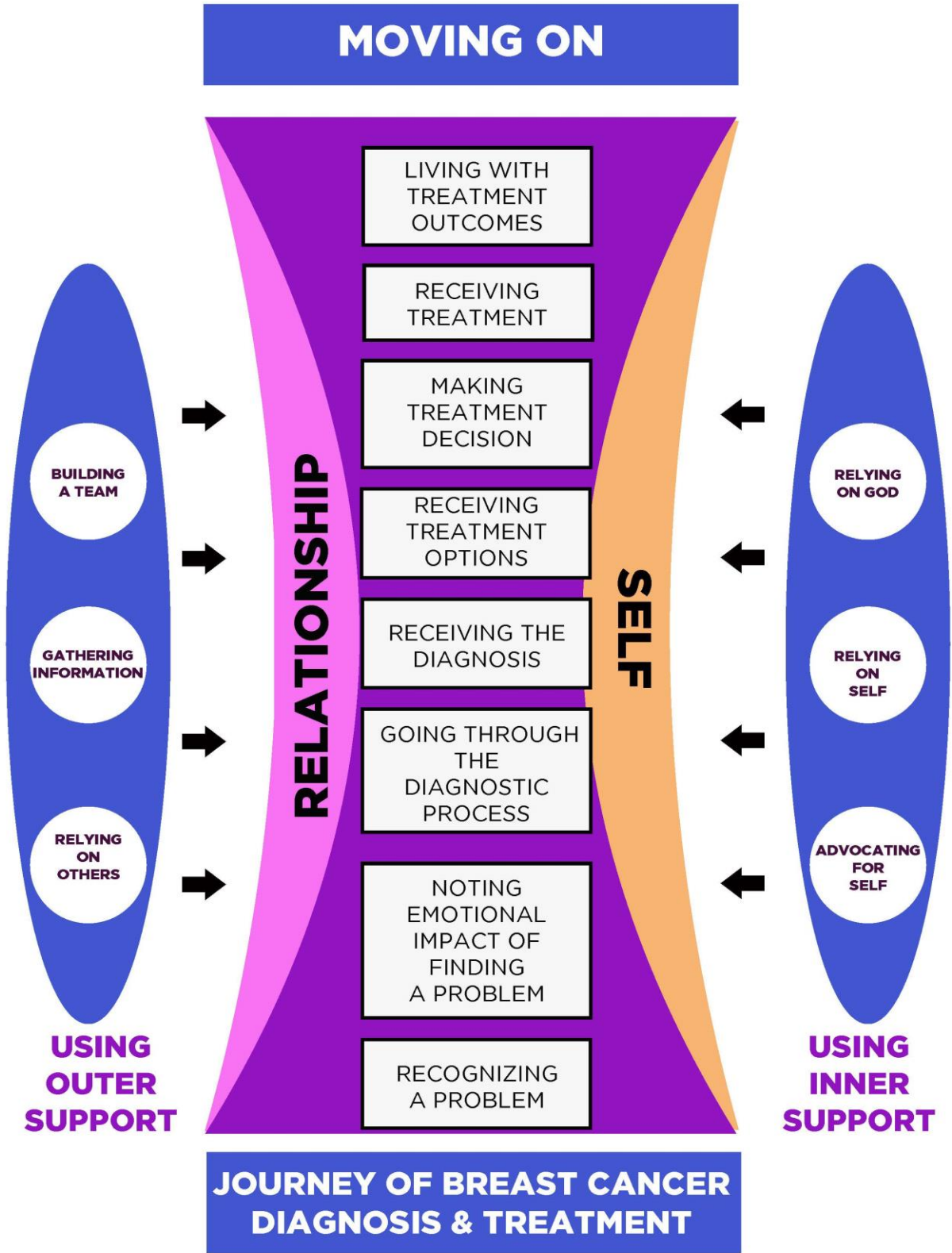
Age	
40-45	1
46-50	2
51-55	3
54-60	2
Education	
Some College	4
College Graduate	2
Graduate School	2
Income	
Less than \$20000	2
\$21000 - \$40000	2
\$41000 - \$60000	1
\$61000 - \$80000	1
\$81000 - \$100000	2
Duration of Relationship	
0-5 years	1
5-10 years	3
10-20 years	0
20-30 years	3
More than 30 years	1
Racial Ethnic Group	
Black or African American	1
Hispanic	1
Hispanic/White	1
Non-Hispanic White	4
Black or African American/Native American	1
Stage at time of Diagnosis	
Stage I	2
Stage II	5
Stage III	1
Stage IV	0
Treatment Received	
Radiation	8
Chemotherapy	7
Lumpectomy	3
Mastectomy	4
Combination Therapy	7
Reconstructive Surgery	1

Table 4: WAST Screening Results

	Describe relationship with partner	Work out arguments with	Arguments ever result in feeling down or bad about yourself?	Ever result in hitting, kicking, or pushing?	Ever feel frightened by what was said or done?	Ever abused physically?	Ever abused emotionally?	Ever abused sexually?	Score
Participant #1	No tension (0)	Some difficulty (1)	Sometimes (1)	Never (0)	Never (0)	Never (0)	Often (2)	Never (0)	4
Participant #2	A lot of tension (1)	Great difficulty (1)	Never (0)	Never (0)	Often (2)	Never (0)	Often (2)	Never (0)	6
Participant #3	Some tension (1)	Some difficulty (1)	Sometimes (1)	Never (0)	Sometimes (1)	Never (0)	Sometimes (1)	Never (0)	5
Participant #4	Some tension (1)	Some difficulty (1)	Sometimes (1)	Never (0)	Never (0)	Never (0)	Sometimes (1)	Never (0)	4
Participant #5	Some tension (1)	Some difficulty (1)	Often (2)	Never (0)	Never (0)	Never (0)	Sometimes (1)	Never (0)	5
Participant #6	A lot of tension (1)	Great difficulty (1)	Often (2)	Sometimes (1)	Often (2)	Sometimes (1)	Often (2)	Sometimes (1)	11
Participant #7	A lot of tension (1)	Great difficulty (1)	Often (2)	Sometimes (1)	Often (2)	Sometimes (1)	Often (2)	Sometimes (1)	11
Participant #8	Some tension (1)	Some difficulty (1)	Often (2)	Never (0)	Never (0)	Never (0)	Often (2)	Sometimes (1)	7

Positive WAST-SF (short form) screening questions if answers “a lot of tension” and “great difficulty”. Positive WAST-SF should be followed by completion of part 2. Interpretation of part 2 is based on clinical judgment (no fixed positive scoring is assigned). However, for this study a cutoff score of ≥ 4 was used to indicate eligibility to participate.

Figure 4: Journey of Breast Cancer Diagnosis & Treatment



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