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Perceptions of Positive Growth Following Breast Cancer in Survivor Couples

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RUNNING HEAD: Perceptions of Positive Growth Following Breast Cancer

Perceptions of Positive Growth Following Breast Cancer in Survivor Couples

By
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Submitted in partial fulfillment
of the requirements for the degree
of Doctor of Philosophy
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2013

SETON HALL UNIVERSITY
COLLEGE OF EDUCATION AND HUMAN SERVICES
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Abstract

The purpose of this study was to explore the lived experiences of couples following breast cancer and their perceptions of growth as a result of their experiences with the illness. Qualitative methodology, specifically a phenomenological research design, was utilized to gain understanding of couples' perceptions and interpretations of growth, particularly within the contexts of couple relationships. Ten survivor couples participated in the study. Study data was collected through semistructured interviews with the couple jointly. Genograms were constructed for each couple and were utilized to track couples' experiences with illness, care-taking, and growth following adverse or traumatic situations. Data analysis revealed in the emergence of thirteen primary themes. The results indicated that both female and male participants' initial reactions to the breast cancer diagnosis were primarily characterized by fear, shock, and unpreparedness. Couples experienced the impact of the illness within several areas of their relationships including physical functioning, emotional climate, sexual intimacy, and relational closeness. Several of these disruptions were compounded by difficulties related to partners' abilities to establish mutually comfortable ways of communicating about emotions, which resulted in engagement in ineffective and unhelpful behaviors and contributed to experiencing emotional distance within the relationship. Despite this, couples were able to communicate effectively with one another in other ways and employ dyadic coping strategies that aided in their adjustment to the illness. All ten couples identified that their primary resource for support was their own relationship, and intimate acts of care-taking, along with a shared perception that challenges could be overcome together, were perceived as significant factors contributing to mutual coping. All ten couples perceived both positive change and growth as a result of their shared experiences. Areas of change included prioritizing leisure/time together and healthy living habits, and increased open emotional communication. Growth was described

in terms of increased emotional closeness, relational trust and confidence, appreciation for life and awareness of mortality, gratitude, perspective of what is important, and spiritual development. Couples mutually perceived survivorship and growth as active processes that involved learning. Descriptions of growth illustrated the rebuilding of altered assumptions and perceptions of transformation beyond the pre-diagnosis ways of living and relating. Findings from this study expand the existing literature on couples' experiences with breast cancer and contribute a relational perspective to the concept of posttraumatic growth. In addition, it is essentially the first study to explore couples' shared experiences of relational growth following breast cancer.

Acknowledgements

Nothing happens unless first a dream – Carl Sandburg

The start of this journey begins with my parents, to whom I am ever thankful, for encouraging me to dream big and instilling in me the belief that the only limits in life are those that we place upon ourselves. These messages, resounding from childhood through adulthood, have proven to be a great source of motivation for me to remain curious of my own potential and continually seek new challenges and opportunities to enrich my mind, body, and soul.

The horizon leans forward, offering you space to place new steps of change – Maya Angelou

I am truly blessed by the presence of my husband, my co-survivor, in my life. The gratitude I feel for your devotion to showing me how beautiful and amazing life after cancer can be is immeasurable. I am inspired by the depth of your capacity to love, and I draw strength and courage from your kindness and compassion. The extent of my gratitude reaches far beyond the limits of these pages but I am most grateful for your passion to live every aspect of our life together fully. I consider both this project and surviving cancer to be *our* accomplishments because you have actively participated every step of the way, contributing your patience, encouragement, generosity, and, of course, your unique sense of humor. Thank you for continually reminding me that the obstacles that landed in my path were challenges to be overcome rather than deterrents to me achieving my goals.

*To accomplish great things, we must not only act, but also dream; not only plan, but also believe
– Anatole France*

I extend my deepest appreciation to the friends, whom I consider my family, who have lovingly invested so much time and energy in caring for me in numerous ways. I am most grateful for your contributions of humor. Never in my life have I known such laughter than

when in your company. I am fortunate that you so often created opportunities for me to stop working, stop planning, and especially stop thinking in order to take time to enjoy the pleasures of living. Thank you for walking by my side through my struggles (sometimes even carrying me) and celebrating my victories, no matter how small.

Make the most of yourself, for that is all there is of you – Ralph Waldo Emerson

Last, but certainly not least, I wish to thank my dissertation committee. I consider myself extremely fortunate to have crossed paths with such able and intelligent individuals. It is never far from my thoughts that I could not have achieved my goal without you. I have experienced each of you as genuinely dedicated to your work and to those you mentor. My thanks to Dr. Robert Massey for your inspiring enthusiasm and evident passion for our field. You have gently but firmly guided me towards becoming a well-rounded scholar and practitioner. Your genuine expression of belief in my capabilities was incredibly motivating and continues to serve as a source of encouragement for me to continue to pursue intellectual endeavors. Thank you Dr. Ben Beitin for your willingness to share your knowledge and expertise. Your aptitude for qualitative research provided me with the confidence to venture forth knowing that your expertise would guide me in approaching this project in the way I felt would be most meaningful. Thank you Dr. Sharon Davis Massey for your evident dedication to this project. Your thoughtful feedback and insightful guidance encouraged me to push my critical thinking skills. I greatly appreciate the support and validation you have offered me throughout my time at Seton Hall as well as with this project. Finally, I wish to thank Dr. Pamela Foley. Your interest and knowledge of various aspects of the topic made you a true asset to this project. I appreciate the contributions you made towards assisting me with expanding my depth of understanding. Thank you for encouraging me to take this project further. I am excited and ready to run with it.

Dedication

This project is dedicated to the courageous couples who willingly shared their stories, exposing both their struggles and their successes, for the sake of those who will be diagnosed with breast cancer after them. I also dedicate this project to my “Dream Team” – two of the most amazing women and physicians I have ever met. Thank you for saving my life, both literally and figuratively, and for teaching me the art of surviving with grace.

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CHAPTER ONE

Introduction

“An individual doesn’t get cancer, a family does.”

Terry Tempest Williams
Author: *The Clan of One-Breasted Women*
(Retrieved from <http://www.cancer.org>)

According to the American Cancer Society’s (ACS) 2013 statistics, approximately 232,340 new cases of invasive breast cancer and 64,640 new cases of ductal and lobular carcinoma in situ (DCIS, LCIS) (non-invasive early form of breast cancer) will be diagnosed in 2013 alone. In addition, it is anticipated that approximately 39,620 women will die from breast cancer, making it the second leading cause of cancer-related death in women, exceeded only by lung cancer. These statistics demonstrate that breast cancer is a serious public health concern. For some, the words *breast cancer* alone can be an example of the power that language can have to bring forth intense emotions such as fear, disbelief, anger, and sadness, especially to those who have had a personal connection with the disease. However, there is another aspect of this issue. At this time, there are over 2.9 million breast cancer survivors in the United States. According to the National Cancer Institute (NCI) (2013), more women than ever are surviving breast cancer. Between 1998 and 2010 (the latest year for which updated statistics are available), the breast-cancer-related death rate has been steadily declining by approximately 1.9% per year. Although less consistent than the current trend, increases in survival rates have been seen since the mid 1970’s. This progress has been attributed to a number of factors including advances in early detection, new screening technologies that are more widely available and utilized, development and use of combined therapy modalities, broader application of adjuvant and maintenance therapies, and increased emphasis on systemic surveillance of individuals living long term after cancer (Rowland, 2008). Whereas breast cancer currently remains a fatal illness

for some, it is anticipated by the National Coalition for Cancer Survivorship (NCCS) (2011) that, in time, it will become a curable disease for more individuals and a chronic illness for most.

During the last several years there has been an increase in the attention paid to the field of cancer survivorship. According to Rowland (2008), cancer survivorship research emerged in direct response to the need for better understanding of the unique qualities and concerns of this population by survivors, practitioners, policy makers, and the public. Despite the progress made, research on the long-term impact of surviving cancer is still in its early stages (Heppner et al., 2009; Sadler-Gerhardt, Reynolds, Britton, & Kruse, 2010). Historically, cancer-survivorship studies were focused on the many ways that cancer could damage and disable individuals, or cause survivors and their loved ones to become dysfunctional. Over time, and as more researchers focused their studies on the experiences of cancer, it became apparent that for many survivors, cancer may have a “silver lining” (Rowland, 2008, p. 364). Referred to as *benefit finding*, *stress-related growth*, or *posttraumatic growth*, researchers are discovering that positive outcomes are also present along with the negative outcomes in survivors’ lives posttreatment. The confrontation with cancer can result in an increased sense of mastery and self-esteem, an opportunity to review or alter priorities, a greater sense of purpose, more concern for others, and an enhanced or deepened appreciation of oneself and one’s life (Sadler-Gerhardt et al., 2010; Schroevers, Helgeson, Sanderman, & Ranchor, 2010; Sherman, Simonton, Latif, & Bracy, 2010).

Women with breast cancer do not cope with the disease or grow from the experience in isolation, but instead, within the contexts of their relationships. According to Weiss (2004), social support has been shown to not only decrease the prevalence of negative affect and stress-related symptoms, but also to facilitate positive change. Morgan et al. (2005) asserted that, with

specific regards to intimate partner relationships, both women and their partners experience adverse physical, psychological, and psychosocial consequences as a result of breast cancer. Partners rely on one another for support and adjustment throughout the disease process, and many view merging strengths and uniting to work together to cope as means of “living together through and beyond a breast cancer diagnosis” (p. 981). Northouse, Templin, and Mood (2001) posited that couples who learn to work as a team to cope with breast cancer tend to have positive psychological adjustment to the challenges of the disease and draw closer to one another other through the experience.

Background/Rationale

A relational conceptualization of growth in a couple following the experience of breast cancer is difficult to understand without first developing an understanding of events and experiences couples encounter along a breast cancer trajectory. The significant toll that breast cancer takes on an intimate relationship is now well understood. Over the past few decades, numerous studies have been geared towards understanding the experience of cancer (Carver, Lechner, & Antoni, 2009; Dorros, Card, Segrin, & Badger, 2010; Fergus & Gray, 2009; Helgeson, Snyder, & Seltman, 2004; Kim et al., 2008). Initially, the goal in conducting many of these studies was to gain understanding of a breast-cancer patient’s experiences. More recently, researchers have begun to examine experiences of breast cancer from the perspective of a couple. In addition, somewhat more attention is being paid to the experiences of the partners who live through this with their loved ones.

Breast cancer is known to cause substantial distress and disruption in the lives of both the women who are affected and their partners. Often times, a partner’s distress may not differ significantly from a patient’s (Dorros, Card, Segrin, & Badger, 2010). Patients cope with

emotional consequences of being diagnosed with a life-threatening illness, deal with invasive medical treatments, and worry about recurrence. Partners struggle with the realization that they may lose their life companions, and are faced with their own worries about recurrence, and how to provide practical and emotional assistance to their partners. These experiences may take an emotional toll on both partners and their relationships.

Both women and their partners are highly impacted by the diagnosis of breast cancer and often experience distress as a result. According to Fergus and Gray (2009), women often experience grief over the loss of independence and decreased abilities to function in the roles of mother, partner, and care-taker. Men often experience distress related to feeling helpless in their abilities to ease a partner's discomfort, lack of understanding of a partner's needs, and increased familial responsibilities. Both men and women may experience distress related to the fear of death and loss of the relationship as well as guilt over focusing their attention on their own experiences. Kim et al. (2008) posited that, although each person's psychological distress tends to be the strongest predictor of one's own quality of life, partner's distress and the (dis)similarity in distress of the couple also plays a significant role in one's quality of life. Stress in women with breast cancer is significantly associated with lower physical health and emotional well-being in their partners (Dorros et al., 2010). In addition to the impact of breast cancer on the individual, couples can experience disruption in their spousal relationship as a result of breast cancer and the distress each experience arouses. Stress and tension in the marital relationship as a result of breast-cancer related issues are often a primary concern identified by couples (Shands, Lewis, Sinsheimer, & Cochrane, 2006).

Couple Relationships

Couples dealing with breast cancer inevitably have to adopt strategies to deal with the practical and emotional consequences associated with this diagnosis. They must learn new ways of communicating and problem-solving. Often, many of the typical ways of functioning are no longer effective or appropriate. This may be because a couple is facing unknown territory which they have not had to maneuver through. Unfamiliarity of experiences such as illness often translates to a lack of specific skills needed to effectively adjust. In essence, a couple is faced with having to learn how to do what they have never done before.

Couples can struggle in their shared coping. They may continue to utilize their old strategies of enduring, and, when previous solutions continually result in ineffective adjustment, a couple may experience further despair, in addition to what cancer has already generated. Some couples may not know where to begin or even how to communicate about cancer. This again, generally leads to ineffective coping or even emotional avoidance. Other couples may resort to individual ways of coping if they are unfamiliar with how to come together as a couple when difficult situations arise. All of these factors can contribute to distress and further diminishment in the quality of life experienced by couples dealing with breast cancer.

In relation to the emotional and cognitive processes associated with the adjustments of couples, their perceptions about the illness guide their response to the cancer as well as to their partner. Couples who are able to perceive illness as adversity that can be overcome together are more likely to engage in seeking any needed social supports. For those who experience more difficulty adjusting to illness, there is increased vulnerability to unhelpful behaviors, such as protective buffering, avoidance, and withdrawal. These behaviors have the tendency to increase tension and distress while decreasing cohesion and closeness in the relationship as a result of a lack of communication and engagement in problem-solving (Manne et al., 2007).

In addition, the way in which one engages in dyadic coping influences personal adjustment. Partners who resort to the use of hostile dyadic coping (e.g., ridicule, distancing, or minimizing) generally experience poorer adjustment as well as higher illness intrusiveness (illness-induced lifestyle disruptions) than those who engage in positive dyadic coping (communication of emotion and problem-focused stress) (Feldman & Broussard, 2006). According to Segrin et al. (2006) it is not uncommon for partners to experience depression as a result of the stresses associated with breast cancer, but successful adjustment and adaptation are more likely when relationship satisfaction is experienced.

The ways that couples communicate about cancer-related issues can either help or hinder a relationship. Use of avoidant and demand-withdraw communication strategies are associated with higher degrees of distress in couples while those with mutual constructive communication experience lower degrees of distress (Manne et al., 2006). Manne, Ostroff, Rini et al.'s (2004) interpersonal process model of intimacy is based on the premise that patients and partners who are able to demonstrate responsiveness and open self-disclosure towards their significant others have a high propensity to experience feelings of intimacy including acceptance, understanding, and caring. These factors can improve the quality of couples' relationships, which, in turn, can improve both physical and emotional well-being for both partners.

Manne and Badr's (2008) expanded model, the relationship intimacy model of couples' psychosocial adaptation to cancer, includes identification of both relationship-compromising and relationship-enhancing behaviors. Relationship-compromising behaviors include avoidance of one's own and/or one's partner's cancer-related concerns via subtle insensitive behaviors, criticism of how one's partner is coping with the cancer, and pressure-withdraw patterns of engagement. These behaviors have consistently been associated with reduced marital quality as

well as psychological distress. Relationship-enhancing behaviors include reciprocal disclosure of feelings and concerns regarding cancer experiences, demonstrating responsiveness to one's partner, and relationship engagement (viewing cancer in relational terms). These behaviors have been shown to aid in adjustment to cancer and promotion of intimacy within the relationship.

Couple Interventions

To date, few interventions have been developed to work with couples dealing with breast cancer. However, as a result of greater understanding of the unique challenges that couples with breast cancer face, several preliminary couples-based interventions have been recently designed to assist couples with the coping process (Baucom et al., 2009; Kayser et al., 2010; Naaman, Radwan, & Johnson, 2009; Scott, Halford, & Ward, 2004). The development of some of these interventions was based on both the positive and negative aspects of the couples' experiences with breast cancer. On the negative side, there is recognition that couples often experience significant distress and relationship disruption as a result of breast cancer, and may require interventions or guidance in order to cope with the situations. On the other hand, there is greater understanding of the relational qualities and coping strategies that are most likely to contribute to positive adjustment to breast cancer. In addition, the research indicates that, when couples are able to utilize these relational strengths and coping strategies, they have the potential to experience relational closeness and understanding (Manne & Badr, 2008).

For couples who are able to overcome relationship challenges associated with the illness, there is potential for mutual growth and enhancement of their relationship. Additionally, couples who are able to cope with and adapt effectively to breast cancer tend to experience lower levels of distress overall. More importantly, they are more likely to be able to recreate their beliefs about themselves and the illness, which often leads to greater acceptance of themselves, their

partners, and the illness as well. Partners also report increased abilities to find meanings in their experiences of breast cancer (Manne et al., 2009). Picard et al. (2006) stated that "...the bond of love plays an essential role in the adjustment process of couples confronted with breast cancer" (p. 131). Many couples draw on this bond to transform their experiences of suffering into meaningful and constructive life experiences personally and relationally. The struggle to deal with negative or stressful experiences can result in positive changes in views about oneself and one's relationships (Manne, Ostroff, Winkel et al., 2004). Essentially, survivorship and the positive changes that can come about as a result of the breast-cancer experiences can be viewed as a relational process.

Significance of the Study

Much has been written about the issues of women with breast cancer, and there is a growing body of research addressing positive change and meaning-making processes that can result from the experiences of living with and through breast cancer. It is becoming an accepted fact that models of stress and coping need to incorporate a relational perspective; however, researchers who study couples with breast cancer still primarily focus on issues, coping, and growth experiences of individuals. Over the past few years, slightly more research has been devoted to examining experiences of spouses of breast cancer survivors (Feldman & Broussard, 2006; Loiselle, Devine, Reed-Knight, & Blount, 2011; Weiss, 2004). Although this represents progress in the field of breast cancer research, it also continues to demonstrate the predominance of an individualist approach to the task of studying breast cancer.

Within the literature regarding posttraumatic growth, stress-related growth, and benefit finding, there are consistent data that show evidence that positive growth is relatively common among breast-cancer survivors. The available data suggest that between 60% and 90% of

survivors report positive changes as a result of their experiences with cancer. Positive effects reported ranged from existential changes such as altered views on spirituality to behavioral changes such as improved attention to health practices (Manne, Ostroff, Winkel et al., 2004; Rowland, 2008; Sadler-Gerhardt et al., 2010; Schroevers, Kraaij, & Garnefski, 2011; Sherman et al., 2010; Thrombre, Sherman, & Simonton, 2009). Like their wives, spouses of breast-cancer survivors tend to experience positive life changes in the aftermath of the breast cancer experiences. According to Weiss (2004), 80% of husbands reported positive changes such as enhanced interpersonal relationships and greater appreciation for life following the encounter with their wives' breast cancers. These results are not surprising since, as stated earlier, husbands share the sufferings of their wives, and this suffering can lead to positive personal growth. Not all individuals experience growth following breast cancer; however, these statistics show that there is little question regarding the potential for individuals to perceive growth as a result of the breast cancer. What these statistics do not show is the prevalence of couples who experience relational growth. Studies were not found in the literature.

The few studies available that include relational perspectives tend to involve the exploration of how the relationship dynamics or partner behaviors influence the individual's experiences as opposed to how the couple and the relationship itself change as a result of the couple's experiences (Kayser et al., 2010; Kim et al., 2008; Manne & Badr, 2008; Manne, Ostroff, Winkel et al., 2004). What becomes evident is that there is a severe lack of attention in the literature devoted to the lived experiences of a couple and relational perspectives on positive change following breast cancer. A more comprehensive understanding of the experiencing of growth within the couple following breast cancer and the processes that influence the perceptions of positive relational change was addressed by this study.

Another significant feature of this study was qualitative research, specifically phenomenology, as a means to explore experiences of positive growth following breast cancer among couples. No previous studies of this type, with a specific focus on growth and experiences of couples, were found. In reviewing current literature, only two studies were located in which researchers utilized qualitative methods with breast-cancer couples, and these studies pertained specifically to coping strategies used by couples. By using qualitative research to study the subjective experiences and meanings of positive growth, the focus of research on this topic can be balanced and understanding can be enhanced.

According to the principles of hermeneutics-- the science of interpretation-- interpreting and understanding personal experiences are based on language, actions, and contexts of everyday life (Morrow & Smith, 2000). The ways in which couples think about, and subsequently talk about their experiences of cancer, have an impact on meanings given to illness and perceptions formulated about positive growth. The naturalistic philosophy (to understand behavior in a natural setting) of qualitative research was consistent with my aim to seek understanding rather than causality.

The principal focus on the couple's experiences of the phenomena of positive changes was a significant and unique feature of my study. Most of the available literature on posttraumatic growth, stress-related growth, and benefit-finding included a component of assessing whether phenomena were generalizable to others or not, a question of validity in quantitative research. Although there is value in understanding the commonalities among individuals and couples following breast cancer, as well as in the demands within the field of research to demonstrate significant probabilities and generalizability of research findings to wider groups, the available research illustrated a clear neglect of a search to understand

meanings given to life experiences or phenomena from the perspectives of participants (Van Manen, 1990).

There is certainly value in seeking a means of normalizing a phenomenon; however, when this becomes a primary goal of study, there is little attention paid to meanings within context. In addition, when generalizability is not established, results are often devalued due to the assumption that they have minimal significance if they do not represent larger populations, as opposed to being respected as reflecting the variability in the specific circumstances of the individuals or couple (Chase, 2005). According to Schutz (1967), experience, truth, and knowledge are relative, socially constructed, and uniquely interpreted as opposed to being identifiable and subject to evaluation by the scientific method, post-positivist assumptions utilized in quantitative research. A phenomenological research approach was selected in order to focus this study on the couples' subjective understandings of their experiences of positive growth following breast cancer and their interpretations and perceptions of meaningfulness. This approach is consistent with Van Manen's (1990) claim that phenomenological research is not only a strategy of inquiry, but also a school of philosophy, based in the process of attempting to understand the *lived experiences* and *essence* of human experiences from inside. Experiences that couples undergo with breast cancer and breast-cancer related growth may be common, but the goal of this study was to explore the ways a couple mutually understands the shared experiences of positive growth and makes sense of this in their relationship. Further review of qualitative research and phenomenological methodology is presented in chapter three in order to provide support for the selection of this particular mode of inquiry.

Definition of terms

There are several key terms used throughout this study, some of which have overlapping meanings. In order to facilitate a clear understanding of these terms, as well as distinguish one from another, they are defined briefly in this section. A more detailed review of these terms and their applicability to the topic of study is discussed within the literature review.

First, language must be established to describe the couples involved in the study. According to Rowland (2008) in 1986, when the founding members of the National Coalition for Cancer Survivorship (NCCS) met to collaborate on the creation of this partnership, the term *cancer survivor* was rarely used. On the rare occasions when it was used, it specifically referred to individuals who had remained cancer-free for five years or more, otherwise those dealing with cancer were referred to as *victims*. As mortality rates declined and increased numbers of individuals were living five years or more beyond the absence of cancer, the members of the NCCS recognized that the reluctance to talk about cancer survivorship was becoming an impediment to having the necessary conversations about life after the illness. It became apparent that the language used to describe a person with cancer had to change. The evolution of the term *cancer survivor* began with the proposition that that people could call themselves survivors from the moment of diagnosis through the remainder of their lives, regardless of whether their subsequent deaths were cancer-related or not.

Further along the process of defining cancer survivorship, the NCCS broadened the definition to include family caregivers. This was done with the understanding that these individuals are vital to a patient's health and survivorship and that they also often experience many significant, albeit different, challenges when cancer affects their loved ones. This definition--individuals and caregivers living with, through, and beyond a cancer diagnosis--continues to be the NCCS's definition of choice and has also been embraced by the National

Cancer Institute (NCI). The basic tenets of this definition, specifically the inclusion of caregivers and perspective of encompassing the full cancer trajectory, was utilized and expanded upon to build a conceptual foundation of this study. The aim of this study was to focus specifically on intimate partners/spouses or *survivor couples* in order to capture the unique experiences of this particular type of relationship. More so, the purpose of including partners/spouses was to increase understanding of the *shared experiences* of the couple rather than to gain a secondary individual perspective. In addition, although the definition begins with the diagnosis of cancer, couples involved in the study were limited to those who have completed treatment and have been cancer-free for at least one year. It was recognized that the processes involved in positive growth include experiences along the trajectory of breast cancer; however, the focus of the study was on the perceptions of growth as a result of the breast-cancer experience; therefore, exploring this following the diagnosis and treatment phases allowed for a broader view of the experience.

In preliminarily reviewing the available literature, it was evident that many individuals and couples refer to the experiences of cancer or specific aspects of the experiences as traumatic in nature. The most commonly known definition of trauma is that which is included in the descriptions of Posttraumatic Stress Disorder (PTSD) and Acute Stress Disorder in the *Diagnostic and Statistical Manual of Mental Disorders* (4th Ed., Text Revision) (DSM-IV TR) (2000). In the DSM-IV TR (2000), trauma is described as exposure to an extremely stressful event “that involves actual or threatened death or serious injury, or other threat to one’s physical integrity” (p. 463). The diagnostic criteria for these disorders include responses to the stressor characterized by “intense fear, helplessness, or horror” (p. 467). A breast-cancer diagnosis is considered a potential life threatening illness that includes aggressive treatments that threaten the

integrity of self. The symptoms commonly experienced by women as a result of the diagnosis and treatment of the disease now meet the criteria for PTSD, though not all traumatic stress leads to PTSD. Not all women diagnosed with breast cancer will experience PTSD; however, according to Andrykowski et al., (2000), PTSD-like symptoms including re-experiencing the trauma of the diagnosis or treatment (nightmares or flashbacks), avoidance of trauma reminders (non-adherence to treatment), and hyperarousal (irritability, sleep disturbance) are common among survivors. In addition, the DSM-IV TR (2000) definition also includes the witnessing of an event that involved actual or threatened death to others as criteria, thus may apply to partners as well as to women with breast cancer (p. 467).

Trauma researchers often describe trauma with this definition (Park, 2004), but, as the field of trauma research continues to expand and include research on positive growth following traumatic events, this definition has also evolved. Calhoun and Tedeschi (2006) offered a broader conceptualization of trauma, defining it as: (a) a set of circumstances that significantly challenge a person's preexisting assumptions about the world, (b) an event that disrupts the meaning a person gives to his/her life events, (c) an event that divides one's life into separate categories of before and after the event, and (d) an experience of grief, suffering, loss, or other negative affect that alters the view of self, others, and philosophy of life. Although cancer survivors may endure experiences similar to one another, not all will perceive such events as traumatic. The specific association of cancer and trauma will be discussed further in the literature review.

As stated earlier, the occurrence of positive growth following breast cancer has been referred to by various terms including *posttraumatic growth*, *stress-related growth*, and *benefit-finding*. The most commonly used term for growth following a traumatic event is *posttraumatic*

growth (PTG). According to Tedeschi and Calhoun (2004), PTG can be defined as “positive psychological change experienced as a result of the struggle with highly challenging life circumstances” (p. 1). However, these authors also cautioned that there can be no one, all-encompassing definition due to the wide variety of individual experiences and differences among people. In addition, they acknowledged that the definition of PTG has been subject to questioning regarding what factors constitute growth and what parameters determine the occurrence of growth (Calhoun & Tedeschi, 2006). Calhoun and Tedeschi (2006) indicated that emphasis on the disruption of the assumptive world is a reason they have selected the term *posttraumatic growth* as opposed to other terms such as *benefit-finding* and *meaning-making* that do not imply acknowledging this level of disruption to peoples’ lives. They suggested that the ways the personal narrative is disrupted will reflect the individual’s encounter with the event and the level of trauma experienced. According to Park (2009), researchers in the field have yet to arrive at a consensus on the terminology, and as such, generally use the various terms interchangeably. Tennen and Afflect (2002) are among the few who make a distinction between the terms. They utilized the term *benefit-finding* as a means to discuss perceptions of change and distinguish this from actual or veridical change (though perceptions of change may be veridical or non-veridical). Although the differences between veridical and perceived, but non-veridical, growth (illusory) may be important, most researchers in the field do not make this distinction in their terminology and may utilize any of the terms to discuss perceptions of positive life change following trauma or stress regardless of whether the perceptions reflect actual or illusory change (Park, 2009).

In addition to questions raised as to whether an individual’s perceptions of growth accurately represent veridical growth (Sumalla, Ochoa, & Blanco, 2009), there has also been

evident difficulty gaining a consensus among researchers as to the most effective ways to assess change, measure growth, and determine indicators of true growth. Despite the lack of distinction in the terminology used within the literature, Park (2009) proposed that stress-related growth is less dramatic or radical than posttraumatic growth and arises through attempts to make meaning by reappraising a stressor or one's global belief, as opposed to rebuilding altered assumptions and drastically restructuring life. Park and Lechner (2006) posited that the questions of whether growth has occurred or not, and whether changes are significant enough to constitute growth can only be answered by the individuals who have experienced the trauma. The goal of my study was not to determine whether positive changes in the couple and their relationship were significant enough to be labeled growth; rather, it was to gain understanding of the couple's personal experiences of growth and positive change. Therefore, their personal definitions and perceptions were the focus of attention.

Resilience is a term that has also been associated with survivorship; however, there are multiple usages of the term. This can lead to confusion. Despite that, the term has been used interchangeably with the other terms depicting growth following breast cancer. Many researchers agree that resilience is not the same as benefit finding or growth in that it is the demonstration of positive adjustment to adverse life situations or traumatic events whereas benefit finding connotes perceptions of change, and PTG represents veridical change or transformation (Calhoun & Tedeschi, 2006; Helgeson, Lopez, & Mennella, 2009; Tedeschi & Calhoun, 2004). The term *resilience* appears to be used less frequently than the other terms, but since it has been presented within the literature, it is important to define. Lepore and Revenson (2006) suggested that posttraumatic growth is a form of resilience. They identified three related but distinct uses of the term *resilience* in the literature. These three usages represent different

dimensions or forms of resilience: (a) recovery from the experience, (b) resistance to stressors, and (c) reconfiguration, or the capacity to change one's self to adapt to a stressor.

Reconfiguration resilience is most similar to posttraumatic growth (PTG) in that they both involve personal transformations that go beyond returning to normal functioning. The difference is that PTG specifically refers to positive elements of change whereas reconfiguration may include both positive and negative changes. Resilience is the result of an individual's ability to resist and recover from stressful events, or reconfigure his/her thoughts, beliefs, and behaviors to adjust to ongoing and changing demands. Lepore and Revenson (2006) state that, "we view PTG as one possible outcome for individuals who go through a reconfiguration process" (p. 27). Tedeschi and Calhoun (2004) regarded resilience as the personal characteristics that allow a person to manage challenging life events. They disagreed with Lepore and Revenson's (2006) position of calling PTG a form of resilience based on the fact that resilience was never defined as transformation or reformulation. They indicate that dictionary definitions of the term convey that resilience is "the power or ability to return to the original form or position after being bent, compressed, or stretched" or "to recover readily from illness, depression, or adversity" (Calhoun & Tedeschi, 2006, p. 11). Lepore and Revenson (2006) concluded that it is important to avoid confusion by clarifying what usage is being considered. In addition, it is especially important to avoid using the terms *resilience* and *PTG* to describe both processes and outcomes in a single study, and to be clear about whether measures or interpretations reflect outcomes or processes. Calhoun and Tedeschi (2006) also cautioned that it is very important to maintain a clear distinction between the two concepts of posttraumatic growth and resilience in order to avoid inaccurate associations. In the event that any of the couples in this study made reference to

resilience, additional discussion was used to clarify their personal usage and understanding of the term.

In concluding this discussion of definitions of terms, it is important to clarify that the identification and explanation of these terms was meant to provide foundational understanding of the concepts and language associated with positive growth following difficult situations. These terms frequently appear in the literature and have commonly been referred to by individuals and couples involved in breast cancer research. In an effort to remain true to the philosophy of phenomenological methodology, these terms and concepts were presented in order to serve as reference points when they emerged within the narratives of the couples; however, were not intended to represent the prediction of any specific experience, perception, process, or association with a particular construct.

Purpose Statement

The purpose of this study was to explore the lived experiences of couples following breast cancer and their perceptions of positive growth as a result of their experiences with the illness, utilizing a qualitative, phenomenological methodology. Historically the focus of most breast-cancer research has been on the etiology, diagnosis, treatment concerns, and prevention of the disease, typically from a medical perspective (Ganz et al., 2004; McPherson, Steel, & Dixon, 2000). Until recently, researchers concentrated their attention almost exclusively on the breast-cancer patient within the diagnosis and treatment phases of the illness trajectory. However, progress has been made in expanding the literature to include studies of survivorship, living beyond breast cancer, and the potential for growth as a result of breast cancer. In addition, there has been a shift from an individual focus to a relational focus, with researchers seeking to better

understand the experiences of loved ones, as well as the impacts of breast cancer on one's primary relationships.

Research Questions

Phenomenological research questions are questions of meaning designed to help the researcher understand the lived experience of the participants (Dahl & Boss, 2005). The exploration of couples' perceptions of positive growth after breast cancer was guided by the following research questions:

1. How do couples who have experienced breast-cancer experience the impact of the illness on their relationship?
2. What are the processes and qualities that couples who have experienced breast-cancer believe were essential for coping?
3. How do couples who have experienced breast-cancer perceive the cancer-free period following treatment?
4. What do couples who have experienced breast-cancer believe about positive growth or what current experiences serve as indicators of growth?

Summary

What continues to be lacking in the current body of literature is research with the goal of understanding the phenomenon of positive growth from perspectives of intimate couples within context of intimate relationships. Therefore, the purpose of this study was also to begin to fill this gap in the literature and contribute to expanding the field of breast cancer research. In turn, through greater understanding of the ways in which couples perceive themselves and personal factors that influence change after living through breast-cancer diagnoses and treatments, clinicians and support resources may be better informed about unique needs, qualities, and

strengths of this population. New discoveries about how couples perceive change as a result of their experiences with breast cancer adds to the clinical knowledge base and increases the potential for practitioners to be helpful in guiding couples to utilize the resources and qualities of their relationships that can help promote positive growth. In addition, practitioners may also be better informed regarding ways to use the couple's personal narratives to guide support and interventions. Therefore, a final purpose of this proposed study was to demonstrate the importance of considering the unique perspective of individual couples as well as the shared perspectives among couples. This was in an effort to respect the individual contexts and unique qualities of a couple while acknowledging connection through shared experiences with breast cancer.

CHAPTER TWO

Literature Review

Due to the expansive nature of the field of breast-cancer research, review of the literature will be focused primarily on the context of the couple. As previously indicated, positive growth as a result of a challenging situation has frequently been associated with the overcoming of struggles related to the stressor. There has been little debate over this concept and much research has been dedicated to exploring the difficulties that couples with breast cancer face. However, it is also possible that growth may result from other positive factors related to the experience, such as particular strengths and characteristics of the couple. Before one can begin to comprehend the phenomenon of positive growth following breast cancer, it is necessary to first establish an understanding of the various theories and processes associated with a dyadic experience of breast cancer.

The format of this review was designed to represent the progression of the illness trajectory and included review of studies related to the adjustment, cognitive and social processes, intimacy issues, as well as interpersonal well-being of couples coping with breast cancer. The goal was to establish an experiential conceptualization about progression from diagnosis through posttreatment growth. In this review, I addressed the core concerns of couples and the specific vulnerabilities they faced, both individually and as a couple. Specific attention was paid to exploring the following topics: (a) ways that couples experience distress and attempt to adjust to it, (b) ways that couples talk about cancer and the role of communication, (c) ways in which couples come together in a crisis and attempt to understand one another, (d) the role of interdependence and intimacy, (e) response within the field to research findings and the development of theories and couple-based interventions, and (f) the healing process, meaning-

making, benefit-finding, and positive growth associated with the breast cancer-experience. Both quantitative and qualitative studies were reviewed in order to conceptualize the topics from multiple perspectives.

Vulnerabilities and Distress

The significant toll that breast cancer takes on an intimate relationship is now well researched and understood (Feldman & Broussard, 2006; Fergus & Gray, 2009; Kayser, Watson, & Andrade, 2007; Manne, Ostroff, Fox, et al., 2009; Manne, Ostroff, Norton, et al., 2006). Couples face a multitude of demands and disruptions that influence functioning. The most commonly faced stressors that couples face as a result of diagnosis and treatment for breast cancer include the renegotiation of family roles and responsibilities, reduced sexual engagement and social activity, difficulty dealing with changes to the patient's physical appearance, feelings of inequity, increased financial strain, communication barriers and difficulty talking about the future, fears about the cancer and potential recurrence, and preoccupation with thoughts of mortality, loss, and abandonment (Fergus & Gray, 2009; Manne, Ostroff, Rini et al., 2004). Shands, Lewis, Sinsheimer, and Cochrane (2006) reported that, of all the stressors encountered, couples tend to be most concerned with the tensions that arise in a relationship as a result of these stressors.

Several patient characteristics were identified as impeding couple adjustment. The majority of women in Fergus and Gray's (2009) study identified strongly with their roles as mothers and caretakers, and they were not comfortable attending to their physical and emotional needs in a focused manner. Despite the fact that patients often struggle with the notion of making themselves the focus of care-giving attention, self-absorption was a characteristic that emerged. The demands of the illness were so consuming that self-care gave way to self-

absorption and failure to appreciate or recognize the impact of the illness on the male partner. As a result, some men felt unacknowledged or excluded by their partners.

Exaggerated dependency on the part of the patient was also identified as a straining process in relationships. In this case, when a patient repeatedly discussed her fears of recurrence or expressed dissatisfaction with her altered body, partners often became frustrated (Fergus & Gray, 2009). Women described these behaviors as a means of attempting to prompt their spouses to indicate understanding of what it was like to have breast cancer (Shands et al., 2006). Although a woman may continuously seek validation or reassurance from her partner, her inability to be consoled, despite his efforts, often leaves a partner feeling frustrated and ineffective (Fergus & Gray, 2009). Shands et al. (2006) reported that men struggled with knowing how to respond to their partners and experienced frustration at not acting or communicating satisfactorily, especially about feelings related to their wives' physical changes. Men often did not know what their wives would find supportive and, as a result, frequently responded in ways that their spouse found unhelpful. For example, one woman indicated that she wanted her husband to refrain from telling her "everything's going to be okay," and, instead, just hold her when she cried. She explained feeling as if his statement was minimizing of her emotions, and she, therefore, felt that she needed to hide them from him (Shands et al., 2006). In addition, some men found that, when their partners were in this state, the concepts of them as being strong and self-assured women were challenged (Fergus & Gray, 2009).

Fergus and Gray (2009) noted that, by the same token, some women struggled with becoming more dependent on their spouses. This conflict sometimes manifested as a type of counter-dependency that had the effect of pushing their partners away and impeding adjustment. This was usually motivated by a desire to maintain normalcy and to limit the impact of the

illness on others. Some women tried to retain a sense of independence by continuing to work and maintain family responsibilities to the degree that they had prior to diagnosis. In the women's efforts to ensure that life remained normal, spouses reported feeling insignificant and sidelined. One patient exclaimed, "I think that I was just so independent, sometimes I just wouldn't, as I say, even admit to myself that I needed help. Because I wanted to be...I wanted things to be OK" (Fergus & Gray, 2009, p. 1315). Following this counter-dependency was the tendency for patients to become over-controlling and directive about how to accomplish roles or activities that were in the patient's domain prior to the illness. Patients struggled with relinquishing control to their spouses since this was another reminder of lost autonomy. From the male perspective, the over-controlling characteristic instilled greater feelings of inadequacy around ability to make a positive difference. One spouse reported, "I'm trying to sort of do something to help, and I think I'm helping, but I'm told quite sharply that actually, like that's not helping at all. So there's disappointment. You know, there's kind of like, well, what do I do?" (Fergus & Gray, 2009, p. 1315).

Fergus and Gray (2009) also identified spouse characteristics that impeded couple adjustment. Male partners described often feeling inadequate in their roles as caregivers. This prompted becoming solution-driven. In the context of feeling helpless, many men fell into the trap of attempting to problem-solve without sufficiently listening to or empathizing with their partners' feelings. Some spouses came to realize that trying to arrange a fix did not compensate for a lack of understanding of how to support a woman through breast cancer and was generally counterproductive. It is not difficult to fathom that anger was a prominent feeling experienced by many spouses. Unchecked anger was another response seen as unproductive to adjustment. Some spouses reported that it was hard not to be angry at a partner for having cancer. As

irrational as this may be, it became difficult to distinguish anger at the patient from anger at the disease. The impeding dynamic of this is that the patient's perceived fragility made it difficult for men to express anger openly. The unexpressed anger tended to be expressed indirectly, which, in turn, generated tension in the relationship.

Along these lines of *stuffing* one's feelings, Fergus and Gray (2009) indicated that not reaching out was another problematic area. Without an acceptable outlet for strong feelings, some spouses turned inward and withdrew from their partners. Sometimes this was related to withholding expressions of grief or worry, so as to not burden their already stressed partners. However, a number of men also indicated emotional incompetence rooted in masculine socialization. This was evidenced in their disinclination to share their feelings with family, friends, or professionals as well. Some noted that talking with others at this level did not even occur to them as an option because it was so far out of their normal frames of reference. Not prioritizing the patient was also a characteristic that was discussed. Despite this lack of prioritization of caring for one's own emotional needs and reaching out to supports, some men still admitted to *feeling sorry* for themselves that they had to take a backseat to their partners during the course of the illness. One spouse discussed how his frustration resolved once he made a conscious decision to accept that, for the time being, his partner was the priority and needed to be the focus of attention for both of them. This change in attitude helped to mitigate his experience of personal loss. Although most spouses were able to cope with the distresses encountered with breast cancer, Walsh, Manuel, and Avis (2005) found that the majority of relationship separations and terminations were initiated by the spouse and the predominant reason for doing so was an inability to cope with the problems brought on by the diagnosis and treatment of breast cancer.

Fergus and Gray (2009) divided the relationship dynamics that can impede couple adjustment into the categories of pitfalls and challenges. Pitfalls were relationship processes that tended to be associated with greater relational distress and poorer adjustment to the illness. Navigating pitfalls often included recognition, trial, and error, and, therefore, had implications for the couple's development. Communication barriers were major pitfalls for couples. Certain topics were not easy to broach, such as the woman's mortality, and many couples found the possibility of death too difficult to acknowledge openly. Without a means of introducing death or other difficult experiences into their discourses, couples tended to avoid the topics all together. Women reported feeling silenced by partners who either dismissed or minimized their fears. Spouses reported feeling ineffective in offering reassurance to their partners. A common process occurring in these situations was the tendency for both partners to withdraw into themselves at times. Withholding-withdrawal is a pitfall that often was prompted by a lack of skills to effectively communicate with a partner about feelings of guilt. One woman stated:

There's guilt, you know. I'm getting cancer, and now it's not only your life that's changing, but it's your family and your friends' and your husband's...their life has to change because of what you have. It's like cancer is mine, I own it, now I have to share it...unwillingly (Fergus & Gray, 2009, p. 1317).

According to Fergus and Gray (2009), guilt was also often a contributor to the pitfall of under-burdening. Patients did not want to add to the burden of a spouse who was juggling multiple responsibilities; spouses did not want to add to the burden of partners who were dealing with cancer treatment. Each was attempting to be strong for the other; however, not expressing vulnerabilities had the effect of decreasing the potential for emotional intimacy and creating greater distance between partners. When partners lacked a shared philosophy in relation to the

illness, they were disadvantaged in their efforts to cope with breast cancer. When partners are unable to find common understanding, they may face the pitfall of having conflictual intentions. Common conflictual areas include decision-making regarding course of treatment and discrepant views over the timeline of the illness and recovery. The absence of a unified perspective impeded dyadic coping and was a source of frustration for both partners. These communication barriers interfered with collaborative problem-solving and the exchange of mutual support.

Unlike pitfalls, Fergus and Gray (2009) suggested that challenges were generally unavoidable for couples; however, when successfully resolved, they tended to draw partners together and strengthen the relationships. Figuring out what was helpful or not to the other person was a process of trial and error for couples. The challenge of negotiating support was difficult for many couples. When spouses' attempts at care-giving were not well received by their partners, then a sense of inadequacy was reinforced, and it became hard for them to empathize with their partners. Failed support attempts could become viciously circular and self-perpetuating.

Another area of negotiation concerned each partner's capability in accommodating change in the other. The extreme nature of the situation revealed different qualities in each partner as he or she tried to cope. Partners' inability to be flexible and supportive of each other's endeavors usually led to tension in the relationship. In contrast, when spouses were able to appreciate the significance of a partner exploring new directions, then not only did the relationship involve incorporating the changes, but it also became enriched by them. Subtle emotional and behavioral shifts in partners also had to be accommodated. One man spoke of how observing differences in his partner's character that were so at odds with his perception of her as a strong, confident woman that impacted his attraction towards her negatively. He

commented, “She’s a very very strong person, a person who is always in control... But she wasn’t that strong at that point, and I’d never seen her like that. It struck home...how really bad the situation was. And from then on I started seeing her different, she wasn’t the same person” (Fergus & Gray, 2009, p. 1318).

Couples reported that the demands of the illness took precedence over all else, including their time alone without their children. They needed to find ways to focus on their relationship again, and some couples found it difficult to ask others for help because this did not seem to be a valid reason to ask others to extend themselves. In addition to this, couples spoke of needing time to do more fun activities. This was related to wanting time as a couple and a break from the demands of the illness. One man spoke of wanting to interact with his wife without discussing worries or concerns, which had become the focus of their conversations since the diagnosis (Shands et al., 2006). For many, the interference with quality relational time together also impacted the couples’ sexual life.

Fergus and Gray (2009) commented that coping with sexual disruption caused by the stress of the illness and the side effects of treatment often presented a major challenge for couples. Although both partners may admit to struggling with how to retain intimacy and feelings of closeness without their usual sexual routines, for the male partners this tends to be particularly difficult. Some men compensated for the sexual loss through more frequent masturbation. Some men noted that they found it difficult to sustain an erection while engaging with their partners. One man attributed his inability to perform to the “constant reminder” (Fergus & Gray, 2009, p. 1318) of cancer and the symbolic significance of the mastectomy scar. Other men described how their roles of caregiver set up a type of “parent-child dynamic” (Fergus & Gray, 2009, p.1318) which made it difficult to see their partners in sexual ways.

Women spoke of the disruptions caused by physical pain of surgery and treatment, as well as their self-consciousness regarding the appearance of their bodies following surgery. Thus, it was difficult for many couples to separate their sexual interactions from the illness. One individual believed that it would have been difficult to adapt to the sexual changes without acknowledging the fears of death, loss, and separation that were present during intimacy. The challenge of incorporating death and separation into the couple's daily life extended beyond sexuality. Anticipatory loss was often an unspoken undercurrent in the life of the couple, particularly when the woman's disease was more advanced. One woman added, "It's me that's dying. So the things that go through your mind...what if he got married again. I'm not part of that, I'm not in his life...you realize how separate you are and what a personal journey cancer is. As much as your family or husband can support you, it's still a personal journey" (Fergus & Gray, 2009, p. 1318).

Couples can experience distress in response to concerns related to the impact of the breast cancer on their children. Specifically, concerns involved trying to read the impact; worrying about the lingering effects; and not knowing how to respond. Parents spoke of not knowing what the impact of the illness was on their children, especially when the children did not talk about the breast cancer. Some verbalized confusion over how to assess behavioral changes they observed in their children and whether these were attributable to the breast cancer. Parents voiced concern that their children's needs may not have been fully met during the intense early phases of the illness, and they worried about lingering effects and delayed consequences of this. Parents also wanted to know if their children needed help, and, if so, the best way to provide that help. They felt unsure about how to respond to these issues (Shands et al., 2006).

Shands et al. (2006) discussed couples concerns related to managing the threat of breast cancer. Couples reported feeling vulnerable and incompetent as to how to manage the presence of cancer in their lives, including how they made treatment-related decisions. Distress was associated with lack of understanding regarding preventing recurrence; fearing recurrence; and needing assistance in seeking medical information. Couples often wanted “the answer” (Shands et al., 2006, p. 1061) about ways to prevent recurrence and tried to determine the factors that may have caused the cancer. Many had done research on behaviors and health habits that might contribute to a cancer recurrence, but they continued to wonder if there were any other precautions to take. One couple expressed fear about recurrence explicitly. The spouse explained it this way, “The fear...and the not knowing and the mental stress...that’s dominating everything right now” (Shands et al., 2006, p. 1061). Another couple needed help seeking alternative medical opinions regarding treatment options. Couples often do not know where to go in addition to the primary treatment team they have already been working with.

Kim et al. (2008) contended that, although each person’s psychological distress has been shown to be the strongest predictor of one’s own quality of life (actor effect), one’s partner’s distress (partner effect) and the (dis)similarity in distress levels of the couple also played a significant role in one’s quality of life. For male partners, dissimilarity in distress showed a beneficial influence on their well-being and quality of life. This was often the result when a male partner was emotionally disconnected from his ill spouse and, therefore, was less distressed by the impact of breast cancer. In addition, a disconnected male is less likely to suffer from emotional abandonment when his ill spouse is unable to be attentive to him. He may also be more likely to have his time and energy freed up, which may result in better self-care and physical functioning. In couples in which the levels of distress were similar, the extent to which

a woman psychologically adjusts to the situation plays a role in her spouse's well-being and quality of life.

Dorros, Card, Segrin, & Badger (2010) suggested that close network members (e.g. kin, spouses) experience increases in distress as the family member with major illness becomes more distressed, reflecting interdependence within the family system. This is consistent with Broderick's (1993) family-systems theory (as cited in Dorros et al., 2010). Dorros et al. (2010) were able to document a pattern of influence whereby the interaction of high levels of depression coupled with high levels of stress in women with breast cancer were significantly associated with lowered physical health and well-being in their partners. An explanation offered for these results is that the partners' physical health suffers due to increased activation of stress. This agitates normal physiological processes and activates disturbances in physical health. They concluded, "Our findings suggest that cancer patients' heightened depression and stress not only predicts their own compromised health but the health and physical well-being of their partners" (p. 124).

Feldman and Broussard (2006) suggested that "although dyadic coping and chronic illness studies depict that both partners are affected by each other's coping styles, no research explores the factors that enable some male partners of breast cancer patients to adjust more successfully than others" (p. 119). They referenced the work of Bodenmann (1997) to explain that stress is dyadic if it affects both partners and takes into consideration both verbal and non-verbal stress signals of one partner and the coping reactions of the other partner to these signals. Given the challenges of coping with breast cancer, many men experience depression. Segrin et al. (2006) reported that there is evidence that men had higher symptoms of depression if a partner's treatment involved mastectomy. In addition, men generally exhibited poorer mental health as their partners reported more distress with symptoms. Depressed individuals typically

have difficulty engaging in and maintaining a relationship-focused approach to problem-solving with their partners. Positive dyadic coping strategies involve this approach when partners are interacting. Depressed individuals often display disengagement and isolation, which makes constructive engagement difficult for them. Increased levels of hostile dyadic coping patterns in men often result in poorer adjustment in relation to higher illness intrusiveness (Feldman & Broussard, 2006). However, Segrin et al. (2006) assert that relationship satisfaction proved to be beneficial to men's mental health as they coped with a partner's breast cancer diagnosis and treatments.

Manne and Badr (2008) noted that traditional researchers have sought to describe the level of distress experienced by the patient. However, over the 20 years, the recognition of the importance of viewing cancer in the family context has encouraged researchers to assess and compare patient and partner distress levels as well as gender differences in distress. More recent reviewers have specifically suggested that the differences in distress levels between patients and partners can be accounted for by gender differences in the reporting of psychological distress rather than role differences (Hagedoorn et al., 2008). The previous literature has also been focused on studies of the psychological impact of care-giving on spouses and evaluation of the impact of cancer on the general quality of marriage (Kim & Carver, 2007). Manne and Badr (2008) identified what they believed was missing from the literature, which is the adoption of a couple-level perspective whereby the cancer experiences are viewed in relational terms. Implicit in this perspective is the notion that the illness is a process that happens to the couple and, thus, focusing on the patient and partner separately may not be as beneficial from a theoretical and clinical viewpoint as focusing on the relationship. In addition, Manne and Badr took into consideration the belief that the marital relationship is a resource for partners to draw from

during difficult times and included recognition of the contributions partners make to preserve and even improve the quality of the relationship. Viewing cancer as an opportunity for enhancing the relationship prompted Manne and Badr to refocus attention onto the interactions between partners and how these affect the couple's sense of closeness and adaptation to cancer. They affirmed, "We believe that identifying and targeting key relationship processes can facilitate the design of efficacious, couple-focused interventions aimed at improving psychosocial adaptation to cancer for both members of the couple" (p. 2543).

Coping and Adjustment

In response to experiencing distress and facing vulnerability, couples may employ a number of coping strategies in their efforts to adjust to and cope with the challenges they face. Not all of the strategies utilized are helpful or effective. One of the ways that couples manage their worries and concerns is to turn to one another for emotional support (Manne et al., 2007). The degree to which partners share their concerns has been shown to impact the couple's adjustment to breast cancer (Northouse, 1988). Despite the benefit that couples may derive from sharing their concerns, communication of these issues can be difficult and problematic. This can lead to hesitation to engage in open discussions. As a result, couples may engage in protective buffering which was defined as efforts to protect one's partner from upset and burden by concealing worries, hiding concerns, and yielding to the partner to avoid disagreements (Manne et al., 2007).

Patients' uses of protective buffering have been associated with increases in their own psychological distress but not in their partners' distress, whereas partners' uses of protective buffering have been associated with their own as well as their spouses' psychological distress. Interestingly, partners hid negative feelings and avoided conflict more often than patients. This

may be a reflection of gender differences in the adoption of protective buffering as a coping strategy. In addition, it could also suggest that partners had higher motivation to shield the ill partner from additional distress. Regardless of the positive motivation and good intent, the level of distress felt as a result of the use of this coping strategy was increased further when couples perceived themselves to have satisfying partner relationships (Manne et al., 2007). This is consistent with social-cognitive processing theory in postulating that hiding concerns and less disclosure about a difficult life experience are detrimental to one's mental health, and constraints on the disclosure process do not facilitate recovery (Janoff-Bulman, 1992). When patients in satisfying relationships engaged in protective buffering, it was more detrimental to their well-being than when patients in less-satisfying relationships engaged in the same behavior (Manne et al., 2007).

When couples are able to engage in open communication, the process of disclosing can have the potential to increase feelings of closeness and intimacy. Examining Reis and Shaver's (1988) interpersonal-process model of intimacy in the context of breast cancer, Manne, Ostroff, Rini et al., (2004) suggested that there are gender differences associated with the process of intimacy in this context. From this perspective, feeling close during disclosures about breast-cancer-related concerns was consistently related to feeling understood and cared for regardless of the partner's gender, but the role of self- and perceived partner disclosure in intimacy differed by gender. The female partner felt closer when her male partner disclosed, and she perceived these responses as more caring and accepting. The male partner felt close when both partners disclosed, and he felt his partner responded in a caring fashion. The process of intimacy can be influenced by the cancer diagnosis. Manne, Ostroff, Rini et al. (2004) stated, "In couples in which one partner is seriously ill, the disclosure of the ill partner may not set the tone for

perceived intimacy because the level of disclosure of the ill partner is going to be high. Rather, it is the decision of the healthy partner to disclose or not disclose that determines the sense of intimacy” (p. 596). This was evidenced in the fact that, although patients reported a higher level of self-disclosure, how the partner chose to disclose was more salient to the patient and thus more predictive of the patient’s feelings of closeness.

The ways in which couples communicate about breast-cancer related issues also has an impact of the couples coping. Manne et al. (2006) found that couples typically engaged in three communication strategies, which include mutual constructive communication, mutual avoidance, and demand-withdraw communication. All three of these communication methods influence the levels of distress within couple relationships. Couples who engaged in more avoidance and demand-withdrawal communication methods when discussing cancer-related issues experienced higher levels of personal distress and decreased relational satisfaction whereas couples who were able to utilize mutual constructive communication experienced lower degrees of distress and more relationship satisfaction. Walsh et al. (2005) found that some women who were contemplating separation from their partner as result of the distress associated with breast cancer identified communication avoidance as a contributing factor. This pattern was consistent beyond the diagnosis and treatment phases into survivorship, suggesting that the transition to survivorship poses challenges for couples that continue to require them to negotiate solutions together.

Similarly, Kayser, Watson, and Andrade (2007) proposed two patterns in the relational-coping process: mutual responsiveness and disengaged avoidance. Their conceptualization of dyadic coping was influenced by Bodenmann’s (1995, 1997, 2005) systemic-transactional theory which involved the proposition that coping is a stress-management process in which partners

either ignore or react to each other's stress signals to maintain a level of stability in the relationship on the individual and dyadic levels. Each partner's well-being mutually depends upon the other partner's well-being as well as upon the couple's ability to use resources in the social environment. Kayser et al. (2007) expanded this framework of dyadic coping by presenting a model to view dyadic coping as a process that varies according to how couples appraise the cancer-related stress, communicate about it, coordinate their coping efforts (both behavioral and cognitive strategies), and make meaning from the cancer experiences. In terms of mutual responsiveness, these couples often assessed the stress as *ours* and talked about the breast cancer as changing their lives as a couple. The appraisal of the disease as a *we-stress* did not necessarily mean that both partners were identifying the same aspects or changes as being the most stressful. This disagreement did not mean that the couple was not coping together or were less relational in their coping. An important characteristic of mutually responsive couples is their abilities to accept differences in their perspectives. The couples using mutually responsive coping attended to each other's emotional and physical needs in a coordinated manner to manage the illness. Both problem-focused (dealing directly with stress demands) and emotion-focused (managing or processing feelings about the stress) coping behaviors were used by these couples. Through mutually responsive coping there was growth, both individually and as a couple. Couples identified a strengthening of the relationship or a change in their priorities as positive outcomes of the illness (Kayser et al., 2007).

With regard to disengaged avoidance, couples who engaged in this form of coping tended to appraise the breast cancer as an individual stressor. Responses were often in the form of *I statements* even in the cases in which they were specifically asked about changes *as a couple*. The responses often referred totally to the partner's own emotional reactions to the stress and

conveyed little recognition of the other partner's reactions. Disengaged-avoidant couples coped by avoiding or denying the stress of the disease. The denial on the part of one or both partners may be functional to some degree, but does not allow for support of one another's coping or coping together. Avoidance of dealing with the cancer directly also carried over to not talking about it to their families. The partners were frequently trying to protect one another from stress and buffering their families. Their own disengagement led to disengagement from others. The result was that these couples were rarely able to identify a positive as a result of the diagnosis, and, if they did, it was related to the individual as opposed to the couple. These couples rarely mentioned how cancer strengthened their relationship. If they were closer, they would not attribute it to going through the cancer experience (Kayser et al., 2007).

Kayser et al. (2007) also identified relational qualities that facilitated the coping as a couple. Among these, relationship awareness, mutuality, and authenticity were the most important processes that facilitated the communication between partners, so they could talk about the cancer experience and work out agreeable ways to manage both the physical and emotional demands of the illness. Relationship awareness, as defined by Kayser et al. (2007), involved thinking about one's relationship in the context of the illness. They found that husbands were more likely than wives to talk in reference to the relationship and talk in relational terms when appraising the stress. This may be the result of the stress being indirect for the husbands, and, thus, the appraisal of the stress includes the wives in relation to themselves. Wives may focus on their own physical and emotional well-being because they are dealing directly with the stress. This is not to say that the women were not aware of the impact of illness on partners (Kayser et al., 2007).

Coping with cancer can be a new and overwhelming experience for couples. As such, it is critical that each partner has the ability and desire to be open and honest with feelings and needs. Kayser et al. (2007) defined authenticity as the disclosing of genuine feelings and not hiding them. The results of their examination of the process of coping from a relational perspective indicated that authenticity appeared to facilitate relational coping by allowing partners to be aware of each other's feelings and needs in relation to the cancer, and, ultimately, helped them to respond to those needs in an effective way. Associated with this was mutuality, the third quality identified in the narratives. This process involved empathy and a way of relating in which each partner was participating as fully as possible in shared experiencing. According to Kayser et al. (2007), this fostered effective coping by providing the support needed to deal with the emotions related to a serious illness. Furthermore, they stated, "Learning more about the ways in which relational coping occurs will help further our understanding of the ways in which we can assist couples to manage cancer as a 'we-disease'" (p. 417).

Picard, Dumont, Gagnon, and Lessard (2006) contended that clinical observations highlight the reality that the threat of loss generally initiates a re-evaluation of the marital relationship on the part of the couple and leads to changes in the relational dynamic and in the process of developing the marital bond. These theorists proposed that the development of the relational bond occurs in three primary phases: idealizing, differentiating, and taking responsibility. In short, these phases each has its own characteristics and influence the strategies used by the couple to adjust to the life events that affect them. Similarly, the couple's relationship is founded on a dynamic process in which the challenge is for partners to maintain a balance between forces conducive to maintaining individual liberty and those conducive to safeguarding the couple's bond. The way in which this inherent duality is resolved can contribute

either positively or negatively to the couple's cohesion. The manner in which the couple as a dyad deals with the disruptions and demands related to breast cancer and its treatments can be understood within the context of this framework.

Picard et al. (2006) distinguished the principle issues confronting couples in the first year after the breast-cancer diagnosis as well as the strategies they used to deal with these issues. These issues and coping skills are among the most widely identified by couples and researchers in the field of breast cancer research. For ease in managing the extensive amount of information on these topics within the literature and conciseness of reviewing them, each issue and the strategy used to address it will be discussed simultaneously. Due to the prevalence of couples identifying these issues, the review will include a more detailed discussion.

The first issue was related to dealing with the unknown. Following diagnosis, couples must attempt to comprehend a vast amount of information related to the disease itself and its seriousness, therapeutic treatments, and likelihood of a cure. This can be a frightening experience and leave couples feeling vulnerable. Coping is focused on mastering the unknown and reducing the associated anxiety. The strategy used by couples was sharing stages of the information-gathering and treatment process (Morgan et al., 2005; Picard et al., 2006). Essentially, couples found it helpful when both partners were present during medical visits and treatments. The patients reported feeling more supported with their partners present. Partners felt that being involved demystified the disease and their partner's experiences for them and allowed them to feel useful instead of powerless. As a result, couples reported that they engaged in more conversations and sharing (Picard et al., 2006).

The next issue was in dealing with the threat of loss and the uncertainty of the future. Couples experienced shared anxiety related to the possibility of death and the subsequent loss of

the marital bond. The disruptions in their visions of the future prompted couples to re-evaluate the depth of their feelings and their commitment to their marital bonds. Five strategies were used to confront this issue. First, many couples engaged in renewing their marital commitment and emotionally investing themselves more fully in their relationships. Each couple developed their own personal and creative means of demonstrating their mutual love. This had the effect of calming fears of abandonment and the threat of loss (Picard et al., 2006). Couples made it a priority to intentionally spend more time with each other and their families. Enjoying life and living in peace were two ways that couples identified improving their time together. Couples also sought out opportunities to laugh together and learned to find meaning in simple pleasures (Morgan et al., 2005). Another strategy involved partners each taking responsibility for one's own suffering. For women, this often entailed grieving her lost health and relearning how to take pleasure in life. For men, this generally meant accepting the possibility of losing his partner. These processes took place in the context of mutual support that allowed for privacy and respect for the other's subjective experiences. Taking care of one's self, the other, and the couple were also identified as adjustment strategies. Both individual needs and the couple's needs were taken into consideration. This supported the adaptability of the dyad itself. The development of balance between these individual and relational factors was couple-specific and varied with the stage of the disease and the demands of the situation (Picard et al., 2006).

The next strategy was called safeguarding zones of well-being in everyday life. Basically, this meant putting the different dimensions of the couple's lives into perspective in order to keep them from becoming too overwhelmed by the disease-related disruptions. Finally, as couples became aware of the finite nature of life and the future's uncertainty, they tended to re-evaluate the value of their relationship as a couple. The strategy of providing meaning in the

life of the couple often involved reflecting individually and as a couple on the meanings of their relationship then and in the future. The uncertainty of the future caused them to place high value on their relationship and the moments shared. For some, it also led to gained appreciation and respect for one's partner (Walsh et al., 2005). Achieving shared dreams became a priority for some (Picard et al., 2006). According to Morgan et al. (2005) couples frequently described adjusting together as surrendering to the unknown and to the *new normal* after the breast-cancer diagnosis. This entailed embracing the reality that this life-changing experience had altered their lives forever. The process involved setting new priorities based on new perspectives on life and their relationship.

The third issue was in reference to dealing with the woman's personal transformations in the couple's sex life. Most couples reported experiencing decreased sexual desire and frequency. These changes were directly linked to the woman's physical changes (tiring easily, scars, and pain) and to the impacts these had on her self-perceptions and self-esteem. Walsh et al. (2005) added that, in addition to physical pain and sensitivity related to treatment and side effects, unmet emotional needs contributed to sexual problems. The strategy established was related to the intimate relationship that a woman maintains with herself and was focused on assisting women to come to terms with their own bodies, sexuality, and femininity. The strategy of respecting the woman's illness trajectory and supporting her self-esteem was defined primarily by the adoption of a respectful attitude by men in recognition of a wife's vulnerable psychological state (Picard et al., 2006). Expressions of respect conveyed appreciation of the woman as a person and the relegation of aesthetic issues to a secondary status (Morgan et al., 2005). According to Walsh et al. (2005), the increased closeness some women experienced as a

result of the emotional support provided by their partners contributed to increased sexual intimacy. One woman stated, “We make love more now than before surgery” (p. 86).

The last issue identified through the interviews concerned organizing a social-support network. Although responses from loved ones can often be comforting, there are times when they can also be a source of disappointment and frustration. This is especially the case when responses are tension-laden stemming from loved ones’ difficulty coming to terms with the fact of the illness and its true impact on the couple’s life. Couples expressed their needs for relationships with loved ones to reflect the hopes that the couples nurtured. In order to cope with this, couples used the strategy of adjusting the forms of support to the couple’s needs. Essentially, what this strategy involves is a prioritization of calling upon those loved ones whom the couple deems to be positive sources of support and avoiding those viewed as being sources of tension. Picard et al. (2006) commented that “This study emphasizes that the bond of love plays an essential role in the adjustment process of couples confronted with breast cancer” (p. 131). Most couples appeared to draw on this bond to develop confidence in their abilities to deal with the issues associated with this disease and to transform this experience of suffering into a meaningful and constructive life experience personally and relationally. It was noted that several respondents affirmed that the couple in which “love existed before the disease” (p. 132) has a better chance of growing from the experience.

Theories and Couple-based Interventions

The following is a brief overview of theoretical frameworks that have been adapted to the context of breast cancer. Cognitive-social processing theory includes the premise that difficult life experiences challenge people’s beliefs about themselves and their environments and cause people to question those core beliefs (Manne et al., 2009). According to this theory, emotional

distress arises from the discrepancy between people's beliefs about themselves and their environments and the meanings that are inherent in the trauma. A reduction in emotional distress can be achieved by confronting, contemplating, and reevaluating the experience with the goal of adjusting one's beliefs. This integration is termed "cognitive processing" (Manne et al., 2009, p. 51). A common way that people process events is by sharing their thoughts and feelings about the experiences with others. Despite the fact that individuals often report a desire to share with others, Manne et al. pointed out that there is little evidence that talking alone assists adaptation. They contended that how others respond to these disclosures can either aid or interfere with effective cognitive processing. This process has been labeled social modulation of cognitive processing. Cognitive-social processing theory in the context of breast cancer is based on viewing the marital relationship as an important resource in adaptive cognitive processing on the part of the individual with the cancer. Key constructs include disclosure, processing, and how others facilitate an individual's processing of the events associated with cancer. This theory involves the adoption of an individual-level conceptualization of the role of the marital relationship, and, therefore, there is little attention given to couples' interactions (Manne & Badr, 2008).

Similarly, social-support theories also involve the inclusion of an individual-level conceptualization. These theories are based on the view of marriage as a resource for the individual with cancer. Researchers have been successful in identifying behaviors engaged in by others that are perceived as either supportive or unsupportive to the patient (Manne et al., 2009; Manne, Ostroff, Rini et al., 2004). Also in the category of individual-level perspectives is equity theory focused on individual psychological adaptation. However, a key advantage of this theory

is that it illustrates the exchange of support between partners and the values that partners place on the level of equity in their support-related exchanges (Manne & Badr, 2008).

Whereas resource theorists focus on the individual as the unit of study and conceptualize the relationship as a resource to draw on, dyadic-level theorists focus on the couple as a unit of study and examine the ongoing contributions that both make to preserve or improve the quality of their relationship as they cope with the cancer experiences. Relationship-resilience models involve viewing the cancer as a stressor that affects both partners, and making efforts to maintain and/or enhance the relationship may play an important role in couples' adaptations.

Understanding the behaviors that help couples enhance the quality of their relationship is important and is promoted through the encouragement of relationship awareness. These include, but are not limited to, interacting in an optimistic manner, making statements of commitment, and sharing daily living tasks (Canary, Stafford, & Semic, 2002, as cited in Manne & Badr, 2008). The interpersonal process model of intimacy and intimacy theory (Manne, Ostroff, Rini et al., 2004) was discussed in the previous section. In short, according to this model, both self-disclosures and partner disclosures contribute to the development of intimacy to the degree to which the speaker perceives his or her partner to be responsive (i.e., caring and understanding). Behavioral-marital-theory models involve the evaluation of how relational partners influence one another. Behavioral exchange, improving adaptive communication, conflict resolution, and problem-solving skills are considered important processes of relationship functioning and satisfaction. As such, these elements are targeted in behavioral approaches to marital therapy. As identified by Manne et al. (2006), less pressure-withdraw communication, less mutual avoidance, and greater mutual constructive communication of cancer-related problems have been associated with less distress and greater marital satisfaction for both partners.

Manne and Badr (2008) proposed the relationship-intimacy model of couples' psychosocial adaptation to cancer. This is an overarching, heuristic model based on the adoption of a meta-analytic, dyadic-level approach. The model includes two categories of relationship processes: *relationship-enhancing* and *relationship-compromising* behaviors. This integrative model involves three relationship-enhancing processes, which have components associated with the various theories discussed above. The first of these is reciprocal disclosure around concerns and feelings regarding cancer experiences. The second is partner responsiveness, which is defined as feeling understood, cared for, and accepted by one's partner. The third process is relationship engagement, which is an overarching term used to represent a view of cancer in relational terms and includes the engagement in behaviors that are aimed at sustaining or enhancing the relationship while coping with cancer. Relational engagement is characterized by an awareness of the challenges that cancer poses and openness to discussing these, along with aspects of the relationship that have changed or need to change. In addition, it involves making efforts to maintain components of the relationship that are important to either partner during the illness (Manne & Badr, 2008).

Relationship-compromising behaviors, which have been associated with reduced marital quality and/or psychological distress, were divided into three broad categories: avoidance, criticism, and pressure-withdraw. Avoidant responses are subtle, insensitive behaviors, such as conveying discomfort when a partner is attempting to talk about the illness. Critical behaviors are intentionally unsupportive reactions, such as a partner criticizing how a patient is coping with cancer. Finally, pressure-withdraw occurs when a partner pressures the other to discuss a cancer-related problem and the other partner withdraws. Relationship intimacy was selected as the primary way that relationship-enhancing and relationship-compromising behaviors exert their

effects on couples' adaptations. Relationship intimacy was defined as the experience of feeling close to and cared for by a partner with regard to the cancer experience. The primary outcome in the model is couple-level psychological and marital adaptation. Manne and Badr (2008) included marital adaptation along with distress in their conceptualization because a dyadic perspective is carried into all aspects of the relationship-intimacy model.

Based on their conceptualization of relational intimacy, Manne and Badr (2008) developed and pilot-tested an Intimacy-Enhancing Couples' Therapy (IECT) for women diagnosed with early-stage breast cancer and their partners. This is an intervention to target relationship-enhancing behaviors by enhancing reciprocal disclosures and responsiveness, assisting couples in viewing the illness in relationship terms, enhancing relationship maintenance activities, and encouraging the couple to consider changes in the priorities in their relationship both pre-cancer and post-cancer. Relationship-compromising behaviors are also addressed through structured training and practice of adaptive communication skills with therapist feedback. The preliminary data suggested that IECT has positive potential as a couple-based intervention in that it increased relationship-enhancement behaviors, increased relationship intimacy, and reduced couples' distress levels.

Relationship Enhancement (RE) (Baucom et al., 2009) is another couples-based intervention created to assist couples coping with breast cancer and to improve both individual and relationship functioning through effective communication and joint decision-making. RE is a limited treatment which involves a focus on teaching the couple to function adaptively as a unit in approaching breast cancer rather than intervening in relation to individual coping. According to Baucom et al.'s pilot-study results, couples who engaged in RE changed in explicitly positive ways, showing gains in posttraumatic growth. Couple-coping training (CanCOPE) (Scott,

Halford, & Ward, 2004) aids in increasing supportive communication and coping efforts in couples with the goal of decreasing psychological distress and increasing avoidance of intrusive negative cognitions. CanCOPE was designed to help the couple conjointly to cope with cancer and support one another. In this intervention, supportive communication includes teaching couples the speaker-listener skills of validation, self-disclosure of thoughts and feelings, and empathic listening. Partner support entails partners identifying behaviors they can do, or say, to help each other to cope. They are taught how to accurately monitor and evaluate the effectiveness of their support attempts, recognize and challenge negative thoughts, and address unhelpful relationship- or self-schema. Couples were encouraged to discuss their goals for resuming mutually satisfying sexual lives and were provided with counseling on problematic areas. Finally, couples in CanCOPE were assisted to explore the existential meanings they attached to their experiences of cancer. Scott et al. contended that CanCOPE produced a large increase in observed couple-coping supportive communication, improved couples' coping efforts, and decreased psychological distress and avoidance of intrusive negative cognitions. In addition, there was improvement in women's sexual self-schema, intimacy with their partners, and perceptions of their partner's views of their bodies.

Emotionally Focused Therapy (EFT) is an evidence-based, time-limited therapeutic approach which was designed to treat relational stress and which is firmly rooted in attachment theory (Naaman, Radwan, & Johnson, 2009). EFT involves viewing the marital relationship as a bond with another person that is irreplaceable. One's partner is considered to be the primary source of support, comfort, and a secure base from which the physical and emotional stress of illness can be faced. EFT practitioners regard distressed relationships in terms of insecure bonds whereby attachment needs for physical or emotional closeness are not met. The overarching goal

of EFT is to foster the creation of secure bonds between partners which, in turn, facilitates emotional connection and resilience in the face of adversity. By focusing on the quality of attachment exchanges and promoting emotional engagement, EFT practitioners offer partners an opportunity to respond to each other in more supportive ways, thereby creating more secure connections. Secure connections, in turn, facilitate resilience. Partners learn to step away from reactive cycles of negative emotions, express their needs more clearly, and use one another for support in regulation of the fear, helplessness, anger, and uncertainty often associated with breast cancer and facing the future. As the positive interactions became enacted, the partners experienced a greater sense of security and increased abilities to tolerate and cope with adversity (Naaman, Radwan, & Johnson, 2009).

Although most of these interventions are in the early stages of development or are considered to be pilot projects at this point in time, they represent progress in the field of breast-cancer research. Many of these researchers indicated that these interventions were the product of increased awareness of the importance of considering the breast cancer experiences from a relational point of view (Baucom et al., 2009; Kayser, Feldman, Borstelmann, & Daniels, 2010; Scott, Halford, & Ward, 2004). Tedeschi and Calhoun (2004) suggested that, although currently scarce, interventions that involve techniques to promote benefit-finding have been identified as one possible pathway to better overall outcomes for survivors and are worthy of continued development. For example, cognitive restructuring may help increase positive reframing while decreasing pessimistic appraisals (Antoni et al., 2001). Expressive writing and other therapy techniques may assist survivors with processing the emotions associated with the illness, which, in turn, may promote benefit-finding (Stanton et al., 2002). Among persons with a religious

affiliation, the use of religious coping, which often entails benefit-finding, may promote growth as a result of engaging in and overcoming the struggles of breast cancer (Carver et al., 2009).

Positive Change, Benefit-Finding, and Posttraumatic Growth

Many breast cancer survivors have described the experience of positive change and other psychosocial or existential benefits after their experiences with cancer (Calhoun & Tedeschi, 2006; Manne, Ostroff, Winkel et al., 2004; Weiss, 2004). Carver, Lechner, and Antoni (2009) found that the ability to find benefits from an illness contributed to better adjustment to the illness and much research has lent support to this view. With regards to people with various types of cancer, researchers have found links between benefit-finding and lower levels of distress, greater well-being, less anxiety, higher self-esteem, greater life satisfaction, and estimates of future life satisfaction (Carver & Antoni, 2005; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Tomich & Helgeson, 2002, 2004; Urcuyo, Boyers, Carver, & Antoni, 2005). Cordova et al. (2001) noted the possibility that a greater threat from the experience of breast cancer results in a “greater...opportunity for growth” (p. 176). Similarly, Carver et al. (2009) found that the experiencing of benefit-finding is one aspect of a general sense of well-being for a person who is actively seeking to deal with a serious illness. Specifically, this appears to be true “if, and only if, the person is actually experiencing the health threat as a serious adversity” (p. 59). Therefore, a degree of life threat may be necessary for the growth process to unfold in persons with major illness (Calhoun & Tedeschi, 2004).

Benefit-Finding

It is important to distinguish the differences between benefit-finding and benefit-seeking. Sherman et al. (2010) suggested that effortful seeking tends to be more characteristic at earlier phases of the treatment trajectory. In their study of illness-meaning and breast-cancer outcomes,

they found that individuals who were actively searching for benefits during the diagnosis and early treatment phases of breast cancer did not necessarily demonstrate better adjustment or quality of life. Some individuals experienced negative effects such as preoccupation with seeking benefits and unproductive rumination that can amplify the distress already being experienced as a result of breast-cancer related issues (Park, Edmondson, Fenster, & Blank, 2008; Segerstrom, Stanton, Alden, & Shortridge, 2003, as cited in Sherman et al., 2010). Protracted, unfruitful efforts of seeking benefits during the crisis may also inhibit an individual's ability to seek or find benefits later on in the trajectory (Park et al., 2008). In contrast, individuals who reached a period of stable survivorship or completed primary treatment had reported having found benefits; however, few described actively searching for those benefits. Instead, benefit-finding was identified as a result of the healing process and practice of other positive endpoints such as gratitude, altruism, and improved health behaviors (Sherman et al., 2010). Research on benefit-finding has included the examination of positive findings as identified by breast-cancer survivors including a reappraisal of life and the meanings of life (Sears, Stanton, & Danoff-Burg, 2003), enhanced sense of purpose, positive self changes, and improved intimacy in relationships (Antoni et al., 2001; Weiss, 2004), increased engagement in spirituality practices (Bloom, 2002), improved health behaviors (Manne, Ostroff, Winkel et al., 2004), and reappraisal of goals and priorities (Bellizzi & Blank, 2006). Attribution of positive meanings to the experiences of breast cancer is indicative of increased self-knowledge and awareness as well as potential healthy adjustment (Taylor, 2000).

Calhoun and Tedeschi (2006) posed a similar idea. They suggested that trauma may overwhelm the psychological resources and disrupt the cognitive mechanisms necessary for processing the subtleties that can be influential in constructing perceptions of growth. A major

life crisis may lead an individual to engage in ruminative processes. When this rumination occurs in the immediate or early aftermath of the event, the processes of cognitive engagement are brooding and more intrusive than deliberate. These generally involve a preoccupation with mere survival. Further along the trajectory individuals are more likely to be able to engage in more deliberate processing which is involved with producing posttraumatic growth (PTG) (Calhoun & Tedeschi, 2006). The contents of this deliberate, reflective rumination process tends to be the repair, restructuring, or rebuilding of the individual's general sense of understanding the world (Nolan-Hoeksema & Davis, 2004). Posttraumatic growth is more likely to be experienced when an individual productively ruminates with a wide variety of content including the establishment of comprehensibility, which is more accessible later in the illness trajectory (Calhoun & Tedeschi, 2006).

The results of Manne, Ostroff, Winkel et al.'s (2004) investigation also indicated that some cognitive processes were related to patient growth while other cognitive processes were not related to growth. Women who contemplated more the potential reasons why they might have developed breast cancer had more growth over time. Engaging in more attempts to search for meaning in breast cancer was marginally associated with gains in patient growth. Manne, Ostroff, Winkel et al. (2004) noted that these results are consistent with cognitive processing theory built on the perspective that the more a person actively tries to make sense of an experience, the greater the chances for posttraumatic growth. However, other cognitive processes, including intrusions, searching for a cause for developing breast cancer, and positive reappraisal, were not associated with growth. A possible explanation is that patients discriminate between cognitive processes, and not all of these processes facilitate growth. They stated that "searching for a cause of one's breast cancer may lead to self-blame, which is associated with

poorer adaptation to breast cancer” (Manne, Ostroff, Winkel et al., 2004, p. 456). The differentiating factor between contemplating reasons for developing cancer and actively seeking causes was that contemplation allowed for broader consideration of both personal and external possible contributing factors while the need to have an answer, as associated with active seeking, often inhibited the ability to consider multiple perspectives other than perceived personal contributing factors.

In terms of emotional processing, Manne, Ostroff, Winkel et al. (2004) found that emotional expression predicted growth whereas emotional processing did not predict growth. Patients who evidenced above-average emotional expression about cancer over the three assessment-time points maintained higher posttraumatic growth across time. In addition, the interactions between time and emotional expressiveness indicated that it was the sustained effort to express emotions over time that was crucial to subsequent growth. In addition, expression of feelings may have facilitated growth through feedback about one’s personal strength and prompted consideration and recognition of ways cancer had changed one’s life. Lastly, at least one domain of growth--relationships with others--could be directly affected by emotional expression. Enhanced closeness in relationships could be a direct consequence of emotional self-disclosure. Supportive reactions to such expressions would directly reinforce the feeling that others are compassionate and thus enhanced closeness (Manne, Ostroff, Winkel et al., 2004).

In contrast, Manne and colleagues (2004) observed that emotional processing was not associated with posttraumatic growth. The findings regarding emotional processing were particularly interesting when considered together with the results indicating that emotional expression and one dimension of self-searching (contemplating the reason for breast cancer) were associated with growth. Taken together, these results indicated that cognitive self-searching

may facilitate growth more than emotional self-searching. There were two potential explanations for this pattern of results. First, these findings were consistent with the hypothesis that emotional expression about a stressful event that is accompanied by an attempt to make sense of the stressful event promotes posttraumatic growth. However, Manne, Ostroff, Winkel et al. (2004) did not evaluate the impact of engagement on both emotional expression and cognitive self-searching. Second, it is possible that the findings were a reflection of the measurement methodology. Although the measure of intrusions was lengthy, in this same study, the researchers assessed searching for meaning, searching for cause, and contemplating reason through the use of single-item measures. The measures of emotional processing and emotional expression were also relatively brief.

Posttraumatic Growth

The positive growth and discovered benefits of breast cancer-survivors are most frequently referred to as PTG within the literature, though, as previously noted, the terms are often used interchangeably (Calhoun & Tedeschi, 2006). Calhoun and Tedeschi offered an expanded framework which is the most comprehensive model of PTG to date, and their work has widely been referenced by researchers throughout the available literature. Initially, qualitative data were utilized in order to determine the broad categories of growth. This resulted in the identification of three general domains: changes in the perceptions of self, changes in the experiences of relationships with others, and changes in one's general philosophy of life. Factor analysis on subsequent data yielded a five-factor approach to PTG. These five sub-domains include personal strength, new possibilities, relating to others, appreciation of life, and spiritual change.

The first core domain is changed perception of self, which includes the sub-domains of personal strength and new possibilities. This area of growth has been summarized by the phrase “vulnerable yet stronger” (Calhoun & Tedeschi, 2006, p. 5). On one hand, this change represented the recognition of one’s own vulnerability and experiencing one’s world as more dangerous and unpredictable than previously realized. On the other hand, the encounter with a significant life disruption brought about a sense that one had been challenged and had survived the worst, which was a reflection of inner personal strength. Surviving a life crisis can instill confidence that one has the strength to also survive other crises that may present in living. Some individuals also reported the ability to consider new possibilities for their lives such as engaging in new activities, following a new path in life, and developing new interests.

Changes in the experiences of relationships with others and in ways of relating are the next domain and sub-domain. Calhoun and Tedeschi (2006) suggested that, while the trials of difficult life events can disrupt important relationships in one’s life, the results of coping with these events can include changes in relationships which can be experienced as positive. An example of this type of change is that a person who has experienced a crisis may view others differently than he/she did prior to the crisis. Survivors have described how their own experiences with a crisis had brought about a greater feeling of connection to others in general and an increased sense of compassion for others who suffer. Calhoun and Tedeschi indicated that their qualitative data suggested that the increased sense of compassion was associated with greater involvement in altruistic acts; however, this is yet to be examined empirically. This increased sense of closeness often includes greater sense of intimacy and freedom to be one’s self. Some individuals were more likely to disclose personal information including socially undesirable elements of one’s self or one’s experiences, despite the negative consequences that

may occur. Calhoun and Tedeschi summed this up with the statement, “You find out who your real friends are and those that stay you get a lot closer to” (p. 6). Family members also frequently reported a greater sense of closeness in the process of dealing with the illness (Calhoun & Tedeschi, 2006).

The final domain, changes in one’s philosophy of life, includes the sub-domains of appreciation of life and spiritual change. A changed sense of priorities and what is most important in life can be experienced as PTG. The goals and objectives that held importance prior to the crisis may no longer hold the same value while others attain greater significance. Calhoun and Tedeschi (2006) quoted one survivor who stated “We now realize that life is precious and that we don’t take each other for granted” (p. 6). Although this is experienced differently by various people, the common theme is the articulation of greater meaning found in intrinsically important priorities (e.g. spending time with people one cares about) and less importance given to extrinsic priorities (e.g. making financial gains).

Existential and spiritual growth has been identified by many survivors as the most significant elements of PTG. There has been variation in the time frame in which changes in this area occur, with some people experiencing changes earlier in the posttraumatic process than others. Calhoun and Tedeschi (2006) indicated that this may reflect the differences in the trajectories despite the quality or content of the experiences being similar. Although most people report positive changes in their philosophies of life, for some, the losses or sense of tragedy can induce them to lose faith and experience existential despair. This type of process did not predominate in the sample of persons studied in the United States (Tedeschi & Calhoun, 2004) because reports of positive spiritual change were not uncommon for them (Calhoun & Tedeschi, 2006); however, other researchers studying populations outside of the U.S. did find a slightly

higher occurrence of this experience (Maercker, 2004; Znoj, 2004, as cited in Calhoun & Tedeschi, 2006). This suggests that the spiritual component of this domain may not be relevant in some contexts; however, the general arena of questioning one's philosophy of life and purpose appears to be significant for many people dealing with life crises (Calhoun & Tedeschi, 2006).

There has been some debate regarding the relationship between PTG and adjustment. Calhoun and Tedeschi (2006) posited that the answer to the questions raised depends in part on the general approach that is taken to define and measure adjustment. Researchers have most frequently favored the view that adjustment consists of a decrease in distress and an increase in psychological well-being, and these are the desired outcomes for people who have encountered traumatic events. However, it may be beneficial to broaden the perspective of what constitutes adjustment to better represent understanding of the struggles and challenges people face in the aftermath of a crisis. Calhoun and Tedeschi suggested that engaging with and responding to the existential questions and questions about how to live life to the fullest may be more important than the reduction of psychological distress. The data on the relationship between growth and the distress-perspective of adjustment have been mixed and inconsistent; however, studies that included the broadened perspective resulted in data that showed evidence that the presence of PTG was an indication that people who experience it are, from their own points of view, living their lives in ways that are fuller and more meaningful. Calhoun and Tedeschi referenced the famous quote by Samuel Johnson, "The prospect of death wonderfully clarifies things" (p. 7) and added that the clarification may not result in a decrease in psychological distress, though it may indeed produce growth. Additionally, they stated that "some degree of psychological upset or distress is necessary not only to set the process of growth in motion, but also some enduring upset may accompany the enhancement and maintenance of posttraumatic growth" (Tedeschi &

Calhoun, 2004, p. 13). Janoff-Bulman and Berger (2000) contended that if the reality of death is prompted by the trauma, then an enhanced appreciation for what it means to be alive can ensue. “That which we may lose suddenly is perceived as valuable” (p. 35). The anxiety associated with the reality of potential loss remains, but can function so as to bring one’s attention on the fact of existence rather than non-existence. There is more consistent evidence that PTG is associated with increases in positive affect and other aspects of psychological well-being including higher level cognitive and motivational states. Urcuyo et al. (2005) found that breast-cancer patients who reported finding more benefits following breast cancer also experienced higher levels of interest, challenge, and fulfillment in everyday life.

Posttraumatic growth is not a universal experience, and determining how much and what kinds of changes constitute growth have been topics of debate among researchers. Estimates of the prevalence of growth have relied on quantitative assessments rendering percentage rates of occurrence and mean scores on established measures of growth, such as the Stress-Related Growth Scale (SRGS) (Park, Cohen, & Murch, 1996) and the Posttraumatic Growth Inventory (PTGI) (Tedeschi & Calhoun, 1996). There remain questions regarding what appropriate cutoff scores should be used to establish the criteria of growth (Calhoun & Tedeschi, 2006). Qualitative studies have also shown variability. Individuals reported differing degrees of growth and different kinds of growth as well as assigned varying levels of significance to the positive changes they experienced (Calhoun & Tedeschi, 2006; Salter & Stallard, 2004). Calhoun and Tedeschi (2006) contended that it is not sufficient to rely on single, precise scores on growth scales, although these may be useful for understanding aggregate data. A single specific score does not adequately allow for understanding the experiences of an individual.

We are not discouraging the use of cutoff scores to create groups for statistical analysis or similar uses to which such data points might be put. We are somewhat skeptical, however, of the degree to which average scores on inventories can capture the importance, quality, and centrality of the changes experienced by individuals in their struggle with trauma...The answer to the question “was the change sufficiently positive to merit the label posttraumatic growth?” is one that seems most appropriately answered by the individuals affected. (p. 15)

Sears et al. (2003) made a similar statement earlier, contending that the PTGI does not tap the domain of health-related benefits reported by samples of cancer patients as well as other medical samples and thus may not reflect the range of positive changes that participants in these samples endorsed.

Overall, the burgeoning literature shows a high propensity for positive life changes and personal growth following a cancer diagnosis. With specific regard to breast cancer, Sears et al. (2003) reported that 83% of women reported finding some benefit in their experiences. Less is known about the potential for positive growth among family members and friends of individuals dealing with breast cancer. According to Manne, Ostroff, Winkel et al. (2004), their study was the first to use a longitudinal design to examine posttraumatic growth after cancer among patients and their partners. The results revealed three key findings. First, shortly after diagnosis, patients and partners reported positive psychological changes, and posttraumatic growth increased for both patient and partner over the one and a half year period they were involved in the study. Second, cognitive and emotional processes contributed to increases in patient psychological growth, but fewer variables predicted partner growth. Third, the results related to couple-level growth illustrated the importance of considering the dyadic context when

attempting to understand patient and partner posttraumatic growth. Since Manne, Ostroff, Winkel et al. (2004) have conducted the most extensive research on posttraumatic growth after breast cancer and since there is limited other literature that includes partner and couple perspectives, it is worthwhile to review their study more comprehensively. Some data may overlap with information previously discussed; however, it is helpful in transitioning the discussion to partner and couple perspectives.

To briefly review Manne, Ostroff, Winkel et al.'s (2004) findings related to patient perspectives, the data analyses revealed that women with breast cancer reported positive changes in their lives relatively shortly after being diagnosed. Specifically, women reported that they developed closer relationships with others, appreciated their lives more, recognized their positive qualities and strengths, and developed a better understanding of spiritual matters. In addition, there were gradual increases in all posttraumatic growth domains over the one-and-a-half year period these women were involved in the study. Increases in posttraumatic growth were seen in a sense of personal strength, the realization of new possibilities, and new appreciation of life and for relationships with others. These findings are consistent with the findings of other researchers discussed earlier regarding the positive changes associated with the experiences of breast cancer (Antoni et al., 2001; Belluzzi & Blank, 2006; Calhoun & Tedeschi, 2006; Sears et al., 2003; Tedeschi & Calhoun, 2004; Weiss, 2004). Younger age was the only demographic predictor of posttraumatic growth. This had not been reported in previous studies of breast-cancer survivors. There were two potential explanations provided for this finding. First, a breast-cancer diagnosis is less normative, more threatening, and more distressing for younger women. The greater threat may prompt more growth. Second, younger women may be more aware of and influenced by

expectations to adopt a positive attitude and thus may evidence more growth (Manne, Ostroff, Winkel et al., 2004).

Partners also reported positive changes after the breast-cancer diagnoses. Gradual increases in all domains of growth over the period of one and a half years were noted for partners. The domains of growth evidencing the greatest gains were similar to those found for patients, with increased sense of personal strengths and new possibilities for life. Lower-magnitude gains were shown for appreciation of life, relationships with others, and spirituality. It is interesting, and not surprising, that partners reported less posttraumatic growth than patients. Because the direct threat to life and exposure to traumatic experiences such as chemotherapy and surgery were encountered directly by patients, the potential for growth was likely to be greater for patients than partners. With the exception of age, predictors of partner growth differed from predictors of patient growth, and they were as follows. Among the cognitive processes studied, intrusive thoughts, positive reappraisal, and emotional processing were all associated with more partner growth, but none of these variables was associated with patient growth. The effects of positive reappraisal depended both on the level of positive reappraisal and on time. Partners who reported below-average engagement in positive reappraisal reported significantly lower growth over time whereas partners who reported above-average engagement in positive reappraisal did not report a decline in their original levels of growth. These differences suggested that partners who work at finding the silver lining in the cancer experience may also find it easier to perceive positive changes in themselves and their relationships as a result of their partners having breast cancer. The effects of partner emotional processing also depended on the time of assessment. Partners who were below average in attempts to understand their feelings were more likely to report a significant decline in growth over time. As noted, the cognitive and affective variables

predicting partner growth were completely different from the variables predicting patient growth. Manne, Ostroff, Winkel et al. (2004) suggested that it was possible that the psychological processes underlying posttraumatic growth of individuals directly affected by a difficult life experience differ dramatically from those processes underlying posttraumatic growth of family members indirectly affected by the same life experience. However, as noted, it is also possible that the results reflect limits of the measures of cognitive and emotional processing.

One of the most interesting aspects of Manne, Ostroff, Winkel et al.'s (2004) study was the couple-level analyses. The results indicated five key findings. First, patients who reported higher levels of contemplation about the reasons for their cancer experiences evidenced more growth over time than their partners. This is consistent with the individual-patient model results. Second, the effect of physical impairment on discrepancies between patient and partner growth was a function of both level of impairment and time. Over time, patients who reported less physical impairment reported more growth than their partners whereas patient growth and partner growth were more similar if the patient reported more physical impairment. Third, the effect of partner positive reappraisal on discrepancies between patient and partner growth was also a function of time. There was an increasing level of congruence between patient and partner growth over time if the partner was above average in the use of positive reappraisal whereas there was decreasing congruence between couples' growth over time if the partner was below average in the use of positive reappraisal. Fourth, women whose partners were above average in their emotional expressiveness reported greater posttraumatic growth than their partners compared with women whose partners were below average in emotional expressiveness. These findings suggest that patient growth is not solely an individual activity. Patients report more growth when their partners discuss their own feelings. One explanation is that a more expressive

partner sets the stage for open communication and more comfort for the patient to discuss her concerns, thereby promoting patient growth. Finally, marital quality did not predict couples' growth. Manne, Ostroff, Winkel et al. (2004) noted that it was possible that marital quality was a consequence of growth rather than a predictor. In addition, it was possible that marital quality was stable particularly in the present sample of couples whose average relationship length was over twenty years. Thus, the variability in marital satisfaction might have been an issue.

The PTG model (Calhoun & Tedeschi, 1998) includes specification that the social environment can facilitate the engagement in constructive rumination by providing emotional support and new cognitive schemas. Because the contemplation of the trauma-related thoughts can be an emotionally painful process, a social environment that is comforting can help one continue the cognitive processing without becoming overwhelmed. The social environment may also be of assistance in exposing one to individuals who provide modeling of ways in which life can be satisfying and even improved in the new circumstances after the trauma. Weiss (2004) examined the association between PTG and social environment specifically among husbands of women with breast cancer. The results of the study supported Weiss' (2004) assumption that the social context in which husbands struggle with the trauma of their wives' breast cancer is related to PTG. General social support, positive qualities of the marital relationship, and the level of wife's PTG were significantly associated with husbands' personal growth. As Weiss (2004) reportedly expected, general perceived social support was positively associated with PTG. The more a husband felt that his global social environment included sources of acceptance, validation, and comfort, the greater was his level of personal growth. This association may be due to the role social support plays in modulating the physiological and emotional impacts of

trauma and in allowing an individual to engage in cognitive processing associated with PTG (Manne, Ostroff, Winkel et al., 2004; Weiss, 2004).

The positive qualities of marital relationships were also positively associated with husbands' PTG whereas marital conflict was unrelated. In the context of a supportive marriage, a husband is more likely to report benefits from the struggle with breast cancer, regardless of how much conflict the relationship endures. Of the two positive qualities of marital relationship, only depth of commitment was a significant predictor of husbands' PTG. According to Weiss (2004), it appeared that a husband's global perception of the positive role his wife plays in his life is more closely related with PTG than his wife's support. The fact that depth of commitment in the relationship was a significant predictor of husbands' PTG, rather than general social support, might indicate that the wife, despite being in the sick role, is the most important factor in the development of personal growth. Similarly, exposure to a wife who grew from the trauma was a predictor of husbands' PTG rather than exposure to any other person who perceived benefits from the struggle with breast cancer. It appears that exposure to a wife who makes positive interpretations of the negative cancer experience can be *contagious* or that there is transmission of GTP between marital partners.

CHAPTER THREE

Methodology

The focus of this study was to explore the lived experiences of couples following breast cancer and their perceptions of their development as a result of their shared experiences with the illness. Qualitative methodology, specifically a phenomenological research design, was utilized to gain understanding of couples' perceptions and interpretations of growth, particularly within the contexts of couple relationships. The objective of qualitative research is to understand the participants' meanings given to the life experiences or the phenomenon of interest from the perspectives of the participants (Merriam, 1998). Qualitative methodology involves a naturalistic approach based on the assumption of a socially constructed rather than objective factual reality. This approach entails searching for understanding instead of causality and is conducted by a researcher who immerses him or herself in the setting as an instrument of the research and in relation to the participants, not one who is detached and focused on data collection (Newman & Benz, 1998). Qualitative research is context-oriented and involves efforts to understand participants within their specific social contexts. The ability to generalize findings to other individuals or groups is not a priority within this type of research (Merriam, 1998). However, since this study was aimed at understanding phenomena of positive growth from a relational perspective, couples' intersubjective perceptions and interexperiences were of interest.

The concept of intersubjectivity, as presented by Schutz (1967), includes the idea that people create common-sense shared meanings through their interactions with one another. Through this process of common-sense thinking, they share a definition of the situations and interactions they encounter together. In addition, the systems in which people cognitively function are in conformity with other people and are influential in the shaping of ideas and

relationships. Individuals may have different perspectives of an event; however, these are experienced within a common “we-relationship” that is motivated by the common-sense thinking (p. 115). Intersubjectivity brings forth awareness that “I am experiencing a fellow human being” (p. 114). Laing’s (1967) conceptualization of interexperience involves exploring the relationship between individuals’ experiences of one another. An individual cannot experience another’s experiences directly, yet can experience that other individual is *experiencing*. Since experience is invisible, individuals make interpretations of the other individual’s experiences of the first-person’s self and use these interpretations to guide responses and interactions. Within the context of this study, the goal was to explore the ways couples perceived and experienced each other’s experiences of positive growth and to understand the common-sense thinking and shared meanings couples constructed in these situations.

Phenomenology

Phenomenological research includes a focus on the participant’s subjective understandings of everyday life and how he or she interprets the actions of self or others as meaningful. It is a process of exploring lived experience “from the inside” rather than from the science of measurement (Van Manen, 1990). Moustakas (1994) wrote that “scientific investigation is valid when the knowledge sought is arrived at through descriptions that make possible an understanding of the meanings and essences of experience” (p. 84). Essence refers to the core meanings that are mutually understood about common experiences (Van Manen, 1990). Wertz (2005) wrote, “One starts with a concrete example of the phenomenon of which one wishes to grasp the essence and imaginatively varies it in every possible way in order to distinguish essential features from those that are accidental or incidental” (p. 168). Phenomenological researchers study how people experience phenomena through the descriptions

participants give about their experiences. In order to control for or reduce the influence of researcher bias on the interpretation of participants' experiences, the researcher engages in the procedure known as *epoche*. *Epoche* is a Greek term which refers to refraining from judgment and ordinary ways of perceiving, knowing, and understanding experiences, situations, and objects (Moustakas, 1994). The researcher abstains from placing undue influence or bias on the descriptions by bracketing one's own preconceived ideas about the phenomenon in order to understand the lived-through meanings from the perspective of the participant (Wertz, 2005). In bracketing, the researcher's prior experiences and professional knowledge are set aside to allow him or her to be open, receptive, and naïve in listening to and hearing the participant's experiences of the phenomenon. However, in order to bracket one's preconceptions and presuppositions, one must first make them overt and as clear as possible (Dowling, 2007). The suspension of judgment, or process of *epoche*, involves the researcher explicitly articulating his/her own experiences so as to be as able to bracket in being receptive to others' meanings. Suspending judgment and bracketing can be difficult tasks and these processes require ongoing attention throughout the course of the research project. Moustakas (1994) wrote:

As I reflect on the meaning of the *epoche*, I see it as a preparation for deriving new knowledge but also as an experience in itself, a process of setting aside predilections, prejudices, predispositions, and allowing things, events, and people to enter anew into consciousness, and to look and see them again, as if for the first time. (p. 85).

Dahl and Boss (2005) presented the basic philosophical assumptions of the phenomenological family-therapy researcher. These assumptions relate to how we know, what we need to know, and where the researcher locates himself/herself in the research process. There are eight assumptions which include (a) knowledge is socially constructed and, therefore,

inherently tentative and incomplete. Truth is relative and not determined through use of the scientific method (b) because knowledge is constructed. Objects, events, or situations give rise to a variety of meanings to a variety of people in the family. (c) We can know through both art and science. (d) Common, everyday knowledge about family is epistemologically important. (e) Language and meaning of everyday life are significant. (f) As researchers, we are not separate from the phenomena we study; our feelings, beliefs, values, and responses influence our questions and interpretations. (g) Everyday knowledge is shared and held by researchers and participants alike. There is no hierarchy of experts. And (h) regardless of method, bias is inherent in all research and is not necessarily negative, but must be made explicit at the beginning.

Researcher Stance

As stated in the above assumptions, phenomenological researchers are not separate from the phenomena they study, and their values, beliefs, and feelings have the potential to influence their inquiries. As such, it is appropriate to make researcher biases explicit from the start (Dahn & Boss, 2005). Reflexivity is a strategy of self-reflection that is utilized in order to enhance the credibility of the study. This strategy entails the researcher openly discussing his or her potential biases and assumptions that may influence the research process or conclusions (Lincoln & Guba, 1985). It was with dedication to this study and to those who will participate, that I presented with an openness to share myself and the personal journey that led me to the study of couples' perceptions of positive growth following breast cancer.

In the context of this study, the most explicit way that I can define myself is that I am a breast-cancer survivor. I was first diagnosed when I was 30 years old (I am now 39 years old). Since my initial diagnosis, I have experienced two additional episodes of breast cancer, which

included recurrence in the initial site and diagnosis of a new primary cancer in the other breast, and a subsequent diagnosis of ovarian cancer. Each of these events was characterized by qualities of both uniqueness and familiarity. Having multiple episodes has broadened my perspective of what it means to have breast cancer. With each experience I became more familiar with navigating the healthcare system, assertive in engaging my treatment providers, and effective in my overall coping. However, with each episode, I also became more familiar with the anxiety of waiting for results, the discomfort of surgery and adjuvant therapies such as radiation therapy and chemotherapy, the fear of the potential for recurrence, and the awareness of increased threats to my mortality.

Each of my encounters with cancer entailed very different circumstances which has expanded my range of experience. This lends to my bias in some ways while minimizing it in others. I have endured the least invasive treatments as well as the most invasive. My care has been in the hands of multiple treatment teams and I have had varied experiences with these providers. There have been occasions when I felt that I was being told what to do and pressured to make decisions about treatment options that I did not truly understand. There have been other occasions when I experienced my care providers as patient, positive, and collaborative and I felt that my concerns and opinions were heard and that I was the ultimate decision-maker for my treatment. I have experienced mild trauma-related symptoms at times and more significant symptoms at other times. As my experience with cancer progressed, so did my ability to utilize effective coping strategies and resources. Prior to this, however, I, like most people dealing with the initial unfamiliarity of cancer, struggled with the adjustment to cancer. Being a professional in the field of psychology gave me the advantage of knowledge of coping strategies and signs of distress. These professional experiences were useful in guiding me to cope with the disruptions

in my life, but did not prepare me for the cognitive and affective states I was to experience. In some respects, in the early stages of my cancer, my professional background allowed me to minimize the anticipated impact of cancer on my life and approach the situation with an overconfidence that inhibited some aspects of my self-awareness. Many of the variations in my experiences are a result of time and familiarity. Each episode brought new learnings that I could utilize in the next. I experienced myself differently along the way as well. I witnessed myself becoming increasingly more assertive and resourceful. I saw myself transform my perceptions of what having cancer means. Initially I felt compelled to hide the condition from others because I did not want to be seen as weak or “sick”. Later, I felt empowered by my survival and motivated to share my experiences when I believed they could be helpful to others.

As the opening quotation reflects, I did not get cancer; my family did. Although our experiences were different, every time I had an experience with cancer, my family members had their own experiences. As suggested in Laing’s (1967) writing, I experienced my loved ones experiencing me and experiencing cancer in their own way. Most significantly, my spouse’s experiences were most a part of my own. We encountered many of the same challenges as other couples described within the literature on couples surviving breast cancer. We maneuvered through the obstacles of restructuring our lives around the presence of cancer. Each of our encounters with cancer triggered different lifestyle changes. During the first episode I was reluctant to ask others including family members for help, which, in turn, placed more responsibility on my spouse to compensate for my decreased functioning in most areas of our daily life including maintaining our household both physically and financially. I later realized that my sense of pride and difficulty with perceiving myself as *weak* and *sick* had many negative effects. I recognized that I was slowing my healing process by denying myself the rest and self-

care that I needed. I was inhibiting my spouse's ability to find relief in the assistance of others. Finally, I was not affording those who cared about me the opportunity to be involved in my care and have a sense of satisfaction in their efforts to be supportive. During later episodes my spouse and I were both more able to communicate our needs for help to one another and to others, thus reducing the stress we were experiencing. We encountered struggles in our intimate relationship as a result of physical pain and body image issues on my part. We shared the experience of guilt. I felt guilt over not being able to meet his needs while he expressed guilt over feeling denied. As we became more familiar with illness and the treatment side effects, we were better able to communicate about our intimate relationship. This allowed us to better understand one another's needs and find ways to rebalance our sense of intimacy that did not compromise our own comfort and which fostered self-acceptance rather than guilt. These are just a few examples of the many challenges and obstacles we faced as a couple, but they illustrate that our survival was impacted by our ability to learn new ways of communicating, problem-solving, behaviorally functioning, and understanding our relationship.

Other relationships were impacted by breast cancer as well. I had disconnected from some friends and family due to having limited energy and motivation to engage with others. Some loved-ones were able to support me or learn to support me in ways that I found helpful while others were not able to do so. I found myself distancing from those with whom I felt stress in interacting. As I have moved through the illness trajectory multiple times, I experienced my own transformation of self. I began redirecting my life goals and finding ways to energize and motivate myself to return to my doctoral studies, which I had been unable to do during treatment. I re-established connections and began to nurture relationships with people whom I care about. The realization that my risk of death had dramatically increased with each episode prompted me

to make changes in how I was living my life and engaging in my relationships. My experiences mirrored those discussed in the literature on survivorship, especially Janoff-Bulman's (1999) conceptualization of rebuilding the shattered core assumptive beliefs about the world.

Prior to dealing with cancer, I had viewed myself as someone drawn to logic and empirically validated knowledge. I found comfort in the structure and lack of ambiguity of quantitative methodologies and had presumed that I would utilize these for my dissertation. As my experiences with cancer progressed, and I encountered more and more women similar to me, I became intrigued with hearing their stories of survival. An ironic aspect of my journey is that I began listening to women's stories of survivorship several years prior to my own diagnosis when the thought that I would someday be diagnosed had never crossed my mind. I had volunteered to participate in a breast-cancer fundraising event as a way to show my support for a friend who was undergoing breast-cancer treatment. This week-end-long event was filled with interactions of women who had survived cancer and stories of empowerment and strength. This was such a powerful and emotionally moving experience for me that I participated in this event a few times throughout the years before my diagnosis. I kept the stories I had accumulated in my mind as I endured my own treatments. I valued the time I had to be surrounded by these women and I allowed them to serve as my role models and motivators even in their absence. As beneficial as this has been to me, I also acknowledge that I recognize how this has biased my perceptions. Having been exposed to breast-cancer survivors in such a positive context validated my belief in growth following trauma. I lived by the mantra: *what doesn't kill you, makes you stronger*. At the time, I did not know many women who had endured breast cancer; therefore, I was relatively naïve to the true nature of the struggles and hardships that cancer often involves. I knew cancer

was terrifying, but I had been exposed only to the celebration of surviving it...until I experienced it.

Having been through such a diverse set of experiences myself, I gained a new realization that breast cancer was not all about celebrating and that not all women survive. After having such a fantasy-based view, I was almost ill-prepared for the reality. But, as much as those stories became a means of hopefulness for me, they also heightened my curiosity to hear more stories from a wider lens. I needed to hear stories of other women struggling in order to validate my own feelings and experiences because I was acutely aware that I was not in the same emotional place as the women I had met at the fundraising events. I wanted to feel a connection to others who shared this context, and I wanted to not feel alone in the struggles. As I connected to more women who had faced breast cancer, I became aware of the differences and similarities in the stories. I recognized the diverse nature of the lived experiences and meanings attributed to cancer.

My motivation to engage in this study came from two specific points of interest. First, out of a newly found appreciation for the diversity that personal descriptions can provide, I decided that qualitative research was a good fit for my desire to better understand the lived-experiences of others in their everyday encounters of dealing with, surviving, and growing from breast cancer (as opposed to in the context of a structured event aimed at celebration). Second, I am motivated by what I did not hear in the stories women told, and what I did not read in the literature, which were relational experiences and perceptions of breast cancer and positive growth.

I recognized that my motivation must be balanced with awareness of the potential for my personal experiences with breast cancer to influence the manner in which I conducted interviews

with participants. There are two specific aspects of my experiences discussed above that I believe have increased possibility of actuating bias: 1) that I experienced trauma-like symptoms in varying degrees during some phases of my illness trajectory, and 2) that I perceive growth within my partner relationship as a direct result of experiences with breast cancer. This study was primarily focused on understanding *how* couples experience these phenomena and I was quite cognizant that there was a broad range of variability possible in this area. However, it was imperative that I not make the assumption that all couples encounter either or both of these experiences. This was particularly relevant to growth since this aspect was accentuated by my exposure to celebratory environments related to breast cancer and the fact that some study participants may be referred through connections I have made during my participation in some of these events. Awareness of these potential biases prompted me to acknowledge the importance of asking *if* participants have had experiences with trauma or growth prior to asking *how* they have experienced these. In addition, it led to me making the decision to not disclose my personal experiences with breast cancer to participants prior to or during the interview with the recognition that doing so could potentially influence participant responding in ways such as 1) limiting the details of a conversation based on assumptions of my familiarity with an experience, 2) exaggerating descriptions of their own growth as a result of formulating impressions about my growth and perceiving expectations of similar level of functioning, and 3) altering responses in order to align with me based on sharing a similar life event.

Method of Recruitment and Participant Criteria

Couples were recruited from a nonclinical population through the use of purposive sampling and the snowball technique. Purposive sampling was appropriate since data from a particular group was required and couples were selected based on specific qualities that they

possessed. The snowball technique or word-of-mouth sampling involved participating couples suggesting other potential couples who may be willing and interested in participating (Nelson & Allred, 2005). Potential participants were contacted initially by phone in order for me to explain the purpose of the study and to conduct a brief interview to ensure that the couple met the participation criteria and possessed the qualities of the intended group for study. I clarified at that time that, in order to participate, primary breast cancer treatment must have been completed at least one year prior to participation in the study. In addition, both members of a couple must have agreed to participate in order to be included. Their relationship must have been committed, intact, and stable at the time of the initial breast-cancer diagnosis and must have been maintained throughout the treatment process and following breast cancer until the present time.

Participation was limited to heterosexual couples. Couples who completed the study were asked to refer other couples who met the criteria in the event that additional participants were needed. Additional referral resources included medical professionals, local breast-cancer-related organizations, and breast-cancer-related community events. Following the initial phone contact, I sent a formal letter of solicitation to interested couples who met the participation criteria. This letter contained detailed information regarding the nature of the study. All participants who volunteered for and met the study criteria were permitted to participate.

Confidentiality and Informed Consent

The phenomenological approach generally involves a small sample size based on the fact that the study entails obtaining in-depth descriptions of the experiences of each of the couples in order to achieve transferability rather than generalizability (Dahl & Boss, 2005). Because of the likelihood that this study would encompass a small sample and because of the personal nature regarding the meaning questions, confidentiality was especially relevant. To ensure

confidentiality, identifying data and demographic details were altered in order to protect the participants' identities. Furthermore, I utilized pseudonyms for each participant in order to provide the participants with anonymity. Participants were informed that they were permitted to withdraw from the study without repercussions at any stage of the process, including the presentation of results. This was in an effort to provide participants some protection from uncomfortable or unwanted exposure as suggested by Dahl and Boss (2005). All research materials, both written and recorded, were maintained in a locked file to which only I had access.

Prior to inclusion in the study, participants received an informed-consent form providing relevant information related to the study (see Informed Consent Form, Appendix A). This form outlined the purpose of the study, my role as investigator, the participants' roles, the intended use of written and recorded study materials, and terms of confidentiality. My contact information, along with that of the project mentor and the Institutional Review Board for Protection of Human Subjects (IRB) was included. This form was reviewed with each participant to ensure understanding of the content and opportunity to ask clarifying questions, if needed. Upon agreement, participants were asked to sign the form to indicate their understanding of the study and consent to participate. A statement of IRB approval was included, and approval was established prior to any recruitment activities.

Qualitative Data Collection

Phenomenological methods of data collection are designed to enable participants to define phenomena for themselves and to describe the conditions, values, and attributes they believe are relevant to that definition in their own lives (Dahl & Boss, 2005). According to Van Manen (1990), in phenomenological research, the emphasis is always on the meanings of lived experiences. The goal of this type of research is to "borrow other people's experiences and their

reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole human experience” (p. 62). Collecting the data on other people’s experiences allows for the researcher to become more experienced as well. Data collection through multiple methods and resources increases the trustworthiness of the study; therefore, a variety of means were utilized in this study.

Demographic Data

A demographic data sheet (see Demographic Data Questionnaire, Appendix C) was completed at the start of the interview. The data sheet included questions related to age, ethnicity, educational level, work experience, and relationship status, which I asked both partners. The form also included questions specifically related to information about the breast cancer diagnosis and treatment. I requested that, as appropriate, the couple jointly answer the questions in order to promote a collaborative, relational approach to their participation.

Semistructured Interviews

Data for this study was collected through the use of semistructured interviews with the couple jointly which lasted one-to-two hours (see Interview Protocol, Appendix D). Interviewing couples together can provide both verbal and behavioral information not evident in individual interviews, such as the ways in which a couple interacts together in response to the questions posed by the researcher (Beitin, 2008). In addition, according to Morris (2001), joint interviewing “places emphasis on the relational possibilities of a pair’s situation, asking them to represent themselves not just as individuals but also as concurrent participants in a relationship; mutually created meaning is highlighted as they speak” (p. 558). By utilizing this format, the interview itself became a shared lived experience, directly reflecting the goal of this study. This

also allowed me to observe the level of congruence between content and process within a couple's interactions. Discussion between the partners assisted me in noting the presence of differing emphases in the presentation of shared experiences. Interjections, prompts, or passing of the narrative back and forth between partners assisted in filling in any gaps and developing a fuller account of the experiences (Morris, 2001).

In qualitative research, interviews are used as a means for exploring and gathering experiential data that may serve as a resource for developing a richer and deeper understanding of a phenomenon. Semistructured interviews can assist the researcher with developing a conversational relationship with the participants about the experience of interest (Van Manen, 1990). In addition, these interviews allow the researcher to most accurately represent the "expressed daily life conditions, opinions, values, attitudes, beliefs, and knowledge base of the respondents" (Dahl & Boss, 2005, p.72). Van Manen (1990) noted that, as the researcher interviews participants about their experiences of a certain phenomenon, it is imperative to stay close to experience as lived and to "explore the whole experience to the fullest" (p. 67). In addition, it is generally easier for participants to talk than to write about their personal experiences because "writing forces the person into a more reflective attitude" (p. 67) which may make it more difficult to remain focused on a lived experience. In this study, the interview served the specific purpose of eliciting couples' personal accounts of their lived experiences with breast cancer and their perceptions of the process/phenomenon of positive growth. In order to explore the experience to the fullest, the interview included exploration of the full illness trajectory. This allowed for greater understanding of the couples' perceptions and the processes that lead to growth.

Utilizing a semistructured format and interview protocol guided the conversations within the context of the research questions while still providing opportunities for flexibility with the process and couples' self-determined ways of expressing their experiences. Couples were asked to jointly answer interview questions and were allowed the opportunity to converse with one another in order to identify the shared experiences. The interview protocol was modified as needed as additional questions arose or as themes began to emerge. Throughout the interviewing process, additional questions were posed to the couple as they responded and interacted with each other and with me in order to gain clarification or elicit further descriptive conversation. The interview protocol allowed for themes to be explored as they emerged in order to capture the unique and diverse experiences of each couple. Interviewing techniques such as paraphrasing, circular questioning, and reflecting were utilized as needed. Patience and silence were also important components of effective interviewing. According to Van Manen (1990), these techniques can be used as tactful ways of prompting the couple to gather recollections and to proceed with a story or description.

Interviews were conducted in settings that were mutually agreeable between the couple and me. These settings included a quiet room at a local library, an available office at Seton Hall University, or a private interview room on the third floor of Jubilee Hall at Seton Hall University. With the permission of the participants, interviews were audio-taped to allow for thorough review and greater accuracy in analyzing the data. All interviews were transcribed verbatim by me following the conclusion of the interview.

Genograms

Genograms were utilized to gather demographic information about the couples. Information relevant to the genogram was collected during the interview. When possible,

genograms were constructed during the interview process to allow for collaboration with the couple and to offer opportunities for clarification, identification of themes, or richer dialogue. Specific to this study, genograms were helpful in tracking the couples' experiences with illness, care-taking, or growth following adverse or traumatic situations within their families-of-origin. In addition, they provided a means of visually representing themes of familial strengths and difficulties and for displaying complex patterns of relating, functioning, and responding. The genogram was also used for the identification and documentation of ethnicity, spirituality, class, education, and other socioeconomic factors (Cater & McGoldrick, 1999).

Observations and Field Notes

Another way of gathering experiential data is through observation. Qualitative researchers seek to enter the lifeworld of the persons whose experiences are relevant to the research project by engaging relationally with involved persons and by observing these situations and experiences (Van Manen, 1990). With regards to this study, it was important for me to observe myself, the participants, and the interactions that occur. Self-observation entailed remaining aware of and monitoring my own reactions, feelings, and thoughts throughout the study process. It was also relevant to observe the participants, their environments, and their ways of relating to and interacting with one another and with me. Field notes were an important tool for collecting data and tracking patterns, conversations, and interactions. This entailed creating a detailed description of what had been observed and documenting unspoken elements of the interactions such as body language and gestures, affect, and other unique qualities of the interactions or environment (Glesne & Peshkin, 1992; Marshall & Rossman, 1999; Patton, 2002). According to Van Manen (1990), keeping a journal or notes can be helpful for recording insights gained, discerning patterns of the work in progress, reflecting on the experiences as a

researcher and on previous reflections, and making the activities of research part of the study. As such, field notes were written following the conclusion of each interview and were supplemented as new information became available. These notes contained reflective accounts of the experiences described which were of phenomenological value.

Debriefing

Although it was expected that the risks of adverse reactions or consequences would be minimal in this study, debriefing was made available to all participants. Couples were offered opportunities to share their experiences of being involved in the study and of the interview process. They were provided with time to ask any questions they might have or to voice any concerns. In addition, I asked participants about any reactions they may have had as a result of involvement in the study. Although no participants did so, in the event that any participants chose to withdraw from the study, I was agreeable to offering debriefing to provide individuals with an opportunity to voice any feelings, concerns, or issues that may have influenced the decision to withdraw and to encourage sharing of any study-related issues they may have had with me, the advisor, or the IRB.

Transcriptions and Feedback

As stated earlier, interviews were transcribed verbatim. Participants were given a copy of the transcript pertaining to their interviews and were instructed to review the transcripts for accuracy. They were offered the opportunity to correct any errors, amend content, or provide clarification. They were encouraged to provide feedback regarding whether they believed the transcript accurately represented their experiences and regarding suggestions for modifications. Once the participants provided feedback, transcripts were returned to me and modifications were made as indicated. Participants were asked to convey approval of the final revisions.

Data Analysis

Dahl and Boss (2005) maintained that data collection and analysis go hand in hand and “each informs the other in a dynamic, reciprocal, nonlinear process of questioning, reflecting and interpreting” (p. 74). Furthermore, the purpose of analysis in phenomenological research is to describe and understand the experiences of the participants, not to connect findings to an endpoint. Hess and Handel (as cited in Dahl & Boss, 2005) presented three assumptions regarding data gathered through phenomenological inquiry. First, researchers must attempt to connect the data. Implementing structure to organize data helps to incorporate ideas and increase accurate understanding. Next, the data provide necessary information about specific meanings given to experiences and how meaning is assigned. Finally, experiences can be accurately understood only within the participants’ contexts and other experiences within that context help to enhance understanding. Hess and Handel described the process as moving in and out of one type of data to another, one participant’s story to another’s, from one set of themes to another with the intent of looking for *meanings that connect* and *meanings that differentiate*. Dahl and Boss (2005) added that accurate understanding of participants’ experiences may come through a variety of techniques, such as line-by-line analysis of a description or searching for significant words or phrases. However, the signature characteristic of phenomenological analysis is that the researcher “makes every effort to stay connected to the experience of the participants” (p. 74).

The method of analysis for this study was Moustakas’ (1994) modification of the Van Kaam (1959, 1966) method of analysis of phenomenological data. The following is a brief overview of the steps that were taken in the analysis process. First, the complete transcript of each couple’s interview was used in the analysis and was read several times in order for me to gain a general impression of the data content. The first step of the modified method is *listing*

and preliminary grouping, which refers to the process of horizontalization. In this step, data was reviewed for all expressions and statements that were relevant to the couples' shared experiences with breast cancer and positive growth. Moustakas (1994) noted the importance of the researcher remaining receptive to every statement and viewing each statement as equally valuable in contributing to an understanding of the participants' experiences.

The next, second, step is *reduction and elimination* to determine the invariant horizons or constituents. The listed statements were reviewed in order to identify those that reflected the unique qualities of an experience. Moustakas (1994) indicated that each statement should be tested to see if it meets the following requirements:

- 1) Does it contain a moment of the experience that is a necessary and sufficient constituent for understanding it?
- 2) Is it possible to abstract and label it? If so, it is a horizon of the experience. (p. 121)

Statements that did not meet these requirements, and those which were repetitive, vague, or overlapping, were eliminated. Those that remained were considered the invariant constituents.

The next, third, step was to cluster the constituents that were related and assign a thematic label. This is referred to as constructing *thematic portrayals* and represents the core themes of the participants' experiences. The constituents and themes were validated for accuracy by checking them against each of the complete transcripts. The process of validation was to ensure that the constituents and themes were either expressed explicitly in the transcript or were compatible if not expressed explicitly. Those that were not explicit or compatible were considered not relevant to the participants' experiences and were eliminated (Moustakas, 1994).

The validated themes were used to provide an individual textural description of each of the couples' experiences of breast cancer and positive growth. These descriptions included

verbatim examples from the transcribed interviews. From these, individual structural descriptions were constructed. These descriptions provided an account of how feelings and thoughts connected with the phenomena of interest were aroused in the couple and were based on the individual textural descriptions and imaginative variations. Imaginative variation is the process of depicting the essences of the experience. Moustakas (1994) wrote that “from these processes a structural description of the essences of the experience is derived, presenting a picture of the conditions that precipitate an experience and connect with it” (p. 35). The result was a textural-structural description of the meanings and essences of the experience, incorporating the constituents and themes for each individual couple.

From the total group of individual textural-structural descriptions, a composite textural description was developed to depict the meanings and essences for the total sample of participants. The meanings and themes of every couple were used in representing the experiences of the group as a whole. From the composite textural description and use of imaginative variation, a composite structural description was constructed. This description provided a way of understanding how the couples as a group experienced what they experienced. The final step involved integrating the composite textural and composite structural descriptions, thus providing synthesis of the meanings and essences of the experience (Moustakas, 1994).

Enhancing Rigor and Trustworthiness

Lincoln and Guba (1985) presented four standards by which qualitative inquiry may be assessed: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability. Credibility refers to the degree to which the study results accurately represent the lived experience of the participants. A greater degree of credibility can be achieved through the method of triangulation, which involves utilizing several information sources to confirm a conclusion (Lincoln & Guba,

1985). In this study, credibility was developed by interviewing several couples, providing preliminary interpretations to couples and making adjustments to ensure accurate representation of the couples' experiences, and engaging in consultation with my advisors. The use of tape-recorded interviewing and verbatim transcriptions were tools used to confirm that findings had direct links to the actual words of the participants.

Transferability connotes the degree to which findings can be transferred to or represent similar people, settings, and times as those presented in the original study. The researcher's responsibility is to identify key characteristics of the participants and contexts with the goal of providing readers with rich descriptions, in-depth details, and comprehensive information in order to determine transferability (Lincoln & Guba, 1986). Utilizing various data sources, providing detailed descriptions of participants and their contexts, and incorporating participants' actual words are strategies that were employed to support the results that emerged.

Dependable investigations are those which can be relied upon to be accurate and impartial representations of the findings that emerged from the data (Lincoln & Guba, 1985). Measures need to take into account the researcher's influences and situational factors that may impact the research process. The advisor and committee members had access to the study data to affirm the logic and dependability of the results as well as accurate representations of the data. A statement of my stance as the researcher was provided in order to make known my assumptions, motivation, and reasoning for engaging in this study, and personal history that could potentially influence the research. Field notes including documentation of my feelings, thoughts, responses, and experiences were used to assess phenomenological veracity and bracketed perceiving.

Confirmability denotes the degree to which the results of the study can be intersubjectively corroborated and verified by the data collected (Lincoln & Guba, 1985).

Strategies used to address transferability and dependability, such as triangulation, participant feedback and verbatim quoting, advisor and committee consultation, and review of field notes were used to enhance confirmability.

Summary of the Study

The aim of this researcher was to utilize a phenomenological research design to explore how couples experience and perceive positive growth following breast cancer. The study was designed to also allow for exploration of how couples experience breast cancer within their relationships, how they define growth, and what qualities or processes they attribute positive growth to. The phenomenological approach allowed me to focus on the couples' feelings, perceptions, and lived experiences through the use of qualitative research methods including semistructured interviews, observation, genograms, demographic data forms, and reflective field notes. The phenomenon of growth following traumatic events has been widely researched; however, most researchers have utilized quantitative methodologies. Although increasing research attention is focused on growth following illness, specifically breast cancer, very few qualitative studies have been conducted, and a limited number have involved the context and perspectives of the couple.

CHAPTER FOUR

Findings

The following findings represent data obtained from ten breast cancer survivor couples through the process of semi-structured interviews. Discussions presented highlight the ways in which couples reacted to the breast cancer diagnosis, experienced and coped with the impact of the illness, and perceived positive growth as a result of their shared experiences. In addition to a collective description of the participants, pertinent demographic information and case studies are presented for each couple in order to provide additional context within which to understand the themes which emerged from the data synthesis. A demographic chart including female and male partner ages, relationship status and length, family composition, and education level is presented. For female survivors, age at diagnosis, stage of breast cancer, treatments received, and results of BRCA testing where applicable are identified.

Themes and subthemes incorporated into this chapter were derived from the couples' descriptions related to their experiences with breast cancer and perceptions of growth following survival. Descriptions were provided through both open conversation and responses to inquiry related to impact of the illness, coping, perceptions of change, and indicators of growth. Verbatim excerpts of responses and dialogues are included within each case study to capture the essence of the couples' lived experiences as well as within the subtheme discussions to exemplify the themes.

Participants

Participants in this study included ten female breast cancer survivors and their male partners. All couples met the following criteria for participation: (a) primary breast cancer treatment was completed at least one year prior to the time of their participation, (b) their

relationship was committed, intact, and stable at the time of initial breast cancer diagnosis and was maintained throughout the treatment process and following breast cancer until the time of their participation, and (c) both partners participated in the interview. Couples were selected from a non-clinical, eastern United States population.

Female participants ranged in age from 35 to 66 years old. The mean age at the time of diagnosis was 45-years-old representing an age range of 31 to 59 years old. Male participants' were between the ages of 37- and 66-years-old. With the exception of one female participant who identified as Hispanic, all other participants identified as Caucasian. Religious affiliation consisted of Jewish (three female, two male), Catholic (three female, three male), Christian (two female, one male), and no affiliation (two female, one male). Eight of the ten couples were married and the other two were cohabitating. Length of relationship ranged from 8 to 46 years. Seven of the couples had at least one child living at home at the time of the female's diagnosis; one whose child was from the female's previous marriage. Of the remaining three couples, one had adult children not residing at home, another did not have children, and the last had a child at the time of the interview but who had been born after the breast cancer diagnosis. Both female and male participants varied in their educational levels. Among the ten females, two completed high school, two completed some college, one achieved a technical certification, two achieved bachelor-level degrees, one completed some master's-level coursework, and two completed master's-level degrees. Male participants' educational achievement included one who completed eleventh grade, one who completed high school, one who completed civil service training, two who achieved technical certifications, one who completed some college, one who achieved an associate-level degree, one who achieved a bachelor-level degree, and two who achieved master's-level degrees. Participants' descriptions of their communities varied equally between

rural and suburban, all within the middle to upper-middle class range (see Table 1 for demographic information).

Table 1

Demographic Chart - Couples

Participant	Age	Education	Marital* Status	Relationship* Length	Children* Ages
Annika Darren	35 38	B.A. M.B.S.	Married	10 yrs	15 mos. **
Kara Clark	43 46	M.A. M.B.A.	Married	18 yrs	15, 13, 10
Susan Rob	44 46	H.S. 11 th grade	Married	21 yrs	25, 19
Nancy Rick	39 39	H.S. + Tech. H.S. + Civ. Serv.	Partnered	8 yrs	14***
Lisa Dan	46 48	B.S. Assoc.	Married	21 yrs	17, 14
Debra Keith	48 49	M.S. B.S.	Married	30 yrs	17, 15, 11
Meryl Craig	66 69	B.S.N. M.B.A.	Married	46 yrs	40, 44
Diana Steve	35 37	B.A. H.S. + Tech.	Partnered	10 yrs	N/A
Jessica Brian	39 38	Some College**** H.S.	Married	15 yrs	8
Delia Hugh	52 53	Some College Some College	Married	28 yrs	26, 23

*Data pertains to both female and male partner

**Annika and Darren's son was born via surrogate after Annika completed treatment

***Nancy's son from previous marriage, resides full-time with her and Rick

****Jessica completed C.N.A. shortly after interview

Specifically related to the female participants, four were diagnosed with Stage-I breast cancer and six were diagnosed as Stage-II (see Table 2 for breast cancer staging information). Five participants underwent lumpectomy surgery, one who required two procedures to produce clean margins, and one who subsequently underwent bi-lateral mastectomies at a later date. Two

participants had single mastectomy and three underwent bi-lateral mastectomy. All participants who had mastectomy surgery (single and bi-lateral) underwent reconstructive surgery. With regards to adjuvant treatment, five participants received chemotherapy and radiation therapy, two received chemotherapy only, one received radiation therapy only, and two did not receive either treatment (bi-lateral mastectomy only). Six of the ten women were prescribed hormone therapy and another declined the recommendation. One woman underwent full hysterectomy surgery as part of her breast cancer treatment while two others had partial hysterectomies. Finally, all but one participant was tested for BRCA gene mutation. Of the nine tested, seven tested negative and two tested positive (see Table 3 for female participants' breast cancer information).

Table 2

Breast Cancer Stages

Stage	Description
0	The cancer has not metastasized beyond the breast; referred to as non-invasive. Ductal carcinoma in situ (DCIS) – abnormal cells in lining of the breast duct Lobular carcinoma in situ (LCIS) – abnormal cells in the lobules of the breast Paget disease – abnormal cells found in the nipple only
I	IA – Tumor is 2 cm or smaller and is isolated in the breast IB – Small clusters of breast cancer cells are found in the lymph nodes and either a) no tumor is found in the breast or b) the tumor is 2 cm or smaller
II	IIA – Any one of the following: a) no tumor is found in the breast but cancer is found in 1 to 3 axillary lymph nodes or to lymph nodes near the breastbone, b) tumor is 2 cm or smaller and has spread to 1 to 3 axillary lymph nodes or lymph nodes near the breastbone, or c) tumor is larger than 2 cm but not yet 5 cm and has <u>not</u> spread to the lymph nodes. IIB – Any one of the following: a) tumor is larger than 2 cm but not yet 5 cm and has spread to 1 to 3 axillary lymph nodes or to lymph nodes near the breastbone, or b) tumor is larger than 5 cm but has <u>not</u> spread to the lymph nodes.
III	IIIA – Any one of the following: a) no tumor or tumor of any size is found in the breast but cancer is found in 4 to 9 axillary lymph nodes or lymph nodes near the breastbone, b) tumor is larger than 5 cm and small clusters of cancer cells are found in the lymph nodes, or c) tumor is larger than 5 cm and has spread to 1 to 3 axillary lymph nodes or to lymph nodes near the breastbone IIIB – Tumor may be any size and has spread to the chest wall and/or the skin of the breast; may have also spread to up to 9 axillary lymph nodes or lymph nodes near the breastbone IIIC – No tumor or tumor of any size is found in the breast and may have spread to the chest wall and/or the skin of the breast; has spread to: a) 10 or more axillary lymph nodes, b) lymph nodes above and below the collarbone, or c) axillary lymph nodes and lymph nodes near the breastbone

IV Cancer has spread to other organs of the body, most often brain, bones, lungs, or liver, or a combination of any of these.

Note: Cancer that has spread to the skin of the breast may also be inflammatory breast cancer and may be stage IIIB, stage IIIC, or stage IV.

Adapted from <http://www.cancer.gov/cancertopics/pdq/treatment/breast/Patient/page2>

Table 3

Breast Cancer Information – Female Participants

Female Participant	Age at Diagnosis	Breast Cancer Stage	BRCA* Results	Primary Treatment
Annika	31	II	Neg	Mastectomy (Single) Chemotherapy Hormone Therapy Hysterectomy (Partial)
Kara	40	I	Neg	Lumpectomy Radiation Therapy Hormone Therapy
Susan	39	II	Pos	Lumpectomy Chemotherapy Radiation Therapy Hormone Therapy Hysterectomy
Nancy	35	I	Neg	Mastectomy (Bi-lateral)
Lisa	41	II	N/A	Lumpectomy Chemotherapy Radiation Therapy Hormone Therapy Hysterectomy (Partial)
Debra	45	II	Neg	Lumpectomy Chemotherapy Radiation Therapy Hormone Therapy
Meryl	59	II	Neg	Mastectomy (Single) Chemotherapy Radiation Therapy Hormone Therapy
Diana	32	II	Neg	Mastectomy (Bi-lateral) Chemotherapy
Jessica	36	I	Neg	Mastectomy (Bi-lateral)
Delia	41	I	Pos	Lumpectomy

Mastectomy (Bi-lateral,
Prophylactic)
Chemotherapy
Radiation Therapy
(Declined Hormone Therapy)
(Declined Hysterectomy)

*Breast Cancer Susceptibility Genes 1 and 2 (BRCA 1, BRCA 2) are tumor suppressor genes. Mutation has been linked with the development of hereditary breast and ovarian cancer, and increased risk of developing other cancers: BRCA 1- cervical, uterine, pancreatic, and colon. BRCA 2-stomach, gallbladder, bile duct, and melanoma (<http://www.cancer.gov>).

Case Studies

Annika and Darren

Demographics

Annika and Darren were the first couple to participate in the study interview. Annika is a 35-year-old Caucasian (mixed European descent) female who self-identified as a breast-cancer survivor. She and her husband Darren, a 38-year-old Caucasian (mixed European descent) male, have been in a committed relationship together for 10 years, and have been married for the past five years. At the age of 31, Annika was diagnosed with Stage II breast cancer and underwent treatment including single mastectomy, chemotherapy, and hormone therapy, which she currently continues. Approximately one year following her initial diagnosis, Annika was re-diagnosed with Stage IV breast cancer because of the cancer metastasizing to her ovaries, requiring her to undergo a hysterectomy. The couple did not have any children prior to the hysterectomy; however, with the aid of fertility planning professionals, they were able to employ oocyte cryopreservation measures (egg freezing) and surrogacy to subsequently have a child. Their son was 15 months old at the time of the interview (see genogram, Appendix F).

At the time of her initial diagnosis, Annika was employed as a public-health representative (B.A., Public Health Administration) for a large-scale medical facility. She applied for and received short-term disability benefits, which allowed her to refrain from

working while she recovered from her mastectomy surgery. She chose to resume her employment during her chemotherapy treatment and had the flexibility to adjust her schedule to accommodate her treatment needs. Subsequently, she was laid-off from that job and has since chosen to assume the role of stay-at-home mother. Annika described Darren as having been “very supportive” and “available” to her during the course of her treatment. Although Darren did not take an extended leave from his position as an engineer (MBS, Engineering) with a medical electronics company, he was readily able to take sporadic days off to assist her or accompany her to appointments.

Prior to their own experiences, Annika and Darren had some knowledge of breast cancer, and cancer in general. In her early 20’s, Annika had a co-worker whom she was close to that went through treatment for breast cancer and, at times, utilized Annika as a support and confidant. In addition, the department she worked in was located within the breast center of the medical facility. Although her department was not directly associated with the breast center, the proximity provided her with opportunities to be exposed to the comings and goings of a breast-cancer-related treatment environment. Within Annika’s family of origin there is a significant history of cancer. With regards to her paternal relatives, both her grandfather and father were diagnosed with colon cancer. Her father was diagnosed approximately 12 years ago and was successfully treated. She did not recall details pertaining to any treatment received by her grandfather and believed that he passed away due to complications related to the cancer metastasizing to his bones. In addition, she has an aunt who was diagnosed with and treated for ovarian cancer. On the maternal side of her family, Annika reported that her mother was diagnosed with and treated for basal cell carcinoma (skin cancer), and her grandmother was diagnosed with and treated for uterine cancer.

The only member of Annika's family of origin identified as having had a known history of breast cancer was Annika's aunt on her mother's side, who was also successfully treated. Despite the significant family history, Annika indicated that she had minimal direct involvement with her family's cancer-related issues and activities. Most of her knowledge was obtained through family stories. She reported that the most prominent exposure she had to breast cancer was in 2003 when her mother-in-law was diagnosed with and treated for Stage-I cancer. Darren indicated that exposure to his mother's diagnosis and treatment was the only experience he had ever had prior to Annika's diagnosis. His mother underwent a lumpectomy and radiation treatment, which he described as "much less involved" than his wife's case. Darren described a supportive and caring relationship with his mother but indicated that he was not very involved in her care during her treatment. He reported that his mother "didn't really have any side effects or anything or need much help," but he was conscientious about offering assistance as needed. He further acknowledged that he used his previous experiences with his mother's illness as a point of reference, which caused him to somewhat "minimize" Annika's diagnosis initially and underestimate the extent of care she was going to need.

Annika and Darren both identified their siblings as part of their family structure and support system. Annika had a younger brother whom she was close with. He was killed in Iraq in 2005 while deployed with the military. Darren comes from a family of four children. He has one older and one younger brother as well as a younger sister. He reported that he is relatively close with his siblings, though they do not have frequent contact because of living in separate states. The couple identified as Christian, but do not actively practice their religion.

Case Study

The interview began with a discussion of the impact that breast cancer had on this couple's relationship and the ways in which they coped together. Annika and Darren began with a conversation about the circumstances under which the couple first learned of the breast cancer and their reactions to this news. Annika discovered a lump in her breast while performing a self-exam. She shared that, because of the fact that she had a history of having cystic breasts, she assumed this would be the explanation for the lump and initially did not experience concern. Darren agreed stating, "Nothing else even crossed our minds; we just thought we're going to do the test, and it's going to be a cyst." Following diagnostic testing, while Darren was out of town on a business trip, Annika found out that the lump was in fact breast cancer. Annika stated, "The hardest thing I've ever had to do was call my husband and tell him I had cancer." She recalled a few moments of silence between her and her husband after she told him the results of her testing. "I think we were, at first, just so surprised by it that we were both in shock." Darren willingly shared that after a few moments, "fear" began to set in, but he was not prepared to handle this emotion and did not want to upset his wife so he did not express his feelings. "I was scared," he stated, "I wanted to be strong for her, so I didn't tell her how I was feeling." Instead, he began to focus his thoughts "on logical thinking." "I needed to get a handle on myself so I started thinking that, in talking about breast cancer, early detection is key, and I figured she's only 31, so it's got to be pretty early detection." He also began to search for a point of reference in order to try to make sense of what was happening. Recalling experiences and knowledge he gained from his mother having gone through treatment for breast cancer a few years earlier, he shared, "A few years before, my mother had a lumpectomy, so I thought, 'Oh, this is bad, but it's not the end of the world.' At the time I had no idea how different and how much more complicated this was going to be."

In the days following the initial diagnosis, Annika and Darren described feeling confused and apprehensive about what was to come. Annika stated,

I think it was very surreal almost. I didn't know what to do with myself or what to do next. I didn't know how to react or what exactly I was feeling because it was all these emotions at once. It was like I couldn't fathom it immediately. I don't think that I cried at all or anything until later. I don't think either of us really fell apart or anything in the beginning. It just hadn't sunk in I guess. I don't think I cried until just before the mastectomy...I don't think I started dealing with the fact that it was happening until a few weeks had passed.

Darren verbalized his agreement adding, "I couldn't even think in terms of what the extent of it could actually be." The couple's initial reactions of feeling surprised, fearful, confused, and apprehensive are consistent with the research findings discussed earlier related to other couples who have survived breast cancer.

Annika and Darren shared their perspectives about the ways they changed the ways they interacted and related to one another throughout the course of Annika's treatment. Like many couples experiencing similar situations, they began to buffer their interactions. Darren described it in these terms:

I think I felt a little overprotective, so I was trying to keep stressful things away from her and not let her be bothered by stuff that just wasn't important at the time. I didn't want to complain if I wasn't happy about something because I didn't want to make her feel bad, especially when she wasn't feeling good.

Like many male partners, Darren became selective about what troublesome issues or emotionally laden topics he chose to bring up in an effort to "protect" his wife from being upset. Instead, he

put forth effort to portray a positive attitude and speak reassuringly when issues related to the cancer arose. Annika responded to Darren's disclosure by stating,

Sure, he was telling me that everything was going to be okay and we could get through this together...I knew he was worried about me, and I was worried about him. I think we were just, like, careful with each other...we didn't want to upset each other or make each other feel guilty.

Although she believed that she engaged in buffering less than Darren did, she recognized specific instances when she would refrain from talking about her negative emotions or issues related to her treatment in order to try to spare Darren from added worry.

Even though the couple mutually verbalized that this behavior was intended to be a care-taking measure and recognized it as such in each other's behavior, they both agreed that communicating in this manner was not always helpful. Although Darren's tendency to talk about issues related to cancer in a logistical fashion was helpful to the couple in their management of daily-living activities and treatment needs, the couple agreed that there were also negative ramifications. Speaking retrospectively, Darren acknowledged that this became a means of avoiding his own difficult emotions and discussions thereof. He recognized that, by limiting his expression of his emotions, he also limited potential opportunities to receive emotional support from others, including his wife. From his perspective, this was not the most effective or healthiest way to cope with the situation. Speaking directly to Annika, he expressed his awareness of the benefits that may have come as a result of being more open with his emotions and the increased emotional connection that may have occurred. Annika's view mirrored her husband's in that she too recognized missed opportunities to connect due to withholding her emotions; however, she focused her attention on the positive aspects she

experienced. She conveyed that Darren's ability to remain task-focused often helped her "stay grounded and not let my emotions take over." In addition, she remarked that, despite Darren's limited expression of his own emotions and her choice to refrain from expressing at times, she always felt that he was readily available to support her when she did choose to communicate about her thoughts and feelings.

Annika and Darren shared the perspective that they "compensated" for communication deficits by increasing their efforts to connect with one another through physical closeness.

According to Annika,

Our conversations were a lot about logistics, but I think were also able to go back to that nurturing space, just being intimate in the sense of being close to each other. I'm not talking about sexual intimacy so much, just like coming home and just sitting together on the couch. I felt like I had his support.

Annika disclosed that spending more time physically close to Darren helped her feel a sense of emotional closeness. During the first few months, the couple prioritized spending time together. Darren made a point to attend all of Annika's medical appointments with her while she limited her independent social engagements in favor of socializing as a couple or spending time at home as a couple.

As the conversation progressed further into specific ways breast cancer impacted their relationship, Annika and Darren were able to focus the discussion around the areas that they feel were most significant to them. The primary relational aspects identified as most significantly disrupted were relational autonomy, division of responsibilities, and sexual intimacy. Both physical and emotional changes were factors in the disruption. Although the couple identified changes in the level of Annika's independence and changes in the division of responsibilities

separately, there were overlapping components linking these to aspects together. When asked if they recognized any specific ways that their relationship was impacted, Annika's reply was "I would say I became a lot more dependent on him than I was before." Initially she described dependency as the reliance on Darren to assume more of the household responsibilities because of her being physically limited by pain and side effects from her treatment. She added, "I used to be very independent; then all of a sudden there were a lot of things I needed him to do because I couldn't...simple things, like loading the dishwasher, became chores." During this time Annika often relied on Darren for assistance with other physical tasks such as self-care activities. In addition, she regularly deferred to him when it came to general decision-making and daily planning with the exception of issues related to her treatment.

Darren contributed another perspective by stating, "It seems a little bit like the physical dependence transferred into a little bit of emotional change, but I wouldn't necessarily say that was all bad." Although Annika's increased dependency on Darren to assist with physical activities took a toll on her sense of autonomy and self-confidence, Darren suggested that there were positive outcomes as a result as well. Specifically, he noted that he believed being involved in taking care of Annika's physical care needs increased their level of emotional closeness. He described it as such:

I think it's like, because you do all these things, empty surgery drains and wash her hair, things like that, you become closer. When I was doing these things for her it made me feel closer to her because it made me feel like I'm doing things she wouldn't be comfortable letting anyone else do. As I do these things that require real closeness, then we feel even closer because of it. It's almost like you're invading someone's personal space and only someone close is allowed in that space.

Annika's response to this was "Absolutely, I agree. It was a very vulnerable time, and nobody else saw or did the kinds of things that he did."

Following Darren's introduction of this positive perspective, Annika contributed by acknowledging her ability to cope with some of these disruptions through the use of her personal strengths. Having worked in the medical field for quite some time, she felt very confident navigating through that system. Taking on the responsibility of managing her medical care, such as having conversations with her healthcare providers, doing research on cancer and her treatment options, and making the final decisions regarding her care helped to balance disruptions by adding a sense of normalcy. She stated, "I'm usually a very involved patient, and I'm better at this stuff, so I did all of that on my own. I do feel like I was very much in control of the diagnosis and treatment of my cancer." Taking charge of this area of her life was not to the exclusion of her husband. She mirrored his view that allowing him to take part in some activities contributed to their sense of closeness. She talked about how, when her hair began to fall out from the chemotherapy, she decided that she wanted this to be on her own terms, so she invited him to take part in shaving her head. Both Annika and Darren acknowledged that they were fortunate to not have had children at the time since this would have made the situation far more complicated.

The couple moved on to talk about how the disruption to their sexual intimacy was the most significant area affected. Multiple physical and emotional factors contributed, thus making the ability to cope more challenging. In addition, the disruption was prolonged due to ongoing illness-related complications. Physically, sexual interaction became difficult due to pain, fatigue, and discomfort associated with both surgery and chemotherapy side effects. After Annika completed her chemotherapy treatment and began to regain her strength, the couple was slowly

able to increase their level of sexual activity. Shortly thereafter, the discovery of the breast cancer metastasizing to her ovaries was made, and a hysterectomy was performed, thus causing the re-emergence of disruption due to pain and ongoing issues associated with problematic vaginal lubrication.

Annika and Darren mutually indicated that sexual intimacy was an important part of their lives as a couple and an activity they engaged in regularly together. They were able to address the vaginal lubrication issue relatively easily with synthetic products, and the pain-related factors resolved through the healing process. However, the couple agreed that emotionally related factors were much more difficult to manage. Annika gained approximately 70 pounds from the medications she was taking. This, in conjunction with body dysmorphia caused by the presence of scars and an incomplete breast reconstruction greatly affected her body image and physical confidence. She shared that,

It's made an impact in the sense that I think he's attracted to confidence, and I didn't have any, or at least not the way I used to have about my physical self. I don't think he can possibly be as attracted to me as he was before. It's not that I think he's unattracted. I just think it has to be different for him and my lack of confidence impacts how we interact that way.

Darren agreed that it is different in the sense that it is "less acrobatic," but that his level of attraction has not changed. He indicated that he has tried to convey this to Annika, but she has yet to accept this because "it's really about how she feels about herself." In addition to her decreased confidence, Annika made the connection that the loss of being able to have a baby on her own negatively affected her view of herself as a woman, which she directly linked to her view of her sexuality. According to Darren, "I remember her saying that she was losing all the

parts of her body that made her a woman.” The couple agreed that their mutual desire to improve their sexual intimacy prompted more verbal discussions than any other area of disruption. Annika admitted that she was often the one who initiated conversations about sex because she was dissatisfied, but she verbalized feeling pleased that, as a couple, they were able to focus their attention in a productive fashion by acknowledging one another’s feelings and working together to find ways for each of them to have their needs met.

Annika and Darren provided a rich description of the experiences that were most significant to them as a couple, which easily allowed for the conversation to shift to a focus on their perceptions of change and positive growth. Annika began this dialogue by expressing her perceptions about breast cancer:

Breast cancer is part of who I am, but it’s not how I define myself. It’s part of who we are as a couple, but not how we live our life. There are people who stay stuck in that role, define themselves that way, and live their whole lives around cancer. That’s not us because we know who we are outside of that, and we don’t let cancer dictate our lives.

When asked about aspects of breast cancer that they believe they coped most effectively with, Annika added, “We coped by moving forward with life. Instead of focusing on what we couldn’t do or giving up the things we wanted, we started asking ourselves ‘HOW can we do it?’” The couple spoke at length about their resourcefulness and dedication to exploring alternative ways to achieve their goals, especially those related to having children, and expressed the pride they shared as a couple in being able to do this. Darren added, “It also helped that we tried to stay focused on what’s important...rather than waste our energy on little things that don’t really matter.”

The couple shared many views about the ways they perceive themselves and their relationship as changed as a result of their experiences with breast cancer. Annika began by expressing her perception that the ways she views herself and life are “completely different now.” She remarked,

I think I’m pretty resilient, and I see that now. I don’t really think I would have used that word to describe myself before, but, after surviving cancer, I felt like I had to decide who I was going to be and if I was going to have a good life or not. Cancer happened, and that did suck, but you need to appreciate life and do what you can with it and what you have. I have a good life, I have him, I have friends, and I’m grateful for that.

When asked how she personally defined resilience, Annika stated that she believed this involved the ability to “not get stuck in traumatic events” and to “get back to living your life.” Darren mirrored Annika’s sentiment by saying, “We now have a mutual understanding that our happiness is something that we have to choose and be proactive in making happen. We have so much to be thankful for, and we’ve grown so much.”

As the conversation progressed, it became evident that, for this couple, perceptions of how they changed were intertwined with perceptions of positive growth. All of the changes that they shared seemed factors that they believed contributed to positive growth in their relationship. Exploring Annika and Darren’s beliefs about the potential for positive relational growth to occur as a result of surviving breast cancer provided the couple with the opportunity to share their personal definition and experiences of growth. Darren began by assertively stating,

Absolutely I think growth is possible. When you’ve gone through something so traumatic and been through so much together, I don’t see how you could not be changed. You can’t just rewind and go back to where you were before, but we are fortunate that

some good things came out of it for us...we've grown closer because we got through it together. I have to be honest and say, though, that I don't believe in like 'what doesn't kill you makes you stronger'...I definitely do think it's the case for us...but I don't think it's the case with everybody.

Annika verbalized her agreement, adding, "It didn't just happen; we had to try and it took a lot of effort on our part to make good things happen out of this. We took care of our relationship, and that's what helped us be able to grow together." Annika and Darren shared the view that going through difficult life situations created "opportunities" for them to interact and behave in ways that helped them experience an increased sense of emotional closeness. "If you never have anything difficult to deal with, you don't really get the chance to learn from it," commented Darren. He added his analogy that "I'm not equating myself to a hero or anything, but, if you think about it, there can't be a hero if there isn't some kind of adversity."

Both Annika and Darren believed they had learned new ways of caring for one another and their relationship as a result of their experiences with breast cancer. They presented a very balanced perspective evidenced in Annika's statement that "We want to learn from the experiences we've had going through breast cancer, but not go overboard. We want to do things for the right reasons and because they're good for us." They talked about how they try to do more activities that they enjoy together or have wanted to do, but have neglected. Annika admitted that the thought that she could experience a recurrence and "not be around to do these things" motivates her to "make doing the things we want to do a priority." She indicated that this change in perspective has contributed to her growing sense of adventurousness. "I'm more open to new experiences...but I'm not reckless by any means," she commented. Darren's reaction to this statement was one of the few times during the interview that the couple identified

having a different experience. He retorted, “That’s funny, because I found myself much more cautious.” He clarified that he did not view himself as “hyper-vigilant or overly cautious,” rather that he found himself to be more thoughtful about his actions and decisions in daily living. He explained, “I guess when you’ve seen that life can be very fragile or you could lose it without much warning, it changes how you look at risks...,or I guess I should say it has changed *me* this way.”

Despite somewhat differing views of their perspectives on risk-taking, the couple did agree that making healthy decisions and living in a healthy manner had become more of a focus than prior to breast cancer. As the dialogue progressed, it became clear that this primarily related to taking care of oneself and one’s partner emotionally. Annika described living healthy as “avoiding unnecessary stress” and admitted that “I used to not set limits with other people, but, going through cancer, I’ve learned that sometimes you just have to take care of yourself.” She continued on to report, “I take care of myself and our relationship much better than I used to. I don’t want the good mental place that we’re in to be brought down by letting other people’s crap get in the way.” She credits Darren with helping her with this early after her initial diagnosis and continuing to do this along with her now. She pointed out that it was a positive coping skill that has been maintained, and, as a couple, they are more proficient in balancing their self-care and their desire to be supportive to other important people in their lives.

Other positive coping skills that the couple identified as acquired or improved upon throughout their trials with breast-cancer-related issues include their turning to friends and family for emotional support and their abilities to communicate effectively with one another. In terms of support, although Annika and Darren focused primarily on the support they offered and received from one another, they did briefly mention that engaging with friends and family

socially was helpful to them and contributed to establishing a sense of normalcy as they progressed through the disruptions in their lives. Annika credited herself with being able to reach out to friends in Darren's absence when she was first diagnosed. She also acknowledged that she felt increased emotional closeness with the individuals who were present to assist her during a very difficult time. Although social activity was limited at times, the couple agreed that being around accepting and supportive people they trusted contributed to their sense of well-being. They did not speak at length about supports outside of their own relationship, and conversations about support resources were continually redirected back to their own relationship. With regards to communication, Darren spoke briefly about that fact that they have found more effective and balanced ways to express their needs and feelings to one another. He gave several accounts of instances in which one or the other had been able to talk about a sensitive topic with the gentleness they had come to value, but with more openness and less perceived fear of upsetting one another. In addition, there were fewer instances of arguments because of their mutual effort to "let go of the stuff that really doesn't matter."

The only exception to the improved ways of communicating was with regards to discussions about the possibility of recurrence. When asked how they deal with this possibility, Annika quickly responded that Darren does not initiate conversations about this issue. She explained that she feels Darren resorts to his previous manner of communicating in terms of logistics because it is too difficult for him to talk about his feelings in this area. She acknowledged that Darren is always receptive to her when she wants to discuss concerns, but that his support remains focused on offering her reassurance. "He never tells me how he feels about it. He never tells me if he's afraid of me having a recurrence or dying, never ever" she commented. Darren interjected, "Yes, I do think about it...,of course, it's very scary for me....I

guess it's easier for me to try to stay positive." He acknowledged that his difficulty expressing his emotions likely has an impact on Annika by quietly stating, "Sometimes it probably seems to her like I don't really care, which isn't the case at all." Annika responded, "Sometimes I'm like 'Oh my God! Do you not know that this could happen?'" The fact that her cancer has metastasized once already contributes to what she called her "realistic view of the possibility." Although she verbalized her frustration at Darren's avoidance of the issue of recurrence, she was also able to compliment the ways he was able to be reassuring to her during her times of concern. She acknowledged that Darren's ability to remain grounded and focus on positive aspects, such as advancements in treatment, improved survival rates, and availability of quality healthcare, often helps her manage her negative thoughts and stay focused on the present.

Remaining focused on the present is one way Annika and Darren cope with the possibility of recurrence. Darren described feeling overwhelmed on occasion with trying to figure out how to do all the activities they want and still pursue having a family and buying a house. He believed that Annika's concerns over recurrence and the possibility that her mortality may be in jeopardy sometimes caused her to put pressure on them to accomplish goals quickly. His opinion of this was, "I don't want to plan things because we're afraid we'll miss the chance or because cancer threatens us to do it. I want to plan them as the time is right as we go on with life." Although this is not a regular occurrence, Annika agreed that this does happen for her, and she verbalized being thankful for Darren's positive influence.

The possibility of recurrence and the couple's verbalized increased awareness of mortality also contributed to their sense of positive growth. The conversation progressed to Darren sharing that he believes that overall they have grown in their abilities to live in the moment and enjoy every day. Annika shared her belief that "Every day's a gift...and it's

important to live life, like *really* live it, not just go through the motions.” She indicated that she has always felt this way, but, that after going through breast cancer, she is much more aware of it and committed to making it part of her daily living. She continued on, saying,

There’s happy things all around us, and I don’t want them to slip by unnoticed anymore. I feel so much gratitude now....I’m so grateful that we’ve been able to come out strong and not let cancer destroy us like it does so many other couples. Having gratitude the way we do now is definitely something that’s changed for the positive, and we share that feeling. It’s increased in the sense that I want to celebrate things. That’s a way of acknowledging that you’re alive.

Annika and Darren were asked if they believed surviving cancer impacted their abilities to handle other stressful life events. Annika shared that the death of her brother was extremely difficult for her, and she credited the growth that she and Darren experienced together as a significant factor in her ability to cope. “I think we were more emotionally strong and emotionally supportive and better able to get through it than we would have before,” she explained. “I definitely feel, now, we’re much more intimately closer together than we were before cancer came into our lives.” Darren added, “Going through all that we have, I think it gave us some confidence that we could get through this together too. I know I felt like if we could get through that we could get through anything.” He commented that he felt like he and Annika were a “team” and was extremely proud of their cooperative and caring efforts. He continued on to say,

Here’s something I guess I’ve never told Annika....we didn’t have a lot of guidance, but we tackled it together. It made me feel like I could help her get better and be a part of

that, not just helpless on the sidelines. Besides it helping me not feel helpless, it made me feel really good about us and proud of us.

When asked if they wanted to share anything further, Annika stated, “I want you to know something else about me. I always dress up and wear make-up, so that I look healthy. I do this around people who knew I was sick because I don’t want them to see me as sick anymore because I’m not.” When asked how that was helpful to her, she said, “People saw me as sick for a long time, and, now, I want them to look at me and see a survivor because that’s what I am.”

Researcher’s Experience

The interview with Annika and Darren was held in their home upon their request. They indicated that evenings were the only time they were available; however, this was also sometimes a difficult time for them because their fifteen-month old son frequently had trouble going to bed at night. I was agreeable to their request because they presented as very willing and enthusiastic about participating and because I empathized with their desire to limit utilizing a babysitter as much as possible during that time. Initially the interview did not go smoothly. Annika and Darren’s son was having difficulty going to sleep which caused Darren to leave the interview multiple times to comfort or check on him. After a prolonged amount of time, in an effort to be sensitive to the needs of the family, I offered several times to reschedule the interview and attempt it again at a later date. Annika and Darren were insistent that they would like to continue. Although I recognized that I was feeling some slight frustration, I redirected my thoughts to the motivation I perceived from them. With the disruptions, I found it a bit difficult to organize my thoughts and resume the flow of the interview; however, after some time, the child fell asleep, and the interview was able to progress smoothly.

Once Annika and Darren settled in, they appeared very comfortable with the topic of discussion and moved easily from responding independently to questions I asked to engaging in a conversation amongst the three of us. As this occurred, I began to perceive an emotional closeness within their relationship. This perception emerged as I observed the couple interact with one another in a more natural fashion. They altered their initial seating postures from upright and formal to more relaxed and leisurely. Annika even moved from one side of the couch to the other, placing her in closer proximity to Darren. They spoke with ease, frequently maintaining eye-contact with one another as they spoke about shared experiences, though not to the level of excluding me from the conversation. They were able to shift from communicating to me to communicating with one another in order to formulate their joint responses. In general, Annika and Darren's way of communicating with one another was supportive and responsive. They frequently verbalized when they shared a viewpoint or agreed with each other's statements, and they encouraged each other's verbal contribution by asking for feedback rather than requiring prompting from me. Interestingly, there were very few areas of discussion in which they expressed varying opinions.

Although they seemed to be a couple who mutually valued recognizing the positive aspects of their situations and experiences, this was not at the exclusion of acknowledging the negative. They spoke openly about what they perceived as negative aspects of their experiences, demonstrating that their focus on the positive was not a means of avoiding those emotions or ways of coping that they were less than proud of. A strength that I perceived in this couple was their abilities to offer a balanced account. When discussing what they thought was a deficit in the other, they also make an effort to acknowledge that that person did well in the given situation. More surprisingly, during the conversations related to positive growth or perceptions

of change, they did not shy away from pointing out missteps. In my opinion, this gave the interview a very realistic feel. I perceived them as a couple who were willing to be open and genuine without the need to exaggerate their trauma or sugar-coat their growth. In fact, I was surprised with the level of openness they displayed right from the start interview. I was especially surprised with the depth of conversation that they were willing to have with me about their intimate sexual relationship. They had indicated that their sexuality was a very important part of their relationship, so it made sense that they may spend significant time discussing the impact breast cancer had on this area of their lives. It was during this part of the conversation that I was aware that I entered the interview with a pre-conceived idea that it was going to be difficult and/or uncomfortable for the couples to engage with me on this topic. That preconceived notion caused me to initiate that portion of the interview with caution and with my own sense that I was, in some way, intruding upon their privacy despite the fact that I purposefully offered them the opportunity to limit disclosure to a level they were comfortable with or bypass the topic all together if they so chose. I do not find the topic of sexuality uncomfortable to speak about; however, I have experienced that many people do, and this motivated my hesitancy. Annika and Darren's self-initiation of this topic quickly allowed me to sidebar my caution.

I took note of an internal struggle I was experiencing over how much structure to impose upon the interview. My desire to be thorough seemed to be in conflict with my goal to embrace phenomenological research methods. I truly wanted the couple to guide the conversation in the direction that was meaningful; however, I felt some pressure knowing I needed to elicit certain information from them in order to meet the goals of the study. At times, I prompted them to speak further about a specific topic that they had offered little information on or elaborate on a

statement that seemed vague. The internal dilemma emerged when the couple moved past my inquiry, offering little elaboration. For example, when asked about their support system, Annika and Darren primarily spoke about the support they provided and received from one another. I attempted to explore additional sources of support, but found that they offered minimal dialogue on this and mutually returned to the support they experienced within their relationship. I did not prompt further and was concerned that the interview may not be a rich enough account. I reminded myself that I had informed them that, in the instance that I needed further information, I requested the option to contact them at a later time. Upon reviewing the transcript, I realized that the interview had in fact captured what was meaningful and significant to this couple. I felt reassured that I had not neglected to explore any particular areas of interest, rather I provided the option and allowed the couple to respond to those topics which were personally significant to them. The result was a concentrated verbal illustration of their personal shared experiences.

Comments that the couple made to me upon the conclusion of the interview were extremely helpful. I approached the process with a sense that I was imposing myself upon people's time for the sake of my personal goal. This perception was challenged when the couple thanked me for allowing them the opportunity to participate. Annika shared that she felt very satisfied with having been given a chance to do what may benefit others in the long run. This feedback reminded me of what I often teach others -- that asking others for help often creates and opportunity for them to be helpful and experience a sense of purpose through that.

Kara and Clark

Demographics

Kara is a 43-year-old breast-cancer survivor who has been married to her husband Clark for 18 years. Together they have three children; a 15-year-old son, and two daughters ages 13

and 10, all of whom were residing at home during the time Kara was diagnosed (see genogram, Appendix G). Kara was diagnosed with Stage-1 breast cancer at the age of 40. Her treatment regimen included lumpectomy surgery, radiation therapy, and hormone therapy which she continues to be prescribed by her physician. She was employed part-time as a preschool teacher at the time of her diagnosis and throughout her treatment; however, she had previously obtained a Master's degree in music education and had worked full-time as a music teacher until her second child was born. Clark is currently 46 years old. His highest level of education is an MBA in Corporate Finance, and he is currently employed in the finance industry. During Kara's treatment he applied for and was approved for family medical leave, but stated he did not take an extended leave. He was able to use other benefit time off to accompany Kara to appointments as needed. Kara utilized other support resources for assistance, so that Clark would not need to be absent from work. This family identifies as Jewish in both their ethnic and religious backgrounds. They are highly active in their temple and in their practice of Jewish traditions at home. They reside in a primarily upper-middle class suburban community which they describe as both culturally and socio-economically diverse.

Prior to Kara's diagnosis, the couple reported that they had very limited experience with breast cancer. Kara does not have any history of breast cancer in her family. Clark reported that he had two aunts with breast-cancer histories, though he had limited exposure and no involvement in their care. He vaguely recalled that, in high school, he knew that his aunt was going through chemotherapy treatment but that he was "removed from the whole situation." He added that his other aunt never told anyone she had gone through treatment for breast cancer until the other aunt was diagnosed. By that time several years had passed. The only other experience they identified was that a close family friend was diagnosed a few weeks before Kara.

Although this friend's course of treatment differed from hers, Kara indicated that there were times when her friend was able to offer guidance or share helpful personal information as they both progressed through treatment. Kara described the relationship as mutually supportive, though she did not feel she could offer guidance due to her limited knowledge and experience. With regards to cancer in general, Kara reported that her maternal grandmother passed away due to complications associated with metastatic uterine cancer. Clark's mother passed away from cervical cancer. He indicated that by the time her cancer was diagnosed it was Stage IV with end-stage prognosis, making palliative care the appropriate course of action. She passed away only a few months after being diagnosed.

Case Study

Kara and Clark were referred to the study through a local breast-cancer-related organization with which Kara had been involved. In contrast to Annika, Kara did not detect the lump in her breast. It was discovered by her physician during a routine annual examination. Kara described that the process of diagnosing the cancer happened very quickly. Within four days of her doctor discovering the lump, a mammogram and breast biopsy were performed. Less than a week later, she was told over the phone by her doctor that she had Stage-I breast cancer. At the moment of being told, Kara described feeling overwhelmed, confused, and a great sense of sadness. She stated,

I was in complete shock. I actually don't have any memories if I called [Clark] or not...I was hysterical and I started crying.... I honestly don't remember telling [Clark] at all, but, of course, I did. It was literally like my stomach dropped. It was just immediate despair...I never had the thought I was going to die....It was more about what hell or shit

am I going to go through until I'm at the other end of it, and how long is that period going to be? That completely overwhelmed me.

Clark confirmed that Kara had, in fact, called him at work. He added, "I'm not the most communicative guy, so I really didn't know what to say." He described himself as "analytical" and disclosed that he is often uncomfortable with emotions and responds to crises in ways that reflect his logical nature. He illustrated two separate thought processes that occurred during his reaction to the news. First, he shared what was happening internally:

I keep a lot internally, especially in this situation. Of course, the thought goes through my mind, is she really sick? How dangerous is this? I'm trying to analyze it, probably so I can find a way to tell myself it's going to be fine because they caught it early... "It's probably fine" I told myself, but the thought creeps in "but what am I going to do if it isn't?" In my head I would take the steps... what if it's this, what if it's that... never speaking that to her, never letting her know that. I thought, okay I'll quit my job, and I'll take care of the kids. Luckily we have enough money where I can quit for five years and not worry about it. Then I'll worry about things after that. The important thing is that I would be home for the kids. I actually thought this through briefly in case the worst happened.

Then he shared the thoughts he was experiencing as he responded to Kara:

My reaction to her is always going to be "It's going to be fine." Even if I have concerns, I'm not going to show her those concerns because I wanted her to feel like everything was going to be fine. It wasn't like I was trying to fool myself. I just wanted to be strong for her. I never lost it. I was never in tears. Even if I did, I would never do that with her around.

Clark explained that this was a brief thought process, but was likely reflective of the underlying emotional reaction he was having that he was unable to connect to. In general, he experienced difficulty recognizing and expressing his emotions and was aware of this enough to articulate it. When asked to describe the emotions he was feeling upon learning of Kara's diagnosis, he said, "That's actually hard to do. I guess a little bit of fear, concern for her and the children, but not so much for myself."

Clark's report of intentionally keeping his emotions internalized mirrored Darren's in that both men perceived this as a way to be "strong" for their wives. Both believed that breaking down emotionally could potentially impact their wives' feelings of security in being able to rely on them for support during difficult times. This was especially the case for Clark in the first few weeks after learning about Kara's breast cancer diagnosis:

I was just trying to help her with her emotions. She was upset, so sad. Me not being a good communicator in general, I guess at times I felt inadequate that I couldn't support her that way as much as she probably needed. I guess that's why I introverted, so that she wouldn't see what a struggle it was for me or see my weakness.

Although both Kara and Annika suggested that this pattern of withholding emotions was not helpful in some ways, they also both felt that there were advantages to the logical approach their husbands took to the situation. Kara explained that the overwhelming sadness she initially experienced lingered throughout the month between being diagnosed and having lumpectomy surgery. She also described being preoccupied with her own thoughts, "I just wanted it out, and all I could think about was this disease festering in me." During that time, she had difficulty focusing her attention on how to proceed with treatment and how to plan accordingly for what daily-living changes were going to come about. She credits Clark with assuming much of the

responsibility for facilitating appointments, addressing insurance issues, and handling the majority of the logistical tasks, indicating that she had difficulty performing these tasks because she could not refrain from crying whenever she had to speak about the cancer. Clark encouraged Kara to participate with him in researching breast cancer, treatment options, and various other breast cancer resources as a way for Kara to take an active role in her own care. These were tasks the couple could do together in the privacy of their home and that facilitated necessary decision-making conversations, which provided Kara with some sense of control over what was happening to her. In addition, Kara began to keep notes of all cancer-related information she received as well as of dates and details of all events related to her care. She believed that this was her way of coping with the overwhelming amount of information she needed to process and helped her be able to communicate more effectively with Clark and her physicians about her needs and decisions.

Within their household, Kara primarily handled the family's needs. Clark's willingness to take on some of the responsibility of managing the logistics of her treatment relieved Kara of that stressful burden, allowing her to focus her attention on other family and household responsibilities, which Kara reported contributed to her desire to "feel like a normal person." Kara and Clark mutually agreed that their primary way of trying to cope with the impact breast cancer was having on their lives and family was to maintain as much "normalcy" as possible. With the exception of taking off a few days following her lumpectomy surgery, Kara continued to work part-time throughout the rest of her treatment. She scheduled her radiation treatments during the day on her days off, so that it did not interfere with the household routines and family activities. She stated, "I felt like I had to fit it into my life, not let my life revolve around it." Unlike Annika and Darren, Kara and Clark did not make significant adjustments to the division

of household and family responsibilities. Kara continued to attend to the needs of the household while Clark maintained his regular work schedule. She explained that she felt it was very important that her children experienced as little disruption as possible, and she did all that she was able to do in order to keep their routines running smoothly. She shared,

I was just trying to keep it normal. As much as I think I wasn't myself during the whole time, I did my best. I even asked my doctor to write me a prescription for Xanax so I could keep myself together, and I didn't want my kids seeing me cry. I thought if something would help me just keep that balance, at least when it was family hours, then I could get in bed and do whatever I had to do to handle the sadness.

Clark agreed with Kara that trying to keep routines as normal as possible for their children was a priority for them. He also understood that Kara was dealing with depleted energy and that keeping the children's schedules and the household routines going would leave little energy left to be devoted to their relationship. He stated, "It was most important to focus on herself first, then the kids. I could handle being at the bottom; that's the way it should have been. I was ok with being low man on the totem pole." Kara responded that she felt bad about this, but that Clark was correct. She shared,

I was trying as much as I could to keep the kids on the right path, and I was exhausted, so it definitely affected his and my relationship. I just couldn't focus on it all and keep us in a good place too.

The couple described themselves as "family focused" and reported taking pride in the way they were mutually involved in their children's activities and shared a common view on parenting. Clark repeated multiple times that their goal for their family was to "keep moving forward" until they were through this ordeal. Both agreed that they recognized their strengths in

working together to keep their family functioning in a balanced way and focused on continuing to use these strengths to get them through this difficult time. Clark admitted that his focus on trying to maintain the status quo became intense initially, and he discussed that there were times when he may have been too rigid in maintaining their routines. He gave an example of being persistent about not cancelling the family's annual ski trip which was scheduled in the middle of Kara's treatment. She was uncomfortable with the idea of missing any of her radiation therapy, so she came home and spent the week alone. Clark recognized in retrospect that the "normalcy" he was trying to maintain provided him with a way to avoid looking at the impact cancer was having on their lives. He stated,

If we were doing our usual things, then I guess in my head I could think everything was okay. If I had to see things fall apart, I'd have to struggle with how to deal with that emotionally. I know that keeping everything moving forward was helpful in the long run, but now I see how it was helping me cope.

When Clark spoke about making minimal adjustments to his work schedule other than taking time off to assist Kara after her lumpectomy surgery, he spoke about having had apprehensive feelings about this. He explained that the decision of whether or not to take an extended leave was confusing to him, and ultimately he went along with Kara's suggestions. He asked her on several occasions if she wanted him to go with her to radiation, but each time she responded, "No." Clark shared,

I kept thinking to myself that maybe she really did want me there, but wouldn't say it because she felt bad about pulling me away from work and that would make things difficult for me. I had guilt about that and wondered if I should have been there and gone with her...I felt like I was never as supportive or doing enough to make her feel better.

Kara was quick to respond to Clark's statement, "I think sometimes we're more about the doing than the feeling part. You did the doing part." She described them as a couple who worked very well together and who genuinely loved and cared for one another, but who were not emotionally expressive or very physically affectionate. She indicated that they had always been this way and that "it wouldn't be fair to expect him to be who he's not just because [she] had cancer."

Therefore, she did not ask for his emotional support or indicate in any way that she was seeking that. She proceeded to praise him and acknowledge his strengths in working cooperatively with her in other ways to cope with the impact that cancer was having on their lives. Clark responded by saying, "She always tried to make me feel good about what I did." He agreed that the way they work together as a couple is a definite strength in their relationship and added that it was "easy and natural" for them to communicate with one another in this fashion. They mutually described that they are very much "in sync" with one another and can often "read" one another so well that their communication is "unspoken."

The ways in which Kara and Clark communicated with one another and with their children was identified as an asset that helped with managing the issues associated with breast cancer. As a couple, they verbalized that their personal way of communicating is a source of pride and one aspect of their relationship that they believe works exceptionally well for who they are. Kara added that their way may not be through expressions of emotion, but it did, however, bring about a sense of closeness between them. From the start, together Kara and Clark met with each of their children separately to talk about Kara's breast-cancer diagnosis in terms that were appropriate for his/her level of understanding. Following that, they utilized their tradition of having a family meeting every Sunday as a forum to talk about breast cancer and how it was affecting them. The couple agreed that this was an invaluable tool during this time because their

children had become comfortable with gathering in this way. They would review the week before and discuss the week ahead, focusing on both cancer-related and non-cancer-related topics. Kara made sure that she was open with them about what was happening and let them know how she was feeling week to week. She wanted to role-model for them that it was okay to talk about their thoughts and feeling about cancer and to ask questions. Clark maintained his way of keeping his emotions and concerns to himself and, instead, focused on easing his children's concerns and providing them with the information and reassurance they needed. He remarked, "I needed to be their rock. So if they could see that I'm fine, they'd feel like they were going to be fine too." He wanted them to balance trying to keep their routines "normal" while still encouraging them to recognize that a significant event was having an impact on their lives. There were times when the children were asked to help with household tasks when Kara was not feeling well.

The impact of breast cancer on Kara and Clark's intimate sexual life was significant and the aspect of their relationship which sustained the most disruption. From an emotional perspective Kara perceived Clark to be even more emotionally closed-off than he had been before she had cancer. Clark did not disagree and explained that, although it was not his intent to disconnect from Kara, he often found himself behaving cautiously around her. Due to her highly emotional state and his difficulty responding to those emotions, he feared inadvertently "triggering" Kara by misspeaking. He went on to describe buffering behaviors similar to those described by Darren. "I was walking on egg shells, just not wanting to upset her in any way. That was a huge concern to me, and she had enough to be upset about without me contributing to that." Kara was able to understand Clark's intentions, and even identified tempering her own communication in order to not overwhelm him with her emotions, but admitted that she believed

it put a “wall” between them which influenced her desire to engage sexually with him. Kara’s buffering behavior did not cause Clark to feel emotional distance, and both seemed to feel it was actually helpful in this case. He did, however, relate to the analogy of a wall being between them, but from his perspective, it was the decreased sexual intimacy that brought about his feelings of distance in their relationship.

Radiation therapy was the primary aspect of breast cancer treatment that the couple described as most impactful. In terms of the influence this had on their sexual intimacy, Kara indicated that going through this process was the most difficult for her. She explained that having people looking at her breasts on a regular basis made her feel very vulnerable. She added,

When I’d come home, I’d be like “I did that already.” I didn’t want to be naked and exposed anymore. We would go to bed, and I’d be like “don’t touch me.” I was embarrassed about it, and I found it humiliating. These tattoos they put on you were no badge of courage in my eyes.

Kara acknowledged the impact of her emotional state on her ability to physically connect with Clark. She explained, “Whatever is physical in our relationship is a sign of our emotional connection.” Similar to Annika and Darren’s story, Kara projected the feelings she had about her own body onto Clark. Although her level of embarrassment and view of dysmorphia were not to the extent of Annika’s, her dissatisfaction with her body caused her to believe that Clark was also dissatisfied. Like Darren, Clark tried, to no avail, to reassure Kara and express his attraction. “It didn’t matter what I told her...that I wanted to see her naked...that she still excited me...she wouldn’t believe me.” Both Kara and Clark recognized that the inhibited emotional expression between them was having a different effect than it ever had before. Prior

to this traumatic event in their lives, they had been satisfied with the way they emotionally connected. Other ways of engaging, including enjoying leisure activities together, working cooperatively to raise their family, and sharing mutual goals and values had brought about a mutual sense of closeness. However, the influence of breast cancer changed the emotional dynamic within their relationship in ways the couple had not been prepared for.

Kara indicated that she had never experienced a life-changing event that altered her emotional state and needs in such a drastic way. The closeness she and Clark had always been able to “create” before had facilitated her desire to sexually engage with him. Clark commented that their sexual intimacy had always contributed to his feelings of closeness within their relationship. He added that he had also never encountered a situation that was so emotionally heightened, and he was unskilled in his ability to respond effectively. He added that he was concerned about sounding as if he were placing blame on Kara, but wanted to be honest that he experienced her emotional sensitivity as the aspect of breast cancer that was most disruptive for him. He found it difficult to “keep the pulse of the family” because, “If she’s not herself, it affects the whole house, and it did.” The couple commented that they had always view themselves as a “compatible” couple and “great pair” in their unique way, but during this time could not recognize that their previous ways of engaging were not working in their new and unfamiliar situation.

Kara reinforced that she felt that Clark was a source of support for her in many ways, but that she also understood that he was not going to be the primary person to offer her the emotional support she needed to cope. Her primary support network was comprised of a group of female friends whom she felt very close to. None of these women had ever had breast cancer, so she sometimes felt that it was difficult for them to understand what she was experiencing, but she

found value in their willingness to listen and felt they could relate as women. “They would just let me talk through the emotional part of it. I didn’t need them to respond.” She also confided in her family friend who was going through treatment as well. She stated, “It wasn’t like she was going through it with me, but there was something comforting about when we spoke...that she knew exactly every emotion I was talking about. It made me feel less alone in this journey.”

Kara indicated that her relationship with her mother was “complicated” and that her father “doesn’t do well with this sort of stuff;” therefore, they were limited in their abilities to offer her support as were other extended family who reside out-of-state. Other sources of support included the couple’s community and temple. Neighbors and co-workers from the school Kara worked at brought food, offered to carpool, or extended play-dates to the children. The rabbi at their temple offered visits or opportunities to pray together. Kara had always maintained contact with her children’s teachers and felt comfortable sharing what was occurring with her health. She asked them to take notice of any signs of disruption or changes in their behaviors that might indicate they were having difficulty dealing with what was happening at home. Clark was offered support through his company’s Employee Assistance Program, but indicated that he did not utilize that service. Neither Kara nor Clark was offered support services by her treatment providers.

When asked if they believed surviving cancer influenced the ways they handled other difficult life events, the couple indicated that they had not had any other significant events, but they did believe going through cancer had an impact. Kara began by talking about her perception that, as a couple, she and Clark developed greater competency in handling stressful events. She disclosed, “We’re not the most self-reflective people in the moment, but we

definitely learn a lot by looking back on things.” She indicated that her perceptions of their competency stemmed from observing her children. “It’s my evidence,” she stated,

We went through this horrible, traumatic time, and they are okay. The fact that they adjusted so well to everything that was going on and were not majorly disrupted means we did something right. If we can do it well once, we know we can do it again if we need to. You don’t know how strong you are or how well you can do until you’re faced with having to do it. Now we know we can do it.

The couple was asked about ways they believed they have changed positively as a result of their experiences with cancer. Kara answered first, stating “Cancer changed my life....I felt like, after I got through it, I needed to anything and everything I could to be a good and productive person. That became very important to me.” She discussed feeling that her time could be spent in ways that were more productive and satisfying to her as well as contributing to the well-being of others. “I don’t think I ever said it out loud, but I guess I felt like I was given the gift of life, and I needed to make the best of that life,” she remarked. Kara described many of the changes that she has experienced as “multifaceted.” She gave the example of increasing her involvement in charitable endeavors. She identified that she felt a strong need to “give back,” but that these endeavors also gave her the opportunity to try activities she had never done before and to challenge herself in new ways. She talked about her involvement in fundraising activities stating,

I wanted to do these active things for a cause I obviously felt strongly about, but I also showed myself that I could do it. I snow-shoed three miles; I walked 40 miles; I walked down a runway in front of a large audience. I never would have done them before. I was doing these things as much for me as for the people who it was going to help. I got

something emotionally positive out of it....I really felt like I was an actual strong person and in more control of my emotions.

She added that having the opportunity to spend time around other survivors greatly contributed to her ability to connect with her own sense of survivorship and gave her “perspective” on her own strength and endurance. She shared that early in her involvement in these kinds of activities she had a tendency to compare the details of her breast cancer with other women’s cases. This often resulted in her feeling her case was “not even close” to what other women had endured and, therefore, not deserving of accolades suggesting she was “strong” or “courageous.” Over time she recognized how varied the experiences of survivors were and ceased comparing these experiences. The more she listened to other women’s stories, the more connected she felt to the common experiences. She stated, “I started to be able to see in myself the things that others saws in me. I finally learned how to embrace being a survivor.” Both Kara and Clark attributed the importance they have placed on being altruistic to the increased gratitude they have experienced. They verbalized feeling extremely fortunate to have had so many caring people reach out to them and offer assistance. They have also made it a priority to encourage their children to become involved in charitable activities, to teach them the benefits of doing for others, and to help them recognize opportunities to express gratitude.

When the couple was asked if they believed it was possible to experience positive growth as a result of surviving breast cancer, they mutually answered that they did hold that belief. They believed that they, as a couple, had grown as a result of their shared experiences and offered their insights into this. They agreed that they had developed a greater sense of empathy towards the struggles of others and, as a result, are more willing to offer support. Clark explained, “I’m more understanding of others going through troubling situations. I may not be

the shoulder they cry on or the person who offers them words, but I'll be there in other ways like monetarily, or if their kids needs a ride, or if I can help with a task." Kara added that she believed they became more aware of what was happening in the lives of people they cared about and this increased their sense of community and connection to the people around them.

Surviving breast cancer brought about growth in Kara and Clark's ability to gain perspective on what they feel is important in life. Although they had always been involved in their temple, both Kara and Clark indicated that, prior to going through cancer, they had not viewed themselves as religious people, and their involvement had been more about following their family's tradition than anything else. However, they expressed that their perspectives on spirituality had changed as a result of their experiences. They shared that they did not necessarily talk about how they felt about spiritually, but agreed that they had changed the way they engaged in spiritual activities. They both became involved with the youth groups in order to be positive role models for the children of their temple. Clark commented that he felt more inclination to sit Shiva or other occasions where he believed he could be supportive. He noted that he had come to value the presence of supportive people through seeing the impact it had on Kara during her treatment and viewed this as a spiritual act. He stated, "I guess I've come to realize that sometimes just showing up and being there means a lot. Again, I'm not the most emotionally supportive, but I can show up. I try to do that more even if it means my support is in the peripheral."

The couple was asked how they cope with the possibility of recurrence. They had similar experiences in that acknowledging the possibility brought about an acute awareness of mortality. Although they shared this view, they did not necessarily cope in the same ways. Kara stated, "When the thought of recurrence comes up, I'm reminded that we only live once. I try to stay

grounded and stay in the moment.” She explained that being concerned about the possibility of recurrence had been a daily thought for the first year following the end of her treatment. Now it is generally triggered only when she has a pending physical exam. Prior to her check-ups, she has experienced increased anxiety and emotional sensitivity, which generally subsided once her doctor told her she is still cancer-free. She shared that knowing there is always the possibility motivates her more than ever to make a conscious effort to make the most of every moment.

In response to Kara’s disclosure of the anxiety she experienced related to her appointments, Clark confessed that he was aware that he often appeared unconcerned during those times when, in fact, inside he was feeling very concerned. It was easy for him to resort to his old way of coping by withholding his expression of emotions even though it also meant that he was not providing Kara with the acknowledgement or support she needed. The couple shared that this is an area in which they have just recently experienced some growth. Kara has begun to verbalize her emotions more openly on a regular basis, but is conscious to do so in a way that will not overwhelm Clark. She has begun to express her needs for his support instead of just discounting him from the start. She stated, “If I didn’t tell him that it upset me when he acted like he didn’t care about the appointment, then he would never know because I used to just act like it was okay.” She acknowledged that Clark had been willing to assist her with anything she asked for, so she was now learning to ask for the kind support she needs. Clark conveyed his desire to improve in this way, stating “It’s an opportunity to learn from what we’ve gone through with cancer and use it to help our relationship change for the positive.” He smiled as he stated, “I already took the day off for her next check-up.” He discussed the fact that, even though he continues to find it difficult to express his emotions, he has gained greater awareness about how he handles his emotions and how this impacts others. Together, the couple affirmed that, despite

the struggles they faced, they believed that surviving breast cancer together brought with it opportunities to learn about one another and to grow as a couple. They continue to set goals as a couple to build on the growth they have achieved and make additional changes in response to the awareness they gained about themselves and their relationship. Kara commented,

We're not the perfect couple; we didn't do everything the best way, but we sure did learn from it. It might have taken us a while, but at least we can have the satisfaction of knowing we didn't let cancer win. We can actually look at our life now and literally see the good things that came out of all of this. That's a very empowering feeling...it's like we more than survived it, we one-up'ed it.

Researcher's Experience

I approached this interview with an increased awareness that I needed to remain cognizant of any signs of discomfort the couple might demonstrate. Kara had disclosed to me that Clark was generally quite shy, and, although he was willing to participate, she was unsure about how much he would contribute verbally. She voiced her concern that she did not want the interview to be a waste of my time. I reassured her that it would not be a waste of my time and that we could check-in with Clark regarding his comfort level as we went along. I spoke with Clark directly to explore any concerns or questions he had and to assess both his comfort level and willingness to participate. He assured me that he had no reservations about being involved and sounded at ease during the conversation. At the start of the interview, I reminded the couple that they could say as much or as little as they were comfortable with and that they had the option to discontinue the interview at any time. Observing his body language, Clark appeared relaxed and attentive as we sat at a table in the community room of their temple. He did not demonstrate any visible signs of nervousness or apprehension.

At the start of the interview, Kara did the majority of the talking. As I posed questions to them as couple, Clark automatically looked to Kara to respond first, and then would simply nod in agreement. I did not immediately change the way I was asking questions or prompt Clark in any way because I wanted to continue to observe how the couple interacted with one another. In addition, I had hoped that allowing Clark to determine when he would respond verbally would contribute to the feeling that this was their story to tell in their own way. I understood that the ways they talked about cancer now may very well reflect how they experienced and coped with cancer at the time or how they had changed as a result. I wanted to remain open to recognizing any parallels that may have been presented. Despite my understanding, I was well aware that Clark's perspective was an essential part of capturing the couple's shared experiences and that I may need to take a more active role in prompting his participation. I was relieved when he initiated verbal participation on his own.

Interestingly, once Clark began to engage in the conversation, he required minimal prompting to offer his perspective and contributed throughout the rest of the interview. It was at that point that I felt that I was fully engaging with the couple because I was no longer concerned with how to respond to Clark. Apparently Kara was surprised by Clark's active involvement, and, after concluding the interview, she joked about him being an imposter while praising him at the same time. Clark himself even commented on how unusual it was for him to do that and attributed it to my ability to make him feel at ease and comfortable. I appreciated the genuineness of his compliment and felt reassured that my gentle, stand-back-and-watch approach was in fact the right decision. I also felt deeply satisfied when the couple disclosed that they found the interview to be very eye-opening. Both Kara and Clark remarked that they had never before discussed many of the topics they did during this conversation. They also agreed that the

interview process itself and the questions being asked prompted them to think and talk about their experiences in a way they had never done before. They also both commented that they had gained additional insight as a result of their participation.

During the interview I noted some interesting characteristics about the way Kara and Clark interacted with one another and talked about breast cancer. The couple had described themselves as a “doing” couple as opposed to a “talking” couple when it came to emotional matters. I gained some insight about this relational dynamic by observing how they responded to the interview questions. The descriptions they gave of themselves as a couple who did not readily talk about their emotions with one another was mirrored in their conversations of emotional topics. Each of them gave a separate account of experiences and did not engage one another in those accounts. However, they mutually engaged in conversations that revolved around topics that involved activity or “doing” aspects of their experiences. As we moved the conversation towards change and growth, I witnessed a similar pattern. It seemed that Kara and Clark associated the idea of growth with changes that were either emotionally based or more abstract in nature, such as gratitude or spirituality. Although they were able to readily identify areas of growth, they appeared to have more difficulty expressing themselves on these topics and used activities (doing) as a way to illustrate their feelings. Conversely, during the discussion on change, the couple spoke with ease. They seemed to interpret change in the sense of physically doing differently as opposed to an internal change of feeling different. Once I recognized that they understood their experiences in the same way I was able to effectively alter how I spoke with them to reflect their communication styles.

Susan and Rob

Demographics

Susan, a 44-year-old Jewish-American female, was diagnosed with Stage-IIB breast cancer at the age of 39 years old. She and her husband Rob, a 46-year-old Italian-American male, have been married for 21 year. Together they have two children, a 25-year-old daughter and a 19-year-old son (see genogram, Appendix H). Both children were residing at home at the time Susan was diagnosed. The couple come from different faith backgrounds; Susan identified as Jewish while Rob identified as Roman Catholic. Both reported that they do not actively practice their religions though consider themselves “spiritual.” Treatment for Susan’s cancer included lumpectomy, radiation therapy, chemotherapy, and hormone therapy. Susan underwent genetic testing and was determined to have a positive BRCA-1 mutation, suggesting increased risk of developing hereditary breast cancer. In light of this discovery, and in conjunction with known family history of cancer, Susan’s treatment team recommended she have a hysterectomy. She followed through with this recommendation a year after completing her treatment for breast cancer. Susan and Rob own their own business and report that they had the ability to adjust their schedules to accommodate Susan’s treatment needs and appointments. Susan has a 12th grade education; Rob completed 11th grade.

Susan and Rob had a significant amount of experience with cancer prior to Susan’s diagnosis; however, their experiences were with other types of cancer. Within Susan’s family of origin, her maternal grandmother passed away at the age of 59 years old due to complications associated with gynecological cancer. Susan was unsure whether this was ovarian or uterine cancer. Her grandmother’s sister also passed away due to cancer-related complications. She had been diagnosed with throat cancer and passed away in her mid-60’s. Susan’s father passed away six weeks before Susan’s diagnosis. He had been diagnosed with bladder cancer 17 years prior, which later metastasized to his prostate. His aunt had been diagnosed and treated for ovarian

cancer. Rob reported that his father had passed away due to complications of bone cancer just a few months prior to the interview. His father was diagnosed at age of 66 years old and survived approximately one year. Susan and Rob were as involved in his care as they could be, traveling to Florida every three weeks to assist as needed. Fifteen years prior, Rob's father had been diagnosed with kidney cancer. They reported that surgery was the only treatment needed, and he did not experience any further issues. They also indicated that they were told that the kidney and bone cancers were not related.

Case Study

Susan and Rob became involved in the study through a word-of-mouth referral. At the start of the conversation exploring how they learned of the cancer and how they initially responded to these findings, both Susan and Rob poignantly expressed that the experiences they had were some of the worst they had throughout their ordeal. Susan began by explaining that she had found the lump in her breast on her own and suspected it was breast cancer. She was seen by her gynecologist quickly, but had to wait for six weeks to get an appointment for testing. When the results were available, she and Rob met with her gynecologist to discuss the results. She stated, "Deep down I think I knew I was going to hear that I had it, but I didn't expect to hear it the way I was told." Susan explained that her doctor came into the exam room, told her that she had breast cancer, and left the room quickly. She and Rob were ushered out by a nurse. This came as a surprise, especially for Susan since she had been in treatment with this doctor for several years and had been happy with the quality of her care. She added, "I left the doctor's office not knowing what my next step should have been. I had no idea what I should have done." Rob remarked that they were not given any information or an opportunity to ask any question. He commented, "Maybe if the doctor had given us some kind of education on what

was going to happen, it might have been a little easier on her. She left there pretty much upset.” Susan quickly responded, “I wasn’t just upset, I was mad. We were left clueless.” She continued on to describe being so focus on her anger that she had difficulty processing what she had been told:

We got home forty-five minutes later and just stopped and looked at one another. Then I was like, “Oh my God, did she just tell me that I had breast cancer?” No matter how much you suspect it before hand, it doesn’t prepare you to actually hear those words.

Compounding this negative experience with her healthcare provider was the fact that Susan’s father had passed away from cancer-related complications just six weeks prior. Susan recognized the impact that was having on her reaction. She stated, “All I could say at that moment it hit was, ‘Get me to the hospital and get this out of me now.’ I couldn’t stop crying.” Rob added, “And the fact that we were so disregarded by her doctor, I knew we weren’t going to play around with any small doctors. I told her, ‘We’re going straight to Sloan-Kettering; they’re the best,’ and that’s what we did.” He tried to console her by telling her everything was going to be alright. “Not that I really knew it was going to be okay, but what else could I say? I wanted to believe it was going to be okay,” he said. Susan stated, “I never thought I was going to die, I just felt an urgency to get it out of me. Maybe subconsciously I was afraid I would die if it stayed there too long.” In an effort to try to make sense what was happening and understand what to expect, Susan and Rob began to research breast cancer and treatment options on the internet. They found the wealth of information overwhelming and did not know how to focus their attention on the information that was relevant to them. Susan commented that they had made an appointment at Sloan-Kettering Hospital but, were uneasy with the ambiguity they

faced. She recognized that they did not have enough information to know what to look for, but they continued because it helped them feel like they were being productive.

The days following learning of the breast cancer diagnosis were described by Susan and Rob as “the worst days of our lives.” Having to tell their children and their family, while they were all still grieving the loss of her father, that Susan had cancer was “devastating” according to the couple. Susan shared,

That had to be the worst day of my life....I was probably more concerned about telling them than I was even about myself. That was bad. We were really in a bad way to begin with. The little one screamed, then hit the floor. The other one just sat there in shock....We would tell them all the time “Papa’s going to be okay.” Papa’s not here anymore, and now I’m telling them I’m going to be ok. They didn’t want to hear that because they didn’t believe it.

Rob added, “That was the hardest part out of this whole thing. I can still remember them looking at me like they didn’t believe me either.” They both described feeling extremely “sad” that their children had to go through another experience of watching someone they love go through the struggles of cancer.

Susan and Rob perceived themselves as drawing closer to one another from the start. Rob commented that he always felt it was “their” fight, and he was committed to being present for Susan and doing all in his power to help. He stated, “It was a tough time for us obviously, but we stood together through every moment of it.” He made it a priority to be involved in all aspects of her care and to be present for her as she needed him. They educated themselves, attended appointments, and spoke to her healthcare providers always doing so as a couple. Susan commented that she didn’t mean to make it sound as if they were without their share of

disruptions; however, she believed that the way they handled them together greatly decreased the impact they had on their relationship and on their daily lives. She admitted that there were times when she was on “an emotional rollercoaster” and could be very pessimistic or irritable, but that Rob showed understanding in the way he responded to her. He agreed stating,

I did the sponge thing. If she snapped at me or said negative things, I would normally say “Are you crazy? Why are you saying that?” I didn’t do that though; I just took it. I didn’t want to let her start a fight because I knew it wasn’t good for her to add more stress. And I knew being negative wasn’t going to be helpful to either of us.

Rob purposely changed the way he was reacting to Susan’s emotional expressions by choosing to offer a reassuring response or by not responding to a negative comment when he felt it was appropriate. Unlike Darren and Clark, he indicated that he never felt apprehensive about expressing his thoughts or emotions or that he had to “tip toe” around Susan in order to not upset her. Instead, he found that Susan responded well when he shared his feelings with her. She agreed, stating “I felt like he was acknowledging my feelings and trying to show me he cared instead of needing to be all tough and macho.” Rob added that he never felt that Susan would see him as “weak” if he shared his emotions because he felt that his actions demonstrated that he was going to remain strong and take care of her. Both he and Susan commented that their abilities to openly communicate about all that was occurring in their lives was a strength that served them well throughout their experiences with breast cancer. In addition, they spoke about the importance of humor in their communication. Susan described Rob as “very witty and just the right amount of sarcastic.” Rob quickly learned that continuing to be “himself” in this regard was helpful. Susan explained,

He always knew when to use a joke to lighten me up if I was in my negative mind set. He was very good at getting me to laugh, but never made me feel like he was minimizing what I was going through. At the same time he also knew when not to joke. We probably laughed more than most couples going through breast cancer. I'm so grateful for that, and it's one of the things I love about him.

Like most couples who were interviewed, Susan and Rob found that the side effects and schedule demands of treatment impacted the daily routines within their household. Rob explained, "Normal things that would have gotten taken care of were put to the side because obviously this trauma in our lives took up most of our time and attention." They mutually decided that they were not going to allow that to become cause for stress, and they accepted it as a temporary condition of their situation as opposed to a "disruption." In fact, during their early conversations about what was going to happen and how they were planning to manage the situation, Susan and Rob recognized that they were likely going to have fewer opportunities to engage in enjoyable activities once chemotherapy started. Their response was to create opportunities to enjoy some of their favorite activities before the side effects were likely to be severe and to make it a priority to enjoy their leisure time while they were able. Rob remarked, "We love to travel, and I knew we wouldn't be able to for a while, so I said 'Let's take a couple of vacations.' I thought it would be good for us." They took one vacation before Susan's surgery and another the week after her first chemotherapy treatment before she began to lose her hair and experience significant side effects. Susan stated, "It was such a good idea. It got my mind off stuff for a while and brought some good feelings into our lives. I think it made it easier to go full force into chemo then because I was in a really positive mind set."

With the exception of their initial experiences learning of the diagnosis and talking with their family about it, Susan and Rob approached many aspects of dealing with breast cancer with an awareness of a dual process occurring. As they faced each difficult situation, they also perceived an opportunity to overcome the challenge. When asked about the ways breast cancer impacted their relationship, Rob responded, “It wasn’t fun or easy, but I would say the impact on our relationship was positive.” Susan agreed stating,

He did a lot of things that he normally would never even think of doing. If you just say the word ‘blood,’ he would probably hide in the corner. Yet here he was emptying my drains and taking care of my incisions. That was a big thing for him, and I knew it, and for him to do that made me feel how much he loved me. I can’t even put into words how much I appreciated that.

Rob added that, “Our appreciation level was instantly raised. I appreciated when she tried to do stuff around the house even when she didn’t feel good, just to take care of us.” They both discussed the appreciation they felt towards Susan’s mother, who would come to help with cooking, laundry, or cleaning. They credited her with helping to make the foregone chores minor annoyances instead of major disruptions to their functioning. Although Susan reported feeling guilty at first that her mother was taking on these tasks in the midst of mourning her husband’s death, she came to understand that there were mutual benefits to be gained. She commented, “It took me a while to understand that taking care of me was helping my mother to cope with my father’s death. Instead of sitting home thinking about it, she was doing something positive instead.” Rob credited the dedication of his employees with taking on some responsibilities of running the business so he could be with Susan as he needed to be. The couple agreed that the impact of breast cancer on their daily lives was greatly reduced by both

the assistance they received as well as their “acceptance” that “It wasn’t important at that time for things to be in perfect order,” as Rob stated.

Susan and Rob assumed a similar attitude regarding changes they experienced in the sexual aspect of their relationship. They described changes in the frequency of their sexual engagement as a result of Susan dealing with the physical side effects of her treatment; however, they conveyed that they did not experience this as a major disruption. The couple mutually indicated that their sexual intimacy was important to them, and they made it a priority to take advantage of when Susan was feeling good. Susan smiled as she stated, “Well, on the weeks that I wasn’t on chemo I felt so much better, so we made up for it.” Rob added that he never felt that his needs were not met and explained “During those times she wasn’t up for it I was so aware of what she was going through and that she was uncomfortable. I couldn’t think of anything but how happy I was that she was here.”

For Susan, maintaining an active, passionate sex life with her husband contributed to her ability to accept the physical changes to her body. Like both Annika and Kara, Susan initially experienced some dissatisfaction with her physical appearance. She did not like the way her breast looked after her lumpectomy. She explained, “These’s this huge chunk missing and, even though all I felt was numbness, I didn’t want him to touch it because I thought it would feel gross to him.” Like the previous couples, Susan’s perception of what Rob was experiencing about her body was incorrect. Rob verbalized that he tried to reassure her that he didn’t feel any less attracted to her and that it upset him that she would think about him the way she did. He stated, “That’s a shallow way to be, and I’m not shallow. It made me sad that she would think I could be like that.” Rob’s verbal reassurance did little to convince Susan otherwise; however, Susan herself indicated that actually experiencing passionate sexual intimacy with Rob helped her

quickly regain her sense of femininity and sexual confidence. Unlike some other couples, Susan reported that her feelings about her body did not cause her to avoid engaging sexually with Rob. She explained how physically engaging in sexual activity with Rob and experiencing him as passionately engaged actually helped her change her perspective:

No matter what I was feeling about myself physically, I realized that he accepted my body as it was. Even when I would say things like, “Oh, my God, I look like a freak,” and he would tell me I didn’t, I actually trusted him. I trusted that he really meant that and was still attracted to me. The way he was able to be passionate with me made me feel better because I could clearly see that he still wanted to be with me.

With out prompting or responding to a question, Rob spontaneously remarked, “I can see how some couples could not make it through this.” When asked what incited this comment he explained,

All that we’re saying right now; putting it all together like this just makes me realize how hard we both worked to not just get through it but to make the best of what we could. I think we did so much more than just cope with it. I guess I knew it, but not to the extent I see when you talk about it all at once. All the little things really made a difference. Like going out together and enjoying a meal after her chemo treatment, just things to balance the stress and bad times. I think we would have made it through anyway, but maybe we wouldn’t have gotten stronger like we did.

Rob’s statement transitioned the conversation to a discussion of the ways the couple viewed themselves and their relationship as different as a result of their shared experiences with breast cancer. In terms of how they manage conflicts, Susan identified that she sees herself as more “selective” about what she chooses to argue about. “Before, I could be a little hot-headed.

Now I don't want to waste my energy on an argument. I don't want to create tension between us over things that aren't important," she stated. Rob agreed, taking the conversation further, "Now we look at things different than we did....We came over this big hill, and now there are things that used to seem important that aren't really so important anymore. The perspective is changed a little bit." The couple indicated that they were not a high-conflict pair to begin with, and they always communicated well with one another, but that they noticed increased forethought when responding to issues or topics that could potentially elicit conflict.

Susan and Rob shared that spending time together had become a priority for them. They have taken more time to discover hobbies that they mutually enjoy and that can be active in together. Rob commented, "I know this is crazy after all this time being together, but we've found out that we have a lot more shared interests than we even knew." In addition to spending leisure time together, they also spend more time doing routine activities together. Susan gave the examples that, "Normally my husband doesn't do housework, but it's become 'our thing' to make the bed together every morning. He even goes food shopping or whatever with me most of the time." She expressed her view that, although these are small efforts, she believes they impact their relationship because she values that he does these things now whereas he never used to.

In conjunction with spending time together, Susan and Rob talked about their newly gained focus on their goals. They reported that they have always had goals, but are now more motivated to actively pursue these goals and participate in activities they have never done before. According to Susan,

We've even done a lot of things in the past few years that weren't goals. Things I never would have thought of doing before like going in a hot-air balloon. I swore I would never do it, but I did that last year. My mother said to me, "But you're so afraid of

heights!” I was like, “Mom, if I beat cancer, there’s nothing else that’s going to hurt me.

If I can do that, I can just about do anything. I am definitely more adventurous.

Rob added,

I guess we’ve got a bucket list now, and it’s getting pretty full. We’re still doing things and making a lot of plans, especially plans to travel to places we’ve never been to....One day it’s going to be over; we obviously can’t live forever, so until then we try to enjoy it.

Susan and Rob described their perception of change as being “progressive,” meaning that they view their lives as changed as a result of surviving breast cancer together, and these changes have motivated them to pursue goals and engage in activities they have been wanting to do. In turn, by doing so they believe their lives are further enhanced. They verbalized feeling grateful that “good things” continue to come from their experiences with breast cancer. One of the “good things” identified by the couple is that they have become more proactive in their involvement in breast-cancer-related activities and events. They mutually agreed that they experience a sense of satisfaction in feeling as though they have the ability to positively influence other survivors’ and couples’ lives. Susan remarked, “Anybody that asks me, I tell them our story because knowledge is power.” Rob added that he is proud of the fact that they have maintained the positive changes and views these as “life changes” as opposed to “short-lived occurrences that trail off once the emotions settle.”

The couple mutually held the perspective that they believed positive growth was possible after surviving breast cancer together. In conversation with one another, they expressed their definition of positive growth as “not just going back to what we were, but changing for the positive and then keeping it going.” Rob added, “If we can grow old together and look back on our lives and say we learned from what we’ve been through, then that’s real growth.” When

asked to describe ways they believe they have grown, Rob contributed, "I'm a lot more sympathetic to women who have breast cancer and people who are sick than before. We try to help other people's lives." Both Susan and Rob expressed that they believe they have grown in their spiritual faith as well. Susan explained that both she and Rob grew up in households where their parents did not practice their religion; therefore, neither of them is knowledgeable of the practices. However, each indicated that they practice their faiths in their own way. Susan shared that she spends more time in prayer "thanking God for this gift of life he has given me." Rob stated, "I'm not sure if it's praying, but I go to St. Patrick's Cathedral a lot when I'm in the city, and I light a candle for her. I think about how thankful I am for everything good in my life."

Rob shared his view of how he has experienced Susan's growth:

She's a lot stronger emotionally. It's amazing how she worked through that terrible tragedy and survived it. She has such a better attitude now...I feel appreciated and so do the kids and other people in our lives. She's just amazing. I didn't realize how strong she was until now.

Susan agreed that she has grown in her ability to appreciate the people she loves and in her expression of her gratitude. She stated, "I'm not a very emotional person, but I try to tell him how much I love him. That's a huge step for me; I never really used to say that very much."

The topic of how the couple copes with the possibility of recurrence was one area of the conversation that Susan and Rob differed in their perspectives. Rob quickly stated, "I wanted her to get a mastectomy. I told her, if she's one percent more at risk, then it's too much for me."

Susan explained that:

I think it's always on our minds because of the fact that I didn't want to do [the mastectomy], but he wanted me to. I was afraid; everyone talked about how painful it

was. My oncologist told me that doing a lumpectomy and having chemo and radiation had the same survival rate as doing a mastectomy. I remember asking her, "If you were me, what would you do?" She just laughed and smiled. I knew right then she would do the mastectomy, but she said to me all the time that I didn't have to do it if I didn't think it was right for me.

Rob added, "We talk a lot about it. I even think about it a lot when I'm not talking to her." The couple continues to have differing views regarding mastectomy surgery even now that Susan has long since completed her treatment. Rob shared that he and Susan's mother are in favor of her proceeding with a mastectomy as a preventative measure. He stated, "Whatever we can do to try to prevent it, but again it's so hard. I have to respect her wishes." Susan remarked that she is not unwilling to do it if it is necessary or if she has a recurrence, but would prefer to wait until that time. She also recognized that her level of concern may increase once she discontinues the hormone therapy, and this may influence her decision. Rob responded directly to Susan, "I can't make this decision for you, but, if it does ever come back we'll stand and face, it again, and we'll stand together."

Researcher's Experience

Susan and Rob's laid-back, relaxed demeanor made it very easy to connect with them early in the interview process. Rob's use of humor and witty banter along with Susan's playful response gave me the impression that they were quite comfortable both with me as an interviewer and with the topic of conversation. I experienced them as approaching the interview with the same positive outlook as the way they described approaching most breast-cancer-related events. As they were discussing how they immediately came together as a couple at the onset of Susan's diagnosis and prepared to confront whatever was ahead of them together, I took note that

the way they were interacting with one another during the interview mirrored their dialogue. When posed with a question, they took time to converse with one another before offering a response. This occurred frequently throughout the interview with the exception of when they were both aware that they had differing perspectives or when I directly addressed one or the other. When Rob asked to take a short break to answer a phone call, Susan chose to wait until he returned to continue the conversation even though she had been in the process of talking about an individual experience of her own. This gave me the impression that the interview itself was a task to be completed together and possibly even an experience for them to share.

I felt a distinct change in the climate of the conversation as the topic of recurrence was being explored. Rob's light-hearted banter was replaced with a more serious tone, reflecting the concern that he was discussing. Susan appeared to have more difficulty articulating her thoughts as evidenced in her tendency to leave trailing sentences. This seemed to mirror the confusion she was describing regarding her thoughts about mastectomy surgery. I felt a noticeable change within myself at this point as well. I was acutely aware that I was reacting emotionally to their conversation about their differing perspectives on pursuing preventative mastectomy surgery. Aspects of their discussion personally resonated for me, and I found that I had to actively refocus my attention on Susan and Rob and away from my own thoughts. I was very cautious in my responding and posing further questions in order to not project my personal experiences to affect the conversation. I purposely referred to my interview protocol to direct the language of my questioning. I did not want to impose my views in any way into the couple's story. I was thankful that I have a tendency to be highly self-monitoring and viewed that as a strength I could utilize in this particular case. Upon thoroughly reviewing the transcript, I found no evidence to

suggest that I had influenced the course of the dialogue and felt that I had successfully managed the situation.

Nancy and Rick

Demographics

Nancy is a 39-year-old Hispanic female who has been in a relationship (cohabitating) with her fiancé Rick for eight years. She was diagnosed with Stage-1A breast cancer at the age of 35 years old. Rick is also 39 years old and identified his ethnic background as Irish and English. Both Nancy and Rick have been married previously; Nancy has a 14-year-old son from her previous marriage who resides with her and Rick but has visitation regularly with his father and step-mother (see genogram, Appendix I). The family resides in a middle-class, suburban community. Nancy is employed at a local hospital as an x-ray technician; Rick is a government civil service worker. Both report that they are Catholic, but grew up in non-practicing households.

Nancy's breast cancer treatment included bilateral mastectomy with reconstruction. She did not need to undergo any other adjuvant treatment such as chemotherapy or radiation therapy. Prior to her own diagnosis, Nancy indicated that she had very limited experience with or knowledge of breast cancer. She mentioned that she had a co-worker whom she was close with who opted to have prophylactic bilateral mastectomy surgery after testing positive for BRCA gene mutation. This friend shared information with Nancy which she felt was helpful and influenced her own treatment-related decision-making. Nancy was tested for BRCA gene mutation, and the results were negative. Rick shared that both his ex-wife's mother and sister passed away as a result of breast-cancer-related complications. He was married to his ex-wife at the time and described his relationship with her mother and sister as "close" and "involved."

Rick's father passed away two months prior to the interview as a result of lung-cancer-related complications. Rick was also actively involved in his father's care.

Case Study

Nancy and Rick were referred to the study by a mutual friend of another couple. The couples did not know one another; however, this mutual friend was familiar with both of their stories. Upon hearing about the study from the other couple, this friend requested to share the information with Nancy and Rick. At the start of the interview, Nancy commented that, although she was not acquainted with the other couple, she was aware that their experiences were very different based on brief comments made by their mutual friend, but that she hoped sharing their story would help show "how varied breast cancer can be." Nancy reported that a lump in her breast was detected by her gynecologist during her routine annual examination. She was referred to have a baseline mammogram. She stated, "I didn't think anything was really going to be wrong at all" and indicated that she did not experience any concern at that time. She described feeling "in shock" when her doctor called her at work and told her she had breast cancer. She explained,

My doctor said "Hey I got bad news and good news. Bad news, you have breast cancer.

The good news is that it's in the very first stages." He made it sound almost like it wasn't that big of a deal. I didn't know anything about it, so that really freaked me out.

Nancy reported that she stayed at work for the rest of the day, thinking, "I'm going to just put up a front, like everything is ok and get through the day." She took some time to speak with a friend who works in the breast center of the hospital she is employed at and was able to obtain some information.

Nancy commented that, after her initial feeling of shock, she experienced fear. She felt apprehensive about telling Rick because she was unsure how he was going to respond in light of his previous experiences with his ex-wife's family. Nancy shared, "I was scared to tell him because of his history with cancer within his ex-wife's family. I was scared that he might leave because he wouldn't want to go through it again." She indicated that she was so preoccupied with these thoughts that she was "surprised" when he reacted calmly and responded with verbalizations of his support. She stated, "He was scared, but he was strong. He said, 'I'm here for you' immediately, and I knew we were going to be ok." She added that she felt guilty for thinking he would leave because he had always demonstrated his care and support in their relationship. After hearing Nancy share this information during the interview, Rick spoke directly to her stating, "I'm sorry you felt that way....You didn't say anything about being scared about me leaving. I wasn't going to leave."

Rick shared more about his reaction to hearing the news of Nancy's diagnosis. He explained,

I was scared primarily for one reason. I was just hoping it wasn't the same type of thing I'd seen before. The doctors tell you, "Oh it's a light diagnosis," and that it's no big deal, but it just gets worse and worse, and you keep getting bad surprises. I was hoping it wouldn't be that.

He recognized that his previous experiences were influencing his emotional reactions. "I just felt like we should just attack it,...get on this thing aggressively from the start with talking to the doctor and getting done what we need to get done." Nancy remarked that she agreed with Rick's perspective that they should take an aggressive approach, and together they began to thoroughly research breast cancer and explore treatment options. She explained,

I didn't want to go and jump the gun, so taking it one step at a time helped me keep my head straight. There was a time in my past where I would freak out about stuff. I reminded myself that I can't freak out about things I know nothing about, so I needed to learn about this, so I could figure out how to deal with it.

Together, Nancy and Rick weighed their options. The initial recommendation from Nancy's doctor was that she undergo lumpectomy surgery followed by radiation therapy. It was Nancy's decision to explore the option of bilateral mastectomy surgery, but she reported that her doctor was supportive with helping her understand all of her treatment options. She commented, "I wanted to do what's right to make sure that I prolong my life. I have a child, and my main concern is that he has a mom." Additionally, her decision was motivated by her desire to feel reassured that all the cancer cells were removed and that the likelihood of recurrence was reduced as much as possible. She recalled hearing stories of other women who had similar diagnoses and opted for lumpectomy surgery, but subsequently experienced recurrences. Nancy stated, "I didn't want to have that possibility" and made the decision to take the route of mastectomy surgery.

There was a period of approximately four months between the time Nancy was diagnosed and when she began her treatment. Both Nancy and Rick held the perspective that this was "moving ahead fast" and, to their satisfaction, unlike other couples who reported feeling impatient with waiting periods much shorter than this. They spent that time continuing to research and prepare for what was ahead of them. Nancy remarked, "I'm all about facts. I needed to know everything that was going to happen, but not in a stressed out way." She watched videos of the surgery and researched the procedure online. Her doctor showed her and Rick pictures of how her breasts would likely look like at each stage of her reconstruction. She

found that this helped dispel some inaccurate preconceived ideas she had and to feel reassured that she made the right decision for her. She commented, “When I saw that I was not going to have a flat chest with scars going across, I felt better about it. Knowing I could have the reconstruction done at the same time as the mastectomies probably sealed my decision.” Nancy had not been fully satisfied with the appearance of her breasts prior to her diagnosis. When she and Rick saw how her breasts could potentially look after the reconstruction, they both agreed that she may likely feel this could be an “improvement” for her, especially since she was able to have fat removed from her belly to reconstruct her breasts instead of needing implants. Rick shared, “I knew how she felt about her breasts after having a child, so I was kind of excited that this could actually make her feel better about her appearance. It was kind of like an anticipation, but scary at the same time.”

Nancy chose not to tell a lot of people about what was happening in her life. She reserved her disclosures to a few close friends at work and in her neighborhood and to her immediate family. Her reason for doing so was because she felt that other people’s reactions may make her feel more scared than she already was. She described it this way, “I had my own strength internally, and I thought other people’s fear or sadness might rattle me.” She felt that the people she chose to disclose to were people whom she believed could provide her with the support she needed. Her mother came and stayed with her and Rick for two months after her surgery. Although both Nancy and Rick expressed feeling thankful for the assistance Nancy’s mother provided, they also mutually agreed that having her there was a source of stress. Rick remarked with a subtle laugh, “We actually had an argument about how long her mother was going to stay.” Nancy responded, “Yeah, that was a stressor.” Nancy explained that she felt “babied” by her mother at times, and this was frustrating because she felt that her mother was

inhibiting what little sense of independence she was holding onto. She stated, “I just wanted to do the things I was able to do, so I could feel a least a little like my normal self.” She acknowledged that she knew her mother had good intentions, but that her mother’s “disregard” of her requests for “space” often resulted in an argument. Rick added that his role in these situations became to mediate between the two, primarily because he wanted to “protect” Nancy from the unnecessary stress.

Overall, Nancy and Rick believed that they coped well with the impact of breast cancer on their lives. They agreed that neither of them would classify the changes that occurred as “disruptions.” They shared the perspective that their extensive preparations helped them cope with the physical, emotional, and practical aspects of breast cancer. Nancy stated,

By talking it through together we even came up with the idea to buy a recliner before the surgery, so I knew that I could sleep comfortably. We prepared for everything. I even spoke to a woman at work who had gone through it, and she helped me know what to expect. I guess Rick’s experiences with his ex-wife’s family, the reason I thought he would leave, actually turned out to be a blessing, though was sad. He was already very educated...that made him stronger and prepared for what was to come.

Rick added that their honest and open communication about every aspect of what was occurring in their lives was “one of the best things we could do to get through this.” Neither of the two felt any inhibitions in this regard, and, according to Rick, “What’s ever on our minds just comes right out.” “I don’t have a filter,” Nancy commented with a laugh.

In terms of running their household, Nancy described her and Rick as a “well-oiled machine.” The couple reported that they share all of the household responsibilities and know what needs to be done. Rick indicated that he had no difficulty stepping in to take care of the

majority of the household tasks. “We work really well together, and we’re good at organizing chaos,” he said. Both he and Nancy attributed their abilities to systematize their lives to the organizational and adaptability demands of their jobs. They also recognized that their jobs may have also influenced their abilities to emotionally cope as well. From Nancy’s perspective, being exposed to the hospital environment, medical-related issues and procedures, and patients’ emotions on a daily basis likely decreased her sensitivity to some of her experiences. She commented, “Things weren’t as dramatic for me as they would be for someone who isn’t exposed to it all the time. I don’t want to say I’m more like a guy, but I’m not as sensitive as some women I’ve met.” Rick agreed, sharing his experience that “On my job I see a lot of traumatic stuff happen....When you see it all the time,...you’re not immune to it when something like this happens but you’re better able to know how to push through it.” Both he and Nancy recognized that they needed to balance their emotional expressions when they talked with her son about what was happening. Nancy explained,

We talked with him together and were up front and honest. He’s a lot like us; he rolls with the punches pretty easily. But we didn’t want to come across too nonchalant where he might feel he’s not supposed to be worried or anything. We didn’t want to overdramatize either. We wanted him to know it was ok to feel whatever he was feeling and he could talk to us about it.

With respect to coping with the actual outcome of the physical changes to Nancy’s body, she stated,

I actually embrace it. I have some scar lines on my belly, but they’re just part of my life’s story. Maybe I have tattooed areolas on my breasts or man-made nipple bumps,

and these little scars....Those are the lines that helped save my life, not lines that are going to stop people from loving me.

Nancy shared that the one aspect of the changes to her body that had the most negative impact on her was the realization that she would no longer have the capability to breastfeed in the event she had another child. “Not that I was planning on having another child, but that made me a little sad. That’s the purpose of having breasts, and it’s one of the most nurturing things you could do for a baby.” Rick voiced his appreciation that Nancy included him in decisions about the aesthetics of her breasts, even though he believed those decisions were solely hers to make. He joked, “It was a little awkward when you’re in the doctor’s office looking at a book of different areolas. They treat it like you’re shopping for a car; it’s a catalog.” Aside from his humor, he felt that being included in the entire process was helpful because he had a greater understanding of what Nancy was experiencing physically and how to help take care of her.

The issue of the possibility of recurrence is a topic that Nancy and Rick indicated that they had not talked about. Rick’s response to the topic being introduced was, “If it were to happen, we would do the same things that we’ve done. We’ve gotten through this well, so we know we could do it again.” Nancy added that she rarely thinks about it, but on the few occasions on which it has come into her thought, she distracts from focusing on it by reminding herself that, per her doctor, “there’s only like a 0.5 percent chance of recurrence in cases like mine.” In talking about their confidence in being able to handle a recurrence if it were to happen, the couple naturally transitioned to a conversation about the ways they see themselves as positively changed as a result of their experiences together. Rick stated, “It’s brought us closer in a way. It was a journey that we took together.” Nancy added, “It makes us know our path more clearly now.” One of the steps along this “path” is greater attention to their physical

health. The couple has made it a priority to work out regularly and eat a more nutritious diet in order to maintain healthy weights.

Rick's perspective was also that, as a couple, they have more fun together. He commented, "We know we have responsibilities, but we don't waste our time worrying about them to the last detail. We take all the opportunities to have fun that we can." He added that spending more time engaged in activities they enjoy enhanced their sense of closeness. The couple also spoke about their increased involvement in charitable activities. They mutually agreed that breast-cancer-related activities have become an important part of their lives. Both Nancy and Rick felt that there were many benefits to involving themselves in these types of events. For example, the couple generally chooses physical activities such as charity walks or runs. They enjoy the physical activity and feel challenged by it, but also have a way to contribute to a cause. Nancy added that training for these events has helped her stay motivated to maintain a healthy lifestyle. In addition, she feels that she emotionally benefits from surrounding herself with other survivors and celebrating their lives together. "It's a reminder of what you've been through, but in an empowering way," she shared. Rick found personal satisfaction in feeling like he was a role model for other men. "You don't see a lot of men participating in these things. I think it's good for the men on the sidelines to see us doing this as a couple. Maybe they'll realize it's a good way to support their wives or girlfriends," he remarked. "Being one of the few men kind of makes you like a celebrity at these things. That's not too shabby either!"

The couple mutually agreed that they believed positive growth had occurred within their relationship as a result of the experiences they shared surviving breast cancer. Nancy remarked, "We're a stronger, more committed couple. We're more emotionally connected because we

know we're in this for the good times and the bad. If he can stick with me through this, I know he's going to stick with me through anything." Rick added, "No matter what we've been through before, similar or not, it's a whole new aspect of our life because it's uniquely our own as a couple." Nancy stated,

To be honest this is a difficult question for me. I have no doubt I and we have grown, but I have a hard time putting it into words. It's not in my nature to have these big epiphanies or go and make big worldly or life changes like other people describe. It's more of an internal process for me. I just think that I survived, and now I get to keep on living. I am fully aware that things could have been different, so I am grateful beyond words. I'm grateful for every single person who made an effort on my behalf. I guess I've grown to value myself as a survivor, and I've grown to value my story. I'm going to share what I can when I can.

Nancy continued this train of thought and indicated that she feels that both she and Rick have become more caring towards people with cancer. As a couple, they have been willing to share their stories with others when they felt it could be helpful. In return they have found that people approach them for support. Nancy talked about a neighbor who was recently diagnosed and who approached her to hear her story because, as Nancy explained, "Before she was faced with her own diagnosis, she didn't get why I chose to have bilateral mastectomies when I could have just had a lumpectomy." Nancy, recalling the value she had found in a friend doing the same for her when she was diagnosed, willingly shared her experiences. She stated, "I wanted her to hear about someone who made it instead of always the tragedies."

Similarly, Rick had received a phone call from a husband who worked with one of his co-workers. This gentleman had shared with the co-worker that his wife was recently diagnosed

and that they were having a difficult time coping. The co-worker encouraged him to reach out to Rick. “I didn’t have any other men to bounce stuff about this off of. It would have been good to have another guy’s perspective or be able to learn from them. I offer that when I can,” Rick shared. He added that he believes there are not enough support resources for spouses and that a lot of men may not use them even if they are available. “At least in my experience, I think a guy is more likely to talk to another guy. I talk about our experiences, so that men will see that it’s ok to talk about this stuff, and, if you’re afraid, it doesn’t mean you’re weak. Never in a million years would I have done that before.”

When the couple was asked if there was anything else they would like to share, Nancy commented that she was aware that her experiences may be different from other survivors because she did not go through chemotherapy or radiation therapy which can prolong the impact that breast cancer has on someone’s life and involve side effects which can contribute to the physical and emotional challenges faced. She concluded,

Breast cancer, or any kind of cancer, is a sad, horrible thing that I wouldn’t wish on anyone. I may not have given you anything profound in this interview but if there’s one thing I would want people to know it’s that you can get through this, and you can come out stronger than you were before. I know we have....I know how I feel inside, and I see proof of it around me. My son is thriving; Rick and I are happier and healthier than we’ve ever been....It’s been four years, and we haven’t gone back to the way we used to be. Not only is that growth, but to me it says that what we went through was life changing.

Rick closed with this statement, “We make it sound easy when we talk about it, but it wasn’t. It was hard as hell.”

Researcher's Experience

Nancy had contacted me about the study and, after reviewing the details, voiced her interest in participating. She indicated that she had a few concerns she would like to discuss. First, she inquired as to whether her story would “fit” with the other survivors’ stories and whether it would be “helpful” or not because she did not go through chemotherapy or radiation treatment. She recognized that these were major aspects of breast cancer treatment and thought that her story may not have enough to offer to the project. She was aware that the study was related to positive growth and expressed her thoughts that going through experiences as “traumatic” as chemotherapy may have a different impact on a person’s sense of survivorship and growth than on someone who has not had these experiences. In order to present as a neutral observer, I explained to her that there were no specific participation criteria based on the type of treatment a breast-cancer survivor underwent. I reviewed the criteria with her and informed her that, based on the information she had provided me, she and her fiancé met the study requirements and were appropriate for the study. To offer her further reassurance, I explained that it was expected that there would be varied situations with regards to the treatment experiences of participants and that the aim of the study was not to compare participants with one another based on this.

Nancy’s second concern was similar in context to her first. She wondered whether the fact that she had voluntarily opted to have bilateral mastectomies when this was not necessarily indicated by her treatment providers would change how her story would be viewed. I was curious about what her thoughts were about this, and I saw this as an opportunity to learn more about her, so I chose to cautiously explore her question further. I did so by asking her how she thought this might impact the way her story was received. She explained that she thought some

people may view having a choice differently than not having a choice and that choosing somehow made an experience less difficult or traumatic. After listening to her speak for a few minutes, I had the impression that she was attempting to elicit my opinion on this. I asked her if she had concerns that I might view or portray her story in that way. Her response was that she just wanted to make sure I knew these details about her experience and that I still felt she was a good candidate for the study because she had encountered other people who had the opinion that optional mastectomy was “somehow not as bad.”

My initial intuition was to respond with validation that I did not view any one person’s experiences as more or less traumatic than another person’s. However, I quickly recognized that responding in that manner projected my opinion. I also realized that I needed to be cautious in order to not inadvertently imply or minimize the presence of trauma in any particular situation. The interview had not yet been conducted, so I did not have Nancy’s perspective on this issue. I wanted to be careful to not convey my personal opinions or convey any expectations of her perceptions. With this in mind, I decided to validate the fact that she had a personal and unique story that she shared with her fiancé and that this is what I was interested in. I explained to her that the goal of the study was to understand couples’ experiences from their own perspectives and that I was not looking for her to fit a profile. I reassured her that it was her own opinions and impressions that were of interest, not how I or anyone else viewed her situation. She verbalized feeling “relieved” and conveyed that she did not personally believe her experiences were any less “valid” and that she hoped others could learn from her. She added that she was looking forward to sharing her story and was pleased that this could be an opportunity for her to possibly help someone else.

During the interview with Nancy and Rick I had the opportunity to observe them interact as a previously undisclosed experience was shared. Nancy confided that she feared Rick would leave her upon hearing of her breast-cancer diagnosis. She had never told him about this concern before. I observed Nancy's body change as she spoke about this fear. She withdrew her eye-contact from Rick and slouched back in her chair as she allowed time for him to respond. His expression changed from smiling to more serious for a few minutes as he told her he was sorry she felt that way and that this made him sad. The expression on his face was congruent with the feelings he was verbalizing. At this time, even though Nancy had explained that her fear had immediately been alleviated once Rick expressed his support and had not resurfaced, he offered her reassurance that he had never intended to leave. This real-time exchange mirrored the care and concern that the couple had described throughout the discussion of their experiences. I was grateful that I had the opportunity to witness this couple interacting this way. I was also hopeful that this was an indication that one or both of them felt comfortable enough in my presence to share a vulnerable moment. Nancy conveyed that she thought Rick had known about her fear. This, along with my own observations of the couple's interaction, made me feel confident that the interview itself had not been utilized as a tool to distract away from any unwanted responses. In addition, I noted the fact that I was again witnessing that the interview process was eliciting dialogue between partners on subjects they had not previously communicated about. Nancy and Rick, similar to the other couples, had never had a conversation about their perceptions of growth with one another or talked about the changes in their relationship until they were involved in the interview. I felt the same satisfaction as I had with the other couples that the interview process was an unexpected opportunity for Nancy and Rick to affirm their strengths and share these with one another. I did not assume that this was a positive experience for them.

My satisfaction was motivated by Nancy and Rick's verbalization of this being a positive outcome of the interview during our debriefing conversation.

Lisa and Dan

Demographics

Lisa and Dan have been married for 21 years. They have two daughters together who are 14 and 17 years old (see genogram, Appendix J). Lisa is a 46-year-old Caucasian female of English and Irish descent. She is employed by an in-home private nursing agency and has a B.S. degree in marketing. At the age of 41 years old she was diagnosed with Stage-II breast cancer. Her treatment regimen included lumpectomy surgery, chemotherapy, radiation therapy, and hormone therapy. With regards to lumpectomy surgery, Lisa indicated that two surgeries were required, the second coming after cancer cells were still detected in the treatment area after completion of the first surgery. In addition, Lisa also had a partial hysterectomy two years ago as a result of uterine-wall damage associated with side effects of hormone therapy. Her husband, Dan, achieved an Associate's degree in criminal justice and is employed as an officer with the Department of Corrections in the county where they reside. The couple identified as Catholic and practice their religion regularly. They currently reside in a rural, middle-class community.

Prior to Lisa's diagnosis, neither she nor Dan had any first-hand experience with breast cancer. Lisa had knowledge that her paternal grandmother was diagnosed with breast cancer after going through treatment for a type of gynecological cancer. She was unsure of the details about this other than the fact that her grandmother passed away at age 84 as a result of cancer-related complications. Lisa did not maintain a close relationship with her grandmother and resided in a different state; she therefore, had no direct exposure any aspects of her grandmother's cancer treatment. Similarly, Lisa was aware that an uncle through marriage was

diagnosed and treated for breast cancer, but she had no further information about this. She added that this was the first case of a male being diagnosed with breast cancer that she had ever heard about. Lisa had not had any genetic testing for breast cancer gene mutations. Other family history of cancer included Lisa's father who passed away approximately one month prior to Lisa and Dan's interview as a result of liver-cancer-related complications. He was diagnosed approximately five months prior to his death, and since the prognosis was determined to be end-stage; no treatment was indicated. Dan reported that he had no known family history of any type of cancer and had no direct contact with anyone who had been through treatment for any type of cancer except Lisa's father.

Case Study

Lisa and Dan were referred to the study by the organizers of a local breast-cancer-related charity event. Lisa's breast cancer was detected through a routine mammogram followed by a tissue biopsy. She described her diagnosis as "a complete surprise" because she had not felt any lumps or detected any abnormalities during her self-exams. She and Dan had taken their family on vacation the day after her biopsy, and she reported that she was relatively unconcerned that anything serious was wrong. She became concerned after arriving home and receiving a phone call from her doctor's office insisting she come in as soon as possible. Lisa was due to be at the doctor's office later that same week with her daughter, but was told the doctor wanted to see her immediately. She stated, "My heart just sank because I knew at that point the news wasn't going to be good." She was at work at the time and had a friend drive her to the appointment because she suspected she would not be in any condition to drive following the meeting with her doctor. "My doctor was very supportive, but seemed so sad having to communicate the diagnosis to me," she said and continued to describe the encounter:

I just remember looking at her saying “I’m sorry, what did you say?” She repeated it again, and I just started to cry because it just didn’t seem like it was real to me. It was devastating.

Lisa reports that she was in such a state of shock and unable to communicate what was happening that she needed her doctor to inform the friend that had accompanied her of what had transpired.

Lisa described her husband as “the voice of reason” during her time of emotional upheaval. Dan, like the other male partners, approached the issue from a task-focused perspective. He remarked, “I didn’t want my emotion to take over. I wanted to find out what the problem was and what steps we needed to take to address it. That’s the way I am, but I wanted to be gentle about it.” Together the couple began to gather the information they needed to make decisions regarding the course of treatment they would pursue. They attended medical appointments and researched their options thoroughly. “We talked about everything,” Lisa noted, “What if I have to do chemo? What if I lose my hair? We went through the whole gamut of what could potentially happen and hoped for the best. We were ready for whatever was dealt to us.” Both Lisa and Dan agreed that focusing their attention on learning all they could about breast cancer and the treatment options was their way of coping with their feelings of “fear” and “uncertainty.” Lisa added, “Words cannot say how appreciative I am of how much support [Dan] gave to this process.”

Lisa and Dan mutually identified chemotherapy as the aspect of breast cancer that they believed had the most impact on their lives and their couple relationship. Lisa explained that she experienced severe nausea and fatigue throughout her treatment. This greatly diminished her ability to attend to daily household responsibilities and manage her children’s activity schedules.

“Dan stepped up and took it on. Normally we share the responsibility of the kids but all of a sudden he was responsible for all of it. It became a lot of pressure for him and more stress than he’s used to.” Lisa described feeling “guilty” that she could not function the way she was accustomed to. “I was seeing him getting tired, and my heart was just breaking. It made me feel like ‘Oh my God, I wish I could help you.’” Dan agreed that a lot of responsibility was placed on him; however, he viewed taking on these additional tasks as a way that he could help his wife. “I couldn’t get chemo for her, and I couldn’t take away her pain, but these things I could do, and I knew they were helping her. When you love someone, you do whatever you can for them; there’s no question,” he commented. He added that being able to support Lisa prevented him from feeling “helpless” in the situation.

The hair loss Lisa experienced was a contributing factor to the disruption caused by chemotherapy treatment. She shared, “Losing my hair was one of the hardest parts. When you don’t have hair, and all of a sudden you don’t have eyelashes; you don’t have eyebrows....It’s visually hard on everyone around you. It just screams that you are sick.” Lisa and Dan’s way of coping with this was to shave her head together. Lisa stated,

We decided that we were going to take control of it; it wasn’t going to control us, and we weren’t going to watch my hair go down the drain every single day. [Dan] gave me the strength to do that. He never altered how he loves me or how he treated me. He never, ever, made me feel like I was any less beautiful in his eyes than I was before.

Dan replied, “I didn’t want her to suffer watching it fall out.” He admitted that, when they first shaved Lisa’s head, it was “shocking” at first to see her that way. Throughout most of her treatment Lisa wore a wig whenever she was in public. As a way to help her daughters feel involved in the process and to help them adjust to the changes, Lisa and Dan allowed the girls to

assist with selecting the wig. “We were very careful,” Dan stated, “We gave them the information they needed as we went along, and we tried to include them in ways we could.” Lisa continued, “We knew the hair loss would freak them out, so we thought it might help to let them have a say in what I chose.” At home, Lisa felt more comfortable going without her wig. Dan was in favor of this, and he explained, “I know it might seem weird, but I preferred to have her without the wig. It was more comfortable for me to just have her in her true form.” When Lisa’s hair began to grow in, she “took a leap” and decided to go to work without her wig. She explained that it had become uncomfortable to wear and when she contemplated going without it, Dan encouraged her saying, “Don’t dip your toe; just go for it, and don’t wear it.” Lisa remarked, “It was very liberating. People were very warm and welcoming and didn’t make me feel odd or anything. I don’t think I could have done it if [Dan] didn’t say to me ‘go for it.’”

Chemotherapy and the associated side effects were also contributing factors to changes in Lisa and Dan’s sexual intimacy. Lisa reportedly felt that this was more of a disruption to their relationship than Dan did and attributed this primarily to the “guilt” she experienced over withdrawing sexually. The toll chemotherapy took physically often rendered Lisa depleted of the energy required to engage sexually and with diminished physical desire. Emotionally, she admitted that she experienced a decrease in her level of self-esteem and felt somewhat more inhibited in her sexual behavior. “It wasn’t that we weren’t sexually intimate; it was just my own hang-ups,” she explained, “I probably wasn’t as receptive as I normally was because of my own insecurities.” These insecurities were primarily associated with Lisa’s hair loss. She indicated that having a bald head impacted her self-image far more than the changes to her breast that resulted from surgery.

Dan responded to Lisa's disclosure by verbalizing, "I never wanted her to feel any sort of guilt, especially about that. Taking care of herself had to be the priority, and I accepted all that that entailed." He continued on to share that, although there was a decrease in the frequency of their sexual activity, he did not feel that his needs were neglected by Lisa. He commented, "Maybe we didn't have sex as often as we normally would, but we still felt really close and connected to one another. She did a lot to remind me that I was important to her even when she couldn't physically show it." He added, "It was a little bit of a balancing act for me too. I wanted her to know that I thought she was beautiful and that I was attracted to her, but I had to try to find ways to show her that wouldn't make her feel pressured to have sex." Lisa responded to this by saying, "I can't imagine going through it with somebody else that wasn't like him. He was so tuned in to what I was going through and what I needed as a woman."

The couple mutually perceived positive changes as a result of the experiences they shared surviving cancer. Dan commented first stating, "We don't sweat the small stuff anymore. We are so much better at looking at the big picture and letting go of what doesn't really matter." Lisa added, "We don't get stressed over things that used to bother us. I think it's because we've let go of unrealistic expectations that life needs to run smooth and orderly. Now we accept life as it comes at us." They agreed that as much as they work together to maintain a tension-free home for their children, they have also learned that the experiences they have gone through have helped their children to cope with difficult situations more effectively. "They've learned how to be able to stop and think about situations and not overreact or just emotionally react without thinking," Lisa remarked. Both she and Dan believed that this was a result of their daughters watching how they reacted to the various situations they encountered and how they responded to one another. According to Lisa, "We've learned some different ways to cope and resolve

conflicts, and it all stems from having honest conversations about the situations. We see them doing the same now with situations they have at school or with friends.” The couple agreed that going through breast cancer was a learning experience in terms of how they communicate about difficult situations with their daughters in addition to how they communicate with each other. They expressed feeling confident that future communication during difficult situations could “flow a little bit easier than if we hadn’t gone through all that.”

Change was also identified as occurring in the way the couple perceives time. First, they have reevaluated how they engage in leisure activities and have prioritized setting aside time for relaxation. Having fun with their children and “creating happy memories” has become an essential part of their family life. “We don’t put things off or say ‘Oh we’ll do that next year.’ The next year is this year, and we live in the present,” Lisa stated. Dan shared that he feels strongly about the importance of this because he now sees that these contribute to family connections and “help to balance out the tough situations that come up.” Lisa and Dan have also increased the amount of time they engage in activities they enjoy as a couple. They believe that going through the “ordeal” of breast cancer has helped them gain greater awareness of the need to nurture their relationship as a couple. They described themselves as a “close” couple prior to Lisa’s diagnosis, but recognized that they have gained more balance in being able to focus on both their children’s needs and their own relationship needs.

The couple shared the perspective that positive growth was possible as a result of surviving cancer. Their response to the question of how they, as a couple, defined positive growth was answered as follows:

For us, growth is found in the fact that, as hard of a journey as that was to make, we found rewards in it for our family on the other side. It brought us closer and taught us that we could deal with anything, no matter how big or small.

In addition, both Lisa and Dan described their perceptions that they have grown in their capacities to feel compassion for others. Lisa shared that even though she had been in the field of healthcare for a long time, she discovered that she developed a greater ability to relate to others dealing with medically related struggles. She stated, “If I can advocate for someone or encourage someone not to skip that mammogram by sharing my own experience, I’ll do that now. That for me is growth because I would have never thought of going there before.” Dan has also found value in sharing his and Lisa’s experiences,

I guess it’s made me more aware of other women who might be talking about it. I’m more understanding, and I share my experiences of what we went through with them. There are female staff members around me who will talk about doing a mammogram. I tell them, “You’ve got to do it. As much as it probably sucks, I can tell you first hand that you’ve just got to do it.” I tell them what happened to me and my family and how we got through it. They seem to like hearing it from a man. They tease me and tell me I’d make a good spokesperson or cheerleader for breast-cancer survivors.

Lisa expressed her opinion that Dan has become more understanding of females overall stating, He has grown as a husband and a father. He learned everything he could about breast cancer, which is primarily a female-oriented disease, and how to care for my needs as I went through it. He also really had to grow and step up to dealing with the girls when I wasn’t able to. He was thrown into all kinds of unfamiliar territory with them. He became such a nurturing person because of it.

Dan agreed that he learned a lot as a result of becoming more involved in the female-oriented aspects of his daughters' lives. He added that he believed there was a secondary benefit to this in that it created an opportunity for him and his daughters to connect on a level they had never experienced before, and he remarked that, "We are closer than ever. The girls and I are proud of ourselves for being able to figure things out and get things done together in their mother's absence."

Lisa and Dan both perceived growth in their emotional connection as a couple. Both verbalized their thoughts that going through a "traumatic" experience like breast cancer together brought them an increased sense of relational closeness and "redefined what real, true unconditional love is," as per Lisa's words. The couple has received validation of their growth from external sources as well. Family members, including Lisa's sister and father, were supportive and involved throughout Lisa's treatment and were able to witness the interactions that occurred between Lisa and Dan. Lisa's sister expressed her deepened respect for Dan and her recognition of the emotional bond that the couple shares. As per Lisa, "After seeing him go through this with me [my sister] loves him even more because of how caring he is and how much he's with me."

Spiritual connection was another aspect of growth which the couple identified. Although their experiences and perceptions of spirituality differed, they agreed that they share the opinion that faith was a "guiding force" throughout their experiences with breast cancer. Lisa expressed that, when she felt overwhelmed by her breast cancer diagnosis, she relied on prayer and the "grounding" she felt when she practiced her faith. She shared, "I've always believed that God has bigger plans for us. I knew this was a challenge put in front of me, and I needed to rise to it and trust that I was not going to die yet." She indicated that the increased connection to her faith

that she experienced through her difficult times with breast cancer has motivated her to continue to nurture her spirituality with more devotion. Dan reported that he does not practice his faith in the same manner as Lisa. He views his sense of spirituality as reflected in his “character.” He explained, “It’s my faith that gives me character and guides what I do in my life. It’s what makes me believe we can overcome the obstacles in front of us, and it’s what keeps me going instead of quitting.” Similar to Lisa, Dan expressed his desire to continue to nurture his spirituality, though he stated that he prefers to do this “out in the world” instead of in a church and through actions that build his sense of character.

With regards to how the couple copes with the possibility of recurrence, Lisa and Dan mutually shared that they made an “active decision” to not focus their attention or expend their energy thinking about this extensively. Lisa explained,

I’m doing everything I need to do to take care of myself. For our own mental health, we can’t think about what if it comes back. We can’t go through our days like that. We have to accept that I went through treatment and was cleared and just look forward. If we need to revisit that, we will, and we’ll do it the same way we did it the last time.

She clarified that there are occasions, such as prior to her mammograms, when she experiences apprehension and feels the need to talk with Dan about it. He responded, “I will always be there when she needs to talk about it, but in general we’re not the kind of people to dwell on what was or what could be. We don’t let it consume our lives.” Lisa closed the interview stating, “It’s a very hard journey to make, and, if you’re not willing to learn how to cope with it or talk about it, it makes it very difficult to thrive on the other side like we have.”

Researcher’s Experience

Lisa and Dan had described themselves as a closely connected couple from the start of my contact with them. During my initial phone contact to review the details of the study, they were very responsive to the fact that I was interested in focusing on couples specifically. They verbalized their thoughts that not enough attention is paid to the stress that breast cancer puts on a relationship. They then proceeded to speak about their own relationship. Lisa began by describing Dan as her best friend and the person she talks to about everything. She stated that their bond was “as strong as anything” she could imagine for herself and that she could not put into words how close they are now. Dan contributed by expressing his opinion that they have a “really special relationship.” Both Lisa and Dan presented as highly motivated to participate in the study and to share their story. Lisa remarked that she had recently heard about a few couples whose relationships ended in divorce after going through the stresses of breast cancer. She believed that her relationship with Dan “spoke volumes” about how couples could get through cancer with the right supports and even “improve” as a result of it. She and Dan expressed that it has come to be important to them to help others by sharing their story and letting others learn from them.

I found myself attuned to the level of enthusiasm expressed from Lisa and Dan. I had not had a couple who had talked about their relationship this way during an initial contact. I noticed myself reacting, but I was unsure of what specifically I was reacting to. I decided to note the observations I had of both the couple and of myself in order to go back to this at a later time and explore the basis of my reactions. Upon doing so, I recognized that I was experiencing some apprehension regarding the motives behind the couple’s level expression. The fact that it was beyond the level I had previously encountered at this point in the process made it stand out and draw my attention. I was concerned over my own perception that the couple seemed to be trying

to convince me of their closeness before I had inquired about it. The only prompting I could identify was in the general description of the study I provided. They had not indicated having any contact with other couples who had participated. My concern was that the couple may have been making preconceived assumptions about specific outcomes expected of the study and attempting to respond in accordance with this. I decided that I could address this at the start of the interview by clearly articulating that there were no right or wrong responses and no expectations of any specific experiences. I did so and paid special attention to making sure I clearly expressed that the intent of the study was to understand the experiences of individual couples and hear their unique story. The couple responded that they understood. During the interview I was particularly focused on listening for expressions of the closeness they had described or aspects of their story that may have been contradictory. To my relief, Lisa and Dan told their story in such a way that it clearly mirrored their expressed closeness. They provided accounts of specific behaviors and occurrences that illustrated their perceptions of their relational closeness. In addition, they spoke briefly about receiving support from family members, but redirected the conversation back to the ways they coped as a couple reflecting their perspective that their growth and survival were primarily influenced by the strength and connection they perceived within their own relationship. I was able to recognize this quickly and let go of the cautiousness with which I had approached the interview, allowing myself to engage more fully in the interview and with the couple.

Upon reviewing the couple's transcript, I noticed that Lisa repeated the phrase "all of a sudden" during her discussions of changes that had occurred as a result of the impact breast cancer had on their lives. I found this phrase interesting because it suggested an unexpected quality or unanticipated timing of an event. I took note of this particularly because early on in

the interview Lisa had described having a plan to proceed with her treatment in a way that made her and Dan feel prepared for “whatever was dealt” to them. The dissonance between these statements was reminiscent of characteristics of other stories I had heard. Most prominently I recalled couples expressing that no matter how much they researched breast cancer in an effort to anticipate the impact it may have, it was nearly impossible to fully prepare for the ways breast cancer would touch their lives. I recalled women who had said they suspected that they may have cancer or anticipated hearing the diagnosis, yet still felt unprepared to hear it and surprised by the actual words. Reviewing the previous stories in this context highlighted the fact that each couples’ experiences were truly unique, and, although some aspects of breast cancer could be planned for, the ways their lives would be impacted and their reactions to these were hard to determine until one was actually living and experiencing the phenomena.

Debra and Keith

Demographics

Debra and Keith have been in a relationship together for 30 years. They have been married for 22 years and have three children together; two sons, ages 17 and 11 years old, and a daughter who is 15 years old (see genogram, Appendix K). Debra is 48 years old; she achieved a Master’s degree and is employed as a physical therapist in a hospital-based rehabilitation center. Keith is 49 years old; he achieved a Bachelor’s degree and works in the financial industry as a bond broker. Their ethnic backgrounds are Italian and German on Debra’s side and Irish on Keith’s side. The couple and their family reside in an upper-middle class suburban community. They both identify as Roman Catholic and actively practice their religion.

Debra was diagnosed with Stage-II breast cancer (lobular) at 45 years of age. Her treatment regime included lumpectomy surgery, chemotherapy, radiation therapy, and hormone

therapy. Prior to her own diagnosis her experience with breast cancer was limited to patient contact in the physical rehabilitation center that she works in. She indicated that the people with whom she had contact were generally long-time survivors, not individuals who were newly diagnosed or in the process of treatment. Debra had a friend who was diagnosed with breast cancer at approximately the same time as she was. She and her friend went through treatment together and were resources for support for one another. Debra indicated that there is a history of prostate cancer in her family. Both her father and paternal grandfather were diagnosed and underwent surgery with no further treatment needed. Debra noted that her father was diagnosed with cancer while she was undergoing chemotherapy for her own cancer. Keith denied any known history of cancer in his family and reported that, prior to Debra's diagnosis, he did not have anyone close to him who had been diagnosed or treated for breast cancer.

Case Study

One of the first areas of discussion during the interview pertained to the couple's description of first learning of the breast-cancer diagnosis and the circumstances within which this came about. Debra responded to this inquiry by commenting that she often shares her story about breast cancer with others and feels it is especially important to talk about the circumstances surrounding her diagnosis. She stated that she believed the experiences she had were somewhat unique, but could serve as helpful reminders to others that "a woman knows her own body better than anyone else" and of the importance of "being your own advocate." Debra began by explaining that she had very cystic breasts dating back to her teens. It was not uncommon for her to detect lumps in her breasts, but she was aware of how these changed as she progressed through her menstrual cycle and dissipated once she began menstruating. When she felt a lump at the top of her breast while touching the cross necklace she wears (reportedly a

habit), she took note of it and planned to monitor it through her cycle. She noticed that it did not change as she ovulated and did not dissipate once she began to menstruate. She consulted her gynecologist who then sent her to have mammogram and ultrasound testing. Debra was told that the results came back normal.

Debra continued to feel the lump unchanging and recalled that she felt “uneasy” about it. She reported that she approached her gynecologist a second time telling her, “This is not one of my lumps.” She was then directed to consult a breast specialist, who proceeded to tell her it was “nothing” and “just something very benign,” but ordered additional mammogram and ultrasound testing as a “precaution.” The technician performing the ultrasound called in a radiologist, the reason being that she could feel the lump in Debra’s chest, but could not see it. Debra continued on to say that, once again, she was told it was “nothing.” She remarked,

The radiologist comes in and says to me, “This is normal, it’s nothing, but I’ll write a report noting it’s in an unusual place.’ I questioned, “How do you not see something on that and tell me it’s normal, but I can feel it. It’s there and it hasn’t gone away.”

With her concerns remaining unresolved, she returned to her gynecologist a third time, again telling her, “I know my breasts. I know my lumps. This is not one of my lumps.” Upon Debra’s insistence that additional measures needed to be taken, her doctor referred her to a surgeon to perform an excisional biopsy. Debra stated,

I pushed my doctor, and she told me “You know your body better than anybody else, so let’s go the next step, but we’re probably doing this for nothing.” She said that, if removing it was the only way I was going to feel okay about it, then it made sense instead of doing a needle biopsy.

Two weeks later when she returned to see her doctor to review the biopsy results, Debra was told she had breast cancer. She shared, "I went in, and the doctor had a strange look on her face. She shook her head and said to me 'I can't believe I'm telling you this, but its breast cancer.'" According to Debra, her doctor further explained that lobular breast cancer mimics breast tissue and is often not detected until it is in the later stages of development. "She basically told me I saved my own life by being persistent," she said. Despite her "gut feeling" that something was not right, Debra described feeling "Like someone took the last breath of air from me and then hit me in the head" as she was being told the news. She became overwhelmed and unable to process what the doctor was telling her. She said,

Instead of being able to be in control and ask all the questions I needed to ask, I just lost it at that point. I couldn't stop crying. I told the doctor "We have to talk another day.

I'll come back with my husband because right now you're talking, and I can hear you, but I'm not listening."

She ended the appointment agreeing to return with her husband at another time.

Keith spoke about what it was like for him to hear that Debra had breast cancer. He remarked that she had not given him any indication that she suspected there was something more serious than a cyst present. "She called me and told me, and I was shocked," he stated,

I was devastated just like she was. I didn't know what to expect, but I started thinking about what was going to happen to her and to us. Whenever you hear cancer, the next thought is usually is she going to die? It was the first thing that popped in my head, and how am I going to take care of the kids without her?

Debra responded that she had not shared her concerns with Keith because, although she suspected something more than a cyst, she did not see a reason to make him worry if the results

confirmed it was benign. Keith continued on to describe an intense feeling of apprehension as he processed the information. He disclosed, “That first night I remember going upstairs and crying by myself. I just needed to release all those feelings, so I could focus on going forward and thinking positive.” In general, Keith indicated that he has a tendency to prefer to deal with his emotions internally or when he is alone. In this particular situation he felt the need to “put up a brave front” for her and their children. His perspective was similar to what was described by other male partners in that he believed it was his role to remain strong in the eyes of his family.

The process of diagnosing Debra’s cancer took approximately three months; however, she indicated that the next steps in treating the disease happened very quickly. Within a week’s time of learning of her diagnosis she was scheduled to have lumpectomy surgery. The couple described the days leading up to surgery as “emotionally confusing,” starting with feeling shocked, then progressing to concern over how to tell their children. Debra’s family had been told and also reacted with great surprise. “They were blown out of the water by it and it made me even more scared to tell the kids,” she said. She went on to share that she personally transitioned to feeling angry. “I was pissed. I was angry at life, but not God. I couldn’t understand why me. In my head I didn’t fit the profile. I was a non-smoker with no family history, and I hadn’t been on birth control since my 20’s. It didn’t make sense,” she explained.

Like all of the previous couples, Debra and Keith attended medical appointments together and worked cooperatively to get the information they needed in order to devise a plan that they hoped would minimize the impact breast cancer had on their lives. From the time of Debra’s lumpectomy through her chemotherapy and radiation therapy, they took what Keith described as “a work-man like approach.” “It might sound cold or callous,” he said, “but we took it on as a job almost, and, if we were going to get through it, we had to get things done.” Debra added that

their day-to-day life required a lot of coordinating, and they both felt they needed to be task-focused in order to keep their household from becoming chaotic. She remarked,

Even through chemo I still got out of bed every morning and took my kids to school.

Unless I was feeling really crappy, I went and picked them up because we decided that we were going to keep as much normalcy as we could even though there was nothing normal about it. There was as much routine and structure as possible in our home for our kid's sake, and to keep them on track and not let things just fall apart. That sounds almost like a business agreement. I think people hearing that would think that's callous, but it was just the way we worked, and behind that we're a very genuine, loving family.

Similar to the stories of other couples, the division of household responsibilities shifted as Debra experienced the side effects of her treatment. She remained intent on doing as much of her usual routine as she was physically able to, but relied heavily on Keith to assist her and take on the tasks she was unable to perform. She shared her feelings that it was important for her to maintain a sense of control over what was happening in her life. "You lose control when you're told you have cancer and you have to have surgery and you have to have chemo. I didn't want cancer to totally wreck my life. Anything I could have control over I absolutely did," she explained. She believed that the best way for her to cope with the disruptions caused by breast cancer was to involve herself in as many aspects of her "normal" life that she was able, even if that required assistance from others. She continued to work but would take time off around her chemotherapy treatments. She remained involved in her children's activities by attending events halfway through, so she could be present for the finish. Together, she and Keith would run errands and go food shopping, so that she could feel productive while still having his assistance. "I felt better when I could do things my own way," she recalled. Debra remarked, "In hindsight I

should have taken time off to have the treatments. I was a very different person during that time, and it would probably have made it easier to cope with for all of us.” She recognized that, although there were positive aspects to her drive to remain productive, part of her motivation was based on her fear that, if she did not remain active, she may fall into a depression that would limit her functioning even further.

Keith agreed that coping with the impact of breast cancer was difficult at times. He verbalized having “mixed reactions” to the additional responsibility he assumed in the household and with the children. He noted that, although he found it gratifying to be able to support and care for his wife in a way that contributed to her well-being, he also experienced the situation to be very stressful at times. In addition to what was occurring within his household, several changes were happening within his company which increased the level of demand placed on him. Some of his usual business routines, such as taking out-of-town clients to dinner, were put by the wayside. Keith stated, “There were only so many hours in the day, and home took priority.” He expressed his gratitude that his co-workers were very understanding and supportive to him during this time; therefore, he was able to maintain his performance requirements despite the adjustments he needed to make. In addition, he had long-term relationships with many of his clients and had established rapport with them to a level at which he felt comfortable sharing information about Debra’s diagnosis. He found both his co-workers and clients to be very accommodating, and he attributed this to the long-standing, positive relationships he was able to foster over the years along with his reputation for being a loyal and dependable businessman.

Debra and Keith’s intimate sexual relationship was impacted significantly as well. They mutually agreed that fatigue was the most influential factor on both of their parts. Debra reported that she often felt too physically sick to engage in sexual activity or too tired by the time

they had time alone together. Keith attributed his fatigue to the added responsibility he was taking on. He commented that sex was “put on the back burner” because there were always other tasks that needed to be taken care of, and he did not have the energy to manage it all. In addition to the fatigue, Debra expressed that she had a hard time feeling desire because she did not feel “sexy” enough to have those feelings brought up within her easily. Debra and Keith described a pattern of misconceptions similar to that of other couples in that Debra assumed Keith was not attracted to her once she lost her hair from the chemotherapy and put on some weight because she was unhappy with her own body. Keith reportedly did not experience this in the way that Debra had believed and verbalized that he remained as attracted to her as he had always been. He attempted to help Debra’s comfort level by adding an element of playfulness to their sexual encounters. “I would tease her that she could play the role of a sexy assassin or G.I. Jane like Demi Moore,” he explained, “Anything to help her laugh a little and relax.” Debra found this helpful and gave Keith credit for trying to maintain their sexual connection when they were both physically up for engaging. “He knew it would make me feel better when we were able to have sex. It helped me feel normal and like I could fulfill some of his needs since all the attention had been on taking care of mine,” she stated.

The couple agreed that one of their primary means of coping with the stress occurring in their lives was to spend quiet time together. This began when Debra was experiencing fatigue caused by the chemotherapy and needed to rest frequently. She wanted to be near her family, so she often napped on the couch where she would not be isolated from the family activity. Keith would join her, so he could be close to her, and soon the children began to do so as well. He remarked that their couch became the central spot where they came together as a family. Initially it was very difficult for him to see Debra physically drained because he had always

perceived her to be an active and vivacious person. Using their time together on the couch to connect through physical affection benefitted the couple's sense of emotional connection.

Utilizing other resources for support played a key role in helping Debra and Keith cope with the impact of breast cancer on their lives. People in their neighborhood offered support by supplying the family with meals. A close friend of Debra's organized a schedule and coordinated the community efforts. Debra expressed her gratitude that this was "one less stress that we didn't have" because of the generosity of their neighbors. There were other individuals, such as Debra's sister and a close friend, who offered to accompany her to chemotherapy. Although Keith preferred to go with Debra, they accepted the offers on a few occasions when he had significant events occurring at work. Keith shared that he had two co-workers who were also dealing with cancer in their own families. One co-worker's wife was diagnosed with breast cancer after Debra was, and the other co-worker had a son in treatment for Hodgkin's Lymphoma. "We would compare chemo stories and stuff," he commented, "It was nice to have someone else to talk to that was going through almost the same thing." Keith disclosed that he found it comfortable to talk with these men because he felt that they could relate to one another's experiences of "being on the other end of it" without needing to "get too emotionally deep about it."

The conversation transitioned easily to a discussion about the couple's perceptions of positive change as Debra made a spontaneous statement that she believed "things could always have been far worse." She began by speaking from a personal perspective about her belief that her ability to empathize with others, especially the patients she works with, has changed significantly as a result of her own experiences with a serious medical issue. "It gave me insight about the way I empathize," she stated,

I respect the struggle people go through, and I understand how illness can make even the little things in daily life exhausting. I guess the cliché about walking in someone else's shoes is right because I didn't know until I had to go through something like that myself. It's put that piece of life into perspective.

Debra indicated that the change in her perspective has also motivated changes in the way she practices. Her increased level of understanding has influenced the way she interacts with the patients she works with. "I'm better at promoting their ability to participate, even if it's the least amount they can, and recognize that even the smallest of accomplishments are good." There are times when she will share information about herself when she observes an individual to be struggling particularly hard or when she believes it will enhance the therapeutic relationship. "I'll tell someone I know what it's like to be so ill that getting out of bed was a struggle. It gives a sense that I really can relate to what they are going through, and it sometimes makes the working relationship better," she explained. Debra reported that she works with a lot of people who have experienced severe traumas. She has found that she is less likely to compare the level of a person's suffering based on physical injuries alone because she has greater understanding of how a person's life and family can be impacted in other ways, such as emotionally, functionally, and financially. She stated, "I really treat the whole person now, and part of that is helping them find ways to cope and handle the other aspects of their life that have been disrupted. I even include families more in the treatment plan." Finally, Debra commented that being able to observe the struggle of others in a new way has increased her appreciation for her own circumstances, recognizing that her experiences may have been very different if she had not had the resources and support that she was "blessed" to have.

As a couple, Debra and Keith identified ways that their relationship has positively changed as a result of the experiences they shared. Debra shared her perspective that “Compared to most couples, we probably spend more time together than any of the couples we know.” She and Keith have made it a priority to nurture their relationship as much as they nurture their family. “We spend a lot more time doing things we enjoy together,” Keith said. The couple has even explored new hobbies to find activities they enjoy engaging in together. “We cook together a lot,” Debra shared, “I love to cook and he never knew how much he’d like it until he started to do it with me.” The couple has continued to share some of the activities they engaged in together out of necessity during Debra’s treatment. They continue to go food shopping together, and Keith laughed stating, “That’s my favorite. A couple other women we know started bringing their husbands, and the guys always tease me saying, ‘See what you got me doing!’”

Another aspect of nurturing their relationship involves Debra and Keith setting limits with family members, so that other people’s issues do not interfere with their peacefulness. Debra explained that as the oldest sibling, it was her role to take charge of the younger children and take care of others’ problems. “We’re adults now, and I can choose to not get involved in their squabbles,” she commented. “Going through so much stress has made us realize what’s important is what’s under our roof. We don’t need to take on extra stress and take care of everybody else’s problems,” Keith added. Debra laughed, stating, “I’ve gotten very good at not answering the phone when I know something’s brewing in my family, and we’re all way happier that way.” In conjunction with changes in how they communicate with their family members, Debra and Keith remarked that they have also changed the ways they communicate with one another. Debra admitted that she used to be more emotionally reactive to stress than she is now. “I’d flip out pretty easily before, but I’ve become way better at not doing that and talking calmly

about things,” she reported. She attributed this change to her desire to keep the peacefulness in their home that they have achieved and to her increased ability to let go of insignificant issues. Keith was in agreement that Debra has progressed greatly in this area, and he verbally praised her for putting in the effort.

Debra and Keith stated that they “absolutely” believe in the concept of positive growth resulting from traumatic experiences. One of the ways they perceived growth is in their connection to their spirituality. It wasn’t until this point in the conversation that Keith disclosed that he did feel anger towards God for putting his wife and his family in the circumstances they all had to face. He stated, “I was just so overwhelmed and kept asking God, ‘What else are you going to throw at me?’” He continued to go to church regularly with his family, but noticed a sense of spiritual disconnection. He did not pray or practice the traditions of his religion in the ways he had before Debra was diagnosed. After going through the experience of surviving breast cancer, Keith commented that he now believes there were “spiritual lessons to be learned.” He shared,

Going through something like this really puts you in perspective because it all could have been taken away very easily. I thank God every single day that she’s here and that I have three great kids who are healthy. I thank Him for protecting us and allowing me to see what’s really important in life. And I thank Him for teaching me about real appreciation and gratitude.

Keith spoke further about how he has grown to appreciate all that he has in his life. He shared that there have been times when he was distracted from this by focusing on what he did not have. Living in an affluent area, he often found himself comparing his lifestyle to others around him and feeling resentful because he did not have as much financially and materialistically. He

indicated that he no longer felt that way and reported that he experienced a sense of “relief from the burden of trying to keep up.” He expressed that his deepened connection to God and his sense of gratitude had brought him greater peace and contentment in his life. Debra verbalized that she shared this experience with Keith and believed that, as a couple, they have incorporated their values of gratitude and appreciation into their relationship and their family. In addition, she remarked that she does not pray in the traditional sense of reciting scripted Catholic prayers, but rather has “conversations” with God and find herself “thanking way more than asking.”

When asked about their personal definition of growth, Debra began by stating, “I believe growth is making a commitment to improve yourself or your relationship in some small way every day.” As a couple Debra and Keith believed they have grown in their abilities to relate to and interact with one another in ways that continually strengthen their marriage. “We went through some tough times, and we see that a marriage isn’t going to stay a good marriage unless you both have the same attitude about what a marriage is,” Keith said. Debra added, “He’s right. We communicate about what we think a good marriage is, and we work towards that.” Keith spoke about the growth he has experienced within himself. He explained, “Don’t get me wrong, things were really stressful, but at the same time I saw what I was capable of being as a husband, and I’ve realized my potential.” He continued on to talk about the “pride” he feels about the way he cared for Debra and his family, and how he handled the difficulties placed before him by sharing:

I’ve learned a lot about myself by having to step up in ways I didn’t know were possible. I can cope with life’s challenges, and I have a good ability to roll with the punches when bad things happen. If anything, this has taught me that I have to live for the present. I

know it's corny and cliché, but the reality is that you don't know if there's going to be a tomorrow. Now that I see that, I try to be the best man, husband, and father I can be.

Debra responded to Keith's remarks by stating, "I said I believed in the concept of growth from trauma, but trauma weeds out the men from the boys. It really makes those that are able stand strong and hold fast. I think [Keith] has grown from this."

When the couple was asked how they cope with the possibility of recurrence, Keith remarked, "That's why I pray every day." He indicated that praying for health gives him an effective way to manage his fear and focus his thoughts in a positive direction. Debra shared that she is most likely to think about recurrence when she experiences physical ailments. She experienced a period of time where she found herself "hyper-vigilant" and "near panic" each time she felt any kind of unknown pain, anticipating that it would be a tumor. She has since experienced a significant reduction in her level of reaction and credited her oncologist with helping her feel "grounded" and "confident that I'm in good hands" with regards to her treatment team monitoring her. Debra and Keith both indicated that the topic rarely comes into conversation at this point, but had come up frequently just after Debra had completed her treatment. "We talked through everything just like we did before," Debra stated. "We kind of made a plan ahead of time that, if anything happened, we would approach it the same way. We're not saying it will happen; it just helps to feel like we have a plan in place," she added.

In terms of helping their children cope with their fears, Debra and Keith indicated that they never shy away from any questions their children have. They offer them the reassurance that they are doing everything they can to keep on top of monitoring for any further issues.

Debra shared,

My daughter said to me that you are never the same after you have breast cancer. She understands that people change both emotionally and physically. I'm thankful that she sees all the ways we've changed for the positive, but she said to me, "I wouldn't say we should do it all over again....It's not like Disney, you know. I don't want to ride this ride again." All I could do was promise her that, if we did have to ride this ride again, I would fight just as hard as I did the last time. As a parent, that's the only thing I could promise her.

Researcher's Experience

Aspects of Debra's story about the circumstances surrounding her diagnosis resonated poignantly with me. As she described the "gut feeling" she had that something within her body was not as it should be, I related to experiences I had that I called the same name. As she spoke about the frustration she felt over being told nothing was wrong, but "knowing" something was, for a brief moment I recalled a sensation of frustration. Debra's story was the first that had elicited this type of emotional response within me during an interview. I immediately recognized that my reactions were based on beliefs and feelings I had about my own experiences and that I needed to set those aside in order to avoid placing undue influence on my understanding of Debra's experiences. It had not been a common occurrence for me to encounter reactions like this when in conversations with others, during interviews, or otherwise about topics related to breast cancer. Therefore, I perceived this as significant and took notes of it in order to revisit it at another time once the interview had concluded. Since my response was unusual and not necessarily highly charged, I did not perceive any difficulty moving past this and refocusing on Debra and Keith's dialogue. I explicitly asked the couple to provide additional details about their perceptions of their experiences in order ensure that I was fully listening to

and understanding their perspectives. Upon later exploring the connection I was making to Debra's story, I reviewed the ways in which I could remain aware of my own perspective and effectively refrain from placing my judgment on Debra's story. In remaining committed to adhering to the premises of phenomenological research, it was clear that it was appropriate for me to articulate my experiences and make them overt before proceeding to any form of analysis with the interview data.

The circumstances surrounding my diagnosis are part of personal experiences that I do not often share with others. Similar to Debra, I was in a position in which I needed to be persistent with my doctor in order to have my concerns addressed and for satisfactory measures to be taken regarding my health. It was suspected that the lump I found in my breast was likely a cyst. As I monitored it in the way I was instructed to by my doctor, none of the expected changes occurred. Despite this, I was sent away several times being told it was nothing to worry about. Unlike Debra, I did not have a doctor who responded well to my persistence or who believed that I knew my body best. One of the most vivid memories I have of this experience is of being told by my doctor that I did not "fit the profile" for breast cancer, which apparently became his basis for discontinuing to explore the problem. It took four months from the time I discovered the lump to be diagnosed with breast cancer.

Until Debra shared her story, I had not encountered other women who had similar difficulties with the diagnosis process, and it was an aspect of my experience that had a tendency to prompt negative reactions and conversations from others. People who knew of my circumstances often looked to blame my doctor for certain unexpected outcomes or would become preoccupied with this aspect of my story. I had worked very hard to resolve my feelings of frustration and anger and to accept that I could not change the past and needed to focus on

moving forward. Although I recognized that the negative reactions of the people around me were often out of care and concern for me, the subsequent discussions of my doctor's perceived medical incompetence were not of any benefit to my well-being; therefore, I often avoided sharing the details of my diagnosis in an effort to avoid negativity. Although I did initially recall those negative experiences as Debra told her story, I also felt a deep sense of respect for the strength and perseverance I perceived in her. Hearing her talk about returning to her doctor to voice her concerns without caring about how she would be perceived was very enlightening for me. Debra was evidently proud of herself for making her self-care a priority, and she recognized that other people would likely not have been so eager to challenge their doctors. Hearing another woman speak about this put it into a new perspective for me. Before this I had thought about this only in terms of how it made my experience different from other survivors' experiences. I was aware that I had effectively advocated for myself, but I had never stopped to think about the specifics of this and viewed it simply as an acquired skill. Debra's willingness to share her story provided the opportunity for me to relate to someone else on this level and reflect upon my own experiences. I was able to recognize that my ability to advocate for myself was more than just a skill, and I was able to self-acknowledge the characteristics of strength and persistence I saw within myself and in my own way. This was, in part, prompted by Debra's ability to express her personal sense of empowerment in "saving [her] own life." It was not the case that I believed these qualities were absent within me; rather, it was the fact that I had never taken the time to think about the role these qualities played in this particular scenario, though I was aware of them in other contexts related to my experiences with breast cancer. From my perspective, I had acted on what felt like a natural inclination and had not considered it further until my interaction with Debra prompted reflection.

Meryl and Craig

Demographics

Meryl is a 66 year old Jewish female who was diagnosed with Stage-IIB breast cancer when she was 59 years old. She has been married to her husband Craig, a 69-year-old Jewish male, for 46 years and they have two adult sons ages 44 and 40 years old (see genogram, Appendix L). Both of their sons were married and living independently at the time of Meryl's diagnosis, but resided within neighboring town, being close enough to provide support as needed. Meryl achieved a Bachelor's degree in nursing and completed some Master's-level course work. She is employed as a registered nurse at a local hospital. She reported that she took a two-month medical leave and additional days off as needed throughout her treatment, which included mastectomy surgery with reconstruction, lymphadenectomy surgery (removal of cancerous lymph nodes), chemotherapy, radiation therapy, and hormone therapy. Craig is currently retired. At the time of Meryl's diagnosis and treatment he was self-employed, owning a business in corporate finance. His highest degree of education is a Master's degree in business administration. Craig reports that he attended every medically-related appointment with Meryl and had the flexibility to take time off as he chose. The couple reported that they believe in God, but do not attend temple on a regular basis.

Prior to Meryl's own diagnosis she was highly knowledgeable and experienced with breast cancer. In her profession as a nurse, she was well-educated regarding the symptoms and treatment of the disease. In her personal life, she had several friends who had been diagnosed, and she had provided support in ways she was able as determined by the level of closeness within each relationship and the needs of the individual. Within Meryl's family of origin the only known history of breast cancer was associated with a distant female cousin on her mother's

side of the family (her great-uncle's daughter). Meryl did not have contact with this cousin; she obtained this information through relatives while she was exploring her family history prior to BRCA testing. She tested negative for any gene mutation. Other family members with a history of cancer included her maternal grandmother who passed away because of complications associated with brain cancer and her father who had been diagnosed and treated for prostate cancer. Craig indicated that he had no direct experience with breast cancer prior to the experiences he shared with Meryl. He did, however, indicate that his sister was diagnosed and underwent lumpectomy surgery, radiation therapy, and hormone therapy. His sister resides in the southwest; therefore, Craig's experience was limited to information shared with him by her and her husband via telephone contact only. Craig denied any other known family history of cancer.

Case Study

Meryl's story about how she came to learn that she had breast cancer had some similarities to the account Debra shared of her diagnosis. She had a long history of having cystic breasts and was very familiar with the unique characteristics of her breasts. She had been under the care of a breast surgeon over the course of several years, and on multiple occasions needed to have cysts aspirated. As a result of many years of monitoring her breasts and maintaining contact with breast-care professionals, she considered herself to be proficient in identifying breast-related issues. She reported that the process of diagnosing her cancer began when she noticed that one of her nipples appeared to be misshaped from the way it normally looked. She did not feel a lump or any noticeable mass, but was aware of an obvious change within her breast thus causing the altered appearance. She consulted her gynecologist who also did not detect a lump and who told her there was nothing wrong. Meryl stated, "I didn't think that was the right

answer. Not that I thought I had anything like breast cancer, but I felt like it was definitely something, if only another cyst.” She did not feel comfortable leaving the issue unexplored, so she consulted the breast surgeon she had been in treatment with. He did not feel a mass either, but, as a precaution, performed a needle biopsy. A few days later she and Craig were told that she had breast cancer and needed treatment.

Meryl described hearing the diagnosis as being “like an out-of-body experience.” She indicated that her usual response to crisis situations was to remain grounded and focus on what needs to be done. This had been her way of reacting in both personal and professional situations, so it was a surprise to her when she found herself unable to remain “emotionally in control.” She remarked,

Craig said that I said to him, “Why me?” but I don’t remember saying it. Actually, the only thing I do remember is that I wanted to take care of it as soon as possible. I was too stunned to think about or feel anything else.

She added that the next thought and feeling that she could remember was anger at the realization that her cancer could have gone undetected if she had not questioned her gynecologist’s opinion. She recalled,

I couldn’t even fathom what could have happened to me; how far it would have progressed before it was caught. I was not happy. I thought she should have said to me “I don’t see or feel anything, but, since you seemed concerned, let’s look at it further” or “You should see a breast specialist.” But she didn’t; I did it on my own. Can you imagine if I wasn’t in healthcare and I didn’t know how to advocate for myself that way?

Craig agreed that hearing the news was “shocking.” He equated his emotional reaction to dealing with the death of a loved-one, stating,

If somebody close to you dies, it doesn't hit you for the first few weeks because it doesn't seem real. Then, after all is said and done and people stop paying their condolences, you're by yourself, and that's when you realize what happened. It was the same way with Meryl getting the breast cancer. It took time to sink in, and then you have to try to get your thoughts together and just continue working it out together by ourselves.

Both he and Meryl commented that her long history of dealing with breast cysts had contributed to their abilities to easily dismiss the possibility that a more serious process could be occurring, therefore, making it even more surprising when the diagnosis of cancer was revealed. "You go through these minor things so many times with it always turning out to be nothing of any seriousness that you kind of get conditioned to expect the same results," Craig explained. Meryl agreed that in the early years of developing cysts she would have occasions where she would worry that more was wrong, but after so many years, had become "desensitized" to the discovery of abnormalities in her breasts.

Meryl and Craig agreed that, once the initial shock had subsided, they quickly resumed what they considered to be their normal ways of coping with difficult situations. Craig remarked, "We stopped panicking and started making plans to have the situation addressed. Once the emotional level settled down and the mental fog dissipated, we could start talking more effectively." Meryl added that she found it easy to talk with Craig, and they were very open with one another about their thoughts and feelings when it came to discussing treatment options or reviewing other decisions that needed to be made. She credited him with helping her make one of the hardest decisions she faced, which was whether or not to tell her elderly mother, who was residing in Florida, what was happening. As a couple they decided not to tell her mother until Meryl had completed her treatment. "She was 93 years old and living in a different state. I

wouldn't have been able to handle the guilt of upsetting her and knowing she would worry and not be able to do anything about it," Meryl shared. She added that her mother had passed away recently, and she found comfort in feeling like she had made the right decision to withhold her disclosure until she was medically cleared and to offer a "simplified version that made it sound much less serious than it actually was." "It saved her from stress that she didn't need to be dealing with at her age, and it saved me from feeling bad that I was causing her discomfort," Meryl concluded.

Meryl and Craig mutually shared the perspective that, although they were very effective in communicating about the logistical aspects of coping with cancer, there were changes in the ways they were communicating about their emotions. Craig commented,

[Meryl] said I avoided talking about my emotions with her. I guess she is right about that. I'm a total optimist at heart, and I felt that everything was going to turn out alright, so I didn't want to belabor the negative side. I tried to address more positive things.

Meryl verbalized her agreement that Craig's way of coping with difficult situations is to focus on positive thinking. She added that she recognized his efforts to be supportive and communicative in ways that would not upset her; however, there were times when she felt that his "positive attitude" prevented him from being able to relate to what she was feeling.

He didn't want to upset me, so he didn't talk about his feelings. He was always positive with me, but I was nervous. The word 'cancer' is very frightening. Sometimes I just wanted to know he was scared too or at least for him to say that he understood what I was feeling instead of telling me to stay positive. It's hard to say it because he was so wonderful through it all, but I guess I could have used a little more validation of my

feelings. I never said anything about it because I figured his positive nature was good for me.

Similar to the reports of other male partners interviewed, Craig responded to Meryl's disclosure by expressing that he had good intentions in trying to "save" Meryl from worrying about his emotional state, but acknowledged that he recognized how his limited emotional sharing subsequently contributed to an inaccurate perception that he lacked concern. Meryl commented that she was "relieved" when she heard from a few friends that Craig had been talking openly with them and was sharing his emotions about the situation. "I was happy he had people he was comfortable with. At least I could stop worrying about him bottling up his feelings; that's so unhealthy. I can understand how it was easier to talk to other people than to me," she said. Craig belongs to a running group and indicated that there were people in the group whom he felt close with and who had gone through similar situations, so he was comfortable talking with them.

Craig shared that, in addition to his belief in the importance of positive thinking, care-taking was a primary means of coping with the disruptions caused by breast cancer. He shared, "I guess my paternal instincts kicked in. Care-taking for [Meryl] was my primary focus." When Meryl was dealing with pain associated with her surgeries or side-effects from her chemotherapy and radiation treatments, he assisted her with any aspects of her daily functioning that she had difficulty performing, and he assumed more responsibility in taking care of the household chores. He made it a priority to be present at all of her medical appointments and to make sure he was educated on how to properly attend to her medical needs at home. Meryl commented, "He was always there, helping me do things or getting things for me." She laughed as she remarked,

Sometimes I just wanted to be left alone, but he was intent on being helpful. I let him because I saw how loving and caring he was trying to be. I heard stories about other women who had their husbands leave because of the stress breast cancer put on their relationships. Maybe not while they were sick, but shortly afterwards. Some men found it ugly or disgusting to see a woman whose breasts are removed or deformed. Craig was not like that at all. I couldn't fault him for wanting to take care of me.

The couple shared the perspective that care-taking efforts enhanced the closeness and sense of being emotionally bonded they experienced within their relationship.

Using various resources for support was a key component in the couple's ability to cope with the impact that breast cancer was having on their lives. Craig remarked that he believed he and Meryl made very good use of the social opportunities available to them in order to engage in pleasurable leisure activities that promoted a sense of normalcy. Spending time with family and friends had a beneficial effect on Meryl's emotional state. "We have many, many friends that are more like family who we enjoy a lot of activities with. Even with all that went on, they remained constant and it really helped keep Meryl in a positive frame of mind," Craig stated. He added that humor was a characteristic of their social interactions that they valued and tried to take advantage of as often as possible since "laughter is the best medicine as they say." Other resources for support included their adult children and their spouses, members of the running and veteran's groups that Craig belongs to, and co-workers from Meryl's job. "We're very fortunate," Craig stated, "People were very good to us, and they know we'd do the same for them." Acts of support by people close with the couple included preparing meals, offering to assist with errands or household chores, sending thoughtful gifts, or offering companionship through a visit.

On an individual note, Craig recognized the importance of managing his own stress by engaging in activities that contributed to his well-being, such as going to the gym and meeting with his running group every morning. For Meryl, continuing to work as she was able allowed her to feel a sense of productivity and drew her attention away from her own difficulties for brief periods of time. “It kept things in perspective for me. Being able to take care of other people was a reminder that I was doing pretty darn well and that the situation wasn’t as bad as it could have been,” she explained. Together, the couple viewed the closeness they felt in their relationship as a source of strength and support. They agreed that, in addition to participating in mutually enjoyable leisure activities, engaging in sexual intimacy and bonding through physical affection enabled them to maintain their sense of emotional connection and nurture their relationship despite the stresses they were faced with. Meryl shared that this positively influenced her sense of “womanhood” and minimized the impact that the side-effects of treatment had on her self-image. She was able to focus her attention on the possible benefits that could be associated with the changes to her breasts. She shared,

At first I was pretty upset with the thought of having implants. But then I realized that I got something I’d never had before –full breasts. I had always been flat-chested, so, in order for my reconstruction to look normal, they had to give me an implant on the healthy side also. Now, out of this awful situation, my body was enhanced in a way that both Craig and I could enjoy. Believe it or not, keeping our sex life active actually helped me change my perspective about the implants. Craig had already shown me that he was still attracted to me even though I had no hair or whatever, so it was kind of like a bonus instead of another thing to make me feel like a cancer patient.

Experiencing other changes in their perspectives about life was part of the way Meryl and Craig perceived themselves as positively changed as a result of their shared experiences surviving breast cancer. Craig indicated that he likes to use sayings as a way to stimulate his thought processes and offered these thoughts:

There's an expression that hit home for me: I cried when I had no shoes until I met a man who had no feet. After what we went through with cancer, and the fact that it could have cost Meryl her life, nothing else that we encounter can really be worse than that. We let go of things we used to get upset about because we've learned that they're not so significant in the grand scheme of things.

Meryl agreed with Craig's statement and added that focusing on what they deem important has influenced her sense of gratitude. She noted, "It all ripples outward. When we let go of petty things we open ourselves up to seeing what is important. When we see what's important we appreciate that God has provided that for us." This increased perception of gratitude has been a contributing factor to changes Meryl has made in the way she connects to her spirituality. She indicated that her beliefs about God have not changed, but how she engages in practicing her spirituality has. She reported that she spends more time in prayer and she takes time to thank God for her "blessings." "I can do this anywhere, anytime. I don't believe that I need to go to temple to do it. It's happening in the real world and in real time, and it's more meaningful to me to do it in the moment," she explained. Craig also remarked that he engages in prayer more frequently and viewed prayer as a component of positive thinking. "I'm not a big believer in religious customs, but I do believe there is a Higher Power. After what we've been through and seeing the bigger picture in life, I feel it's important to express my gratitude to the powers that be," he said.

Like all of the couples interviewed thus far, Meryl and Craig reported that they have made it a priority to spend more time together. They have increased their engagement in activities that they mutually enjoy and view as enhancing their lives. “We’ve traveled a lot since Meryl had cancer,” Craig commented. “I think it’s a great way to heal the mind after going through something traumatic; exploring the world and seeing life from so many different lenses,” he added. Many of the vacations the couple have taken have included a component of charitable service, such as helping to raise needed funds for orphanages, schools, and programs to decrease poverty. Meryl shared, “It all relates back to our mental state. By doing these things we get to see the world, experience new people, and see things that enrich our lives.” She added that both she and Craig have come to value the healing power of contributing to the well-being of others. She has included her involvement in breast-cancer-related fundraising efforts among the activities that she believes have positively contributed to her sense of “survivorship.” Craig’s perspective was that, “If you can help someone else heal, it helps you heal as well.” Finally, the couple reported that they make it a priority to spend their time in the presence of “positive-minded” people. Meryl explained, “It’s contagious. When somebody is positive or fun, or someone’s there for you, it brings that out in you. The same goes for negative people, so we chose to spend our time with people who help bring out the best in us.”

Meryl and Craig perceived their increased sense of contentment with their lives as evidence of the positive growth they believe has occurred as a result of surviving breast cancer together. Craig commented, “I’ve come to a point where I want for nothing other than my family’s health and happiness.” Meryl shared that she has perceived growth in her ability to experience enjoyment and offered her perspective:

The only way I can explain it is that I enjoy things in life differently now; I feel it more than I did before. I guess I've grown to recognize how fragile life can be, and I appreciate it more, so I'm more open to my experiences, or I'm just more able to focus on the good parts. This is how I want to live.

Craig responded that he has grown in his ability to be introspective and experience peacefulness stemming from the confidence he feels about his inner strength and ability to cope with the difficulties that occur in his life. He again noted his inclination towards expressions and referenced the saying, "Strength through adversity," as a good representation of how he views the growth he perceives within himself as an individual and within his relationship with Meryl.

Meryl verbalized her agreement in terms of perceiving growth within herself as well as in her relationship with Craig; however, she voiced her opinion that she does not believe "strength through diversity" is a universal concept. "I believe in it, but not everybody can do it," she stated, "You have to have a foundation first because trauma or adversity can also destroy you. It's not easy, but you have to have some foundation to grow from even if it's miniscule." She briefly referred back to her earlier statement about knowing couples whose relationships were not able to survive the "destructive forces of cancer," but resumed her attention on her own perceptions of growth. "I never believed I was very strong," she commented,

I've had to be, but, before this, I've always done it with Craig's help. But, when it comes to cancer, no matter what, you're in it by yourself. I hate to say it, but it's about you and only you. You're the one who has to be strong because people can help, but nobody can fight it for you. I appreciate every last bit of support I received, but now I know how strong I really am.

Meryl added that she believed going through breast cancer gave her the opportunity to recognize her inner strength because, prior to this, she relied on Craig's strength to get them through difficult times and never "needed to extend [herself] this way."

Similar to the report of other couples interviewed, Meryl and Craig reported that they do not often talk about the possibility of recurrence. Meryl shared, "I'm always afraid it's going to come back" and indicated that she is particularly preoccupied just prior to her check-up appointments. She "struggles" with the thought that it may have been a "wiser choice" to have bilateral mastectomies instead of a single one in order to have minimized both her risk and concern. She copes by remaining aware of herself and her body and by not letting ailments go unaddressed. In addition, she pays more attention to her overall health by maintaining a healthy diet and exercising regularly. Craig reported that he does not experience the level of concern that Meryl does because he does not allow himself to focus on negative thoughts about recurrence. He verbalized again that he strongly believes in the power of positive thinking, and this is another way he practices this belief. Despite their differing experiences, Craig expressed his desire to continue to support Meryl; therefore, he tries to listen to her concerns whenever she feels the need to talk. Craig concluded the interview stating that, instead of focusing on the possibility of recurrence, he finds it more helpful to simply remain aware of his mortality and allow that to motivate healthy living. In addition, instead of focusing on the disruption that breast cancer caused (or could cause in the case of a recurrence) he believes that it is more beneficial to focus on the ways he and Meryl have been able to grow through their experiences. He stated, "The way we faced the challenges of breast cancer together has improved the continuity of the way we exist together."

Researcher's Experience

Meryl's was the second story I had heard about a woman needing to advocate for herself in order to have her breast-related concerns addressed by medical professionals. As I listened to her speak, I experienced a similar sense of personal satisfaction in my ability to be among women who had the strength of perseverance. I noticed that I did not experience the same level of emotional reaction as I had upon hearing Debra's account, and I found it easy to take note of my internal response and to refocus my attention on the interview dialogue. I attributed this to the fact that Debra's story was the first I had heard that included issues related to difficulties obtaining necessary healthcare and, therefore, elicited a greater degree of surprise. However, relating to Meryl's account of her experiences as I reviewed the interview transcript provided me with an additional opportunity to further contemplate this phenomenon and to explore the similarities and differences in experiences of these women and myself. Debra and Meryl had the commonality of having developed familiarity of their breasts through their long histories of dealing with cystic breasts, which contributed to their awareness of changes within their bodies. Although they both pursued further exploration of the problem when they were not satisfied with the responses they received from their healthcare providers, it appeared that their varying degrees of knowledge and experience determined their courses of action. Unlike Debra and Meryl, I had not experienced difficulties with breast cysts and did not know what to expect regarding changes within my body. The role I took in pursuing further care was most similar to that of Debra, who had limited knowledge and experience with breast cancer and relied on her doctor to guide the steps taken to determine her illness. Meryl, on the other hand, had a broader range of experiences with and knowledge of breast cancer which proved to be an asset to her when she needed to pursue addressing her concerns independently.

This train of thought was prompted by a statement made by Meryl that caught my attention, which was, “Can you imagine if I wasn’t in healthcare and I didn’t know how to advocate for myself that way?” This statement brought my attention to the fact that there was a common factor among Debra, Meryl, and myself. All three of us were in the field of healthcare and worked in hospital-based settings, and we each attributed our abilities to advocate for ourselves to the experiences and knowledge we gained within these contexts and settings. Besides noting this commonality, Meryl’s statement mirrored a question I had asked myself on many occasions over the past several years—What if I had not had experiences interacting with other healthcare professionals or the confidence to question my doctor? I had realized that it was my experience with navigating the healthcare system and my belief in advocating for quality healthcare that influenced me to pursue exploring my concern further, not my education about breast health. This realization became a significant source of motivation for me to become involved in breast-cancer awareness and education initiatives in order to assist other women in understanding both how to care for their breasts and how to access necessary healthcare. Through my involvement in community awareness activities and my work with a primarily indigent population, I have witnessed that, although breast-cancer knowledge is much further reaching than it had been a decade ago, there continues to be people who lack the educational opportunities and advocacy supports that they need. Although the topic of this particular project is not directly related to this issue, my motivation lies in a desire to expand the scope of research related to breast cancer and the factors that contribute to survivorship in order to promote the improvement of support resources provided to individuals facing breast cancer and their families.

Diana and Steve

Demographics

Diana is a 35-year-old Ukrainian-American female who has been cohabitating with Steve, a 37-year-old Italian- American male, for six years (together for ten years). The couple does not currently have children, but are considering adoption since Diana is unable to conceive children as a result of chemotherapy-induced infertility (see genogram, Appendix M). Diana completed a Bachelor's degree in fine arts and owns a jewelry-design studio. Steve completed studies through a national aviation academy and is employed as a certified private airplane pilot and certified flight instructor for a small privately owned aviation company. The couple described their community as suburban middle-class. They identified that they were Christian, but do not actively attend church.

Diana was diagnosed with Stage-II breast cancer at 32 years old. Her treatment included mastectomy surgery with reconstruction and chemotherapy. Although single mastectomy was presented as an option, Diana chose to have the surgery done bilaterally. Prior to her own diagnosis, Diana indicated that she had a moderate amount of knowledge about breast cancer. Approximately two years prior to her own diagnosis Diana had a close friend who was diagnosed with Stage-II breast cancer. Diana was not directly involved in her friend's medical and treatment appointments, but did spend a significant amount of time in her friend's presence and assisting with household tasks. Within her family of origin, Diana's maternal grandmother's sister (her great-aunt) had been diagnosed with breast cancer at 30 years old and underwent mastectomy surgery. No other treatment was administered. Since this was before she was born, the information was obtained from her mother, who assisted her with completing a family-history questionnaire required before BRCA testing could be approved. Diana indicated that there was no other known history of breast cancer within her family, but her mother had been diagnosed

with cervical cancer at the age of 34 years old. Diana was tested for BRCA gene mutation, and her results were negative.

Steve indicated that he had only general knowledge of breast cancer prior to Diana's diagnosis and did not have anybody related or close to him who had experienced it. Within his family of origin he has had several family members who have passed away as a result of cancer-related complications; however, he has very limited knowledge of the specifics about each person affected. He reported that within his family there was little sharing of information among the members, especially from the older generation to the younger. In this particular case, Steve was aware that all three of his uncles (his father's brothers) and his father had been diagnosed with cancer. His father was diagnosed and treated for bladder cancer. One uncle passed away at 30 years old from what Steve believed was lymphoma. Another uncle passed away in his 50's due to lung cancer-related complications. Steve was unsure of what type of cancer his third uncle was diagnosed with and whether his death at the age of 62 years old was a direct result of cancer-related complications or not. Additionally, Steve indicated that his maternal grandmother had passed away due to cancer-related complications when he was a child. He had been aware that she was ill for a long time, but the details of her illness were not shared with him by family members. During this inquiry Steve made the statement that, "All I really know specifically about cancer in my family is that no one ever survives it."

Case Study

The interview began with Diana sharing details about how she came to learn she had breast cancer. A lump in her breast was detected by her gynecologist during her annual examination. Her doctor initially suspected it to be a cyst and attempted to perform an aspiration; however, when no fluid was obtained, he informed her that the lump was a solid mass

but most likely benign. Due to the dense nature of the mass Diana's gynecologist recommended it be removed and referred her to a general surgeon for an excision and biopsy as a standard procedure. Later the same week Diana was contacted by a nurse at her doctor's office and was told she needed to come in and speak to the doctor about the analysis results. Prior to this phone call Diana reported that she had not experienced the least bit of concern about the lump because her doctor did not seem concerned. With some fleeting concern she made an appointment to see him a few days later. She stated, "It's never good when they don't give you the results over the phone, but I just kept thinking it was nothing, but I had to go to the office, so the doctor could check my incision." She added that she was "so convinced" that this was the case that she did not have anyone accompany her to the appointment. "I was in a state of complete shock when he said, 'I'm so sorry to have to tell you this, but you have breast cancer,'" she shared.

Diana spoke about feeling a strong need to maintain her composure while she was at the doctor's office. She shared, "I just needed to keep it together. It would have made it worse for me if I had fallen apart in front of these people that I hardly knew. I'd have been embarrassed." As she was driving home she described that a feeling of "fear" slowly began to increase within her, but was "taken over by frustration." She explained,

I just started thinking about all the things I should have done differently. I should have seen a breast specialist instead of a general surgeon. I should have considered the possibility that the lump could have been cancer. I would think most people would initially think cancer than talk themselves out of that worry, but I didn't even let myself consider that. I guess I was in denial from the start, so hearing I had cancer was like getting hit by a Mack truck. I think I went to frustration because it was easier to deal with than being scared. I clung to being frustrated.

Diana reported that it was very difficult to tell Steve she had cancer. “I did a lot of minimizing, saying it wasn’t a big deal and for him not to worry,” she remarked, “I probably said, ‘I’m okay’ about a hundred times.” Steve shared how he responded to hearing the news by stating, “My initial reaction was immediate fear. My only experience with cancer in my family was nobody ever survived from it. I didn’t know how to handle it, especially with her.”

Similar to the reports of other couples, Diana and Steve spent the coming weeks attending doctor’s appointments together and getting the information they needed to proceed with treatment. They mutually agreed that it was a “confusing” time in their relationship, and they took turns sharing their perspectives. Steve began by commenting that, as he learned more and more about what was going to happen to Diana, he increasingly felt “helpless”. “I felt helpless because it wasn’t happening to me, so there wasn’t anything physically that I could do. Everything everybody was telling me was basically that she had to do this herself,” he explained. Steve took Diana’s hand as he shared more about his experiences:

I didn’t know exactly how to be supportive. I knew not to just constantly stand around her and just be like “Rah, rah, rah you’re good, stay strong.” I know you can’t do that all the time to somebody because it wears them down. She knew she had to stay strong. She knew what she had to do. For me to be like that would have been counter-productive, but I just didn’t know what to do. That’s where the helplessness came in.

He spoke briefly about the difficulty he had communicating during this time. He considered the fact that, when people are facing difficult situations and are feeling overwhelmed, sometime they want a reprieve from talking about it. This thought caused him to feel unsure about initiating conversations about what was occurring in their lives. In addition, he identified that he was not a strong communicator at the time, and this made him feel even more apprehensive about engaging

in difficult conversations. “I didn’t even know how to say to her, ‘Is there anything you want to talk about?’ or ‘What do you need?’ so I never asked anything. I just tried to be supportive in other ways,” he explained.

Diana also identified that she did not believe she was communicating well at that time and attributed this to “irrational fears” that Steve may not want to stay in the relationship with her. She shared, “I kept saying ‘I’m okay’ because I didn’t want to overwhelm him.” She reportedly experienced “conflict” between her thoughts and emotions and described it in this way:

Intellectually I knew he wasn’t going to leave me. That’s just not who he is, and I knew how much he loved me. I just started to have these thoughts that this was all going to be too much for him. He doesn’t do well with hospitals and doctors; he gets very anxious. Now he was going to have to do all this stuff that was really uncomfortable for him. He had always been devoted to me and supportive of me, but all of a sudden I started to feel like I was defective. Why would he want to stay with someone is damaged goods?

Diana reported that the combination of worrying about making Steve uncomfortable and viewing herself as “defective” caused her to think “irrationally” about their relationship. Despite the fact that the couple had maintained a long-term, committed, and mutually supportive relationship, she viewed the fact that they were not married as “an easy out” for him. Prior to this she had never viewed their relationship as any less committed than people who were married, and she recognized that her thoughts did not accurately represent the “loving” relationship they had created. She expressed feeling “guilty” that she had these thoughts because she felt it was “disrespectful” to Steve and the effort he put into being a supportive partner. Diana shared her insight that much of her reaction stemmed from her role within her family. She identified that

she had generally been the person who takes care of everyone else; therefore, she experienced difficulty asking for support because she had become accustomed to dealing with problems on her own. She became overwhelmed at the thought of not being able to care for herself and of placing that “burden” onto Steve.

The couple agreed that there was a dramatic change in the dynamics within their relationship once all of the consultations were completed and they had decided on and were connected to the treatment team of their choosing. Diana laughed as she remarked, “All the crazy thinking and confused emotions finally settled down.” She further disclosed that she found it somewhat embarrassing to share about those first few weeks because she and Steve both viewed their interactions as “out of character” for who they were as individuals and as a couple. “I’m telling you because it’s important for people to know that cancer can throw you into a tail-spin that you never saw coming,” she stated. After sharing this information, the couple proceeded to describe their perceptions that they “came together” as a couple and felt “united” as they transitioned into the treatment phase. They were able to have productive conversations about their thoughts and feelings related to the various treatment options as well as the impact that breast cancer was having on their relationship. Diana commented that it was important for her to hear Steve’s thoughts because she wanted him to share in the decision-making process with her. She added that she and Steve often view scenarios differently, but that this had been an asset in their relationship on many occasions. “I felt better about making decisions when we could talk about them. We see things differently, and Steve could give me another viewpoint I might not have considered. I felt like together we covered all angles,” she stated.

Steve credited the two surgeons who were performing the mastectomies and reconstruction with providing him with a sense of direction that helped him manage his emotions effectively, so he could “think clearly.” His own words describe the experience best:

Those two women were a God-send. They spent time talking with me about what was going to happen, and they gave me instructions on exactly what to do to help [Diana] each step of the way. I felt more directed, like I knew specifically what I needed to do. It was easier for me to deal with because I finally felt like I could help her get through this, and I knew what was coming next, and I was prepared for what I was supposed to do.

Steve identified that he felt “respected” by the surgeons because they took the time to acknowledge him and directly included him in all conversations related to Diana’s care. He stated that the reconstructive surgeon continued to be a resource for support for both him and Diana throughout the treatment process. The reconstruction process occurred over the course of several months, so this allowed for an extended amount of doctor-patient contact. In addition, this surgeon’s primary specialty is handling breast cancer cases, so she was knowledgeable about various aspects of the treatment process and maintained communication with Diana’s other healthcare providers, therefore, could offer clarification or support as needed. She made herself readily available to the couple to answer any questions or address any concerns they had.

Following Diana’s surgery and as her treatment progressed she and Steve initially experienced differences in their perspectives about care-taking. Steve played an active role in caring for Diana and experienced satisfaction in being able to physically assist her. He explained, “I couldn’t take the chemo for her or fix the nausea and fatigue, but I could get pillows for under her arms and empty her drains. At least there was something physical I could do that made me feel like I was helping her heal.” Steve also assisted with Diana’s hygiene

needs and took over the majority of the household tasks. Diana stated that she understood Steve's perspective and felt gratitude for the "love he showed through his caring acts"; however, at the time she found it very difficult to need to rely on him. She shared,

In the moment it wasn't easier for me. It's easier for me to try to do things on my own. It's a very vulnerable position when you need to rely on someone for even your basic needs. Also some things he had to do were not pleasant. He was emptying my surgical drains and measuring the fluid....It was pretty disgusting, and it's hard to have someone see you like that....He's the only person I trusted to help me with these things, but I still felt very exposed. It was another case of confused emotions....I was grateful for the help, but resented that I needed it.

The couple mutually remarked that the differences in their experiences became the catalyst for continuing to improve the communication between them. Steve shared that Diana's willingness to talk with him about her discomfort helped him understand that her apprehension was not related to discomfort she experienced with him personally, but rather to her discomfort with feeling helpless. He explained, "When she talked about it that way, I could totally relate to what she was feeling. I tried to do things in a way that was respectful of her feelings, but let her experience being cared for." He added that he believed there was a part of her that wanted to feel cared for, even though it was uncomfortable, and he felt that she appeared to become more comfortable as he continued to take care of her. Diana agreed with Steve's perspective and added that being taken care of in this way was very unfamiliar to her, but that she did, in fact, feel increasingly at ease. "He challenged my thinking that I had to do it all by myself," she stated. "And even though I wouldn't ask for it, I knew, by the way he went about it, that he was going to be there for me through it all."

Utilizing the support offered to them by friends and family played a significant role in Diana and Steve's ability to cope with disruptions occurring in their lives. From Diana's perspective, she learned to identify those individuals in her life with whom she felt safe to reach out to and allow herself to be vulnerable in front of. She recognized that there were other people in her life who were not able to be supportive in the ways that she would have liked; therefore, she needed to have "realistic expectations" about the ways they could contribute. She remarked, "You certainly learn who your friends are and who's willing to go the extra mile for you when you need them." From Steve's perspective, he agreed that having a good support system was of great benefit to him. He explained,

I have to agree that the whole support system thing was huge in this. Even just to have someone show up to cheer us up or to sit with me in the hospital for twelve hours to keep me company and help me keep it together while [Diana] was in surgery. I learned how valuable even the smallest efforts were...I'm sure we would have survived without that, but I think it would have been a lot harder to get through this without being able to count on people to help you out. It definitely made a difference for me.

Diana and Steve shared the perspective that the mastectomy surgery was the aspect of dealing with breast cancer that contributed most significantly to the disruption in their lives. In addition to the care-taking issues that arose, the mastectomies were associated with difficulties that surfaced in the couple's sexual intimacy. Diana shared that she experienced dissatisfaction with the way she viewed her body, and this directly affected the level of self-confidence she experienced during sexual engagements. She stated,

The mastectomies were a huge blow to my sense of femininity and my body image. I have scars on both my breasts and down both of my sides where they moved muscle from

my back to the front to help support the implants....Every time I looked in the mirror all I saw was the scars. I'm a very visual and detail-focused person, so my eyes automatically go to the scars, and, when they do, all I can see is imperfections.

Similar to the stories of other couples interviewed, Diana acknowledged that she often had misconceptions about Steve's opinions of the physical changes to her body because she "assumed" he was viewing her the way she viewed herself. "I thought that, when he looked at me, all he saw were the imperfections that I saw," she explained, "I was reacting to how I thought he saw it and what I thought he wasn't going to be attracted to." At this point in the interview Diana requested an opportunity to describe what it was like for her to have her mastectomies and reconstructive surgery performed during the same surgery. She verbalized that she believed this was relevant in order for other people to fully understand the impact this had on her and Steve's intimate relationship. She described the experience as follows:

It's a strange thing to go into surgery having to wrap your head around the idea that you're losing your breasts, but then you come out, and you have breasts. Then you look at them, and you see them there, but you know they're not your breasts. I had a hard time making sense of my body because they're there, but they're not mine. They're something foreign, and I couldn't get my head around how I integrate this into who I am or how this becomes a part of me....I had no feeling in that area, so it created sort of a disconnect. If Steve is touching them, but I can't feel it, then it's not really like he's feeling *me*. He's feeling something fake, and I'm not feeling his touch. It's hard to make sense of that.

Diana expressed feeling "disappointed" by her reaction because she had tried to get excited over the fact that the implants would enhance her figure in a way she viewed as positive, but that initially they served as a reminder that she had cancer. She remarked, "It's hard to go to a

doctor's appointments and have that doctor and the nurses raving about how great I looked and how I was the other doctor's best work when all I could see is what was missing." During the initial phase of the reconstruction she did not have areolas or nipples. She described the difficulty she felt adjusting to her appearance because when she looked in the mirror what she was appeared "unnatural" and not what resembled "normal" breasts.

Steve shared his perspective that the disruption they experienced was primarily due to the fact that they were "over-thinking the whole thing." He identified a series of behaviors that he believed described the cycle they found themselves in. He stated that he had shied away from touching Diana's breasts because he was afraid of hurting her and because he was aware of the fact that she had not yet adjusted emotionally to having the implants. He was afraid that, if he touched her and she could not feel it, she would become upset. However, Diana interpreted his lack of physical contact as confirmation that her body was unattractive to him, which he stated was inaccurate. "We were stuck in a big head game, and it was a tough wheel to jump off of," Steve laughed as he remarked. Diana also laughed and commented that, prior to dealing with the impact of breast cancer, they had never experienced difficulties in their sex life or in their abilities to talk openly about sex. "It just shows that cancer changes everything. We knew how to talk about sex, but not about sex through the lens of cancer. It seemed like a completely foreign concept," she said. The couple agreed that, once again, the ways they initially tried to communicate about the disruption were not effective. Diana shared her insight that they were not accustomed to "holding back" from expressing themselves regarding issues related to sex; therefore, when they each perceived the other doing so, they interpreted this behavior to be an indication that he or she was refraining from speaking truthfully in order to not hurt the other's feelings. Steve verbalized his agreement with Diana's account of the events and added that,

I was trying to reassure her that I was still attracted, but I wasn't talking about what I was thinking or feeling, so she thought I was just saying nice things and what I thought a good partner should say. Same thing the other way around, I thought she didn't want to tell me she didn't want me to touch her because she didn't want me to feel bad. When we finally started to talk about it without tip-toeing around each other, we realized how off-track we were with understanding each other's intentions. Putting it all out there honestly was one of the best things we did through this whole thing, and it got us back on track with one another.

The couple mutually believed that being able to communicate openly with one another about these issues not only stopped the cycle of misperceiving, but also led the way to being able to explore ways of sexually interacting that would be comfortable for each of them. The components of working together to solve an issue, openly communicating with one another, and engaging in mutually satisfying sexual activity all contributed to the couple's perceptions of emotional connectedness. Additionally, they believed that establishing this level of openness and further developing their abilities to communicate about sensitive subject matter became an asset when they were faced with the challenges of chemotherapy. Diana and Steve both acknowledged that the physical side-effects of the treatment, including nausea, fatigue, and hair loss, had the potential to create similar disruptions in their relationship and their sexual intimacy, however, did not as a result of their abilities to connect emotionally through their dialogue and effectively communicate regarding their thoughts, feelings, and needs.

Diana and Steve mutually agreed that they perceived the changes in their ways of communicating with one another to be the most significant positive change they have experienced as a result of their shared experiences with breast cancer. Diana remarked, "I think

early on we both started to feel like every conversation was about cancer, and we didn't want that. We were motivated to figure out how to communicate better so cancer wouldn't have that much power in our lives." She added that, even though she still initiates conversations more frequently, she feels satisfied because they are more productive and far more comfortable than they were previously. Steve shared that he recognized that he needed to be more assertive and verbalize his thoughts even though this was initially uncomfortable for him. He commented,

When life is just cruising along, you just do what you always did. But, when you have something like this happen, you're forced into a lot of conversations you never had to have before because you don't have much of a choice. It's either going to push you to learn how to communicate better, or you're going to crash and burn pretty quickly....We realized pretty quickly that we had to figure this out, or we, our relationship, was just going to fail....If we had to find something positive out of this, then I would say the way we've learned to talk to each other will help us for the rest of our lives. It's brought us closer because we continue to try hard at it even now when there's no crisis happening.

Diana agreed and added that their improved ability to communicate has positively influenced the trust they feel within their relationship. "Getting through cancer together has been a catalyst," she stated, "I trust him more. I feel confident that I can bring an idea to him, and he'll listen to me and share his opinion. We can resolve issues so much quicker and easier without all the confusion." In addition, the couple believed that they were more able to focus on the positive benefits that would come from reaching understanding about a difficult topic than the discomfort the conversation may temporarily entail. Steve laughed as he commented, "A lot of couples are probably more selective about bringing up sensitive topics, but we don't shy away from them anymore. We're not looking for conflict, but we're just not afraid of it now."

The couple was asked to speak about their perspectives on growth as a result of surviving breast cancer together. Diana indicated that for her and Steve, as a couple, growth is viewed as changing in positive ways that “demonstrate a degree of permanency.” Steve explained this to mean that changes are either maintained or continue to progress in a positive direction and that they, as a couple, do not revert back to old ways of behaving. With regards to their philosophy about life, they shared the perspective that they have grown to be increasingly aware of how they live life on a daily basis. They indicated that they have had conversations about the ways they view themselves as positively changed and how they would like to see themselves “living life.” Steve explained,

We pay more attention to things as they are happening now. I guess we’ve been reminded of how life can be taken away from you pretty quickly, and things can be taken out of your control....We just want to absorb our experiences and not just float through life.

At this point in the interview, Diana encouraged Steve to share his changed view of mortality as he has communicated it to her. He willingly did so, stating,

I think before all this, I had the mentality that, when your time comes, it comes. I didn’t have a death wish or anything, but I certainly didn’t fear it. I didn’t really care if it happened tomorrow or if it happened fifty years from now....So I didn’t think about how I was spending my time....After going through cancer with [Diana] I see how important it is to take the time to enjoy life. I don’t have that passive “whatever-happens-happens” attitude I used to have. I want to relish the moments because it does matter if they’re gone tomorrow. There is a lot more value of life in me now than there was before.

Diana mirrored Steve's expression and described increased awareness of her mortality that contributes to her sense of value for life. She stated, "I've become very protective of this great life we have together and our happiness. I'm much more selective about who I spend my time with and what I'm willing to participate in." She described setting boundaries with people and limiting the amount of time she allows herself to be exposed to other peoples' negativity which she feels intrudes upon her happiness. She laughed as she stated, "Not only did I get two new breasts; I got a backbone out of this deal too."

Diana and Steve talked more about their perspectives that there is a connection between positive change and growth. They engaged in a cooperative dialogue to explain their views that it is the quality of maintaining positive change that allows the change to be defined as growth. They highlighted the fact that they have maintained the positive changes they have made and continue to work on improving upon the ways they engage as a couple and live their definitions of a healthy life. They clarified that, although some of the discussion points had emerged through the inquiry of change, they view all of their progress as contributing to their growth as a couple. Together they found the motivation to continue to nurture their growth through the "positive rewards" they have experienced as a result of their efforts and dedication. According to Diana, "There has been so much positive reinforcement that it excites me to continue. We've grown so much closer as a couple, and we are genuinely happy like we've never been before. This is how I want our life to be." The couple reported that they have received positive and encouraging feedback from friends, family members, and other couples they have encountered that has served as indicators of their growth. According to Diana, "People have told us we're an extraordinary couple. It's empowering to get that feedback, and it's reinforcing when other

people see the changes that we see in us.” Much of the feedback that Diana and Steve have received from others has been based on observations of the couple interacting with one another.

Gratitude and acknowledgement are concepts that Diana and Steve introduced within the conversation of positive growth and indicated that both were factors that greatly influenced their behaviors. Diana remarked that they have found new meaning in celebrating significant moments in their lives and that celebrating has become a way of acknowledging and expressing gratitude. In her words, “We take every opportunity to celebrate the wonderful moments in life, whatever they are. To celebrate is to acknowledge these moments as gifts and express our thanks for them.” More specifically, she described the new-found importance she personally feels about celebrating birthdays. She explained,

We were taught that birthday celebrations were for kids. We didn’t pay as much attention to them as adults.... The first birthday I had after beating cancer was very emotional because I realized it’s not a given that you’re going to get another one. They have become very significant for me because they remind me that I’m alive for another year and I’m still here and that is worthy of celebrating. But it’s not just my own....the birthdays of the people I love have also become important to me. I celebrate their lives too and show my gratitude for the ways my life is better because they are in it.

Steve contributed by acknowledging that gratitude has become a motivator for them to incorporate philanthropic endeavors into their lifestyle. He expressed that he and Diana share their beliefs in the important of “giving back” and in the concept of “paying it forward” as a way of acknowledging the kindness that has been showed to them. Efforts related to breast-cancer awareness and fundraising are an aspect of charitable work that the couple has found value in;

however, they agreed that it is important to extend themselves beyond just this single cause.

Steve explained it as follows:

We participate in breast-cancer events because it is personally important to us, but our belief in paying it forward is bigger than that. Everyone has different issues they have to face, and no one cause is greater than another. If we were dealing with something besides breast cancer, we know we'd have just as much support for that issue....People came to our aid with our struggles....We try to do the same in return. The bigger picture is about giving of ourselves for the sake of helping other people with whatever it is they are facing or what is important to them, not just in ways that benefit us or are only about the causes that personally apply to us.

Diana expressed her wholehearted agreement with Steve's statement, but also found it important to mention that she felt it was very "healthy" for her to have contact with other breast-cancer survivors with whom she has developed meaningful relationships and an expanded support network. Steve verbalized his agreement that he has found it satisfying to be able to support other men and share his experiences from the partner perspective. Overall, the couple mutually viewed their involvement in a variety of charitable events as helpful to them in remaining focused on a sense of greater purpose. Diana added that there are also times when she needs "a break from thinking and hearing about cancer," and their connection to other causes allows her to remain active without feeling "consumed" by cancer.

The couple spoke about their thoughts related to the possibility of recurrence. Steve shared that he found some relief in his concern when Diana's oncologist shared some statistical information with him. "The doctor told me that [Diana's] chances of having any recurrence were diminished by like 97% because of the treatment we opted for....Those hard numbers gave me

something solid to work with, and I felt better about it,” he said. He added that he was not “naïve enough to believe there’s no chance it will happen again,” but had not known anything about recurrence rates, so the statistics gave him a way to gain perspective and understand what an appropriate level of monitoring would be. Diana’s doctors continue to be resources for support even now that her treatment has been concluded for quite some time. Steve indicated that he has “complete faith” in their abilities to continue to care for Diana. He laughed as he shared a recent experience he had at one of Diana’s check-up,

This is funny, but most of the talk from the doctors is about what a great job they did.

It’s never like, “Yay, everything is good, she’s healthy.” It’s always like “Wow, we did a really good job.” That’s the thing they talk about now, so I feel like their concern is down. They’re a hell of a lot smarter than I am, so, if their concern is down, and they’re that much more comfortable about it, why shouldn’t I be? I trust them one-hundred percent.

Diana agreed that her level of concern has slowly decreased over the passage of time. She admitted that she continues to get anxious when it comes time for her check-up, but no longer thinks about recurrence on a regular basis.

It was just another aspect that I had to learn to put into perspective. At first I had an unrealistic impression that I could never get breast cancer again because I had mastectomies and didn’t have to get mammograms anymore. I stopped doing my self-exams, and, when my doctor found out she gave me a wake-up call that it was still possible....I can’t live in it and in the worry. I need to be in the present, but that doesn’t mean I’m passive. I do what I can do to keep up with my health, and that’s how I cope.

Diana agreed with Steve's statement that her treatment team continues to be a support resource. She feels that her doctors are "watching out" for her and trusts that they will know how to address any future issues with the compassion and competency they have shown her thus far.

The couple shared that they deal with the possibility of recurrence by reminding themselves of the relational strengths and bond that has contributed to their survival. Diana remarked that the experience they have had together with breast cancer "has reinforced that [Steve] is in this one hundred percent with me, and we will continue to do this together even now with something as routine as a check-up. I don't have to do this alone now or ever." Steve nodded in agreement as he added his opinion that "I'm not going to jump in when there's a crisis and then back off when things settle. We do this as a couple and will continue. I told her I would be at every appointment, big or small, as long as she wants me to." The couple's perception of increased emotional closeness and relationship strengthening with friends and family also serves as resources for coping with the possibility of recurrence. From Diana's perspective, "Just knowing there are people around us who are going to be there to support not just me but both of us no matter what happens makes a world of difference and is very important to me. It eases my mind."

Approaching the conclusion of the interview Diana and Steve were asked if there was anything else they wanted to contribute that would offer greater understanding of their experiences surviving cancer. Diana took the opportunity to praise Steve for the improvements he has made towards attending to his own health. She laughed as she admitted to being "persistent" in her requests for him to pay more attention to the ways he takes care of himself. She verbalized, "I don't live in denial anymore. Things are going to happen, and life is unpredictable, but it's important to be proactive about how you live your life, whether it's your

relationship, your health, or any other aspect.” Steve acknowledged that he has come to understand the importance of taking care of himself in order to take an active and healthy role in his relationship. He stated, “We don’t know how much time we’ll have on this planet, so we’ve decided that we’re going to live it well and healthy, as best we can.”

Researcher’s Experience

During the course of Diana and Steve’s interview there were several distinct observations that I made that greatly contributed to my understanding of the couple’s experiences. The most powerful of these was my perception of the ways they non-verbally communicated with one another throughout the entire interview. Diana and Steve were highly physically interactive with one another and integrated the use of both touch and facial expressions into their story-telling. During times when the couple was speaking about feeling disconnected as a result of the disruptions they were experiencing, one or the other would initiate physical contact such as holding the other’s hand or stroking his or her arm. Similarly, during conversations where they were described experiencing reconnection or greater connection as a result of an experience, their account was illustrated through their bodies. They looked at one another frequently through these conversations, and I observed exchanges of facial expressions mirroring the verbal story-telling. There were times when the couple appeared to visually express the emotions as they coincided with actions being described. In an effort to not misread these cues or impose my interpretation, when the couple was not verbally describing the emotions, I asked them to tell me about the emotions associated with the experiences. Whether I was prompting them to communicate directly about their feelings or not, Diana and Steve appeared highly emotionally engaged throughout the conversation. It was also evident that, from the initial descriptions of ineffective communication patterns to the highly engaged communication the couple

demonstrated in the interview, they had worked hard to improve their abilities to interact well with each other. Despite the various topics explored, the couple's focus on communication throughout the descriptions of the survival process illustrated the importance and value they placed on this within their relationship.

Being a highly visually-oriented person, I was attuned to the ways the couple offered one another visual cues and communicated through their physical expressions. Their uses of touch and facial expressions appeared to mirror not only the experiences they were recalling, but also the experiences they were having as they were sharing their stories. For example, during one particular conversation in which Diana and Steve were sharing their perceptions of feeling disconnected as a result of their failed efforts to understand one another's needs, they frequently made eye contact and spoke directly to each other. Their visual expressions displayed their feelings of sadness. It appeared that even talking about being emotionally disconnected elicited emotional responses, and they seemed to counter this by reinforcing their connections or allowing themselves to experience the connections in the moment through touch as they spoke. Likewise, during dialogue about the emotional bond the couple felt or occasions of connecting emotionally with one another, I observed the physical displays of that connection and bond through behaviors such as moving closer to one another or putting an arm around the other and drawing them near for a moment. The high level of non-verbal communication in conjunction with their abilities to provide detailed accounts of their experiences provided me with a comprehensive illustration. I felt immersed in their stories because they provided me with the means to participate with greater sensory involvement. This greatly contributed to my understanding of their perceptions.

In addition to the non-verbal communication, there were two verbal occurrences that I found interesting. The first was related to Diana's reactions to having breast reconstruction and implants. She had indicated that she was a very "visual" and "detail-focused" person, which had served her well as a jewelry designer, but also proved to negatively influence her appraisal of her body when she had difficulty distracting her attention away from what she perceived to be imperfections. As I stated earlier, I am also a visually-oriented individual, so I felt I could relate to both the benefits and difficulties associated with this characteristic. In this particular case, I believe our shared visual nature contributed to my ability to understand the emotional conflict Diana was describing in terms of her physical appearance. The verbal description she provided about what she saw when she looked at herself in the mirror was so richly detailed that I was able to visualize the image she was presenting. I was fully aware that my visualization was of my own creation and not a fully accurate rendition; however, being able to almost see what she was recalling aided in my understanding of the emotional experiences she was having with her own body. This was further enhanced through her ability to verbally and non-verbally express her state of conflict and confusion. The coming together of these verbal and non-verbal elements provided the opportunity for what I perceived to be a powerful interaction.

The final point of interest is related to my observation of Diana and Steve referring to the concept of "respect" on several occasions throughout the interview. Steve utilized the term more frequently than Diana, but the fact that they made mutual references to it gave me the impression that it was a concept of importance within their relationship and experiences. Although they had provided their own definitions within the content of the particular topics of conversation, upon reviewing the transcript multiple times, I noticed a pattern of usage. The term "respect" was not used to reference general regard or consideration or to verbalize esteem or sense of worth; rather,

it was used within a particular context. Each time the word was used it specifically referred to gaining understanding of the emotional experiences of another person in a particular instance and utilizing this understanding as a means to guide one's behavior. I found this interesting because of the consistency of the word usage. In addition, the couple's behaviors and references to positive change frequently seemed to reflect this concept whether they directly referenced respect or not.

Jessica and Brian

Demographics

Jessica is a 39-year-old breast-cancer survivor who has been married to her 39-year-old husband Brian for 15 years. Together they have one child, a son who is 8 years old (see genogram, Appendix N). Jessica identified her ethnic background as Polish and German while Brian indicated that he is of Italian and German descent. Both individuals completed twelfth grade, and Jessica continued on to complete two years of business administration training at a local community business school. With the exception of a few part-time retail positions several years ago, Jessica has primarily taken on the role of stay-at-home mother. At the time of the interview she was not employed or enrolled in any educational program; however, following the interview she completed a nursing assistant certification and is currently working for a Hospice agency. Brian owns his own business in landscape management. The couple resides in a private rural community. Brian indicated that he was of Catholic faith, but does not attend church. Jessica did not identify with any religious affiliation, but described herself as "spiritual."

Jessica was diagnosed with Stage-I breast cancer at 36 years old. She indicated that, although her tumor size was considered small and the cells were confined to one area, the course of treatment she opted for was bilateral mastectomy surgery instead of a more conservative

approach involving lumpectomy surgery with radiation therapy. This treatment plan was recommended by her physician due to there being a significant history of breast cancer with metastasis within Jessica's family of origin; however, Jessica tested negative for BRCA gene mutation. At 34 years old her mother had been diagnosed with and treated for cancer in her lung. Then at 48 years old she had been diagnosed with breast-cancer which quickly metastasized to her other lung. She passed away within one year of her breast cancer diagnosis due to cancer-related complications. Jessica commented that it was her understanding that the cancer detected in her mother's lung had actually been breast cancer cells, but that she was unable to provide further explanatory details. In addition, Jessica's maternal grandmother had passed away at 54 years old as a result of complications associated with breast cancer which had metastasized to her bones. Jessica indicated that there were additional cases of breast cancer among extended family members on the maternal side of her family, but she did not have specific details related to these individuals. She clarified that, although she felt experienced with breast-cancer-related care-taking needs, she felt limited in her general knowledge about breast cancer itself. Brian remarked that he believed the same about himself. He had assisted Jessica and her family in taking care of her mother, but stated that he was not necessarily educated about other aspects of cancer. He indicated that his experiences with Jessica's mother had been his only direct involvement with cancer. There was no known history of cancer within his family of origin; however, his mother suffered three strokes, and Brian stated that he had been active in helping to care for her before she passed away due to stroke-related complications. Jessica indicated that there was also history of other types of cancer within her family of origin. Her paternal grandmother had been diagnosed and treated for gynecological cancer (specific type unknown), her maternal grandfather had died of prostate-related complications in his 60's, one of her

maternal uncles was diagnosed and treated for skin cancer, another uncle was diagnosed and treated for prostate cancer, and a cousin had died of leukemia in 2011.

Case Study

Jessica began the story about how she came to be diagnosed with breast cancer by stating, “You would think with my family history and all it wouldn’t be much of a surprise. I should have almost expected it, but it was very shocking.” She explained that the reason she was “so shocked” was because she had not felt a lump in her breast or had any indication that there was a problem. Her gynecologist had prescribed a mammogram as a precaution due to Jessica’s family history and because her mother had been diagnosed at a young age. A mammogram had been prescribed for Jessica when she was 27 years old right after her mother had passed away. She had not been instructed to have any further testing performed until this occasion nearly ten years later when she was being told it was “just a precaution” and “nothing to worry about.” Jessica and Brian happened to attend the mammogram appointment together because it was Brian’s day off, and they had made plans to spend the day together after the appointment, not because they anticipated any negative news. Following Jessica’s mammogram she was told by a nurse that she needed to wait to speak to the radiologist. This is the time she began to “sense” there was a problem. “We were sitting there waiting, and everyone else had been seen and was leaving,” she said. “And the way the nurse was looking at us, we just knew.” Upon being told she had cancer, Jessica described a “surreal” feeling that “it just seemed impossible.” She recalled that she had started to cry, but could not identify the specific emotions she was experiencing other than feeling “numb.” Similar to the reports of other interviewees, she shared her viewpoint that she did not believe there was any way a person could truly prepare herself to hear that she has cancer.

Brian shared that his immediate reaction was feeling “scared.” Like several of the other partners interviewed, he did not want Jessica to see the depth of his concern and actively put forth efforts to conceal his worry. He shared, “All I could think about was what happened to Jessica’s mom, and I had these terrible visions of her being in the same situation.” “But he never let on that he felt that way,” Jessica added. The couple shared the perspective that shortly after hearing the diagnosis they experienced an emotional disconnect in their relationship. Although they came together to work cooperatively on the logistical steps they needed to take in order to pursue treatment, they agreed that they were not sharing their emotional experiences with one another or utilizing the strengths of their relationship to cope with the emotional impact. Like the stories of other couples, at the time, the couple believed they were behaving in ways that were in their partner’s best interest, but in hindsight they recognized that a lack of communication prevented them from understanding and fulfilling one another’s emotional needs. Many of the caring acts they engaged in were not interpreted as such, and the good intentions behind these acts often went unrecognized.

Jessica shared her perspective that their emotions “became the elephant in the room.” She was able to identify a series of behaviors that she and Brian engaged in that contributed to the emotional disconnection they both experienced. She began by assuming “responsibility” for part of the cycle by not managing her feelings in ways she viewed as effective. “I’m a very good suppress-and-deny person,” she stated, “I distract myself from what I’m feeling by focusing on everyone else instead.” Brian added, “I think that she tries to deal with stuff by not dealing with it if that makes any sense.” Jessica agreed while also pointing out that she often resorted to using humor as a means of coping with stress. This had been a common occurrence in her family of origin for many years. “My sister understood more about how I handle my emotions. The way

we coped was to make fun of things and be silly and stupid, maybe even a bit crude. But that doesn't work for him," she said. She described that she indirectly tried to provide Brian with the emotional support he needed by reaching out to people he was close to and requesting that they "keep an eye on him" and offer him support as they were able. She commented,

He cried here and there, broke down a little bit, but it was like neither one of us would go there with each other. I didn't think that he would reach out to anybody because he doesn't do that, so I let some people know what was going on with me, so they could be there for him. I knew he wasn't going to open up to me that way. He was more likely to do that with someone else because he thought he had to be strong for me.

Jessica indicated that she recognized that her efforts to distract away from her own feelings limited her ability to respond directly to Brian's. "I guess I couldn't go there with him because I was afraid my own feelings would be in my face, and I wasn't ready to handle that," she stated. She added that Brian's responses to early attempts she made to share her feelings were repeatedly "be positive" or "you can't think that way." She believed this was also a contributing factor to the breakdown of their communication and remarked,

I felt like I couldn't go to him even if I wanted to because I wasn't allowed to have any kind of negative emotions....It's hard to be standing in your kid's bedroom, watching him sleep, thinking he might not have a mom and be told to think positive. So, I just cut it off. I felt like it wasn't okay to say "I'm not okay" or to not be positive.

Brian took the opportunity to share his perspective of the situation. He verbalized agreement that he and Jessica's difficulty coping with their own emotions caused disturbance in their abilities to effectively communicate and support one another. He first responded to Jessica's comments about the impact of his encouragement for her to stay focused on the

positive. He indicated that in retrospect he was able to see how this response contributed to Jessica's perception of him not being open to her emotional expressions but that it was never his intention to cause her to feel as if she should not say anything negative. "I was just thinking that, if we stayed positive, something positive would come of it. I didn't mean for it to come off the way it did. That's all I could think of to say," he shared. He disclosed that he had not faced many emotionally difficult situations in his life; therefore, he "didn't really know any better" and "didn't really have coping skills." He found it extremely difficult to see his wife in pain and not know how to cope with this. In addition, his way of coping with any previous negative experiences was generally to work at seeing the positive attributes of the situation, but he acknowledged that the unfamiliar intensity of this particular situation may have influenced his ability to modulate this coping strategy and remain aware of the impact his responses were having on Jessica.

In response to Jessica's conversation about her efforts to ensure that he had the support he needed, Brian indicated that he had not been aware of the measures she took. At the time he was able to perceive only a sense of disconnection in their relationship. He felt this even more as he witnessed Jessica displaying an increased level of irritability. He remarked, "I think her holding in her feelings made them come out in different ways. She would get upset about silly little things that didn't usually bother her, and it'd turn into an argument." Jessica acknowledged Brian's point and commented that it took her a long time to realize that she was non-verbally expressing her emotions through certain behaviors or projecting them through unrelated issues and verbal conflicts. She admitted that she had not spoken to Brian about her realization because she felt "guilty" about "taking [her] feelings out on him." Brian mirrored this by disclosing his

own sense of personal dissatisfaction over negatively impacting their relationship with his misdirected responding.

Jessica and Brian mutually agreed that physical intimacy aspects of their relationship were also significantly disrupted by the impact of breast cancer. They clarified that this pertained to more than just their sexual activity. Jessica explained that they both perceived this to be the most significant disruption because there were multiple contributing factors, and the disruption spanned the course of their entire experience with breast cancer. She acknowledged that the emotional disconnect that resulted from the couple's communication difficulties interrupted their desire to physically connect in the early weeks following her diagnosis. However, the primary factor was related to the difficulty she experienced adjusting to the changes of her body after mastectomy surgery and throughout the reconstruction process. Much of Jessica's explanation resembled the stories of other interviewees. She experienced a significant amount of discomfort following her surgery which inhibited her tolerance for being touched. The reconstruction process took several months and involved extended periods of physical discomfort and cramping due to the need to insert tissue expanders and go through the process of progressively filling them until an implant was able to be placed. She remarked, "If I had to pinpoint the worst part it was the four months of pain I had getting those expanders filled." Jessica described feeling self-conscious about the presence of scars and the appearance of her breasts during the incomplete phases of the reconstruction. She stated, "Even though we had been together for so long, I was more self-conscious about my body in front of him than I had ever been in my entire life." She resorted to not allowing Brian to see her breasts at all, even while engaging in sexual activity.

Brian contributed to the conversation by expressing the “sadness” he felt over losing this aspect of intimacy. “Sometimes she used to sleep topless and lying next to her like that made me feel close to her. That didn’t happen anymore,” he explained. The couple agreed that the frequency of their sexual engagement did not necessarily change, but they mutually experienced a decreased sense of intimate emotional connection during their exchanges. This continued beyond the time Jessica’s implants were placed, and she reported that it did not improve significantly until other aesthetic aspects of the reconstruction were completed, such as the construction of her nipples and the tattoos that created the illusion of an areola. She indicated that she had needed time to adjust to the ways her breasts both looked and felt. Jessica’s depiction of her experiences with breast implants and reconstruction most resembled Diana’s story in that she had difficulty acclimating to the presence of the implant. She shared,

The implant felt so foreign. It feels like there are these weird objects in my chest, and it is a really strange feeling when they move around. It’s uncomfortable and an unnatural sensation. When I touched them they felt gross to me, so I didn’t want [Brian] to touch them and feel that either....Even after they were all done, it still took me a while to get used to them.... I didn’t understand that myself because I went through the whole process of getting everything done, so I would look as normal as possible, but I didn’t feel normal.

Early in the process Jessica had difficulty accepting Brian’s reassurance that he was comfortable with her breasts and continued to find her physically attractive. Like many of the other female interviewees, Jessica perceived her own dissatisfaction with her body to be Brian’s view as well, and she held onto her assumptions that the “imperfections” negatively influenced Brian’s sexual attraction to her. She experienced further discontent when, during a social gathering, she over-

heard a woman comment to another person that her breasts appeared “fake.” Jessica remarked that this other woman had not been aware of her recent ordeal with cancer, and the episode made her feel as though “everyone who looked at me saw fake breasts, not a survivor.”

With regards to the daily routines and responsibilities, the couple indicated that there was little change with the exception of Brian managing the household tasks immediately following Jessica’s mastectomy surgery. They shared the view that this had both positive and negative implications. Remaining involved in everyday activities was important to Jessica and contributed to her sense of purpose. She stated that she did not want to be “catered” to, but recognized that she was engaging in more physical activity than was in her best interest. She commented,

I wanted to feel normal, so I tried to do as many of my usual chores as I could.

Sometimes I think I gave [Brian] the impression that I was better than I actually was because I never complained or let on that I was having a hard time doing it all....I guess I wanted other people including him to see me as strong, but in a way it back-fired on me....When he didn’t take it upon himself to do things, I felt like this was all just a done deal for him,...but it wasn’t for me, and he didn’t understand the gravity of that part. It’s my own fault because I was giving the mixed message of “see me as strong, but also that I’m not back to normal, yet” and that’s confusing.

Brian agreed that it was a confusing time for him, made more frustrating by the lack of effective communication. From his point of view he had tried to be respectful of Jessica by allowing her to set the parameters of how much responsibility she maintained while still offering his assistance and encouraging her to not push herself beyond what was comfortable. He stated,

I tried to be more helpful at home, especially since I thought she was doing stuff she probably shouldn't do. I would say, "Let me do that for you" or "I don't want you to hurt yourself," but a lot of the time she did it anyway. I thought she was showing that she was okay....It's hard to know when to step in when someone has an injury or medical issue, but isn't completely debilitated....I didn't know she was looking for me to show I cared by just doing things instead of asking or waiting until she was already doing.

Brian stated, "I wonder if it's as confusing for other couples as it was for us. We understand it now that we're through it and can look back and learn, but we stumbled all the way." Jessica laughed and added, "I put him through a lot of crap. I made everything so twisted and confusing because I didn't know what I needed or how to handle all the contradictory feelings I was having."

Despite the couple's shared perspectives that communicating about the emotional toll breast cancer took on their relationship was difficult, they eagerly engaged in discussing the ways they came together as a couple to address the issue of breast cancer with their son. Not only did they view their communication with him as effective, but also perceived that they communicated well with one another about their thoughts and feelings related to supporting him. Jessica explained, "We knew it was important for us to be on the same page, so he was hearing the same things from both of us, especially since he knew my mother died from cancer." Together, Jessica and Brian made determinations about what information they believed was important for them to share in order for him to make sense of what was happening and understand how Jessica's cancer was different from her mother's. "We knew we had to be straightforward with him, but we had to put it in terms he could understand, so it didn't end up scaring him more, so we talked through everything we were going to say," Brian added. This

conversation progressed to Jessica and Brian talking about their son's adjustment as being one of their "signs" that they "did something right in all of this." The couple agreed that their shared views on parenting and their mutual concern for their son's well-being became a catalyst for increased communication and emotional connection. In reference to their son, Jessica remarked, "I think he reminded us that we really do have a strong bond, and we needed to come back together in order to get through this."

Brian described their son as being "very proud of his mom" and "having a sense of pride in his mother's strength." Jessica shared that he was very open with others about his feelings related to breast cancer, and she felt relieved that he appeared comfortable talking about it. She commented, "He even talked to his school buddies about it. When a teacher reprimanded them for talking about breasts, his friend defended him by saying they weren't saying bad words, they were talking about breast cancer." She added that she was "impressed" that young children could behave so compassionately and offer this type of support. Finally, Jessica shared that their son often expressed his pride through his artwork. She gave the example of a teacher sending her home an envelope which contained a picture she found in the child's desk. The drawing included images of pink ribbons and hearts with "Mom" in them and what was meant to say "breast cancer" with a circle and line through it. "He may not have known how to spell it, but he sure got his message across," she stated. "I'm so glad his teacher shared that with me. It felt good to just know that he was okay."

Jessica spoke about the difficulty she initially experienced in being able to view herself as a "strong woman" and a "survivor." "I see myself that way now, but I didn't always," she remarked. "Being able to recognize my own strength and courage is definitely one of the ways I've grown from these experiences," she added. She described the confusion she felt over how to

self-identify in terms of going through these experiences and how to understand her experiences in relation to how she viewed herself to be as an individual. She explained her thoughts as such:

I didn't go through what so many people with cancer go through. I didn't have chemo and have to deal with the hair loss and months of feeling sick. My recovery process was long and uncomfortable, but I didn't feel like what I had to deal with even compared to what other people had to suffer through....Once again, it was a mixed-messages situation. Some people minimized my breast cancer because I didn't have chemo while others told me how strong I was....I started to do a lot of qualifying of what I went through compared to other people, and I always concluded that I had my fair share of pain involved, but it could have been so much worse....With that thinking I started to feel like I didn't earn the title of "breast-cancer survivor," and I shouldn't even fall into that category.

Jessica continued on to discuss how she wanted to be viewed by others as strong, especially by her son, but she had difficulty accepting the praise she received. She began to explore how to make sense of her experiences by involving herself with other survivors and listening to their stories. She did this by starting a breast-cancer support group in her community, to which she welcomed both survivors and their female family members or other significant females in their lives. The motivation to start this group was in response to a realization that she was attempting to understand herself through the impressions of others who had not experienced breast cancer. In addition, she recognized her own need to gain the support of women who could relate to her experiences and with whom she would feel comfortable disclosing to if she so chose to. She stated, "I needed other women to talk to or hear from, so I could figure this out. I thought that I would value the feedback from other women who went through it far more than the opinions of

people who didn't." She continued on to explain, "I also didn't want to lay it on my friends and family all the time. I spent so much time watching people be uncomfortable around my mother and not know what to say to her. I didn't want that."

Together as a couple Jessica and Brian acknowledged that they believed there were significant benefits to their relationship and survival as a result of Jessica's involvement in the support group. Jessica indicated that, although she recognized the need to develop a support network for herself, she was highly motivated to be proactive in establishing the group by focusing on the positive ways it could serve others. She shared, "I knew I needed it, but it was easier to think about how it would help others. I could focus on them instead of myself, but in the end I had no idea how much it was going to help me or help us." Through sharing personal experiences and exchanging helpful ideas, Jessica was able to make sense of her feelings and choose alternate ways of responding to others, including Brian. She learned the importance of interacting with him in ways that would strengthen their connection in order to enable them to cope more effectively as a couple. She stated,

I could still choose not to talk about something if I didn't feel up to it, but I learned that I could do that without shutting people out, especially Brian. Sometimes I just wanted to keep my "happy-go-lucky-fun-Jessica" side around people. I felt good about that because now it was genuine, not forced. It wasn't a struggle to do, and I didn't have to stuff all my feelings in order to put up a front.... I had a place where I could deal with the feelings, and they became less of a burden in my life as a result. Now I could ask [Brian] for comfort when I needed it and tell him I just needed a hug even if I didn't feel like talking about anything. And I could set aside thinking about all the crap going on because I knew I had a time and place to face it.

Jessica discussed several other personal gains she experienced as a result of engaging with other women who had survived breast cancer. She was encouraged to view her experiences with breast cancer as personal and uniquely her own as opposed to in comparison to the experiences of others. By doing so Jessica reported that she was open to seeing her personal strength and courage. When asked whether this influenced her perspective on survivorship, she indicated that not only was she able to view herself as a survivor now, but also she gained understanding about her personal definition of survivorship, based solely on her own ideas and experiences rather than the terms and conditions of others. She shared her definition as follows:

Survivorship is the ability to get stronger and wiser because you've overcome a significant adversity while also becoming more humble. It's about discovering strength within yourself that you never knew was there and embracing it through the rest of your life. Survivorship is not letting the adversity get the best of you and keep you as a victim. It's taking what you learned and using it to your advantage and leaving the rest behind.

Jessica viewed this definition as pertaining to her as an individual as well as to her and Brian's relationship.

Brian agreed that he perceived significant improvement in several areas of their relationship following Jessica's initiation of the support group. He indicated that Jessica demonstrated greater willingness to talk with him about thoughts and feelings related to her body image and the reconstruction of her breasts. This, in turn, created opportunities for the couple to engage in dialogue which fostered understanding of their differing perspectives. Brian commented that Jessica's willingness to be open with him allowed him the chance to offer her verbal reassurance of his sexual attraction to her, satisfaction with her physical appearance, and desire to engage physically with her in both sexual and non-sexual ways. Jessica nodded in

agreement and added that she perceived several positive changes occurring from these new ways of relating to one another. She shared, “After I explained how I was feeling, I noticed that he was gentle and more sympathetic with me. He was reacting very positively, even though I know my feelings didn’t make a lot of sense to him.”

Jessica also credited her involvement in the support group with influencing these changes. Being able to share her thoughts with other survivors and consider a variety of differing perspectives and experiences helped Jessica develop greater appreciation for her body. In addition, she indicated that, more importantly, these women helped her consider the “male perspective” by sharing thoughts expressed to them by their own male spouses. She was able to ask Brian more questions instead of making assumptions about his view and to listen to him share his opinions with greater acceptance. She found more ease in accepting his offerings of reassurance and believed him when he praised her appearance. She understood his perspective and that he fully approved of her breasts and viewed the implants as “enhancing” to her figure. She laughed as she joked about her breasts, “The poor guy was finally able to reap the benefits of all the effort he put into picking them out.” The couple shared that, as they communicated about matters of intimacy with one another in more open and caring ways, they experienced a greater sense of emotional closeness which enhanced their desires to be physically close to one another in both sexual and non-sexual ways.

As a couple, Jessica and Brian confirmed that they did believe that growth was possible as a result of surviving breast cancer together. They also agreed that it took some time and reflection in order for them to recognize the growth that they believed had occurred within their relationship. Brian explained,

You don't always know what you did well right away. At first we were too busy beating ourselves up for our mistakes. Then after that we were just too exhausted to think about anything but getting through it. We needed some time away from it before we could look back on it a little clearer.

Jessica added, "Just the fact that we're still sitting here together after some of the not-so-helpful ways we treated one another and we feel closer than we ever did before is our proof that we've grown." She further discussed that she and Brian shared an increased sense of safety and security because their relationship remained intact, even through these difficult times. Brian commented, "We made each other crazy. We didn't pay enough attention to each other at times. But I can look over and hold her hand and know without a doubt that she loves me and that we can get through anything that happens to us." As a couple, Jessica and Brian perceived themselves as being more prepared to handle future difficult times, but indicated that they had not yet faced a situation which caused them significant stress. Their rationale for this belief was that they have witnessed themselves to be more aware of their emotions and behaviors in the moment and, therefore, better able to express themselves and offer support to one another.

A primary aspect of growth identified by the couple relates to their overall abilities to communicate effectively with one another. According to Jessica, "Going through breast cancer actually gave us the potential to break some of our communication cycles and make better choices versus just doing the same thing over and over again." She acknowledged that being able to view the situation from an alternate perspective and recognize Brian's positive intentions has allowed her to feel more comfortable asking him for what she needs. In addition, Brian self-acknowledged his growth in being able to understand the importance of expressing empathy and caring and balancing this with problem-solving or focusing on the positive. He stated,

I just think we're very devoted to each other and to trying to learn from our mistakes. It bothered both of us when we really saw how we weren't there for each other early on the way we could have. It was eye-opening to realize that the stress of the breast cancer just made our bad habits worse, not better. We don't want to be like that to one another, and we knew we had to build a better foundation so other stressful things don't cause the same issues.

Jessica mirrored Brian's statement and praised him for his dedication to their relationship. "I can go to him with anything and know that he'll really listen now. And he doesn't have to worry that I'll take my emotions out on him the wrong way. It is so much more relaxed and peaceful," she remarked.

Jessica and Brian shared the perspective that they had grown in their abilities to appreciate one another. Each provided accounts of events or behaviors that caused frustration or were misunderstood at the time, but which they were able to view differently in retrospect. In particular, Brian was able to talk about coming to recognize how "protective" Jessica was of him. He remarked, "I've moved to a place where I can appreciate the love and kindness that was behind some of her actions even though at the time I was upset and couldn't see it." This appreciation has translated to Brian developing more ability to stop and examine situations before reacting and to offering his responses with greater sensitivity. Jessica spoke about her appreciation of the ways Brian tried to be helpful to her as well. She stated, "He was doing what he thought would be helpful. I didn't know what he was thinking, and I just thought he wasn't responding to me." For her, this appreciation served as motivation to approach situations differently also. "I've come to realize just how differently we can see things, so now I don't assume to know what he's thinking or why he's doing something, I ask. Better late than never!"

she said. Both agreed that they have experienced great satisfaction in recognizing the new, positive ways they interact with one another. In addition, they “enjoy” the feeling of being appreciated by the other for their contributions to the relationship.

The positive changes that Jessica and Brian experienced together have contributed to an overall sense of increased relational closeness. Brian began this dialogue by expressing emotionally, “I think that feeling of love was...” He paused briefly before continuing on, “After this happened...maybe made me love her even more because I just couldn’t envision life if we weren’t together. I just feel more love.” Accompanying this was Brian’s greater awareness of Jessica’s presence in his life. She mirrored his sentiment stating, “How can you not love somebody more than you ever thought you could who goes through that with you and for you?” Brian responded to this by indicating that, for him, Jessica’s verbal expressions of love for him were the most significant positive changes that came about. “Jessica wasn’t usually one to say ‘I love you’ very much,” he explained. “I think I was a little starved for that, but now she says it more often. Not just as a greeting or something, but really looking at me and saying it with genuineness,” he said. Both he and Jessica perceived their increased verbal expressions of love and affection as deepening the bonds they felt with one another.

In terms of the couple’s philosophy on life, Jessica and Brian shared the viewpoint that it remains important to be actively involved in “making a good life” for themselves. Jessica offered what she termed as their new mantra for living which is, “live proactively.” Brian added that they also felt drawn to the expression “create a life worth living.” Jessica remarked that these sentiments reflected their shared philosophy that “If you’re in a situation and you don’t like it, change it or make the best of it. Just realize that you woke up that day and it will be what you make it, so make the best of it.” Both clarified that their attitudes were not meant to minimize

the efforts needed to change a situation or to suggest in any way that this was an easy task, but rather, to remind them that they are not helpless and to motivate them into action. Jessica commented that as a couple they understand the difficulty of trying to learn new ways of coping when the previous ways no longer work. The struggles and learnings she and Brian shared, and the appreciation they felt for the support they were provided, served as motivating factors for them to seek ways they could be of assistance to others facing breast cancer. One example of this is that they became involved in a mentor-type program recently started at the hospital where Jessica received her treatment.

Due to the success of Jessica's support group and the positive feedback conveyed by group attendants to various staff at the hospital's breast-center, Jessica was contacted by a hospital advocate about her willingness to participate in the mentoring program. Through this program the couple has been able to share their personal experiences and offer support to both individuals and couples dealing with the impact of breast cancer. In addition, the hospital includes the support group among the community-resource referrals they provide to patients. Brian remarked,

We could not have made the changes that we did without the help of the people who supported us.... [Jessica] may have coordinated the group, but these women helped to motivate and guide us. Sometimes you just need someone to help you find the way, the right path, then you can take off running. I think it saved our relationship from a lot worse damage, and we hope to be able to help others the way we were helped and to maybe support some growth in them too.

Brian verbalized his satisfaction with being able to be involved even in small ways with supporting others because he did not feel that there were adequate support resources available for

the men or couples in his community. In reference to the community and hospital support resources he commented, “It was kind of one-sided, which I get, but it would have been nice if they told me there was somebody available to talk to me. Maybe I could have done things differently if I had that option.” He continued on to explain that he felt it would have been helpful if there were somebody to offer him guidance or help him be prepared for what was to be expected.

Following the dialogue about appreciating the support they were given, Jessica and Brian indicated that their senses of gratitude had grown markedly. Jessica disclosed that she was the recipient of a healthcare grant provided by a breast-cancer-related organization. At the time she was diagnosed she did not have health insurance. This grant covered all of the medical expenses associated with her treatment. She stated, “I don’t know what would have happened to me without that grant. There is no way we could have afforded the treatment. There are no words to express how grateful we feel for that gift.” The couple agreed that this particular charitable gesture significantly contributed to the growth they experienced in their abilities to feel and express gratitude, and it served as a motivating factor to become personally involved in breast-cancer-related charitable efforts. However, both noted that this increased sense of gratitude and appreciation has “spilled into all areas of our life” as Brian stated. He added, “It’s hard to have something so huge done for you and not realize how lucky you are. It’s like this one thing opened our eyes to all the ways we are fortunate every day.”

Jessica and Brian reportedly perceived a shift in their priorities as well. “Being more grateful for your life has helped us not lose sight of what really is important,” Jessica stated. Like other couples interviewed, Jessica and Brian identified increased efforts to attend to their physical health through exercise and better nutrition, nurture positive relationships with family

and friends, and limit negative interactions with others, including among themselves. They set aside time to engage in mutually enjoyable activities as a couple. For Brian, connecting with his spirituality also became a priority. He shared, “I know it’s typical when something is wrong people pray. I did that too, but I haven’t stopped since then. I ask for strength to be a good man and I thank God for all I have.” His definition of being a good man included being a positive role model for his son on ways to be caring towards others and how to be a loving partner and father. “We’ve watched [our son] grow to become a very compassionate child. Our kids are always the best mirror for our strengths,” Brian said. For Jessica, finding “purpose” in her life had become a priority. She found “meaning” in being able to use her talents for taking care of others to continue to develop breast-cancer support networks within her community. During follow-up contact after the initial interview, Jessica indicated that she had continued to pursue finding meaningful use of her care-taking strengths by branching out beyond the scope of breast cancer. She enrolled in a nursing-assistant certification program and had obtained employment with a hospice agency. She reported that she found this to be very rewarding work, and she experienced a sense of personal satisfaction with the direction she had taken her life.

When asked about any last thoughts or feelings they would like to share, Brian offered up his advice to other couples:

If I could tell couples one thing it would be to be there for each....No matter how they choose to do that or if they do things differently than we did, just listen and talk with each other so you can figure out how to be there for one another. We were there for each other, and that’s what helped us survive. Two are stronger than one.

Researcher’s Experience

I experienced the climate of Jessica and Brian's interview to greatly mirror what appeared to be two separate and distinct components of their story. Jessica and Brian seemed to relate to their experiences through the lens of "positive" or "negative." Throughout the initial conversations they were highly focused on the personal behaviors and attributes which they considered to be "negative." They primarily spoke about the ways in which they viewed themselves as ineffective and characterized their attempts to cope as "mistakes" and other negative descriptives. Their dialogue reflected a person-focused viewpoint as opposed to a cancer-focused viewpoint. By this I mean that I noticed that the couple spoke in less specific terms about breast cancer and the direct impact it had on them than they did about the impact of certain qualities within themselves. This in turn gave me a different perspective on responsibility than I had experienced within the other interviews. Jessica and Brian seemed to take more personal responsibility for the disruptions in their lives. Their references to various aspects of breast cancer seemed to indicate the context within which the disruption occurred, but not as significantly stated as the cause of the disruption as noted in the interviews of other couples. My personal perception of Jessica and Brian's story is that it conveyed less of a balanced perspective on the influences of self along with the influences of cancer. I had not been aware of how other couples seemed more able to distinguish disruptions attributed to personal factors and those attributed to the specific impact of cancer until I took note of the highly personal-attribute focus of Jessica and Brian's perspective. In response to this way of perceiving, it did not surprise me to notice that both Jessica and Brian's body language and non-verbal expressions reflected the negative qualities they spoke of and seemed to reflect the personalization of the causes for the disruptions.

Similarly, the couple's demeanor changed drastically as they transitioned the conversation to the ways they perceived themselves to have changed and grown in positive ways as a result of their experiences. They maintained their person-focused perspective, which seemed to also allow them to assume more personal responsibility for the positive outcomes they perceived. Unlike some of the other couples who attributed their growth primarily to experiencing specific aspects of breast cancer, Jessica and Brian attributed their growth more to themselves and the personal efforts they put forth. Just as their body language and non-verbal expressions mirrored their negative self-statements, their self-satisfaction was reflected in movements toward upright posture, improved eye-contact, caringly touching one another, and brighter affect. Likewise, the couple's language included more self-affirming statements and positive descriptive of one another and their relationship.

Upon reviewing notes from pre-interview phone contact and Jessica and Brian's transcripts, I made an observation about the timing of Jessica's disclosure about being the recipient of a grant to cover her medical expenses. During the initial phone contact, Jessica had spoke briefly about her involvement in breast-cancer-related fundraising and awareness events as well as about the support group which she started, which was how she came to learn of the study. A significant portion of the interview was focused on the positive impact that the couple had experienced as a result of the support provided to them by others, followed by conversation about making it a priority to support others just as they had been supported. Given the extent of dialogue dedicated to the topic of support, I found it interesting that the disclosure of a grant given by a major charitable organization came about almost at the end of the interview. It was not mentioned at any time prior to this or during previous discussions of support received or connection to breast-cancer support organizations.

In an effort to avoid inadvertently making assumptions about this observation, I spent some time exploring my own thoughts. I explored several reasons why Jessica may have chosen to disclose at the time she did in order to open my mind to the vast number of possibilities and to challenge myself not to accept my impressions as truth. I also wanted to actively think about this in order to bring any pre-conceived ideas I may have had to my own awareness. By doing so I became more aware of the duality of the situation. Instead of just considering why she had not disclosed during certain conversations, such as those related to support resources, I was also able to consider the disclosure within the context of the conversation within which it was brought forth. For example, I considered the possibility that sharing about inability to manage the financial responsibility may be uncomfortable for the couple. Perhaps Jessica and Brian were concerned about judgments being made about their employment choices, reasons for the lack of health insurance, money management, or use of charity. I also considered the possibility that the couple greatly valued personal and engaging types of support, therefore, chose to focus their attention on the meaning they found in these interactions. I realized the importance of not assuming what value the grant should hold and instead paid more attention to what Jessica and Brian had said about the meaning of the grant. They spoke about this charitable endowment within the context of gratitude and shifting priorities which is where Jessica and Brian felt most personally connected to its significance. During this exploration I made an observation about my own thought patterns. No matter what way I was considering the information, I remained focused on the personal rather than logistical aspects, which mirrored the personal-focused climate of the interview. Through this exercise I was able to maintain a neutral stance and exert greater attention towards my efforts to understand Jessica and Brian's unique perspectives and experiences.

Delia and Hugh

Demographics

Delia is a 52-year-old Caucasian female who was diagnosed with Stage-I breast cancer when she was 41 years old. She has been married to her husband, Hugh, a 53-year-old Caucasian male, for 28 years. Together they have two children, a 26-year-old daughter and a 23-year-old son (see genogram, Appendix O). Both Delia and Hugh are of mixed European descent. Delia identified her ethnic background as English and Irish; Hugh identified his as Italian, German, and English. They indicated that they are of the Catholic faith and practice their religion actively. Delia and Hugh both completed some college credits in business and went on to pursue self-employment. Delia currently works as a private fitness instructor and has a studio in her home; however, at the time of her diagnosis and treatment she was a stay-at-home mother. Hugh is the owner of a small company and had several employees whom he was able to rely on to assist with the business in order for him to be available to attend medical appointments with Delia as needed. The couple described the rural community within which they live as “caring” and “close” in general, but “exceptionally supportive” during Delia’s treatment for breast cancer.

Delia’s breast-cancer treatment included surgery, chemotherapy, and radiation. She shared that she initially underwent lumpectomy surgery and that two procedures were needed because residual cancer cells were detected in the breast tissue surrounding the tumor after the first procedure was completed. Within a few months of completing all of her treatment, Delia opted to have prophylactic bi-lateral mastectomy surgery with reconstruction. She made this decision after testing positive for BRCA 2 gene mutation. An additional influencing factor was related to the type of breast cancer Delia was diagnosed with, which is generally termed triple-negative or hormone-negative breast cancer. This means that the three most common types of

hormone receptors associated with breast cancer cells were not present in the cancer tumor. Delia reported that her oncologist informed her that this type of breast cancer was often BRCA 2 related and was considered to be an “aggressive” cancer yielding higher relapse risk in the first three to five years. Hormone therapy and a hysterectomy were both recommended by her oncologist as precautionary measures; however, after researching these options and consulting her doctor on the potential risks and benefits, Delia decided against both of these. She indicated that this decision was made based on the fact that hormone therapy is ineffective with triple-negative cancer, and, therefore, she was not willing to risk the possible health complications associated with this treatment when she did not see a high potential for her to develop another type of breast cancer. She declined the hysterectomy for similar reasons and believed it would be best to allow her body to go through a natural menopause.

Prior to Delia’s diagnosis, both she and Hugh reportedly had very little experience with breast cancer. Delia denied any knowledge of breast cancer history within her family of origin and did not have any close friends who had already gone through it. She did share that a friend was diagnosed approximately six months after her, and they went through some of their treatment together and were able to offer one another emotional support. Hugh indicated that his maternal grandmother had been diagnosed with breast cancer when she was in her 70’s. She underwent mastectomy surgery only and lived until she was 96 years old with no further complications. Hugh stated that his grandmother’s breast cancer impacted his family very little. Due to Delia’s breast-cancer history and testing positive for BRCA 2 gene mutation, her oncologist recommended that her siblings also be tested. Her sister tested negative for any mutation while her brother tested positive for BRCA 2 mutation. Delia commented that she

would like her children to be tested, especially her daughter, but that her daughter has declined so far because she is “not ready” to deal with it.

Case Study

Delia and Hugh were referred through word-of-mouth recruiting and were the last couple to be interviewed for the study. Delia began by describing a multi-step process that occurred in order for her breast cancer to be accurately diagnosed. She had made an appointment to see her general practitioner after sustaining an injury to her upper ribs and surrounding area. During the evaluation her physician detected a lump in the tissue of her breast and had referred her for mammography testing. The physician assisted with arranging for her to be tested that same day at a local hospital. Delia’s mother-in-law, who had accompanied her to the appointment with the general practitioner, offered to accompany Delia to the hospital as well. After being told that her mammogram results looked “suspicious,” Delia underwent ultrasound testing. These results ruled out the possibility that the lump was a cyst; therefore, it was recommended that she stay and consent to having a needle biopsy performed. At this point she called her husband at work to inform him of what was transpiring. He insisted on joining her at the hospital, but arrived after the biopsy had been done. They were then told that there were not enough cells collected to test, so a second needle biopsy was performed. Delia and Hugh were told that no abnormalities were found. Delia shared, “We were very relieved at that point, hugging and kissing. All we could say was ‘Oh my God, thank God it was nothing.’”

During a follow-up visit Delia’s general practitioner recommended that she have the lump removed. According to Delia, he told her, “You have to have that out. You can’t just go by that needle biopsy because that needle can miss.” She was agreeable to having a lumpectomy and scheduled to have it done two weeks later. In the meantime, Delia went for a second

opinion. This was at the recommendation of a friend whose partner is a pathologist at another nearby hospital. During this consultation, per Delia, the pathologist gave his opinion that the biopsy was “inconclusive” because there were not enough cells to determine whether the mass was malignant or not and that she should proceed with the lumpectomy as planned. “I was fine with that. I wanted it removed because I didn’t like the thought of it being there anyway. He told me there was about an 80% chance it was going to be benign, so I wasn’t worried,” she stated. Shortly thereafter, accompanied by her sister, Delia had lumpectomy surgery. She recalled, “I told Hugh there was no need to take off work. It was a busy time for the business, and we really weren’t expecting anything bad to happen.” Prior to being discharged from the hospital the removed tissue was tested, and Delia was informed by the surgeon that she had breast cancer.

Delia described feeling “shocked” upon hearing the doctor tell her she had breast cancer. “I just couldn’t believe it,” she stated. “I was like ‘How can that be? I’m in perfect health, I eat right, never smoke,...all the things the doctors always tell you to do.’” she added. Delia recalled that she looked at her sister and was unable to speak to her. She explained:

My sister was always terrified that we were going to get breast cancer, and I always said to her, “We are not. We’re never going to get that. Our family doesn’t have breast cancer.” I was just shocked. I didn’t know what to say to her. I never knew where her fear came from. I didn’t know that such a small percentage is familial, and the rest is environmental, so I just thought she had this fear out of nowhere....It’s weird that she was the one terrified of getting it, but turned out to be the only one of us three siblings who was BRCA negative.

She continued on to talk about how having to call her husband and tell him was one of the most difficult experiences she has ever had. She shared that Hugh had plans to go to a sporting event after work, but she knew he would be “upset” and feel “awful for going to the game” if she waited until he arrived home late that night to tell him. “It was so bad. I felt trapped. I felt cruel telling him over the phone, but I couldn’t just tell him to come home, and I would tell him when he got here. Leaving him hanging would have been worse,” she stated. Hugh joined the conversation by confirming that he would not have handled “being left hanging” well and remarked that he would likely have become “mad” or “panicked” over not being provided with information when it was evident that something was wrong. He spoke about what it was like to hear Delia’s diagnosis. “I instantly felt afraid when she told me. I really couldn’t believe it. I was feeling the fear, but I couldn’t even think. I guess it couldn’t sink in at that moment, so it was pure emotion.”

Similar to other couples who were interviewed, Delia and Hugh identified feeling very stressed while they waited for additional information. Unlike some couples who had to wait to hear whether breast cancer was present or not, they received the information immediately, but were not provided with any further information about the specific characteristics of the cancer or the treatment measures that would ensue. Instead, they needed to wait until additional tissue testing and a sentinel node biopsy were completed before they would be given specific information and recommendations on how to proceed with treatment. Delia commented,

The waiting, it was awful! The whole week was awful, just awful. The whole time I was just worrying that they didn’t get it all. I guess after thinking I was fine then being hit with “You have cancer,” I was just expecting to hear the next bad news. It sort of felt like when you get tricked, how you don’t trust the next move. I didn’t trust anyone’s

speculations. I needed to know for sure, and, until I knew, all I could think about was “What’s it going to be, and what stage am I? What am I going to face?” It was really, really scary to not know.

Following the week of waiting, Delia was informed that the tissue surrounding the tumor still showed evidence of cancer cells, and she would need to undergo a second surgery in order to remove additional tissue. “That meant more waiting,” Delia stated, “And it was unbearable for me.” She described what she experienced during that week:

I can vividly remember the fear, total abject fear. I remember being up in my bedroom, staring out the window all day, and not being able to eat the whole week. I lost weight and was eating frozen juice bars because that was all I could get down. I tried to eat a piece of chicken, and I choked on it. Just like that...like fear. I’m 41. I had younger kids, and all I could think about was not being here to see them grow up. It was terrible....After they didn’t get it all, I couldn’t help but think the worst because the worst seemed to keep becoming my reality.

Delia remarked that she did her best to “put on a good face” and maintain the children’s routines as much as possible, but felt as though she were simply “going through the motions in daze.”

Hugh shared his experiences during this period of time as well. He indicated that his thoughts and reactions were somewhat different from Delia’s, but that he was also trying to “keep a strong profile.” He shared that one of the most difficult aspects for him was to see Delia in such emotional distress. “I couldn’t believe the condition that she was in and that this was happening to her. It killed me to see her so distraught. Whenever I wasn’t with her, she was all I could think about,” he said. Despite the discomfort he felt with the situation, Hugh reported that he would not allow himself to consider the thought that Delia was not going to survive. He

shared, “I just focused on the thought that everything was going to be all right. It’s bad, but we’re going to take care of it, and we’re going to go on with life. I knew she was a strong person and could beat it.” He disclosed that, although thoughts of mortality did not arise for him, he experienced a great deal of fear and worry about what Delia was going to have to go through. He did not verbalize his emotions and explained his reasoning as such:

I think, if I freaked out, it would have made a hard time even worse....I tried to keep everything as calm as I could. I tried to keep everything settled down. At that point little things would happen, and [Delia] would freak out. I felt it was best to step back and not react, so I could keep things settled down. It would have been a nightmare if the kids saw both of us freaking out.

Hugh termed his approach to coping with the emotional impact of breast cancer as “do what you’re best at.” He explained that, for him, this meant to help his family remain as emotionally stable as was possible and to keep the household functioning the best that he could. He shared that he continued to go to work during that time, though had considered taking time off to stay home and sit with Delia. “I knew that she wouldn’t want me to do that. She would say, “Try to keep your routine; stay with what you’ve been doing”. But at any point that she needed, I would have been there,” he remarked.

Hugh encouraged Delia to look to her strengths for coping as well. For her, this began with embracing her spirituality. On the day of her second lumpectomy surgery and sentinel node biopsy her doctor began speaking to her about chemotherapy and how they would devise an appropriate plan once the biopsy was completed. Delia reported that she became very emotional, stating, “All I could say was ‘Chemo? You’re kidding me. Why?’” She added, “I couldn’t believe I was hearing the word chemo. That totally blew me away. I don’t know why it hadn’t

dawned on me before then that I would probably have to do chemo.” Hugh added that Delia’s emotional level had escalated to the point where he had to leave the room in order to calm himself and not allow her to see him “fall apart.” It was at this point that Delia indicated that she began to pray. She explained:

I’m very faithful. It was all I could think to do at that moment,....do what I know how to do. When I was finally going in for the biopsy, even though [Hugh] had left the room, I just really felt peaceful. I felt like God was with me, and everything was going to be okay. Then I came out, and they told me they got the rest of the cancer, and I had no lymph node involvement. I felt like I was finally starting to move forward.

Hugh reported that this particular day was among the most overwhelming times he had encountered throughout his dealings with breast cancer. He explained that he had begun to feel “closed in” and felt that he might pass out, which he believed would have upset Delia further and made the situation even more difficult. He stated, “I didn’t want to make things worse, so I had to take myself out of that situation for a little bit.” Delia had assured him that she was fine and he could step out of the room, but he had not been aware that she would be going to the operating room shortly thereafter. When he came back to find her gone, he became very upset. Delia stated, “He just lost it. He called my sister and was sobbing, saying that he couldn’t believe that he left me. In the meantime, I was fine.” Hugh commented that the most difficult part for him was that he “wasn’t strong enough to be there for her.” From his perspective he had “let her down” by leaving her. Delia turned to Hugh as she stated, “But I told you to go and that I was okay. I knew you needed a break.” Then she added, “To this day he still feels guilty about that no matter how I try to reassure him.”

Unlike many of the other couples interviewed, chemotherapy did not cause significant physical disruption to Delia's daily life or to her and Hugh's relationship. Delia reported that she felt minimally impacted by the chemotherapy and experienced very mild side effects, though she remarked that she was fearful at the start. She spoke about a conversation she had with her doctor that she found particularly helpful in preparing herself to begin treatment:

When I went to see my doctor, there was a woman there who was in treatment, and she had a kerchief on her head. Oh my God, she looked so pale and frail, like the look of death, and I said to him, "Is that what I'm going to look like?" He said "No, why would you think that?" I said, "Because she's in treatment, and I'm going into treatment." He said, "You would never allow yourself to look like that. You're going to put your make-up on, and you're going to dress nice. You'll probably decide to get a wig for yourself. You're not going to look like that because that's not who you are." He was right. From that moment on I decided that I wasn't going to stop doing what I was doing because I was in chemo....I wasn't going to stop being who I was because I was in chemo. I told myself, "I'm not going to skip make-up today because I'm in chemo. I'm going to put more on today because I'm in chemo." But it was weird....I couldn't get my mind off that woman the whole time I was in treatment.

Delia added that she had made a conscious decision to live life as "normally" as her symptoms would allow her. "I don't remember that the routine changed much when I was in chemo. I felt good, so I was making dinner, cleaning the house, and doing my usual stuff," she recalled. Hugh voiced his agreement, stating, "She's right. I don't think we missed a beat as far as what was happening in our household. We both stayed strong, and our kids seemed to be doing well with it all."

Delia and Hugh both agreed that their ways of staying strong and coping with the emotional impact of breast cancer did not involve communicating with one another about their emotions or reaching out to one another for emotional support. Delia commented that, even though she had experienced minimal physical disruption, she found it more difficult to cope with the emotional impact she was experiencing. She verbalized her perspective that she had to find ways to deal with her emotions on her own and that, due to Hugh's involvement in running his company and his propensity towards keeping his emotions to himself, she could not expect him to provide the support she was in need of. She recalled an occasion when it became clear to her that she needed to find alternate resources for support. They had gone out to dinner with friends, and Hugh had become annoyed when Delia began talking about details of her treatment and other cancer-related topics. She described the interaction:

I was talking about different things that had happened, and he was just like, "Can we just not talk about it tonight? Like for one night, can we just not have to hear about it?" He didn't understand that, when you're the patient, it consumes you. All I wanted was to talk about it with my best friend. I needed someone to talk to and process with, but he wanted a night out without dealing with it. He said, "Let's talk about something fun. Let's enjoy ourselves." I didn't realize that by me constantly talking about it with everyone that it was bothering other people around me, like it was impacting them negatively.

Delia recognized that, because she was home much of the time, she had limited opportunities to obtain the support she needed; therefore, when social engagements occurred, she took advantage of the chance to seek support. She made it clear that her intent was not to criticize Hugh, but to

illustrate the effect that not talking was having on her. He shook his head in agreement and acknowledged that he found it difficult to verbally respond to Delia, adding,

She's right. I wasn't very helpful in that way. To me, it's like how much can you talk?

What could I possibly say about it that I hadn't already said? It's a long process, but how many ways can you say, "It's going to be fine" or "We're going to deal with it and get through it?" It's not like they took it out, and now she was done, but there were only so many ways I could say it. I didn't know what else to say.

After this occasion Delia recognized the need to expand her support network beyond her sister, mother-in-law, and a few close friends in order to not put emotional strain on these relationships. She continued to receive support from these individuals; however, she also began talk therapy with a psychologist, so that she could have opportunities to process her experiences, receive guidance on ways to cope with her emotions, and allow her social engagements to be more leisure-focused. Delia reported that she continued therapy for several months through her treatment and found it helpful. She verbalized satisfaction with being able to learn ways to cope effectively without relying on anti-depressant or anti-anxiety medication.

At the mention of their children, Delia disclosed that one of the hardest parts of dealing with breast cancer was to observe her daughter's response to her during her treatment. She noted her impression that her daughter appeared relatively unaffected by what was happening and remained "self-involved" through the entire process. She took into consideration that her daughter was a teenager and active in a variety of extra-curricular activities which kept her busy, but she still felt that her daughter "didn't feel much about it at all." Delia remarked, "When we told her, she was like, 'Oh Mom, that's terrible.' Then she was just like, 'Well, I've got to go here, and I have to do this,' and that was the end of it." As a couple, she and Hugh considered

the possibility that their daughter was distracting away from having to face a difficult situation. However, they mutually agreed that they did not observe any noticeable changes or increases in their daughter's activity level. From their perspectives, their daughter's life seemed to go on exactly as it had before Delia was diagnosed. Despite her willingness to consider that her daughter's behavior may be "normal teenage behavior," Delia stated that she could not help feeling "very sad" that her daughter was not able to respond in more empathic ways. She provided an example to illustrate her experience:

When I had my reconstruction, I was in the hospital for five days. I wasn't going to do the laundry, so I left instructions and asked her to do it. She didn't do one single load, and I was so upset about that. I think more than losing my breasts. I remember crying, like really crying real tears over that....I was like, "What the hell? Oh, my God, this kid is so self-involved that she couldn't even help me in this time of need, when I just had my breasts removed, and she's a woman.".... I didn't know how she could not understand outside of herself what was happening in this family, in this household, and with me as a woman. She was 17 years old then, not a young child anymore.

Delia and Hugh both remarked that their son demonstrated a far greater ability to show empathy and caring towards both of them, evidenced in his offers to assist with various chores, inquiring as to whether they needed any assistance from him, and offering words of encouragement. They acknowledged that their children have very different personalities, personal strengths, and ways of responding to emotional situations, and that they did not expect their daughter to be like their son, but that they continued to feel "disappointed" by what they perceived to be their daughter's self-centered attitude during a difficult time in their family-life. Before moving on to another topic Delia concluded, "We don't really have any explanation for that. She's a great kid in so

many ways. Maybe we have made our whole lives revolve around our kids that she grew to believe her needs were most important.”

As a couple, Delia and Hugh believed that there were ways their relationship was positively impacted by the experiences with breast cancer they shared. Delia began by stating, “I think it made it stronger in a lot of ways because we realize that we just have each other. Your kids are your kids, and they’re great, but you really only have each other at the end of the day.” She clarified that, to her, becoming stronger as a couple meant experiencing more appreciation for the presence of her partner in her life. She provided an example about how she used to look forward to Hugh going away on trips because she could have time to herself; however, after being faced with the reality of mortality, she has greater awareness that “one day one of us is going to lose the other,” and she values the time they spend together and misses him when he is absent. It was important for her to clarify that she did not believe that they developed a dependency as a result of going through breast cancer; rather that they experienced a change in their perspectives about the importance of spending time together. “We’re more selective about the time we spend away from the family at night. We have this little pocket of time, and we don’t easily give it up,” she explained. Hugh mirrored Delia’s sentiment and agreed that they have made it a priority to spend more quality time with each other engaging in mutual hobbies and enjoying one another’s company. He smiled as he stated, “Just having her with me is a blessing.”

The couple shared the perspective that they had changed in the ways they interact with one another. Hugh confided that, in the past, both he and Delia had a tendency to argue over minor issues. However, since going through the trials of dealing with breast cancer, they both perceive themselves and one another to be more patient with minor inconveniences, selective

about what they argue about, and aware of the language they use to voice their concerns. Hugh remarked that on occasions when he has become upset and responded in “inconsiderate” ways, he has been able to quickly recognize and acknowledge this in order to redirect the conversation towards more “helpful” dialogue. Delia agreed and added that she viewed them as more tolerant of each other’s habits and less motivated to try to change those that are different between them.

When asked whether they believed there were any benefits to facing difficult situations such as breast cancer, Delia responded,

We can think of positive aspects. It really made us grateful for life, for our friends and family, and for normal everyday experiences. I pray in bed every morning, “Thank you for today, thank you for my house, thank you for my kids, and thank you for our health.” ...I can admit that, before I had cancer, I took these simple things for granted, and I was more focused on material gains....Now it’s like I don’t need to chase the next thing because I see all the amazing things in my life right in front of me, and I feel content like I never had before.

Delia took Hugh’s hand in hers and looked at him. He smiled at her as he commented, “I think we have a really strong marriage now. Someone referred to Delia’s breast cancer as ‘a bump in the road,’ but it was much more than that. It was life changing.” He explained that the term “life changing” held significance because it has been eleven years since Delia was diagnosed, and they have continued to grow in positive ways as a couple and have maintained their perceived progress.

From Hugh’s perspective, a significant benefit of getting through challenging times was that he and Delia became “less selfish” individuals. “I don’t think we really realized how selfish we could be,” he said. “Now it’s about how much can I do for her, and she feels the same way

about me.” “Right,” Delia added, “We always put the other person first. It’s not all about me. I always think about how something is going to impact him or what he’s going to think. When we do that, it makes us feel closer.” The couple concurred that, although they do not always verbalize their feelings, they mutually perceived increased closeness, both physically and emotionally. They reported that they demonstrate their senses of emotional closeness through demonstrations of physical affection and everyday “acts of kindness” and “sweet gestures.”

One aspect of their lives that Delia and Hugh perceived that they had grown in together was in their spiritual devotion, though both identified feeling challenged at times to remain faithful. Hugh shared,

This is hard for me to admit, but at first I was upset. I was like “How could [God] do this to me?” Even then I was so selfish about it. I think [Delia’s] faith brought me strength. Getting through this has taught me that I need to count my blessings every day, not just because things turned out good, but because there were so many good things and good people along the way. I have become more faithful than I ever had been in my life.

Delia responded by saying that maintaining her faith had be a struggle for her at times. She spoke about her friend who had been diagnosed with breast cancer six months after she had been diagnosed and who had passed away due to cancer-related-complications. She described her friend as “the most faithful person in the world,” and she found it difficult to cope with her friend’s death while she was facing the same illness herself. In her words,

The hardest part of staying faithful was accepting that things don’t always turn out your way and accepting that God has a plan for you whether it’s the plan you want or not. [My friend] reminded me of that, and it helped me to work my faith in a good way for me. I was faithful before, but I think that faith is a journey and cancer made me really

work on it. Cancer definitely increased my faith. It deepened my spirituality a hundredfold.

Surviving the challenges of breast cancer and experiencing a deeper connection to faith influenced Delia and Hugh's perspectives on mortality. Both indicated that they feel at peace with death because they have a greater acceptance of it as "part of the human experience." Delia remarked that it wasn't always easy for her to talk about death, especially when facing her own mortality and the possibility of recurrence. "It's been eleven years now that I've had to face that possibility," she said, "But it's also given me time to think about mortality in a different way. The more I began to truly live and enjoy life, the less I feared death." Although she stated that she no longer feared death, Delia pointed out that her experiences with breast cancer have increased her awareness of mortality in general. Hugh verbalized his agreement that "she's right; awareness doesn't equate to fear." He continued on, "We have a bucket list. We probably would have had one anyway, but we're aware of how we spend our time and decided not to put things off until we're older."

With regards specifically to coping with the possibility of recurrence, Delia and Hugh had employed several tactics together. They initially began by approaching their concerns from a logical perspective, researching medical information and statistics that would ease their minds. "We tried approaching it rationally instead of emotionally, but that didn't work," Delia explained. She described what these conversations generally entailed:

We would bounce back and forth between details and never really get anywhere. We'd identify something positive that decreased the risk, like that I didn't have lymph node involvement or it wasn't advanced-stage, but there was always another negative. We'd go back to the information from the doctor that there's a high recurrence rate in the first

five years with triple negative cancer. Then it was that there were lower-than-average recurrence statistics beyond that and into the long term...One oncologist said to us “Well, some people in your position do well, but you know, some don’t.”...I always ended up landing on the fact that my friend had similar circumstances and was gone two years later, and that was so scary. We were trying to educate ourselves, but it seemed like we were just playing mind games instead. We couldn’t make sense of it or figure out how to cope like that.

Delia paused before stating, “It was so chaotic at first. We literally felt like a couple of ping pong balls, back and forth, back and forth.” Hugh interjected, “We finally decided that we had to stop that cycle because we couldn’t live like that.” The couple decided that they were no longer going to immerse themselves in thinking about cancer. Motivated by anxiety, Delia had been seeing her oncologist three to four times per year, even though he had told her it was not necessary. She made the step to decrease her appointments to twice a year, then to once a year as recommended by her doctor. She recognized that the frequent appointments were keeping her focused on her worry about recurrence. She utilized her therapist for assistance with managing her anxiety and redirecting her thoughts. Both she and Hugh engaged in prayer, seeking comfort in faith. Hugh added that he practiced reminding himself to stay in the present. He stated, “I would think to myself, ‘She’s with me now. There’s nothing wrong, so don’t make something wrong.’” Over time and with practicing these coping strategies, the couple reported that their concerns decreased. Their increased connection to spirituality assisted them in accepting that “If we had a recurrence, it was God’s will,” and they would deal with it as they had before. Delia concluded, “I had this realization that anything could happen in life, not just recurrence. There

are risks involved with being alive, but you can either live life or miss out while you're waiting for something to happen.”

Another way in which Delia and Hugh perceived themselves as growing was in their sense of security in their relationship. Delia remarked that, for her, this was primarily influenced by Hugh's response to the physical changes her body underwent. She stated that, prior to her mastectomy surgery, she had experienced concerns about whether Hugh would continue to find her physically attractive and want to engage sexually with her or not. She described him as “very sexual” and was unsure of how he would respond to the feel of her implants, the presence of scars, or disruptions in the frequency of their sexual activity. For her, sex was less of a priority in their relationship, though she enjoyed the sexual intimacy they shared. She indicated that she did not experience any difficulties with her body-image and was quite happy with the results of her reconstruction, and even considered her enhanced figure a benefit. The only apprehension she experienced was related to her inability to anticipate how Hugh was going to cope with the changes. “I didn't assume he was going to feel one way or another. I really just didn't know,” she stated, “I was in great shape, and the surgeon gave me the best results possible, but some people can't get past knowing they're not natural or feeling the difference. It was unknown territory.” She illustrated her point by sharing a story about a woman she met during her chemotherapy treatment who joked about having an affair because her husband no longer desired her after she lost her breasts.

Delia verbalized that she was “completely surprised” by the way Hugh demonstrated understanding towards the situation. “He didn't seem to have any problem with the fact that there were times when we weren't having sex, and there was never a time where I felt that he wasn't attracted. My worry was for nothing,” Delia stated. Hugh laughed as he joked, “I think I

surprised myself.” He agreed with Delia’s term “unknown territory” and described similar apprehension; however, he also indicated that the outcome was a surprise to him. He explained:

Sexual intimacy had always been important to me, but all of a sudden it wasn’t so important. I guess my priorities changed, and the most important thing was [Delia] and making sure she was comfortable...I loved our intimate time together, but, when she wasn’t feeling well, I never thought twice about it. I have a high sex drive, and I didn’t think anything could change that, but the breast cancer put my head in a completely different place. Maybe that’s linked to becoming a less-selfish person.

The increased sense of security identified by the couple was influenced by their perceptions of feeling “accepted” by one another. For Delia, security stemmed from her experience that Hugh “unconditionally” accepted her as she was and that his presence in the relationship had not faltered as a result of the stress they faced. For Hugh, the fact that Delia made efforts to attend to him sexually even though their needs were different meant a great deal to him and made him feel cared for. To him this represented that she accepted him without trying to change him, and he felt a sense of security knowing that he was important to her even when she declined sexual engagement.

At the conclusion of the interview, Delia and Hugh were given the opportunity to provide any additional thoughts or remarks that they thought would help illustrate their experiences. Delia stated,

I hope people will see that we are living proof that good things can come from tragedy, and they can find the strength within themselves and each other to push through. We have eleven years worth of living happier and healthier than we ever were. If that doesn’t

define survival, I don't know what does. Or maybe I should say that's how *we* define survival. It's worth fighting for.

Researcher's Experience

During the initial phone contact with Delia and Hugh, it came to my attention that there were some characteristics of Delia's breast cancer that were similar to my own that I had not encountered during other interviews. In preparation for the interview I reviewed my notes to remind myself to remain aware of these similarities in order to set aside my preconceived ideas and refrain from placing undue bias based on my own experiences with these circumstances. As a visual prompt, I made a note in my journal to remind myself to remain aware of any reactions I may experience and document these accordingly, so I could process them later. At the start of the interview I felt well-prepared and vigilant. The preparations I made proved to be invaluable when, during the interview, Delia looked to me to validate her experiences. I had not made it a practice to voluntarily disclose my personal breast-cancer history to participants since I was aware of the many ways that could complicate the study; therefore, I was surprised when she made a comment early in the interview process that, since I was a survivor, I could understand what she was talking about. She had apparently gained that knowledge through word-of-mouth channels stemming from my involvement in breast-cancer-related activities.

At various times during the interview Delia would reference my knowledge of and experience with breast cancer or ask if my experiences were similar. My initial reaction was to anticipate that this was going to be problematic; however, I discovered that her inquiries and statements provided a unique benefit in these particular circumstances. Each time she would refer to me, I would actively redirect the conversation back to her. This heightened my attention to maintaining the focus on her and Hugh's story and moved me away from my own thoughts

and reactions. There were occasions when I needed to be more proactive than usual in prompting Delia to describe her own perceptions and experiences because it was evident in her statements that she was being vague due to her assumptions that I already knew or understood what she was explaining. The more I verbalized my interest in hearing her unique experiences and thoughts, the more it brought my own attention to her story. In a sense, having to guide Delia in this way made it difficult for me to get pulled into my own thoughts and reactions. This is not to say that I wasn't aware of myself in this way. It was my perception that the characteristics of the conversation heightened my attention to all of the dynamics occurring, thus avoiding any preoccupation with any one aspect. While it is not typical for me to become overly focused on my own thoughts and reactions while engaging with another person, being able to consider the possibility based on the similarities in our stories and prepare myself accordingly, enabled me to approach the interview with a sense of confidence and competency. I was able to proceed through the interview with clear understanding of my presence in the process.

A unique characteristic of Delia's story-telling that I observed was that she frequently used specific events and scenarios as tools to describe her experiences. Recalling a specific incident seemed to assist her in being able to identify the emotions associated with particular aspects of dealing with breast cancer and to create a verbal illustration of her experiences. Although it is not uncommon for participants to include examples in their stories, since this was such a prominent feature of Delia's dialogue, I felt that it was important to structure the written case study in such a way as to reflect this. Including some of the examples she provided seemed to be the best way to present a synopsis representative of the qualities of this interview. Although this created a case study that was more quote-laden than the others, being able to

exercise some flexibility in my writing style allowed me to distinguish essential features of my interaction with the couple and to better capture the essences of their experiences.

Defining Survivorship

As discussed in Chapter One, the most recent generalized definition of cancer survivorship predominantly included references to living with, through, and beyond a cancer diagnosis. This definition has continued to be the definition of choice among members of predominant cancer organizations including the National Coalition for Cancer Survivorship (NCC) and the National Cancer Institute (NCI), and has been expanded to include family caregivers in recognition of the challenges they face when their loved ones are affected by cancer. This definition has been adequate as a common-sense descriptive within general discussions pertaining to cancer-related topics; however, it does not fully represent the subjective understanding of the definition of survivorship from the perspective of the participants of this study. In an effort to adhere to the principles of phenomenological research and gain greater insight into the participants' experiences, it seemed essential to explore the characteristics of survivorship that the couples found most meaningful and incorporate these into a working definition. Essentially, utilizing a generalized definition or label of survivorship would increase the likelihood of both researcher and reader bias, thus limiting comprehension of the couples' lived-through meaning. With this, couples were asked to define survivorship in their own terms. Since the concept of survivorship was introduced at the start of the couples' involvement (i.e., being asked to participate as a "survivor couple") and, therefore, served as a frame of reference to their responding, it made sense that their interpretation of this role or title be established at the start of the interview. The presentation of this definition at the start of the discussion related to emerging themes is meant to parallel the interview process and provide context within which to

understand the relevance of the themes. Couples' personal experiences of survivorship are discussed in terms of the specific themes, which emerged within this area of exploration and are presented later in the findings amidst topics associated with the completion of the treatment trajectory.

Couples who responded to the question as to how they would define survivorship all described active processes. Survivorship was not simply about surviving in the literal sense of not dying as a result of a traumatic experience, nor was it about passively tolerating discomfort until the event was over. Rather, couples included proactive characteristics within their definitions. They suggested the need for an individual to "move" himself/herself forward and through the trauma. Steve illustrated this in his statement that, "If you're not moving forward, then you're going backwards. If you're not moving forward, you're not surviving. You have to be proactive about how you live your life if you expect to survive." Responses seemed to suggest that there is the potential for individuals to continue to function in debilitated ways if he or she is unable or unwilling to take a proactive role in overcoming a difficult situation. Darren conveyed this by saying, "If you don't do anything to help yourself get through it, you're going to wallow in self-pity and stay stuck exactly as you are." He added, "I don't believe in 'What doesn't kill you makes you stronger.' It might not kill you, but it doesn't automatically make you stronger. You have to be active in the fight to become stronger from it." Similarly, Dan suggested, "You can't overcome anything if you don't try everything you can. Survivorship is built on character. You survive because you don't quit. You keep going." Although the language used within cancer-related literature has evolved, replacing the term *victim* with the term *survivor* to reflect increased focus on life after cancer (Rowland, 2008), participants of this study also perceived these terms to represent passive and active elements. Annika shared her

view that, “Moving forward with life, that’s how you avoid becoming a victim. You accept whatever it is that you’ve had to deal with as part of your life, but you don’t live in the past, otherwise the problem dictates your life, not you.” Nancy provided what she termed as her “blunt definition,” “You didn’t die, so there’s no reason to stop living now.”

A second primary characteristic of the couples’ definition included the idea that in order to survive and cope with a trauma, one must engage in the process of learning. Keith commented, “Survivorship is about learning to roll with the punches and when bad things happen you learn how to cope with them in order to move on and not live in the past.” Couples recognized that traumatic events often put people in unfamiliar situations, which they may not be prepared to handle. There was a general consensus that people could not expect to know how to cope with certain difficult events if they have never had to face those specific challenges before, and a degree of learning was necessary in order to adapt. Lisa remarked, “It’s a hard journey in unfamiliar territory but if you’re not willing to learn along the way, you’re not going to survive.” Jessica spoke about her impression that people had a tendency to gauge survivorship by the degree of difficulty they believed the event entailed. She shared her belief that the experience of trauma was “in the eye of the beholder.” She explained:

It’s like pain, well, I guess it *is* pain whether physical or emotional, and everyone has their own threshold. Some people have high tolerance and some don’t. That’s why one person can be affected a lot by a situation, and another might not be affected at all by the same situation. Survival isn’t about how one person’s struggle compares to another’s. It’s about how you learn to get through your own struggle, so you can come out the other side.

The overall message conveyed by the participants was that survivorship entailed taking an active role in learning ways to cope with the challenges of a difficult situation, and to learn from those experiences in order to thrive rather than just “exist” following a traumatic event. Being proactive in efforts to surmount obstacles for the benefit of one’s quality of life was the defining characteristic of a survivor.

Defining Positive Growth

Consistent with the rationale for establishing a working definition of survivorship, the term *positive growth* was approached in a similar manner. Since couples were introduced to the term via recruitment materials and the informed consent form early in their involvement with the study, it seemed appropriate to explore the general ideas participants had about the definition. It was recognized that once the term was presented, couples would likely begin to form their own impressions even before the interview began. With this in mind, a general conversation about how positive growth could be defined was initiated with each couple at the start of the interview. The primary goal was to understand the couples’ general perceptions of the concept before the specific interview topics were presented and to better comprehend their responses. An additional aim was to begin to introduce the couples’ meanings and incorporate these into the formal definition presented in chapter one. Since the basis of the study was to explore the ways in which couples’ perceived positive growth following breast cancer (*how not if*), and because participants were selected based on their belief that growth was possible (pre-established notions), there was little concern that this early conversation would influence later responding or suggest the occurrence of the phenomenon. In fact, the working definition was likely reflective of the couples experiences, therefore, establishing a viewpoint could potentially assist with understanding the significance of certain responses. Although the term was introduced within

the context of surviving breast cancer, couples were not asked to share their thoughts about the possibility of growth as a result of experiences with trauma, or to discuss their personal perceptions of their own growth. This inquiry was reserved until later in the interview during conversations about their personal experiences as they progressed through the treatment trajectory and will be discussed within the context of the emerging themes.

Consistent with the definition presented in chapter one, couples initially identified the process of “positive change” as the primary characteristic of the concept. To be more precise, they described being changed in permanent ways or at least in ways in which one cannot return to the original pre-trauma state. Keith expressed the view that, “You’re no longer exactly the same as you were before you went through it. You never are. You are very different mentally, emotionally, and even physically. But it’s positive because you are stronger because you got through it.” Darren’s description mirrored this as he remarked, “You get pushed down a different path and you can’t just rewind and go back to where you were before. But growth is about finding the good that can come out of it for you.” Similar to the definition given of survivorship, learning was identified as a key component of positive change. Annika stated, “Learning from the experience is what makes you grow.” Common among the couples was the impression that positive growth was specifically a product of learning. Diana articulated it as, “To learn in some way that is going to change you permanently.” Nancy also shared this perspective. She responded, “You learn things you didn’t know before and you do things that you never knew how to do before. It stays with you even if you continue to change because its part of you and everything that comes after builds on it.” Also similar to the definition of survivorship, the descriptions couples gave implied an active process requiring effort on the part of the individual. More directly stated, Debra conceded that, “It’s a daily chore. To grow you

need to work on improving in some way. You need to do more than you did the day before. Changes aren't necessarily going to stay good if you don't put work into it." Jessica's perspective aligned with Debra's, evidenced in her like statement that growth meant, "To become aware of things you weren't before, and to try harder in the areas you had trouble in...trying to do it better even though the difficult time may have passed." As represented in Jessica's statement, couples did not necessarily specify when the learning needed to occur in order to result in positive growth, nor did they define a timeframe in which they expected growth to take place. The general consensus was that both learning and positive growth could continue long after the traumatic event had passed because these were processes that could be built upon over time.

Themes

Synthesis of the participants' interviews resulted in the emergence of themes within twelve areas of conversations, (a) initial reactions to the breast cancer diagnosis, (b) beliefs about breast cancer, (c) impact of breast cancer, (d) adjustment to the illness, (e) communication, (f) resources for support, (g) experiences of survivorship, (h) perceptions of positive change, (i) charitable endeavors, (j) perceptions of positive growth, (k) indicators of change and growth, and (l) perspectives on recurrence.

Initial Reactions to the Breast Cancer Diagnosis

At the start of the interview, couples were asked to describe their experiences of first learning of the breast cancer diagnosis. As they provided details about the events preceding learning of the diagnosis, and circumstances under which they were told breast cancer was present, a theme related to initial reactions to hearing the news emerged. This theme included the subthemes of (a) female partners' reactions to the diagnosis, and (b) male partners' reactions

to the diagnosis. Each of these subthemes will be discussed separately, beginning with the reactions of the female partners.

(Female Partners) Nothing can prepare you to hear those words. As female partners described the events and circumstances leading up to learning they had breast cancer, all ten conveyed that they experienced a lack of mental preparation to hearing the words, “You have breast cancer.” Although the stories they told about their personal situations varied, nine of the ten participants indicated that being unprepared was directly linked to the nature of feedback and cues they had received from their physicians and other medical professionals, which they interpreted as directing them away from concern. For Kara, Nancy, and Jessica, feedback suggesting that a diagnostic procedure was “routine” or “precautionary” was perceived as being a contributing factor. Kara believed her sense of feeling unprepared stemmed from her perception that “everything happened so fast that I didn’t even have time to consider the possibility.” She shared that the mass in her breast was detected by her gynecologist during a routine exam, and within four days a mammogram and biopsy had been performed, and she was being told over the phone by her doctor that she had breast cancer. She remarked, “Nobody along the way said anything about suspecting something bad. I kept being told the tests were just precautionary. There were no clues to make me think to prepare for the possibility.” Nancy’s mass was also detected during a routine gynecological exam, and she was instructed to have a mammogram. She indicated that she did not experience any concern because her doctor told her that “lumps weren’t uncommon” and that it was “standard procedure” to perform a mammogram, so she should not worry. She stated, “How could I have been ready to hear that I had cancer? We didn’t even have any family history, and I was young and healthy.” Similar to Kara, Nancy indicated that she did not get any feedback that would have served as a cue to prepare her to hear

bad news. “I work as an x-ray technician,” she reported, “So I know people doing the tests aren’t allowed to give medical opinions, but there’s usually some kind of sign that lets you know something isn’t right. Unless I missed it, there was nothing.” Finally, Jessica shared hearing the same feedback that the mammogram was “just a precaution” and “nothing to worry about.” She spoke about the fact that despite the history in her family, it “never dawned” on her that she could have breast cancer because neither she, nor her gynecologist, felt any lumps in her breasts; therefore, the mammogram was of no concern to her.

Feedback suggesting that a detected lump or abnormality was likely a minor issue contributed to Debra, Diana, and Annika’s state of unpreparedness. Both Debra and Annika indicated that they had histories of breast cysts and were told by their gynecologists that the lump they each found in her breast was likely “just another cyst,” as Annika stated it. She added that her gynecologist did not appear concerned; therefore, she did perceive any reason to think anything but that she had a cyst. She also remarked that it was not uncommon for her doctor to order testing when a lump was detected, so being instructed to do so did not raise any sense of alarm in her. “I was so used to dealing with cysts that it never crossed my mind that it could be something else. I guess it didn’t cross my doctor’s mind either,” Annika remarked. She added that her level of concern was so minimal that Darren left on a business trip before they received the biopsy results. Similarly, Debra was accustomed to undergoing testing when an abnormality was detected by her or her gynecologist. When inquiring further after being told by her doctor that her mammogram and ultrasound results came back normal, Debra recalled being told it was “nothing” and probably “just something benign.” Additional testing performed as a “precaution” rendered the same results, and Debra was once again told it was “nothing.” She stated, “They were saying ‘It’s probably just a fibroid.’ I figured they could be right, but since it wasn’t one of

my usual lumps, I wanted to know exactly what it was.” Debra shared that, after multiple negative test results and reassurances from her doctor that it was benign, she was not prepared to hear that she had cancer upon having the lump removed at her own insistence. The lump in Diana’s breast was also suspected to be a cyst; however, after her gynecologist performed an aspiration and did not retrieve any fluid, Diana was told that the lump was “most likely benign.” She commented that her doctor did not order a mammogram or any other testing and did not give any indication of concern, which eased her mind. Diana was told that it was “standard procedure” to remove any lumps that were dense in nature, as was hers.

In Meryl and Delia’s cases, the statements they provided, which indicated that they were unprepared to hear they had breast cancer, referred to feedback they had received after being evaluated suggesting the absence of any problem at all. Meryl observed that her nipple appeared misshaped, and she sought consultation with her gynecologist. Neither she, nor her doctor, detected a lump, and her doctor told her there was nothing wrong and no further measures were needed. She stated, “I didn’t think that was the right answer. Not that I thought I had anything like breast cancer, but I felt like it was definitely something, if only another cyst.” Like some of the other participants, Meryl had dealt with breast cysts for many years and was very familiar with the contours of her own breasts and changes that occurred. She assumed that her misshaped nipple was probably caused by a cyst, and she set up an appointment with a surgeon she had been seeing for years, who usually performed needle biopsies when a lump was detected. Her surgeon also did not detect any abnormality but, “as a precaution,” performed the needle biopsy which resulted in the diagnosis of breast cancer. Meryl remarked, “I knew it wasn’t absolutely nothing, but I never imagined it would be something more than a cyst.” She added, “I’m 66-years-old. I’ve been dealing with breast issues for over forty years. It’s never been anything

more serious than cysts, so that's what I expected...or maybe even nothing since there was no lump."

Delia commented, "After being told everything was normal, I completely dismissed the possibility of anything serious like cancer from my mind." She described feeling unprepared to learn that she had breast cancer because, when a lump was detected during an exam for an injury, diagnostic testing was performed, and she was told that no abnormalities were found.

I had a mammogram done first, and they said it looked 'suspicious,' so then they did not one, but two needle biopsies to be sure that enough cells were collected. They told me there was nothing abnormal. We were so relieved at that point, hugging and kissing. All we could say was 'Oh my God, thank God it was nothing....My G.P. (general practitioner) told me to have it out anyway, so I said 'fine.' But after all that testing and re-testing, I never expected to hear anything different.

Finally, for Lisa the perception of being mentally unprepared to hear of the breast cancer diagnosis occurred despite having had a period of time when she suspected a serious problem. In her case, the absence of any feedback regarding the nature of the problem, or perceived cues indicating a serious issue, contributed to her perception of being unprepared. Initially, Lisa was not concerned when a tissue biopsy was performed after a "spot" was detected on her routine mammogram. She indicated that she had not felt any lumps, or detected any abnormalities during her self-exam, and as such, did not believe any significant problem was present. In addition, she did not receive any information about potential causes for the "spot," or any indication that there was an issue to be concerned about. She and her family left for vacation the day after her biopsy. It was upon returning home and receiving a phone call from staff at her doctor's office informing her that the doctor wanted to see her as soon as possible, that she began

to suspect that something was wrong. She stated, “I knew at that point the news wasn’t going to be good because they don’t usually make you come in if it’s good news.” She added that, even though at that point she suspected there was a problem, she did not specifically think about breast cancer or prepare herself for that possibility. “I’m not the type to overreact and assume the worst” she stated, “I try to control my thoughts until I have something solid to go by.” In reference to being told that her “spot” was breast cancer, she commented, “I don’t think there is any way to prepare yourself emotionally to hear it even though somewhere in your mind you know something is wrong. At the moment I was told, it like it was this completely foreign idea.”

Susan also experienced a sense of being unprepared to hear that she had breast cancer, but did not associate this with the presence or lack of feedback. She indicated that she quickly considered the possibility of breast cancer when she discovered a lump in her breast. Her gynecologist examined her, and wrote her a prescription to have a mammogram done. Like Lisa, she was not given any information regarding the possible etiology of the lump, and stated that there were no evident signs “either way” as to whether there was need for concern or not. She had to wait six weeks before she could get an appointment for a mammogram, and reported that over that period of time she began to “intuitively” feel like there was a serious problem. Susan spoke about the fact that deep down she knew she was going to hear that she had breast cancer, but despite that, did not feel ready to hear it. She described feeling similar to Lisa in that she logically understood there was a problem, but when she actually heard the words “You have breast cancer” spoke to her, it was as if the possibility was never considered. She said, “No matter how much you suspect it before hand, it doesn’t prepare you to actually hear those words.”

Regardless of the specific circumstances surrounding the event of being diagnosed with breast cancer, the perception of lacking a sense of mental preparedness to hearing the news was shared among the female participants and created a significant subtheme within the findings. For most of the participants, the nature of feedback and other cues from one's healthcare providers and medical professionals was perceived as a primary factor influencing their sense of not feeling prepared to hear the breast cancer diagnosis.

(Female Partners) It was a complete surprise, shocking really. Within the participants' conversations of feeling mentally unprepared to learn of the breast cancer diagnosis, all ten female participants described experiencing intense surprise or shock upon hearing the news. Although it would seem logical that a person may experience surprise upon hearing information they were not prepared to hear, a separate subtheme arose out of the terminology utilized by the participants to describe their emotional reactions. This subtheme can be considered within the context of the first subtheme discussion since there is an association between the two experiences; however, separating the subthemes allows specific attention to be paid to the language of choice among the participants and the consistency in reactions. There were several variances in the circumstances surrounding learning of the diagnosis, which make the commonalities among the verbal accounts of their initial reactions even more noteworthy and significant. Seven of the ten participants identified their reactions through the use of the term *shocked*, while two others used synonyms of the term (i.e. stunned, surprised). All of the participants' accounts of their reactions illustrate the experience of shock, such as perceptions of the events being surreal or incomprehensible, or physical reactions associated with the emotional state of intense surprise.

The presence of a subtheme is evident among the statements provided by the participants regarding their experiences. The most prominent way to illustrate this subtheme is by following the pattern of statements between participants.

Annika: I think it was very surreal almost....We were, at first, just so surprised by it that we were both in shock....It was like I couldn't fathom it immediately.

Kara: I was in complete shock. I actually don't have any memories if I called [Clark] or not. I was hysterical and I started crying. It was literally like my stomach dropped. It was just immediate despair.

Susan: That had to be the worst day of my life....I was like, "Oh my God. Did she just tell me that I had breast cancer?"....I couldn't even process what I had been told....I couldn't stop crying.

Nancy: I was in a lot of shock.

Lisa: It was a complete surprise. I remember looking at my doctor going, "I'm sorry, what did you just say to me?" She repeated it, and I started to cry because it just didn't seem like it was real to me. It was devastating....My heart just sank.

Debra: It was like someone took the breath right out of me and hit you in the head....I was shell shocked, utter disbelief.

Meryl: It was like an out-of-body experience. I guess I shouldn't have been surprised, but I was. I was too stunned to think about or feel anything else.

Diana: Suddenly you're shocked, like you'd never expected to hear that.

Jessica: Very shocking. I was more shocked than anything....It seemed impossible.

Delia: I just couldn't believe it....I was just shocked. I was like, "How can that be?"

The participants' responses illustrate the overwhelming reaction many women experience when learning they have breast cancer. Presenting the participants' statements back to back was intended to poignantly demonstrate the stress that can be associated with breast cancer from the point of diagnosis. In order to better understand the significance of experiences of positive growth and positive change, it is important to understand the stress and challenges associated with the event that needed to be overcome in order for growth to occur. Therefore, gaining a clear picture of the participants' emotional states from the start is essential in being able to comprehend the lived experiences as fully as possible.

(Male Partners) I need to be strong for her but inside I'm really afraid. All of the male partner participants spoke about fear being their initial reaction to the diagnosis, while simultaneously feeling a need to present themselves as strong and emotionally stable for their partners' sake. The perception of needing to put up a strong front resulted in male partners withholding expressions of their emotional reactions. Some viewed this as consistent with their beliefs about their roles as husbands and partners in that they felt a responsibility to remain the primary support within their family. Others indicated that they believed it was in their partner's best interest, because disclosing their fear may cause greater stress for their partners, who are already facing the crisis of being diagnosed with breast cancer. Partners identified two primary tactics used to aid them in masking their emotional upheaval. The first was to respond in a task-focused manner, focusing on logistics and information-gathering measures to be taken. The second was to respond in a manner which portrayed a positive attitude and an optimistic outlook. These tactics can be noted within the partners' statements and are directly linked to the efforts put forth to maintain the persona of strength; therefore, although this was represented prominently enough within the partners' statements to warrant being presented as a separate

subtheme, it is included in this discussion to highlight the connection. Furthermore, there was evidence within the interviews that taking a logistical position was not limited to the initial reaction only. Rather, for most partners, this was maintained throughout a significant portion of their experiences with the breast cancer, and will be discussed in further detail in the context of other themes.

Darren's reaction to learning that Annika had breast cancer is a prime example of experiencing fear and resorting to information-focused tactics to maintain his composure. He shared that "fear" began to set in quickly after hearing the news, but he did not want to upset his wife, so he did not express his feelings. "I was scared," he stated. "I wanted to be strong for her, so I didn't tell her how I was feeling." He was concerned that the situation would be harder for Annika to cope with if she had to worry about him as well. Instead, he began to focus his thoughts "on logical thinking," and responded with information about the importance of early detection and reassurance that she was going to be okay because she was young, instead of sharing his emotions. Rob's fear was compounded by the ambiguity he experienced due to the fact that he and Susan did not get the information or education they needed in order to understand fully what was happening, or what they needed to do next. Like Darren, he attempted to respond reassuringly by telling Susan that everything was going to be alright, and discussing his plan to obtain the best care available for her. "Not that I really knew it was going to be okay, but what else could I say?" he remarked.

Although Clark described himself as "analytical" and having a tendency to keep his emotions internal, when asked to share about his reaction to learning of Kara's diagnosis, he was able to convey that he experienced fear and concern for Kara and his children, which was amplified by the many "what if" questions that immediately began to go through his mind as

soon as he heard the words “breast cancer”. His statements reflected the duality of what he was experiencing internally and what he presented to Kara externally. He remarked, “My reaction to her is always going to be ‘It’s going to be fine’....I’m not going to show her [my] concerns because I wanted her to feel like everything was going to be fine.” He added that any emotions he let out would not be done in Kara’s presence because he did not feel it would be helpful to her. Instead, he directed his responses towards the need to gather information in order to begin to make decisions about what to do to address the problem. In similar fashion, Dan disclosed that he experienced “fear” and “uncertainty” but responded in a task-focused manner. In order to contain his own emotional reactions, he focused his attention on logistics as well, responding to learning of the diagnosis by stating, “Let’s go to the specialist. Let’s hear what they have to say.” He commented, “I didn’t want my emotions to take over....so I couldn’t think about it or talk about it. I was all about, ‘What’s our next step?’ ‘What do we need to do?’ And ‘How do we fix this?’”

Like Clark, Craig believed that maintaining a positive persona, despite the emotional reaction he was experiencing, would be in his wife’s best interest. He explained:

It was shocking at the time....It didn’t seem real....It’s hard to believe because it’s scary. Meryl said I avoided talking about how I felt. She’s right....I wanted to be the optimist for her, so she would feel like everything was going to turn out alright. I focused on how we were going to go about helping her. That’s what I know how to do.

Keith was also intent on not showing his emotional distress in front of Debra. He shared that his initial reactions to hearing that his wife had breast cancer were to feel “shocked,” “devastated,” and “afraid” of what was going to happen. Despite the intensity of his emotions, he responded to Debra in a way in which he believed conveyed optimism, telling her, “We’re going to fight this.”

He described experiencing an overwhelming and intense feeling of apprehension, which led him to seek solitude so that he could cry by himself and have the emotional release he needed, while still being able to “put up a brave front” for his family. Other partners conveyed similar feelings, such as Steve, who said, “My initial feeling was just fear. But I tried to be upbeat and be the strength that [Diana] needed,” and Brian who remarked, “I was just scared, but I never let on. I just tried to be positive for Jessica.” Ongoing sentiments such as, “I had to keep it together,” from Hugh, and, “I wanted to keep strong for [Nancy]” from Rick, continued to highlight that male participants shared the view that remaining emotionally strong was an important factor in their perceptions of themselves as partners, and that expressing emotions such as fear and apprehension did not signify strength. Like other male participants, Rick and Hugh held the perspective that, in order to care for their partners, they needed to withhold their own emotional reactions so these would not cause their partners further distress. This was evidenced in Rick’s statement that he did not want to have his fear cause Nancy to be more afraid, and Hugh’s declaration that, “I couldn’t let her know I was afraid....If I had broken down, she would have too....and I couldn’t let that happen.”

In closing, female and male partners described that their reactions were compounded by their preoccupation and rumination of negative thoughts. They described that these thoughts were intrusive and disrupted their ability to modulate their reactions. Some conveyed that they experienced a cycle effect in that the more they thought about cancer, the more they experienced emotional reactions. In turn, the more they reacted, the more focused they were on the negative thoughts. In conjunction with experiencing their emotional reactions, some partners also experienced periods of being easily distracted and unable to concentrate.

Beliefs about Breast Cancer

The data analysis revealed that couples beliefs about breast cancer were predominantly shaped by their own previous personal experiences dealing with the disease or other types of cancer. Two separate subthemes emerged and were based on whether couples had experiences with cancer-related-death or cancer-related-survival. The following discussion illustrates the divide among the couples' perspectives, and highlights the experiences that contributed to their beliefs prior to the experiences they shared as couples surviving breast cancer together. It should be noted that pre-conceived beliefs about survival or death associated with breast cancer did not necessarily pre-determine the partners' perceptions about death or survival in their own situations. In addition, partners' perceptions about the possibility of death as a result of breast cancer in their own situations were highly variable. For example, regardless of prior beliefs, some partners reacted with fear of death immediately after hearing the diagnosis; however, dismissed this thought once the initial shock had subsided. Conversely, some partners did not initially consider whether or not death was a possibility, but experienced fear about this once they began to process the information or experience treatment. More often than not, the couples' beliefs about breast cancer influenced other ways of perceiving and reacting besides fearing death.

A lot of people get cancer. It's not that big of a deal. As couples shared their beliefs about breast cancer, some explained how previous experiences influenced their abilities to fully comprehend what was occurring in their own lives, or understand the implications of the diagnosis of breast cancer. Darren explained that his beliefs about breast cancer were highly influenced by knowledge and experiences he gained as a result of his mother undergoing treatment a few years prior to Annika's diagnosis. He shared that his mother had progressed through lumpectomy surgery and radiation treatment with ease and experienced minimal side

effects; therefore, required little assistance. He indicated that his belief about breast cancer was that “it was bad, but not the end of the world.” From his perspective, this “minimized” impression caused him to not anticipate “how much more complicated” dealing with breast cancer could be and underestimate the extent of care Annika was going to need. Annika agreed that, prior to her own diagnosis, she also believed breast cancer was “not a big deal.” Her beliefs were influenced by the fact that several family members had been diagnosed and successfully treated for cancer. She explained, “When you grow up hearing about it so much it kind of numbs you to it. Until it’s you who’s facing it and you learn there’s a much broader scope of complications.”

Debra and Keith’s experiences were similar to Annika and Darren’s in that their beliefs about breast cancer included an impression that it was far less complicated to manage than what they actually experienced for themselves. Like Annika, Debra had family members who had been diagnosed with various types of cancer and were treated successfully. She indicated that surgery was the only treatment needed, which contributed to her belief that cancer was “serious, but relatively easy to treat.” Keith indicated that his only experiences with cancer were hearing details of his father-in-law’s surgery. Neither he nor Debra had experiences specifically with breast cancer. He shared that he was not “naïve” about breast cancer, but lacking exposure limited his understanding. He commented, “You see all these commercials on TV for breast cancer walks and pink ribbon stuff is everywhere you look. It seemed like so many people had it that, it was like a common thing these days.” Keith explained that his limited personal knowledge, and impression of breast cancer as “common,” contributed to what he described as an “inaccurate” belief system, which equated “common” with “not a big deal.”

Lack of exposure to real-world experiences with breast cancer was identified as a contributing factor to Craig's beliefs about breast cancer. Like Keith, he commented that he was not naïve about breast cancer and acquired "general knowledge" that most people obtain from the media; however, he described his beliefs about breast cancer as "simplified." He explained that his experiences with breast cancer were limited to hearing "minor" details over the phone from his sister, who was living "across the country" at the time she was in treatment, and from Meryl, who would occasionally mention "a detail or two" about one of her girlfriends going through breast cancer. "You can only understand something as much as it is explained to you, or you experience it for yourself," he remarked. He added, "Meryl is a nurse, so she talks very casually about these types of things, and my sister prefers to be somewhat private, so she filled us in on her general progress." Meryl agreed that her exposure to illness on a regular basis, along with having several friends who were successfully treated for breast cancer, contributed to a belief system which included a "desensitized" impression of the impact that breast cancer can have on a person's life. Both Craig and Meryl remarked that these pre-conceived beliefs did not help "desensitize" their reactions to Meryl's diagnosis. Meryl stated, "It's hard to hold on to any beliefs you had before when now it's you that has it."

Finally, Kara and Clark spoke about the experiences they had with cancer which helped shape their belief system. Like several other couples, neither had any family members or close friends who had been diagnosed with breast cancer; therefore, their knowledge was limited to that which they obtained from the media. Their beliefs were primarily generated through experiences with family members who had other types of cancer. Kara's grandmother and Clark's mother had both passed away as a result of cancer-related complications. Each had been diagnosed after the cancer had progressed significantly. The combination of experiences with

their own family members, and the impressions they formed from media information, contributed to a belief that breast cancer was “difficult,” but primarily a major risk in cases where it was not detected early.

An interesting observation is that the way couples interpreted the information they obtained through media sources was highly subject to the beliefs they already had about breast cancer. In the cases above, where couples described their own beliefs as minimizing, simplifying, and desensitizing towards breast cancer, the media exposure contributed to the impression that, because breast cancer appeared to be prevalent in the population, it was “not that big of a deal.” A few couples spoke about their perspectives that lacking direct experiences to connect to the media images contributed to a diminished understanding of the potential impact that breast cancer could have.

Everyone I know who has had breast cancer has died because of it. Couples who spoke about experiences of loss associated with breast cancer or other types of cancer contributed to a subtheme related to a general belief that breast cancer had the potential to be a lethal disease. For some couples, this belief influenced the ways in which they pursued treatment in their own situations. Jessica and Brian explained that Jessica’s decision to undergo bilateral mastectomy surgery, despite the fact that her breast cancer was detected early, was highly motivated by the fact that both her mother and grandmother had passed away as a result of breast-cancer-related complications at relatively young ages. She and Brian were both involved in her mother’s care and directly witnessed the impact of breast cancer. Jessica shared, “I saw what it did to my mother. Under all my denial, I knew it could kill me, so I wasn’t taking any chances.” Brian agreed that his general belief about breast cancer was based on his experiences with Jessica’s mother, stating, “I had nothing else to go by really. Besides, nothing has more of a powerful

impact than what you see with your own eyes.” He added that he immediately thought of Jessica’s mother when Jessica herself was diagnosed, stating, “All I could think about was what happened to Jessica’s mom, and I had these terrible visions of her being in the same situation.”

Similarly, after experiencing the death of both his ex-wife’s mother and sister as a result of breast cancer, Rick also believed that there was a strong association between death and breast cancer. This led him to encourage Nancy to pursue the most aggressive treatment available to her. He stated that, although Nancy’s cancer was described as “very early stage,” he could not avoid associating his previous experiences with this situation. Susan and Rob shared the perspective that their beliefs about the lethality of cancer developed after suffering multiple losses within both of their families-of-origin; however, was further accentuated by the fact that Susan’s father had passed away from cancer just weeks before Susan was diagnosed. They mutually felt the need to pursue treatment as quickly as possible.

The accounts of the remaining four couples were consistent with one another in conveying that their experiences of loss due to cancer greatly influenced their impressions that breast cancer had the capability of causing death. This belief was maintained whether the losses were associated with breast cancer or other types of cancer. In addition, multiple losses further compounded these beliefs. Steve disclosed that he had experienced multiple losses in his family as a result of cancer, including his grandmother and three of his four uncles, and that his direct personal experience was that “no one ever survives it,” and that he did not have any “good experiences” to look back on for a frame of reference. He stated,

When you’ve had these kinds of things happen, you can’t just turn that off. When you hear that someone you love has cancer, you can’t help but fear what’s going to happen. Even if it’s a completely different case or whatever, in your head you still believe you

could lose the person because you've known it to be true before. At least that's how it was for me.

Other couples mirrored Steve's perspective that, regardless of whether or not one circumstance was comparable to another, previous experiences of loss due to cancer greatly influenced the beliefs they had about breast cancer prior to their own or their partner's diagnosis. Interestingly, these couples rarely referred to media information about breast cancer, likely because they had personal experiences from which to draw their impressions, unlike some couples who appeared to rely on outside information in order to form beliefs because they lacked the influence of personal experiences.

Impact of Breast Cancer

The diagnosis of breast cancer and the treatment associated with surviving it affected the couples in multiple ways. As they shared their experiences about the influence of breast cancer on their daily lives, a theme related to the impact of breast cancer on the couple relationship emerged. Four subthemes were deduced from the analysis and were as follows: (a) impact on physical functioning, (b) impact on emotional climate within the relationship, (c) impact on sexual intimacy, and (d) impact on overall perception of relational closeness. These subthemes are highlighted in the following discussion.

Keeping up with the everyday physical demands put a lot of pressure on our relationship. Several couples discussed their lives being affected significantly by the need to redistribute family and household responsibilities in the wake of physical limitations imposed upon female partners, caused by post-surgical pain and side effects associated with adjuvant treatments. As Annika stated, "I was a lot more dependent on [Darren]....There was a lot I needed him to do because I couldn't....Simple things like loading the dishwasher, cooking a

meal, or folding laundry became chores.” Both female and male partners expressed experiencing a sense of pressure to negotiate daily demands, and they shared the perspective that their relationships were affected as a result. Male partners needed to make adjustments to accommodate the impact of the illness by taking on more responsibility within the home, while continuing to be accountable for their out-of-home obligations, such as employment responsibilities. Despite the difficulty of adjusting to an increased workload, male partners approached the task with attitudes of acceptance and understanding, some noting that it was an inherent aspect of their roles as loving husbands or partners. A conversation with Lisa and Dan serves as a representative example of the experiences shared by the couples. Lisa shared that she experienced severe nausea and fatigue throughout her chemotherapy treatment, which greatly diminished her ability to attend to household responsibilities and manage their children’s activity schedules. She explained:

[Dan] took it on...He stepped up and took it all on. He had to figure out things he had no clue about, especially things with our daughters. He didn’t know how to put their hair up for their cheer competition, so he called the coach and arranged to meet her at 5:00a.m. so she could help him. He had to make supper, get homework done, be at their games....It was a lot of pressure for him and more stress than he’s used to....I was seeing him getting tired, and my heart was just breaking. It made me feel like “Oh my God, I wish I could help you.”

Dan’s response to Lisa’s statement was reflective of his sense of responsibility to his wife and family. Although he agreed that he experienced a tremendous amount of pressure to “do it all” and stress related to “juggling so many hats,” he also viewed his willingness to take on the

burden of additional responsibilities as a way that he could help ease his wife's struggle. He stated:

You do what you got to do to get things done....I couldn't get chemo for her, and I couldn't take away her pain, but these things I could do, and I knew they were helping her. When you love someone, you do whatever you can for them; there's no question.

Lisa and Dan acknowledged that both aspects of the situation, the shift of responsibilities as well as the physical limitations caused by breast cancer, had an impact on their relationship. The commonality in their perspectives was that the impact of breast cancer on their physical functioning disrupted the level of engagement within their relationship. Not only was Lisa unable to perform her usual daily tasks, she shared that the nausea and fatigue she experienced frequently rendered her "unavailable" to Dan. She shared, "Sometimes I felt like an absent partner. I spent a lot of time in bed. I was either too sick or too tired to spend any quality time with him." Dan agreed that, at times, he felt Lisa's absence but understood the toll treatment was taking on her and wanted her to do what she needed to do in order to take care of herself. He added that he also felt that he was not able to be present in the relationship the way he would have liked to be. He attributed this to the time demands associated with solely managing the majority of the responsibilities, as well as to his own resulting fatigue. He remarked, "When we shared the responsibilities, things got done quicker and weren't such a burden on either of us. Doing it myself, I was exhausted from running ragged all day. At the end of the day I had nothing left to give."

Lisa and Dan's story encompassed many of the aspects of accounts shared by other couples. Meryl remarked, "Craig did more...he did everything." Craig responded that, although he likes to joke about how "diversified" he is in that he can now do cooking and laundry along

with plumbing and electrical work, the pressure he experienced was “serious.” He explained that owning a business in corporate finance posed its own time demands and stressful challenges even prior to those added by the impact of breast cancer, but that it was important to him as a husband to make his wife’s needs his priority. Like Dan, he viewed his helpfulness as a way to reduce the impact that breast cancer was having on Meryl. He stated,

She was in pain after her surgery, sick from the chemo, and exhausted from the radiation. That’s more than enough for one person to have to deal with, let alone having to think about cooking and cleaning. Plus, she was still working when she could. Physically, she just couldn’t do it all even if she wanted to....Whatever I could do to ease the physical burden on her, I did. If I could take care of the household chores, it was one less thing she had to worry about....She took pride in taking care of our household, so if she didn’t have to see things undone, she wouldn’t have to be reminded of her limitations, even though they were temporary.

Meryl commented that sometimes she wanted to try physical activities even though she knew it was not in her best interest because she did not want all of the burdens to be placed on Craig. She recognized that his efforts were his way of caring for her and showing his love for her, but she was concerned about the affect this had on their relationship. “There were some days where we were both just physically spent. We could hardly do more than crash on the couch and watch TV. We barely interacted. That was not good for our relationship.”

Comments made by other couples provided further evidence of the subtheme. Rob and Susan spoke about the fact that the pressures of keeping up with the everyday physical demands caused tension in their relationship. Prior to beginning her treatment for breast cancer, Susan had assumed most of the responsibility for the household tasks, but when treatment-related pain

and sickness interfered with her ability to perform her usual tasks, Susan remarked that Rob “did a lot of things that he normally would never even think of doing.” Similar to Craig, Rob was running his own business along with trying to assume additional household responsibilities and management of their children’s activities. “It got pretty stressful at times and tense between us,” Susan commented. They mutually agreed that they needed to allow some of their usual tasks to be put aside and accept the physical limitations as a temporary condition in order to manage the disruption being caused in their relationship. They also experienced disruption in their ability to attend to their relationship because “dealing with this trauma took up all of our time and energy.”

Delia and Hugh’s experiences greatly resembled those of the other couples who had the responsibility of running their own businesses. Delia remarked that Hugh had to take on more responsibilities at home because she was unable to move freely after surgery, but that she resumed as much of her usual household routine once she was healed and throughout her chemotherapy. Hugh acknowledged that he felt an incredible amount of pressure to take care of both his home and business responsibilities. He explained,

I was fortunate that I had employees that could help, but when your business is your livelihood, and your means of supporting your family, you have to give it as much of your energy and focus as possible. In my business, it was never a nine-to-five day. Even when I wasn’t at work, I was usually working. I was really stressed and that was a tough time for us. I know that my stress level put extra stress on our relationship. I had trouble keeping up even though I was doing the best I could. It was just too much.

Although Debra and Keith did not own a business, Keith experienced similar difficulties as described by Hugh. His job often involved after-hours activities with colleagues or clients visiting from out-of-town. Being employed within the financial industry, these activities were

essential for acquiring and maintaining business relationships, which ultimately influenced Keith's own financial income. Being aware of this, Debra continued to work as she was able and tried to do as many of her usual tasks as she was physical able to do. Never the less, the impact of treatment on Debra's physical functioning was significant, and Keith was relied upon to take on additional household responsibilities. He stated, "There were only so many hours in the day and home took priority." He noted that, although he found it gratifying to be able to contribute in ways that were helpful to his wife, he found the situation very stressful. Co-workers were gracious and supportive, often offering to assume some of his off-hours obligations, so that he could meet his performance requirements; however, Keith was highly concerned with the impact his absence was going to have on some of his business connections where less rapport had been established. Keith shared that he was "completely overwhelmed" with the increased responsibility and had significant difficulty adjusting. Both he and Debra felt that the fatigue and stress associated with trying to keep up with the physical demands of daily living left them depleted of energy to actively engage in their couple relationship. Keith shared his perspective that he was "put on the back burner" because everything around the home took priority.

Kara and Clark's story differed in that they made minimal adjustments in the allocation of household responsibilities. Clark helped in small ways around the house or with carpooling, but for the most part, Kara maintained most of her daily routine. The commonality they share with the other couples is that keeping up with the everyday physical demands did put pressure on their relationship; however, the pressure to fulfill the responsibilities was experienced by Kara. She reported, "I tried as much as I could to keep the household running and the kids in their routines and activities. I didn't have the stamina to do all that and be an attentive wife, so our relationship definitely suffered." She acknowledged that many of the interactions and activities

that she normally engaged that contributed positively to her relationship with Clark were put by the wayside. She added, “I couldn’t focus on so many things to keep the relationship good and unfortunately it was put by the way side.” Clark responded that, although he recognized that the impact of surgery and radiation therapy on Kara’s ability to function physically was a valid reason for her to have to prioritize how she distributed her energy, it was still difficult to be “low man on the totem pole.”

In addition to the demands of everyday physical functioning discussed above, three of the couples identified that the demands of treatment contributed to the stress they experienced. Kara indicated that the “daily grind” of radiation made it even more challenging for her to maintain her household routines and responsibilities. Besides the treatment itself being exhausting, she found it very tiresome to have to incorporate treatment into her daily activities. “I had to fit it in,” she remarked. It added to her level of physical exertion, which, in turn, made it more difficult for her to complete other physical tasks, such as food shopping and running errands. Debra shared that radiation five times per week was also something she had to “fit in” and which left her with less energy to devote to her home and relationship. Finally, Meryl and Craig contended that it required a great deal of effort to “constantly” be going into the city for treatment and was a physical strain on both of them, further depleting their physical energy.

She was on an emotional rollercoaster and I couldn’t help her get off. The impact of breast cancer on the emotional climate within the couples’ relationships was primarily defined by the difficulty partners experienced in their ability to find a common means of relating to one another emotionally. More specifically, the emotional dynamics within the relationships involved female partners experiencing and demonstrating significant distress, while their partners experienced a sense of helplessness in their ability to help ease the emotional upheaval.

A key component of this subtheme was that the foundation of the male partners' responses was directly related to the female partners' emotion states. Essentially male partners spoke about how they felt about their female partner's emotions.

The predominant emotions experienced by female partners included fear, sadness, anger, and vulnerability. Many described vacillating between all of these emotions or feeling confused over which was dominating at a given time. Some women who spoke about feeling angry or irritable recognized that this was secondary to the other noted emotions. Kara's account of her experience illustrates the "emotional rollercoaster" that many of the female participants recalled. She explained,

Well, I mentioned earlier that I felt an overwhelming sense of sadness for a long time....pretty much throughout the course of my treatment....and it was very draining. But there were also times when I distinctly felt angry and was pretty irritable. I know that this was my reaction to having to do radiation. It was humiliating and embarrassing.... I felt exposed, and that made me mad....I know that, a lot of times, anger is a really a mask for other feelings, like it's easier to show a strong emotion than a weak emotion. I guess it was easier for me to be angry than to show how humiliated I felt....I could really have dark moods. They were hard for [Clark] to handle....When I felt like he was pulling away because I was emotionally-psycho as I call it, then I pulled away too.

Clark agreed that he had difficulty coping with Kara's emotions. He shared, "Kara being disrupted was what was most emotionally hard for me, and I struggled with that." His efforts to help bring some stability to Kara's moods were ineffective. "I felt...inadequate, and that I

couldn't emotionally support her as much as she needed. I had a little bit of guilt about that. Mainly, I felt helpless to make her feel better."

Dialogues resembling Kara and Clark's echoed throughout the interviews. Susan, Debra, and Jessica spoke about the anger they experienced over having to deal with cancer. Susan stated, "I could be really irritable because I just wanted to get this shit over with and be done with it," while Debra expressed, "I was pissed that this was happening to me. I was angry at life." Jessica shared,

I have to admit that I was nasty and bitchy....I took it out on him. Any aggression, aggravation, fears, anger, whatever, was taken out on [Brian]....I put him through a lot of crap. I didn't make it easy for him to be around me.

Their partners, Rob, Keith, and Brian, provided descriptions that mirrored Clark's in that the most emotionally difficult aspect was witnessing their partners experience emotional distress. In addition, they experienced a sense of helplessness in their ability to reduce their partner's emotional pain. Rob and Keith conveyed that they tried to remain calm and react passively when their wives were directing their anger towards them. Rob described this as doing the "sponge thing" and absorbing it instead of reacting negatively, and Keith stated that he just "took it," also meaning that he chose to not respond. Brian, on the other hand, reported that he experienced more difficulty with Jessica's "lashing out" and these situations often resulted in the couple having an argument.

Diana and Steve spoke about the emotional climate within their relationship. Diana shared that her inability to maintain a stable emotional state contributed to her sense of vulnerability. "I was all over the place. Feeling like I didn't have any control over my emotions made me feel very vulnerable because I'm not comfortable breaking down in front of people."

Steve responded that, when Diana became emotionally overwhelmed, he often felt very helpless in the moment. “I just didn’t know what to do. I never knew what to say to comfort her and that made me feel helpless.” Craig also described the experience of helplessness; however, for him it was not based on not knowing what to say, rather, was related to the ineffectiveness of what he did say in an effort to respond to his wife’s emotional distress. Meryl shared that there were times when she experienced fear and especially sadness, and that Craig’s tendency to respond by telling her to “stay positive” left her feeling that he was unable to relate to what she was feeling. Craig acknowledged his feelings of inadequacy when it came to responding to emotional situations any other way. Finally, Hugh shared that it “broke his heart” to know that Delia experienced fear to the extent of emotionally debilitating her at times. He commented that he “couldn’t believe the condition she was in,” and described feelings of inadequacy that he was not able to “take care of it” like he could with other situations.

Overall, the emotional climate within the couples’ relationships could be best described as disconnected. The experiences shared by the couples illustrated the difficulty they had in finding effective ways of relating in order to counteract the impact that breast cancer had on their relationship. Several of the female participants commented that their partner’s inability to respond to their emotional distress lead to them feeling that their feelings were not validated in the ways that they would have liked and that would have been helpful. Most indicated that this feeling was temporary, and their discussions related to this were brief and fleeting. Upon further inquiry of the topic, minimal additional details were provided as the participants generally indicated that their experiences were not significantly meaningful, thus this experience did not warrant highlighting as a separate subtheme.

I thought I was unattractive, so I thought he did too. All ten couples indicated that they experienced changes in the frequency of their sexual activity as a result of treatment-related factors, such as post-surgical pain and side-effects, including nausea and fatigue, associated with chemotherapy and radiation treatments. However, for most couples, this was not identified as the factor that influenced their intimate sexual relationships the most. Those who experienced breast cancer as having impacted the sexual intimacy within their couple relationship primarily attributed this to issues related to body-image and perceptions of attractiveness. Seven of the couples described a pattern of projection, in which female partners experienced dissatisfaction with her bodies following breast-cancer-related changes and ascribed these feelings of unattractiveness to their male partners. For example, Debra commented, “I think I look like crap. I think he thinks I look like crap too, but he wouldn’t say it.” Subsequently, male partners offered reassurance of their attraction; however, perceived this as being rejected by their female partners. Keith’s response to Debra illustrated this point: “It didn’t bother me, but there was no telling her that....No matter how many compliments I gave her.” A detailed statement provided by Diana encompasses many aspects of the couples’ experiences:

The mastectomies were a huge blow to my sense of femininity and my body image. I have scars on both my breasts and down both of my sides where they moved muscle from my back to the front to help support the implants....Every time I looked in the mirror, all I saw was the scars. I’m a very visual and detail-focused person, so my eyes automatically go to the scars, and when they do, all I can see is imperfections....My breasts didn’t look natural, especially before the reconstruction was fully done. I didn’t like what I saw, so I covered up thinking [Steve] wasn’t going to like it either....My breasts didn’t feel natural either, so I avoided letting him touch me....I felt like my

breasts became an emotional wall, which ended up being a physical wall....He was telling me that he was just as attracted as he'd always been, but I didn't believe him. My confidence level was shot and so was our sex life for a while.

Steve described his experience with trying to reassure Diana of his attraction:

I was trying to reassure her that I was still attracted....She thought I was just saying nice things, and what I thought a good partner should say....The scars really didn't bother me, and she was the same beautiful woman to me. I believe that showing someone holds more weight than telling them, but she seemed so uncomfortable when I tried to be intimate with her that I kinda backed off.

Other couples expressed that, although they may have continued to engage in sexual activity with their partners, they experienced a decreased sense of intimacy in their sexual relationship stemming from their differing levels of acceptance towards the physical implications of breast cancer, and their inability to align with one another on physical and emotional aspects of connection. Like Diana, Jessica had difficulty adjusting to having breast implants, and she indicated that this influenced how she sexually engaged with Brian. Due to her impression that her breasts looked "weird" and felt like "foreign objects," she continued to engage sexually with Brian; however, remained partially clothed in order to prohibit him from touching or seeing her breasts. She commented that she felt "more self-conscious than ever," while he remarked that she "looked better than ever" but was "shot down" his efforts to compliment her.

Kara also mirrored the connection Diana made between the physical and emotional elements of intimacy, remarking that, "Whatever is physical in our relationship is a sign of our emotional connection." She explained this to mean that she recognized the connection between physical and emotional aspects of intimacy and that these elements each affected the other in

somewhat of a circular fashion. Specifically, she recognized that the emotional reaction she was having to her perceptions of dysmorphia created a barrier to being open to expose her physical self fully to Clark. Kara expressed feeling embarrassed by her scars and stated, “It was no badge of courage. It was something I was hiding.” To which Clark responded, “She wasn’t happy with her body. No matter what I said, it didn’t matter...I couldn’t change the way she was feeling about herself.” He added that he tried specifically telling her he was sexually excited by her, and that he enjoyed seeing her naked. Keith reported that he tried to take a “playful” approach to sex with Debra, hoping to lighten the mood and reduce her apprehensions.

Part of the difficulty for the female partners was trying to gain understanding of how their partner’s attraction to them could remain unchanged when some of the features that originally provoked the sexual attraction had changed. For example, Annika commented, “I know he was always attracted to my confidence. It made me more sexually outgoing. I lost that, and I didn’t know how he couldn’t be different if I was now different.” For most couples, returning to what the couples perceived to be their usual level of intimate connection, or experiencing improvement in this area, progressed in parallel to progress towards body acceptance and responsiveness to partner’s impressions. Once female partners could accept their partners’ own opinions of their bodies, regardless of whether it differed from their own, they experienced a greater degree of comfort and lesser degree of apprehension engaging physically with their partners.

We both enjoyed my new and improved figure! The three couples who indicated that they did not experience disruption in their sexual intimacy all shared the perspective that the changes to their bodies (i.e. breast reconstruction) had positive benefits which they took advantage of. Nancy and Rick commented that they mutually believed that Nancy’s view that

her breast reconstruction was an “improvement” to her figure served as an advantage to their sexual intimacy. Nancy remarked that she “embraced” the positive aspects of the situation even though she was aware of other factors she perceived as negative, such as no longer having the ability to breast-feed in the event that she had another child. Her reconstruction involved tram flap surgery, which involves using fatty tissue from the patient’s own abdomen to reconstruct the breast. In her words, “I got a tummy tuck and new breasts out of the deal.” Rick added that he was aware that Nancy was not satisfied with the appearance of her breasts prior to her diagnosis; therefore, he was excited about the possibility that the reconstruction could help her feel better about her appearance. “That’s exactly what happened,” he stated. He shared that Nancy displayed increased self-confidence and less apprehension about showing her body, and he perceived her as engaging more fully in their sexual activity as a result. She agreed, and added that she felt increased comfort with her body, which allowed her to focus more on Rick than the parts of her body she felt self-conscious about during their sexual encounters. In turn, Rick reported that Nancy’s increased comfort allowed him to relax and engage more fully as well. Both partners shared that they experienced an overall increase in their perceptions of intimacy within their sexual relationship.

Delia and Hugh conveyed a similar story. Like Nancy, Delia was not satisfied with her breasts, and attributed this to having nursed her two children and “the natural sagging that comes when you hit 40,” she stated. She remarked that she was “fit” and exercised regularly, but that there were few ways to improve one’s breasts. She was very satisfied with the results of her reconstruction and stated, “I’m in shape, so now my [breasts] go with the rest of my body.” As a result of her satisfaction, Delia indicated that she did not experience any issues related to her body-image. Instead, she was concerned about how her husband was going to react to the

implants. She described Hugh as “very sexual” and as having a high sex drive. Although she enjoyed their sexual interaction, Delia disclosed that sex was not as important to her as it was to Hugh. Her concerns lay in the fact that she believed, “...Some people can’t get past knowing they’re not natural or feeling the difference,” and indicated that this was “unknown territory” for them. To Delia’s surprise, Hugh was highly satisfied with the results as well and did not experience any changes in his level of physical attraction to her. Similar to Rick, Hugh viewed Delia as gaining additional self-confidence, which was “extremely helpful” during the rest of her treatment. He noted that although they needed to decrease the frequency of their sexual activity during periods of time when Delia was not feeling up for physical activity, he did not perceive this as negatively impacting their sexual intimacy. In his opinion, Delia was able to maintain her sexual confidence by being able to focus on her enhanced figure instead of other features she felt self-conscious about, such as her hair loss and minor weight gain from chemotherapy. He explained, “It was like a balancing factor. She liked [her breasts] and wanted to show them off to me because she knew I liked them too, so it was like she forgot all about her head.” Delia and Hugh mutually agreed that, despite the negative impact breast cancer had on their ability to physically engage with one another, they perceived their overall sense of intimate connection as stable. Delia added that Hugh’s acceptance of the changes in her body helped her feel comfortable enough to want to have sex with him when she was feeling well.

Finally, Meryl and Craig’s experiences featured many of the same components as those of the other two couples. Meryl shared that she was initially apprehensive about having breast implants because she specifically associated them with the fact that she had breast cancer, but also considered the positive effect they would have on her figure. She indicated that she had always been “flat-chested,” and her reconstruction allowed her to have full breasts. She stated,

“Now, out of this awful situation, my body was enhanced in a way that both Craig and I could enjoy.” She and Craig had maintained an active sex life prior to her diagnosis with breast cancer. She attributed her ability to maintain a positive view of her body to the enhancements she perceived as resulting from her reconstruction. This ability to continue to feel confident aided her with being able to continue to enjoy engaging in sexual activity with Craig because she could focus her attention on the benefits associated with the changes to her breasts. Both Meryl and Craig agreed that Meryl’s sense of “womanhood” was enhanced and the impact of breast cancer on her self-image was minimized. They also shared the perspective that their ability to maintain their sexual intimacy contributed to being able to continue to feel emotionally connected, despite the other stresses they were contending with. Meryl added that she recognized a “chain-reaction” had occurred. She commented that the implants helped her maintain the body-confidence she needed to feel comfortable engaging in sexual activity, but that, in turn, keeping an active sex life changed her initial perspective about implants, which was that they were a “bonus” instead of “another thing to make me feel like a cancer patient.”

Unlike the couples who experienced the impact of breast cancer as disruptive to their sexual intimacy, these three couples’ experiences were markedly different. This seems to be primarily related to their perspective on breast reconstruction. Whereas the other female partners struggled with issues related to their body-image, which decreased their sense of self-confidence and desire to engage sexually, these three women perceived benefits to their physical appearance, which aided them in continuing to feel comfortable with sexual interactions despite other treatment related side-effect. In addition, the previous couples experienced difficulties in their ability to relate to their partner’s perspective, which caused further rifts in their sexual intimacy. These couples’ perceptions, however, were highly aligned, which may not have

necessarily increased their sense of intimacy, but eliminated it as a problem they could have potentially faced.

We were tip-toeing around, trying not to upset one another. As couples shared their experiences of the impact of breast cancer on their relationships, some spoke about feeling the need to protect their partners from further distress by guarding the way they displayed their own distress. This entailed behaviors such as hiding one's worries, denying concerns, and yielding to one's partner to avoid further upset, which is commonly known as protective buffering. Although this is often associated with discussions related to communication, couples who described this behavior during their interviews primarily did so within the context of how this impacted their perceptions of closeness within their relationships. They contended that this was not a way of behaving that they typically engaged in, rather, it was in response to the impact that breast cancer had on their relationships. Couples identified that the need to "tip toe" around their partners was based on their perceptions of increased emotional sensitivity, whether spoken or not. Interestingly, both male and female partners engaged in buffering, as well as perceived it as influencing the experience of relational closeness, unlike during the conversations related to initial reaction to the diagnose, where only male partners discussed withholding behaviors. In addition, couples described buffering efforts other than just tempering their verbalizations, which provided further substantiation that the topic warranted inclusion separate from the upcoming discussion related to communication.

A comments made by Meryl and Craig illustrate the overall messages conveyed by several the couples. Meryl noted,

Craig sometimes seemed a little shut-off to me. He didn't want to upset me by letting me see his worry or do anything to make me think he was worrying. He'd put on his

“positive face.” He’s usually a very positive person, but this felt different. It felt a little cold.

Craig responded that he believed Meryl’s impression was correct. He remarked, “Subsequently she felt like I didn’t show her enough caring on my part as far as my being worried about her, but that wasn’t really the case. I was worried. I was trying not to burden her with that.” He added that there were times when he would deliberately avoid contact with her if he felt it would be difficult to hide his worry. This usually entailed going for a run or running errands, which were typical activities that would not be perceived as avoidance by Meryl. Both agreed that during these occasions, they did not experience as much relational closeness as they were accustomed to.

For some couples, the perception of protecting their partners was the focus of their conversations. Annika and Darren shared their feelings about this. Annika explained that she and Darren were worried about one another, and were being “careful” not to cause the other to get upset or feel guilty. Darren expressed that he was selective about what topics of conversation he initiated in an effort to avoid those that might be emotion laden. He added that he tried to remain aware of not complaining about things he was unhappy about because he wanted to “shield” Annika from feeling bad or that she was a burden to him. Rick, Delia, Diana, and Steve specifically indicated that their central motivation for the behaviors they engaged in that constituted buffering was to reduce their partners’ worry for them. Delia shared that she believed it would be difficult for Hugh to stay focused on what he needed to focus on if he were spending too much time worrying about her. Likewise, Diana noted that Steve’s job required a lot of focus, and she did not want him to be distracted by worrying about her. She commented, “I didn’t want to overwhelm him when he needed to have a clear head....I did a lot of

minimizing so he wouldn't worry." Steve mirrored her statement adding, "And I didn't want to give her anything to worry about or make her focus on me instead of herself...If I was overwhelmed, I just pretended to be okay." In these cases, the most common response by couples was that they could "sense" when their partners were purposely masking or buffering and that this created a feeling of "distance" within the relationship.

Clark and Brian shared the experience of feeling the need to yield to their partners in order to not upset them or, in Brian and Jessica's case, to avoid a disagreement. Clark described, "I was walking on egg shells, just not wanting to upset her in any way. That was a huge concern to me, and she had enough to be upset about without me contributing to that." He added that he tried to avoid doing or saying "the wrong thing," so he often acquiesced to her suggestions or withheld a differing opinion. At times, the buffering factor became to "pull back or even stay away to not cause more anguish." Brian shared that, "Sometimes it felt like it was Jessica's bad day every day." He added that sometimes the only ways to keep from upsetting her was to "yes her to death," which meant to do or say whatever she wanted him to, or keep his distance. Their partners both sensed when they were creating space, but admitted that they were also engaging in buffering in order to protect from further upset. Kara admitted that she often told Clark she was "fine" when, in fact, she was not feeling well, because she knew it was difficult for him to deal with emotional issues. "I didn't want to burden him all the time with my craziness. He dealt with it enough. I figured he needed a break sometimes," she stated. Along a similar line of thinking, Jessica tried to avoid complaining about what she was going through because she wanted to "protect [Brian] from having to hear or feel things that he didn't want to," which she indicated would be things that would be emotionally upsetting to him. For these couples, the

feeling of having to sensor themselves, or not be genuine with their partners, contributed to a diminished perception of relational closeness.

Overall, at the time they were engaging in buffering behaviors, couples believed that they were acting in their partners' best interest. When dialogue related to the impact these behaviors had on perceptions of relational closeness, most acknowledged that they recognized this but wanted it to be known that their intentions were good despite the negative effect. Some repeated their motivation to *protect, care for, or shield* their partners and avoid further distress or burden because they recognized the toll breast cancer was taking on their partners and on their relationships. The descriptions offered by couples suggested that these perceptions of diminished relational closeness were periodic and temporary, as opposed to sustained throughout their experiences with breast cancer, and were specific to occasions when buffering occurred. Further evidence of this was noted when some of these same couples shared that, despite these episodes of decreased closeness, their overall impressions were that their relational closeness improved as a result of their experiences together with breast cancer.

Adjustment to the Illness

As couples shared about experiencing the impact of breast cancer on their relationships, they spoke about ways they attempted to cope with the situation they were faced with. Through these conversations, a theme of adjustment to the illness emerged. As dialogues progressed, two primary tactics utilized in efforts to adjust were identified and which constitute the following subthemes: (a) research, and (b) maintaining normalcy.

As they say, if you fail to plan you plan to fail. Five of the couples conveyed that they engaged in research as a means of aiding their adjustment to the illness. They mutually believed that gathering pertinent information about a multitude of breast-cancer-related topics allowed

them to have forethought in their planning and make better decisions regarding how to approach coping and decision-making. Some couples, such as Annika and Darren, verbalized that doing research on cancer and options for treatment aided their adjustment because it enabled them to feel more in control of the situation. Although Annika did the majority of information-gathering, such as searching the internet and acquiring additional literature, she and Darren were able to discuss the findings and mutually compose the questions they wanted to review with Annika's doctors. Darren contributed to the research by also asking additional questions and seeking clarification of any information that was not fully understood. Annika stated, "We didn't just let anyone tell us what was or wasn't going to happen. We looked into it, we asked questions, and we talked about what we had learned." Engaging in the research process together provided the opportunity for both partners to have their questions and concerns explored, and was mutually beneficial to their adjustment. Darren added that it was a little easier to adjust when he had more information about what to expect.

For other couples, such as Delia and Hugh, engaging in research assisted their ability to adjust to the illness by having ideas about what to expect. Delia's experiences were very similar to Annika's, and she described that doing research assisted her with feeling "grounded." She shared, "When I had a clear sense of what was happening and what to expect, I didn't feel so chaotic. I don't like ambiguity, it makes me feel uneasy. The more information I have, the more rationally I can think." Hugh remarked, "She researched everything and brought it to me and we went through it. She's very well-read and looked up everything about it then told me." He indicated that this was extremely helpful to him since he also feels uneasy when he does not know what to expect or how to prepare for a situation. Despite the emotional difficulty that Kara described experiencing, she and Clark also identified that their ability to adjust to the illness was

improved through their active involvement in research activities. Per Kara, “We both got analytical. We did a huge amount of research on cancer, tests, whatever.” She added that, after the initial diagnosis, “There were no surprises. We knew exactly what was going to happen, and what we were going to have to do in order to keep our lives moving.” Clark remarked that being able to be involved in the research gave him the opportunity to feel like he could assist Kara in a way that she would find helpful. He also commented that being able to anticipate the obstacles prepared them to have to manage these and “navigate” around them. Although they did not make a lot of changes in their household routines or other aspects of their lives, he conveyed that they adjusted to the illness enough to “not be bowled over” by the challenges. Kara agreed, and remarked that she did not believe she would have been able to keep her household functioning the way she did if she had not known what to expect in order to work around it.

Lisa and Dan, along with Nancy and Rick, held the perspective that their adjustment to breast cancer was positively influenced by the research they conducted. Not only did they identify benefits of knowing what to expect, they also indicated that they made several accommodations based on the information they had obtained. Lisa stated, “We researched, we planned; we were ready for whatever was dealt to us.” She added that she and Dan obtained as much information about what could potentially happen, and were able to have detailed conversations about the possible ways they could address each of the potentially problematic scenarios. Dan added, “We looked at it from all angles, so there wouldn’t be anything we were floundering around to figure out.” Along this same line of thought, Nancy and Rick believed that they were better able to adjust because they could anticipate and plan for any potential difficult situations. They began preparations based on their research even before Nancy underwent any treatment. This included buying a recliner chair to assist Nancy with sleeping

more comfortably and arranging for her mother to move in for two months to offer assistance. Nancy remarked, “I needed to know everything that was going to happen,” and remarked that she even went as far as watching videos of the surgical procedure she was going to undergo. She indicated that the extensive research they did was not only for the purposes of planning, but also so that she and Rick could talk about what to expect, and she could feel assured that he knew what to expect as well. Rick commented that he felt better prepared to be involved in the process with Nancy because of their research efforts.

For some couples, the perception of adjusting to the illness involved having a sense of knowing what to expect and mentally preparing to cope, while for others this entailed the process of planning for various scenarios or even making accommodations for the impact of breast cancer ahead of time. Despite the differing perspectives, all five couples perceived themselves as adjusting to the illness more effectively as a result of engaging in research efforts than they would have if they had not done research before beginning treatment. In addition, all five couples spoke about their belief that engaging in the process of research, and reviewing the information obtained by one partner or the other, provided them with a way to talk about breast cancer and how it was or was going to impact their lives. Couples also indicated that mutual involvement in the research process lead to mutual involvement in decision-making, including decisions directly related to treatment, as well as those related to the accommodations that would be made to manage the impact of breast cancer.

Normal ISN'T just a setting on the dryer! The most prominent experience shared by couples related to their adjustment to the illness was value they placed on maintaining what they perceived as normalcy. All ten couples expressed a desire to keep things *normal* as they progressed through treatment, though the meaning they found in this varied. Some talked about

normalcy in terms of maintaining daily routines, schedules, and activities for the sake of their children, while others described engaging in their usual activities as a means of distracting their attention away from breast cancer for a while. For several of the female partners, normal referred to a desire to perceive themselves, and be perceived by others, as separate from their illnesses, and their view of being able to maintain their usual lifestyles and routines often served as indicators of their functioning and overall wellness. The meanings couples attributed to their experiences of functioning in what they perceived to be a normal fashion were not mutually exclusive, and some believed the meanings were connected.

Experiences shared by Debra and Keith illustrate that the perception of normalcy served multiple purposes for some couples. They perceived their ability to “keep as much normalcy as we could even though there was nothing normal about it” as an indicator of their adjustment to the illness. They believed that it was in their children’s best interest to maintain the usual routines and structure in their home, and that in doing so, they were contributing to their children’s ability to adjust to the illness as well and experience as little disruption as was possible. In their perspective, maintaining what they perceived as their normal life was an indicator that they were coping effectively with the impact of breast cancer. Debra also explained that involving herself in as many aspects of her “normal life” was helpful for her self-esteem and sense of being productive. She stated, “I wanted to just be Debra, not Debra the cancer patient. I felt like I was losing my identity, and I felt a very strong need to the things I always do so I could feel like me.” She continued on to share that doing as much of her usual routine as she was capable of helped her feel like she had not lost control of her life to breast cancer. Debra recognized that maintaining normalcy required a substantial amount of energy, but both she and Keith believed the benefits were worthwhile, and Keith offered to assist Debra

with activities and tasks so that she could continue to be involved. He stated, “She felt better about herself when she could do something like show up at one of the kid’s games and it made them feel better about things when they saw her do it.” He added that he believed this was beneficial to their overall adjustment to the illness as a family and to Debra’s self-esteem.

Other couples shared their experiences related to maintaining normalcy for the sake of their children and the influence they believe this had on their adjustment to the illness. These conversations conveyed the belief that children’s adjustment was based on how they perceived their parents to adjust to the situation. Couples described feeling that their children would adjust better if they remained involved in their usual activities and had the structure they were accustomed to. In addition, couples believed that if their children witnessed them engaging in their typical routines, it would reduce worry and offer reassurance that their lives were going to be alright. Delia shared that her initial motivation was to “put on a good face” and maintain the routines as much as possible, so that her children would experience as little disturbance in their lives as possible even though she felt as though she were “going through the motions in a daze.” However, she indicated that doing so was beneficial to her own adjustment. She explained,

My therapist uses the phrase “Fake it til you make it.” That’s what I was doing. I was going through the motions even though I felt like crap. But, the reality is that it was helping me cope even though at first I didn’t feel any better. It got me up, ya know, and out of bed and doing what I needed to do instead of isolating myself in my room like I had started to do....I actually started to feel good that I could do it, and I wanted to keep that up.

Hugh added that he had discussed taking time off from work with Delia, but that when she quickly realized the benefits of maintaining the normal routines, she encouraged him to keep his

routine as well. Both Delia and Hugh agreed that this was a good decision for their family, and they adamantly verbalized that it was a significant factor contributing to their overall adjustment.

Kara and Clark's dialogue resembled Delia and Hugh's in that Delia's initial motivation was to focus on what was best for their children, and maintain her "usual presence" even though she was not feeling like her "usual self." She shared that this improved when Clark took over the burden of handling some of the logistical aspects of her treatment, which allowed her to concentrate her attention on her family and household routines. Ultimately, Kara believed that this contributed to her adjustment because it allowed her to "feel like a normal person." She and Clark shared the perspective that their primary way of trying to cope with the impact of breast cancer became to maintain as much normalcy as possible. Lisa and Dan verbalized a similar process in that their desire to maintain the calm, tension-free environment that their children were accustomed to motivated them to work hard at continuing to engage in their usual activities. They mutually agreed that this was beneficial to the whole family's adjustment.

Expressions regarding the desire to feel normal were not limited to female partners, although they did verbalize this to a greater degree. Meryl and Craig shared the perspective that continuing to engage in as many aspects of their usual life as possible was beneficial to both of them. Meryl spoke about how important it was to her to continue working while in treatment. She commented, "It gave me a distraction and helped me feel productive." Craig indicated that he also tried to stay involved with his usual activities. "I thought it was good for me to do my usual things to keep balanced," he explained. They also felt it was important to engage in their usual activities and routines as a couple, and believed that their dedication to doing so improved their ability to adjust together to the impact of breast cancer. Susan and Rob's perspective was similar to Meryl and Craig's, and they expressed their view that maintaining normalcy greatly

influenced their ability to cope with the disruptions caused by breast cancer, but that they believed maintaining the routines they shared as a couple was the greatest factor contributing to their ability to adjustment to the illness.

Messages highlighting the importance of maintaining normalcy dominated the conversations related to coping with the impact of breast cancer on the lives of these couples. This perspective was one of the most prominently expressed ideas throughout the interviews. Regardless of the differences in situations or motivating factors, the general meaning expressed by these couples can be summed up in one simple statement from Jessica, “If things were going normal, then things weren’t so bad after all.”

Communication

As couples spoke about their experiences with breast cancer and their perceptions related to the impact upon their lives and relationships, they were asked to share about the ways in which they communicated about breast cancer as a couple. Couples primarily spoke about the communication that occurred within their own households and were limited to the following relationships: (a) communication between partners and (b) communication with children. These represent the subthemes which emerged within the theme of communication about breast cancer. It should be noted that couples did speak about communicating with others outside of their households; however, this was generally in the context of conversations about their support networks; therefore, will be presented during that discussion.

The art of surviving lies in logistics. As couples described the way they talked about breast cancer with one another, patterns in the ways in which couples related to one another became more salient. Most couples identified that their conversations about breast cancer were predominantly focused on the logistical aspects of managing the impact of the illness. Upon

further synthesis of the interviews, it became apparent that focusing attention on the logistics served a dual purpose within most couples. From one viewpoint, it was a task of necessity. In order for couples to make treatment-related decisions and coordinate their households, they needed to review the details of the situation, assess their resources, and plan accordingly. Taking this approach was generally viewed as a means to avoid chaos and the break-down of the family systems. From another viewpoint, it was a means of avoiding conversations related to the difficult emotions being experienced in the wake of breast cancer. These two aspects of communication were not exclusive of one another, rather, were mutually present within several of the couples.

Annika's description of the communication between her and Darren illustrates the dual functioning of logistical dialogue. She stated, "Our conversations were a lot about logistics.... [Darren] usually resorted back to this because it was too hard to talk about the emotions going on inside." Annika added that, although she recognized that it could have been beneficial for them to verbally share their emotions with one another, she acknowledged that Darren's "task-focused" approach was helpful in helping her stay "grounded" and "not let my emotions take over." Darren agreed with Annika's depiction of the situation and added that engaging in logistical conversations allowed him to remain "thinking logically instead of emotionally" and "stay strong for her." Similarly, Kara had characterized herself and Clark as a "doing" as opposed to "feeling" couple, and the description she provided of their communication style illustrated this perspective. She explained, "We're really good at talking about what we need to do, so that's what we did. We're very much in sync that way. We don't do the touchy-feely, emotional thing." She and Clark took pride in the way they coordinated their lives around breast cancer, and Clark shared that communicating in this fashion was "easy and natural" for them.

Like Darren, Clark acknowledged that taking an “analytical” approach with communication made it possible for him to “be that rock” that he felt he needed to be. Like Annika, Kara shared that she believed it would have benefitted she and Clark’s relationship if they had been more “open” about their feelings, but that she could not expect him to “be who he’s not just because [she] had cancer;” however, she was extremely proud of how effective she and Clark were in communicating about the logistics of managing breast cancer.

Couple after couple described their communication in terms of their focus on logistical aspects and illustrated the dual functioning, as evidenced in the following sampling of responses:

Lisa: We talked about the ‘what if’s.’ We went through the whole gamut of what could potentially happen....We talked about a plan for every scenario we could think of....We talked about everything.

Keith: We took a work-man-like approach....Our communication basically involved talking about what needed to happen to keep our family functioning. We talked about stuff like options for treatment and what was going to happen, then we came up with a plan together....It was very straight-forward...We kept our emotions out of it...well I guess I did anyway. I did the “brave guy” thing.

Craig: I didn’t want to overwhelm her by belaboring the situation. My conversations were usually task-focused....What’s our next step? What do we need to do?

Steve: We talked about the things we needed to plan for. I needed to, so I could know how to help her. And I think she needed to, so she could slow down her thoughts and think more rationally.

Brian: We avoided talking about emotions in favor of the practical side.

Delia:I tried to only talk about the factual things, the appointments, the next steps, the things we needed to make decisions about. Those things I knew he would talk about with me.

Nancy: We talked about tactical stuff. Being that [Rick] is in a sorta military job, that's what he does. It's all about our plan of action, as he puts it, and being prepared. We talked through every aspect, every possible scenario. We talked about changes that could occur. We planned and planned and planned. I didn't mind it because it made it all less scary.

Although couples primarily identified buffering behaviors within the context of the emotional impact breast cancer had on their relationships, the couples' conversations about the ways in which they communicated illustrated the points made during those discussions. In addition, the focus on logistics as a way to avoid emotional conversations made it possible for several male partners to continue to project an image of being strong for their partners. It was clear that to venture into the emotional may put the ability to maintain the brave front at risk. Essentially it could be deduced that focusing on logistics was a way for male partners to emotionally survive breast cancer. On a side note, an interesting observation was that nine out of ten couples identified that communication revolved around logistics at the exclusion of emotional experiences, yet several couples made the statement that they "talked about everything" together.

Laughter is the best medicine, as they say. With conversations about ways in which breast cancer was talked about, five couples expressed their belief that humor was a positive characteristic of their communication styles. These conversations were relatively brief; however, clearly conveyed the value couples found in incorporating humor into their conversations about

breast cancer. Although a little more subtle in nature, humor seemed to serve a dual purpose. Some couples suggested that humor made it easier to talk about difficult topics, as well as provided a distraction away from emotion-laden discussions.

Susan described Rob as “very witty and just the right amount of sarcastic” and remarked about his ability to use humor as a way to draw her out of a “negative mind set.” She commented, “He always knows when to use a joke to lighten me up...” but noted that she never perceived his humor as minimizing her experiences. “We probably laughed more than most couples going through breast cancer. I’m so grateful for that...” she stated. Rob expressed that he initially avoided using humor because he did not want to appear disrespectful; however, quickly learned that returning to his usual way of incorporating humor worked well for both her and Susan. He recognized that she responded well to it and it was a helpful way to distract her from getting “stuck” in negative thinking. In addition, he found it easier to communicate with Susan about sensitive topics when the climate within their relationship “wasn’t so serious.” He explained, “I never made fun of her feelings, but I did find it a lot easier to talk about the heavy stuff if we could find something to laugh about in it.” Meryl and Craig’s experiences and perspectives on humor were congruent to Susan and Rob’s. As Craig explained, “I make jokes about everything, as long as it’s not going to be hurtful.” He commented that he likes to use quotes to express himself and “laughter is the best medicine” is one of his favorites. Meryl agreed that, “in this case,” Craig’s humor was helpful with getting her to focus on “something other than what was going wrong.”

Keith and Rick also expressed that using humor made it somewhat more comfortable for them and their partners to communicate about difficult topics. Keith described himself as “playful” and indicated that, when appropriate, he often took this approach when talking about

issues that were particularly sensitive, especially those that Debra was feeling self-conscious about. “If I could get her to laugh about it or see it from a humorous point of view, she usually didn’t feel so bad about herself or whatever the issue was,” he explained. He gave the example of using humor to “lighten” a conversation about the difficulties he and Debra were experiencing in their sex life. He explained that Debra was feeling very self-conscious about her appearance, so he approached the issue with playful banter about role-playing and joked about ways they could use her appearance to their advantage. Debra responded well to Keith’s use of humor because she recognized his motives to help her, and she believed that he was very conscious of incorporating it appropriately. She stated, “It made it a lot easier to talk about. I know it wouldn’t have gone as well for either of us if it was all serious.” She made the point that humor actually made conversations productive because it provided a way for them to relate to one another and distracted away from the ineffective cycle that was typical of their emotionally difficult discussions. Rick’s perspective closely resembled that which Keith described, and Nancy added that, “We used humor and we laughed a lot. It kinda made things not so scary.” She shared her belief that this was true for Rick as well, although he did not directly state this himself.

Steve and Diana’s dialogue regarding humor touched on many of the previously discussed points. Diana also described Steve as “witty,” and shared that when she could experience Steve being humorous during their interactions about serious topics, she felt a reduction in her level of anxiety because she interpreted this as a “sign” that he was “doing okay” with the situations they faced. She commented, “When he stops laughing and joking, you know something’s wrong or he’s not alright.” Steve agreed that humor “comes naturally” to

him, but that it was even more important during their time coping with breast cancer. He remarked,

I know I made jokes to lighten things up when it got real intense. I'm not very good with knowing what to say when things get like that. But, that's not the only time I kidded around. She thinks a lot about everything, and it makes her more anxious. I knew if I could make her laugh, then she could relax a little. Usually it helped her stop overthinking because I was showing her that whatever it was she was worried about wasn't a big deal to me....What I mean is she was usually worrying that something was going to be hard for me, so if I could be light-hearted about it she could stop worrying....I have to be honest and say though that being goofy was self-serving at times. I love seeing and hearing her laugh. I guess when I could have that, I felt like everything was going to be okay.

It was evident from the couples' accounts of their experiences with humor in this context that both male and female partners perceived benefits to including this in some of their conversations about breast cancer. It was also apparent that those who expressed humorous ideas did so in ways that demonstrated their conscientiousness and respect for their partners. In addition, some verbalized being aware of the ways in which they used humor to distract away from uncomfortable situations, yet, did so in ways that did not minimize their partner's experiences or demonstrate inappropriate timing. Humor had been a regular characteristic of these couples' communication styles before breast cancer entered their lives. It was an element of their relationships that they were already accustomed to. Essentially, these couples learned how to talk about unfamiliar topics in a familiar manner. They went back to what they knew and

found a common way to relate to one another, especially during conversations where this was difficult.

We need to help them understand without scaring them. Six out of the seven couples who had children living at home at the time of the breast cancer diagnosis and treatment spoke about their experiences with communicating about cancer with their children. The couples' discussions of this subtheme were far less extensive than those related to their communication with one another; however, this is not unexpected since the couples were aware that the focus of the study was on the couple relationship and the interview protocol primarily focused on the interactions between partners. Despite the limited dialogue, there was a common perspective among the couples, which was that children would gauge their reactions by watching and listening to their parents. There was a general understanding that children would comprehend the meaning of the situation based on the cues presented to them.

Most couples expressed their opinion that the best way to communicate with their children about cancer was in an honest and open fashion, allowing the children to ask questions at will. Couples' responses provided evidence of their awareness of using age-appropriate language and considering what content was within their children's abilities to understand. In addition, couples shared the responsibility of talking with their children about breast cancer.

Lisa and Dan shared their experiences of talking to their two young daughters. Lisa explained,

We were careful how we spoke with them because they were watching everything we did and how we were reacting. We had to be honest with them, but we were aware that they were going to react however we presented it to them. It was really a learning experience for us...to really step back and figure out what is the best way to communicate this.

Dan explained that they also chose not to give their daughters all of the information at one time. He remarked, “We told them what they needed to know step by step as things were happening.” The couple mutually agreed that they believed this would help their daughters prepare for each phase without overwhelming. Lisa and Dan indicated that they encouraged their daughters to talk freely about their thoughts and feelings, and found ways to have them be involved with the process or helpful, so that they would have opportunities to talk about what was happening. Nancy and Rick’s approach was similar and Nancy added, “He’s a smart kid, but we didn’t want him drawing his own conclusions. We wanted to talk with him together, up front and honestly, because we knew he was going to take his cues from our reactions.”

For some couples, the most difficult aspect of communicating about breast cancer was finding the appropriate words to help guide understanding and reacting. Delia and Keith shared that they initially tried to talk about what was happening without using the word *cancer*, or, as Debra referred to it, “the ‘C’ word.” She and Keith believed that the word would induce fear and worry in their children, especially the two older children who knew what cancer was. They tried to talk about the illness without putting a name on it with the thought that using less descriptive language would create an impression that the problem was mild, and convey the message that there was nothing for them to worry about. This tactic did not work as they had anticipated. In fact, according to their report, the opposite had occurred. In their perception, the vague nature of their explanations had caused more anxiety for their two older children because they had awareness that something was happening, but did not have the means to make sense of it. Debra shared, “They filled in the blanks on their own and started to imagine horrible things.” They were encouraged by their son’s school guidance counselor to talk more openly with their children. This was after a teacher had noticed some changes in the children’s demeanor. Debra

and Keith changed their approach and chose to speak with each child separately in order to provide the details appropriate for his or her level of understanding. In addition, they focused on offering their children the reassurance they needed and encouraged them to ask any questions they had. They indicated that they observed that their children spoke more openly about what was happening and how they were feeling once they changed their approach. Debra verbalized that she understood how their “shying away” from the topic may have given their children the impression that they needed to do the same. She and Keith also continued to talk with them throughout the process to model that it was acceptable and encouraged to do so.

Finding the language to ensure accurate understanding was imperative for two couples in particular. Jessica and Brian spoke about the “necessity” of being open and honest with their son in order to help him understand that his mother’s breast cancer was not the same as his grandmother’s had been. Jessica’s mother had passed away as a result of breast-cancer-related complication. Although their son was not yet born at the time of his grandmother’s passing, he was aware that she had died from breast cancer. Jessica stated, “We had to help him understand because all he knew was that people die from breast cancer. We had to talk to him about it, so he could see that this was different and it’s not the same for everyone.” Brian commented, “He wasn’t sheltered from anything going on. We believe in being honest with him, but we made sure to put it in terms he understands, so it didn’t totally freak him out anyway.”

Susan and Rob’s situation was similar in that they were concerned about how their children would react to hearing the word *cancer* since they had also lost a loved one to the disease. In their case, the loss of Susan’s father as a result of cancer came just weeks before she was diagnosed. The most complicating factor was that they had told their children that their grandfather was going to be okay. They experienced a tremendous amount of difficulty trying to

find ways to communicate that Susan was not going to die like their grandfather had. Susan stated, “That had to be the worst day of my life....I’m telling them I’m going to be okay. They didn’t want to hear that because they didn’t believe it.” Rob shared that this was one of the hardest part of dealing with breast cancer for him as well. He stated, “I can still remember them looking at me like they didn’t believe me either.” He shared that they had intended to offer their children reassurance, but instead, “it was like we had lied to them.” They focused their attention on continuing to offer reassurance and encouraging their children to talk about their feelings. They provided them with the information they needed about what was going to happen and continued to distinguish Susan’s situation from her father’s. They paid particular attention to letting the children know about positive progress and feedback received from Susan’s doctors. They monitored their reactions knowing that the children would be “looking for evidence that everything really was going to be alright,” as Keith explained it. This also included allowing the children to see them laughing or being humorous about appropriate topics. They shared that their children slowly began to communicate more with them, and they noticed a significant reduction in the emotional upheaval as they continued to do so.

Finally, Kara and Clark identified that a key component of their communication with their children was that used a weekly family meeting a forum within which the children had opportunities to get information about what was happening, ask questions, express their thoughts and feelings, and observe their parent’s reactions. Kara indicated that she was open with the children about what she was experiencing, while Clark preferred to communicate about the “concrete facts.” Both actively engaged in offering their children reassurance. Clark shared that he did not voice concerns or any emotional reactions he had because he believed that if the children saw him as “okay” they would feel like they were “okay” as well. He verbalized that he

understood that the children's sense of security would be based on how well they perceived their parents to be. Kara commented that she also did not voice concerns because she did not want the children to worry, but she was more open about other aspects of her experiences, such as when she was not feeling physically well. Kara and Clark mutually agreed that utilizing a family meeting was highly effective in opening the lines of communication within their family. They reported that their children engaged well and took advantage of the opportunities to talk. Kara expressed her sense of relief knowing that, even if their schedules were busy, time was set aside to ensure their children received the support they needed.

Overall, the couples conveyed a high degree of satisfaction regarding the effectiveness of their communication with their children, despite the difficulties they may have experienced early on. They were able to focus on the effective ways they communicated with their children throughout the process instead of only the problematic beginnings. More so, they expressed a great deal of pride in their abilities to come together as partners and work towards finding shared language in order to mutually engage in the task. This was especially relevant because some of the couples acknowledged that they were able to communicate better with their children than they had with each other, and they had been more effective with finding a mutual way to communicate when they came together for this purpose than they had in their efforts to relate with one another. As Jessica stated, "We might not have figured out how to talk to each other, but we came together when it came to talking to our son."

Resources for Support

Couples identified the fundamental sources they utilized for support in order to cope with the impact of breast cancer on their lives. Each of the following entities emerged as a subtheme

of resources for support: (a) perceptions of relational care-taking, (b) family/close friends, (c) community, (d) medical/clinical, and (e) religious/spiritual.

When you feel so vulnerable, it's a relief to be in the hands of someone you trust. All ten couples identified that their primary resource for support was their own relationship. Acts of care-taking by one's partner were perceived as the most significant forms of support by most couples. Although the experiences of female and male partners differed in that female partners were primarily the recipients of caring acts while male partner were primarily the providers of such support, both partners perceived the relational support as a shared experience. Both female and male partners spoke about benefits they experienced as a result of engaging in relational care-taking.

Female partners who underwent surgery that required the placement of post-surgical drains shared the perspective that the physical care offered by their partners was the most meaningful support they had received. These women described feeling extremely vulnerable due to several factors, including being unable to independently perform their activities of daily living (ADL's), being seen at what they perceived as their worst, and having what they identified as unpleasant medical issues which needed to be attended to. Their stories conveyed that the trust each felt towards her partner made him the only person she felt comfortable enough with to have take care of her in such a personal manner. Delia commented, "It was nice to have a partner to help you deal with it. Someone to lean on; someone who you trust so much to help you with embarrassing stuff or see you at your worst." Likewise, several of the male partners spoke about satisfaction they experienced at being able to support their partners in such personal and meaningful ways. Darren shared about his experiences related to caring for Annika's physical needs:

I think it's like, because you do all these things, empty surgery drains and wash her hair, things like that, you become closer. When I was doing these things for her, it made me feel closer to her because it made me feel like I'm doing things she wouldn't be comfortable letting anyone else do. As I do these things that require real closeness, then we feel even closer because of it. It's almost like you're invading someone's personal space and only someone close is allowed in that space.

He described feeling satisfied that there was a level of trust within their relationship that allowed this support to occur. Annika responded, "It was a very vulnerable time, and nobody else saw or did the kinds of things that he did."

Similarly, Steve played an active role in caring for Diana and experienced satisfaction in doing so. He explained,

I couldn't take the chemo for her or fix the nausea and fatigue, but I could get pillows for under her arms and empty her drains. At least there was something physical I could do that made me feel like I was helping her heal...I could wash her hair and bathe her. I wanted to be supportive instead of on the sidelines, and I wanted her to feel taken care of.

It was initially difficult for Diana to accept that she needed to rely on someone, but she came to recognize that Steve's willingness to support her in this manner was his way of showing his love and commitment to her. "He challenged my thinking that I had to do it all by myself," she remarked, and credited him with easing the discomfort she experienced over feeling helpless. She described Steve as "squeamish" when it came to medical issues and acknowledged that "He was doing things he never dreamed he'd be able to do," and that he "stepped out of his comfort zone to be there for everything I needed."

Female partners expressed gratitude for their partners' willingness to be their primary source of support and acknowledged that this was not always an easy role to be in. Susan commented,

He did a lot of things that he normally would never even think of doing. If you just say the word "blood," he would probably hide in the corner. Yet, here he was emptying my drains and taking care of my incisions. That was a big thing for him, and I knew it, and for him to do that made me feel how much he loved me. I can't even put into words how much I appreciated that.

Male partners also appreciated the efforts their partners made to try to support them in any ways they were able. Rob stated that he appreciated when Susan would try to do thoughtful things for him just to show her care for him, and her gratitude for his support. Nancy shared, "[Rick] was my support network. The drains and stuff, he helped me with that. He washed and dried my hair when I couldn't pick up my arms. He took care of me in every possible way, and I'm so thankful."

Statements made by Craig illustrate the overall messages conveyed by couples about the meaningfulness of finding support within one's own relationship. He explained,

It seems to me that support should start at home. Forty-six years ago I took a vow that I would love and support her for better or worse, in sickness and in health. It's important for me to stay true to that. I wanted to be that for her. She's the most important person in my life. Besides, I wouldn't trust anyone to take care of her like I would....It seems so logical that your partner should be the person you rely on first, the person you trust and count on to get you through the hard times....But I know not all couples have that. Meryl says all the time how she knows of women who have to look for support from other

people because their husbands are too busy or self-centered to be there. To me, that's just downright sad. I know she appreciates what I try to do and that makes it worth doing.

We were together every step of the way. Experiencing one's partner as being *present* and *available* was identified as a principal characteristic of the support experienced with the couples' relationships. This was chiefly described in terms of attending appointments and treatment sessions together and being present to offer support during those times. As discussed in the previous section, despite the differences in roles, both female and male partners perceived this support as shared based on the fact that they were engaging in these activities together and with the mindset that they were mutually involved in processes associated with breast cancer. The presence of one's partner at appointments and treatment sessions was viewed as supportive for both practical and emotional reasons. Meryl spoke about how helpful it was to her to have Craig drive to the appointments because it provided an opportunity for them to spend time together before an appointment, which helped ease her nervousness, and it relieved her of the burden when she was often not feeling exhausted after treatment. Jessica stated,

[Brian] was involved at every step. He was at every appointment. He gave his input and had a say in what was going to happen. Even if he just sat in a waiting room, I saw that as being supportive because he took the time to be there for me.

Male partners shared their experiences of being present to attend appointments and treatment sessions. Steve responded that it meant a lot to him that Diana allowed him to be involved in every aspect of her care. He felt it was important for him to be present, so that he could have the information and feedback he needed in order to be able to care for Diana's needs in the best way possible. He expressed his view that Diana was supporting their relationship by not excluding him from significant events. He stated, "We do things as a couple. That's how we

show our support for each other, and I didn't see this as any different. I'm not gonna just be there when things are easy, then bail when they get hard." He added that he wanted to handle every step of the process together as a couple. Craig voiced his belief that "just being there is the easiest way to show support, yet, it probably holds more weight than anything else you can do."

The responses offered by the other three couples who identified being present as a significant characteristic of the support within their relationships, were analogous to those presented here. The responses above embody the overall shared messages conveyed with the couples' conversations. Interestingly, several couples expressed their perspective that physical acts of caring, and being present and available, compensated for the deficits they experienced in their communication and offerings of verbal support through conversations about emotions. Although Annika and Darren were the only couple who actually used the word *compensated*, other couples expressed this general idea by indicating that *showing* emotional support "made up for," "balanced out," or "counteracted" not *verbalizing* support. Some male participants commented that they found it easier to do specific acts to show their support than to talk about it.

A kind word goes a long way...most of the time. Eight of the ten couples identified statements of reassurance and positivity as an element of the support within their relationships. Interestingly, they mutually discussed this in terms of support as opposed to communication. Some female and male partners experienced this differently and described varying perspectives on how these statements contributed to their perceptions of support. For example, some female partners had talked about how their partners frequently encouraged them to *think* or *be positive*. Although they appreciated their partners' abilities to focus on the positive, some women perceived that their feelings and experiences were not always validated by these statements or that it was not viewed favorably if they could not maintain a positive outlook; therefore, they

limited how they expressed themselves. Meryl commented that Craig's persistent encouragement for her to "stay positive" left her feeling like she could have used "a little more validation" of her feelings. She rarely contested Craig's statements because she figured his "positive nature" was good for her. She stated, "He's a very firm believer in the power of positive thinking and that philosophy has been very good for him." Despite feeling that his "positive attitude" prevented him from being able to relate to what she was experiencing at times, she was hesitant to confront him about this because she did not want to discourage him. Jessica commented that Brian's frequent response to her to "be positive" sometimes left her feeling that she could not go to him when she was having difficulty expressing positive thoughts because she perceived that there were times when "it wasn't okay to not be positive." Despite her own reactions, she understood that Brian was trying to help her achieve a more positive mindset.

Regardless of the negative aspects, female partners continued to identify these statements as a component of support. These female partners, and others who had similar experiences, spoke about recognizing that their partners had good intentions when offering these encouragements. Through further inquiry, it became apparent that the good intentions, which were the motivation behind these statements, were what these partners perceived as supportive. They recognized that their partners had made efforts towards being supportive; therefore, they were able to embrace this, despite whether or not they actually found the behaviors helpful. It should be noted that not all statements encouraging positivity were perceived in manner described. It often depended upon the female partner's mindset at the time, or in what context the statement was made. In addition, not all female partners perceived statements to think or be positive as invalidating. Although it was important to introduce the above information, note

relevant observations, and illustrate the dichotomous nature of the perceptions expresses in order to provide an accurate representation of the topic, the discussion below highlights the couples' overall perspectives regarding statements of reassurance and positivity as aspects of relational support.

Offers of reassurance were viewed by some couples as a positive component of the support they experienced within their relationships. Lisa and Dan identified this as one of the most meaningful forms of support that they experienced. Lisa shared that Dan's reassuring statements provided her with the confidence and strength she needed to exert her control over breast cancer. She provided several examples including making the decisions to shave her head once her hair started to fall out from chemotherapy and go out in public without a wig on. With regards to shaving her head, Dan had offered her reassurance that she was "beautiful in his eyes" no matter what, and that her hair did not impact his love for her. He also reassured her that it was the right decision because it would relieve her of the discomfort of watching it fall out each day. When she had contemplated not wearing her wig in public, but was feeling too vulnerable to follow through, he had reassured her of her own inner strength, and reminded her that she "could handle it." She remarked about how appreciative she was of Dan's support, and stated, "I don't think I could have done those things without his reassurance."

Dan and Clark both described feeling supported by their partners through the reassurances they received regarding the efforts they put forth to be helpful. Dan remarked that Lisa's assurances that he was doing a good job with unfamiliar "female parenting tasks" and caring for her and their family restored his confidence during times when he was struggling to manage the added responsibilities. Clark also experienced Kara's reassurances as confidence-restoring. He explained that he often felt inadequate in his abilities to care for her in helpful

ways and frequently did not know what to do. She conveyed her appreciation and approval of his efforts. He stated, “She always tried to make me feel good about what I did.” Kara commented that, although Clark struggled with being able to offer her the emotional support she needed, she tried very hard to positively reinforce that she valued the other ways he contributed to her care and well-being. She stated, “I wanted him to know that what he was doing really did make a difference.” She described reassuring him that tasks he deemed as insignificant were actually quite significant for her.

Statements of reassurance were also viewed as supportive efforts to offer comfort. Annika and Nancy both spoke about the calming effect of their partner’s words. Annika indicated that Darren “was always telling me that everything was going to be okay, and we could get through this together.” She added, “Sometimes I just needed to hear it from him before I could believe it. It helped get me out of my funk.” Nancy explained that Rick’s way of reassuring her that she was making the right decisions regarding her treatment greatly reduced her anxiety. “He reminded me that I’m smart, and I’m strong, and I can make the best decision for myself, but it was good to know that he was going to back me up on whatever I decided to do.” Steve talked about how he perceived Diana’s effort to reassure him that she was alright as very supportive. He stated,

It’s something she went out of her way to do for me. Even if I never said it, she could tell when I was worried or scared for her. She made sure to look at me, so she could see that I was paying attention to her, and then she would tell me that she was okay. She never let me sit with those feelings....I don’t think a lot of people going through what she was going through would spend so much time thinking about what their husbands or boyfriends were going through. Usually, it’s the well person reassuring the one with the

illness that they're going to be okay. I did that too, but it means a lot to me that she wanted to support me as much as I wanted to support her.

Couples also expressed their ideas about the ways in which statements of positivity were perceived as supportive. Diana described feeling “uplifted” by Steve’s positive attitude and remarked that she was able to draw strength from this when she was “preoccupied with the negative stuff.” She acknowledged that Steve was proficient in knowing when it would be helpful and when it would not be well-received. She remarked, “I tease him that he made a great cheerleader. He really did though. He knew exactly when I needed the positive reinforcement.” Susan shared this viewpoint and commented that Rob “had a knack for putting a positive spin on things” when she was only able to see the negatives.

Male partners also shared their experiences, but this was predominantly in the role of offering the support. Rob verbalized his belief that keeping a positive attitude was in both his and Susan’s best interest. He explained, “I tried to stay as positive as I could. I thought it was the right thing to do and would keep us from getting too down in the dumps.” Brian’s response to Jessica’s disclosure (discussed above) that she did not always find his positive statements helpful was that he believed, “if we stayed positive that something positive would come of it.” He reiterated that he had good intentions and did not intent to be disrespectful of Jessica’s feelings. He added that he wanted to try to help lift her spirits and did not know any better way to do so. He did express his appreciation of Jessica’s willingness to recognize that his “heart was in the right place.”

Despite the fact that some people may view a few of these support measures as unidirectional or more heavily directed towards one partner, these couples conveyed that they perceived benefits to both partners. Partners mutually agreed that, since both actively engaged in

acts of caring together, regardless of who was offering and who was receiving, these were shared experiences of relational support.

We were fortunate to be surrounded by great family and friends. Secondary to the support couples perceived within their relationships, many identified positive experiences of support offered by those they considered closest to them, including both family and friends. Couples spoke about both individual and shared experiences. During conversations related to individual experiences, family and friends were frequently linked in conversations pertaining to gender-specific ways of offering support. This was less evident during experiences shared as a couple.

Couples who perceived the support provided by family and close friends as shared experiences, expressed appreciation for both the practical and social benefits they were offered. Eight couples in total shared their perspectives about the support they had received. For some, the assistance of family willing to help with household tasks was invaluable in relieving the stress partners felt over trying to manage these responsibilities, along with the demands and limitations associated with treatment. Female couples perceived this assistance as beneficial in reducing the pressure they felt to try to accomplish more than they were physically able to in an effort to maintain the household functioning. Susan and Rob voiced their gratitude for the support Susan's mother provided. Susan indicated that, if it were not for her mother's help, tasks such as cleaning and laundry would often have gone undone. Lisa and Dan felt a large burden lifted when family members assisted with meals, knowing that both Lisa and Dan were generally exhausted by the end of the day. Lisa and Debra found it helpful to have family members available to accompany them to treatment sessions in their partners' absences.

Partners mutually agreed that the assistance offered to them made it possible for male partners to continue to work, and relieved them of some of the added burden of responsibility placed on them during this time. Nancy and Susan both expressed feeling guilty at times that their family members were taking on these responsibilities in order to provide relief; however, they, along with Debra and Lisa, recognized that their family members were experiencing benefits of being involved as well. Susan shared that she believed providing support helped her mother feel useful. She added that, since her father had passed away not long before her own diagnosis, her mother's ability to be a source of support aided with both distracting from her own grief, as well as helped her healing process by feeling that she could ease her daughter's discomfort when she had not been able to do so for her husband. Nancy also perceived that "feeling helpful" was beneficial to her mother. Although she described feeling "smothered" and "babied" by her mother, she genuinely appreciated her mother's willingness to move in for two months in order to help take care of her. She found it difficult to balance her need for independence with her mother's need to care for her. She stated,

It was tense sometimes, but I can understand how hard it must have been for her.... As a mother to see your child in pain and want to do everything possible to make it better. I respected that, and I really did appreciate the help, so sometimes I had to learn how to keep my mouth shut and just be grateful. I'm lucky to have a mom like that.

Lisa and Debra's family members had also conveyed a desire to help, which made it easier for them to accept the assistance without feeling guilty. Debra remarked, "When I saw that it made them feel better to be able to help, I didn't feel so much like I was inconveniencing them." Keith added that, although he generally preferred to be present at Debra's appointments, he was occasionally willing to step back in order to create opportunities for her family to be involved.

Five of the couples shared their experiences related to the benefits they perceived from the social support offered by friends and family. Many described that these engagements as balancing agents in that they provided opportunities to incorporate laughter and leisure into their lives, as well as enabled temporary distractions from the stresses they were dealing with. The following examples illustrate the perceived benefits to coping experienced by the couples.

Annika and Darren perceived the social support from friends aiding their efforts to maintain normalcy. Annika stated,

We went to barbecues, family gatherings, and as many of our usual activities even if I couldn't participate as much as I wanted to. It was a good distraction. Being able to have fun with people we were comfortable around was great. Our friends definitely got that it was a break from the crap for us, so they went out of their way to invite us.

Likewise, Meryl and Craig relied heavily on socializing with friends and family, and perceived the support they received as positively contributing to their ability to maintain positive outlooks and balanced moods. Similar to Annika and Darren, Craig and Meryl utilized the social opportunities available to them because they shared the belief that engaging in leisure activities helped promote a sense of normalcy within their relationship. Acts of support also included practical efforts, such as preparing meals or assisting with errands and household tasks; however, the couple viewed the offers of companionship as especially beneficial to their emotional well-being. With regards to their close friendships, Craig commented, "Even with all that went on they remained constant..." Steve mirrored Craig's sentiment in his conversation about the significance of friends and family simply being present. He commented, "Even just to have someone show up to cheer us up or to sit with me in the hospital for twelve hours to keep me company and help me keep it together while [Diana] was in surgery. I learned how valuable

even the smallest efforts were.” He acknowledged that they would have “survived regardless” and figured out how to manage their practical needs, but that experiencing people “being there for you, literally” made the process easier.

In terms of the individual support partners received from family and close friends, female partners primarily spoke about the coping benefits they experienced through their social interactions with other women including, but not limited to, other survivors. Eight female couples remarked about the value of having female connections and supportive relationships with others who could relate to them as women. Many conveyed that they received emotional support in ways that their partners were not able to provide. Kara’s dialogue about her experiences included many of the points made by other female partners as well. She explained that her primary support network was comprised of a group of female friends whom she felt very close to. Despite the fact that these women had never experienced breast cancer, and, therefore, may not have fully understood what she was experiencing, she felt that they could relate as women. In addition, she expressed that the most valuable aspect of their support was often providing her with the opportunity to talk about her feelings, which she felt inhibited to do at home. She remarked, “They would just let me talk through the emotional part of it. I didn’t need them to respond.” She added,

I relied on them a lot. I could speak to them multiple times a day if I needed to and they were always willing to offer me support....Most people would probably get tired of hearing someone ramble on, but they never did, or at least never let on to me....I always knew someone was there when I needed to talk, or laugh, or forget for a while. They were really good at getting me to laugh.

Kara spoke briefly about also having a close family friend who was going through treatment at the same time that she was. She shared that "...there was something comforting about when we spoke...that she knew exactly every emotion I was talking about. It made me feel less alone in what I was going through." She described this relationship as unique to the others because she and this particular friend connected on a personal level in a way that "only two people who have gone through it can truly understand."

Other women shared similar stories and highlighted the unique aspects of their personal experiences. Jessica described that her and Brian's opinions differed when it came to using humor as an outlet for serious issues. She noted that she was able to make jokes and "goof around" with her sister and girlfriends, which "broke the tension of the situation." She stated, "I couldn't joke about boobs and girl stuff, and especially not cancer around [Brian]. He was always so serious, and he didn't get it anyway." Nancy remarked that the support she received from a few close girlfriends encouraged her to open up and share about her experiences. This was particularly valuable to her because she had chosen to limit who she chose to disclose to about her situation because she was concerned that their reactions would overwhelm her. Having this trusted group of friends allowed her to obtain the emotional support she needed while still feeling that her privacy was protected. For Diana, the support received from close girlfriends helped ease her preconceived ideas that she needed to be self-reliant. She had generally maintained the role of care-taker and had difficulty accepting that she needed support. She shared,

My girlfriends were going to be there to support me whether I asked for it or not, and of course I didn't. But they made sure they were there anyway. They even talked to one another to make sure I had what I needed because they knew I wouldn't ask....Once I let

my 'I can do it myself' attitude go, it actually felt good to know I didn't have to do it by myself.....You learn who your friends are...They had my back all the way.

Interestingly a few male partners commented on their thoughts about the importance of their partners having female companionship and their recognition that these relationships offered a different type of support than they were able to provide. Steve shared, "It was comforting to know that [Diana] had girlfriends who support her better than I could or relate to things I knew nothing about." Hugh offered an equally valid perspective. He stated that Delia had limited female friends she could rely on to offer her support, and he described that her sister "wasn't very strong or supportive"; therefore, he felt very satisfied that his own sister had stepped in to be a resource for Delia. He remarked, "Just sitting with her woman to woman was huge. She could be there for her in ways I couldn't." Delia agreed that her sister-in-law was a resource to her and commented that she appreciated the support offered by her and a few other close friends because she did not have many sources for emotional support. She indicated that Hugh discouraged her from talking about breast cancer when they were socializing with friends as a couple, and she recognized that some of these friends were overwhelmed by her. Therefore, she relied heavily on the few women she trusted to be available to her.

Male partners were not the only ones to comment on their partners' individual support. Meryl and Jessica both verbalized feeling "relieved" that their partners had support resources outside of their couple relationships. Jessica had made the initial contact with some of Brian's close friends to let them know what was happening in their lives and to "ask them to keep an eye on him." She reportedly did this as an indirect way to support him because she believed he would not talk to her about his feelings. Brian responded well to support offered by his friends and opened up to them in ways he felt inhibited to do with Jessica because of the situation.

Jessica stated, “It was a relief to know he had people watching out for him, and who he could talk to because he wasn’t going to talk to me.” Likewise, a friend had made Meryl aware that Craig was utilizing a few close friends to talk to, and she reported that it was good to hear that he was getting his own emotional needs met. Craig agreed that this was helpful to him and he felt comfortable that he could talk about what was going on in his life in a casual way without it becoming “emotional overload.” Keith and Clark both made brief statements also about having a few friends whom they felt were supportive. Keith described the “ease” he felt talking with two of his friends who were also dealing with illness in their families. “We would update each other and compare notes; then we would go have a beer and laugh. It wasn’t all that heavy emotional stuff, just a couple of guys hanging out.”

Although both female and male partners identified the unique qualities of the support they received from friends and family of the same gender, and the benefits of having opportunities to engage with other independently, most shared the opinion that the social support they received as a couple and the social opportunities they took advantage of together were of more value to them. Several believed that engaging with their support resources together created an opportunity for them to also draw closer to one another. In addition, some felt that their relationship was strengthened when both partners were equally receiving support. Darren described this as such: “When we did this stuff together, it was like we were both getting our batteries recharged. We were both drawing energy from our friends, and then were sharing it with each other.”

We felt embraced by our community. Conversations about other resources for support were briefer than those presented above but none-the-less illustrated the emergence of themes. Five couples shared their experiences of feeling supported within their communities. They

described being provided for in primarily practical ways, such as Debra and Keith's neighbors organizing a system to provide them with meals nightly, and Kara and Clark's neighbors offering car-pooling assistance. Meryl, Rob, Craig, and Keith spoke about efforts made by co-workers within their work environments offering to take on some of their responsibilities or accommodate their absences. Rob and Craig spoke about the gratitude they felt towards employees who were willing to help run their businesses, so they could be available to attend medical appointments and treatment sessions with their wives. Meryl indicated that several co-workers were willing to change shifts with her if she was not feeling well or needed to attend an appointment. Kara and Clark were active in both their temple and school systems, which resulted in an outpouring of offers for various kinds of support including babysitting, yard work and household chores, and meal preparation. Similarly, Meryl and Craig were members of several organizations and received the same types of offers.

Kara and Debra shared that they were most appreciative of the support they received from their children's school staff. Kara had informed a few of her children's teachers that she was undergoing treatment for breast cancer and requested that they let her know if her children displayed any signs of distress or disruption. She remarked that she felt very "relieved" to know that the people caring for her children were willing to offer support to them during a personally difficult time. Likewise, Debra had established rapport with her children's teachers and was grateful for feedback she received regarding signs that her son was struggling emotionally with the events going on at home. She and Keith received guidance from a school counselor about ways to age appropriately communicate with their children about cancer. Debra stated, "It was wonderful, as a parent, to know that there were people watching over our kids and who were willing to lend a little extra support even though it wasn't a school-related issue."

In general, couples who had been active in their communities found that these connections became resources for support during their time of need. In addition, having school-aged children who were involved in extra-curricular activities also provided multiple opportunities to gain support from teachers, coaches, and other parents. Couples verbalized gratitude for the assistance they received and acknowledged that every effort was meaningful and “one less stress we had to deal with,” as Keith stated.

The doctors were invaluable resources for support and guidance. Five couples shared their experiences regarding support offered by the doctors caring for the female partners. Support mainly came in the form of providing the necessary information to couples in order for them to make treatment-related decisions and being available to answer any questions couples had about their options. As was clear from the synthesis of the interview materials, not all couples experienced their doctors as available or supportive. Those who did perceive their care providers as support resources expressed their impressions that these individuals went above and beyond what they typically expected of their doctors. More specifically, they perceived these individuals as being both *available* and *invested*. Steve and Diana shared their experiences with two particular doctors whom they felt were assets to the treatment team. They described specific characteristics of their interactions with these doctors, which contributed to their perceptions of support. Diana stated:

They had a way of speaking that instilled confidence without being egotistical. They would give detailed explanations of things without using a lot of jargon or big words we didn't understand, but at the same time, never talked to us like we were stupid either. I needed information and asked a lot of questions. That's how I managed my anxiety and

neither one ever rushed me because they understood what I needed....They had a very calming effect on both of us. We knew we were in excellent hands.

Steve shared Diana's perspective and added his own personal input:

Those two women were a God-send. They spent time talking with me about what was going to happen, and they gave me instructions on exactly what to do to help [Diana] each step of the way. I felt more directed, like I knew specifically what I needed to do. It was easier for me to deal with because I finally felt like I could help her get through this, and I knew what was coming next, and I was prepared for what I was supposed to do.

Steve explained that this provided him with a sense of direction that helped him effectively manage his emotions, so he could "think clearly."

Other couples spoke about feeling *respected* by their doctors. This was especially significant to male partners who appreciated that their questions and opinions were responded to with regard. Rob shared that Susan's doctor took the time to sit with him individually while Susan was having tests or treatments performed. He commented, "She sat with me and answered all my questions, never rushing me....She let me take my time to figure out how to say what I was thinking....She always focused on Susan, but she cared about how I was doing too." Rick had a similar experience and stated that Nancy's doctor's willingness to involve him in the discussions helped him feel secure that his role as Nancy's partner, and the person who would chiefly be responsible for her care, was recognized. In addition, both he and Nancy indicated that there was a substantial amount of contact prior to Nancy's mastectomy surgery, and her doctor took extensive efforts to provide them with the information they needed to prepare for the surgery and post-surgery needs. He offered the couple multiple forms of information to ensure that they felt reassured in their decisions. Nancy remarked, "He showed us pictures and directed

me to informational websites. He recommended videos because I wanted to know everything that was going to happen. He assured me there would be no surprises.”

Jessica and Brian’s experiences closely resembled Nancy and Rick’s, and they described Jessica’s doctor as “very sensitive to the situation.” Jessica explained that her doctor recognized that her experiences differed from those that an older female might have, and he openly spoke to her and Brian about this. She stated, “He really understood how tough my decision was and that it might be difficult for me, as a young woman, to handle losing my breasts. He brought up things I hadn’t even thought of because he wanted to make sure I was making the right informed decision for me.” Brian added that this doctor was also conscientious about explaining the changes that were going to occur to him. Brian remarked, “Like Jessica said, he realized that we were younger and maybe more focused on appearances. With Jessica’s approval he encouraged me to give my input. It was always her decision but he respected me enough to include me.”

Finally, Kara credited her doctor with “giving a couple of analytics all the informational reading material they could handle;” however, suggested that the emotional support she received from her doctor far out-weighed any factual information she could provide her. This statement represented a shared message present within these couples’ accounts of their experiences which was that they expressed feeling genuinely cared-for by their doctors.

We found comfort in the power of prayer. Seeking support through religious or spiritual channels was discussed by six couples. The common factor among these couples’ descriptions was that they experienced comfort as they engaged in prayer or spiritual conversations with their higher power, and perceived of this as a resource for support. These perceptions of prayer as a form of spiritual support were independent of whether or not couples attended a religious institution or engaged in religious rituals and structured activities. Delia shared the ways she

perceived her faith as a source of support. She stated that she “worked” her faith. “I started praying a lot. Every day I was saying a rosary. It brought me peace to feel the presence of God with me and it helped me be positive.” Hugh shared that he initially found it difficult to maintain his faith, but felt support in the prayers offered by the members of the church he and Delia attended together. He indicated that seeing Delia’s devotion to her faith helped draw him “closer to God.” Debra and Keith shared a similar story where Keith admitted to “being angry with God” initially following Debra’s diagnosis, but that her unwavering faith helped him reconnect with his spirituality. They attended church as a family, but conveyed that praying together as a couple brought them the greatest degree of peace.

Kara and Clark presented a parallel perspective in that although they were active in their temple and experienced their congregation and rabbi as supportive, they had generally viewed their involvement as source of community connection. They mutually believed that their sense of spiritual support was generated through their engagement in prayer at home rather than through their temple activities. Although not all partners engaged in prayer or spiritual conversations in the same manner, they expressed that they shared a value for the support these activities provided and mutually agreed that their spiritual connections were important resources for coping. Jessica and Brian explained that they do not share the same spiritual beliefs; however, they do share the perspective that their relationships with their higher powers are assets from which they can draw support.

The shared experience among these couples was that they experienced support within the ways they engaged with their higher power. Some couples found additional support in engaging in these activities with one another, while others engaged separately, but held a common belief in the importance of such activities.

Experiences of Survivorship

Prior to transitioning interviews to perceptions about positive change and growth, couples were asked to share their overall impressions of survivorship. The predominant way that couples described experiencing survivorship was through their perceptions that they had learned as a result of going through cancer together. The following represents the couples' preliminary responses.

We survived because we learned from our experiences. Couples described experiencing survivorship through their perceptions that they had learned from their personal observations of and encounters with various aspects of breast cancer. Interestingly, couples did not initially identify specifically what they believed they had learned, rather, indicated that the perception of having learned contributed to their sense of experiencing survivorship. Most did not provide specifics regarding the lessons they had learned until the discussion progressed to topics related to change and growth. Regardless of the non-specific quality of the initial responses regarding experiences of survivorship, evidence of a shared perception that learning was a key factor to experiencing a sense of survivorship warranted acknowledgement.

Steve and Diana described their general impression of learning, which lead to experiencing themselves as survivors. Steve explained:

We had to be more creative in the situations we were dealing with. If you've never had something like this go on, and your life goes along smoothly, you're not forced to do anything different. We didn't know how to deal with breast cancer, and we were floundering bad trying things that didn't work....We knew we had learn something new to do or we weren't going to make it....We always say breast cancer didn't give us a

choice, which kind of does a disservice, but we both knew it was a choice and it was on us.

Diana added,

You learn how to balance life. You use what you've learned, and you embrace it, but you don't let yourself be consumed by it. I've learned to really value certain things and make a lot of changes, but survivorship isn't about letting cancer become your identity. I'm a daughter. I'm a partner. I'm a friend, and I'm a survivor. I'm all of these things and survivorship means to nurture all of them, not the cancer patient I used to be.

Other couples described similar perspectives and their responses serve as poignant expressions of survival. Nancy remarked that, even though Rick had experiences with his ex-wife's family, she was a different person, and, in order for them to get through it together, they had to learn what worked for them. She added that this was especially true since she had not had any previous experiences. She stated,

It was a whole new experience. Things [Rick] might have known about beforehand...it's like I said, it was a blessing because he was already educated on the subject, but it was a whole new aspect of life for me that I didn't know existed beforehand and for our relationship....We survived because we learned how to deal with it on our own terms and in our own way.

Rob credited his wife, Susan, for being "amazing" in her efforts to "work through that terrible tragedy." He noted that if it weren't for Susan's ability to "figure out" how to deal with the impact of breast cancer, he did not know how they would have survived it. Annika and Darren spoke about experiencing survivorship through their ability to incorporate what they have learned without "going overboard." Annika explained that this meant that survivorship was not

about making “radical” changes that “go to the opposite extreme,” rather, that true survivorship was about incorporating what was learned in healthy ways. She further explained:

Survivorship is about learning from the experiences we’ve had and learning to do things for the right reasons in the right way, because they’re good and healthy for us. We’ve seen some people who go overboard and everything they do seems so extreme and driven by cancer....We understand that cancer is part of who we are, but not how we live our life.

Darren added that their experiences with breast cancer created opportunities for him to take of Annika and learn ways to “be a more caring husband all the time.” He stated, “If you never have anything difficult to deal with, you don’t really get the chance to learn from it.” He added that he “feels like a survivor” because “we made good things happen out of a bad situation.”

Some couples commented that they learned how strong they were as a result of surviving breast cancer, and this experience of strength was directly associated with their experiences of survivorship. Lisa and Dan explained that their experiences of being survivors stemmed from their perception that they had learned to recognize their strength as a couple. Lisa remarked, “We see ourselves as survivors because we’ve shown that we can master any challenge that comes to us.” “And we can grow with hardship,” Dan added. Finally, both Jessica and Brian, along with Kara and Clark, conveyed that they experienced a sense of survivorship through learning that they were stronger as a couple than they realized they were. Brian summed this up by commenting that they did not have prior experiences which posed this degree of challenge, therefore, being able to “find [their] way” showed them that they were stronger as a couple than as individuals.

Perceptions of Positive Change

Synthesis of the data showed that couples perceived positive change within three primary areas of their lives: (a) leisure activity/time spent together, (b) communication, and (c) healthy living. Couples identified positive change as improvement in the ways in which they engaged in these aspects of their lives together. Responses about positive change generally pertained to the re-prioritization of these behaviors as a result of a renewed perspective of their importance in daily living. In addition, partners described mutual experiences which they perceived as contributing to a shared perspective of positive change.

We make it a priority to have more fun together. Eight couples shared that they perceived changes in the way they spend time together. Engaging in leisure activities, shared hobbies, and new experiences together became greater priorities after surviving breast cancer. Some couples spoke about the need to adjust their routines and ways of engaging in daily activities in order to allow for more time to be spent with their partners. For Nancy and Rick, assuming a more relaxed attitude about household responsibilities opened up more time for leisure enjoyment. Rick explained, “We know we have responsibilities, but we don’t waste our time worrying about them to the last detail. We take all the opportunities to have fun that we can.” Susan and Rob shared that simply spending more time in each other’s presence has become important to them, and they have created new opportunities by mutually engaging in routine tasks and chores together, instead of individually as they had done in the past. Susan expressed her satisfaction with this because Rob had never done this with her and “now making the bed together is like a sacred act.” Keith shared that he began to go food shopping with Debra out of necessity during her treatment; however, decided to continue doing this, along with other routine activities, because they have learned how to have fun with one another in the process. Keith illustrated his perception of fun through his humor, remarking, “A couple other women we

know started bringing their husbands and the guys always tease me saying, ‘See what you got me doing!’” Delia indicated that she and Hugh have become more selective about the out-of-home activities they involve themselves in, and the time they spend away in the evenings, in order to consistently make time to be with one another. She stated, “We’re more focused on spending time together and we’re willing to give up some other things because being together is the priority.”

Finding common interests and participating in mutually enjoyed hobbies have become ways for some couples to incorporate more quality time into their relationships. Susan and Rob reported that they have taken time to explore various hobbies in order to find those that they mutually enjoy and can be active in together. Rob commented that in the process, they have discovered that they share more interests than they were previously aware of. Likewise, spending time together has provided Debra and Keith with opportunities to discover mutual interests. Debra shared, “I love to cook and he never knew how much he’d like it until he started to do it with me.” Keith agreed, stating, “We’ve found more things we like to do together.” As a couple they shared the perspective that they “probably spend more time together than any of the couples [they] know.” Meryl explained that she and Craig have many common interests, such as ballroom dancing, but needed to make it a priority to set aside time to enjoy these together. She commented, “I want to do things with Craig now and have fun, not wait until we’re too old to really enjoy them.” Craig reported that they have traveled frequently since Meryl had breast cancer, and they mutually agreed that this has enhanced their lives and contributed to their “healing” after going through a “traumatic” event.

Sharing new experiences together became a priority for five of these couples. Some expressed this in terms of experiencing an increased sense of adventure and desire to participate

in activities they have often dreamed of trying. Couples occasionally referred to these activities as being part of their *bucket list*, which generally represents a list of things to accomplish before one's death. Delia and Hugh indicated that they have a bucket list and have begun to pursue these activities. Hugh remarked, "We figured why wait until we're older. We see how important it is to try new things and have fun in life. We've already done some things we never made time for before or thought we'd do them in the future." Susan and Rob shared this perspective, and stated that their bucket list is "getting pretty full." They reported that after experiencing breast cancer together, they perceive themselves as more motivated to pursue new experiences that they can enjoy together. Susan reported that they have tried several activities in the past few years that she had never thought of doing prior to surviving breast cancer, such as ride in a hot-air balloon, take a flight on a sea plane, or go zip-lining. "I am definitely more adventurous," Susan remarked. Kara indicated that she and Clark do not have a bucket list, but that they try to do "silly things" they wouldn't have normally done. "I used to be too scared, but you only live once, so now I go for it. I actually got up and sang in front of an audience at Disney American Idol," Kara stated.

In general, couples spoke about reassessing how they engage in leisure activities. In addition to perceiving positive change related to the amount of time engaged in leisure activity, couples also indicated that they valued the importance of time together differently than they had before surviving breast cancer. Dan indicated that he and Lisa had reevaluated how much time they make for relaxation and shared his impression that engaging in leisure activities "help to balance out the tough situations that come up." He and Lisa mutually agree that having fun and "creating happy memories" has become an important aspect of their lives. Although not all partners experienced the same degree of adventurousness, they shared the perspective that

engaging in more leisure activities and spending time enjoying one another's company was a significant positive change that resulted from going through breast cancer together. Annika and Darren mentioned that they do not share a love of adventure, but they value spending time together, so they put forth a lot of effort to find mutually enjoyable activities that they can be involved in together. Meryl summed up her experience by stating, "Having fun has been contagious too...the more fun you have, the more you want to try new things and do more fun things together."

Communication is the key to creating a strong relationship. Eight couples shared their perspectives about positive changes occurring in the ways in which they communicated within their relationships. Positive change was perceived predominantly in the degree of openness partners demonstrated during their verbal interactions. Couples generally acknowledged their difficulties with communicating about their emotions during their experiences with breast cancer and indicated that the positive changes perceived were the result of learning from those experiences. Regardless of how well they had communicated about practical matters and logistics, couples recognized opportunities to improve their relationships by being able to relate better emotionally with their partners. Rob stated, "Whether it's cancer or putting a pool, we're going to communicate about it." Diana indicated that she and Steve were motivated to learn how to communicate better "so cancer wouldn't have that much power in our lives." She stated, "We learned how to talk to each other without having to censor it. It's changed the openness and honesty in our relationship." Steve commented, "I've become more confident about communicating. I tell her more about what I'm thinking or feeling." He added that the ways they have learned to talk to each other will continue to benefit their relationship.

Some couples experienced greater ease in communicating about difficult topics or voicing their needs. Darren spoke about his impression that he and Annika had found more effective and balanced ways to talk about sensitive topics. He shared that their increased willingness to be open with one another contributed to a decreased fear of upsetting one another. In addition, they experienced fewer arguments as a result of their ability to communicate about their needs. Annika remarked, “I talk about what I need more and encourage [Darren] to also. We don’t expect each other to be mind-readers. That usually lead to feeling resentful and starting an argument.” Both Jessica and Brian, along with Kara and Clark believed that their ability to communicate more openly about their needs was a positive change for their relationship. Jessica indicated that it was easier for Brian to speak openly than it was for her, but she identified making progress in being able to do so. “I’m more open with him now. I’ll ask for a hug if I need one or I’ll tell him how I’m feeling. I’m even more open about telling him I love him, which I hardly ever did before.” Brian remarked that Jessica’s openness in verbally expressing her love for him was, in his opinion, the most significant positive change. Kara shared her experiences of opening up to Clark more. She explained,

I have more private intimate conversations with [Clark] and I share more of my feelings.

I definitely did not do that before....I realized that I wasn’t telling him how I feel or what

I need. Now I do. So I’d say it led to a good thing.

Clark commented that, while it is still not “natural” for him to initiate conversations about his feelings, he is better able to respond to Kara’s emotional expressions, and is continuing to develop somewhat more comfort in contributing his own emotional feedback. Lisa and Dan also described increased ease in engaging in open communication. “There’s nothing we don’t talk about now,” Lisa remarked. The couple agreed that going through breast cancer was a learning

experience in terms of how they communicate about difficult situations, and they perceive themselves as more open to having these conversations because they “flow” easier now.

Similar to Annika and Darren’s experiences, other couples also identified that the increased openness they perceive in their verbal interactions has had a positive effect on their abilities to avoid or diminish conflict. Nancy and Rick shared their experiences in this regard. Nancy indicated that they engage in more emotional communication than they had before she had been diagnosed with breast cancer. “We put it all out there now,” she stated. “We say what’s on our minds, and we don’t fester over it until it becomes something to argue about.” Meryl’s perspective of the way she and Craig have changed their communication was comparable. She explained,

Now we tell each other what we really think. Maybe we bicker a little more as we do it, but I’d rather bicker a little than fight with each other. We’re more open and it seems to keep our discussions from getting heated.

Finally, Susan and Rob indicated that they did not experience a significant amount of conflict in their relationship to begin with, but they perceive themselves as responding more openly to topics that could potentially elicit conflict. Susan admitted that she used to have a tendency to “yes [Rob] to death” to avoid conflict. She stated, “I wasn’t really being honest and open with him. I would agree or tell him what he wanted to hear just to keep peace.” She added that she could be “hot-headed” at times, and often chose to withhold being open to keep from escalating a conversation.

For these couples, the commonality was that positive change was perceived through experiencing a greater degree of openness in their verbal interactions with their partners. Whether the increased openness contributed to expressing and getting ones needs met,

developing ease during difficult conversations, or minimizing conflict, all of these couples indicated that experiencing their partner as more open and honest with their feelings contributed to an increased sense of emotional closeness within their relationships.

We've learned the value of the saying, "Your health is your wealth." Perceiving positive change as a result of making healthy lifestyle adjustments was discussed by six couples. These couples shared that, as a result of their experiences with breast cancer, they implemented changes in their lifestyles, physically, psychologically, or both, in order to maintain their regained health or achieve greater overall wellness. Several couples specifically identified that they were more aware of their health and valued their well-being to a greater degree as a result of experiencing illness and feeling unwell.

Four couples indicated that they pay greater attention to their physical health and have made it a priority to exercise regularly and consume a nutritious diet more frequently than they had before. Nancy stated, "I'm more aware of my body and my health. I work out a lot more just to be fit, just to be healthy." She and Rick have included more physical activities into their leisure time and "motivate" one another to be more disciplined with maintaining an overall healthy lifestyle. Meryl and Craig, along with Diana and Steve, conveyed essentially the same messages during their conversations. Meryl indicated that, prior to going through breast cancer, she and Craig had never been consistent with their either their diets or exercise routines; however, after experiencing a serious illness, "we're doing a much better job of taking care of ourselves." Craig added, "You can't prevent everything, but we certainly recognize that there are things we can do to try to avoid getting sick." Delia offered her perspective that having been in "pretty good shape" during her treatment contributed to decreasing some of the physical side-effects she experienced. She shared, "It definitely made it better and that motivates me to keep at

it.” She has since progressed to opening a small Pilates studio in her home. Hugh indicated that he has joined Delia in developing healthier habits and remarked,

Before, I think it was more about appearances. It was great for [Delia], but I didn’t really get into that. Now that we both realize what a difference it can make, it’s about keeping healthy. That I can get onboard with.

In addition to developing healthy physical habits, some couples shared that they perceived positive change as a result of making healthy lifestyle adjustments, which benefit their emotional well-being also. Diana stated, “Being healthy isn’t just about taking care of your body. It’s about taking care of your mind as well.” She and Steve shared that, after surviving breast cancer, they have a greater awareness of the importance of avoiding stress as part of a healthy lifestyle. Diana explained, “We used to take on too much and never say no to people. Now we think twice before we say ‘yes’ to request.” She also spoke about reducing stress by improving their ability to separate themselves from other people’s “negativity” and set limits with those who ‘bring stress into our life.” Steve shared his experiences with beginning to set healthy boundaries with people in their lives:

When you’re so stressed out, you just don’t want to be bothered with other people’s drama. While [Diana] was sick, we were real selective about who we spent time with. She has some people in her life who are just drama and negativity all the time. Being protective of her, I started telling them if they wanted to be around her they had to leave their crap at the door....Once we did that, and felt how good it was, we definitely did not want to let it back in. So we’ve been better about it ever since and it feels good.

Debra and Keith shared the perspective that dealing with the stresses of breast cancer and the physical strain of treatment initially motivated them to “set boundaries” with people in their

lives; however, experiencing the absence of other people's problems infringing on their peace increased their attention to incorporating "boundaries" into their healthy lifestyle. Debra commented,

I used to take care of everybody. I've gotten away from that. Now I focus on taking care of us and doing what's best for our health....I've gotten rid of all the drama in my life.

I've definitely learned what boundaries are.

Keith responded, "Going through so much stress has made us realize what's important is what's under our roof. We don't need to take on extra stress and take care of everybody else's problems. It's not good for us."

For these couples, adjusting aspects of their lifestyles was identified as contributing to their perceptions of positive change. Whether these changes influenced their physical or emotional well-being, couples identified that the changes were a direct result of their experiences with breast cancer. Some believed that their experiences with illness increased their awareness of wellness, thus motivating positive lifestyle changes. Others indicated that becoming cognizant of the benefits of certain lifestyle changes made out of necessity contributed to a desire to incorporate these healthy habits into their everyday living. Annika summed this up in her statement, "My therapist once said something about if you neglect your body, your mind will suffer and vice versa. It's true, our mind and body are connected, so we have to take care of both."

Charitable Endeavors

Couples spoke extensively about the fact that their perspectives related to the importance of engaging in charitable endeavors changed as a result of their experiences with breast cancer. Many shared their experiences of being the recipients of good deeds or supportive gestures and

gaining increased awareness of the value of such efforts. Others conveyed that they have developed greater empathy for others struggles as a result of going through their own; therefore, feel more inclined to offer support. Perspectives shared by couples were offered within the contexts of both change and growth, and included references to both behavioral (activities) and psychological (empathy) experiences; therefore, the following discussion may serve as a connecting point between the two themes. The verbalized importance of these endeavors, along with the considerable attention paid during conversations, validated inclusion as an individual theme.

We believe in giving back. The concept of giving back emerged as a tenet among all ten couples. Some referred to this in terms of *paying it forward*, which generally refers to doing a good deed for someone in response to having been the recipient of a good deed by another person. Not all of these couples defined their beliefs with this particular phrase; however, did describe engaging in supportive acts as a result of experiencing an increased sense of empathy and desire to contribute to the wellbeing of others facing difficult situations, including but limited to breast cancer. Included in this, nine couples offered their perspectives about sharing their stories a way to benefit others. Couples engaged in telling their stories, both together and separately, but with a mutual belief in the importance of doing so. Finally, a few couples conveyed their accounts of recognizing mutual benefits from being involved in charitable and supportive efforts. Since ideas about giving back, sharing stories, and mutual benefits generally occurred within the same topic of conversation, and even within the same sentence at times, they will be discussed simultaneously, rather than as separate points. This is in an effort to better convey couples' descriptions that their overall perceptions of the importance of giving back were greatly influenced through their multi-faceted, multi-forum experiences.

Kara and Clark's extensive discussion of their perspective illustrated how these various aspects related to giving back were often overlapping in conversation and simultaneously experienced by couples. Their dialogue captured several major points made among the couples and will be supplemented by other couples' responses. Kara offered her personal perspective related to concept of paying it forward:

Getting out there and getting involved became very important to me afterwards. I do all these specific charities for breast cancer because I am definitely more aware of the importance of giving back....All these people did it for me. Their examples led me to where I am, and I hope I can be an example for others and my kids....I want my kids to know that you can do good, not necessarily for what it's going to do for you, but for what it's going to do for somebody else. We certainly have encouraged them in those ways. She then explained that although her motives were to contribute to a cause and benefit others, she experienced a significant degree of personal satisfaction as a result of her involvement in these activities. She commented:

I wanted to do these active things for a cause I obviously felt strongly about, but I also showed myself that I could do it. I snow-shoed three miles; I walked 40 miles; I walked down a runway in front of a large audience. I never would have done them before. I was doing these things as much for me as for the people who it was going to help. I got something emotionally positive out of it....I really felt like I was an actual strong person and in more control of my emotions.

Finally, she spoke about the dual role exchanging personal stories had played in her experiences. She described an early tendency to compare the details of her breast cancer with those of other women. This often led to her believing that her struggles were less significant than other's and

that she was undeserving of praises for being strong or courageous. Her involvement in breast-cancer-related charity efforts provided her with opportunities to hear a multitude of women's stories. The accumulation of these stories in her mind aided her in understanding the high degree of variability among women while highlighting the common experiences, which she could relate to. She stated, "I started to be able to see in myself the things that others saws in me. I finally learned how to embrace being a survivor." The benefits she perceived from connecting with others through stories prompted her to be more open with sharing her own story. She stated, "If I can help even one woman not feel the way I did or minimize herself, then it's worth putting my stuff out there."

Clark contributed to the dialogue by indicating that their involvement in breast-cancer-related charity has opened the door to expanding their supportive efforts beyond just breast cancer. As a couple, he and Kara contribute to other causes and charity efforts in their community, school system, and temple, or those which their family and friends are involved in. Clark shared that experiencing the support provided by others has enabled him to perceive other people's situations in more empathic ways. He explained, "I'm more understanding of others going through troubling situations. I may not be the shoulder they cry on, or the person who offers them words, but I'll be there in other ways, like monetarily, or if their kids needs a ride, or if I can help with a task." He added that witnessing the positive impact that other people's good deeds had on Kara has heightened his awareness of the importance of giving back and that sometimes "just showing up" is a way to give back.

Jessica offered her perspective on the value of sharing personal stories. She commented that as a couple, she and Brian understood how difficult it can be for couples going through breast cancer to figure out ways to cope with the impact of breast cancer, and the appreciation

they felt for the support they were provided served as a motivation for them to seek ways to offer support to other couples. One way they have done so is by becoming involved in a mentor-type program, which provides them with the opportunity to share their personal experiences and offer support to both individuals and couples dealing with breast cancer. Jessica explained,

I put myself out there more. If I can guide someone or share my story to help someone else, I'll do that. [Brian] has always been pretty open, so it's easier for him but I was very private before. It's a big step for me.

In addition, Jessica highlighted that value can be found in both simple and involved efforts. She noted that due to her propensity towards privacy she had not yet felt ready to be involved in a large-scale organized event such as a walk; however, she and Brian have participated in small, private fund-raising events generally hosted by others participating with the larger organizations. She remarked, "If we can help them fundraise by showing our faces, telling our story, or getting our friends and family to show up, then we're still contributing to the cause."

Both female and male partners spoke about perceiving themselves as having a greater capacity for empathy. They shared their experiences regarding how this influences their everyday efforts to give back in addition to their involvement with larger charity organizations. Debra, Lisa, and Nancy all commented that they have greater ability to relate to the impact illness can have on people's lives. Debra stated, "I guess the cliché about walking in someone else's shoes is right because I didn't know until I had to go through something like that myself." All three women are employed in healthcare fields and indicated that they try to find opportunities to support other women through their work and share their stories when appropriate. Lisa stated, "If I can advocate for someone or encourage someone not to skip that mammogram by sharing my own experience, I'll do that now. That for me is growth because I

would have never thought of going there before.” Debra and Nancy’s occupations both involve direct-care with patients. They described feeling appreciative of good care they received from their medical professionals during their own illnesses and have improved their own ways of practicing in order to be able to provide others with the same “caring” and “understanding” they had experienced.

Several male partners indicated that one particular way they believe they can give back is by sharing their stories and offering support to other men. Rick remarked that, from his perspective, there are few avenues for men to receive support when their partners are going through breast cancer. He, Steve, and Keith had all shared their experiences of offering support to male co-workers who were struggling to cope with the impact of cancer. Steve remarked that although he did not have any male friends who had specific experiences with breast cancer, he was grateful for having male friends who could relate as men and as husbands/boyfriends. He has taken advantage of opportunities to offer support or guidance as a way to “repay the kindness” shown to him. He stated, “My co-worker approached me and the first thing he said was ‘I don’t know what to do.’ I distinctly remember that feeling so I’ll tell them about what we went through and figured out and hope it helps them out.” Rick, who had gone through breast cancer with his ex-wife’s mother and sister prior to his experiences with Nancy, commented that he truly understood the value of sharing his experiences with others. He stated, “Men usually don’t want to get all mushy about it. It can really help to have a guy who can offer the male perspective the way guys talk to one another. There’s not a lot of opportunities out there for that, so I offer it when I can.” Keith remarked that after experiencing the reciprocal support between him and his two co-workers he is more likely to offer the same to others who are facing difficult situations. Dan described a somewhat different situation, in that he generally shares his story

with females he encounters. He indicated that going through breast cancer with Lisa has made him more aware of what the women around him are talking about. He shares his and Lisa's story as a way to encourage women to get their mammograms and check-ups.

Finally, four couples believed that engaging in charitable efforts as a couple allowed them to have greater contributions to the cause. Rob and Susan participate in fundraising walks together in order to reach as many potential sponsors as possible and raise as much money as they can. They also voiced their belief that "knowledge is power"; therefore, if they can both contribute their experiences, more people can learn from their story. Annika and Darren conveyed a similar message and have mutually volunteered at local breast cancer organizations assisting with a variety of tasks. Meryl and Craig's perspective was that they each bring their "unique talents to the table" and allow them to give back in richer ways. Craig verbalized that he is also motivated to be involved because he believes it supports Meryl as well. He stated, "If you can help someone else heal, it helps you heal as well." Lastly, Diana and Steve perceived that they were stronger as a couple as a result of engaging in charitable efforts together, and they hoped to encourage other couples to do the same. Steve noted that this was one more way for him to "have a hand in the fight," and he hoped to serve as a role model for other men to consider becoming involved. He concluded by stating that paying it forward was about passing along the kindnesses shown to them, in any form, to the next person struggling, and that it was "bigger" than the struggles of an individual. He stated that paying it forward was about "giving of ourselves for the sake of helping other people with whatever it is they are facing....not just in ways that benefit us or are only about the causes that personally apply to us."

Perceptions of Positive Growth

Couples conversations regarding the ways in which they perceive themselves as having grown as a result of their shared experiences with breast cancer revealed that couples perceived growth in several ways. They shared their experiences related to the specific ways in which they believed they had grown and their view of indicators which provided personal evidence of growth. These discussions resulted in the emergence of the following subthemes: (a) emotional closeness, (b) perspective of what is important, (c) relational confidence and trust, (d) appreciation for life and awareness of mortality, (e) gratitude, and (f) spirituality. Unlike the subthemes related to change, which were discussed primarily in terms of adjusting behaviors within various aspects of life, the subthemes related to growth reference psychological developments.

Getting through that drew us closer together. One of the most prevalent responses regarding growth pertained to couples' perceptions that they had grown emotionally closer as result of experiencing the difficulties associated with breast cancer together. Overall, nine couples expressed their impressions that a positive outcome of surviving breast cancer together was that they were more emotionally bonded than they were before their experiences with cancer. Emotional closeness and a sense of being *stronger* as a couple were frequently described interchangeably. Some couples became most aware of their increased closeness after overcoming their challenges. Lisa and Dan shared their thoughts that going through a "traumatic" experience like breast cancer together brought about an increased sense of relational closeness and, according to Lisa, "redefined what real true unconditional love is." Dan remarked, "I do think we're even closer. Getting through that together and still maintain your relationship, it does make you stronger when you come out the other side." Annika remarked, "I think when you have gone through something so traumatic and have been through so much

together, that part of it changes your level of closeness.” The couple described feeling a greater degree of emotional intimacy and observing themselves to be more emotionally supportive and expressive with each other.

Other couples indicated that they began to experience deepening emotional closeness shortly after learning of the breast cancer diagnosis, which continued to progress throughout treatment. Feeling emotional closeness was especially significant when couples had felt disconnected as a result of their difficulties verbally communicating about their emotions. Increasing time spent physically close to one another produced a sense of emotional closeness for some partners. Steve commented, “It instantly brought us together. Even when we didn’t know what to say or do, we were together. We stayed close and showed each other love.” Diana conveyed her perspective of the staying power of their growth, stating, “We are so emotionally connected after going through that. Even now, I thrive on that closeness, and I love how it feels.” Annika and Darren also experienced emotional closeness through moving closer together physically. Annika described going “back to that nurturing space” by spending time being with one another and sitting together in the comfort of their own space. Similarly, Debra and Keith spoke about feeling connected by taking opportunities to experience comfort together. Debra shared that she frequently napped when she was feeling fatigued by treatment, and Keith began to join her on the couch in order to hold her and be close to her. She added that they continue to do this as a way of nurturing their connection.

Experiencing a sense of emotional closeness as a result of perceiving a shared goal or challenge also emerged within the dialogue. Rob expressed his belief that Susan’s breast cancer was “their fight” and both he and Susan perceived themselves as drawing closer to one another from the start. Rob stated, “It brought us closer. We both had a fight that brought us

together...we stood together through every moment of it.” Nancy and Rick expressed a comparable view evidenced in Rick’s illustration that breast cancer was a “journey” that he and Nancy “started together from the start.” For both of these couples, engaging in tasks together such as researching breast cancer topics and attending appointments followed; however, they conveyed their belief that their increased sense of connectedness began at the moment they perceived breast cancer as a shared challenge.

Couples described their increased emotional closeness in terms of perceiving themselves and their relationship as bonded in ways they had not previously experienced. Jessica described a level of connection with Brian where they can convey their emotional connection through exchanges of touch and physical affection. Brian agreed and stated, “We’ve been through so much and grown so close.... I can look over and hold her hand and know without a doubt that she loves me and we can get through anything that happens to us.” Brian also commented that the connection he has established with Jessica had increased his motivation to verbally express his emotions more freely with her. Delia described that the intensity of the situation equated to the intensity of the connection she felt with Hugh. She explained, “You can’t go through something like that and be unchanged. And when you go through something so intense and so personal with another person, they not only become part of the experience, they become part of you in a whole new way....There’s such an emotional closeness that you’re just not yourself without your partner.”

In addition to the examples and contributing factors, such as increased physical affection and contact, overcoming challenges together, perceiving a common goal, and increased ability to offer emotional support, couples described experiencing a deepened level of connection through their shared views on other ways in which they believe they have grown (other subthemes). In

essence, experiencing growth together in multiple ways and maintaining mutual beliefs about this contributed to the couples overall perspective that they had become emotionally closer.

We gained perspective of what is really important in life. All ten couples described in some way that they believed their experiences with breast cancer contributed to their sense of perspective about what was important in their lives. In general, conversations about gained perspective focused on two connected ideas; recognizing what is important and letting go of what is not. Several couples spoke about this in terms of identifying what they believed was worth expending their energy on and what was not. Dialogues mainly focused on the actual process of evaluating and recognizing importance or creating a viewpoint, as opposed to discussing specific aspects of life that they deemed important. In addition, when some couples were asked to explain further, they shared their perceptions that gaining perspective contributed to their abilities to avoid becoming frustrated or feeling stress over what they recognized as insignificant issues. Again, couples did not necessarily identify specific issues which they chose to let go of. It is possible that couples responded this way because they had shared their ideas about specific aspects of their lives that they believed were important during other conversations, such as in the context of positive changes made as a result of prioritizing. Responses by Nancy and Rick highlighted this possibility. It was noted in their interview transcript that they had referred to gaining perspective as to “know [their] path more clearly now.” They had also referenced the idea of this “path” while talking about positive changes, identifying increased attention to their physical health as a “step” along the path. This example brought to light the possibility that couples’ perspectives about what is important may overlap in some ways with what they viewed as priorities for change and the specifics simply may not have been repeated during both topics of conversation.

Couples also used a variety of terms to describe gaining a greater sense of what was important. For example, some couples felt better able to distinguish the *big issues* from the *small issues*, the *important* from the *unimportant*, or the *good stuff* from the *bad stuff*. Rob described how his and Susan's world view changed as a result of their experiences with breast cancer. He stated, "Now we look at things different than we did....We came over this big hill, and now there are things that used to seem important that aren't really so important anymore. The perspective is changed a little bit." Kara expressed, "Our viewpoint on a lot of things changed. Certain things have become more important to us. We try really hard to focus on the good stuff and not spend a lot of time on the rest." Annika and Darren spoke about their perception that they have improved in their abilities to put their attention towards "bigger matters," rather than "waste our energy on little things that don't really matter."

Some couples related gaining perspective specifically to their ability to determine whether or not an issue had value enough to warrant reacting to. Lisa and Dan shared their views on being able to avoid stress by putting issues into perspective. Lisa remarked, "We can see that things that were a big deal – in the grand scheme of things don't really amount to much so we don't stress over them anymore....We don't get stressed over things that used to bother us." She shared that being able to gain perspective was "a huge learning experience" for her, which has resulted in increased ability to "not be so reactive" when issues arise. Dan added, "We don't sweat the small stuff anymore. We are so much better at looking at the big picture and letting go of what doesn't really matter." Meryl and Craig conveyed similar ideas. They shared the perspective that going through cancer impacted the ways in which they viewed challenges that arose in their lives and invested their time and energy into addressing those challenges. Craig commented, "We try to ask ourselves if there's a real reason to be upset over

something.” Meryl stated, “It all ripples outward. When we let go of petty things, we open ourselves up to seeing what is important.” Jessica and Brian reported that they have learned to “think twice” about an issue in order to allow time to “get clear about it” and decide whether it’s important enough to worry about or warrants their attention. Hugh explained, “Things don’t upset me like they did before. I can see them differently and recognize what’s important and what’s small potatoes. I don’t let stuff that’s not really important get to me like I used to.”

Craig quoted the expression, “I cried when I had no shoes until I met the man who had no feet.” This captures the general idea conveyed by couples that their experiences served as tools to help them recognize what they truly believed was important in their lives. For most, the process of gaining perspective also involved redirecting focus away from matters of little significance in order to attend more fully to those that were of value. As Debra and Keith explained, although they did not describe themselves as wealthy, they resided in an affluent community and believed that acquiring wealth was important, until their perspectives changed after Debra was diagnosed with breast cancer. She remarked, “Now we have a completely different point of view on what it means to be wealthy. The whole experience opened our eyes to what’s really important in life.”

We knew that if we could get through this together, we could get through anything.

Synthesis of the data showed that seven couples perceived an increased sense of confidence and trust within their relationships, and identified these as specific ways in which they have grown as a result of their experiences together with breast cancer. Surviving the challenges imposed upon them not only increased the couples’ confidence that they could overcome other difficult situations, but also that they could do so without compromising the integrity of their relationships. In addition, it also instilled greater trust and assurance that they could rely on their

partners to be present and available to help them through arduous situations. The perceptions of relational confidence was well represented within the data and responses among couples showed a high degree of consistency with minimal variation. This is illustrated in the following response sample:

Lisa (and Dan): Now, I don't think there's anything we can't face together.

Jessica (and Brian): We've learned just how devoted to one another we are. We feel like there's nothing that can get between us or we can't handle.

Susan (and Rob): This was the most difficult time in our lives, and we got through it, so we know we are capable of facing whatever other crap may come at us.

Two couples, both unmarried but cohabitating, indicated that the increased confidence they felt was especially significant since each had experienced issues related to the female partners' concerns that breast cancer could cause the breakdown of the relationship. Nancy had shared that, upon learning she had breast cancer, she feared Rick might not want to remain in the relationship because he had dealt with serious breast cancer issues in his previous relationship. Nancy explained, "I was scared that he might leave because he wouldn't want to go through it again." Rick indicated that he never had any intention to leave and felt "sorry" that Nancy had felt scared. Diana had described her concerns over Steve leaving as "irrational" because Steve had not given her any reason to believe he intended to discontinue the relationship and had demonstrated his devotion to her regularly. She indicated that her fears stemmed from knowing Steve experienced a great deal of discomfort when dealing with medical issues and hospitals, along with her own perceptions of herself as "defective." Both female partners acknowledged that they had experienced a sense of confidence in their relationships prior to being diagnosed, but that not being married "all of a sudden felt like an easy out," as Diana stated it. Both women

described feeling relieved by their re-established senses of confidence. Nancy stated, “If he can stick with me through this, I know he’s going to stick with me through anything.” Diana remarked, “I grew to trust that he really was going to be there for me through anything difficult that came our way.” In general, both couples expressed that their sense of security and confidence in their relationships not only returned, but intensified as a result of these experiences.

Couples indicated that the skills they have learned and the ways they have changed and grown contributed to their assurance that they could overcome future obstacles; however, with the exception of two couples, they had not faced any other major difficulties to assess how they would be able to implement their coping resources. Annika and Darren, along with Meryl and Craig, discussed that they felt their confidence was reinforced because they had in fact experienced other difficult situations. Both couples remarked that their experiences with breast cancer had improved their abilities to cope with other struggles. Meryl commented, “Craig had open-heart surgery, and I really think we were able to get through that better because of what we’ve already been through together.” Craig agreed and added, “I have great confidence in our ability to cope together since we have learned how to rely on each other.” Annika and Darren expressed similar ideas as they spoke about dealing with the loss of Annika’s brother, who was killed in Iraq while on military deployment. Darren stated,

Going through all that we have, I think it gave us some confidence that we could get through this together too. I know I felt like if we could get through that (breast cancer) we could get through anything....For better or worse and this was worse.

Annika remarked, “I think we were more emotionally strong and emotionally supportive and better able to get through it than we would have before.” She described feeling an increased

sense of confidence prior to her brother's death but that experiencing this "proved" that they could transcend challenges they encountered.

Couples primarily conveyed their beliefs that going through the difficulties associated with breast cancer not only provided them with the opportunity to learn, grow, and acquire skills necessary in order to effectively manage future challenging situations, but also served to reinforce their relational bonds, contributing to an increased perception of relational confidence.

Once you realize that life can end at any moment, you learn to appreciate it even more.

Perceptions of positive growth included greater awareness of mortality and appreciation for life for eight of the ten couples. These two concepts were generally experienced simultaneously; therefore, were predominantly discussed simultaneously. The prevailing thought expressed by couples was that their experiences with breast cancer brought about their awareness of mortality, thus prompting greater appreciation for life.

Responses offered by Delia and Hugh capture the overarching ideas presented among the couples regarding heightened awareness of mortality and the connection to appreciating life.

Delia shared,

Cancer certainly brings mortality to your awareness. It's easier to talk about when you're not facing your own demise. After getting through it though, I can accept that it's part of the human experience. Dying is part of life. It always has been you're just more aware of it now....It does really give you better appreciation for life, friends, family – things that you take for granted before you have cancer.

Hugh was one of several partners who quoted the expression "every day is a gift," and added, "I know that sounds crazy because it's so cliché, but it really is true." Delia and Hugh highlighted the point that "awareness doesn't equate to fear." They shared that there were times when their

awareness brought about feelings of fear, but that they had learned that, the more they began to “truly live and enjoy life,” the less they feared death.

Craig stated, “Sometimes it takes a stimulus like going through something like breast cancer to make you realize that mortality is there....After what we went through, we appreciate life because that could have been the end of it all.” Meryl continued, “I’ve realized that our time on this earth isn’t very long and can be cut short at any time, so I want to enjoy my life.” Their dialogue mirrored that of other couples who spoke about feeling compelled to engage in life more fully through statements such as, “We can’t live forever, so until then, we try to enjoy it,” by Rob, “We make the best of every day knowing it could have turned out different,” by Nancy, and “I felt like I was given the gift of life, and I needed to make the best of that life,” by Kara. Several couples noted that appreciating life also equated to not taking for granted the ways in which they are fortunate. Keith explained, “I know what ‘really happy’ is. That’s because I’ve realized that things can change in an instant and it could all be taken away very easily, so I don’t take anything for granted.”

Three couples shared that they express their appreciation for life through celebrating. Annika stated, “That’s a way of acknowledging that you’re alive.” Partners reported that they mutually believed in the importance of incorporating more celebrating into their lives, despite that it was primary female partners who initially experienced increased desire to do so. Diana and Steve shared their perspective on celebrating and remarked that they take the opportunity to celebrate significant moments in their lives because, as Diana stated, “To celebrate is to acknowledge these moments as gifts...” She explained,

The first birthday I had after beating cancer was very emotional because I realized it’s not a given that you’re going to get another one. They have become very significant for me

because they remind me that I'm alive for another year, and I'm still here and that is worthy of celebrating.

Steve openly shared that before experiencing breast cancer with Diana he did not have the level of awareness of mortality or the appreciation for life that he has now after they've survived it together. He explained that, "I think before all this, I had the mentality that when your time comes, it comes....So I didn't think about how I was spending my time." After going through cancer with Diana, he described experiencing "more value of life." He indicated that these experiences reminded him that life can be unpredictable; therefore, he and Diana want to "absorb" their significant moments in life. Annika and Darren, along with Meryl and Craig expressed their beliefs in these general ideas as well. Annika concluded, "We should celebrate the good things in life because life isn't always good."

We feel grateful for all we've been blessed with. In conjunction with experiencing greater appreciation for life, several couples also noted that they believed they had grown in their overall capacity to experience gratitude. Conversations about gratitude were frequently intertwined with discussions of appreciation for life; however, couples spoke of these experiences separately, which distinguished them as individual subthemes, though related. To clarify, couples perceived appreciation for life as a unique experience separate from gratitude/appreciation for other aspects of their lives. In discussions other than those related to appreciation for life, the terms *gratitude* and *appreciation* were occasionally used synonymously. For example, Annika remarked that it was important to appreciate what you have and then stated, "I have a good life, I have [Darren], I have friends, and I'm grateful for that." A characteristic of many of the conversations related to gratitude was that partners directed their expressions towards their spouses specifically, in addition to general references to friends and family. For

example, Nancy commented, “I’m grateful for every single person who made an effort on my behalf....My friends, my family, and especially for Rick because he was so patient and caring.” Her response captured the general perspective of couples. Her general references to friends and family reflected that the couples’ primary focuses were on their actual feelings of gratitude, rather than on specific details of what they felt grateful for.

Female partners’ messages towards their partners conveyed that they were grateful for the support and assistance they had been provided during their trials with breast cancer. Susan expressed, “I’m grateful for all he did, it made me feel even more loved by him.” Jessica acknowledged that she was thankful for what Brian tried to do to help her “even if I wasn’t always receptive.” She indicated that she was grateful that he continued to support her through times when she was “negatively impacting him.” She stated, “How can you not love somebody more than you ever thought you could who goes through that with you and for you?” Male partners’ expressed gratitude for their partners’ presence in their lives. Brian remarked, “After this happened, I couldn’t envision life without her....I was even more thankful that she was a part of my life.” Craig stated, “I’m very grateful for our life, and I’m content with what we have as long as [Meryl] is here with me.” Hugh shared, “When you go through something like this, it wakes you up and reminds you that that person next to you is the most important person in your life. You realize we’re all we’ve got, and we need to be thankful instead of selfish.”

Couples responses about gratitude illustrated that they perceived growth in their increased capacities to experience a sense of gratitude. It was evident in their conversations that they felt deep appreciation for their partners and others who had been a part of their struggles; however, it was the experience of feeling gratitude within that was most significant.

We grew more faithful through our struggles. Five couples had identified that they perceived positive growth in their senses of spiritual connection. Most described this growth in terms of spending more time in prayer or activities which they believed contributed to a deeper connection to their higher power. Kara and Clark discussed that, prior to Kara's diagnosis, their involvement at their temple had been motivated more by experiencing a sense of community than for religious fulfillment. However, they shared the perception that their perspectives on spirituality had changed as a result of their experiences with breast cancer. They mutually experienced a deepened sense of faith, which changed the way they viewed their activities at temple. Kara commented, "We connected more to the spiritual side of it. It's not just about being socially connected anymore. It's about nurturing the faith we feel inside by being involved in spiritual activities within a community we feel connected to." Clark responded that they still consider themselves "more spiritual than religious," but that temple involvement has provided them with an environment within which to engage in spiritual activities. Meryl and Craig shared that they changed the ways they practice their spirituality as a result of feeling greater sense of connection as well. Meryl explained that her beliefs about God had not changed, but that she experienced feeling "closer to God." She and Craig both indicated that they feel more compelled to express their gratitude through prayer and do so daily. Meryl remarked, "I feel a deeper sense of spirituality. Anytime in my day I can be thinking about something or see something and I'll say 'Thank you God.'" Craig agreed adding, "After what we've been through, and seeing the bigger picture in life, I feel it's important to express my gratitude to the powers that be." The couple shared that their deepened spirituality "came from within;" therefore, they "practiced from within" without feeling the need to be at temple to do so or engage in formal religious practices. Susan and Rob commented that they both experienced a greater sense of connection to

God after overcoming the challenges of breast cancer. Although they come from different faith backgrounds and practice different customs, they feel connected through their shared perception of the importance of prayer.

Couples experiences varied regarding when they began to perceive themselves as developing a greater sense of faith. For some, there was a connection from the start which progressively deepened throughout their experiences with breast cancer as they utilized their faith as a resource for support. Delia shared, “I was faithful before, but I think that faith is a journey and cancer made me really work on it. Cancer definitely increased my faith. It deepened my spirituality a hundredfold.” For others, such as Delia’s husband Hugh, maintaining faith posed more of a challenge and their perceptions of greater spiritual connection were highly influenced by their survival. Hugh described a period of time when he felt disconnected from his faith and was “upset” and questioning, “How could [God] do this to me?” He did not feel compelled to engage in spiritual activity at that time, but continued to witness Delia do so. He believed that, observing Delia’s spiritual devotion and understanding her perceptions about how she believed her faith brought her through their ordeal, contributed to his ability to let go of his anger. Hugh stated, “Getting through this has taught me that I need to count my blessings every day....I have become more faithful than I ever had been in my life.” Despite their differing experiences, Delia and Hugh perceived that they had grown together in their spiritual devotion and engage in spiritual activities together more frequently than they had in the past.

Debra and Keith’s description of their spiritual experiences greatly resembled Delia and Hugh’s. Keith disclosed that he had felt “anger” towards God for “letting this happen,” and although he continued to attend church with his family, he felt spiritually disconnected and did not pray or actively practice his religion as he had before Debra was diagnosed. Debra described

feeling “angry at life, but not at God” and continued to practice her faith as she had been. After going through the experience of surviving breast cancer, Keith commented that he now believes there were “spiritual lessons to be learned,” especially those related to “real appreciation and gratitude.” He and Debra mutually perceived that their faith had grown as a result of their experiences with breast cancer and had become a greater source within their relationship. A common connection between couples who had perceived growth in their spirituality was that they described engaging in prayer or conversations with their higher power differently than they had prior to their experiences with breast cancer. They consistently identified that prayer was primarily focused on expressing gratitude. As Debra remarked, “I do a lot more thanking instead of asking and expressing my appreciation for all the good in our lives.”

Indicators of Change and Growth

Following conversations related to positive growth and change couples were asked to share experiences or perceptions they have had that serve as indicators that change and growth have occurred. Couples identified two primary evidentiary factors: maintenance of gains and observations of children’s adjustment. The following discussions highlight the responses provided by couples.

We didn’t go back to where we were; we continued moving forward. Eight couples identified that their abilities to maintain the changes they had made and growth they had achieved, without reverting back to previous less effective ways of living, served as evidence that improvement had occurred. Hugh stated, “We’ve been able to keep up the changes for eleven years now, so that’s proof enough for me.” He described their experiences of surviving breast cancer as “life changing,” and he and Delia agreed that not only have they maintained their progress, they have continued to grow in positive ways as a couple. Debra and Keith

shared their perspective that continuing “the little changes” were indicators of growth. Keith commented that, “It’s easy to keep up the big stuff. We know we’ve grown when we see the value of the little changes and keep them up even though they don’t change our lives drastically.”

Other couples also expressed their impressions that they have continued to progress beyond the initial ways they viewed themselves as improved. Susan remarked, “I don’t think we went back to what we were. I think we’ve gotten better; we’ve grown and kept going.” Rob further explained, “We’re doing things we never did or thought we would before. Watching how we’re living now, versus how we did before, makes it pretty clear to us.” Craig offered his perspective that,

Well, to grow means to evolve from your original state. We’ve continued to live in the ways we’ve learned and build on it. It’s not hard to see what we do differently now than we did last year or ten years ago before Meryl was diagnosed. We don’t need others to tell us whether we’ve grown or not, even though people have offered their opinions.

Kara and Clark also discussed their impressions about their continued growth. Like Meryl and Craig, they did not look to others for evidence. Instead, they reported that they have maintained their weekly family meetings and continue to use this time to set goals as a couple to build on their growth and continually monitor their progress.

Receiving feedback from others was, however, re-affirming for Diana and Steve. Diana explained that she and Steve had received positive feedback from others who had made observations of their interactions with one another. She stated that, although she and Steve recognized these changes in themselves and their relationship, “It’s empowering to get that feedback, and it’s reinforcing when other people see the changes that we see in us.” Steve added

that they continue to receive input, which reflects their abilities to maintain their progress. Lisa and Dan responded in a similar manner, reporting that periodic feedback from family members continues to serve as an indication that they continue to grow. Steve concluded by stating,

Of course we appreciate when people point out how we're different, but to me, I find my proof in seeing that we're trying as hard now as we did when things were rough. Doesn't mean it always works out, but if you can pin point exactly what specific effort you're making, then you know you're still moving forward.

Our kids are a reflection of us. Of the seven couples who had children residing at home at the time of the breast cancer diagnosis, five couples responded that they saw evidence of their change and growth in their children's adjustment and behavior. Since the interview was primarily focused on experiences within the couple relationship, conversations related to the couples' children were less extensive. In this particular case, couples jointly made observations of their children and related these directly to what was occurring in their own relationships. As Keith stated, "Seeing our kids not only come out unscathed, but doing really well, shows us we did things right. They're doing well because we're doing well." He and Debra, along with other couples, noted that their children's ability to adjust well following their experiences with breast cancer served as an indicator that they had in fact changed and grown. Keith explained, "We weren't always doing well. We struggled. If we hadn't been able to make positive changes I don't think our kids would have fared so well." Nancy also shared her observations:

I see proof of it around me. My son is thriving; Rick and I are happier and healthier than we've ever been....It's been four years, and we haven't gone back to the way we used to be. Not only is that growth, but to me it says that what we went through was life changing.

In addition to being well adjusted, some couples indicated that specific behaviors they witness their children engaging in reflect evidence of growth. Lisa and Dan shared that they have observed their children engaging in some of the same behaviors they had identified as positive changes for themselves. Lisa explained, “We’ve learned some different ways to cope and resolve conflicts and it all stems from having honest conversations about the situations. We see them doing the same now with situations they have at school or with friends.” Dan added, “Our daughters are our evidence. When we see it in them, we know they learned from us.” Likewise, regarding her and Brian’s son, Jessica commented, “We watched [our son] grow to become a very compassionate child. Our kids are always the best mirror of our strengths.” Brian agreed, stating, “Seeing him be so strong, which I’m sure he took from the positives we figured out how to do; he grew because he saw us grow.” Finally, Kara and Clark discussed that, not only are their children achieving well, they have progressed to making independent decisions to engage in behaviors reflecting change and growth. For example, Clark reported that all three children actively utilize their family meetings to express their thoughts and feelings regarding various issues, but also set small personal goals for themselves. Kara added that they have also initiated being involved in charitable endeavors or have requested to join Kara and Clark in these activities. Kara remarked,

Change is hard at first, but when you keep it up it becomes more natural. It’s like changing bad habits. Don’t they say you have to do something thirty days in a row to create a new habit? Well, I’d say we’ve done that and beyond...and now our kids are learning from our new good habits.

Perspectives on Recurrence

Couples were asked to share their perspectives related to the issue of recurrence and share thoughts any thoughts they may have had about coping with the possibility. Responses from couples showed that female and male partners had different perceptions regarding recurrence, but verbalized shared viewpoints about how they would address recurrence if it happened. The following discussion presents both the individual and shared responses.

The worry gets better over time. Female partners discussed their general perceptions regarding the topic of recurrence. Eight women conveyed that they remain fearful of the possibility of recurrence; however, noted that their level of concern and preoccupation with the thought has decreased over the course of time. Most believed that fear would likely never be completely eliminated, but that it would eventually remain primarily in the background of their thoughts. Delia expressed, “Being a cancer survivor, you know there’s always a possibility. You learn to live with that fear.” Diana explained, “It’s always there in the back of my mind. As time passes, I do feel more and more confident that I’m in the clear...I can’t live in it and in the worry.” She added that the times she thinks the most about recurrence and feels increased anxiety is just prior to her medical check-ups, but that keeping up with her appointments is the best way she can cope. “I trust that, as long as I do, that my doctors will catch anything and take care of it immediately,” she stated. Most of the other female partners responded in a very similar manner. Kara shared that, for the first year following her treatment, she had daily thoughts about the possibility of recurrence. She commented, “When the thought of recurrence comes up, I’m reminded that we only live once. I try to stay grounded and stay in the moment.” She indicated that now her concern is generally triggered only when she has a pending appointment, and her anxiety and emotional sensitivity subsides quickly once her doctor confirms that she is still cancer-free. She and Annika both expressed their beliefs that there will likely always be some

anxiety related to cancer, but that it is important to live as “normally” as they can in order to prevent thoughts of cancer from disrupting the positive growth they have achieved. This was especially significant for female partners who were still taking hormone-blocking medication. Kara and Susan both expressed their anticipation that they may temporarily experience an increased level of concern when they can no longer perceive that there are preventative measures in place and will need to rely solely on their coping skills to manage their anxiety.

Other female partners illustrated how the passage of time had influenced their level of fear and anxiety. Debra shared, “I used to think every physical ailment or pain could be cancer. That’s when I thought about recurrence the most. But I learned to not panic and not let my thoughts go automatically to cancer every time I felt a pain.” Similarly, Delia explained that feeling high levels of anxiety following the end of her treatment caused her to become preoccupied with medical appointments in an effort to seek relief. She explained,

I was going for check-ups three-to-four times a year. My doctor kept telling me it wasn’t necessary. The further out you go from your cancer, the less you think about it. I stepped down to twice a year. Now I keep up in a reasonable way, once a year as my doctor instructed. I don’t dwell on it like I used to.

Lisa’s dialogue captured the overarching ideas expressed by these eight female partners. She stated,

I became so neurotic about it that it was like I was still in the middle of it. It will make you crazy if you let it, and I refuse to let it. That doesn’t mean it never comes up, but I refuse to let cancer take up space in my head and distract me from my life....What’s done, is done, and I can’t change that. And what will be, will be. I can’t change that either, and I have no control over whether it comes back or not, so I’m not going to kid

myself into believing I do. I just have to accept that I'm doing everything in my power, even if it's not much, to be on top of it.

I still need to stay strong and focus on the positive. Male partners' responses about the possibility of recurrence followed similar patterns to the ways in which they responded to the initial diagnosis of breast cancer, though the level of internal emotional reaction was not as intense. The congruencies were evident in discussion regarding their perspectives that the best ways to approach the situation is to stay positive, which also involved withholding expressions of their concern. Although the seven male partners who offered their perceptions indicated that they did experience some level of concern and worry over the possibility of recurrence, they all described presenting an optimistic attitude to their partners. Craig stated that he always try to "speak in positive terms about it." Dialogue between Annika and Darren illustrated the predominant messages conveyed by male partners. Darren explained, "I try to be optimistic about it, so we can keep going about our lives." Annika commented, "He never tells me how he feels about it. He never tells me if he's afraid of me having a recurrence or dying, never ever." Darren responded, "Yes, I do think about it..., of course, it's very scary for me...I guess it's easier for me to try to stay positive." In addition, Darren indicated that he generally responds to Annika's concerns by focusing on non-emotional topics, such as medical advancements, new medications on the market, or improved survival rates. Steve described responding in a similar way, by focusing on information and statistics provided to him by Diana's doctors. He explained that he relied on this information to ease his own fears, but also responded to Diana's concerns this way because he often did not know what to say that would offer her reassurance or ease her anxiety.

Withholding the expression of concern coincided with the fact that male partners described not communicating about the topic of recurrence unless the subject was initiated by their partners. In addition, their verbalizations were mainly responses to their partners' concerns, not a reciprocal exchange of ideas. Dan indicated that he does not allow himself to dwell on his concerns about recurrence, but will always make himself available when Lisa feels the need to talk about it. Clark and Craig both acknowledged that their ways of responding are to offer reassurance to their partners that they are taking all the necessary steps to manage their health and sometimes resort to referencing information obtained in the research they had conducted. Both also remarked that they were aware that not voicing concerns or sharing feelings comes across as though they are not concerned. Darren commented that his way of responding to Annika's voiced concerns, "probably seems to her like I don't really care, which isn't the case at all."

The synthesis of the data revealed an interesting aspect related to the ways in which they approached the subject of recurrence. As stated earlier, the ways in which most responded to the possibility of recurrence displayed similarities to the ways in which they had responded to the initial diagnosis of breast cancer, especially with regard to limiting expressions of concern. This is particularly interesting in light of the fact that most male partners had identified making positive changes in the ways in which they communicated with their partners about emotional topics. Overall, they had either conveyed themselves, or agreed with their partners' report, that they experienced greater openness with expressions of emotion and ease in talking about sensitive subjects within their relationship; however, with the exception of Rob and Susan, no other couples specifically identified these changes related to conversations about cancer. Likewise, Rob was one of two male partners whose responses about recurrence did not follow

suit with the others. Rick was the other, and he identified that he and Nancy had never spoken about the possibility of recurrence prior to the interview. Based on the responses discussed, there is evidence that male partners' experiences with communicating about cancer differ from their experiences communicating about other sensitive or emotionally-laden topics.

We would take the same approach that we did last time. Couples conversations related to how they would address the issue of recurrence, if it arose, demonstrated that partners shared the opinion that they would approach it in the same general manner in which they had previously. In general, couples provided brief, generalized statements, such as “We came out of this okay, so we’d deal with it just like we did before,” by Jessica, or “If anything happened, we’d handle it the same way,” by Keith. The overarching message was that couples viewed themselves as successfully surviving cancer; therefore, felt confident in following the same course of action. Couples did not identify specific decisions they would make or treatment options they would select in the case of a recurrence, rather, their responses implied that doing the same thing meant pursuing treatment assertively and proactively engaging in the process of coping. An interesting observation was the fact that none of the couples offered thoughts regarding changes they would make in the areas where they described struggling with coping. For example, none of the couples spoke about changing or repeating how they utilized resources, coped with the impact, or communicated with one another.

Three couples provided slightly more detail regarding their rationale for taking the same approach. Among these couples, all three female partners had opted for bilateral mastectomies, despite having the option of less-extensive measures, such a single mastectomy, or lumpectomy. Although it would be impossible to take the same course of action in a literal sense, their statements that they would do the same thing reflected their attitudes that they would again opt

for the most aggressive treatment available to them. Jessica commented that, given her mother and grandmother's histories, "There's no way I would take the chance of not doing the most aggressive route." Nancy stated, "I had bilateral mastectomies to eliminate the risk. If anything else happened, we would tackle it the same way." Finally, Diana remarked, "With all we've already done, it's just not an option to be conservative. If we're gonna fight, we're gonna fight hard."

Despite the brief nature of this particular conversation point, there was evidence of a theme based on the high tendency for couples to respond that they would "do it the same way we did it the last time," as expressed by Lisa. The couples' responses seem to reflect more about their confidence in their abilities to actively pursue treatment and take all necessary measures in order to survive than about taking the same actions in a literal sense. Essentially, the discussion can be summed up with this statement Delia made to her daughter: "All I could do was promise...that if we did have to ride this ride again, I would fight just as hard as I did the last time."

Summary

Exploration of survivor couples' perceptions of growth following breast cancer was conducted through the process of engaging ten survivor couples in semi-structured interviews pertaining to their experiences with the illness. Couples had been recruited from a nonclinical population through purposive sampling and snowball technique. Referral resources included community based breast-cancer-related organizations and events. Participating couples had all been in their relationships at the time of the initial breast cancer diagnosis and throughout the course of treatment and time of the interview. Ages at the time of the interview ranged between 35 and 66 years old for female partners, and 37 to 69 years old for male partners. Female

partners had all completed their primary breast cancer treatment at least one year prior to their interviews. Ages at the time of diagnosis ranged between 31 and 59 years old. Both partners within a relationship were agreeable to participating in the interviews, which lasted between one and two hours.

Case studies for each couple were presented in order to capture the essences of the couples' lived experiences of breast cancer. These studies highlighted the ways in which each couple was impacted by breast cancer and perceived growth as a result of their experiences of coping with the illness. Included with each case study was a brief discussion of my experiences of engaging in the interview process with the couples. Field notes were kept throughout the course of data collection and synthesis, and included reactions to the couples' responses, experiences related to interacting with the partners, and awareness of personal biases. In addition, information contained within the field notes assisted with identification and recognition of themes developing early in the data collection process.

The themes that were identified and discussed emerged from the case studies and represent patterns of responding across couples. Synthesis of the participants' interviews resulted in the emergence of themes within thirteen areas of conversations, (a) initial reactions to the breast cancer diagnosis, (b) beliefs about cancer, (c) impact of breast cancer, (d) adjustment to the illness, (e) communication, (f) resources for support, (g) beliefs about breast cancer, (h) experiences of survivorship, (i) perceptions of positive change, (j) charitable endeavors, (k) perceptions of positive growth, (l) indicators of change and growth, and (m) perspectives on recurrence. Prior to discussion of the themes, couples' preliminary ideas about the definitions of survivorship and growth were reviewed. This was done in order to understand the couples' general impressions prior to responding to specific interview questions. Couples' initial

responses suggested that survivorship was based on proactively coping in order to move through and beyond a traumatic situation. Positive growth was viewed as changing in response to learning from the traumatic event and demonstrating the ability to maintain or further develop positive changes.

Overall the couples' conversations revealed that both female and male partners experienced a sense of shock and fear upon learning of the breast cancer diagnosis. Male partners believed in the importance of presenting as strong and able to be relied upon to their partners, which resulted in the tendency to withhold emotional expressions. Couples experienced disruptions in several areas of their lives as a result of the impact of breast cancer, including physical, emotional, sexual, and relational closeness. Most attempted to adjust to the illness by engaging in the process of researching breast cancer, focusing on logistical aspects of coping, and making efforts to maintain normalcy in their daily routines and schedules as much as they were able. Several couples found it necessary to re-distribute the household responsibilities as a result of limitations of functioning experienced by female partners due to the side effects of treatment including pain, nausea, and fatigue. The primary resource for support identified by couples was their own relationship. Couples described relational acts of care-taking as the most significant experiences of support. Additional resources included family/close friends, community, spiritual/religious affiliations, and medical professionals.

Couples described positive change in terms of placing greater priority on the ways they engaged in certain behaviors, such as communicating with one another and engaging in leisure activities. All ten couples perceived that they had grown in response to their experiences with cancer and through surviving the challenges they faced. Most indicated that they experienced a greater degree of emotional closeness within their relationships than they had prior to the

introduction of breast cancer within their lives. Couples also discussed their perceptions of deepened spiritual connection, increased relational trust and confidence, greater capacity towards feeling gratitude, and heightened appreciation for life through greater awareness of mortality. The primary ways in which couples sought evidence of their growth was through assessing their ability to maintain positive changes and observations of their children's adjustment and behavior. Increased involvement in large-scale charitable endeavors or personal offers of support both served as means for couples to fulfill their desire to engage in acts of giving back. Some female partners identified that having the ability to interact with other survivors was beneficial to their well-being and ability to embrace the ideas of survivorship. Despite difficulties with communication, disrupted functioning, and initial ways of coping, couples conveyed an overall message of being satisfied with the changes and growth they experienced through surviving breast cancer.

CHAPTER FIVE

Discussion

The following discussion highlights the finding of the data analysis within the context of the purpose of the study and as these data pertain to the research questions that guided this investigation. The purpose of this study was to explore the lived experiences of couples following breast cancer and their perceptions of positive growth as a result of their experiences with the illness through the utilization of a qualitative, phenomenological methodology. Phenomenological research questions designed to facilitate understanding of the participants' lived experiences included: a) How do couples who have experienced breast cancer experience the impact of the illness on their relationships? (b) What are the processes and qualities that couples who have experienced breast cancer believe were essential for coping? (c) How do couples who have experienced breast cancer perceive the cancer-free period following treatment? And, (d) What do couples who have experienced breast cancer believe about positive growth or what current experiences serve as indicators of growth? In addition, discussions related to the contributions of the present research, clinical implications of the findings, and limitations of the study with recommendations for future research are also included.

Summary of Findings

Research Question One: Experiences of the Impact of Breast Cancer

The first research question explored the ways in which couples experienced the impact of breast cancer within their relationships. Within the couples who participated in the study, both female and male partners perceived disruptions in their daily lives and relationships as a result of the diagnosis and treatment of breast cancer. Areas in which couples experienced the most disruption included physical functioning, emotional climate, sexual intimacy, and relational

closeness. The stressors associated with these disruptions included management of family and household responsibilities, difficulties expressing emotions about cancer and the possibility of recurrence, reduced sexual engagement, and misperceptions of shared views regarding female partners' physical appearances and sexual attraction within the relationship. Consistent with the findings of Shands et al. (2006), couples shared the perspective that stressors and disruptions which contributed to tensions within their relationships and periods of diminished relational closeness were of the most concern.

The impact of breast cancer on physical aspects of the couples' lives was evident through disrupted abilities to manage everyday physical demands and engage in their daily routines in the ways in which they were able to prior to the female partners' diagnosis. The majority of female partners experienced post-surgical physical pain and treatment-related side effects, which inhibited their physical functioning and abilities to fulfill their usual physical responsibilities. Tasks that were once deemed simple, such as cooking, cleaning, and laundry were perceived as physically challenging or were unable to be performed at all. Several couples indicated that it became necessary to redistribute household and family responsibilities in order to compensate for the disruptions and maintain household structure and family functioning. Despite this, some women indicated that, at times, they engaged in physical tasks that were beyond their comfort levels or when it was not in their best interest to do so because they hoped to reduce the impact their partners were experiencing, even if it meant that they would experience it more significantly themselves. Male partners adjusted to the impact of the illness by taking on more responsibilities within the home and with child-related activities, while continuing to fulfill their out-of-home and employment obligations as well. Although they approached the situation with acceptance and understanding, they described feeling both physically and emotionally taxed in

their efforts to manage all that was required of them and adjust to their increased workload. In addition, they were frequently challenged with having to learn how to complete unfamiliar tasks and navigate routines they were not accustomed to managing. The experiences of stress were further influenced by self-imposed pressure to be effective in managing the multitude of demands. Male partners' perspectives on the importance of fulfilling these expectations were directly connected to their perceptions of their roles as caring partners, as well as to personal significance they found in being helpful in reducing the impact of breast cancer on their loved-ones.

Female and male partners mutually described experiencing pressure to negotiate the daily demands, and most believed that their relationships were affected as a result. The predominant shared perspective was that the impact of breast cancer on physical functioning disrupted the level and quality of engagement within the couple relationship. Female partners described experiencing pain, nausea, and fatigue, which not only limited their abilities to perform their usual daily tasks, but also depleted their energy to the point where they felt unable to attend to their partners or their relationship. Some women referenced themselves in terms of being *unavailable* or *absent* because they felt too sick to spend quality time with their partners or did not have the stamina to actively engage in interactions and activities which nurtured their relationships. At the same time, male partners felt as though they were not able to be fully present in their relationships because of the time demands associated with managing the majority of the responsibilities and the resulting fatigue. Pressures to keep up with everyday physical demands, combined with disruptions in attending to their relationships, resulted in increased tension between some partners.

A few male partners voiced their feelings that one of the most significant ways they experienced the impact of breast cancer was in their perceptions of relational inequity. This was generally expressed in terms of being *low man on the totem pole* or *put on the back burner* because managing other areas of life, especially those related to their children, took priority. Unlike Fergus and Gray (2009), who found that female partners were so consumed by the illness that they failed to recognize the impact on their partners, female partners in this study did acknowledge their partners' experiences, and expressed feelings of guilt over their limitations in being able to attend to all aspects of their lives, which resulted in their partners feeling excluded at times. Female partners also understood that putting aside activities and interactions with their partners that contributed positively to their relationships influenced the ways in which they experienced the impact of breast cancer, and they verbalized feeling helpless to rectify the situation given their physical conditions. In essence, partners shared the responsibility for the perceived inequities. Although the inequities were experienced negatively, the fact that couples shared the responsibility seems to have reduced the level of resentment experienced among couples in other studies who did not share responsibility or perceive their partners as validating of their experiences.

Despite feeling left out or neglected at times, male partners did not place blame on their partners for these experiences. Instead, they expressed their understanding of the situations their partners were faced with and agreed that the needs of their children had to come first, even if that meant their partners were left with little attention left to devote to them or their couple relationship. In addition, they acknowledged that the physical strain of managing increased responsibilities resulted in them putting aside their own needs in order to care for the needs of their families first. Couples shared the perspective that even though most disruptions in the level

of relational engagement were secondary to the impact of the illness on physical functioning, these were perceived as having greater personal significance. Finally, regardless of acknowledgement and understanding of each partner's experiences, couples shared a mutual sense of inadequacy to address these disruptions in ways that would result in marked improvement or resolution; however, some male partners disclosed that the validation they received helped them transition from feeling sorry for themselves to accepting that they needed to focus their attention wherever it was necessary in order to show that their partners were their priority.

The emotional experiences among female and male partners differed as they individually experienced the impact of the illness. The predominant emotions experienced by female partners included fear and sadness. These emotions were prompted by reactions to factors such as loss of independence, decreased ability to function in their usual capacities, altered perceptions of body-image, and decreased sense of control over one's own life and body. Secondary to this, female partners often experienced guilt associated with their perceptions that their illness and the demands of treatment placed added burden on their partners as well as interfered with their own ability to attend to their partners' needs. A few noted that their experiences of the impact of breast cancer were compounded because they were reluctant to seek emotional support or to burden their spouses, who were already taking on additional household and family responsibilities, with their needs. Male partners primarily described feeling overwhelmed, helpless, and guilty associated with perceived inadequacies in their efforts to ease their partner's discomfort, manage additional responsibilities, and offer emotional support. Similar to the responses of female partners, some male partners believed their experiences of the impact of

breast cancer was influenced by the fact that they would not ask their partners, who were dealing with the challenges of cancer treatment, to contribute in any way to their needs.

Emotional distress related to the fear of death and loss of the relationship was shared between partners. In addition, although much more prominently identified by male partners, both experienced psychological distress upon witnessing their partners' displays of distress as well. This was consistent with Kim et al. (2008) who suggested that, although one's own distress tends to be the strongest predictor of one's quality of life, one's partner's distress also greatly impacts quality of life. This was also consistent with Broderick's (1993) family-systems theory in that male partners' experiences of increasing distress in response to their partners' increasing distress demonstrated interdependence within the couples' relationships. Experiences of emotional distress were heightened further as a result of communication barriers and difficulty talking about emotionally-laden topics. Couples primarily discussed these communication difficulties in terms of the negative impact on their relationships; however, their descriptions illustrated that these were related to ineffective efforts to cope with emotional disruptions; therefore, will be presented below in the discussion related to coping.

Couples also experienced the impact of breast cancer within their sexual relationships. Partners shared the perspective that limited availability of quality alone time due to the demands of treatment and household responsibilities, and the infrequency of periods of time where both partners felt up sexual activity, disrupted the level of sexual engagement. Multiple other factors contributed as well including female partners experiencing treatment related physical pain and side-effects, decreased sexual confidence, and self-consciousness regarding the appearance of their bodies. Most female partners struggled with their perceptions of themselves as sexually unattractive based on their appearances, and experienced difficulty accepting the physical

changes to their bodies, such as scarring caused by surgery, and hair-loss and weight-gain associated with medication side effects. With the loss of their breasts, some women experienced inhibited senses of femininity and described feeling disconnected from their views of themselves as sexual individuals. They frequently projected their perceptions onto their partners, assuming that their partners also viewed them as unattractive because of their physical appearances and less feminine as women without natural breasts.

Unlike Fergus and Gray (2009), who found that male partners experienced difficulty engaging sexually with their partners because of factors such as viewing mastectomy scars as a reminder of cancer, male partners who participated in this study indicated that their desire and attraction to their partners were not affected by the changes to their partners' bodies or by their own perceptions about breast cancer. In addition, they did not report experiencing difficulty seeing their partners in sexual ways due to the shift in their roles to caretakers, which sometimes contributed to a parent-child-like relational dynamic as was found in Fergus and Gray's study. Instead, they described that, although the degree of attraction remained, they were less inclined to initiate sexual activity out of fear of accidentally causing physical pain and concern over responding or behaving in ways that contributed to partners' self-consciousness or discomfort with exposing their bodies. Several made efforts to offer reassurance to their partners and express their sexual attraction; however, during the initial timeframe following surgery and through the earlier stages of treatment, female partners generally had difficulty accepting their partners' reassurances and believing that their attraction was genuine because they were unable to view themselves from their partners' perspective. Male partners often felt disheartened by their partners' rejection of their offers of reassurance and dismissal of their opinions. This was semi-consistent with Fergus and Gray's (2009) postulation that, although female partners may

seek validation or reassurance from their partners by expressing their dissatisfaction with their altered bodies, they are often not consoled by their partners' efforts, which leaves their partners feeling frustrated and ineffective. The primary difference seems to be that male partners in the present study also expressed feeling sad that their partners could not experience the attraction that was present or see themselves the way male partners saw them. The experience of sadness was more prominent than that of frustration, and male partners seemed to respond to this by continuing to offer reassurance instead of withdrawing from doing so. Although statements conveying attraction and acceptance did not immediately console female partners, there was evidence that the consistency of male partners' encouragement had a positive impact on both the emotional climate of the couples' relationships, as well as the progress towards reestablishing sexual intimacy.

For most couples, disruptions in their sexual activities continued throughout the course of treatment. The majority of female partners indicated that it took a long time for them to begin to accept their partners' viewpoint as valid, though differing from their own, and longer still to develop acceptance of their own bodies. Despite the extent of the disruption, female partners believed that the reassurance offered by their partners and the demonstrations of attraction contributed to their progress towards coming to terms with their self-perceptions regarding physical appearances, sexuality, and femininity. Some verbalized that their partners' demonstrations of understanding allowed them to feel safer while exposing both their bodies and their vulnerabilities. These partners were more willing to try to engage sexually during periods of time where they felt well enough physically to do so. Fergus and Gray (2009) found that couples had difficulty adjusting to the sexual changes because they were unable to set aside fears of loss, death, and separation during intimate engagements. The descriptions provided by

couples in the present study illustrated different experiences. Their accounts suggested that the giving and receiving of reassurance helped both male and female partners remain focused on their intimate connection to one another, and, as a result, were better able to separate the illness from their sexual interactions.

Struggling to maintain feelings of physical closeness and intimate emotional connection without their usual sexual routines posed a challenge for most couples. Male partners tended to verbalize this difficulty more frequently than female partners; however, partners shared the perspective that they felt most connected to one another during intimate sexual exchanges. Some female partners indicated that they had less interest in the physical act of sex than their partners but they experienced their partners as more emotionally connected during sexual engagement; therefore, shared the experience of it being a challenge to retain a sense of intimacy during times when sexual activity was disrupted. Female partners frequently assumed the majority of the responsibility for disruptions in their sexual relationships and minimized factors relating to their partners' functioning. Thus, they frequently experienced a great deal of guilt related to their perceived inability to satisfy their partners' needs and responsibility for the overall impact that breast cancer had on their sexual relationship. Maladjusted sexual relationships seemed to slowly improve over time as women experienced their partners maintaining respectful attitudes, demonstrating understanding of their vulnerable psychological states, and supporting their self-esteem by providing positive feedback. Female partners appreciated when their partners conveyed valuing their inner person above their physical appearances and considered their well-being ahead of their own sexual needs. Male partners indicated that their partners' recognition of their unmet needs and efforts to physically connect with them, either sexually or non-sexually as they were able, helped them feel acknowledged and appreciated even though disruptions

continued. This contributed to their perceptions of diminishing the impact breast cancer had on their relationships. Couples shared the view that validation of one another's experiences and efforts to respond in caring ways assisted to ease the felt impact of breast cancer on their sexual relationships. In addition, efforts to physically and emotionally connect in non-sexual ways when sexual activity was not feasible positively benefited both male and female partners. There is evidence that maintaining perceptions of intimacy contributed to female partners' abilities to re-establish their sexual roles within the relationship, while also assisting male partners to continue to perceive their partners in sexual ways, as opposed to the parent-child dynamics observed among participants of other studies.

Research Question Two: Coping with Breast Cancer

The second research question was aimed at understanding couples' perceptions about the processes and relationship qualities which were essential for coping and their experiences of their own abilities to cope. Although some participating couples had previous knowledge and indirect experiences with breast cancer or other types of cancer from which they could draw from, none had experienced cancer directly within their own couple relationship. Several described breast cancer as *unknown territory* which required them to learn new ways of problem-solving and coping. Not all coping strategies utilized were successful or helpful to the couples, and some further impacted the level of distress and disruption within most relationships. For example, some attempts to implement familiar coping strategies and solutions which had been effective in other situations proved to be ineffective and created additional difficulties and stress. Figuring out what was helpful or not was a process of trial and error for most couples, and some found it more difficult to negotiate support than others. In general, couples were able to find effective ways of coping and shared their perceptions that, overall, they believed they had

successfully managed to cope with the impact of breast cancer together. The following discussion will include couples' experiences with both effective and ineffective efforts at coping.

Couples experienced the most amount of difficulty with efforts to cope with the emotional impact of breast cancer through verbal communication. More specifically, couples experiencing more difficulty adjusting to the illness were more likely to engage in unhelpful behaviors such as avoidance, withdrawal, and protective buffering. Female and male partners' perceptions of the situations differed, but they agreed that they experienced an inability to find mutually comfortable ways of communicating about their feelings. For men, the combination of wanting to maintain their partners' view of them as being strong and self-assured, along with struggling with knowing how to respond to their partners' emotional expressions, frequently resulted in them communicating in ways that their partners found unhelpful. In addition, they believed that withholding their emotional expressions was in their partners' best interest and was intended not only to project the image that they were emotionally strong and, therefore, could be relied upon, but also to not burden their partners with their worry. Responses to emotional expressions frequently included statements suggesting female partners should *be positive* and that *everything will be fine*. Some noted that this was the result of not being accustomed to expressing their emotions or having previous experiences which would have contributed to them acquiring the skills to respond in more empathic ways. A majority of male partners reported feeling ineffective and inadequate in offering reassurance or verbal emotional support to their partners. When their attempts at offering support were not well-received by their partners, their feelings of inadequacy were reinforced and it became even more difficult for them to verbally empathize with their partners. Failed support attempts frequently resulted in male partners avoiding emotion-laden conversations.

Women indicated that, although they admired their partners' abilities to maintain positive attitudes and found this uplifting in other contexts, they perceived these types of statements to be minimizing and invalidating of their feelings, especially at times when they were seeking emotional support. It was also conveyed that female partners perceived their male partners as setting the climate of emotional disclosure within their relationships. The general explanation for this was that, initially, most female partners did not experience a significant degree of difficulty expressing their emotions. However, responding to their partners' avoidance of emotional conversations and withholding of emotional disclosures, most women felt inhibited to continue to openly disclose because they were not experiencing reciprocal engagement with their partners. Their perceptions of their partners as not responding to their stress signals diminished the emotional stability they had previously experienced within their relationships. Several women described withdrawing and turning their emotions inward as a result. The co-occurrence of good-intentioned, but unsuccessful, attempts at responding and withholding/withdrawing emotional expressions contributed to both partners experiencing emotional distance within their relationships. Partners were better able to cope with their emotional experiences by seeking alternate support resources which met their needs more efficiently. Most female partners utilized their relationships with other close females as forums to be able to express their emotions and receive emotional support. They felt most validated when they were able to share their experiences with other survivors; however, still found value in their exchanges with non-survivor women based on their abilities to relate as women. Male partners were more likely to talk about their experiences with breast cancer with close male friends or co-workers and described doing so in more factual, less emotional ways. For some, reaching out to others for support was

difficult; therefore, conversations were limited to those experiencing similar situations or when initiated by others.

Most couples used protective buffering as a means of attempting to cope with the emotional impact breast cancer had on their relationships. These behaviors included hiding one's worries, denying concerns, and yielding to one's partner to avoid further upset. Some partners described this as trying to be *careful* with their partners because they perceived one another to be emotionally sensitive, whether spoken or not. Many withheld expressing their feelings about needs going unmet, complaining about things they were unhappy about, or asking any more from their partners in an effort to not place added burden on them. Female partners described minimizing their distress with the intent of *saving* their partners from having to *deal* with their issues or avoid causing their partners to be distracted from their work and other responsibilities. In addition, some believed that their expressions of emotion or conversations about cancer were overwhelming to their partners and should be limited in order to *protect* their partners from having to feel uncomfortable emotions. Female partners spoke about experiencing guilt associated with their perceptions of being a burden to their partners and the *cause* of their partners' disrupted lives, which served as a motivating factor to engage in protective buffering.

Although both female and male partners described engaging in these behaviors, male partners hid negative feelings and avoided conflict more often than female partners. Male partners described greater motivation to shield their partners from additional distress based on their perceptions of them being emotionally decompensated and vulnerable to dysregulation. They voiced their opinions that breaking down emotionally would have further distressed their partners by causing them to worry, feel guilty, or be distracted from their self-care; therefore, if they were not able to adequately mask their emotions, some male partners resorted to

temporarily avoiding their partners. They also described *walking on eggshells* and feeling fearful of saying or doing *the wrong thing*, so they often resorted to withholding differing opinions and acquiescing to their partner's ideas and suggestions. Many reported that they distanced themselves when they perceived their partners as emotionally overwhelmed and avoided emotionally-laden topics of conversation. Some identified that perceiving that they had upset their partners caused them to feel more guilt themselves. *Sensing* when one's partner was deliberately withholding or buffering communication, as well as feeling the need to censor one's own expressions, contributed to partners' perceptions of distance and lack of genuineness within their relationships. Once again, despite the motivation to avoid further anguish and the good intentions behind these behaviors, protective buffering generally resulted in increased distress and decreased perceptions of emotional closeness in the relationship. Couples demonstrated congruence in their perspectives that protective buffering interrupted the level of satisfaction they had experienced in their relationships even prior to the diagnosis of cancer. However, they also indicated that their experiences of diminished relational closeness were periodic and were triggered primarily when buffering behaviors occurred. Most reported that other means of relational coping assisted with re-establishing their emotional bond.

The most prominently described effective mutual coping efforts involved taking measures to maintain what couples perceived as normalcy. This was motivated by both the desire to maintain daily routines, schedules, and activities in order to limit the disruption within their households, as well as to serve as a way to periodically distract attention away from cancer. Couples who had children living in the household believed that remaining involved in their usual activities and structure influenced their children's overall adjustment to the illness. As parents, couples did share concerns with one another related to not knowing what impact the illness

would have on their children. Maintaining normalcy assisted couples in ensuring that their children's needs were met as consistently and fully as possible, especially during times when more cancer-related activity was taking place. Couples also shared the belief that any behavioral changes that their children may display related to their experiences with breast cancer would be more noticeable in the context of their regular routines. In addition, most couples found it easiest to talk with their children about breast cancer, and have their children express concerns or ask questions, while engaged in typical family interactions or usual daily activities. This essentially helped de-catastrophize the illness by not making it an *event* to talk about it, and, instead, modeled and promoted that it was normal and acceptable to talk about. Couples felt better able to assist their children with adjusting to the illness because most saw that, overall, their children responded well to the approach they had taken. Finally, couples conveyed their shared opinions that their children's adjustment was based on how they perceived their parents to adjust to the situation. They also believed that their children witnessing them engaging in their typical routines offered reassurance that the family was intact and reduced worry. Several couples indicated that this was beneficial to the whole family's adjustment, not just their children's, and they personally experienced less concern over the possibility that the impact of breast cancer would have lingering effects.

Female partners believed it was important to retain some sense of independence and autonomy by continuing to work and maintain family responsibilities as much as they were able. Some found it difficult to relinquish some responsibilities because they associated this was a loss of autonomy. Maintaining their lifestyles and routines benefitted their self-esteem and sense of productivity, and aided their perceptions of having a sense of control in their own lives. Most described that these efforts took a substantial toll on their energy levels, but they believed that

the contributions to their adjustment made it worthwhile. Several female partners indicated that engaging in their usual activities as much as possible helped them cope by also providing them with ways to sustain a sense of personal identity separate from the illness. These findings differed from those presented by Fergus and Gray (2009) in that these participants' descriptions did not convey significant degrees of either counter-dependency or exaggerated dependency as reported by these researchers. For the most part, they demonstrated the ability to engage in as many aspects of their daily routines as they found beneficial, but not to the point of significantly compromising their well-being or severely impeding their adjustment by excluding their partners from assisting. At the same time, despite the psychological difficulties associated with needing to rely on their partners more than usual, they were able to relinquish as many responsibilities as was necessary without rendering themselves helpless.

Male partners spoke the least about the importance of maintaining normalcy for themselves as individuals and expressed their opinions primarily in terms of how this influenced their family's well-being. Although they did believe that they personally benefitted from sustaining the usual routines and this helped them cope with the impact of the illness, most spoke about taking on extra responsibilities within the household to ensure the continuance of their families regular activities and household functioning. Essentially, male partners described taking beyond-normal measures in order to support the normal structure and routines of the household; however, although they perceived benefits to their coping, they did not personally perceive normalcy for themselves. In fact, a few shared that, at times, they felt less acknowledged in their relationships because their partners had little energy to devote to the relationship after focusing their attention and efforts on other areas of their lives. Similar to the responses of female partners, male partners perceived the benefits as out-weighing the sacrifices they made, and most

were able to perceive this as in alignment with their views of what it means to be loving partners and providers. They demonstrated willingness to accept the situation based on their perceptions that it improved the family's ability to cope. In general, couples shared the perspective that their overall ability to maintain normalcy was an indicator of effective coping as a couple. Most conveyed that they believed it was important to engage in some of their usual activities as a couple but that they found this difficult to do consistently. Despite this, they did perceive the efforts they made as improving their ability to adjust together to the impact of breast cancer. For example, a few couples found that periodic occasions to socialize with friends or other couples provided them with the opportunity to seek respite from the demands of cancer, and to interact with one another as a couple without focusing on the illness. Consistent with the findings of Shands et al. (2006), one of the barriers to couples finding time alone without their children was that they did not feel that asking others to assist them for the sake of fun or leisure was a justifiable request, especially if others had already extended themselves to assist in practical ways.

Couples' perceptions of breast cancer as a shared experience and a challenge that could be overcome together positively influenced their abilities to seek alternative ways of coping together. Utilizing relational strengths and coping strategies contributed to re-establishing the experiences of closeness and seemed to semi-compensate for or balance ineffective and unhelpful efforts. The predominant characteristic identified by couples as being essential to their coping was their ability to work cooperatively to manage the impact of breast cancer on their daily living. One couple described that they were *more about the doing than the feeling*. This statement reflects the descriptions provided by several other couples. The term most frequently used to describe the couples' experiences was *teamwork*. Assuming a solution-focused, as

opposed to emotion-focused, perspective enabled couples to attend to the demands of the situation in a coordinated manner. Coping cooperatively mainly involved engaging in activities such as attending appointments and treatment sessions, making treatment-related decisions, and accomplishing household tasks together. Female partners felt supported by their partners and perceived their partners as *available* and *present* in these types of interactions. Male partners described feeling satisfied with having ways to be helpful and assume significant and meaningful roles as caregivers, instead of continuing to experience helplessness, powerlessness, and inadequacy. In addition, their involvement helped to demystify the illness and gain greater understanding of their partners' experiences. The satisfaction couples experienced regarding their collaborative efforts and successful management of these areas of their lives instilled greater hopefulness in their abilities to survive breast cancer together. This drew some attention away from the perceived coping deficits and related distress, allowing couples to focus more attention on doing more of what they perceived themselves as good at.

Couples verbalized pride in being able to effectively communicate to establish and achieve shared goals and cooperatively manage the illness, especially in light of the challenges they faced communicating about their emotions. Coping strategies which involved the opportunity for couples to plan, problem-solve, and communicate in logistical terms greatly benefitted couples' perceptions of closeness. The sense of connection was not brought about through the topics of conversation. Instead, the couples' descriptions indicated that the ability to come together and talk about cancer in productive ways that did not emotionally overwhelm either partner positively influenced their perceptions of sharing the burden of dealing with breast cancer. In addition, the positive outcome of these coping measures brought about a sense of relational satisfaction and decreased the couples' experiences of emotional distress. These

coping measures included researching breast-cancer-related-topics and gathering pertinent information in order to master the unknown and reduce the associated anxiety.

Couples who engaged in research together were better able to work cooperatively to make decisions about how to approach treatment, anticipate and prepare for potential challenges, and consider options for coping. They experienced these processes as helpful to their adjustment because it enabled them to feel more in control of their situations and empowered in their beliefs about their abilities to survive breast cancer by approaching the challenge as a cohesive unit. They also felt more prepared for what was to come with each step of treatment and experienced less anxiety when they had a clear sense of what to expect and could mentally prepare to cope. Partners shared the belief that they adjusted better to the illness as a result of engaging in research and planning efforts together because these activities provided contexts within which to have conversations about cancer. They also indicated that during these exchanges, they perceived their partners as fully engaged, demonstrating no need to buffer or withhold communication. Male partners strongly conveyed that they felt more able to cope with talking about breast cancer when they could do so in this type of task-focused fashion. Although female partners expressed that they would have benefitted from more exchanges of emotion, and that these interactions did not nullify their needs for emotional support and understanding, most indicated that experiencing their partners as both mutually and actively involved in these ways contributed to their perceptions of being able to cope with the impact of breast cancer as a couple. These findings were significantly different from those presented by Shands et al. (2006) which illustrated that couples who participated in their study experienced greater feelings of vulnerability and incompetence in terms of how to make treatment-related decisions and manage the demands of the illness.

Other researchers, such as Fergus and Gray (2009), had found that male partners defaulted to problem-solving as a result of feeling helpless, but frequently did so without sufficiently listening to or empathizing with their partners. These efforts to simply fix the problem were generally unproductive. This did not appear to be the case with the couples in this study, although male partners did disclose that taking a solution-focused approach helped them feel less helpless. The difference seems to lie in the ways in which partners who participated in this study engaged with one another in their problem-solving efforts. This did not result in being counterproductive because both partners' perspectives and opinions were considered in order to come to mutual conclusions on what measures would be taken that would satisfy both partners' needs, as opposed to one partner independently trying to fix problems based solely on their own insights and assumptions about what would be helpful to the other partner. In the previous cases, fixing the problem alone did not compensate for a lack of understanding of how to offer helpful support, and the counterproductive measures often led to tension within the relationships and feelings of anger and resentment on the part of the male partner. In the present study, although the interactions surrounding problem-solving did not include the emotional communication female partners would have appreciated, the open exchange of ideas, respect for one another's perspectives, and mutual desire to consider the needs of both partners, as much as was feasible, contributed to a shared experience of being acknowledged and validated. Female partners described feeling that these conversations made them feel as though their partners understood their experiences to a greater degree than they had in the absence of emotion-focused dialogues and were far more productive than the unhelpful coping strategies they attempted to utilize. Couples described being able to establish a shared philosophy about the illness, which contributed to them avoiding further conflicts by focusing on their commonalities instead of

differences in viewpoint. Neither female nor male partners described experiencing the type of anger or resentment experienced by partners in other studies who demonstrated that the lack of a shared perspective impeded dyadic coping.

Utilizing support resources such as family, friends, and community connections was identified as contributing to successful coping; however, couples wholeheartedly believed that the single most influencing factor to their coping was their perceptions regarding relational care-taking. All of the couples identified that their primary resource for support was in fact their own relationship. Intimate acts of care-taking by one's partner were perceived as the most significant factor contributing to mutual coping. This process was described as multi-faceted and greatly enhanced couples' experiences of relational closeness, which they identified as being the most instrumental factor contributing to their perceptions of growth. Female and male partners experienced these processes differently based on their roles as recipients and providers of support respectively, yet both perceived their involvement in the process as positively contributing to their relationship and influencing their ability to adjust to the impact of the illness. Female partners' described feeling extremely vulnerable when they were not able to independently care for their daily living and hygiene needs as a result of post-surgical pain and, for some, the placement of drains. The care-taking offered by their partners, such as emptying drains and hair-washing, not only helped them cope with the physical impact of breast cancer, but eased some of the emotional distress and embarrassment associated with being seen at what they perceived as their worst because they experienced their partners as accepting and compassionate. Male partners indicated that they were better able to deal with the impact of breast cancer and seeing their partners physically distressed through perceiving themselves as able to actively participate in contributing to their partners healing and general well-being. In

addition, they felt acknowledged and significant to their partners because these types of care-taking acts were usually only allowed by those who were intimately connected and most trusted. Couples mutually indicated that engaging with one another in such intimate and meaningful ways was a primary component of re-establishing relational closeness that had been diminished as a result of unhelpful and ineffective coping efforts.

Research Question Three: Perceptions of Change Following Breast Cancer

Partners indicated that it became easier to incorporate positive changes into their lives because they perceived one another as supportive of new endeavors and open to each others' ideas and interests. Couples demonstrated mutual motivation in their efforts based on their shared perspective that both the actual changes and the openness to one another's ideas about change enriched their relationships. Positive change was identified as improving the ways in which the couples engaged in specific aspects of their lives together including leisure activities, communication, and healthy living. For some couples, their experiences with breast cancer brought about greater awareness of the importance of these behaviors and caused them to re-prioritize these within their daily living.

Couples made it a priority to intentionally spend more time with each other, and were more motivated to seek and create opportunities to engage in leisure activities together. For some, this entailed exploring new hobbies or sharing a partners' hobby which they had not previously been involved with. For others, this involved seeking discovery and enrichment through participation in adventurous activities, new experiences, or those that they had wanted to try, but never had or planned to do during retirement (i.e. their bucket lists). Despite the desire to alter their lifestyles in this manner, doing so was generally a gradual process, as opposed to an immediate transformation. Some couples had difficulty transitioning from the seriousness of life

copied with the illness to a more relaxed, jovial climate. They described becoming so accustomed to the distress and pressured living that they felt like they needed to relearn how to have fun and allow themselves to take pleasure in life. Adjusting routines and ways of engaging in daily activities was often necessary in order to allow for more time to be spent together. For some, this was related to allowing more flexibility in the rigid structure they had implemented into their lives in order to maintain normalcy during their encounter with cancer. For others, this pertained to assuming a more relaxed attitude in general about household responsibilities in order to balance the work and leisure enjoyment in their lives. In addition, some couples became more selective about the out-of-home activities they involved themselves in and non-family-related responsibilities they assumed.

Overall, couples perceived their increased leisure time together as nurturing their relationships and providing opportunities for them to learn more about one another and experience one another in new ways. Partners described experiencing greater pleasure in simply spending time together, whether engaged in an exciting adventure or performing household chores together. They expressed finding new meanings in their day-to-day interactions and activities, and created opportunities to engage with one another through mutual involvement in routine tasks and chores, which had previously been performed individually. These chores became more enjoyable and less burdensome, which motivated couples to continue to make them joint endeavors. Couples conveyed feeling satisfied with their abilities to learn how to change mundane tasks into opportunities to connect with one another and incorporate fun into their daily living. Some expressed experiencing stress-reducing effects and increased ability to cope with everyday pressures. Several also made the point that, although they have increased the amount of time they spend with one another, they were cognizant of the need to maintain balance in their

lives by exercising their independence and participating in activities which helped them retain a sense of individuality.

Most couples perceived positive change in the ways in which they communicated within their relationships. Change was specifically related to the degree of openness and emotional expression partners perceived themselves and their partners as demonstrating during verbal interactions. Couples conveyed that these particular changes were especially significant because they perceived them as reflecting that they had learned from their “mistakes” and the difficulties they had experienced with emotional communication during their trials with breast cancer. Partners mutually agreed that the increased openness and avoidance of censoring enabled them to relate better to one another emotionally. Some characterized their interactions as being more “honest,” not in the sense of avoiding deception, but in the experience of them as true to their internal form and fully reflective of their thoughts and feelings. Most couples held the perspective that there was greater ease in communicating about difficult topics because partners trusted that their opinions would be respected, and their feelings responded to. They described an overall reduction in their fear of upsetting one another or initiating a conflict. These improved ways of communicating resulted in fewer arguments and more productive expression of partners’ needs. They perceived themselves as more skillful in communicating productively and in ways that minimized conflict. Some male partners indicated that while it is still a challenge for them to initiate conversations about their emotions, they find it easier to engage when emotional dialogues take place or when they are asked about their feelings. Overall, most described experiencing marked improvement in their responsiveness to their partners’ emotional expressions and in contributing their own emotional feedback.

Incorporating beneficial health habits were primarily motivated through witnessing and experiencing illness. Most couples indicated that they felt greater appreciation for their health as a result of their experiences with breast cancer; therefore, were more compelled to attend to their wellness. Others indicated that some lifestyle changes were made out of necessity, either as instructed by their doctors or a means of coping, but that experiencing positive effects and becoming cognizant of the benefits contributed to their motivation to incorporate these into their daily routines permanently. Although not directly identified as a means to try to prevent recurrence, some female partners perceived improvement of their health habits as a way to maintain their regained wellness and avoid general illness. Efforts to establish and maintain healthy lifestyles involved engaging in regular physical activity and exercise, maintaining a nutritious diet, and minimizing exposure to stress. Couples described finding greater importance in limiting the amount of time they spent with others whom they perceived as *negative* or as being sources of tension. The processes of positive change entailed learning to set limits with others and maintain healthy emotional boundaries. For some, this meant developing the ability to decline requests which did not benefit their well-being and refrain from taking responsibility for or involving themselves in other people's problems without feeling guilty. Partners indicated that their views of the importance of maintaining healthy lifestyles were mutual, and they not only engaged in these activities together, but offered one another support and encouragement as needed to continue their efforts.

Research Question Four: Experiences and Indicators of Positive Growth

Couples perceived that their abilities to overcome the challenges associated with the illness together directly contributed to mutual growth and strengthening of their relationships. Partners expressed their perspectives that experiencing difficult situations and struggling to

navigate through these were inevitable, but that successfully resolving the challenges they faced drew them to together. Couples described feeling more emotionally bonded to one another than they were before their experiences with breast cancer. This included experiencing a greater degree of emotional intimacy within their relationships and observing themselves to be more emotionally supportive and responsive to one another. Perceptions of deepened emotional connectedness were especially significant since most couples had experienced periods of feeling disconnected as a result of their difficulties with emotional expression. Couples felt assured of the love and devotion in their relationships as a result of their abilities to not only re-establish emotional connection, but to survive together in ways that promoted greater relational closeness. One couple explained that the intensity of their bond equated to the intensity of the situation they faced together, and not only were they both part of the experience, they were connected in ways they had never been before.

In addition, experiences of increased emotional closeness as a result of perceiving breast cancer as a shared experience with the mutual goal of surviving the illness together contributed to couples' abilities to consider their experiences of disruption as opportunities for learning and growth. Couples primarily described this in terms of their ability to make positive things happen out bad situations. Some also conveyed their beliefs that being faced with an adverse situation provided the chance to learn how to deal with it and learn life lessons from the experiences. This illustrated Calhoun and Tedeschi's (2006) contention that some degree of psychological distress was necessary to set the growth process in motion. Cordova et al. (2001) suggested that perceptions of greater threat may contribute to increased opportunities for growth. The couples' experiences of increased emotional closeness, in conjunction with their expressions of deepened appreciation and gratitude for the presence of their partners in their lives, may reflect this as well

as Picard et al.'s (2006) contention that the threat of loss may prompt partners' re-evaluation of their relationships and lead to changes in the dynamics within the relationship and contribute to developing the bond between partners. This may also be evident in that some male partners described disruptions in their visions of the future (i.e. inability to imagine their lives without their partners), which prompted them to invest themselves more fully in their relationships. For both female and male partners, being faced with the possibility of losing their relationships as a result of the threat of death prompted introspection and acknowledgement regarding the value their partners held in their lives. To clarify, it was not the case that the threat of loss brought about the perception of value, rather, it brought awareness of the pre-existing value to the forefront of partners' attention and influenced the ways in which value was demonstrated.

Perceptions of successfully managing stressful situations together influenced couples' views of themselves and their relationships. They developed a sense of trust in the stability of their relationships and confidence in their abilities to cope with difficult situations together. This emerged through the recognition of relational strengths, which were utilized to survive a significant life challenge. Calhoun and Tedeschi's (2006) contention that an individual's encounter with a significant life disruption brought about a sense that one had been challenged and surviving the worst was perceived as a reflection of inner strength, was also evident in the shared perceptions of couples. Similar to individual cases, surviving a life crisis instilled confidence within the couples that they had the strength to survive other crises that might arise.

Picard et al. (2006) contended that couples draw upon the bond of love to transform suffering into meaningful experiences. In this case, several couples indicated that sharing the suffering associated with breast cancer reaffirmed the love and devotion they felt for one another which, in turn, contributed to their abilities to perceive their experiences constructively. They

recognized their capabilities and willingness to endure adversity together and acknowledge this to be significant in further developing their relational bond. Some conveyed their beliefs that going through these challenges provided opportunities for learning and acquiring skills essential for managing future difficult situations. Couples also shared the perspective that growth was the result of the efforts they put forth together to heal from their suffering and abilities to recognize gains associated with their experiences of survival. In addition, continuing to nurture the areas of growth and practice the positive changes they had incorporated were viewed as contributing to the on-going growth and development of their lives and relationship.

Although a sense of tragedy caused a few partners to experience temporary lapses in faith and existential despair, positive spiritual growth was experienced by the majority of couples, including those who initially experienced difficulty. Couples described growing more faithful through their struggles and perceived positive growth in their sense of spiritual connection. Most indicated that increased spirituality was identified as growth because it was primarily an internal experience, which partners shared with one another through mutual engagement in activities such as prayer or expressing gratitude to their higher power, as opposed to involvement in religious rituals or structured practices. Couples mutually agreed that their increased faith had become a greater source of strength and connection within their relationships. In addition, for some couples, it also contributed to altered views regarding mortality.

Developing increased awareness of mortality and greater appreciation for life were viewed as connected experiences. Greater awareness of mortality was not conveyed in terms of fear of dying, as can be the case when it is associated with a traumatic event. Instead, couples expressed acceptance of the unknown and acknowledged that their experiences with breast cancer had altered their perspectives on life and contributed to setting new priorities based on

their evolved perspectives of what is important in life. Recognition of the uncertainty of the future motivated couples to value the moments they shared with one another and re-evaluate the ways in which they spent their time and engaged in relationships with others. Couples indicated that they prioritized nurturing their own relationships, as well as those deemed to be sources of reciprocal support and mutual understanding.

Conversations about awareness of mortality were frequently mingled with those related to the possibility of recurrence. Couples described that their means of coping was to focus their attention on appreciating the life they have and living it to the fullest. Calhoun and Tedeschi (2006) suggested that some enduring upset may influence the maintenance and enhancement of growth. This may be reflected in couples' disclosures that, although the fear of recurrence gradually diminishes over time, it is always present on some level and will likely remain as such. This was expressed more by female partners, but agreed upon by their partners, indicating that it was a shared experience. The responses offered illustrated that couples reacted to this fear by engaging more actively in the positive changes and healthy habits they had acquired in order to prevent the fear from disrupting the growth they had achieved. Essentially, they conveyed that even though the residual upset related to the fear of recurrence was diminished, it continued to be meaningful enough to motivate couples to actively work together towards maintaining their growth. This was further demonstrated by the fact that couples who had been able to maintain their growth over longer periods of time conveyed the same ideas as those who had completed treatment more recently.

Couples described that their own experiences with breast cancer brought about an increased sense of empathy for others facing difficult life challenges, whether it be breast cancer or some other life struggle. Several couples found that this motivated their desire to engage in

charitable endeavors. This was frequently associated with couples' experiences of having been the recipients of good deeds and supportive gestures which brought about greater awareness of the importance of such efforts. Some couples described feeling humbled by their experiences and felt more inclined to respond to others who were facing difficult life situations as they had. Several couples referenced the concept of *paying it forward*, indicating that they experienced a renewed sense of importance in repaying the kindness shown to them by passing along a good deed to someone else in need. Engaging in supportive acts was demonstrated in several forms including sharing stories of personal experiences so others could learn from them, offering emotional support, advocating for others, participating in large-scale fundraising and awareness-promoting events, financially contributing to both breast-cancer-related and other charitable causes, and providing practical support, such as meal preparation and carpooling, for others dealing with significant challenges.

Couples viewed their involvement in charitable endeavors as both the result of their growth and a contributor to their continued growth. Many experienced their participation as mutually beneficial. Male partners often conveyed that they viewed their involvement as another way for them to feel as though they "have a hand in the fight," as well as a means to serve as positive role models to other male partners and encourage them to become involved for both their own benefit, as well as for the benefit of supporting their partners. Female couples described feeling empowered by their abilities to contribute positively to the survival of other women, while also drawing support and strength from other survivors they came in contact with. Couples who engaged in these types of activities together indicated that this enriched their lives and relationships by providing opportunities for them to interact in ways that nurtured their

shared beliefs, reflected their mutual value system, and supported one another's psychological well-being.

In general, the experiences described by couples illustrated that growth expanded beyond simple reappraisal of global beliefs to rebuilding altered assumptions. In addition, it involved actually restructuring aspects of life as a result of changes in perspectives, as opposed to just re-evaluating the stressor alone. The couples' descriptions of growth highlight their perceptions that transformation occurred within their lives and relationships, thus creating a new normal, as opposed to returning to their ways of living prior to the breast cancer diagnosis. These descriptions were in line with Calhoun and Tedeschi's (2006) definition of the term *posttraumatic growth*, as distinguished from other terms discussed in chapter one. As stated in the discussion of terms, referring to these terms is for the purpose of better understanding the couples' experiences and providing a reference point from which to be able to discuss distinguishing features of their descriptions.

Couples identified three primary factors that served as indicators that growth had occurred. First, they indicated that they had maintained, and even built upon, the positive changes they had developed. The ability to identify positive behaviors that they had begun, either in response to coping with the impact of breast cancer or through the insights they developed as a result of surviving breast cancer, served as evidence that improvement had occurred. Sustaining these after the crisis had subsided, without reverting back to previous less desirable ways of living and behaving, represented that their experiences were "life changing." A key factor for couples was that, not only had they recovered from their experiences, they transcended beyond their previous ways of functioning. This was identified as the defining characteristic of growth. The fact that these life changes were recognized as being beneficial to

the couples' well-being and valued for the contribution they made to the couples' quality of life, motivated couples to continue to nurture these healthy habits and ways of functioning within their relationships. Some couples described that growth was a continual process, and they believed they had continued to progress beyond the initial changes and ways they viewed themselves as improved directly following their experiences with breast cancer. This was primarily described by couples who had been cancer-free for several years, and their perceptions of longevity contributed to their evidence base.

Next, feedback received from others was viewed as an indicator that growth had occurred. Observations made by others regarding the couples' altered ways of interacting with one another and others, changed lifestyles and behavioral practice, and demonstrations of developed psychological processes served to re-affirm to some couples that they had, in fact, actually grown in the ways in which they had perceived themselves as grown. Couples conveyed that they felt confident in their growth when others praised them or offered positive feedback. Couples did not rely on others to define the ways in which they had grown, rather, experienced other contributions as confirmation. Finally, couples who had children residing at home throughout their experiences with breast cancer indicated that they saw evidence of their growth in their children's adjustment and behavior. Couples perceived their children's ability to adjust well following their experiences with breast cancer as indicators that they themselves had grown. Their rationale was that their children's adjustment was the result of the support they had received from their parents and directly associated with the growth they witnessed their parents demonstrating. Essentially, couples viewed their children as reflections of themselves. This also pertained to specific behaviors they witnessed their children engaging in that demonstrated evidence of growth based on their perceptions that their children had learned to behave in these

ways through observing them. In closing this discussion, it is important to re-state that the intention of this study was not to prove whether growth had actually occurred or not, instead, to gain understanding of the couples' own perceptions and experiences of growth.

Contributions to Research

As indicated in the literature review, numerous studies have been geared towards understanding the experience of cancer. More recently, studies have begun to examine these experiences from the perspective of the couple. However, research devoted to examining breast cancer survivorship continues to demonstrate the predominance of an individualist approach. In addition, despite the progress made towards greater understanding of cancer survivorship, research on the long-term impact of surviving cancer is still in its early stages. Including spouses has generally served the purpose of gaining a secondary individual perspective rather than understanding survivorship within a relational context. The available data highlighted that, individually, both survivors and their spouses did, in fact, experience positive changes in the aftermath of breast cancer, yet there remained a gap in the literature related to the experiences of survivorship and change from the perspective of the couple together, within the context of their relationship. One of the most significant contributions this study adds to the body of research on this topic, is that it is essentially the first study to explore couples' shared experiences of relational growth following breast cancer. No previous studies were found upon reviewing the previous literature. The few studies that did include couples were limited in that they were focused on understanding the impact of relationship dynamics on each partners' experience of change and perspectives on growth separately. Couple-level analysis focused upon comparisons of partners' experiences. Therefore, the present study contributes to the progress towards greater understanding of the experiences of positive growth from the perspective of intimate couples

within the context of intimate relationships. Analysis was not focused on comparing partners' experiences, but, instead, on examining the experiences shared between partners and on the relationship as a single unit, rather than its separate parts. In addition, since there are limited literature resources on the topic of posttraumatic growth after breast cancer other than the very few reviewed in chapter two, this study contributes to this area of research by further validating some previous findings, presenting alternative perspectives on others, and offering new data and research contexts related to the topic. While the study as a whole does not represent the long-term impact of survival, contributions provided by the couples who have been cancer-free the longest (seven and eleven years) do provide additional information in this area and contribute preliminary evidence of the sustainability of positive growth.

Manne and Badr (2008) had also identified that they believed the literature was missing the adoption of a couple-level perspective whereby the cancer experiences are viewed in relational terms. The present study specifically addresses this gap by focusing attention on primarily on the couple relationship and the shared perspectives and experiences of partners, while limiting attention on individual processes to those which assist with understanding the development of a couple-level perspective, and which directly influenced the relational processes. During the interview process, couples were asked specifically to consider the inquiry as it pertained to their relationship and shared experiences and perspectives. Couples were allowed to engage in conversation with one another in order to explore their shared experiences. This also allowed me to focus attention on the interactions between the partners, which frequently illustrated the couples' descriptions of closeness and growth.

Feldman and Broussard (2006) indicated that there were no research studies that explored the factors that enable some male partners of breast cancer survivors to adjust more successfully

than others. Although the present study was not limited to exploring only male partners' adjustment, their contributions regarding their experiences and perspectives about factors that contributed to both their own positive growth, as well as to the growth within their relationships, may widen the knowledge base upon which this topic can be further explored. Although responses related to adjustment were within the context of the couple, male partners actively contributed their perceptions and experiences. Even though the primary goal was to identify shared experiences, they were still representative of male partners' viewpoints about factors that positively influenced their ability to adjust to the impact of the illness. Despite the fact that the present study did not involve comparative analysis with couples who demonstrated poor adjustment and who denied experiencing growth, it does begin to answer questions related to factors that promote positive adjustment by providing some insight related to the influence of relational components. Continued research focused on individual and other potential determinants may provide further clarification of this topic.

Clinical Implications

One of the most significant aspects of exploring clinical implications is to gain better understanding of the perceptions and behaviors of those whom the clinical measures are intended to assist. Researchers and theorists can devise the most clinically sound interventions and treatment models; however, if there are unaddressed barriers that contribute to the underutilization of resources, these efforts are of limited benefit. This discussion was prompted through the examination of the study participants' use of and perceptions about clinical support services. Despite the fact that couples struggled to manage the impact of breast cancer on their lives and relationships, and indicated that they engaged in the process of trial and error in order to find effective ways of coping, none identified clinical services as a primary resource for

support. Conversations with couples about their experiences resulted in the identification of two implications related to the utilization of clinical support resources. The first was that half of the couples indicated that psychological support was not included as part of their treatment plans, and these services were not offered to them. Second, the other five couples described being offered services in ways that made them feel as though they were viewed as *weak, emotionally unstable, or incapable of handling stress*, which caused them to decline the support.

The fact that all ten couples described feeling unsupported in terms of their psychological needs clearly indicated that there is a need to focus more clinical attention on this area of care. The couples had received their primary medical treatment at different locations, though there was some slight overlap. Examining the overlap showed inconsistency among the treatment teams within a given care facility regarding offering support services. For example, the reports of two couples who had received care at the same large metropolitan hospital (advertised as offering specialized cancer care) illustrated different experiences. One couple indicated that they were not offered support services of any kind, while the other indicated that she was “told” she should see “mental health” because she cried during a meeting. These two examples sum up the experiences described by the couples and highlight a need for breast cancer care to be offered in more holistic ways. The extensive amount of research on the impact of breast cancer continues to provide documentation that both patients and their families struggle to cope and that there continues to be gaps in the continuity of care offered. Although there is less research on relational adjustment, there is no shortage of research supporting the positive benefits of offering support services to individuals dealing with breast cancer, which makes it even more surprising that these services were not consistently offered, provided, or incorporated into treatment planning even among top-rated hospitals in the region.

While it may be conceivable that some individuals and couples may be emotionally reactive and hyper-sensitive shortly after learning of a breast cancer diagnosis, the consistency of reports from couples who declined support services draws attention to the implications of the context within which support services are offered. Again, these couples received treatment at various facilities, yet their experiences were very similar. All five described their perceptions that support services were offered as a result of them displaying their emotions. Some couples described feeling “judged,” which caused them to experience a sense of defensiveness at the suggestion that they needed assistance to manage their emotions. They also indicated that they had not reconsidered accepting the offer during other times when they were struggling with their adjustment to the illness as a result of their initial experiences. The descriptions provided by these couples shows evidence that the ways in which support services are presented greatly affects whether couples will consider utilizing them. Although offers of support seemed good-intentioned and presented at times when couples were observed to be struggling emotionally, it is important to recognize that both timing and language usage influence the way couples perceive the support being offered. Couples expressed that being offered “counseling” or “mental health” services when they were upset caused them to feel as though they were viewed as emotionally weak or over-reacting. Some felt embarrassed by the suggestion because they did not perceive their reactions to be out of the ordinary for someone in their situation. Others conveyed feeling as though they were being pushed off onto a counselor because their doctor or nurse did not want to deal with their emotions. Perceptions of and previous experiences with psychological services were not discussed; therefore, it is unclear whether preconceived assumptions or general societal stigma related to psychological services may have influenced couples’ reactions to being offered

this type of assistance. Clinicians can benefit from remaining aware of this possibility in order to approach the topic in ways that are sensitive and non-pathologizing.

The emotional reactions described by female partners, and confirmed by their male partners, were within the scope of what most people who are diagnosed with breast cancer describe and which would be considered typical. However, it is also possible that reactions of shock may have been influenced by the process of unconscious denial that, prior to actually hearing the breast cancer diagnosis, detectable masses and referrals for testing could, in fact, mean that a serious problem was present. In addition, since the perception that the experience of shock was related to the feedback provided by healthcare providers, it is important to consider the implications of communicating with patients about the unknown. Communication indicating that tests were routine or “just a precaution” may reflect healthcare providers’ desire to avoid causing unnecessary alarm or concern before obtaining confirmation of a problem. Despite this, individuals and couples could benefit from support aimed at helping them understand that their reactions are valid and normal for the abnormal situation they are facing. It is likely that couples would be more open to considering the use of support services when they are presented in terms of the overall ways they can be beneficial, instead of only in ways that can be perceived as in response to the couples’ deficiencies. Couples may not always accept support services initially, as many feel the need to present a strong and in-control front; however, they may be more inclined to access services later on during difficult times if they were presented in terms of benefitting their overall well-being and being of assistance in a variety of ways other than just emotion regulation.

Shands et al. (2006) indicated that couples often do not know where to go other than to the primary treatment team they have been working with. Many couples in the present study

indicated that they relied upon their doctors for both medical and emotional support because they were unaware of other options and, as stated above, were not presented with alternatives.

Although some found their doctors helpful, they primarily described that the support was surrounding processing the medical information and planning for at-home care. Support did not include addressing the emotional needs of couples or providing guidance on effective dyadic coping. The findings of this study showed a need for couples to be educated about support resources, as well as provided with ways to engage these services if they are not offered through the facility providing the primary medical care. Much of the information gathered by couples on their own was obtained over the internet. While this source may be helpful in researching specific topics related to breast cancer or gaining greater understanding of information provided by the treatment team, the vast amount of material can be overwhelming and difficult for couples to navigate independently. In addition, couples frequently found it challenging to know how to include or exclude differing viewpoints and contradictory information, as well as manage the inconsistencies that may be present within the material. Despite this, most indicated that it was the only way they knew how to obtain information that they could compare and contrast against what was given to them by their treatment team.

While some couples accepted the opinions of their medical professional without question, others explained that they were not content with only one viewpoint on such a serious issue because they needed to know that they had explored all of their options to feel confident that they were making the best decisions for themselves. This may reflect differing styles of coping among individuals and couples. Miller (1995) identified two primary psychological coping styles for dealing with cancer and other health-related threats: monitoring and blunting. These coping styles characterize the ways in which individuals respond to information related to the

health threat they are facing. Individuals with monitoring coping styles tend to be highly attentive to health-related information and demonstrate more concern and distress about their cancer risk, which can be influenced by the tendency to amplify the threat. They tend to cope better when given more information; however, may also require substantial emotional support to deal with the illness. Individuals with blunting coping styles more often avoid and minimize the same threats. Rather than amplifying the threat, they are more likely to underestimate the risks and distract themselves from facing the threat. They tend to seek less information and take a more passive role concerning health-related decision-making. Miller suggested that individuals manage better psychologically, behaviorally, and physiologically when receiving health-related information in ways that align with their cognitive style.

Couples' descriptions related to the purposes behind seeking information and alternative viewpoints conveyed that they were searching for ways to feel confident about the treatment-related decisions they had to make. Although clinical information provided them with the means to consider the technical aspects of the process, it became clear that most couples were unclear about how to make decisions that took into account their unique needs, lifestyles, perspectives, and beliefs. They described experiencing a lack of support related to helping them understand their medical options within the context of their own lives and relationships. For some, continued efforts to obtain more and more information were motivated by the desire to fill these gaps; however, this approach was rarely successful. Therefore, couples newly diagnosed with breast cancer could benefit from guidance to bridge the medical and relational contexts. Clinicians may assist couples with exploring medical options within the context of their own lives and relationships, recognizing and considering the importance of discrepancies between treatment recommendations and personal belief systems, considering the relational implications

of various decisions, and guiding them to appropriate resources for obtaining additional needed information. Several couples expressed that they wanted to feel empowered in making decisions for themselves instead of being told what to do. Clinicians can promote the couples' self-knowledge and abilities to make sound decisions by utilizing the strengths within their relationships.

It should be noted that clinicians must be clear about what role they play in supporting couples' treatment-related decision-making. Clinicians must practice efficaciously and within the scope of their knowledge and expertise. Since some treatment facilities do not offer these types of support services, clinicians who practice within the community, and who do not have medical training or education specific to breast cancer, must be cautious to not give medically-related advice or offer feedback related to any treatment recommendations suggested by the medical team. Instead, their role should be limited to supporting the couple with engaging together in the processes associated with decision-making and facilitating productive communication between the partners to assist them in reaching couple-determined conclusions. Clinicians who are part of the treatment team, and who are familiar with the treatment options or have the appropriate medical training and expertise may be able to offer additional details related to various options or share knowledge of other couples' experiences with certain recommendations; however, the goal should remain to support the couples' decision-making processes and offer guidance on effective skills to utilize within these processes.

As Northouse, Templin, and Mood (2001) posited, couples who learn to work as a team to cope with breast cancer tend to have better psychological adjustment to the disease and draw closer to one another through the experience. Greater understanding of the ways in which couples perceived themselves and the factors that they believed contributed to positive growth

can assist clinicians with being able to provide support services which better suit the unique needs and qualities of couples facing breast cancer. The discoveries about how couples perceived change as a result of their experiences broadens the knowledge base, thus increasing the potential for clinicians to be helpful in guiding couples in ways that help promote positive growth. With regards to this study, the use of a phenomenological approach demonstrated how utilizing the individual couple's own dialogues could be useful in identifying the strengths and natural resources of couples, which could be used to customize support and interventions, while exhibiting the shared perspectives among couples.

Manne and Badr (2008) contended that identifying key relationship processes could facilitate the development of efficacious, couple-focused interventions which could assist both partners with adjusting to breast cancer. Couples who participated in this study clearly identified their relationships as the primary resource in adaptive coping; however, it was clear that not all coping strategies employed were successful or helpful and not all processes were constructive. The experiences of these couples demonstrated that these processes include both relationship-enhancing and relationship-compromising behaviors, which can greatly affect the adaptive coping of couples. One of the primary compromising processes identified was related to the limited exchange of emotional expression between couples. Emotional expression can enhance closeness experienced in the relationship, which can contribute to the experience of positive growth; therefore, interventions geared towards modeling and teaching effective adaptive communication skills may not only decrease distress, but support the development of the relational bond. Supportive reactions to the expression of emotion can influence the experiences of care and compassion, which can also promote enhanced closeness. In addition, when couples

are equipped with the skills to communicate in ways that promote relational closeness, they may experience less disruption in their relational intimacy, including sexuality.

Couples in this study indicated that their abilities to engage in emotional dialogues improved as a result of surviving breast cancer together; however, all identified that this was challenging throughout the course of the illness and most efforts were viewed as unhelpful and unproductive. Despite the fact that couples reported greater ease in expressing emotions openly and more frequent emotional conversations after their experiences, during their interviews most still demonstrated difficulty engaging in emotional conversations with one another about breast cancer specifically. The descriptions of distress as a result of unsuccessful attempts to cope with the emotional impact of breast cancer and the observations made during the interviews illustrated that couples could benefit from assistance with learning how to effectively engage in support-related exchanges. This is significant in that it is essential in order to improve dyadic coping by replacing unhelpful coping strategies such as avoidance, withdrawal, and protective buffering with mutually supportive and relationship-enhancing exchanges. Guiding couples' to participate in reciprocal disclosure around concerns and feelings regarding their experiences with cancer may contribute to maintaining or enhancing intimacy to the degree that partners perceive one another as responsive. These ways of communicating increases the opportunities for partners to feel cared for, understood, and accepted by one another, which can greatly influence the potential for growth to occur.

Another key observation is that almost all couples indicated that they had not engaged in any conversations about their growth and positive changes prior to their participation in this study. Several couples verbalized that they found the experience highly satisfying and, although they perceived their growth, engaging in dialogue with their partners and exchanging feedback

about personal and relational strengths and ways their lives were positively changed re-affirmed their emotional bond. Encouraging sustained efforts to express emotions may facilitate more conversations between partners which acknowledge strengths, encourage continued use of effective coping methods, and offer validation when mutual efforts have resulted in small successes. This can be of great benefit throughout the course of dealing with breast cancer as well as after, especially for couples who are struggling with adaptive coping and demonstrating poor adjustment to the illness. It is not uncommon for people to experience difficulty sustaining positive habits and motivation to continue to put forth constructive efforts when there is little positive reinforcement. In couples who are struggling to cope, and who are experiencing heightened relational distress, the ability to communicate in these ways may be imperative to maintaining their relational bond. Offering this type of feedback may serve to rebalance their perspectives so that they are able to focus on one another's positive efforts, as well as on areas where they are having difficulty functioning. For couples who have successfully navigated the trials of breast cancer, and who perceive themselves as grown, dialogue may bring forth greater understanding of the strengths and resources utilized, so that they may be accessed during other times of need. In addition, acknowledgement of growth is frequently experienced as a motivator to continue growing.

Calhoun and Tedeschi (2006) suggested that trauma may disrupt the cognitive mechanisms necessary for processing the subtleties that can contribute to perceptions of positive growth. Essentially preoccupation and negative rumination can be highly intrusive. This frequently occurs during the early stages of a traumatic event. More deliberate processing is generally involved with contributing to posttraumatic growth, but often is not achieved until later in the trajectory. Posttraumatic growth is more likely to be experienced when an individual

productively processes a wide variety of content. Based on the descriptions provided by couples who participated in this study, most partners were not equipped with the skills necessary to engage in deliberate or productive processing instead of rumination. This was not a surprise since most had never been confronted with a life-threatening situation that disrupted their cognitive schemas; therefore, had not had prior occasions to acquire these skills. Couples could benefit from guidance on ways to constructively manage intrusive thoughts and formulate alternative ways to conceptualize and relate to their experiences. Since pre-occupation with and rumination of negative thoughts was described as occurring immediately following learning of the breast cancer diagnosis, it would be in couples best interest to receive support during this crucial time. Early intervention efforts and psycho-education could potentially be incorporated into the treatment-planning process, either independently or in conjunction with other intervention, education, and decision-making measures.

Exploring the social environment of the couple can assist them with identifying and utilizing resources and environments, which can provide opportunities for supportive cognitive processing. Several female partners indicated that they felt better able to make sense of their experiences and consider alternative perspectives when they were exposed to other survivors who could provide emotional support, which helps facilitate constructive processing. In addition, they viewed other survivors as models of the potential for life to be satisfying beyond breast cancer. It is important to note that the survivors most female partners had contact with were individuals who were involved in charitable endeavors and displayed evidence of also having grown as a result of their experiences with breast cancer, and who productively embraced survivorship through their involvement in breast-cancer-related activities. This is important because it cannot be assumed that the same results would occur if female partners were engaging

with survivors who had not adjusted well during or following their experiences, which could be the case in some environments such as peer-facilitated support groups. This is not to say that support groups cannot be beneficial, rather, it is simply to point out that a lack of professional guidance and variability in the levels of emotional dysregulation and adjustment among members may be factors which influence the ability of these environments to support constructive cognitive processing. The greater challenge may be in identifying supportive social environments and resources which can support the couple together instead of separately and assist the couple with constructively processing their experiences with one another. Couples generally indicated that they turned to other supportive relationships when they were not able to productively process with one another. Although both female and male partners experienced benefits from receiving support from other members of the same gender, it was clear that they did not perceive this as completely compensating for the lack of processing within their relationships. Based on the descriptions and responses of couples, opportunities to constructively process with both one's partner within the context of their relationship and with same-gender supports who are able to relate to gender-specific experiences would be ideal.

In general, this study contributed to expanding the knowledge base for family therapists and other professionals who work with couples facing breast cancer together. Although this study was not intended to validate any one particular theory or couple-based intervention, the findings and clinical implications did provide additional support for several discussed in chapter two, which have been pilot tested, but have yet to be implemented further. The study led to the development of insight into the ways in which couples surviving breast cancer perceive and experience growth. In addition, it highlighted the processes and dyadic coping measures that couples believed contributed to their growth. Since both these findings, and the results of

previous research, indicated that partners most often rely on one another for support, it is essential that both partners be included in support services. Therapeutic processes should include couple-based interventions and focus on dyadic coping. The accounts provided by couples convey that therapeutic support focused on increasing the opportunities for growth by assisting with: 1) communication which promotes emotional expression and closeness, 2) effective dyadic coping aimed at increasing both relational cohesiveness and mutually supportive efforts, 3) attending to their relational needs in the midst of coping with the impact of breast cancer on daily living and the redistribution of responsibilities, and 4) accessing resources and environments which can provide support to partners together as a couple. These were the aspects viewed as most contributory to growth and, as such, should be included in the primary focus of intervention and support efforts.

Limitations and Recommendations for Future Research

Limitations with this study primarily related to the limited focus on the population of interest. The aim of the study was to gain understanding of the processes and factors which couples believed contributed to their growth in order to contribute to the knowledge base regarding ways to support couples facing breast cancer. Although purposeful, the study was limited specifically to couples who believed they had experienced relational growth as a result of surviving breast cancer together. In order to make this explicit and draw participants who met the study criteria, growth-related language was used in the study descriptions included within both the recruitment materials and the informed consent form. It is possible that this may have influenced participant responding (e.g. exaggerated descriptions) based on interpretations of this language usage as indicating expectations related to type and level of growth. Participant's responses regarding their growth experiences may have also been influenced by the presence of

their partners during the interview. Participants may have been inclined to exaggerate responses for their partner's sake or disinclined to disagree with responses or indicate a lack of growth in an area pertaining to their partner's functioning. Efforts were made to minimize these study limitations by clarifying to couples that there were no specific expectations of type, area, or level of growth, and that their unique experiences were of interest. In addition, participants were prompted to provide detailed descriptions of their experiences and specific examples of their perceived growth in order to both increase understanding of their experiences as well as limit the occurrence of vague, over-generalized responding. Observations of consistency and mutuality in the descriptions provided were made during both individual responding and partner's conversations with one another.

There were several disadvantages to the process of recruiting participants who met the specific criterion. First, the primary resources for recruitment were breast-cancer-related community organizations and events. The study results showed that couples who experienced growth or perceived positive outcomes following their experiences frequently involved themselves in charitable events. Although this was not known prior to the study, it is important to consider that these types of events and organizations often include focusing on the celebration of survival, cohesion among people who share the experience of breast cancer, and involve an overall positive emotional climate. It is not clear whether recruitment through these means had an effect on participant responding. In this case, the use of snowball sampling was viewed as a potential means of diversifying the population in this regard. However, despite recruitment not associated with these organizations or events, several couples who were recruited in this way reported participation in other similar events during their interviews. Therefore, for the sake of efficacy, the potential influence of involvement in these types of events must be considered.

Efforts were made to bring greater diversity to the group of participants by expanding the recruitment area to include several northeastern states and both rural and suburban communities. Although the participants had a high degree of variability in age, level of education, and length of relationship, the group displayed limited ethnic and cultural diversity. All but one female participant identified as Caucasian. In addition, religious/spiritual affiliation was primarily limited to Jewish and Catholic/Christian. Female partners were all diagnosed with either Stage-I or Stage-II breast cancer, and none had experienced a recurrence or separate episode of breast cancer; therefore, it cannot be assumed that women who are diagnosed with and survive later-stage breast cancer or who have survived recurrence, have the same potential or experiences with growth. In addition, female participants had all been cancer-free for at least three years (range = 3-11 years); therefore, the results of this study may not be generalizable to individuals in earlier stages of being cancer-free. As is the nature of qualitative study, the generalizability of the results limited primarily to those who resemble the predominant characteristics of participant group. While the findings of this study met the purpose of gaining greater understanding of couples' perceptions and experiences of growth after surviving breast cancer, the accounts of ten couples serve only to create a foundational knowledge base upon which to continue to study this phenomenon. Utilizing a small sample size makes it difficult to determine whether experiences are typical without further exploration. Future research should include expansion of the participant group and include greater ethnic and cultural variation. Alternate recruitment methods, which include drawing from the general population, as well as from organized groups, may provide insight as to the influence of participation in breast-cancer-related activities on perceptions of growth. Finally, studies which include couples who have survived later-stage

cancer may provide information about whether the potential to experience growth and the contributory factors are consistent among surviving couples.

Another limitation of this study is that, in addition to female breast cancer survivors, only their male partners participated in the study. Shared experiences and growth were shown to be influenced by the intimate nature of the couple relationship; therefore, it is important to expand the research to include non-heterosexual intimate couple relationships. Since men can also be diagnosed with breast cancer, relationships should not be limited to only those involving a female partner who was diagnosed. Although the aim of the study was to specifically understand the experiences of growth within the context of the couple relationship, it is important to recognize that this context limits the understanding of growth in other relational contexts, and the processes and factors that influence other forms of dyadic coping. Future studies aimed at understanding the shared experiences and perceptions of other individuals considered to be in close relationships with the breast cancer survivor, such as children and extended family members, is an important next step in building the research foundation. This is especially significant in light of the fact that individuals who are diagnosed with breast cancer, but who are not in a partner relationship, may rely upon one or more other close relationships for support. Depending on the closeness of the relationship, it is possible that another supportive individual may go through the majority of breast cancer experiences with the survivor, thus potentially creating shared experiences and influencing the growth process. Individuals providing primary support but who are not in an intimate relationship with the survivor may offer varying perspectives and experiences due to their ability to have more separation from the situation. Understanding the ways in which other close relationships influence coping, survival, and

growth is vital in assisting clinicians and other involved professionals with providing support tailored to the specific needs of the people involved.

The primary goal of exploring the lived experiences of couples following breast cancer and their perceptions of positive growth as a result of their shared experiences with the illness was best approached through the use of qualitative methodology. The utilization of this methodology and a phenomenological research design provided an effective means of facilitating this exploration, though posed unique challenges. Research quality is predominantly determined by the skill of the researcher but can also be influenced by the personal biases and idiosyncrasies of the researcher. Measures must be taken to detect and minimize researcher-induced biases, such as engaging in the process of bracketing in order to recognize, remain aware of, and set aside preconceived ideas and beliefs, and previous knowledge and experiences. These challenges were addressed through several measures, including engaging in the process of epoche (see Researcher Stance), utilizing field notes to document thoughts, feelings, and reactions which occurred during interviews and throughout the course of the study, and processing those notes both independently and with the research mentor as appropriate. These steps were imperative to limit interference in the interpretation of the data.

Qualitative inquiry can involve challenges with maintaining, assessing, and demonstrating rigor. Steps taken to enhance the accuracy and quality of the research included use of audio-taped interviewing and verbatim transcriptions, incorporation of participants' direct words, obtaining participant feedback and approval of transcript content, and consultation with research advisor and committee. Semi-structured interviews were conducted with the couple together in order to utilize both partners in providing information and detailed descriptions and accounts of their experiences, giving feedback regarding the accuracy of the transcript, and

clarifying and suggesting adjustments to the data. It was understood that my presence during the interview could affect participants' responses. Although this is unavoidable, taking a conversation-like approach and allowing for flexibility with the process created opportunities for couples' to be self-determined in their ways of describing their experiences and expressing their perceptions. Couples were also encouraged to converse with one another in order for them to be more self-focused than researcher-focused.

Closing Remarks

Calhoun and Tedeschi (2006) indicated that precise scores on growth scales were not sufficient for understanding the experiences of the individual. They believed that the question of whether change was sufficiently positive to merit the label posttraumatic growth was most appropriately answered by the individuals affected. Use of a phenomenological approach to explore survivor couples' perceptions of positive growth following breast cancer allowed for greater understanding of the couples' lived experiences. In addition, it allowed couples to convey their own interpretations of growth and the meanings given to their shared life experiences. Although the ability to generalize findings to other individuals and groups was not a primary function of this study, the intersubjective perceptions and interexperiences which emerged within the conversations contributed to understanding phenomena of positive growth within the context of breast cancer from a relational perspective. This approach was both unique and relevant, as it served the purpose of beginning to address significant gaps in the literature and study of breast cancer research, both theoretically and clinically. In addition, this project contributed a relational perspective to the study of posttraumatic growth.

Kayser, Watson, and Andrade (2007) indicated that learning more about the ways in which relational coping occurs could contribute to assisting couples to manage cancer as a "we-

disease” (p. 417). As previously stated, the primary aim of this study was to access couples who had perceived themselves as growing as a result of their shared experiences with breast cancer in order to better understand the processes and factors which they believed contributed not only to their ability to adjust to the illness, but to their ability to experience themselves and their relationships as positively changed as a result. As clearly indicated in the literature review, positive adjustment and experiences of growth are not a given for all who experience breast cancer. The willingness of the couples who participated in this study to share their experiences of struggle and vulnerability as well as their strengths and successes is essential for researchers and clinicians to gain understanding of how to better serve the needs of this population. Although finding ways of effectively coping with the impact of breast cancer was a process of trial and error for these couples, their accounts of the experiences they found most influential and the factors they believed contributed most to their growth can help in guiding the development and implementation of effective interventions and specialized dyadic coping measures. Greater understanding of the experiences and needs of this population may also assist medical professionals and clinicians in developing ways to incorporate psychological support into treatment measures and increase the likelihood that couples will take advantage of the opportunities to engage actively with growth-promoting resources.

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APPENDIX A

Informed Consent Form

Researcher's Affiliation

Katherine Boyd is the primary researcher for this study. She is conducting this research in partial fulfillment of the requirements for a Ph.D. in Family Psychology in the Department of Professional Psychology and Family Therapy in the College of Education and Human Services at Seton Hall University located in South Orange, New Jersey.

Purpose of the Research

The purpose of this study is to explore how couples experience positive growth in their relationship as a direct result of their experiences together with breast cancer. The researcher is interested in understanding how couples make sense of their growth and the relationship qualities and ways of coping that they believe may positively contribute to their growth.

Procedure

Both partners of a couple will be asked to jointly participate in a face-to-face interview with the researcher, which will last one-to-two hours. Interviews will take place in a mutually agreed upon location that is private and quiet such as a space in a local public library, a private office at Seton Hall University, or a private counseling room on the third floor of Jubilee Hall at Seton Hall University. Although the researcher will have some general questions about couples' experiences of growth following breast cancer, the interview will be flexible to allow for elaborations or discussions of any additional information that may be helpful to the researcher or families who may benefit from this research.

The interview will include questions about couples' perceptions about the impact of breast cancer on their relationship, ways of coping with the illness as a couple, and positive changes that occurred in their relationship as a result of their shared experiences with breast cancer. The following are examples of questions that will be asked:

- In what specific ways do you feel breast cancer impacted your relationship?
- What qualities of your relationship do you feel were beneficial to your ability to cope with the impact of breast cancer on your lives?
- Do you believe your experiences with breast cancer have affected the ways you cope as a couple with other difficult life situations? If so, in what ways?
- How have you mutually coped with/adjusted to physical changes brought on by breast cancer treatment?
- How, as a couple, do you cope with the possibility of recurrence?
- As a couple, how do you define positive growth?
- Do you perceive positive growth in your relationship as a result of your shared experiences with breast cancer? If so, in what ways?
- What specific experiences have you had, or are currently having, show you that growth has occurred as a result of your experiences with breast cancer?

Participants may stop participating in the interview at any time, without penalty. Participants will also be given the option to reschedule the interview for another time or skip any questions they do not wish to answer.

During the interview, the researcher may make observations of participants' interactions, body language, use of gestures, and expressions of feelings and may ask a participant to describe what he/she is feeling or what the meaning of the gesture is. This is in order for the researcher to gain a full understanding of the experiences being described or the experiences occurring during the interview process.

In addition to the interview protocol, a *genogram*, which is like a family tree, will be constructed. This will not take any additional time since the researcher will complete it as participants provide information during the interview. Since the researcher is interested in couples' experiences of growth in their relationship following breast cancer, please be aware that if either partner of a couple decides to discontinue involvement in the interview or in the study after the interview has been conducted, the interview will not be included in the final report of the study. If this occurs, the researcher will provide participants with the option to have the audiotape of their interview destroyed immediately. Participants will also be offered assistance with contacting a professional, or someone of their choosing, to talk further about their experiences if they so desire. All participants will receive a list of support resources and counseling agencies.

A follow-up interview may be necessary to clarify participant's responses or to get further information. Participants will also be asked to review a transcript of the interview and will have an opportunity to make notes and/or changes to this document as well as to discuss this with the researcher to ensure that experiences are accurately portrayed. Once the researcher has reviewed the transcripts with the participants, along with any changes made as determined through discussion about the document, participants will receive a final phone call from the researcher to acknowledge completion of involvement in the study.

Voluntary Participation

Participation in this study is completely voluntary, and participants are under no obligation or pressure to respond to the request to be involved. Participants may choose to not participate, discontinue participation at any time, or request to reschedule an interview without any negative consequences. This study is not affiliated with any medical facility, healthcare provider, or other breast-cancer-related organization.

Anonymity

Complete anonymity is not possible since this study involves the researcher meeting with all participants in person to conduct the interviews. Identities will not be revealed through the study, and names will be changed to protect participants' privacy. The researcher will assume sole responsibility for reviewing and transcribing the audiotapes. Each completed tape will be coded with a number to protect participants' privacy. Tapes will be stored in a locked cabinet in the researcher's office. Access is available to the researcher only. Participants will retain the right to review the audiotapes and may request that the tapes be destroyed upon completion of the study. Otherwise, audiotapes will be stored for a period of three years and then will be destroyed. Additionally, identifying information, such as names, will be removed from the written transcript and will be replaced with a pseudonym.

Confidentiality

Information that is provided in this study will remain strictly confidential between Katherine Boyd, the researcher, and Dr. Robert Massey, her dissertation advisor. Transcriptions of the audiotaped interviews will only be accessible to the researcher and Dr. Massey; however, only the researcher will have access to audiotapes. Audiotapes, informed consent forms, and transcriptions will be securely stored to maintain privacy. Any other information pertaining to participants will be stored on a password-protected USB memory key, which will be stored in a locked safe in the researcher's office. Materials will be kept for three years and then will be destroyed.

Participants will receive a hardcopy of the interview transcript, which will be mailed to the home unless an alternative location, such as office or post office box, is requested. It is recommended that the document be securely stored while it is under review and be accessed only by the participants in order to maintain confidentiality.

The researcher will disclose, without participants' consent, information that would identify him/her as a participant in the research project only under the following circumstances: there are indications of current issues of child or elder abuse in the participant's family, or that the participant is at risk for physical harm to himself/herself or to someone else.

Records

All interview tapes will be transcribed by the researcher. Transcribed records will be kept in a locked cabinet to which only the researcher has access. Transcripts will be stored separately from tapes to ensure privacy. Participants will have an opportunity to review their transcript and to provide clarifying or additional information. Electronic data will be stored only on a password-protected USB memory key. The researcher's advisor, Dr. Robert Massey, at Seton Hall University, may be asked by the researcher to review portions of the transcriptions in support of analyzing and understanding the information for the purposes of this study only. All records will be stored for a period of three years and then will be destroyed.

Risks

In the event that sharing personal experiences brings forth any feelings of discomfort, participants retain the right to discontinue the interview at any time with the option to reschedule at a later date or to withdraw from participating in the project with no negative consequences. Participants will be given the opportunity to speak with the interviewer about their experiences of the interview. Should participants need assistance with obtaining additional support, the researcher will provide a referral list of easily accessible resources and will offer assistance in accessing these resources if needed.

Benefits

The current study is not expected to provide any direct benefit to participants in the process; however, it is possible that some participants may gain increased awareness of their relationship strengths, which may be utilized during future difficult events.

Contact Information

Questions about the research may be referred to the researcher or her advisor, Dr. Robert Massey, c/o Department of Professional Psychology and Family Therapy, College of Education and Human Services, Seton Hall University, 400 South Orange Ave., South Orange, NJ 07079 or by calling [Contact information withheld for privacy]. Questions regarding participants' rights as human subjects may be directed to Dr. Mary Ruzicka, Director of the Seton Hall University Institutional Review Board, at [Contact information withheld for privacy].

Copy of Consent Form

Participants are each asked to sign two (2) copies of this form. The researcher will keep one on file, stored in a locked file to which only the researcher has access. The form will be held separately from audiotapes and records to protect participant's privacy. One of the signed copies will be given to participants to keep in case there are any questions about the study. Participants will be provided with a copy of the signed and dated Informed Consent Form prior to beginning the interview process.

Consent to Audiotape:

I agree to have the interview(s) audiotaped for transcription. I understand that these tapes will not be presented. I also understand that I have the right to review all or any portion of the tape and request that it be destroyed.

Participant Name (please Print)

Participant Signature

Date

Consent to Participate

I have read the material above, and all questions have been answered to my satisfaction. I agree to participate in this study and acknowledge my right to withdraw, without penalty, at any time.

Thank you for your participation in this study. Please sign and date both copies of this Informed Consent Form and return one to me. The other is for your records.

Participant Name (Please Print)

Participant Signature

Date

APPENDIX B

Community Referrals

New Jersey Psychological Association

414 Eagle Rock Avenue, Suite 211

West Orange, NJ 07052

Phone: 800-281-6572

Email: njpa@psychologynj.org

Website: www.psychologynj.org

NJPA provides referrals to psychological services throughout New Jersey.

National Association of Social Workers, New Jersey Chapter

30 Silverline Drive, Suite 3

North Brunswick, NJ 08902

Phone: 800-932-0004

Email: info@naswnj.org

Website: www.naswnj.org

NASW provides referrals to social workers and counseling services throughout New Jersey.

American Association for Marriage and Family Therapy, New Jersey Division

c/o Christian Health Care Center Building #2

201 Sicomac Avenue

Wyckoff, NJ 07481

Phone: 609-771-2119

Website: www.njamft.org

NJAMFT provides referrals to marriage and family therapy services throughout New Jersey.

The Breast Cancer Resource Center

59 Paul Robeson Place

Princeton, NJ 08540

Phone: 609-497-2100

Website: www.bcrcnj.org

BCRC provides support to women and families living with and beyond breast cancer. Services include private counseling, professional and peer facilitated support groups, peer support networking, advocacy, and community outreach programs.

Young Survival Coalition – Northern New Jersey

27 Madison Avenue, Suite 220

Paramus, NJ 07652

Phone: 877-972-1101 or 201-843-6695

Email: yscnnj@youngsurvival.org and resourcelink@youngsurvival.org

Website: www.youngsurvival.org/northernnewjersey

YSC specializes in the support needs of young breast cancer survivors (age 40 yrs and under) from the time of diagnosis through long-term survival. YSC offers a variety of programs including peer support networks, linkage to one-on-one support, educational resources,

advocacy forums, and community outreach programs for women, their families, caregivers, and healthcare professionals.

CancerCare

275 Seventh Avenue

(between 25th & 26th Streets)

New York, NY 10001

Phone: 800-813-HOPE (4673)

Email: info@cancercare.org

Website: www.cancercare.org

CancerCare offers free, professional support to anyone affected by cancer. Services include counseling with qualified social workers and oncology professionals, support groups facilitated oncology social workers offered through face-to-face or telephone forums, educational workshops, community programs, and linkage to a wide variety of resources. Services are specialized to meet the unique needs of cancer survivors, spouses, families, caregivers, and healthcare professionals through all phases of cancer including on-going wellness and long-term survival.

APPENDIX C

Demographic Questionnaire

1. How old are you? Female___ Male___
2. How do you describe your current relationship status: Married___ Partnered___
3. How long have you been in this relationship? _____
4. Do you have children? Yes___ No___
 If "Yes", how many? _____
 How old are they? _____
 Where any residing with you during your breast cancer treatment? _____
5. How do you describe your ethnicity/culture?
 Female _____
 Male _____
6. What is the highest educational level you have completed? Female _____ Male _____
7. What is your occupation?
 Female _____
 Male _____
8. How do you identify your religious or spiritual affiliation, if any?
 Female _____
 Male _____
9. How would you describe the community that you live in? _____
10. What is your combined annual household income level? _____
11. Did you have adequate financial resources to cover treatment expenses (i.e. health insurance, personal funds, grants)? _____

Female Participants

1. How old were you when you were diagnosed with breast cancer? ____
2. At what stage was your cancer diagnosed? _____
3. Was your cancer metastatic? Yes___ No___
4. What type of treatment did you undergo for your breast cancer? (check all that apply)
 Surgery: Mastectomy___ Lumpectomy___
 Chemotherapy___
 Radiation___
 Hormone therapy___
 Other___
 If "Other", please explain: _____
5. Did you receive any of the following support therapies? (check all that apply)
 Naturopathic medication___
 Acupuncture___
 Mind-Body medicine___
 Nutrition therapy___
 Oncology rehabilitation___
 Spiritual support___
 Survivorship support___
 Psycho-oncology services___
 Other___

- If "Other", please explain: _____
6. Where did you receive your treatment for breast cancer? _____
 7. Do you have any biological relatives who have had breast cancer? Yes___ No___
If yes, what relation to you was this person? _____
 8. Have you had any genetic testing for breast cancer? Yes___ No ___
 9. If you were employed at the time of your diagnosis, did you take a medical leave?
Yes___ No___
If "Yes", have you returned to work? Yes___ No___
 10. Please give a brief description of your experience with breast cancer prior to your own diagnosis: _____
 11. Have experienced any recurrences of your breast cancer or been diagnosed with secondary breast cancer? Yes___ No___
If "Yes", when? _____
How was it treated? _____
 12. Have you been diagnosed with any other type of cancer? Yes___ No___
If "Yes", when were you diagnosed? _____
What was the type? _____
What was the treatment? _____
Is it active or in remission? _____
Were you diagnosed when you were in the current relationship/marriage or before? _____

Male Participants

1. If you were employed during the time your partner was undergoing treatment, did you take any leave from your job? Yes___ No___
2. Did you receive any support service? Yes___ No___
If "Yes", please describe: _____
3. Do you have any relatives who have had breast cancer? Yes___ No___
If "Yes", what relation to you was this person? _____
4. Please give a brief description of you experience with breast cancer prior to your partner's diagnosis: _____
5. Have you ever been diagnosed with cancer? Yes___ No___
If "Yes", what was the type? _____
What was the treatment? _____
Were you diagnosed when you were in the current relationship/marriage or before? _____
Is your cancer active or in remission? _____

APPENDIX D

Interview Protocol

Introductory Statement

This interview is designed to gain an understanding of the lived experiences of couples following breast cancer. Specifically, I am interested in your perceptions, as a couple, of ways in which your relationship changed as a direct result of your shared experiences with the illness. This interview will include exploration of the factors and processes that you believe influenced change. In addition, this interview is intended to explore your beliefs about the potential for positive growth to occur as a result of surviving cancer and your observations related to your own growth as a couple. Every couple's experiences are different. My goal is to focus on the unique qualities of your relationship and on the insights that you, as a couple, have about living beyond breast cancer. I will be asking a series of questions related to various aspects of dealing with breast cancer diagnosis and treatment. These questions are meant to guide our conversation; however, please feel free to add any information that you feel is important for me to know. I ask that you answer the questions jointly as a couple. You may take all the time you need to converse with one another about the question in order to determine your answer. At times, I may ask you to elaborate on an answer you have provided, or to clarify a point, in order to ensure that I accurately understand your meaning.

If at any time during this interview you begin to feel uncomfortable, please feel free to stop the interview and we can discuss whether, or how, you wish to proceed. You have the right to discontinue the interview at any time and can choose to reschedule the interview for a later date or to withdraw from the study. Should you decide to discontinue your participation, I will provide you with the opportunity to debrief and discuss any concerns you may have. If there are questions that you do not wish to answer, you are under no obligation to do so and may indicate to me that you wish to pass on that question.

At the conclusion of the interview, you will have the opportunity to discuss your experience of the process with me if you wish. Once a written transcript of your interview is completed, you will be asked to review the transcript for accuracy. Information shared during this interview will remain confidential with the following exceptions. If in the course of our meeting you indicate that there are current issues of child abuse, elder abuse, or that you are at risk for physical harm to yourself or someone else, I am ethically obligated to intervene to ensure the safety of all parties through referral for assistance/treatment and/or report to the appropriate authority. Do you have any questions or concerns before we begin?

Impact of Illness

Please describe what it was like to learn of the breast cancer?

What emotions did you share?

How, as a couple, did you react to the news?

How did you respond to one another at that time?

Please describe for me what your life and relationship were like between the time of first learning of the breast cancer diagnosis and beginning treatment?

In what specific ways do you feel breast cancer impacted your relationship?
 What aspects of breast cancer have caused the most disruption in your relationship?
 What areas of your relationship do you feel were most affected by the illness?

Coping

How, as a couple, did you communicate about breast cancer and the ways in which it was impacting your life and relationship?

What aspects of breast cancer were the most difficult to cope with as a couple?

What do you attribute this difficulty to?

What aspects of breast cancer were coped with most effectively together?

What do you attribute this to?

In what ways were you able to support one another in coping with difficulties?

What qualities of your relationship do you feel were beneficial to your ability to cope with the impact of breast cancer on your lives?

What changes occurred in your relationship that helped you, as a couple, deal with the stresses related to breast cancer?

What changes may have hindered your ability to deal with stress?

What other resources for support did you use to help you cope?

Do you believe your experiences with breast cancer have affected the ways you cope as a couple with other difficult life circumstance? If so, in what ways?

Do you believe your experiences with cancer have affected how you manage conflict together in your relationship? If so, how?

How have you mutually coped with/adjusted to physical changes brought on by breast cancer treatment?

Were there coping strategies that you had used before but found them ineffective in this situation? Please explain

Where there any new ways of coping that you were able to use that you had not used before? If so, how or where did you learn about these? Please describe

How, as a couple, do you cope with the possibility of recurrence?

If applicable to either/both partners:

What was the impact of your own previous experience of cancer on your coping with breast cancer as a couple?

What was the impact of your experiences with a family member's cancer on your coping with breast cancer as a couple?

Perceptions of Change

In what ways have you personally changed as a result of your experiences with breast cancer?

Has your view of yourself changed because of your experiences with breast cancer?

How has your overall life together changed as a result of your experiences with the illness?

Please specifically describe for me how you see your relationship as the same or different from the way it was prior to breast cancer?

Have you noticed any changes in the way you relate to one another? If so, how?

In what ways, if any, have the goals, purposes, and priorities of your relationship changed?

Have your views related to spirituality or how you engage together in spiritual activities changed as a result of your experiences with breast cancer?

Has your philosophy of life change?

Have your views mortality changed?

What specific observations have you made about the ways you interact as a couple indicate to you that change has occurred?

Positive Growth

As a couple, how do you define positive growth?

Do you believe it is possible to experience positive growth as a couple as a result of surviving breast cancer?

Have you experienced any such growth together?

If so, how do you perceive positive growth in your relationship as a result of your shared experiences with breast cancer?

Do you believe that there are benefits to facing difficult situations such as breast cancer?

Are there any benefits that you, as a couple, identify as being a product of encountering breast cancer?

Are there qualities of your relationship that you believe were influential on your growth?

Indicators of Growth

How do you see yourself as having grown from your experiences with breast cancer?

How do you see your partner as having grown from his/her experiences with breast cancer?

How do you see your relationship as having grown from your shared experiences with breast cancer?

What current ways of relating to one another serve as indicators that growth has occurred as a result of your experiences with breast cancer?

How do you, as a couple, communicate about your perceptions of growth?

What specific experiences have you had or are currently having that show you growth has occurred?

Have you experienced any new insights together about life or living as a result of your experiences with breast cancer?

Have any family members, friends, or other people commented on ways they have noticed that you, as a couple, have grown or positively changed as a result of surviving breast cancer?

Have you maintained the growth that you have achieved?

Are there areas of your relationship where your ways of interacting have returned to the way they were prior to breast cancer?

Is there anything else that we have not discussed that you would like to share with me or which you believe will help me to better understand your experiences with breast cancer?

APPENDIX E

Table 4

Coding Template

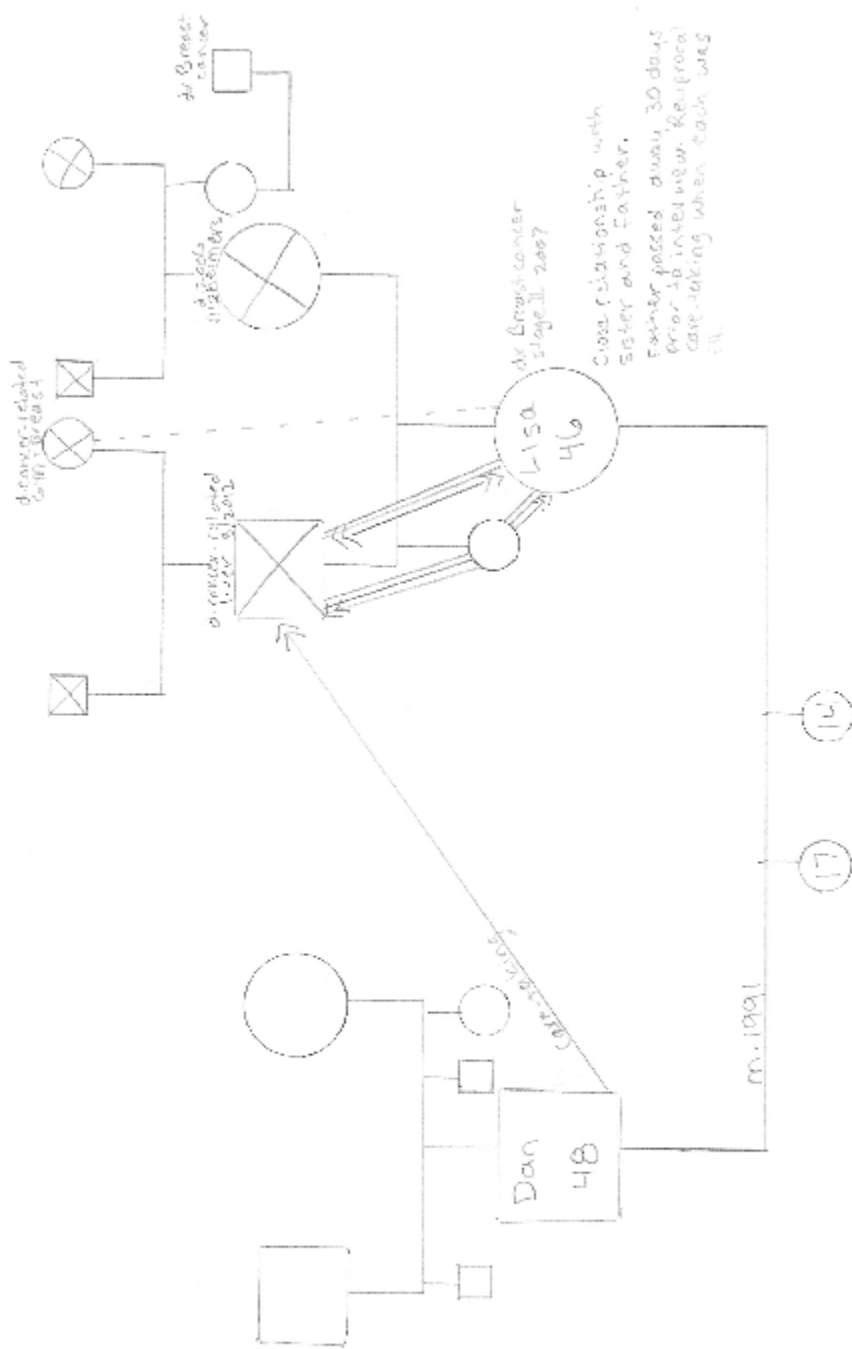
Code	Definition
Reacsh	Initial Reaction- Couple's shared and individual reactions to the initial breast cancer diagnosis
Reacs	- Survivor
Reacp	- Partner
Impc	Impact- Impact of the illness on the couple and their relationship
Impp	- Physical
Impe	- Emotional
Impse	- Sexual
Impc	- Cognitive
Impsp	- Spiritual
Impd	- Daily Functioning
Impr	Relationships- Impact of illness on relationships outside of the couple relationship
Prvex	Previous Experience- Couple's previous experiences with, knowledge of, and beliefs about breast cancer
Adjst	Adjustment- Couple's experiences of adjusting their daily functioning and lifestyle to adapt to the impact of the illness and the demands of treatment
Emot	Emotions- Couple's expressed emotions throughout the course of treatment
Comm	Communication- Couple's ways expressing thoughts, feelings, and needs related to issues and experiences associated with breast cancer
	Support- Couple's experiences of support from family and community resources
Supi	- Immediate Family
Supe	- Extended Family
Supc	- Community
Supr	- Religious/Spiritual
Supm	- Medical/Clinical
Resp	Responsibility Distribution- Couple's experiences around managing responsibilities associated with daily functioning
Care	Care-taking- Couple's perceptions of partner and relational care-taking

Brcash	Breast Cancer- Couple's shared and individual perceptions and experiences of breast cancer
Brcas	- Survivor
Brcap	- Partner
Survsh	Survivorship- Couple's shared and individual perceptions and experiences of surviving/co-surviving breast cancer
Survs	- Survivor
Survp	- Partner
Belc	Belief System- Couple's beliefs, values, attitudes, and assumptions that influence decisions and actions associated with breast cancer
Chng	Perceptions of Change- Couple's perceptions of themselves, each other, and their relationship as changed as a result of their experiences with breast cancer
Gdef	Definition of Growth- Couple's definition and conceptualization of growth, including beliefs about the possibility of growth following breast cancer
Gexp	Experience of Growth- Couple's perceptions and experiences of growth following breast cancer
Gind	Indicators- Factors identified by the couple that serve as indicators of positive change and demonstrate maintenance of growth
Relq	Qualities of Surviving Couples- Relational qualities identified by the couple as being present and influential in their ability to cope with adverse circumstances and necessary for the promotion of positive change and growth following their experiences with breast cancer
Recr	Recurrence- Couple's experiences with and perceptions about the possibility of recurrence

APPENDIX J

Figure 5

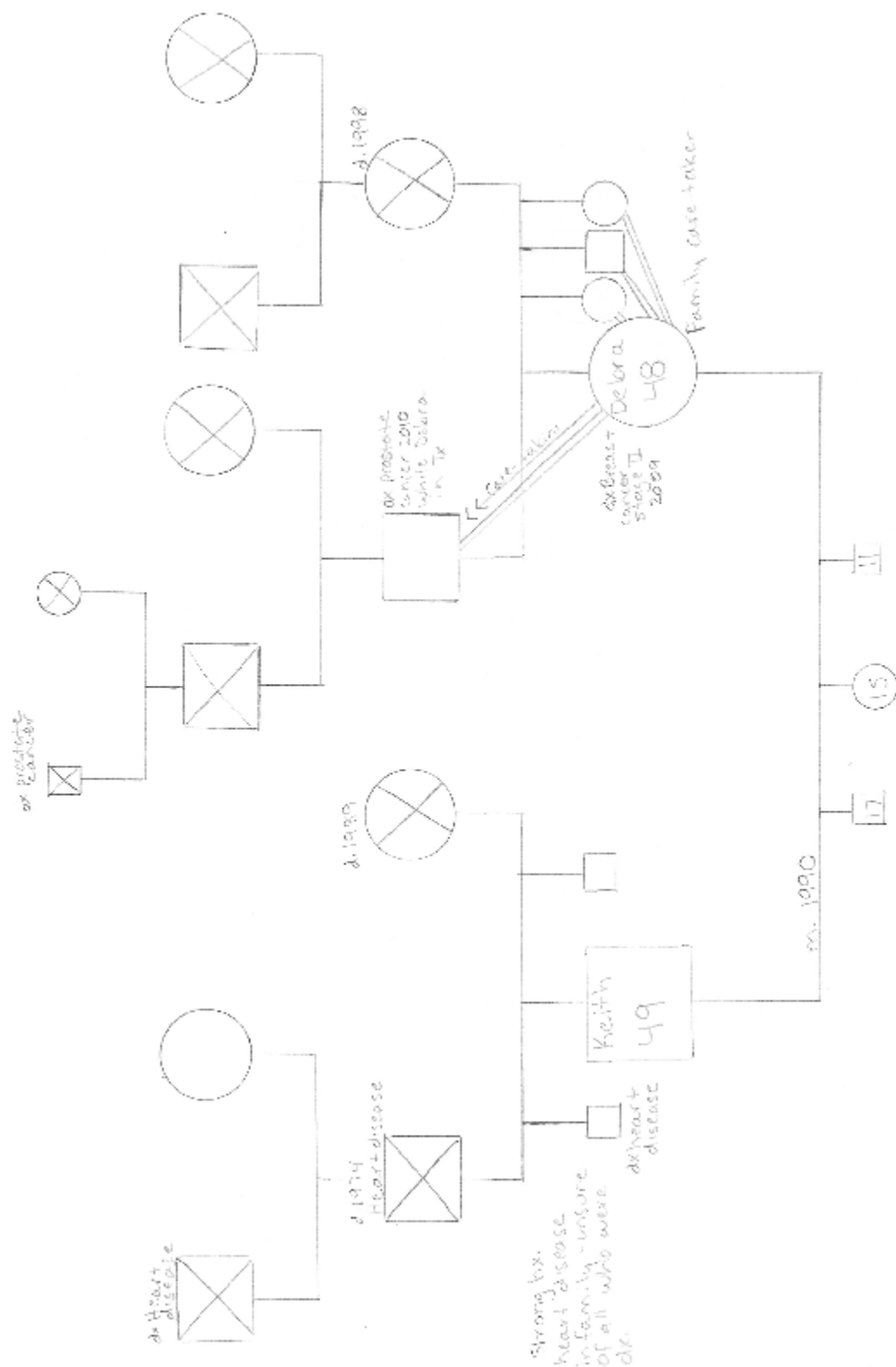
Lisa and Dan



APPENDIX K

Figure 6

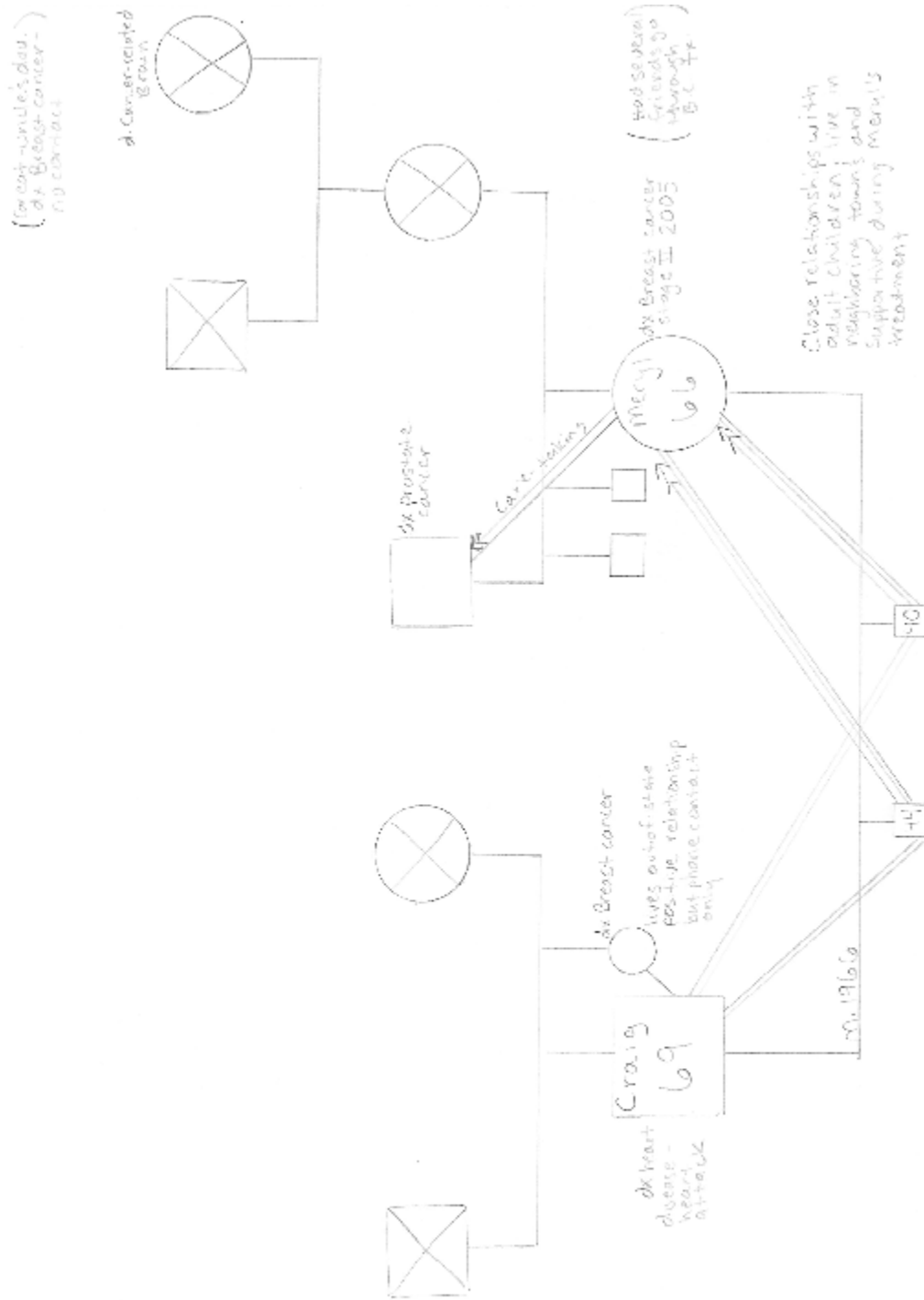
Debra and Keith



APPENDIX L

Figure 7

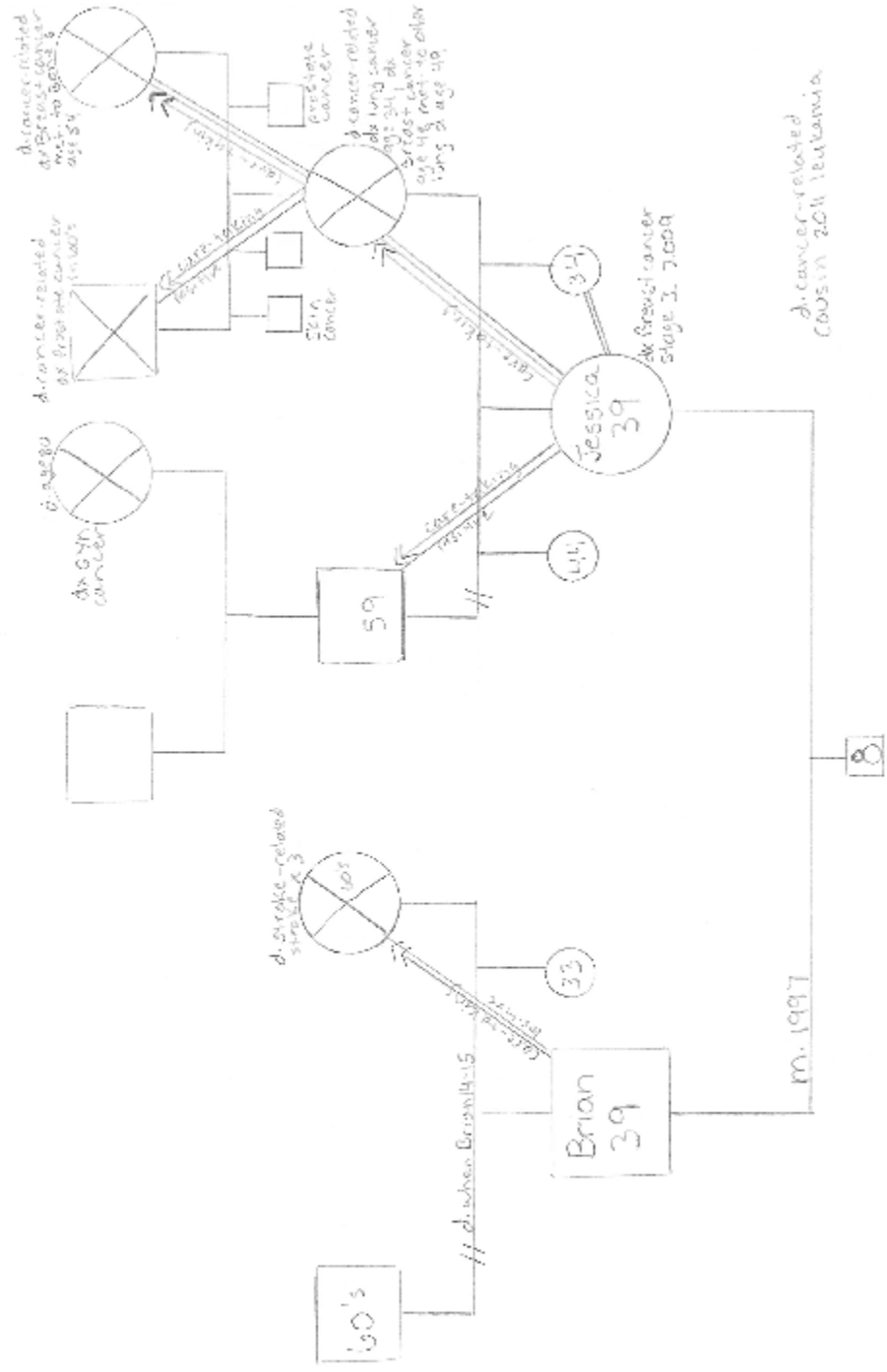
Meryl and Craig



APPENDIX N

Figure 9

Jessica and Brian



APPENDIX O

Figure 10

Delia and Hugh

