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THE EXPERIENCE OF NON-SPOUSAL CLOSE INTIMATE RELATIONSHIPS FOR
WOMEN WITH BREAST CANCER: A JOURNEY OF SUPPORT

BY

ERIN BURKE DOOLEY

Dissertation Committee

Dr. Judith Lothian, Chair

Dr. Munira Wells

Dr. Marcia Gardner

Submitted in partial fulfillment of the
Requirements for the degree of Doctor of Philosophy in Nursing
Seton Hall University

2019

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Date 3/28/19

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Finally, the diagnosis of breast cancer was perhaps one of the most significant events of my life. I believe it was part of God's plan to provide the perspective required to make important contributions to the well-being of others. I pray for his continued guidance as I support, comfort and care for patients with breast cancer in the most meaningful ways possible.

DEDICATION

This dissertation is dedicated to the endless provision of support from my loving family. To my mom, who shared her love of nursing with me. Paul-John, Tara and Shannon who are always a source of unconditional love and encouragement. Know that your presence in my life has always been and will continue to be my inspiration.

To Tom, who has been there from the very beginning of this journey, your constant support, especially during this final approach towards the finish, has been tremendously reassuring and loving. I know you are as anxious as I to get back to our beautiful life together. Take my hand...

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ABSTRACT

An estimated 331,530 women will be diagnosed with breast cancer in 2019 ("American Cancer Society," 2019, p. 10). The purpose of this qualitative, phenomenological, descriptive study was to explore the lived experience of non-spousal close/intimate relationships of women with breast cancer. There are very few studies in the literature examining relationships between women with cancer other than those of partner or spouse. This study's participants consisted of six women, ages 32 to 68. Analysis of these data identified themes reflected along their breast cancer trajectory (1) The journey starts (2) Mid-journey passage, and (3) Journeys end/coming home, as well as nine subthemes. Findings of this study suggest support offered by non-spousal close/intimate individuals is a dynamic provision, by diverse support systems that change over time throughout the breast cancer continuum. Assessment of support required by women with breast cancer is especially important at the beginning of the breast cancer journey but then again at various intervals, for a holistic approach and provision of functional and structural support so desperately needed by women with breast cancer.

Chapter I

INTRODUCTION

I was six years old and in the second grade. My older sister and I would walk to school together. A few weeks after the semester began we started meeting and walking with two other sisters, our ages and in our classes. They lived a few blocks further away and we would meet at the corner of our block and walk to Our Lady Queen of Peace grammar school every day. As we were both painfully shy, communication between Nora and me was initially limited to girlish giggling in response to my squeaky hand-me-down brown oxford shoes, while our older sisters talked non-stop ahead of us. That is the first of many memories and the foundation of what would become a life-long, close and intimate relationship. We each have very separate and distinct lives; we are both married, with children, residing in different states and pursuing different dreams. While we each have had our share of life's challenges and although there have been a number of friends that have drifted in and out of my universe, Nora has been a constant all these years.

My lifelong relationship with Nora has changed very little. Sometimes there are long period of time between communications. However, years of friendship have yielded to effortless dialogue. Whenever a life challenge/stressful event occurs, I reach out to her. In fact, when I was diagnosed with cancer, Nora was one of the first people with whom I shared the news. Our close, intimate relationship became a lifeline when I felt I could not share the fear and darkness of cancer with anyone else.

Close and intimate relationships are a complex and multifaceted aspect of the interpersonal process associated with satisfaction, well-being (Schaefer & Olson, 1981; Waring, McElrath, Lefcoe, & Weisz, 1981) and quality of life (Timmerman, 1991).

Research strongly suggests an association between close/intimate relationships and positive health outcomes (Miller & Lefcourt, 1982; Reis & Shaver, 1988; Prager & Buhrmester, 1998; Hook, Gerstein, Detterich, & Gridley, 2003; Perlman, 2007; Sneed, Whitbourne, Schwartz, & Huang, 2012). Most of this research has been done on spousal relationships. The study of non-spousal close/intimate relationships in the lives of women with cancer is almost nonexistent in the nursing literature.

Aim of Study

The aim of this research study was to examine the experience of non-spousal close/intimate relationships of women with breast cancer.

Phenomenon of Interest

Research suggests an association between support (most often derived from the individual with whom one shares a close/intimate partnered relationship) and psychological and physiological well-being (Miller & Lefcourt, 1982; Reis & Shaver, 1988; Prager & Buhrmester, 1998; Hook, Gerstein, Detterich, & Gridley, 2003; Perlman, 2007; Sneed, Whitbourne, Schwartz, & Huang, 2012). Individuals without close/intimate relationships are known to “experience more stress-related symptoms, are more likely to develop illnesses, have slower recoveries from illness, have higher probability of relapse or recurrence of illness” (Hook et al., 2003, p. 463) and are less resistant to physically disabling diseases (Brown, Harris, & Copeland, 1977). Accordingly, those who have failed to experience close/intimate unions are likely to experience physiological and psychological outcomes that compromise quality of life and well-being. Research suggests that supportive relationships influence one’s reaction to stressful events (Drageset, Lindstrom, Giske, & Underlid, 2015; Miller & Lefcourt, 1982). Absent in the literature is an understanding of a full, rich and detailed experience of non-spousal

close/intimate relationships and the significance of such relationships for women going through the experience of breast cancer.

Research Question

What is the lived experience of non-spousal close/intimate relationships in the lives of women with breast cancer?

Justification for study of the Phenomenon

The Centers for Disease Control and Prevention (CDC) emphasize good health is essential to one's ability to realize social, gainful, and individual development necessary for well-being (www.cdc.gov/heqol/wellbeing.html). Healthy People 2020 incorporates well-being as one of their primary goals: to *promote quality of life, healthy development, and healthy behaviors across all life stages* (www.healthypeople.gov). Consistent with Nightingale's philosophy, the nursing profession embodies a holistic approach for implementation of patient care through interconnectedness of mind, body, spirit and environment (Dossey, 2005). Although the association of close/intimate relationships and positive health outcomes are aligned with the philosophy of nursing, limited scholarly nursing publications exist. A concept analysis of the concept of intimacy, written over twenty five years ago by Timmerman (1991) found close/intimate relationships to be significant to human development, positive mental and physical health and to the promotion of well-being. Timmerman revealed a gap in the nursing literature that strongly suggested that close/intimate relationships are worthy of nursing investigation. The gap still exists today.

One in eight women will be diagnosed with breast cancer. An estimated 330,080 women were diagnosed with breast cancer in 2018 in the United States (Breastcancer.org, 2018). While initial diagnostic issues focus on life or death concerns, relationship dynamics have the

potential to play a significant role in the cancer trajectory as a woman moves forward in the treatment phase of her care. Some international research studies describe intimate spousal relationships of women with cancer (Hordern, 2008; Drabe, Wittmann, Zwahlen, Buchi, & Jenewein, 2013) but there is a paucity of research done in the United States. In the US, research on health outcomes of close/intimate relationships focus on spousal or partnered relationships. Understanding the lived experience of non-spousal close/intimate relationships of women with breast cancer may assist the medical community to better understand the needs of unpartnered women as well as the experience on non-spousal, intimate relationship for partnered women with breast cancer. There is currently scant literature describing the full, rich experience of non-spousal close/intimate relationships of women with cancer, including the meaning of the experience and its effect on the cancer journey.

Relevance to Nursing

Horden (2008) suggests that close, intimate adult relationships are misunderstood and ignored by nurses and physicians. There have been numerous studies of close/intimate relationships from the perspective of child and adolescent development (Bowlby, 1978; Erikson, 1968; Erikson, 1980), psychological and physiological health, marital stability and social support relative to well-being by disciplines other than nursing. However, for nurses to fully comprehend how non-spousal close/intimate relationships influence the lives of women with breast cancer they must first understand the full, rich experiences of these relationships, perceived and expressed by women with breast cancer. Only then, can nurses integrate this knowledge into the healing process and care they deliver to their patients for the best outcome possible.

Chapter II

LITERATURE REVIEW

American Women with Cancer

In 2019 it is estimated there will be 891,480 women diagnosed with cancer ("American Cancer Society," 2019, p. 4). The American Cancer Society (ACS) reports the most common female cancers are breast (30%), lung (12%) and colorectal (8%) cancer. According to the ACS there are an estimated 8,156,120 women cancer survivors in America (2016-2017). The diagnosis and treatment of cancer is an emotionally devastating (Liamputtong & Suwankhong, 2015) and highly distressing experience for patients as well as those they share close/intimate relationships with (Fang, Manne, & Pape, 2001; Badr, Carmak, Kashy, Cristofanilli, & Revenson, 2010; Drabe, Wittmann, Zwahlen, Buchi, & Jenewein, 2013). Individuals sharing close/intimate relationships may experience side effects and cancer symptomology very differently than an individual with no social support in place (Zimmerman, 2015).

Close and Intimate Relationships

Close and intimate relationships are the most common and basic interpersonal connections most people achieve. They are the result of a series of developmental achievements starting from infancy through adolescence (Sullivan, 1953; Erikson, 1960, 1968; Bowlby, 1978). Intimacy is "a quality of a relationship in which the individuals must have reciprocal feelings of trust and emotional closeness toward each other and are able to openly communicate thoughts and feelings with each other" (Timmerman, 1991, p.19). Closeness is characterized as frequency, strength, diversity and length of activity denoting degree of interdependence between two people (Kelley et al., 1983). Kelley et al. posit these four components of interconnected activities have an impact or influence on the relationships of participants (1983). In times of stress or trauma

such as a cancer diagnoses, close and intimate relationships are a source of social support influencing individuals' self-concept (Neimeyer, 2006) as well as psychosocial adjustment to diagnoses and treatment of cancer (Budin, 1998; Malicka, Kozłowska, Woz'niowski, Rymaszewska, & Szczepanska-Gieracha, 2016).

Relationships and Support

A close or intimate relationship is an aspect of social support (Vilhauer, 2008). Evidence suggests greater psychological adjustment to cancer when patients experience increased social support (Badr et al., 2010; Pfaendler, Wenzel, Mechanic, & Penner, 2015; Zimmerman, 2015; Nazione, Silk, & Robinson, 2016). A stable relationship at the onset of a cancer diagnoses is an important consideration potentially influencing physical, social and emotional adjustment to cancer diagnosis and treatment, which impacts well being (Boehmke & Dickerson, 2006; Malicka et al., 2016) and quality of life (Mosher et al., 2013, Zimmerman, 2015). Interventions such as programs specific to the needs of women with little or poor social support can help facilitate psychosocial and psychological adjustment to illness like cancer by decreasing feelings of isolation and helplessness and increasing feelings of self-worth (Neimeyer, 2006).

Types of Support

Support offered in a social setting is considered structural or functional (Helgeson, 2003). Structural support is closely associated with a quantity of something such as how many friends one has or the numbers of interactions an individual may have which correlates to greater quality of life. Just being part of a group enhances quality of life (Helgeson, 2003). Functional support is commonly identified as comfort measures or resources provided by people in one's personal network. Helgeson identified three important functional measures for women with cancer: *emotional*, *instructional* and *instrumental* support. *Emotional* support can be offered by anyone

and is expressed as behaviors of kindness such as being available to listen, to make someone feel loved and cared for or to comfort someone. *Instructional* support includes the provision of education or information appreciated most by specialists such as nurses or physicians (Drageset, Lindstrom, Giske, & Underlid, 2012). *Instrumental* support involves physical assistance such as doing household chores, running errands, loaning money (Helgeson, 2003). Social support is important for the well being of individuals with any chronic or severe health issues (Costa-Requena, Arnal, & Gil, 2015).

Negative Social Support and Loneliness

Social support is not always positive. Sometimes called negative social support (Shiozaki et al., 2011) or social strain (Ryan, Wan, & Smith, 2014), several studies have identified social support constraints in women with cancer (Helgeson, 2003; Mosher et al., 2013; Krigel, Myers, Befort, Krebill, & Klemp, 2014; Yee, 2014). When speaking of their cancer diagnosis and treatment to close friends many women were met with various behaviors of avoidance, discomfort, and minimization of the severity of the disease (Mosher et al., 2013; Yee, 2014), leaving them feeling lonely and frustrated (Mosher et al., 2013). Some women avoided professional or social activities altogether because of unsupportive attitudes of others.

In a qualitative study by Vilhauer (2008) on the experiences of women with metastatic breast cancer, fourteen women participated in interviews, which were then coded for themes in five categories (that was part of a larger study and also assessed quantitatively). The themes that emerged were body image, sexuality, worries about effects of stress, daily activity and social support. More than half of the fourteen women interviewed stated they were unable to freely communicate with their partners, family members or friends because of their less-than-

supportive responses. Others were reluctant to share their concerns with family members for fear of the potential stress of dealing with their grief and anxiety.

My husband practically had a nervous breakdown, which was hard on all of us...He just couldn't handle it...Well, this last spring when I knew that, when I saw my bone scan and I saw that it had flared again, I didn't even tell him about it. It was just easier to talk to my friends, who are now mostly survivors (Vilhauer, 2008, p. 254).

Because of these reactions many women in the study sought friendships with other cancer survivors with whom they could easily communicate (Vilhauer, 2008).

Recent studies explore psychosocial limitations for women with cancer (Krigel, 2014; Mosher et al., 2013; Yee, 2014). An autoethnography by a woman diagnosed with kidney cancer, Yee (2014) provides narrative “snapshots” of various vignettes of her experiences as she transitioned from diagnosis and surgery to post-surgical survivorship. A professor of Asian American studies and women's studies, Yee had great difficulty finding the words to describe or make sense of her cancer diagnosis, what was happening to her or to explain the depths of fear and anxiety cancer presented her with. Similar to Vilhauer's (2008) findings, Yee also experienced feelings of loneliness and isolation and feeling like an outsider. When speaking about her cancer in social settings, the need to limit participation in these communications became apparent when she recognized that most individuals require acceptable and pleasant conversational exchange. People would offer her all sorts of suggestions minimizing and denying her perception of “her” reality. This brought an awareness of her- “insider/outsider status” which was emphasized in everyday instances when individuals repeatedly minimized her cancer experience (Yee, 2014). She explains the “insider” may never realize his or her position, as this has always been the norm. However, as the “outsider” one is always mindful of not being part of

the group and that the group establishes the norms everyone lives by. After she was diagnosed with kidney cancer she became the outsider at her job, with her family and in her community. Ironically, her diagnosis also changed her status from outsider to insider as a cancer survivor (Yee, 2014).

Close/Intimate Spousal Relationships

A study by Badr et al. (2010) examined women with metastatic breast cancer (MBC), their partners (110 couples), and the association of dyadic coping on cancer-related distress and dyadic adjustment. They utilized a Likert-type scale, Dyadic Coping Questionnaire, measuring cancer related stress communication, supportive coping, unsupportive coping, common positive dyadic coping and common negative dyadic coping. The tool was administered at the onset of the study, when patients were just starting treatment for metastatic breast cancer, and then again at months three and six. Women with MBC as well as their partners experienced the stress of cancer equally as a unit (rather than individually), sometimes leaving them unable to support each other, affecting their well being and the quality of their relationship (Badr et al., 2010). Sociocultural differences were not examined due to the rather homogeneous (mostly) White participant population. Also of note, all couples were heterosexual which further limits findings.

There is an abundance of literature on close/intimate relationships between women with (predominantly breast) cancer and their partner/spouse measuring perceptions of various relationship qualities (Moss & Schwebel, 1993; Manne, Taylor, Dougherty, & Kemeny, 1997; Manne et al., 2004, 2014; Badr et al., 2010; Drabe et al., 2013; Zimmerman, 2015). Holmberg et al., was one of the few US studies that examined non-spousal relationship dynamics (family, friends and colleagues) in addition to spouses of women with cancer (Holmberg, Scott, Alexy, & Fifte, 2001). Their focus was to explore changes to close/intimate relationships as a result of

breast cancer and related treatments. This qualitative study included ten women, and five men (partners to five of the female participants) who participated in focus groups and interviews. They were recruited from an oncology practice after referral from their healthcare team. The ages of the women ranged from 31 to 68. Age demographics of the men were not provided.

Holmberg (2001) found that relationship dynamics changed for both women with partners as well as those without, in four key areas. *First*, both strong *and* troubled relationships (prior to diagnosis) met adverse changes and challenges. *Second*, partner communication became less open and the approach in which conflict resolution took place also changed. Some of the men, thinking that stress was a contributing factor in their partners' breast cancer diagnosis, in an effort to avoid issues of conflict, deliberately, did not discuss such matters. This in effect achieved just the opposite outcome. "By putting off the small conflicts of daily life did not really lessen stress, which was the intent, but in fact escalated the level of distress" (Holmberg et al., 2001, p. 56). *Third*, unpartnered women had more difficulty adjusting in general. "The unpartnered women universally experienced little emotional support from their former partners and were likely to be either criticized directly or more subtly ignored" (Holmberg et al., 2001, p. 56). A consideration here may have been that all of the unpartnered women were divorced and their relationships with their ex-husbands were labeled as problematic prior to their breast cancer diagnosis. *Lastly*, the researchers suggest the importance of interventions to assist women with relationship issues. This seems especially true for unpartnered women who were noted to have a much smaller social universe and/or less intimate connections than partnered women (Holmberg et al., 2001).

Summary

We know that the support offered by close/intimate relationships of women with breast cancer is sometimes a positive influence on the trajectory of cancer, other times it is not (Holmberg et al., 2001; Vilhauer, 2008; Badr et al., 2010). There are studies identifying close intimate relationships as social support (positive or negative) offered by close friends and family members (Helgeson, 2003) but they are not identified as non-spousal close/intimate relationships. There are numerous studies examining close/intimate relationships of women with breast cancer and their heterosexual spouses.

There is very little known of the experience of close/intimate relationships of women with cancer with anyone other than a partner or spouse. Missing from the literature are deep, rich descriptions of non-spousal close/intimate relationships of women with cancer experiencing them at times when they are most vulnerable. This research explored the experience of non-spousal close/intimate relationships and their meaning to women with breast cancer.

Chapter III

METHODOLOGY

Phenomenology

Van Manen (1990) suggests phenomenological research seeks to learn what a certain phenomenon means and how one experiences it. Phenomenology is used when researchers want to study how humans live in their world (Van Manen, 2002). Van Manen (1990) states the goal of phenomenology:

Is to transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience (p. 36).

Merleau-Ponty (1962) suggests consciousness is life; it does not dwell within but rather permits existence of being in the world through the body. Similarly, Munhall (2012) explains that embodiment is the experience of being in the world through all the senses (touch, taste, hearing; feelings the body allows). These sensory experiences allow for the consciousness of the individual to grow. One's personal history, through experiences in the world, and how open one's mind is to the world is reflected in the perspective or consciousness the individual holds at any given point in time (Munhall, 2012). Since the purpose of this research was to describe and learn the meaning of non-spousal close and intimate relationships to women with cancer, qualitative methodology, specifically a phenomenological approach, was used to guide the investigation. It is a well-suited design for this little known phenomenon, permitting a deep, rich understanding of the lifeworld of the individual experiencing it. There have been no published

studies in the United States to date studying the lived experience of non-spousal close and intimate relationships of women with breast cancer.

Research Design and Approach

Phenomenological research endeavors to understand the expression or nature of the lived experience from the individual experiencing the phenomena from their world perspective (van Manen, 1990). Phenomenology, a human science, is the exploration of the lifeworld, immediately as we experience it rather than classifying and labeling the experience (van Manen, 1984), which Husserl (1964) referred to as the original, pre-reflective, pre-theoretical attitude. “Human science aims at acquiring understandings about concrete lived experiences by means of language” (van Manen, 1990, p. 23). The reduction of data that grabs the essence of the phenomenon is good qualitative research (Sandelowski, 1993). Phenomenology does not measure, categorize or generalize as in quantitative research but rather seeks to understand the phenomena through the vivid and colorful descriptions of the person immediately experiencing the world in which he or she lives as a human being (van Manen, 1990). The lived experience becomes unveiled, shown, and illuminated (Heidegger, 1962), thus making it easier “to see” the greater significance or meaning being described (van Manen, 1990; Munhall, 2012). Little is known about the experiences of non-spousal close/intimate relationships of women with breast cancer. I utilized phenomenological design to guide this study, which allowed for a richer understanding of the phenomenon. Insights gained from this research will give new direction to the oncological community and influence practice for nurses and all health care providers through a greater understanding of human beings in their lifeworld.

Researchers Stance - My Experience

Munhall (2012) believes it is essential to the phenomenological approach that we acknowledge our own perceptions, beliefs, biases, and knowledge to gain understanding of another and ourselves. New researchers are required to empty their mind as much as humanly possible of preconceived perceptions and understandings of what Heidegger (1962) refers to as experiences of “being in the world.” Munhall (2012) suggests suspension of all prior beliefs in order to “think phenomenologically” (p. 114). The researcher’s familiarity of the phenomenon through personal experience(s) must be acknowledged and recognized, then set aside (van Manen, 1990). In order to gain a full breadth of understanding of the lifeworld of the research participants the researcher must first recognize their own perceptions and beliefs so as not to try to influence the participants during the interviewing process.

In 2006, on June 23rd, I got ‘*the*’ phone call. I remember the events of that day, over ten years ago, as foggy and dream-like but I took the time to calm my inner self before sharing the diagnosis with anyone. Retrospectively, it seems funny the first call was not to my husband or any of my three sisters. But when I was finally able to verbalize my diagnosis, I called my friend Nora.

Although I had no oncological background, when physicians became aware I was a nurse they assumed I knew all about breast cancer. They were wrong. I knew very little about breast cancer. In many ways Nora was my educator and navigator during this period. Her expertise as an oncology nurse enabled my understanding of real-life expectations in a way that could never be achieved through leaflets or searching the Internet. It was this support and guidance that laid the foundation for my current position so many years later as a navigator.

A diagnosis of cancer is given to the entire family, not just the individual (Boyd, 2013). Although my husband was supportive in every other way, we were unable to communicate openly about my breast cancer. I believe “our” cancer diagnosis triggered painful memories for him of his mother’s experience with breast cancer twenty plus years earlier, the mystery surrounding it, and her subsequent death. Although I was unaware at the time, he was rendered incapable of almost all discussion pertaining to “our” diagnosis of breast cancer. I am, however, forever grateful for his loving support which was exemplified in numerous other ways.

Two of our five children, then age 15 and 17 were still living at home with us. Trying not to instill fear I carefully chose words when speaking to them about my diagnosis. The younger of the two was hesitant to discuss anything relating to breast cancer. On the first post-op morning, after my mastectomy, I was relieved when I first looked at the reflection in the mirror. Ever the nurse/educator, and hoping to lessen their fears, I looked forward to the opportunity to show my daughters. Later that day, after the revelation, our youngest daughter, with tears streaming, fled the hospital room horrified.

The behaviors of my husband and daughter revealed vulnerabilities within the family dynamic that truly validated the understanding of cancer as a family diagnosis. All of us tiptoed around the breast cancer elephant in every room. In my effort to shield and protect them, guarded conversations ensued. Feelings of loneliness and isolation became familiar in the long stretches of silence at home. This only added another complex layer to an already difficult time, making interpersonal communication with non-spousal close/intimate friends, outside the family structure, even more essential.

I am aware that my personal experience with breast cancer exists. It was put on hold while this research study took place. Continuous journaling, field notes while data gathering, as

well as member checking contributed in the assurance of validity and credibility of findings. van Manen (1990) spoke of what Husserl termed ‘bracketing’ as the act of appreciating our assumptions and theories first and then to put them on hold in order to have an open mind to the phenomenon being examined. Ely, Anzul, Friedman, Garner, & Steinmetz, (1991) speak of the researcher’s need to gain understanding of the participants experience with the least bias or misrepresentation by the challenging task of recognizing his or her own personal prejudices, assumptions, biases and pre-suppositions. This is achieved through journal and log writing and note taking throughout the entire data gathering process.

Participant Recruitment

The participant recruitment process focuses on the selection of individuals who are knowledgeable of and have had personal experiences with the phenomenon of interest (Streubert & Rinaldi-Carpenter, 2011; Munhall, 2012). Opportunity for participant recruitment presented itself from several sources. Participants were purposively sought from a four-physician oncology practice treating patients in their private office infusion center, the private office of a breast surgeon, a hospital based infusion center at a local community hospital and lastly, a national cancer support program, also located within the hospital campus. These locations were affiliated with a large New Jersey based healthcare system. I am an employee of the hospital, specifically in Cancer Services, and have connections/relationships with administrative and clinical leaders within the hospital system as well as Joan, the director of the Cancer Support Community (CSC). All had direct access to potential research participants. The CSC is a nonprofit organization that provides many supportive and educational programs for cancer survivors and their families. This was an opportunity for “snowball sampling” (Lincoln & Guba, 1985, p. 233) recruitment, when one participant identifies and informs others, who fit the

research criteria and may be interested in participating as well. Distribution of flyers (Appendix B) to the three offices and the CSC to identify potential participants, who fit study criteria, was arranged. The participants had no prior relationship with me.

Participants were women, over the age of twenty-one, fluent in English, who had been diagnosed within three years, for the first time, and treated for stage 0, I, II or III breast cancer. Women with a recurrent diagnosis or stage IV diagnosis of breast cancer were declined acceptance as their supportive needs would be very different than participants with stage 0, I, II or III breast cancer. Interested participants contacted me via email or phone and learned the purpose and details of the study.

Data Collection

Once IRB approval from Seton Hall University (Appendix D) and the local hospital (Appendix E) was attained participant recruitment began. I contacted potential participants who had reached out to me, to explain study details and schedule the initial interview. The consent form (Appendix C) was signed at the onset of the initial interview. Subsequent interviews were arranged at the conclusion of each interview until three interviews were concluded. The plan was for three in-person interviews; however, two interviews were done via phone, as the participants were unable to be physically present.

Seidman (2013) suggests a three-interview process spaced anywhere from 3 days to 1 week is ideal for data collection and researcher/participant relationship development. My plan was to conduct three semi-structured, digitally recorded interviews, lasting 60 to 90 minutes over a 6 week time frame to offer more flexibility and the opportunity for reflection and storytelling (Streubert & Rinaldi-Carpenter, 2011). The interview process averaged a three to four month

time span and although there were a few issues, such as difficulty with audio for one interview that took place via phone, they were relatively unremarkable.

Interviews began in March 2018 and concluded in October 2018. The number of participants required were determined by data saturation, which is the point at which the researcher is no longer learning anything new and repetition of the data is noted (Guest, Bunce, & Johnson, 2006; Seidman, 2013). There were six women participant volunteers for the study.

Seidman (2013) recommends using the following guide when interviewing participants. The goal of the first interview is to gain trust and to gather historic participant background. The second interview allows for the researcher to gather details of the lived experience by the participant of the phenomenon being studied. The third interview permits transcript review and additional questions, if necessary, for participant(s). It allows the participant to reflect on the meaning of the lived experience and where that meaning might take them in the future. I used this guide, as it was flexible and allowed necessary trust building prior to communication of the phenomenon in question.

Interview notes were written immediately after the interview had ended in most cases. The interview recordings were transcribed as soon as possible. All information was kept confidential. Participant's names were changed in logs and dissertation to protect their identity. To maintain confidentiality, after transcription all audiotapes were stored on a flash drive and locked in a secure location. Study participation was strictly voluntary and participants were aware they could withdraw at any time during the research process. Interviews took place at an appointed place of convenience for the participant; a coffee shop, hospital conference room or at the researcher's home. Post interview reflective notes were completed promptly to maintain accuracy.

Data Analysis

Tesch (1990) describes ten principles of qualitative analysis: 1) Data gathering and analysis start together. 2) The analysis process is orderly and comprehensive and ends when no new insights are derived. 3) Data reflection and analytical memos guide the process. 4) Data are divided into meaningful segments but maintain a connection to the whole. 5) Segments are content items or themes that form categories. 6) Comparing and contrasting is used for most of the analysis: developing categories through themes, delineating boundaries, assigning data segments. 7) Categories are flexible. They are modified and refined as the analysis moves forward. 8) Qualitative analysis is researcher specific. There is no right way of conducting qualitative analysis but rather is informed by the creative contribution of the researcher. 9) Artistic freedom is permitted but methodological savvy and intellectual competence must also be tools. 10) The final analysis will produce a greater consolidated picture of the phenomenon (Tesch, 1990; p. 95-96). I utilized these principles throughout the analysis process.

I recorded and then transcribed interviews as soon as possible after each interview. All journaling notes as well as field notes were added in a timely manner. It was important to read then re-read each section, coding in the margins of the transcript. Each individual makes a contribution to the data as a whole (Tesch, 1990) allowing identification of similarities and developing themes. Writing and “rewriting (re-thinking, re-flecting, re-cognizing)” (van Manen, 1990, p. 131) ultimately enable the reader to grasp the full significance of the lived experience.

Trustworthiness

Trustworthiness reminds us “of the issues and processes that must weave their way through and beyond our qualitative research to keep it and us honest and believable” (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991, p. 95). The goal of rigor in qualitative research is to

accurately report the participants' experiences (Streubert & Rinaldi-Carpenter, 2011) while demonstrating ethical principles throughout the entire research endeavor (Ely, et al., 1991). Four operational techniques have been identified by Guba and Lincoln (1985), to ensure trustworthiness of qualitative research: (1) *credibility*, (2) *dependability*, (3) *confirmability*, (4) *transferability* (p.328).

Credibility is the quality or power of inspiring belief (Merriam-Webster.com, 2017). In qualitative research credibility is strengthened with activities such as prolonged engagement, member checking and peer debriefing, which contribute to the believability of the findings (Lincoln & Guba, 1985; Streubert & Rinaldi-Carpenter, 2011). Prolonged engagement, spending adequate time with participants helps build trust and promotes credibility. Confirming accuracy via member checking is another way to ensure the research shows findings consistent with those of the participants' experiences (Lincoln & Guba, 1985). This study consisted of three interviews lasting 60-90 minutes with most participants, which allowed for researcher-participant trust building while facilitating meaningful information sharing by participants. The 60-90 minute interview also enabled enough time to conduct informal *member checking*, which was done at the beginning of each interview to determine whether the participants agreed that the findings were an accurate account. There were occasions during the interviews where clarification was needed. I would then ask participants if they could explain what they meant by that statement or ask them to give an example to support their statement. This validation and confirmation added to the overall trustworthiness and credibility of the findings. Peer debriefing supports verification of research findings by an outside party through analysis (Lincoln & Guba, 1985, Streubert & Rinaldi-Carpenter, 2011). Peer-debriefing took place with my dissertation chairperson, Dr. Judith Lothian, on several occasions throughout the data collection process.

Dependability is a criteria reached once the investigator has established credibility of the research findings (Streubert & Rinaldi-Carpenter, 2011). Dependability of the research study can be achieved through what Lincoln & Guba (1985) refer to as an inquiry audit. “Dependability of the inquiry” (Lincoln & Guba, 1985, p. 318) is confirmed when an internal auditor determines acceptability of the qualitative inquiry process through examination of logs, field notes, personal notes, transcribed interviews and themes. Dependability, as posited by Lincoln & Guba (1985), is achieved only after credibility has been demonstrated. My methodological decisions were documented in field notes, interview audiotapes, interview transcripts, analytic memos and reflective journaling. Interviews took place in settings that were decided by the participant contingent upon participant convenience. With the exception of the first interview, which took place at a breakfast eatery, all other interviews took place at either a cancer support program at a local hospital or the researcher’s home. Two interviews were conducted via phone. Examination of the qualitative inquiry process was done by Dr. Judith Lothian determining acceptability, thereby attesting to the *dependability of the inquiry*.

Confirmability, also achieved by means of leaving an audit trail, is a criteria established throughout the period of the data collection. Findings are confirmed through a record of activities such as audiotapes, reflective journaling, logs, and field notes (Lincoln & Guba, 1985; Streubert & Rinaldi-Carpenter, 2011). Findings are compared to activities outlined in notes, journals, and logs which can give the internal auditor insight on decisions and methods utilized during each step of the data gathering process and provide further evidence of confirmability (Munhall, 2012; Streubert & Rinaldi-Carpenter, 2011). I actively maintained a reflective journal to help form a path of progress that included personal beliefs, thoughts about what transpired during interviews, and my personal biases as well.

Transferability, also known as fittingness, refers to the ability to identify meaning from original research findings to other concepts (Munhall, 2012) or others in similar situations (Lincoln & Guba, 1985, Streubert & Rinaldi-Carpenter, 2011). In this study, the experiences of non-spousal close/intimate relationships of women with breast cancer were related with deep, rich descriptions. Made possible through direct quotes of the participants, these experiences could relate to others experiencing similar circumstances. This enables others to determine if the findings *fit* or if transferability is possible (Streubert & Rinaldi-Carpenter, 2011). These activities helped maintain rigor throughout the process.

Protection of Human Subjects

All human subject research requires participant protection, which comply with federal ethical practice guidelines for informed consent (Lincoln & Guba, 1985; Seidman, 2013). Participants received an informed consent prior to data collection delineating: research purpose, confidentiality, location(s), frequency and duration of interviews, researcher and participant's role, data storage, and participant ability to withdraw at any time without prejudice.

Institutional Review Board (IRB) approval was sought from the local community hospital I am currently employed by, as well as from Seton Hall University. To protect confidentiality participant's names were changed. The participants were not anonymous to me but are to all others. All collected data, field notes, journals and audio recordings were securely kept on a USB thumb drive in a locked designated place.

Chapter IV

INTRODUCING THE PARTICIPANTS

Although the six participants are women diagnosed with breast cancer, each have a story as unique and individual as they are. The vignettes provided here are to help create a visual participant representation through gathered information, for the reader.

Brandy Lynn

Brandy Lynn is a 68 year old woman who grew up in the Midwest. She has a BA in History and an MBA and MS in engineering. She moved to New Jersey 30 years ago. Brandy Lynn was previously married for 26 years and identified herself as being “happily single” at present. She has one child, a 33-year-old son, living out west with his wife and infant daughter. “On again- off-again” is how she describes her relationship with her son. They are currently “on again.”

In July 2015, while turning over in bed, she felt a lump in her breast. Immediately, she knew two things; she had breast cancer, and it would not kill her. The first person she called was her long-time friend, Meryl. She and Meryl met 12 years prior, when their sons became high school friends. Together they created elaborate decorations for various high school events both boys attended. Although their son’s relationship did not flourish, Brandy Lynn and Meryl continued to grow their friendship over the next 18 years. Meryl went with her to her first few surgical appointments, at which time Brandy Lynn’s complete diagnosis and plan of treatment was still unclear. However, through a series of unfortunate events in Meryl’s personal life the relationship between Brandy Lynn and Meryl became (and remains) fractured.

A few years prior to her diagnosis Brandy Lynn, preparing for retirement and knowing most of her relationships were colleague-related friendships, wanted to expand her circle of

friends. She joined a local church as well as a senior center. Since her diagnosis, Brandy Lynn has joined several groups. She stays active through the Live Strong program. She has spent a weekend at Mary's Place by the Sea. She has become part of a *MeetUp* (i-Phone application) group and regularly meets with what she refers to as her "core group of friends." She has gone on two retreats where she has become a Chi gong enthusiast and regularly attends classes at the Cancer Support Community, a national non-profit organization, conveniently located in a local community hospital. She also became involved with a *crochet group*, from which two ladies, Janet and Debbie, drove her on many occasions to and from radiation treatments. In fact, each of the seven (crochet) ladies assigned themselves a day of the week, for several weeks following surgery, where they prepared and delivered meals to Brandy Lynn. She explains she "was fine" when she went alone to her (20) chemo treatments; "I didn't *need* anyone to come with me."

Ironically, the same month Brandy Lynn finished treatment for breast cancer she was diagnosed with cancer again, this time a neuroendocrine tumor (NETS). When asked about the person she most relied on while going through treatment, her response was "me".

Olivia

Olivia is a 54-year-old, married woman. She has a sister, 4 years her junior. She had a challenging childhood in part due to her alcoholic father. Olivia was impacted by her father's drinking and took on the role of caretaker early on in her life. When her parents separated, she lived with her mother, sister and grandmother until age 20, when she lost her mother to bone cancer, at age 43. Almost immediately, her grandmother moved out and her father, fully rehabilitated, moved back into the family home to care for Olivia and her sister. She and her father shared a "good" relationship, after her mother's death.

She grew up in New Jersey and has a master's degree in Public Administration. She has one child, a daughter, who is a college freshman. She has been married for 25 years to an attorney and has an "unusual" relationship with him. "Very non-emotional, very distant and very pragmatic" is how Olivia described him.

On April 17, 2014, Olivia was diagnosed with breast cancer following a routine mammogram. "Two minutes later I got a call from Rose." Rose and Olivia became friends through their daughters, who are school buddies. Rose, who works in the Breast Center as the lead technician, helped Olivia understand the process following her breast cancer diagnosis. Olivia's husband was unavailable emotionally through Olivia's breast cancer journey.

Olivia and her 85-year-old aunt have a close relationship however; Olivia, not wanting to burden her aunt with worry or stress, decided not to share her breast cancer diagnosis. Her aunt lost two daughters to breast cancer. Some of Olivia's neighbors cooked for her and one neighbor, who she had never had a relationship with before, invited her for a family dinner one night. She accepted. Olivia relied solely on herself throughout the treatment phase. However, she admits she felt unconditional support and love from her canine companion. She wishes she had reached out for some sort of formal group support, offered through various local organizations.

Katie

Katie is a single woman, age 42. She moved to the East Coast at age 10. She has an older brother. She is a registered nurse with an MSN in informatics. A 2010 New Year resolution was the catalyst for her new hobby, running. By 2012 she was training for her first marathon and found a new circle of friends in a local chapter, triathlon club.

In 2017, at age 40, following a routine mammography, Katie was notified she needed a biopsy. Sandy, a nurse friend, and one of Katie's closest confidants, was the person she called.

Katie was working when she got the call from the radiologist telling her she had breast cancer. Two of Katie's paternal aunts have a history of breast cancer, one at age 40 as well.

Since her breast cancer diagnosis and treatment, Katie's recreational activities now include fund-raising events for breast cancer awareness as well as those that benefit the Young Survivor Coalition (YSC), a national non-profit organization, specifically for young women who have been diagnosed with breast cancer. She has made many friends through the YSC and talks about feeling an immediate connection with the YSC women and fellow survivors. Similar to Brandy Lynn, Katie was active in several groups prior to her diagnosis, drawing support from a deep pool after diagnosis, when she most needed it.

Mary

Mary is a soft-spoken, attractive, 64 year old woman who has been a lifelong state resident. She has two children, a 28-year-old daughter, with her own little girl, and a 26-year-old son. She attained a masters' degree in special education and speech therapy. She retired last year and spends several days a week sitting for her granddaughter "the love of her life."

At age 19 she married a man she had known since childhood. After 30 years his "overpowering and overbearing" became too much to handle. During that time Mary slowly felt her identity slipping away and the marriage ended in 2003. Despite their divorce her, still unmarried, ex-husband always seems to be on the periphery of Mary's life.

Mary had no family history of breast cancer and had been up-to-date with her annual mammogram. She didn't really think anything of being called back to the Breast Center for additional imaging, as it had happened before. In September 2013, Mary was diagnosed with breast cancer after a routine mammogram and subsequent biopsy. As soon as her ex-husband left

the house that day, she called her two sisters, however Beth, her sister-in-law, was her “go to” person.

Like Olivia, Mary is regretful she did not seek support from any of the local groups. She teared up when thinking back to her most vulnerable times, wishing she had done so. Mary said her breast cancer diagnosis and journey is *always on her mind*; something she thinks about daily. She thinks she could still benefit from some sort of group support and may soon find the courage to give it a try.

Jane

Jane is 40 years old, married for 5 years. She speaks of her childhood as being “a little bit tumultuous.” After her parents divorced, she lived with her aunt for a few years then returned to her mom and stepfather, until it became too violent. She has a half-brother, from her mother’s second marriage that has since dissolved. At age 14 she moved in with her father and stepmother until midway through high school when she resided to live with her mother again. As soon as she graduated from high school she moved out.

She put herself through college, majoring in special education. She returned to school for her master’s degree. Dismayed by her experience with the Board of Education system, she returned to sales; presently marketing food and supplies to high-end hotels. Jane met and married her husband and together they endeavored to start a family.

Unable to have her own children, Jane was preparing her body for egg donation, which included two years of hormonal supplements among other things. They were also looking for a home in a family-friendly neighborhood. In January 2016, Jane felt a lump. However, because the hormone supplements she was taking had side effects that included breast cysts, she did not feel an urgent concern. By the time she had her mammogram, it had been several months since

she had first felt the lump. Two days before Jane and her husband moved into their new home, at the age of 38, she learned she had breast cancer.

Jane's husband was there for her in the way he could be. But because of her mother's near absence in her life, it was her mother-in-law who came to her assistance with "invaluable support." She scheduled appointments, accompanied her to consults and organized all reports, tests and notes in a binder Jane still uses today. Jane didn't have to ask for her help, her mother-in-law just did it automatically. Jane thinks of her as one of the most amazing people on the planet.

Diana

Diana is a 32-year-old woman, born and raised in a loving family unit, in New Jersey. She has an older sister who is a nurse. Diana has an undergraduate degree in business management. In 2015, Diana's mother died, six months after being diagnosed with cancer (primary unknown- similar to Olivia). At this time of vulnerability, Diana and her long-time boyfriend, reunited. After two years of what she describes as "toxicness," and in the midst of her relationship falling apart, she found a lump in her right breast. After persuading her physician, she had further testing which revealed breast cancer. Diana was 31 years of age.

The surgical options offered to Diana were overwhelming. One facility offered nipple-sparing surgery while another one refused to save her nipples. Diana talks about this (decision) time as the "toughest month of my life." Although her sister, father and girlfriends were there for her, she found speaking to other women with a breast cancer history, to be the most comforting and supportive for her. Diana was able to speak with several women who had various surgeries and treatments while faced with a diagnosis similar to hers. Diana is still in contact with these younger women and plans to attend regular meetings and YSC events.

Chapter V

FINDINGS

This chapter describes the individual experiences of close/intimate, non-spousal relationships of six women with breast cancer. The experiences of close/intimate, non-spousal relationships were stories of support; the type of support most needed, at which stage the support was provided, and who provides it, throughout the participants' breast cancer treatment trajectory.

THE JOURNEY STARTS

Chaos and confusion

Core people

Survivor relationships

MID-JOURNEY PASSAGE

Finding the strength within

Being there

Friends- some old, some new

JOURNEYS END/COMING HOME

New normal

Relationship changes

Feeling gratitude

The Journey Starts

The very beginning of the journey was remembered as a period of disbelief, uncertainty, chaos and confusion. The disturbance of the breast cancer diagnosis to the participants' life as

well as taking the necessary steps were overwhelming for most of the women. Most of the participants had a “core” person or group at the onset of their journey, the period immediately following their diagnosis. The core person or group was for the most part various family members and/or long-term friends. At various points in their treatment trajectory, situations arose resulting in new individuals or groups entering the participants’ universe. In need of whatever aspect of support, the participants unknowingly established friendships that would transition along the way into non-spousal, close/intimate relationships. Such is the case, particularly, for those participants who sought additional support and became involved with formal group support programs.

Although some of the identified people offered much more than one type of support, when asked to describe how their core person(s) provided support, each of the participants described *emotional support* behaviors such as: “being there,” “stayed with me,” “just let me talk,” “made me feel hopeful,” “called me,” and “texted me.” These behaviors reinforced the individual’s perception of being loved and cared for. Emotional support is a requirement of all humans but seems especially necessary, not only for those facing the *start of their journey*, but also *the mid-journey passage* and all the way to their *journeys end/coming home* (Appendix A).

Chaos and confusion.

All of the participants talked about the days and weeks immediately following their breast cancer diagnosis. This period of their breast cancer journey, from diagnosis/surgical consult to surgery, was often remembered as a period of *chaos* and *confusion*. Decisions needed to be made in a timely manner, requiring participants to be cognizant of the various choices and subsequently, the treatments related to those choices. At this juncture, all but one participant required information or *instructional support*. The classic mode of instructional support delivery

for breast cancer patients should include educational materials, traditionally provided by the medical team caring for the patients i.e. surgeons, nurses, navigators, and ancillary medical staff. However, often the patients experienced information overload and were unable to process the information or at times, information was not provided.

Jane. Jane recalls her thoughts at the initial stage of diagnosis.

So, there was so much going on. I kind of...in a way I didn't have a minute to think, but I thought I was going to die. When I heard 'cancer,' it kind of really freaked me out and shocked me. So, I was pretty terrified at first. And then you know, the decisions that you have to make (p. 23, lines 20-23; p. 24, lines 14-15).

Jane was offered educational information regarding various treatment options available by her surgical and medical oncology team. However, she really did not understand the full implications until later.

Like....whoa, like when I'm sick and I go to the doctor, they say take this pill and you feel better. This was, you can cut off your boobs or you can do a lumpectomy; there's implants; there is all of these kinds of implants; flap procedures. And then you finish all of that and it's like, so then you need chemo. There is this chemo, which is very aggressive, this one, which is pretty strong. And then there's this one which is a little lighter but the study for this one, which is lighter, is proving effective but it's not really a great study.... information overload! You know, the long-term effects of it and you know, lots of decision-making that I was not expecting (p. 24, lines 15-22; p. 25, lines 1-2).

Olivia. Olivia remembers feeling very busy in the beginning.

That whole...those days I had phone calls. You know I had the coordinator at the Breast Center calling me to set up an MRI. I just seem to remember having my home phone and my cell phone constantly going, talking to people (p. 12, lines 1-5).

Diana. Diana too, had similar memories of the first phase of her journey. "...A little overwhelming! I just wanted like a minute to take it in, but now I know, I understand the

urgency and understand why. They wanted to start this process quickly.” With her family with her for *emotional support*, Diana went to her first surgical consult. She remembers her first meeting with the surgeon and her calm, reassuring and informative manner, demonstrating both *emotional* and *instructional support*.

She (surgeon) was very calm and warm and she made you feel safe. I was with my father and my sister and I think she just saw my dad’s face. And the first thing she said was, ‘You will not die of breast cancer. You’re going to live a long life. You’re going to get past this. We caught it early.’ She answered... She spent a lot of time talking with us and answered a lot of questions. She said, ‘You do not need chemo.’ She said: ‘These are our options...’ (p. 11, lines 13-15; p. 12, 6-10, 14-16, 20).

Katie. Katie, a former surgical nurse, put herself on a self-imposed Internet ban. Katie placed her full trust in her surgeon, depending solely on her for *informational support*.

I said, Dr. C., I’m a nurse. I know a little too much. I am Googling nothing. I said, I picked you as my doctor and I’m going to trust what you tell me. She said, ‘Not that many patients are that trusting, but ok.’ And I said, ‘No, you don’t understand, I know too much. I’ll make myself crazy’ (p. 16, lines 4-5, 7-11).

Brandy Lynn. Confusion and uncertainty surrounded Brandy Lynn’s biopsy results and diagnosis. She was informed that her biopsy tissue was sent to the pathology department and they had “crushed her cells,” making the sampling unsuitable to run receptor studies testing, which provides critical characteristics of her breast cancer diagnosis and subsequently, her overall treatment plan of care. Additionally, in question were various reports (MRI, mammogram, ultra sound) regarding the size of her breast cancer mass. Furthermore, the initial breast surgeon she met with advised Brandy Lynn she did not believe the biopsy results.

Nevertheless, she informed BrandyLynn about her plan to perform a bi-lateral mastectomy, adding further questions to an already unclear situation.

Not feeling the *emotional* or *informational* support connection with her first surgeon or medical facility, BrandyLynn scheduled another surgical consult at a well-known cancer center and was seen within the week. After a very detailed, *informative* consult, BrandyLynn, to her great relief, learned that she did not need a bi-lateral mastectomy. More importantly with the *instructional support* offered, she left the office with confidence in her future breast surgeon, understanding her diagnosis and treatment plan more fully. Additionally, BrandyLynn was offered a spot in a national breast cancer clinical trial, which she eagerly accepted.

Core people.

Jane. Since her marriage, Jane had established a loving relationship with her mother-in-law, Zophia. At the time of her breast cancer diagnosis, her mother-in-law took charge, offering Jane *emotional, instructional and instrumental* support throughout her breast cancer treatment. An extremely organized person, Zophia provided Jane with a binder for anything medically related to Jane's care. She also did much of the leg-work required immediately following a breast cancer diagnosis.

She is a pit bull; one of the most amazing people on this planet. She called everywhere under the sun. I had appointments scheduled for opinion one, opinion two, and opinion three at very regarded... at recommendations... She was amazing. So, I didn't really have to ask for help, she just did it. And she went with me to every appointment. For the consultations, she put it all in a folder... organized... I didn't... it's just invaluable. Things I wouldn't even have known. And I still have that folder; now the folder is like this thick (motions to 6" or so, laughing). And I still build upon it and it's just great. Everything is right there, boom, boom. So, she was pretty amazing (p. 25, lines 16-23; p. 26, lines 1-2).

Jane is ever grateful for Zophia's seemingly endless provision of *emotional, instructional* and *instrumental support*.

Mary. For Mary, *emotional* and *instructional support* came from her ex-husband (described in further detail on p. 21) and Liz, her sister-in-law. Although Mary talked about her two sisters, it was Liz she identified as her “important person”; someone she felt most comfortable with. “It’s just like she’s a sister.” Although they already enjoyed a close relationship prior to diagnosis, her support during this time only solidified it. She explains in further detail.

Ironically, the person I probably talked to the most was my sister-in-law, Liz. Liz, she’s very medical, logical, but also sympathetic. She’s almost... I would say, a combination between both my sisters, which is crazy because we’re not related by blood. You know, Kathy and Wendy (sisters), I love them to death but Liz is the one that I can talk to the easiest. But, um, you know, a lot of questions. ‘Do you know what kind it is? Where is it at? When is your next appointment? What are they going to do?’ You know, very technical stuff. She’s the one that if I have any questions, like I might say, ‘Gee, I wonder’...She must’ve done a lot of research or whatever because by the next time I’d see her, she would have the answer (p. 20, lines 19-23; p. 21, lines 1-2; p. 23, lines 6-7, p. 28, lines 16-17).

Olivia. Although married, Olivia’s main source of support came from Rose, a mammography technologist at the same breast center where Olivia had her annual imaging. Olivia and Rose met years before, through their same-aged daughters, who were long-time school friends. Rose, who worked in the Breast Center where Olivia had her annual imaging, was well versed in the process that followed her breast cancer diagnosis and became her source of support.

Two minutes after hanging up the phone (from the radiologist, revealing her diagnosis) I got a call from Rose. So, she was there immediately with: What can I help you with? It was wonderful because she was able to give me names (p. 11, lines 17-18, 21-23, p. 12, lines 1).

The support Rose provided Olivia was both educationally empowering (*instructional support*) as well as comforting (*emotional support*). She conveyed what she experienced during the initial days of her diagnosis.

It was just a very confusing time and Rose was very helpful not just with her knowledge but just kind of prodding me in directions when she saw I was just flapping in the breeze (laughing), you know? So, that was very helpful. She was very good in trying to choose a surgeon; she was trying to figure out who was in my (insurance) plan without me even asking her or knowing. And she gave me good feedback (p. 13, lines 10-16, 19).

Diana. With her mother deceased, Diana's father, sister and aunts provided *emotional support* for her. She identified her dad as one of her "top people" who offered emotional support but it was more difficult for her to talk to him because it was *breast* cancer. Speaking about her father, Diana said, "He didn't understand the physical end of it." And, "This involves my womanhood, my sexuality and I can't talk to him about that."

My dad helped me with the emotional aspect... be strong, mommy is with you, just building me up a little bit; like emotionally, mentally; the same thing with my aunts and family. They would say, I was a strong person; you're going to get through this. Just having those conversations and them telling me, 'You're going to get through this' and 'There's light at the end of the tunnel'; just giving me that emotional support was important (p.45, lines 5- 12).

Support was not necessarily provided by the individuals with whom the participants had close/intimate relationships prior to their breast cancer diagnosis. The relationship between patient and physician can transition, particularly if the care is rendered over a significant period of time such as that provided to a woman by her obstetrician as her pregnancy progresses.

Similarly, the relationship of a woman with breast cancer and her physician is often perceived to be much more as it transcends into something more intimate, from the patient's perspective.

Feeling overwhelmed after pursuing a second opinion, along with a very different treatment plan of care, Diana phoned her first surgeon with queries.

Anyway, I was just completely torn. I was at a breaking point. I accepted the breast cancer. I accepted even doing a mastectomy at that point. But once we were talking about the reconstruction part I hit a wall emotionally and mentally. So, I remember calling Dr. K. crying. I said tell me why you are telling me we can do this and _____ (other facility) is saying no. She was probably on the phone with me for over an hour, explaining to me about the surgery. And she explained to me that she wants to get to know her patients, that every patient is different and that's exactly how I felt with her (p. 15, lines 14-16, 21-23; p. 17, lines 12-15).

Diana's surgeon made her feel like a human being, not just a number or a diagnosis. She was "there for her" (*emotional support*) and took the time to clarify any questions (*instructional support*) thus enabling Diana to make the surgical decision that was right for her.

Brandy Lynn. Brandy Lynn knew immediately she had breast cancer when she was repositioning in bed and felt a lump in her breast. Meryl, her long-time friend, was the first person she told of her diagnosis. Unfortunately, Meryl, confronting (familial) issues of her own, was unable to be there for her friend. When Brandy Lynn realized this, she began reaching out to others, who filled the *emotional* and *instrumental* support gap for her.

Survivor Relationships.

Several of the women spoke about close/intimate people in their lives offering support “in the way they could” or “the only way they were capable of.” For many of the participants there were times when that support *wasn’t enough* or *not the type* needed at that particular time. Actively seeking more information, four of the participants became familiar with various (breast) support groups, where they met other women survivors who “had gone through it.” They found they were able to communicate with these women in a manner that was *unguarded*. They spoke easily and freely to (other) breast cancer survivors in a way they were unable to do so with those they shared close/intimate relationships with. There was an immediate connection to those survivors who had gone through what they were experiencing. What started out as a pre-surgical exploration for information/education by *unknown others*, turned out to be the foundation of present-day meaningful *non-spousal close/intimate relationships* as their journey(s) moved forward.

Brandy Lynn. Already acquainted with several community and social media groups, Brandy Lynn became more involved with the various members, consequently forming what she referred to as her “core of friends.” She still maintains close ties with them. These friends, although new to her at the time, became her close/intimate friends providing the main source of emotional, and instrumental support throughout her cancer treatment(s) and beyond.

Jane. Jane became aware of a cancer support group, the Young Survivors Coalition (YSC), which specifically addresses the needs of (pre-menopausal) younger women, diagnosed with breast cancer. She not only received *emotional support* there but more importantly, like Diana, she received knowledge empowerment through *instructional support* at a critical time in her cancer trajectory from women who had *gone through it* already. Soon after she was diagnosed, Jane learned, via Facebook, of a high school friend who had been diagnosed with

breast cancer as well. Through an instant message Jane confessed, “I’m freaking out”. Soon the two young women began talking regularly.

Through that connection Jane learned about the YSC. Although living in Monmouth County, her then work-related travel schedule allowed her to attend two Northern New Jersey group meetings; the closest YSC location. She spoke about feeling hopeful when attending her initial group meeting where she met breast cancer survivors, some of who were 5 and 10 years out from their diagnosis. One woman had undergone the same surgery Jane was having and shared her experiences with Jane. Unable to find much information online regarding the procedure, Jane found talking to this woman, who had gone through it, immensely helpful.

...And then knowing about the surgery that I had planned... because not everybody knows about it. The DIEP and the scar sparing (nipple sparing and hidden scar); all the things that I was scared about...I was like, they did it, I can do it. So, that was invaluable to be able to see people thriving...yeah, the surgery sucked, the treatments sucked, but they made it to the other side, they’re fine, they’re happy and they’re normal and they do normal things. That was invaluable, yeah (p. 41, lines 6-10; p. 42, lines 4-6).

As Jane moved along her cancer care continuum into her chemo treatment phase, she continued to seek and receive *instructional support* from YSC survivors.

The amount of knowledge and support... Example: take Claritin if you have Neulasta, it’ll help prevent bone pain. Nobody ever said anything like that to me. You know, other little tricks to help you deal with some of the side effects from chemo, like rinsing your mouth with baking soda, salt water; icing your fingers and feet to prevent neuropathy; all kinds of things (p. 40, lines, 14-19).

Diana. Diana talked about how important it was for her sister and friends to be there *emotionally* for her. Another source of support came from a list of patient referrals, provided to Diana by her breast surgeon. She shares her thoughts about women she spoke to who *had gone through it* and the provision of *instructional/emotional support* she felt.

You can have the emotional and mental support of your family and friends, because obviously they love you and care about you and everything but nobody can tell you how to deal with those thoughts in your head or... some of the things you don't want to say out loud... what you're thinking, because it sounds so horrible. But when you speak to someone (who has gone through it), they have had those thoughts too (laughing). The most helpful thing for me really was speaking to other women that *went through it* and you see that life goes on. That there is life after breast cancer, even after a double mastectomy, nipples or no nipples, you move on. That gave me the biggest piece of mind; just speaking to women who have *been through it* and it's been successful (p. 28, lines 21-23, p. 29, lines 1-8, 10-11).

On that referral list was the founder of the local YSC chapter, Jane, who Diana reached out to. Diana, grateful for the wonderful support she received from her family and friends, explains the difference between their support and that of Jane's.

Women from the support group (YSC) that I met, a few ladies that went through similar surgeries that I did, I was able to reach out to them through either calling or text; even to ask a question like, 'Is this normal or is that normal?' So that was comforting. There was one woman that I was able to... that I spoke to a lot, that I met through the hospital. She was a great contact for my process, my recovery. That was comforting, that gave me peace of mind. I think I spoke to two women that had the same (procedure) that I had. And they were able to share their experience and their positive results. Again, just showing life goes on after this. You may never be the same but you adapt to your new normal. And that was the biggest key in giving me peace of mind. Being able to speak to the women who went through it prior to surgery and after surgery (p. 35, lines 4-9, 11-18).

She further explains how she felt about being in contact with other breast cancer survivors.

To be honest what helped me the most was speaking to women like Jane. They either went through treatment or had a mastectomy and didn't have treatment, like

myself, or had to do lumpectomy, radiation, chemo then do the mastectomy. You know, you spoke to people that have done it all. They (Diana's breast and plastic surgeons) actually said if you wanted to speak to these people they're willing to talk to you. It gave me... it gave me peace of mind because, hey, life goes on and you're not mutilated. I had seen these women that had to go through chemo and radiation then a double mastectomy, I said, Diana... it actually made me realize how lucky I am to be able to do this now and not have to do the treatment too. So that kind of humbled me, and kind of brought me in a little bit, like you know, Diana, this could be a lot worse. And I needed that (p.27, lines 11-14; 20-22, p. 28, lines 1-2, 6-7, 12-19).

Katie. Katie, very physically active in various fund-raising events prior to her breast cancer diagnosis, continued to be involved in these activities during her treatment. Around the time of her surgery, she was notified about a local YSC chapter starting and decided to join it. Impressed with all the support services (*emotional and informational*) and wanting to know more about the organization, Katie decided that she would attend the annual YSC summit in Florida. She found three women, whom she did not know, to share a room with. She too spoke of the *immediate* connection they all felt.

But again, through the experience of breast cancer, we became instant friends. And there were people in all stages and phases of treatment and reconstruction. You didn't feel like you had to hide anything. Everybody knows where you were coming from. It's just a tremendous organization. I do my part to tell people about it (p. 49, lines 16-17; p. 50, lines, 18-22).

She remains active with the YSC and has been attending local monthly meetings for over a year now.

The Mid-Journey Passage

To say that *emotional support* plays a more essential role than any other support type, during the cancer treatment trajectory, would be misleading. Instead, what revealed itself was the need for emotional support *throughout*, but specifically preceding the days, sometimes weeks,

leading up to surgery and the immediate post-surgical recovery period. Pre-operatively, all tests have been completed; surgery is scheduled and the patient is waiting for surgery. The earlier period of confusion has subsided; however, anxiety and fear are ever-present.

Finding the Strength Within.

“Attitude is a little thing that makes a big difference.”

Winston Churchill

Some of the women, much to their own surprise, spoke about relying on themselves for *emotional support*. This was a time of self-reflection, of facing of their fears or perhaps of taking control of their fears, in order to get through the next leg of their journey. Although surrounded by those she shared close/intimate relationships with and feeling their support and love, for Diana the burden of being diagnosed at her young age of 32 was overwhelming. Still healing from the loss of her mother (to cancer) two years earlier, and at a particularly low time in her cancer treatment trajectory, Diana, willed herself to “snap out of it.”

And I remember, I was in a really, really bad place mentally and emotionally. And then I remember waking up about a week before my surgery. And I said, ‘Diana, you better get it together mentally and emotionally because if you think they’re going to find some more cancer and you think something is going to go wrong, it’s going to and they are going to find more cancer.’ “You better get out of this funk.” And I did! I woke up one morning and I said ‘it’s got to go perfect, it’s going to go flawless. They’re not going to find any more cancer, and it’s going to go accordingly. This is the plan!’ (p. 19, lines 3-12).

Mary. Mary too recalls times she felt fearful. She shared her memories about when she was getting set-up for radiation.

I remember getting all my little markers, my little tats for the radiation. They were definitely sometimes scary and really as much as I could, I tried to handle it *myself*. I would cry a lot. By myself...I was really... sometimes I would call my sister-in-law. At times, it was just kind of me, just dealing with what I had (p. 26, lines 8-13).

Olivia. Similarly, Olivia spoke about the strength she found *within herself* as well.

So, it was strange I feel like a lot of the support came from within myself. I was amazed at myself sometimes. I became much more about things that matter versus things that don't matter. You know what? If there's dust bunnies in the laundry room, I don't care (p. 36, lines 13-17).

When Olivia was going through radiation treatments her daughter and husband went on vacation. It actually turned out to be an unexpected but positive experience for her. She pampered herself with activities that were comforting for her.

They (husband and daughter) had a good time. They had kind of a bonding thing of their own. And I had a great time at home! (laughing) I had a great time at home. It was me and the dog. I mean I did my normal routine; work, radiation, and home but it was just different. You know if I wanted to sit in the bathtub for two hours, I did. No one's knocking on the door wondering if I'm dead (laughing). That was a good thing. It turned out to be a good thing (p. 20, lines 7-15).

One of the more surprising sources of *emotional support*, revealed by Olivia, came from her dog. While still in active radiation treatment, her husband and daughter went on a planned (prior to Olivia's breast cancer diagnosis) family vacation.

I think that, oddly enough, one of the good supports, and you're going to laugh at this, came from my dog. I would...I was home. My dog was with me. They know everything. They know when to lie next to you and put their chin on your leg; they know. And, I think my dog was a big support. I would talk to my dog sometimes. I think that that is a release. It allows you to discuss something, out loud, without being judged. So, my little dog was helpful. He is a border terrier; he's a little scruffy, rough-haired terrier. He's a good listener (laughing [p.35, lines 13-21])!

Being There.

Several participants spoke about their loved ones not necessarily doing something but rather, simply "*being there*" which provided emotional support.

Katie. Katie had many friends who were supportive but she was most comfortable when with Kathy.

My one friend, Kathy, she would call me and say, 'I'm on my way, we're going out for dinner.' I would push food around my plate. She would just *be there*. She never expected me to talk about it, she never tried to say it's going to be fine or... she just... she was *there* (p. 38, lines 3-8).

Diana. In a similar fashion Diana felt comforted when surrounded by her certain friends and family.

I have a core group of solid friends that were *just there* for me; took me to the doctors' appointments when I needed them to. There was, I'd say about five girls that were really, really by my side. Yeah, I was lucky enough to have my core group of friends and my family *there* for me (p. 33, lines 19-21; p. 35, lines 1-2).

Jane. Jane spoke little about her husband in the two first interviews. At the third interview I asked about support he may or may not have provided her. With a bilateral mastectomy scheduled she knew she would have upper extremity limitations requiring assistance with activities of daily living, i.e. showering, dressing, etc. Anticipating this as a critical time in her care, he stayed home from work the first week. His parents also stayed to assist. However, when Jane really required (physical) support, Zophia, her mother-in-law, was the one to respond to her needs for *instrumental* support. Disappointed at the time, Jane has worked through this and believes this was his way of supporting her; by simply *being there*.

At the time, I was just disappointed. But I also think he was so terrified that he would do something wrong. In hindsight, I think it's probably better because I think we just would've ended up fighting (laughing). And I didn't really have the energy for that. In hindsight, I think it was better but at the time I think I was upset he was letting his mom do it (p.38, lines1-5, 16).

Friends- some old, some new.

“Some people come into your life as Blessings. Some come into your life as lessons.”

Anonymous.

As their journeys progressed, some of the participant relationships with individuals previously thought to be close and intimate transitioned. Some forged new and unexpected relationships that became close/intimate relationships over time. For others, it was a realization or revelation of sometimes undesirable qualities of their previously established close relationships.

Diana. Diana spoke about a cousin and a long-time friend being absent for her. Diana's mind's eye knows that part of the reason for their absence during her treatment was because her

friend's mother had had breast cancer and Diana's diagnosis caused a resurgence of painful memories for her. But still, her emotional self was saddened when her friend and apartment mate was not there for her. Diana no longer stays in contact with her. She also spoke of one of her cousins, whom she previously had a close relationship with.

Yeah, the one family member that I was close with who wasn't really around... I spoke my mind. It was a female cousin. Since then we've reconciled. She's experienced a lot of loss and trauma in her life and I think I understand where she was coming from too. She was scared and it was hard for her seeing me like that (p.52, lines 15-19).

Diana was surprised in the friendship that developed between herself and Nina, her landlady, who is also a survivor. She became one of Diana's "core people" throughout her cancer journey providing emotional and instructional support.

Another person that... and I think I did mention it, that was really there for me, was my landlord's wife, she's my landlord too. She had gone through breast cancer at age 32 and I was 31 when diagnosed. So, she came to a lot of appointments with me. Her name is Nina. So, she had been there, went through it. She was a great person to bring to appointments because she could take the emotional side of it out. Instead of bringing my sister or my dad, where it's like, they're trying to write everything down, trying to take everything in ...but the emotional part is very hard. So, I brought her with me when I went to see Dr. K. and when I went to ____ (other facility), she came to one of the appointments. And she was able to keep the right frame of mind and everything. And she wrote things down for me that was probably going in one ear and out the other on me because I was on overload. And she helped to ask questions, because she went through it. So, she understood more. She was a great support. Again, she went through it. And I never would've thought she would've been there for me, and she was in my top ten. So, she's a very special and important person (p. 54, lines 17-22, p.55, lines 1-2, 4-12).

Jane. It was a little different for Jane because she moved from New York to New Jersey three days prior to her diagnosis. Most of her friends were in New York making it more difficult to see her. She had some close special friends but some unexpected others as well, that stayed in touch during her treatment who offered *emotional support*.

A few people that were acquaintances, that I didn't talk to often, reached out regularly during treatment. They weren't major sources of support, but I was touched by their generosity and care. The common thread is that they had a personal connection to someone who had passed from cancer (p. 42, lines 15-19).

Jane spoke about her mother and the difficult relationship they have. Although Jane's mother lives in Florida, she has never played a maternal role in Jane's life. Jane talks about *bouncing around* as a child living with her mother and father on and off, also with extended family. She described her mother as being "habitually unemployed and riding unemployment." "I still have a relationship with her but I kind of keep it at arms distance for it to be the healthiest it could be." There was a reversal of roles of sorts for Jane and her mother. Instead of Jane's biological mother being a source of support, Jane felt she needed to be encouraging for her mother.

My mom would be getting drunk and just not really...it would be more of a stressor than anything. That was another awkward conversation. Sometimes she would get a little, whatever, and I'd go, 'You know Mom, I need you to be strong right now.' (p. 32, lines 17-21).

Olivia. Olivia talked about some of her neighbors displaying unusual behaviors that were *instrumentally* and *emotionally* supportive.

Suddenly a couple of the neighbors started leaving little things on my doorknob. When my husband and daughter went away on vacation, one of them invited me over for dinner. I have lived there for twenty years and I don't think I have ever been in their house, but they invited me for dinner. And I went (p. 30, lines 13-18).

Mary and Olivia both expressed negative sentiments regarding their in-laws. Although they were not previously close prior to her breast cancer diagnosis, Olivia's in-laws made no attempt to support her at any time during her cancer journey. With no maternal figure in Olivia's life, this could have been a wonderful opportunity to change the course of their relationship. Here, Olivia's expresses her reflections.

I don't think we've ever really had a close relationship. My husband is an only child. So, I think she kind of viewed me more as, not me personally, just as a daughter-in-law, as somebody whose taking attention away from her; very odd people, very odd. I find... I don't know whether cancer makes you more introspective, I don't know whether that's true or not, but I find over the past few years, it could be aging too, I'm really trying to look at the people around me and how they kind of, have affected me, not in a selfish way but just the fact that ... I think there's a lot that people do... that they don't realize they're doing to other people. I don't have... my mother died a long time ago so I didn't have that support (p. 26, lines 18-23; p. 27, lines 1-7).

Mary. Mary talked about her relationship with her in-laws as well.

His parents...his father was a gambler and used to get paid and would go down to the racetrack and spend all his money and have nothing. His mother was very domineering and you know, it was her way or no way. That kind of interfered later on, during our marriage. You know, it was tough because my husband was in the middle between his wife and his mother. I tried the best that I could but nothing was ever good enough. I didn't do it the right way or 'what do you mean you're not bringing the kids over to see me?'...or whatever. (p. 4, lines 10-18).

Brandy Lynn. Brandy Lynn, at the time of her diagnosis, had already started to put in place several support resources. Having established a relationship with a church congregation, the local senior center and a crochet club prior to breast cancer, Brandy Lynn had many individuals offering their support to choose from. "So, there wasn't any one person. I just kind of

spread it out.” She spoke about seven women, in her crochet club who offered her *emotional* and *instrumental support*. Each of them “took a day” to bring Brandy Lynn meals. “So, Leanna would call me on Sunday morning and Janet would call me on Monday morning. And they would ask: do you need anything? And then there was my Tuesday angel...”

Brandy Lynn spoke about traveling to New York every other week and how taxing it was. She told some of her new acquaintances in her *Meetup Group* that the frequent traveling by herself was too much.

So, it turns out, one of the ladies, Debbie, she said, ‘I’ll go with you.’ I barely knew her. She has come with me and now we’re good friends. Moira has gone with me. Josie actually took me to have surgery this last time. So, people have really stepped up, which is really surprising (p. 37, lines 9-15).

Mary. One unexpected finding was the relationship between Mary and her ex-husband. They have been divorced for fifteen years however, still rely heavily on each other. “Actually, we’re on very good terms now. We got past the whole divorce thing”. Through their years of togetherness and possibly because of the mutual love for their children, they have sorted out a friendship that is kind, respectful and supportive. Although their thirty-year marriage has ended her ex-husband is still very much in her world. “So, (laughing) we’re very, very friendly. You know, it’s worked.” Because she listed him as her *contact person* on her hospital documents, he actually took *the* phone call. Mary recalled the story of the day she found out she had breast cancer.

I didn’t know it and I probably would’ve been really pissed at the time, but he had called the Breast Center and told them that ‘look, she’s going to be in school all day. I know she’s waiting for the call. He said if this is bad news could you please wait until about 4 o’clock, so she’ll be at home by then.’ So, I went home and he was there and the phone rang and I answered it but he was there and heard the news the same time I did. So, I just kind of handed him the phone and I just cried. I heard him say, ‘What does she do now;

what's the next step?' You know whatever. But any other time I would've been, how dare you call and tell them to wait until 4 o'clock while I was waiting all day. But in hindsight, I would've gotten the news in the middle of class or at lunchtime or whatever, that would've been bad enough but then having to drive all the way home with that... So, that was a good thing. But I mean that's typical of what he would do, typical (laughing) (p. 15, lines 13-23; p. 16, lines 1-5).

Providing *emotional* and *instrumental support* again, her ex-husband was also there for Mary when she informed their two (adult) children about her diagnosis. When Mary had her breast surgery, he accompanied their two children to the hospital, stayed through recovery, and brought Mary home. Although they are happy to be divorced, their relationship has transitioned into a true friendship. Mary considers their relationship to be “a good one.”

Journeys End Coming Home

Post-surgical limitations associated with breast cancer often pose physical restrictions for several weeks or longer. Physical changes are obvious, drains may be in place and pain is a reminder of new physical changes. Participants are not able to function independently and requires a type of functional support, instrumental support. This type of support involves physical assistance such as driving an individual to appointments, cooking meals, running errands and the like. As the recovery process comes to an end the need for instrumental assistance also lessens.

End of treatment is when all the busyness of their breast cancer diagnosis (education seeking, testing, surgery, and chemotherapy/radiation therapy) is completed. Physician follow-up appointments start to space out leaving the patient feeling somewhat unprotected and vulnerable, unlike before when appointments were seemingly never ending. None of the participants referred to this part of their journey as a return to normal but rather the start of their *new normal*.

Journey's end has different meanings for everyone. It is a combination of all breast cancer experiences, interactions with existing and new people as well as the unique personal journey each woman attained. This period was a time when emotional support was again very significant, not only from close/intimate relationships but also from their medical team with whom they had established a unique bond. Not quite a close/intimate relationship albeit, certainly a special one.

New Normal.

"Faith is taking the first step even when you don't see the whole staircase."

Martin Luther King Jr.

Mary. Mary talked about *it* (cancer) always being there.

It touches every part of your life. At least I don't think I do anything without thinking about that in the background. It really does become a part of your life but hopefully you can find a place where it's not consuming your life. Like, it's something I think about on a daily basis (p. 24, lines 7-13).

After going through the experience of breast cancer Mary's uneasiness regarding a recurrence is never far off. Whenever she finds something physically different or new, she worries.

If you get little ache or pain somewhere, oh, I bet it's bone cancer. You know, if you have... you know, whatever, oh it must be another type of cancer (laughing). So, it is in your life but it's not always in the forefront, I guess I could say. I mean, it's always there, it's part of your body now. It's like an arm that never goes away. If it cannot always be in the forefront for me, that's what works. I guess I was little bit worried that if I started doing activities it would consume me again. Do you know what I mean (laughing)? It would be a constant reminder. I mean, not that you always don't have constant reminders anyway; every time you get into the shower you see the scar; every once in a while, you come across one of the little markers (radiation tattoo) (p.24, line 16-19; p.32, lines 108).

Mary, she expressed reluctance about (ever) ending follow-up surveillance appointments.

Mary discussed her thoughts about seeing her physicians regularly.

You know, still today, I'm following up with all the doctors. The last time I saw Dr. G. he said you're good for year. I said to him are you sure; because you kind of depend on them. These people are like my security blanket. Like some people say, 'You still go for checkups?' And I say, 'Oh yes, oh yes.' The last time I saw Dr. W. was actually Wednesday, but the time before that I said to Dr. W, because every time I come I start having anxiety. Is he going to tell me I don't have to come any more (worried look)? I said to him, 'So how much longer do you think I might be coming?' And he was like, 'Oh a while yet.' And I said to him, 'Thank you (laughing)...thank you so much.' (p. 14, lines 5-14).

Katie. Katie has also experienced changes after her breast cancer journey although her changes are not of a physiological nature. One day, two months after finishing radiation treatment, her refrigerator "died." "I was totally incapable of making decisions or routine things after treatment. And still to this day, I will tell you, I have no capacity to handle stress anymore, none." She talks about having no *calm reserve*; her new normal is skewed.

You just...you have a different perspective. You treat doctor's appointments a lot differently; heightened anxiety prior to the visit. I just find...I'm still working through trying to learn how to cope with stress again. I feel like all of my instincts and... what's the word... all of your self-defense mechanisms that you built up your whole life to help you handle stress, they were put to the test and then some, through cancer and I feel like I've got nothing left. You know, I've always been independent (p. 40, lines 18-23; p. 41, lines 1, 6).

Relationship Changes.

Diana. Diana and her then boyfriend had an on again/off again relationship for many years. Always there for him, Diana was distressed when he was emotionally unavailable for her.

And also, at that time my ex, well current at that time, boyfriend... he just couldn't handle it. His father was battling cancer at the time. He's not ...I'm an emotionally, mentally strong person. And we basically said after Memorial Day weekend after I had my mamo, that we need to take a break but then we just... He was already dating two weeks later! Actually, the day I went to ____ (second opinion) I was driving and I saw him outside of ____ restaurant, with another woman! Two weeks after we broke up. So, I was heartbroken. I thought to myself I'm going to be mutilated...so I'm like, here's my almost 17 years, if you put them all together relationship coming to an end, at my toughest time. I was always the tough one for him but when I needed him, he couldn't handle it. He was bailing, running off. And I'm thinking to myself, I'm going to be mutilated. No one is ever going to want me again. It was just a lot of mentally, emotionally and physically like, a rough few weeks from that June until about a week before my surgery. That month was the probably the toughest month of my life, besides my mom (dying) (p. 17, lines 15-23; p. 18, lines 1-10).

Olivia. Olivia expressed the manner in which her husband was there for her but also how he was not there for her and the hurt associated with the absence of his emotional support. Olivia's husband was unable to render the support she really needed. Although she felt hurt at the time she does not, cannot, be angry with him for something he was unable to do.

I can't be angry with him for something he's incapable of. He is incapable of the emotional support. Maybe it would've been a little nicer if he focused on a few things other than the finances because that made me feel, in addition to being sick, I was a financial burden. However, I can't really be upset with him for not providing emotional support because I don't think he's capable of it (p. 56, lines 5-11).

After her experience with breast cancer, Olivia reveals an altered perspective of her husband, one she now views through her post breast-cancer-experience lens.

I look at him in more... I believe that he's more self-centered than I ever saw in him. I believe that his unwillingness to adapt is a psychological flaw with him. And I'm not picking on him these are just things that I have observed. If you plan for something, with my husband, if something happens you cannot deviate from your plan, ever, ever. So, for example, if you want to go on a picnic and it's pouring out, that's the way it is. That's just the way it. So, this was a big change for me. I couldn't do everything he wanted. So, this is what made me see him as a much more selfish person, because he couldn't bend with the change. He couldn't embrace the change. Face it, I came through this very well.

You'd think this is something to be joyful over... not so much (p. 37, lines 17-23; p. 38, lines 1-5)!

Feeling Gratitude.

“Life may not be the party we hoped for, but while we’re here we should dance.”

Anonymous.

All of the participants, at some point in the interview process, talked about feeling lucky, not about their experience with breast cancer, but fortunate for various other reasons.

Jane. Jane was so appreciative for the support, both *instructional* and *emotional*, provided by the YSC women of northern New Jersey. For weeks after surgery, Jane was unable to travel to the Northern New Jersey YSC meetings. Her gratitude seemed to morph into a sense of “paying it forward” and after finishing her cancer treatments, she teamed up with YSC and started a local chapter in her community. She, and the local YSC members, stay in touch with the women of Northern New Jersey YSC via their (private) Facebook page. Being able to connect through social media has expanded their YSC community, allowing for greater numbers of survivors to communicate through sharing experiences, advising and supporting each other.

Two of the participants faced similar experiences when they were exposed to “*other cancers*” or people diagnosed with types of cancer other than breast cancer, while receiving radiation treatment. People undergoing radiation treatments come and go on a daily basis for several weeks, sometimes months. It is not unusual for patients to develop friendships while waiting in the designated area for their scheduled appointments. They both wept as they talked about the pain and discomfort other people, with other cancers, were going through.

Mary. Mary feels lucky because of the wonderful support she had. Referring to her family and colleagues, she talks about the smooth transitions she felt moving from different

departments within the hospital and all the *instructional support* she received to make her feel this way.

Everything ran so smooth. If I had a question they answered it. They were so accommodating with my appointments and the sympathy, the nurses, Dr. G's nurse was wonderful. Dr. S's nurse was wonderful. Even the guy that had to do my markers, I think his name was John, he was just so nice. They do make you very, very comfortable. Girls in radiation were wonderful. They were bubbly and had a great sense of humor. You know they got you in as fast as possible. You know so, I think I am lucky (p. 29, lines 6-14).

Olivia. Although Mary and Olivia received treatment at the same facility, Olivia's perception of care from surgery to radiation, was not so positive. Olivia felt her initial medical care from the point of imaging, biopsy and diagnosis, to her surgical experience was very *emotionally and instructionally supportive*. However, after surgery she felt "odd."

As far as the medical people at the hospital I felt that I was very supported through diagnosis, through my surgery and then it was an odd feeling because once the surgery ended I felt like I was dismissed. And I did kind of have to...you know, I felt that, at radiation I was separate from the Breast Cancer Center (p. 28, lines 8-12).

What started out for Olivia as possibly feelings of abandonment by her surgical team, turned out to be a positive experience, once her radiation treatments were underway. She acquainted herself with a new team of technologists she referred to as "wonderful, just wonderful people." More importantly, she gained an insight into her breast cancer diagnosis as the "lesser" of (many) cancers, filling her with an unexpected thankfulness. Mary too had this awareness when exposed to "*other cancers*," individuals diagnosed with different types of cancer, other

than breast cancer, while waiting for radiation treatment. Olivia recounted her memories from radiation therapy.

I was mixed in with patients of many different types of cancers, which was extremely eye opening for me to see what people go through. I considered myself one of the luckiest, easiest (cancer) ones in there. In some respects that make me feel guilty. Because, you look around, I mean, head/neck cancer, unbelievable what people go through. I would be like, I just went to work, I'm popping in here for 15 minutes and then I'm going home. I'm lucky, I'm really lucky (p. 28, lines 13-20)!

Tears sprang again from her eyes as she talked about her appreciation of having the (lesser) diagnosis of breast cancer.

I think with breast cancer, sometimes it's viewed as different from other cancers, for better or for worse. I think that realizing that this is a disease that affects people in many different ways, is very eye opening to me and made me feel a lot better about my situation. So, cancer is the same yet different in all sorts of people. Yeah, I think yes, the pink initiative and all those things are wonderful. But I think sometimes there's a lot, you don't realize, that goes on with other cancers. Because I think with the breast cancer, and with the fact that...I was lucky, I mean, having a lumpectomy and radiation is probably the most minimal treatment you can have (p. 28, lines 20-23; p.29, lines 1-6, 16-19).

Diana shared her thoughts about feeling fortunate her surgery went as well as it did.

So, it was very successful. Everything went according to plan and they sent the rest of my breast tissue down to biopsy it. I wasn't officially cancer free until we got the pathology back. So, I met with her (surgeon) the following week and she said my lymph nodes came back clean (cancer free) and the rest of my nipple tissue was clean as well (p. 20, lines 7-11; p. 20, lines 15-17).

All of the participants, with a sense of wishing to help the breast cancer cause, talked about doing something, in their small way, for others with breast cancer.

Mary- Knitted caps for chemo patients after her treatment was over.

Jane- Started the local chapter of YSC; remains very involved planning activities; also active via YSC Facebook presence.

BrandyLynn- Promotes non-profit organizations that cater to survivors, as her way of helping others get the services they may need at no cost. She remains involved in various groups, crochet club, Cancer Support Community, her local Senior Center and more recently an annual Survivor's retreat.

Katie- Continues her various sporting fund-raising events for organizations that support breast cancer survivors.

Diana- Was interviewed for a hospital magazine article where she shared her breast cancer experience, from her young perspective, in hopes of spreading breast cancer awareness.

Olivia- Does an annual walk-a-thon to raise money for the Cancer Support Community.

“Once you choose hope anything is possible.”

Christopher Reeve

Chapter VI

DISCUSSION

A summary of the study findings will be presented in this chapter. Additionally, a comparison of the findings will be made in light of the existing body of knowledge regarding support that was offered through non-spousal close/intimate relationships *and others* as well as *when* and *by whom*, specific support was most significant. Analysis of the data revealed several themes.

The following themes examine participant support in chronological order in the breast cancer treatment trajectory.

The Journey Starts

Chaos and confusion.

All of the participants spoke about their experience of learning they had breast cancer. Vivid memories were easily retrieved of moment-by-moment accounts of the period immediately following their diagnosis. Similar to previous breast cancer research, all participants reported having feelings of shock and disbelief (Drageset et al., 2012; Kennedy & Rollins, 2016; Torres, Dixon, & Richman, 2016).

McTighe, Molassiotis, Morris, & Richardson (2011) also addressed the narrative by Frank (1995) of the common experience of chaos, shock and confusion by those diagnosed with breast cancer. As the disbelief subsided, and their condition accepted, most of the participants sought diagnosis information. The trajectory of breast cancer treatment is a dynamic period of interpersonal relationships (McTighe et al., 2011) as is the provision of support these relationships bring.

Although some researchers suggest that one of the particularly stressful periods for patients occurs after diagnosis (Alqaissi & Dickerson, 2010) and prior to surgery (Drageset et al., 2012), this study found the entire treatment period stressful for different reasons. In this study, very early post-diagnosis was a time of shock/realization. Some participants were reflective at that time while others reflected later. Soon after the initial shock came the need for instructional support; learning what their diagnosis really meant medically, the available treatment options they might be eligible candidates for and how this *new reality* would affect their lives.

Identified as a type of functional support by Helgeson (2003), instructional support includes provision of education or direction. Although it is often provided to breast cancer patients by various individuals such as friends, family and other well-meaning individuals, it is most appreciated from experts such as healthcare professionals, physicians, and nurses (Drageset, et al., 2012; Helgeson, 2003). The women in this study all sought information about their diagnosis. Some of the women searched the Internet for knowledge empowerment; one woman declined the temptation to search the Web, as she trusted her surgeon's expertise. Two participants sought second opinions. One participant came away from the second opinion confident and decided to seek services from surgeon number two. The other participant, after her second opinion, was overwrought with even more questions, which were addressed with full explanation by her first surgeon, whom she ultimately and happily stayed with.

Core people AND Survivor relationships.

These two subthemes were combined because all of the participants had what they termed as their "core people," or those significant individuals who were present at the start of their journey. For the most part they provided the emotional support the participants' required throughout their cancer treatment trajectory. The literature talks about the 'core people' women

with breast cancer select. Some women choose only family members while others, in an attempt to shield their family, will talk to others; friends or a neutral party such as their primary physician (Drageset et al., 2012).

Along with friends and family members recognized as core people in their lives, the participants recognized their healthcare providers as well. The literature reports both positive and negative accounts of support provision by health care practitioners towards their patients (Drageset, Lindstrom, Giske, & Underlid, 2015; Dumrongpanapakorn & Liamputtong, 2017; Kennedy & Rollins, 2016). In this study, one of the participants sought the care of a second surgeon following several instances of misinformation and confusion regarding her actual diagnosis from the first surgeon. She sought the opinion of another surgeon who conducted further testing for a definitive diagnosis. Being treated respectfully and with dignity (Dumrongpanapakorn & Liamputtong, 2017) by health care providers is reported to have positive outcomes. The ability to rely on and trust one's health care professionals is very important (Drageset et al., 2012; Torres et al., 2016).

What was noted as significant in this study was the nature of the communication between participant and health care provider. The provision of support, though delivered as informational, was also and perhaps more importantly, perceived by the participants as emotionally supportive as well. Diana, although happy with her first breast surgeon choice, acquiesced to the requests of family members and sought a second opinion. Afterwards, however, instead of feeling secure about her initial surgical choice, she came away from it second-guessing herself and her (initial) surgeon. Diana called the first surgeon to discuss and clarify her fears. After a lengthy conversation, Diana's worries and anxiety were calmed. Her surgeon took the time to explain

exactly what “their” plan was. Similar to findings of Kennedy & Rollins (2016) the physician made her feel important and validated her as a person.

Group support for breast cancer patients did not gain recognition until the early 1980s. In one of the sentinel research efforts from the late 1970s comparing various patients, such as those with breast cancer and those with nonthreatening findings (i.e. benign lumps), Meyerowitz laid the foundation for what would become known as group support therapy (Ganz, 2008). Group support, recognized as structural support, is associated with quantitative measures such as the number of social relationships one has, the frequency of interpersonal contacts, and network member relations (Helgeson, 2003) all of which enhance quality of life.

As the participants traveled forward in their journey, those participants who became involved in a formal group support setting with other survivors, developed meaningful relationships with support group members. The literature supports the significance of group interactions with other survivors as an important part of the journey and instrumental in reducing fear and anxiety (Drageset, Lindstrom, Giske, & Underlid, 2015; Kennedy & Rollins, 2016; Malicka, Kozłowska, Wozniowski, Rymaszewska, & Szczepanska-Gieracha, 2015; Pinheiro, De Silva, Mamede, & Fernandes, 2008; Torres et al., 2016).

However, unlike Drageset et al., (2015) findings of some individuals being unable to connect with group support members, the participants in this study, who sought breast cancer group support, reported only positive experiences.

The literature supports the importance of individuals being able to express themselves in a group setting without reserve, and in a respectful environment (Drageset et al., 2012, 2015).

Similarly, Diana conveyed her experience of group support.

And you can have the emotional and mental support of your family and friends because obviously they love you and care about you and everything but nobody can tell you how to deal with those thoughts in your head or... Some of the things you don't want to say out loud or what you're thinking because it sounds so horrible but when you speak to someone (that have gone through it) they have had those thoughts too (laughing) (page 28, lines 21-23; p. 29, lines 1-4).

The relationships between the participants of this study and the group support members underwent a metamorphosis of sorts. Initially strangers, the group members transitioned from providers of functional support to providers of structural support. Meaning, at the onset of their relationships, when instructional support was most significant for the participants, the interactions between group members and participants seemed to strengthen their relationships over time. After treatment, and no longer in need of the functional support initially sought, structural support then became significant enough to maintain interaction with the group(s) as a whole. Merely belonging to a support group has a positive psychological result (Malicka et al., 2015).

Four of the participants sought support via a group setting early in their diagnosis. Three of the younger participants, Jane, Diana and Katie, became involved with the YSC. Brandy Lynn was previously active in several groups prior to her diagnosis but also sought additional (breast cancer support) groups to join. Analysis of the data revealed how significant the received support was to each woman.

The literature does not specifically identify what type of (social) support is required or at which stage a particular type of support is needed during the breast cancer treatment trajectory. Helgeson (2003) reported this may be due to many researchers' belief that *emotional support* is

the most significant type of support, therefore it is the only one measured. The limited existing literature regarding any relationships of women with breast cancer, suggest unpartnered women have fewer intimate connections due to their smaller circle of friends (Holmberg et al., 2001). This study revealed the marital status of the participant had no relevance to existing or future relationships. For one married woman, her husband provided very little support, emotional or otherwise. Although she talked about one friend *being there* for her, she also talked about dealing with her journey for the most part by herself.

Also identified was the need for functional support initially but then, not actively seeking it and seemingly unbeknownst to the participants, structural support needs emerged. All of the participants remain active in their group(s) today. For one participant it has been three-plus years since end of treatment and still she enthusiastically participates in support group activities several times a week. This demonstrates the significance continued (structural) support has and the positive effects each woman (surely) realizes it has had on their quality of life.

Mary and Olivia. Two of the participants, Mary and Olivia, seemed to have the most difficulty adapting. They were the only participants that did not participate in any type of group support despite being made aware of program(s) availability early in their journey. During the interview process, both women expressed multiple times their regret at not joining a support group. In fact, just speaking about group support activities produced a tearful reaction from both women. The stories they told were about limited human contact during their treatment period. Their world was a small circle of, for Mary, her family and limited involvement with colleagues; for Olivia, it was also her limited colleague involvement and her friend, Rose.

Although Olivia spoke about being “good friends” with her work colleagues, she admitted they never experienced any activities outside the office setting. Both women talked

about feeling supported emotionally and instrumentally by colleagues through various behaviors such as allowing for a flexible work schedule (to accommodate tests/treatments), decreased work load and supportive text messages during their recovery period.

Olivia's decision to decline support from a formal group setting may have had to do with her self-image as "the caregiver." She explained her rationale.

I never went to any support groups. I didn't need a support group. I think it was a mistake on my part. I think I probably should've gone to a support group. I just think that it might have helped me. I think I made a lot of this journey solo. I think in retrospect, I probably should've had more people coming with me and doing things (wiping her tears). I wanted to have the *I can do this; I can do this on my own* attitude. And while that was admirable...I think that shut out other people from the experience; it shut out the fact that I could've shared that experience with other people (p. 47, lines 4-6,11-19).

Retrospectively, if given the choice again she "would probably take advantage of support services."

One study uncovered the rationale of one woman who opted for non-participation in any formal support group setting for fear it would prevent her from moving forward but instead getting stuck in the past (Drageset et al., 2015). In a similar fashion, Mary too declined available support services.

Even now I get a monthly newsletter about the activities that are going on here. And I don't really even know why but I never took advantage of that. The only reason I could think of is because I was afraid it would just keep bringing it to the forefront where and I don't want it to take over me. So, I read over the calendar and I think oh yeah that looks interesting or that looks good. And I kind of feel like I should have because that would have probably helped but I was sort of afraid that if I went there everybody would have a pity party and everybody would be... different stages. You know... like, I'm past that, the treatment stages and I'm not sure I want to go visit that again (p.31, lines 13-23).

Mid-Journey Passage

Finding the strength within.

In a qualitative study by Kennedy & Rollins (2016), which explored the perspectives of sixteen African-American women diagnosed with breast cancer, the theme *finding the strength within* is supported. It was important for the participants in that study to actively participate in the management and challenges of their diagnosis. The participants talked about their pride in fighting in combat and winning the war on breast cancer. They were courageous and did what they needed to do. Also relying on self-agency, one day Diana had an epiphany to summon up the courage to face her fears and demanded herself to “shake-it-off”. Olivia too felt that her “life’s role” as a caregiver meant she should care for herself, by herself. In a study exploring meanings of social support by Jordanian women with breast cancer, Alqaissi and Dickerson (2010) also found the need to stay strong not only for self but for others as well, an important coping mechanism for getting through treatment of breast cancer.

Being there.

The theme of *being there* was reported in the literature as well (Alqaissi & Dickerson, 2010; Drageset et al., 2015; Kennedy & Rollins, 2016). Diana spoke about a close childhood friend of hers, her “rock.”

She was always positive. And she rode that emotional, mental roller coaster. Nights, she came and slept in my room with me, let me cry, told me it was going to be okay... many nights of that. Yeah, we slept like girls having a sleepover. She stayed in my room with me. You know, kind of just, just *being there*. She didn’t have to say much (p. 56, lines 6-10).

Katie spoke about her special relationship with Kathy.

My one friend, Kathy, she would call me and say I'm on my way, we're going out for dinner. I would push food around my plate. She would *just be there*. She never expects me to talk about it, she never tried to say it's going to be fine or... she just... she was *there* (p. 38, lines 3-8).

Olivia who, although did speak about her "close" relationship with Rose, was the only participant who did not talk about any close friend activities or speak of anyone just *being there* for her besides her dog. Perhaps the qualitative study by Drageset et al., (2012) who examined the support needed from time of diagnosis until the period before surgery, by women with breast cancer, is reflective of Olivia's situation. Their findings showed some women require very little social support and preferred to handle it in their own way (Drageset et al., 2012).

Friends - some old, some new.

Reflected in the literature, the experience of breast cancer sometimes forces a relationship transition that would not otherwise occur. Although the development of new friendships was considered an especially positive experience, some women experience a distancing by close family and friends (Drageset et al., 2015). Similarly, participants in this study also experienced relationship changes. New relationships were forged while old friendships dissolved. All the new friendships reported were the direct result of relationships started through breast cancer support groups.

Journeys End/Coming Home

New normal.

Similar to findings represented by Allen et al., (2009) the theme of the *new normal* when treatment finishes and patient transitions to survivor were also found in the current study.

Although finishing treatment was a time for celebration, it also meant a change in patient status

when follow-up appointments became more and more spaced-out over time. The relationship of patient/physician transitions from close, frequent monitoring by various clinicians, who provide instructional and emotional support, to a post-treatment sense of reluctant *letting-go* and detachment. Similar to findings by Ganz (2008), every time Mary feels a new ache or pain she fears it is a recurrence or another cancer. She expressed her emotional support needs and why she “never wants to stop seeing her physicians”.

I do get nervous every time I have to come and see a doctor because I'm afraid they will tell me I don't have to come and see them anymore or you know, my appointments are spreading out to be further and further and that's okay but I don't want to *not* come. So, I do get a little bit of anxiousness when I'm due to come, not that I think they will find something. You would think that would be the anxiety part of it, but it's not really even that. It's I don't want to stop seeing Dr. W you know? Don't want to stop seeing Dr. G (p. 29, lines 19-23; p. 30, lines 1-3).

This supports the current literature related to end of treatment supportive needs of breast cancer patients. In a qualitative study Allen, Savadatti, & Levy (2009) reported that women experienced a sense of loss of medical monitoring and support at the end of treatment (Allen et al., 2009). Drageset et al., also revealed participant's feelings of uncertainty at end of treatment, but also fear of having to assume responsibility of self-monitoring their own recovery with an awareness of possible cancer recurrence.

In an earlier study, Meyerowitz found the diagnosis of breast cancer extremely upsetting to all aspects of a patient's life (Meyerowitz, 1980). Similarly, Mary also spoke about her cancer experience. “I mean, it's always there, it's part of your body now. It's like an arm that never goes away” (p.32, lines 3-5).

Relationship changes.

Positive support by a significant other is well documented in the literature as playing important positive roles of support in the lives of women diagnosed with breast cancer (Dumrongpanapakorn & Liamputtong, 2017; Ganz, 2008). However, very few studies examine the negative role of relationship support or lack thereof. One study found Hispanic women with breast cancer reported higher instances of negative spousal support than non-Hispanic women with breast cancer (Jutagir et al., 2016).

For Olivia, her breast cancer experience illuminated just how rigid and “inflexible” her husband of twenty-five years was during her treatment. His refusal to alter vacation dates while she was receiving radiation treatments was a disappointing revelation for Olivia. Perhaps this is a reflection of the poor relationship status prior to her breast cancer diagnosis, which was not disclosed.

Feeling gratitude.

One American qualitative study by Kennedy & Rollins (2016) also supports this theme. They suggest feelings of gratitude, is the last stage of the cancer journey. They also conveyed gratefulness towards God and for their experiences with their health care team. Feelings of gratitude were expressed by all of the participants in this study. In their own way, they are all doing or have done something to pass their sense of gratitude on.

Additional Reflections

Although Olivia and Mary were the only participants to have daughters, neither reported any significant support offered by them. This may be due to the age of Olivia’s daughter, who was just 14 at the time of her diagnosis and possibly Olivia’s attempt at shielding her from any

information that could potentially have been frightening. Mary's daughter, an adult, married with a daughter of her own and living locally was not actively supporting Mary during this time. Perhaps similarly, this might be due to Mary's minimization of her breast cancer diagnosis when she initially told her children. She explained her rationale.

And it's funny because the roles kind of reverse; you're kind of trying to make them feel better. You know you're the patient you're trying to make everybody else... don't worry, I'll be fine, I'll be good, I'll be alright (p. 30, lines 20-22; p. 31, line 1).

There was no report of any type of religious faith or spirituality. Although BrandyLynn reported support from church members, what was significant to her was the instrumental support they provided. None of the participants in this study talked about a belief system or feeling strength or comfort by the act of praying. This could be a limitation of the study due to the homogeneity of the participants. There are a few studies in the literature that found prayer as a meaningful coping method (Torres et al., 2016) and feeling good about having others pray for them (Drageset et al., 2012). In another study, participants found a "feeling of support through God" (Kennedy & Rollins, 2016, p. 97). Again this may be due to the cultural influence of the participants. One was a Norwegian study (Drageset et al., 2012) and the other two studies examined the breast cancer experiences of African American women (Kennedy & Rollins, 2016; Torres et al., 2016).

Although two of the participants were married, neither identified their spouses as their primary source of emotional support. One participant, after twenty-five years of marriage, used terms such as rigid, controlling and living separate lives when referencing her husband and their relationship. According to the participant her husband's reaction to her diagnosis of breast cancer seemed an inconvenience to his lifestyle and his behavior suggested a relationship compromise

had already existed long before the diagnosis. The other (younger) married participant spoke little about her husband. They had been married only three years and were actively involved in her physical preparation for egg donor ship in hopes of starting a family and had just moved from another state three days prior to her diagnosis. Their already complex lives were extremely busy, however, they were traveling life's path very much together. When she was diagnosed, although it was not him providing instrumental support, it was his mother who became her core person. In retrospect, the participant feels he was there for her in his own way; the only manner in which he was capable.

Chapter VII

SUMMARY, IMPLICATIONS FOR PRACTICE AND RESEARCH

Summary

The purpose of this study was to examine the experiences of non-spousal close/intimate relationships of women with breast cancer through deep, rich, descriptions of each participant. Phenomenology was the method selected to guide the exploration. Six women previously diagnosed with breast cancer, participated in the study. Two women were married, two women were divorced and remained single, and two women were single. The ages of the participants ranged from thirty two to sixty eight. Two of the participants were retired, one worked part-time and three were employed full time.

After reflective analysis three main themes were identified: *The journey starts, mid-journey passage* and *journeys end/coming home*. Nine sub-themes were recognized: *chaos and confusion, core people, survivor relationships, finding the strength within, being there, friends – some old, some new, new normal, relationship changes, and feeling gratitude*. What was revealed was the type of support offered by non-spousal close/intimate relationships of women with breast cancer and others, as well as when specific support was most significant along their cancer treatment journey.

Although all the themes were discussed in the current literature, this study illuminates certain aspects of the breast cancer journey that adds to the literature. For example, while other studies found stress to be exacerbated at various phases of the journey, this study showed that the participants' experience of stress was present for their entire cancer treatment trajectory. The participants spoke of their dynamic support needs throughout their journey, but for most, the

need for emotional support was constant. This study also identified what type of support was required and at which point it was most significant.

This research also recognized a transition of support, provided over time, when a formal group setting is the source of support. That is, the support requirements of the participants were initially of a functional nature. As the progression of time through their cancer treatment trajectory occurred, less and less significance was placed on functional support. Instead, structural support became more important towards the end of treatment, extending well into survivorship.

Strengths and Limitations

The utilization of a phenomenological approach for this study was a strength as it is perfectly suited to explore how one experiences a certain phenomenon, living in their own world (van Manen, 2002), though multiple in-depth interviews in which participants expressed themselves easily and freely. This process facilitated the participant's rich descriptions of their experiences, allowing for a greater understanding of the experience of non-spousal close/intimate relationships of women with breast cancer. The interviews took place over a period of nine months giving the participants plenty of time for reflection on their experience in between interviews.

Some limitations should be noted while interpreting these data. The homogeneity of the participants and the sample size may have limited the provision of a richer contribution to the findings. One of the criteria of the study was that all participants were female as women make up the majority of the breast cancer population. The participants were all American born, white, college educated women. Interestingly, five of the participants had graduate degrees. Perhaps their belief in higher education was influential in their decision to volunteer for the study,

anticipating their efforts would contribute to the knowledge and well-being of future breast cancer patients. Participants were recruited from two neighboring central counties of a state located on the East Coast, perhaps further limiting the findings. Also, a possible limitation in this study is that all the women were American. If the participants had been a more diverse sample of cultural and educational backgrounds, findings may have added additional perspectives.

Implications for Practice and Research

The deep, rich descriptions of the experiences of close/intimate relationships of women with breast cancer found in this study, have valuable implications for practice. Most often, after a breast cancer diagnosis, nurses are the first level of health care providers for the patient. They must address the complexity of each patient and their individual and unique (supportive) needs. This includes early assessment of patients' needs related to family and friend relationships (or lack thereof) with anticipated support needs throughout the cancer care continuum.

The findings of this study are clear indicators of the significance of support offered throughout the cancer treatment trajectory, especially from a group setting, not only at the onset of diagnosis but at other intervals during treatment as well. For example, in the particularly stressful period immediately following diagnosis, the need for instructional support is greatest. During the pre-surgical period, real-life support from other survivors, who made the same surgical decisions, appears to be extremely important. There is a need for further research exploring how the supportive needs of women with breast cancer change over time.

Oncology navigators are a constant presence for patients throughout their breast cancer journey. As the role of oncology breast nurse navigator continues to transition the results of this study suggest navigator guidelines should include this critical evaluation as part of their ongoing patient assessment.

The participants of this study shared both positive and negative experiences about interactions with their health care providers. They expressed how compassionate health care includes much more than instructional or emotional support; that validation and self-worth goes hand-in-hand with the provision of care in any respectful provider/patient relationship. This reinforces the significance of holistic care in any setting, but especially one that threatens not only physical loss or deformation but perhaps more significantly, the psychological impact on a woman's self-image, femininity and presence in the world.

Only one participant talked about their surgical team offering the opportunity to speak with prior (breast cancer) patients about their experiences. Although the participant, Diana, later became involved in a group support setting, this opportunity was incredibly meaningful to her. If health care practitioners provided patients with the ability to speak to other *survivors* early in their journey, they could decrease the *chaos and confusion* associated with the early diagnosis period. It is in the best psychological and physiological interest of patients for all nurses who actively render care for oncology patients (infusion, radiation and oncology surgical nurses) but especially breast navigators to be knowledgeable about the supportive needs of the breast cancer patient and to put social support processes in place. Provision of other various support options (transportation, nutritional needs due to treatment, financial navigation and insurance queries) should be offered along the cancer care trajectory as well.

The findings of this study strongly suggest the importance of non-spousal support for the provision of patients' supportive needs at time of diagnosis as well as throughout the treatment period. Guidelines for navigators need to be created. Practical changes to oncological care should be navigator driven, including assessment of the patients' dynamic support requirements at

various intervals during the cancer trajectory. Additional exploration regarding non-spousal support measures may reflect the findings of this study adding further to the knowledge base.

The findings of this study suggest that spouses may not be the primary providers of emotional support for women with breast cancer. Further research might focus on promoting the development of educational empowerment for spouses and support measures/programs to facilitate their understanding of the emotional needs of women with breast cancer.

The inclusion of male participants with breast cancer would have been difficult given they comprise only one percent of the population. However, future studies including male participants and their supportive needs could potentially add to the literature.

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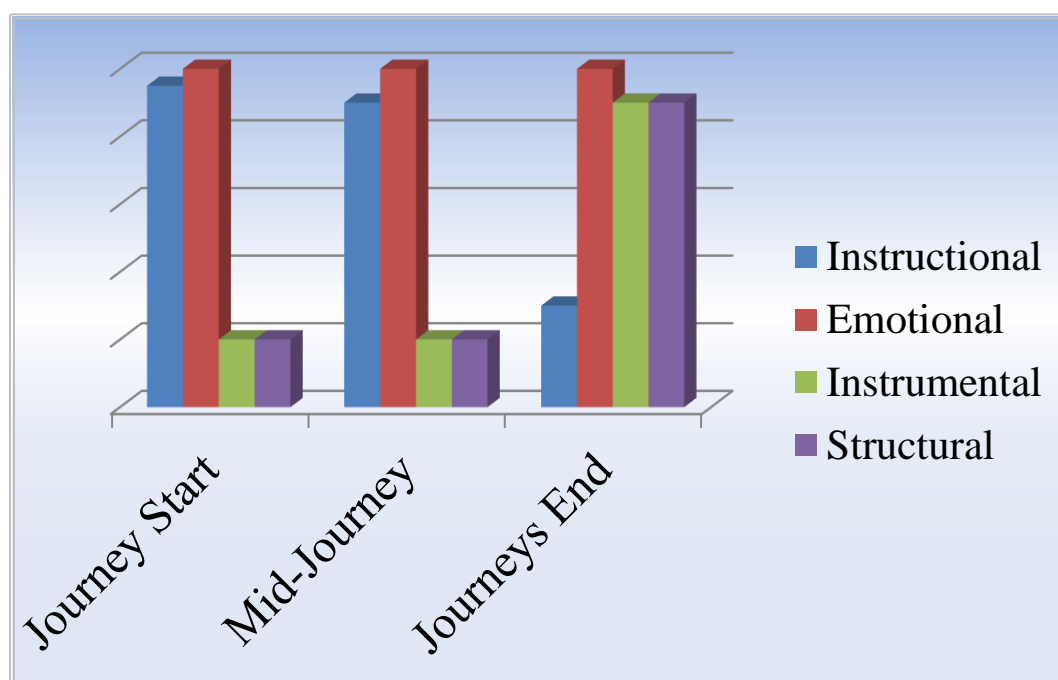
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Appendix A

Support Needed During the Breast Cancer Journey



Appendix B



Invitation to Participate in Women with Breast Cancer Research

Are you a woman who has been diagnosed with and treated for breast cancer within the last three years?

Would you be willing to participate in a research study describing what this experience has been like for you?

Erin Dooley, MSN, RN, CBEC, CN-BN, a doctoral student at Seton Hall University in South Orange, New Jersey is seeking female participants to enroll in a study entitled:

“What is the Experience of Non-Spousal Close and Intimate relationships for Women with Breast Cancer”

The purpose of this study is to learn about non-spousal relationships of women going through treatment(s) of breast cancer from their point of view.

- There will be three, audio-taped interviews lasting 60-90 minutes, within a 3-6 week flexible timeframe.
- All information you share during the interviews will be kept confidential.
- Your identity will be kept confidential. You will be referred to by an alias during interviews.
- To maintain strict confidentiality the researcher will transcribe all audiotapes and store on a memory drive in a locked location known only to the researcher.
- Participation in the study is strictly voluntary and you may withdraw at any time.

In order to participate in this study you must:

- Be a woman
- Be over the age of 21
- Speak fluent English
- Have been diagnosed and treated for stage 0, I, II or III breast cancer
- Your diagnosis must not be a breast cancer recurrence

To learn more about the study please contact the researcher at:

Erin Dooley, MSN, RN, CBEC, CN-BN
Seton Hall University
973-761-9583
Erin.Dooley@shu.edu

Thank you for your consideration in participating in this study. I appreciate and value your experience and the knowledge you may be able to contribute.

College of Nursing
400 South Orange Ave • South Orange, NJ 07079 • www.shu.edu

300 Second Avenue
Long Branch, NJ 07740
732.222.5200

A HOME FOR THE MIND, THE HEART AND THE SPIRIT

Appendix C

Monmouth Medical Center | **RWJBarnabas HEALTH**

Bill Arnold
President and Chief Executive Officer

Seton Hall University
Institutional Review Board

JAN 31 2018

Approval Date

SETON HALL UNIVERSITY

1 8 5 6

Expiration Date

JAN 07 2019

Consent for Participation in Research

Title of Study: The Experience of Non-Spousal Close and Intimate Relationships for Women with Breast Cancer
Investigator: Erin Dooley, MSN, RN, CBEC, CN-BN

- Researcher's Affiliation:** The researcher is a doctoral student in the College of Nursing at Seton Hall University.
- Purpose of Research:** The purpose of this research study is understand the experience of non-spousal, close and intimate relationships of women and their meaning to women with breast cancer.
Duration: The expected duration of the subjects' participation is 3 interviews with each interview lasting approximately 60-90 minutes
- Procedures:** After signing an informed consent, you will be asked open-ended questions about your experiences and your perspectives regarding non-spousal support you may have received going through surgery and treatment of breast cancer. The interviews will be audio taped. If a participants name is used it will not be included in the typed transcript of the interview.
- Typical Interview Questions:** Typical questions that you will be asked will be:

Interview I

 - Tell me about yourself
 - Tell me about your experience with breast cancer

Interview II

 - Please share your non-spousal close/intimate relationship experiences as you went through breast cancer treatment.

Interview III

 - Did I get it right? Does the information transcribed reflect an accurate account of your story?
- Voluntary Nature of Participation:** Participation in the study The Experience of Non-Spousal Close and Intimate Relationships for Women with Breast Cancer is completely voluntary. You may choose to withdraw from the interview process and the study at any time and not be penalized in any way whatsoever. You do not have to give a reason for stopping. Participation or non-participation will have no effect on your medical care.
- Anonymity:** Data will be collected without any identifying information. Except for the signature on the consent form, your name will not appear at any point in the research study. The consent form will be kept in a secure locked site and will not be able to be linked to you personally.
- Confidentiality:** No names, addresses or other identifying information will be attached to the information that you provide. All recorded data will be stored only on a USB memory key or CD and kept in a secure and locked site. The recorded data will be kept for a period of three years after the completion of the study and then deleted.
- Confidentiality of Records:** A typed transcript of the data will be kept for a period of at least three years after the completion of the study. The only people to read the typed transcripts will be the researcher and her university advisor. The typed transcripts will be kept by the researcher in a separate locked and secure site.




Page 1, Participant Initials _____

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400 South Orange Ave • South Orange, NJ 07079 • www.shu.edu

300 Second Avenue
Long Branch, NJ 07740
732.222.5200

A HOME FOR THE MIND, THE HEART AND THE SPIRIT

Appendix C (continued)

 	 SETON HALL UNIVERSITY	Seton Hall University Institutional Review Board JAN 31 2018 Approval Date Expiration Date JAN 07 2019
------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------

9. **Risks:** There is no anticipated risk for you in participating in the study. The questions that you will be asked are about things you may have experienced while being treated for breast cancer. If you experience feelings of distress at any time related to the research study, you can tell the researcher or call the researcher and she will refer you to either your agency's employee counseling center, provide information regarding counseling services at the Cancer Support Community, or if you prefer, to an outside counseling service at your own cost.

10. **Benefits:** You may not experience any direct benefit by participating in the study, however; benefits to participating in the research project will help the medical profession understand experiences perceived and expressed by women with cancer. This knowledge will help with program development for future patients with breast cancer.

11. **Financial Remuneration:** There will be no financial remuneration for participating in the study.

12. **Compensation:** There is no other form of compensation for participating in the study.

13. **Alternative Procedures:** You may decide not to participate in the study.

14. **Contact information:** Participants with questions may contact the primary researcher, Erin Dooley, MSN, RN, CBEC, CN-BN at the PhD Nursing Program at the College of Nursing, Seton Hall University, 973-761-9266, or by cell phone at 732-492-4492, or by email at erindooley39@gmail.com. The researcher's faculty advisor Judith Lothian at Seton Hall University, College of Nursing and can be reached at 973-761-9273, or by email at judith.lothian@shu.edu.

IRB: Address Phone # The Institutional Review Board at Monmouth Medical Center can also be contacted for answers to any pertinent questions about the research and the study participant's rights and can be contacted by calling 732-923-6775.

15. **Audio-Tapes:** The focus group session will be tape recorded and listened to only by the primary researcher, her faculty advisor, and the transcriber. The audio tapes will be transcribed either by the researcher or a professional transcriber. The audio tape will not be labeled with your name, but will be identified by a code number. The tape recorded interviews will be stored in a secure, locked site for a period of three years after the completion of the study and then deleted.

16. **Copy of Consent:** The study participant will be given a copy of this signed and dated Consent Form.

I agree to participate in 3 interviews for the study The Experience of Non-Spousal Close and Intimate Relationships for Women with Breast Cancer. I understand that my interview will be audio taped. I also understand that I will not receive financial remuneration for participating in the study.

Study Participant (Printed) _____ Date _____

Study Participant (Signature) _____ Date _____

Investigator (Printed) _____ Date _____

Investigator (Signature) _____ Date _____

MONMOUTH MEDICAL CENTER
INSTITUTIONAL REVIEW BOARD

APPROVAL DATE: 1/8/18

EXPIRATION DATE: 1/7/19

THIS CONSENT FORM CANNOT BE USED
AFTER THE ABOVE EXPIRATION DATE

Page 2, Participants Initials _____

400 South Orange Avenue • South Orange, NJ 07079 • www.shu.edu

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732.222.5200

A HOME FOR THE MIND, THE HEART AND THE SPIRIT

Appendix D



January 31, 2018

Dear Ms. Dooley,

The Seton Hall University Institutional Review Board has reviewed and approved as submitted under expedited review your research proposal entitled "The Experience of Non-Spousal Close/Intimate Relationships for Women with Breast Cancer". The IRB reserves the right to recall the proposal at any time for full review.

Enclosed for your records are the signed Request for Approval form and the stamped original Consent Form. Make copies only of this stamped Consent Form.

The Institutional Review Board approval of your research is valid for a one-year period from the date of this letter. During this time, any changes to the research protocol must be reviewed and approved by the IRB prior to their implementation.

According to federal regulations, continuing review of already approved research is mandated to take place at least 12 months after this initial approval. You will receive communication from the IRB Office for this several months before the anniversary date of your initial approval.

Thank you for your cooperation.

In harmony with federal regulations, none of the investigators or research staff involved in the study took part in the final decision.

Sincerely,

Mary F. Ruzicka, Ph.D.
Professor
Director, Institutional Review Board

cc: Dr. Judith Lothian

Office of Institutional Review Board
Presidents Hall • 400 South Orange Avenue • South Orange, NJ 07079 • Tel: 973.313.6314 • Fax: 973.275.2361 • www.shu.edu

A HOME FOR THE MIND, THE HEART AND THE SPIRIT

Appendix E



Bill Arnold
President and Chief Executive Officer

Tuesday, January 09, 2018

Erin Dooley, MSN, RN
Monmouth Medical Center
300 Second Avenue
Long Branch, NJ. 07740

RE: IRB Study # 18-001

Dear Ms. Dooley:

Meeting Date: 1/8/2018

At: Monmouth Medical Center

Protocol Title:

The Experience Of Non-Spousal Close/Intimate Relationship For Women With Breast Cancer.(IRB Registration #00003104)

To advise you that the above referenced Study has been presented to the Institutional Review Board identified above, and the following action taken subject to the conditions and explanation provided below.

This protocol is scheduled for next review by January 7, 2019. Progress Report forms requesting specific information on the progress of this research will be forwarded to you for reporting to the IRB approximately one month prior to that date. Continuation of the research beyond that date is contingent on your receipt of written approval from the IRB.

The IRB reminds you of the following requirements: 1) Changes in research activity must be promptly reported to the IRB. 2) Prior IRB approval is necessary for changes in research activity except where necessary to eliminate apparent immediate hazards to human subjects. 3) Unanticipated problems involving risks to subjects or others must be promptly reported to the IRB. 4) Termination of the research must be promptly reported to the IRB. 5) Assent must be obtained from minor subjects.

Internal #: New Appl

Expiration Date: 1/7/2019

On Agenda For: Initial Submission

Reason 1:

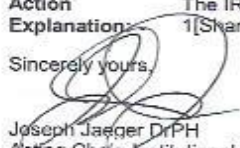
Description Date Received- 12/27/2017

IRB ACTION: **Approved**

Action The IRB reviewed and approved of the Protocol and Informed Consent.(7 approved,

Explanation: 1[Sharon] abstained, 0 against)

Sincerely yours,


Joseph Jaeger DrPH
Acting Chair, Institutional Review Board

An academic affiliate of Drexel University College of Medicine

300 Second Avenue
Long Branch, NJ 07740

732.222.5200

www.barnabashhealth.org/monmouth

Appendix F

Participant Interview Questions

Interview I

Tell me about yourself

Interview II

Can you share your non-spousal close/intimate experiences with relationships as you went through breast cancer treatment?

Interview III

Did I get it right? Does the information transcribed reflect an accurate account of your story?

Appendix G



November 15, 2017

Erin Dooley, MSN, RN, CBEC, CN-BN
Secon Hall University
College of Nursing
400 South Orange Avenue
South Orange, NJ 07079

Dear Ms. Dooley:

The Cancer Support Community would be happy to post your Invitation to Participate in Women with Cancer Research and to distribute flyers to our members to assist your facilitation of participants.

The mission of the Cancer Support Community is to promote knowledge and support throughout the cancer trajectory. Your PhD efforts serve to increase understanding of the experience of women with breast cancer.

Sincerely,

Joan Hogan, MSW, LCSW, OSW-C
Program Director
Cancer Support Community
732-923-6090 - fax 732-923-6094

Appendix H



SURRY H. CHANG, MD, FACP
Breast Surgeon

Erin Dooley, MSN, RN, CNEC, CNRN
Seton Hall University
College of Nursing
400 South Orange Avenue
South Orange, NJ 07079

November 16, 2017

Dear Erin Dooley,

The RWJ Barnabas Health Medical Group, Dr. Surry Chang will be happy to display invitation flyers to potential participants for your Women with Breast Cancer research study.

If there is anything else I can do to assist, please do not hesitate to contact me. Best of luck with your research project.

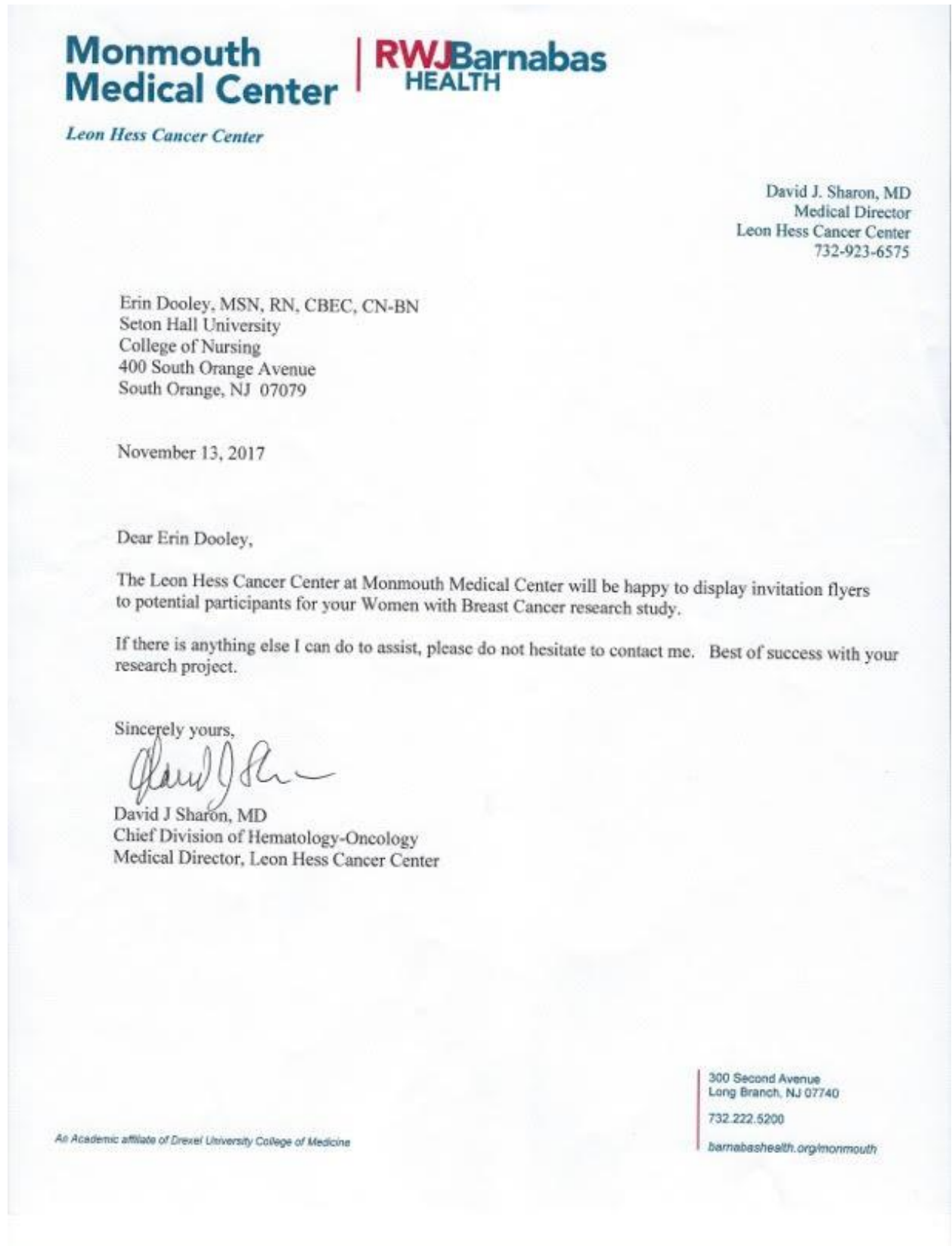
Sincerely yours,

A handwritten signature in black ink, appearing to read "Surry Chang".

Surry Chang, MD

Jacqueline M. Wilentz, Breast Cancer at Memorial Sloan-Kettering Cancer Center
400 Second Avenue • Long Branch, New Jersey 07740 • 732.923.6467 • 732.923.6467 fax • www.barnabashhealthmedicalgroup.org
Community Medical Center
62 Highway 47 West, Riverwood 1, First Floor • Long Branch, NJ 07755 • 732.557.2153 • 732.557.2199 fax • www.barnabashhealthmedicalgroup.org

Appendix I



Appendix J



January 17, 2018

To Whom It May Concern:

This letter is to inform you that I am in complete knowledge of and approve of Erin Dooley conducting the research, "The Experience of Non-Spousal Close/Intimate Relationships for Women with Breast Cancer" with our oncological patient population at Monmouth Medical Center.

Sincerely,

A handwritten signature in black ink, which appears to read "Diann Johnston".

Diann Johnston, MSN, RN, NEA-BC
Chief Nursing Officer & VP of Patient Care Services
Monmouth Medical Center