

THE LIVED EXPERIENCES OF THE INTIMATE PARTNER OF A PERSON
WHO UNDERWENT A MASTECTOMY

A DISSERTATION

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BY

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DEDICATION

Thanks to my family Steven I, Steven II and Jaelyn. You all have encouraged me to fight on and know that the victory is mine! I love you all and thanks for supporting me through it all.

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It is with honor that I acknowledge my committee chair, Dr. Peggy Landrum. She has been both an inspiration and a role model that has not given up on me. She encouraged me when I was at my lowest point and helped me to realize that I could accomplish my goals. It has been a struggle yet with the direction of the committee including Dr. Cesario, and Dr. Malecha I have been successfully able to accomplish the obstacles and continue. Thank you for your support for without none of this would be possible.

ABSTRACT

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The purpose of this study was to answer the research question: What are the lived experiences of the intimate partner who provided support post-operatively to a person (male or female) who underwent a mastectomy during the post-operative phase within the last one to five years? A qualitative research study was used. The study was conducted using a purposive sample to obtain rich descriptions of the lived experiences of intimate partners of a person who underwent a mastectomy.

The study involved face-to-face and online platform audio recorded interviews, which were analyzed using Colazzi's (1978) seven step approach to phenomenological data analysis. A descriptive interpretative phenomenological approach was used to gain understanding of the lived experiences of partners of someone who provided support post-operatively to a person who underwent a mastectomy.

Findings revealed four main themes: initial responses, aesthetics, communication through it all, and resilience. Seven subthemes were also revealed: shock and pride, fearing the unexpected, changes in physical appearance, burdens of surgery, reassurance and supportiveness, and lack of support for intimate partners. The findings from the study may be used to inform nursing practice, nursing education, and future research studies of intimate partners that have provided support to a person that underwent a mastectomy during the post-operative phase.

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CHAPTER I

INTRODUCTION

Focus of Inquiry

Cancer is a leading cause of death worldwide, accounting for nearly 10 million deaths in 2020 (World Health Organization [WHO], 2020). Of all cancer, breast cancer is the second most common cancer, with more than 2.26 million new cases diagnosed each year; additionally, cancer causes the greatest number of deaths among women (WHO, 2020). In the United States, an estimated 281,550 new cases of breast cancer were diagnosed in 2021, with approximately 30-40% undergoing a mastectomy (Shammas et al., 2022). While breast cancer is more prominent in women, men have a minimal risk of developing breast cancer as they have breast tissue. Breast cancer among men account for less than 1% of breast cancer cases (Tretyak et al., 2012).

As cancer develops in the cells of the breast and multiplies, the disease can quickly metastasize into nearby regions such as the lungs, heart, and lymphatic system. A common treatment modality is mastectomy, a surgical procedure resulting in loss of one or both breasts. This surgical intervention involves physical, emotional, physiological, and esthetic alterations (Jabłoński et al., 2018). Jabłoński et al. (2018) reported that mastectomies had adverse effects on women's self-confidence and intimate relationships. The researchers found that female breasts are associated with psychosocial issues, including concerns of women such as sexuality, sexual identity, maternity, attractiveness, and femininity. According to the author, the removal of the breasts diminishes a woman's view of her self-confidence (Jabłoński et al., 2018). If a woman lacks self-confidence due to her appearance after a mastectomy, she may feel incomplete and seek ways to hide the loss of her breasts, such as use of loose-fitting clothing or breast prosthesis.

Intimate relationships involve physical, social, and/or emotional aspects, and individuals feel satisfied with the belonging of another. Breast surgery has an impact on a woman's femininity and may affect a couple's intimacy (Catania et al., 2019). The authors reported that, after mastectomies, women have reported that their intimate relationships have deteriorated (Jabłoński et al., 2018). In some cases, women have avoided intimate relationships with partners following surgery. Women who have experienced a mastectomy have reported difficulties in developing romantic relationships, often due to their dissatisfaction with their body image and lack of self-confidence (Jabłoński et al., 2018). Huynh et al. (2022) reported that sexual health played a part on patients' emotional well-being and their relationship with their significant others.

Mastectomy surgery can be life altering to the mind and body. Numerous research studies have explored the lived experiences of a person who has undergone a mastectomy. Naam et al. (2009) found that 42% of women experienced depression, anxiety, or a combination of both. Fifty-nine percent of women who underwent mastectomy were satisfied with their bodies post-operatively, which leaves an astounding 41% who were not satisfied with the appearance of their bodies (Loaring et al., 2015). The study found that women faced with the disembodiment of a mastectomy may lose interest in sex, experience a loss of femininity, and experience problems adjusting. Additionally, it was reported that women face anxiety regarding possible return of the disease (75%), fear of dying (24%), and body image and sexual unattractiveness (19%; Loaring et al., 2015).

According to the Merriam-Webster dictionary (n.d.), support is defined as giving assistance to someone or something. Partner support can play a protective role by offering comfort while the patient endures pain and/or body image distress (Catania et al., 2019). Intimate partners often feel that they take on a heavy burden because they do not know how to provide the

comfort and support that their loved one needs. They often lack the skills necessary to assist their loved one with care needs, to assume role reversal, or to provide support in other ways that may be necessary. In one study, men continued to experience psychological stress 3 months after their spouses' mastectomy as they participated in the caregiver role (Chronopoulou et al., 2016). The intimate partner can be vulnerable while being identified as the main source of support. The impact of a mastectomy extends to the intimate partner who also must find ways to deal with this significant loss. Intimate partners experience emotional concerns surrounding their partner post-mastectomy that they often do not express. Duggleby et al. (2015) found that male spouses experienced changes in their roles and responsibilities. The partner who carries out the caregiving role has been identified as the most affected person in a family who has been challenged with breast cancer (Çol & Kiliç, 2019). Thus, breast cancer is recognized as a family disease and does not only affect the person undergoing a mastectomy.

Intimate partners also experience varying levels of distress resulting from the cancer diagnosis, treatment, and the survival process of their significant partners. In one study, spouses of newly diagnosed women with breast cancer described changes in relationships, communication, roles, and hope (Duggleby et al., 2015). As the intimate partner learns to manage these changes, they can in turn be supportive and offer empathy to their partners affected by breast cancer and its treatment, which could prove beneficial in caring for their intimate partners. Fang, Chang, & Shu (2015) aimed to show that the negative effect on a woman's body image could be minimized if her partner provided enough empathy and that her perception of greater empathy from her partner could minimize the impact of body image changes on the depressive symptoms she experiences. In another study, spouses viewed themselves as helpless and incompetent and requiring more information specific to caring for their partners' breast

cancer (Fasse et al., 2017). These researchers found that the major contribution was the intimate partners' ability to participate in the decision-making process. The significant other or intimate partner is considered paramount as they are the most important source of support (Badr & Krebs, 2013). While it was important to understand the patient's perspectives, it was equally important to understand the roles and support of intimate partners of those that have undergone a mastectomy. Badr and Krebs (2013) found that both the patient and partner are affected by the cancer experience. The authors performed a systemic review of the literature and found partner support is beneficial and as patient and partner work together, they were better prepared to address relationship concerns. In these cases, the couples were interviewed together, which may have resulted in less transparency if interviewed individually. Carter and Carter (1993) explored how a mastectomy affected marital interactions as a couple and whether a difference would be found between psychological adjustment of spouses as individuals and as a pair. The results of the study indicated the need to involve both the husband and wife in psychological support systems. Husbands have been found to adjust psychologically and functionally to breast surgery of their spouse. When evaluated three years post-mastectomy, husbands displayed no signs of anxiety, depression, and other psychological symptoms (Carter & Carter, 1993). In a similar study, women who received empathy from their partners had fewer depressive symptoms (Fang, Chang, & Shu, 2015). The partner experiences an enormous number of questions, feelings, and overwhelming emotions during breast cancer diagnosis and treatment. The intimate partner must not only deal with role reversals but are also faced with distress of the physical changes of their partner, lack of coping mechanisms, and how to provide emotional support during a time when both are engulfed with stress (Badr & Krebs, 2013).

Support should be offered in the initial stages of breast cancer by the person closest to the person undergoing the mastectomy, which is often the intimate partner (Ghizzani et al., 2018). Research has shown that male partners were affected by the changes in physical appearance of their partners following surgery and did not know how to positively offer emotional support. Men are expected to be supportive during an illness and these changes can cause relationship problems among partners. In addition, intimate partner support and empathy are believed to be vital in the emotional recovery of a woman undergoing a mastectomy (Bultz et al., 2000). In a study conducted by Gürsoy et al. (2017), men were sensitive to their partners' appearance after a mastectomy; however, the male partners suppressed their feelings and refrained from expressing their thoughts as they wanted to be positive and offer support to their partner. Mackenzie (2015) identified the need to understand the prevalence of the effects of perceived partner support on breast cancer survivors. Other researchers found that psycho-educational interventions targeting the partners of a breast surgery patient are rare (Bultz et al., 2000). Further identified gaps in the research include identifying partner factors that would influence the partner's role as either supportive or active (Badr & Krebs, 2013). Catania et al. (2019) aimed to address the gap and explore the partners' perspective in providing support and found the male partner was the main caregiver in providing emotional support and providing household and childcare responsibilities. Just as patients who have undergone a mastectomy have distress, spouses are also overcome with varying degrees of emotional distress, which was found in 48% of husbands of breast cancer patients' post-surgery (Naam et al., 2009). Additional research indicated that women worried about how their partners viewed them and how their partners interact with them post-mastectomy (Gürsoy et al., 2017). Thus, research regarding the experiences of the intimate partner post-mastectomy remains limited.

Problem of Study/Statement of Purpose

The purpose of this study is to understand the lived experiences of the intimate partner who provided support post-operatively to a person (male or female) who underwent a mastectomy during the post-operative phase within the last one to five years.

Research Question

This study aimed to answer the following research question: What are the lived experiences of the intimate partner who provided support post-operatively to a person (male or female) who underwent a mastectomy during the post-operative phase within the last one to five years?

Rationale for the Study

According to Zimmermann (2015), one in eight women will develop breast cancer in their lifetime. Many of those will be faced with the treatment option of a mastectomy, which involves removal of one or both breasts and rarely results in physical complications, with physical recovery between 3 to 6 weeks (Grogan & Mehan, 2017; National Cancer Institute, 2020; National Health Service, 2015). Breast cancer patients often identify their intimate partner as their most important source of support, which can introduce individual and relational challenges for both the patient and partner (Zimmermann, 2015). As women are faced with this detrimental diagnosis, they have experienced emotional and physical concerns, including fear of death and the unknown (Borstelmann et al., 2015). Research has shown that, while experiencing a breast cancer diagnosis, women rely heavily on their intimate partner for support to limit distress, improve coping strategies, engage in problem-solving, and improve their quality of life (Borstelmann et al., 2015; Sawin, 2012).

For most women with breast cancer, the intimate partner is influential in providing instrumental and emotional support during the difficult time of the loss of a breast, which can be a stressful time for both partners (Zimmermann, 2015). Thus, it is important to understand how the intimate partner offers support related to the patient's distress and adjustment throughout the breast cancer diagnosis and treatment (Nicolaisen et al., 2014). The intimate partner's own desires also affect how the partner views the patient's needs as well as decisions about how to provide support (Nicolaisen et al., 2014).

Studies that investigated the intimate partner's experiences following a mastectomy are found in the literature, yet few studies have explored the intimate partner individually instead of the couple as a whole. Rowland and Metcalfe (2014) explored men's experiences of their partners' altered physique and body image post-mastectomy, with a sample of predominantly White, middle class, well-educated men, which was not representative of the entire population. Their results indicated communication breakdowns combined with strained self-esteem could lead to unresolved problems between partners; thus, further research is needed to understand how men live and acclimate to their partner post-mastectomy (Rowland & Metcalfe, 2014). Çol and Kiliç (2019) found positive effects of couple-centered training and counseling programs on family functioning and quality of life of both women that underwent a mastectomy and their partners. The results of this study could lead to developing an interventional program that will support intimate partners as they care for a person who undergoes a mastectomy in the post-operative phase. Catania et al. (2019) performed a qualitative study on male partners of a person who underwent a mastectomy and who were raising children. They found that men felt as they were not prepared to assume the role of caring for the children, while supporting their partner. Loaring et al. (2015) performed a qualitative study and found ways for coping styles and sexual

scripts that influenced intimacy toward wives' post surgically. Gürsoy et al. (2017) found that male partners were affected psychologically, socially, and emotionally by their partners physical appearance and felt the disease process had influenced the relationship.

Philosophical Underpinnings

Descriptive phenomenology was developed by Husserl in 1962, who evaluated the descriptions of human experience (Husserl, 1962). These descriptions allow the human experience to be captured as people experience them by hearing, seeing, believing, feeling, remembering, deciding, evaluating, and acting. Phenomenology aims to examine the perspectives of an individual's lived experience (Mapp, 2008). Phenomenology involves searching for meanings, examining the essences of the experience, and evaluating descriptions of experiences through first person. Descriptive phenomenology is based on two assumptions. The first is that the researcher does not use any prior knowledge of the phenomenon. The second assumption is that there are features to any lived experience that are common to all persons who have the experience (Lopez & Willis, 2004). In order to effectively capture these lived experiences, the principal investigator (PI) utilizes bracketing, intuiting, analyzing, and describing to understand and define the phenomenon. Colaizzi (1978) utilized a seven-step process that provided a rigorous analysis of each step (Colaizzi, 1978). The method depends upon first-person accounts of the experience to provide a concise description of the phenomenon studied (Colaizzi, 1978). Colaizzi's method will be used to extract information in this study to understand intimate partners' lived experience of providing support for the person who has undergone a mastectomy.

Utilizing Colaizzi's method allowed a closer look into the essence of the lived experiences of the intimate partner while supporting a person who had undergone a mastectomy.

The PI utilized bracketing, intuiting, analyzing, and describing to understand and define the phenomenon (Creswell, 2007). Using Colaizzi's method, all participant transcripts were read numerous times to obtain an overall sense of participants' experiences. The transcripts were used to extract significant phrases and sentences pertaining to the lived experience of an intimate partner of a person who had undergone a mastectomy. Meanings were then formed from the significant phrases and statements. Next, the PI clustered the meanings into themes, allowing an emergence of common themes among the transcripts. Once the results were obtained by the PI, the results were reviewed and incorporated into a description of the phenomenon. This approach was chosen as it allowed the PI to understand the lived experiences of the intimate partner of a person that underwent a mastectomy. The PI considered intimate partner experiences to include what was heard, said, believed, felt, remembered, decided, evaluated, and acted upon while caring for their loved one (Polit & Beck, 2021). As identified in several studies, the intimate partner remains an essential part of the recovery process. As the intimate partner seeks ways to be supportive, there are also opportunities for growth in oneself in learning to become an active part of the care process post-mastectomy.

Summary

Breast cancer is the second most common cancer in the United States (WHO, 2020). A mastectomy is a treatment modality for breast cancer. While research has looked at the person undergoing the mastectomy and their lived experiences, fewer studies have devoted much attention to the intimate partner of the person that undergoes a mastectomy. This study aimed to understand the lived experiences of the intimate partner who provided support post-operatively to a person (male or female) who underwent a mastectomy during the post-operative phase

within the last 1 to 5 years. This study utilized a descriptive phenomenological approach to explore the lived experiences of intimate partners of a person that has undergone a mastectomy.

CHAPTER II

REVIEW OF LITERATURE

Introduction

Breast cancer is the second most common cancer globally with more than one million new cases per year and the leading cause of cancer-related death among women (Jabłoński et al., 2018). It is expected there will be 19 million cancer survivors in the United States in the next 10 years; hence, it is important to determine the most beneficial support system during recovery (Ghizzani et al., 2018). Patients experience an array of feelings regarding a breast cancer diagnosis. Treatment often involves breast surgery, which can include a mastectomy. Mastectomy concerns physiology, esthetics, emotions, and symbols, and can affect the patient's body image, mood, and quality of life. Women who have undergone a mastectomy may attempt to accept the physical outcome but find that it is difficult to adapt. A wide range of research studies on women's experiences of breast surgery indicate improved ability to cope when their support needs are effectively addressed (Brown & McElroy, 2018; Carr et al., 2019; Rubin & Tanenbaum, 2011; Stone et al., 2018; Sun et al., 2018).

For many women, the breast is a symbol of femininity and motherhood. Experiencing a loss of a breast(s) can lead to feeling less sexually desirable to their partners. In some circumstances, poor communication, combined with poor self-esteem resulting from altered body image, can lead to conflicts between partners and strain the couple's relationship. For this reason, partner support has been shown to be important for enhancing women's psychological well-being, expediting recovery, and acceptance of new body image (Carr et al., 2019; Rowland & Metclafe, 2014). Several studies examined the importance of experiences for the intimate partner. Çol and Kiliç (2019) evaluated family functioning and quality of life of women and their

spouses following breast cancer treatment. The authors focused their interventions on communication, roles, coping with stress, problem-solving skills, effective responsiveness, and general functioning and found that an appropriate training program provided positive effects on family functioning and quality of life. In addition, this study reported that diagnosis, treatment, and survival process of breast cancer not only affects patients; the most affected family members were their spouses, who were often responsible for maintaining the primary caregiving role (Çol & Kiliç, 2019). Jabłoński et al. (2018) found that patients after breast surgeries showed significantly lower results in body acceptance and experience of intimacy. In another study, the authors found that patients experienced changes to their gender identity, sexuality, and variations in the relationship with their partner (Brown & McElroy, 2018). Furthermore, authors found that men indicated that their partner's altered body image was secondary to her health and well-being (Rowland & Metcalfe, 2014). Recently, Carr et al. (2019) found that women are often concerned emotionally regarding their physical attractiveness post-surgery as well as the effect a mastectomy may have on their partners.

More research is needed to better understand men's experiences of living with a partner who has undergone mastectomy (Rowland & Metcalfe, 2014). This may lead to interventions within clinical practice that will facilitate the process by which intimate partners come to terms with the impact of the cancer and breast surgeries on their own experience as well as the experience of their partners. Additionally, this research can enable partners to maintain their emotional and sexual relationship. This integrative review was aimed at understanding the lived experiences of intimate partners of a patient who has undergone a mastectomy.

Background

Borstelmann et al. (2015) suggested that partner support is essential and associated with improved quality of life, decreased depression, and women diagnosed with breast cancer had a decreased anxiety of 10 to 50%. Women experience feelings of rejection and insecurity while trying to avoid distress, which interfere with how they interact with their partners (Batista et al., 2017). While couples may experience psychosocial distress affecting the way they function, partners and patients do as well (Zimmermann, 2015). Thus, psychosocial adjustment in breast cancer diagnosis and treatment are vital in developing a working relationship. Likewise, couples who work together are able to share each other's worries, provide needed support and work together to develop a satisfying relationship. In one study, husbands experienced burdens of anxiety, depression, and role strain after their spouse's mastectomy (Chronopoulou et al., 2016). Thus, breast cancer surgery introduces individual and relationship challenges for both the person undergoing a mastectomy and her partner (Zimmermann, 2015). Research has shown that some of these issues can cohesively unite the couple, while others can disrupt relationship functioning by negatively affecting communication, intimacy, and decreasing relationship satisfaction at different stages (Zimmermann, 2015). Carr et al. (2019) learned that the support of family members or someone close to them helped the woman to address her feelings of emotional vulnerability, assist her to cope, and relieve isolation. While body image among heterosexual and homosexual women has been associated with women's sexuality and problems, less emphasis has been dedicated to homosexual couples (Fang, Lin, et al., 2015; Rubin & Tanenbaum, 2011). Gathering information of homosexual women may provide information regarding how woman see themselves in social interactions and intimate relationships of same sex partners.

Current research suggests early involvement of the partner in surgical decision-making of cancer treatment assists the patient to have improved body image post-surgery (Kuo et al., 2018). Increasing evidence of breast cancer diagnosis and its treatment reveal that family involvement positively influences the couple's relationship (Zimmerman, 2015).

A gap in the literature continues to exist regarding the experiences of the intimate partner of a person who has undergone a mastectomy. Although several studies have explored partner experiences post-mastectomy, many only reviewed men's experiences as partners and neglected women who have who may have had a mastectomy. The lesbian, gay, bisexual, transgender, and questioning (or queer; LGBTQ) community was omitted. This integrated literature review addresses this gap in the research on intimate partner's experience of a person who has undergone a mastectomy. An intimate partner can be anyone involved in an intimate relationship who has opportunities for decision making and offering support. Much of the literature focuses on couple's interaction post-mastectomy instead of information from intimate partners and their experiences. The intimate partner is usually the main source of support throughout the trajectory of cancer breast disease and treatment for those in an intimate relationship (Nicolaisen et al., 2014).

Aim

This integrative review explores the experiences of intimate partners of patients who have undergone mastectomies. Just as patients experience their own challenges in dealing with breast cancer diagnosis and treatment, partners experience challenges as well. Intimate partners' own needs influence how they interpret the patient's needs, how they support the patient, and how they can cope effectively during this post-surgical ordeal.

This integrative review includes recently published peer-reviewed studies in the last 5 years of publication (2014-2019). The aim of this integrative literature review is to understand the lived experiences of the intimate partner of a patient who has undergone a mastectomy.

Methods

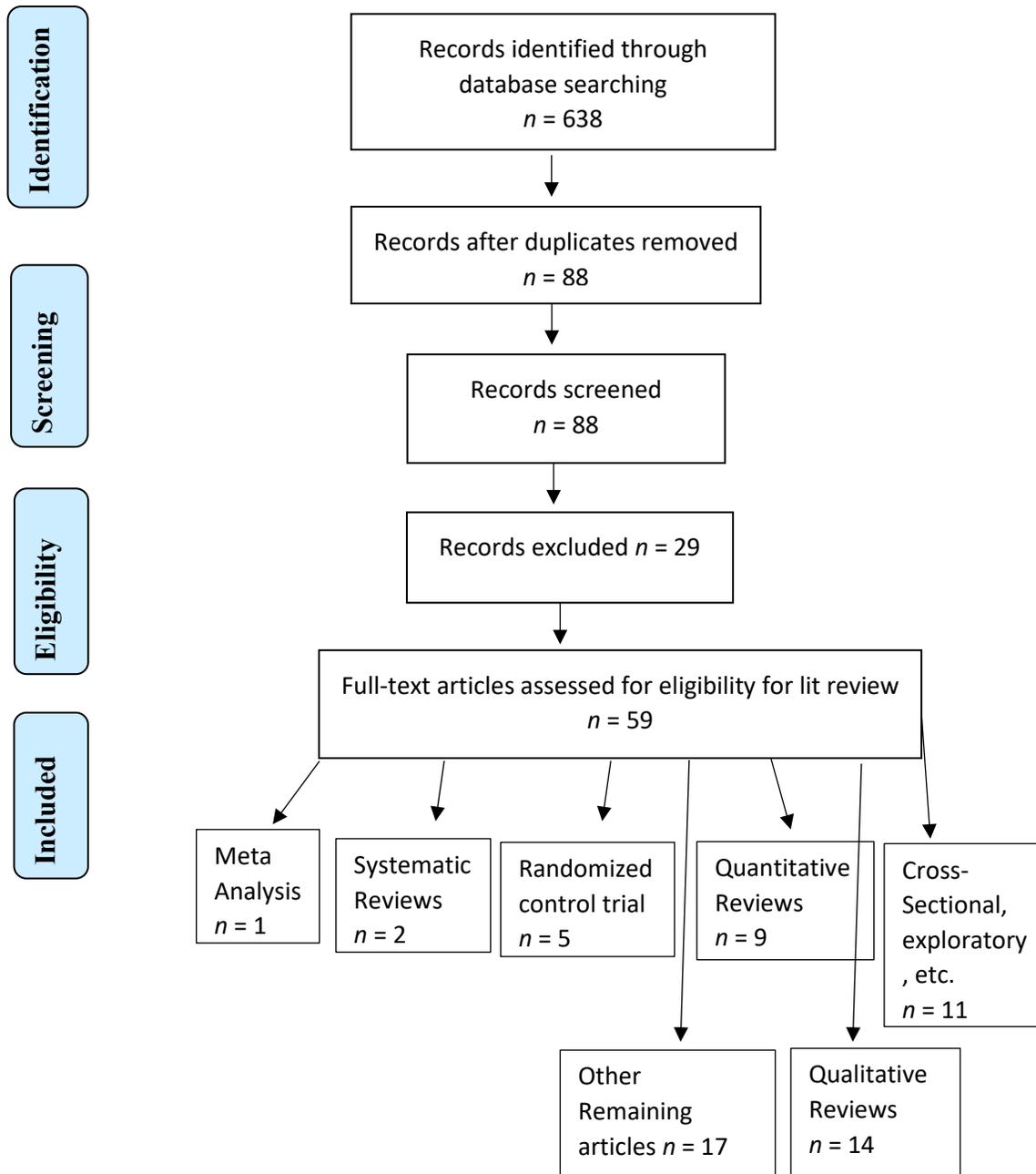
Gray literature from well-established and well-known education organizations was also included. Literature pertinent to the needs of breast cancer patients and their partners post-mastectomy were reviewed and synthesized. Electronic searches were conducted to identify English language journal articles published from January 2014 to December 2022 in the PubMed, EBSCOhost, CINAHL, Medline, Academic Search Complete, PyscArticle and SCOPUS databases. The search terms were “partner support,” “spouse,” “support,” “breast cancer,” “mastectomy,” “sexual minority,” and “sexual orientation.” The MeSH terms in PubMed were spouses, mastectomy, breast neoplasms, and social support. One researcher abstracted data on design, sample size, major findings, research aim, concepts, limitations, and clinical relevance. The studies were assessed for quality using Joanna Briggs Institute level of evidence alongside the document to determine effectiveness. The Prisma flowchart (see Figure 1) depicts the process used to identify and select relevant journal articles for this integrated literature review. The search strategy was repeated on Defense Technical Information Center for gray literature and yielded two military medical articles using the search terms “social support,” and “partner.” Non-electronic versions were requested through interlibrary loan when unavailable electronically, and all study types were considered. Bibliographies of included studies were searched manually to identify other relevant articles. A total of 35 articles were reviewed for relevance for literature review, and 24 articles were used for supporting data in the research.

Study Selection Criteria and Outcome

The inclusion criteria included peer reviewed articles published between 2014-2022. These studies were assessed for inclusion of partners' experiences of their partner who underwent a mastectomy. The researcher reviewed English scholarly peer-reviewed research articles. Articles were included if they had a primary emphasis on breast cancer, mastectomy, social support, spouses, sexual gender minority, and emotional support. Studies on cancers other than breast cancer were excluded. Unpublished dissertations, abstracts and poster presentations for conferences, letters to editors, role of surgeons and other health care professionals, review articles, and press publications were also excluded. Duplicate articles and non-relevant articles were excluded as well as those not meeting the inclusion criteria. The process of selection included one reviewer. The PRISMA flowchart (see Figure 1) provided a detailed synopsis of the process utilized to identify and select relevant journal articles.

Figure 1

PRISMA Flowchart



A matrix was created in Microsoft Word (see Table 1) to obtain information in the following areas: author and year, sample, research aim, concepts, level of evidence, methodology, major findings, and limitations of the study were used in this review. This allowed for ease of reviewing and synthesizing the data.

Table 1*Literature Matrix Review*

Author	Sample	Research question/ Aim	Concepts	Level	Methodology	Major findings	Limitations
Rowland & Metcalfe, 2014	<i>n</i> = 17 citations	Explored men's experiences of their partners' altered physique and body image post-mastectomy	Partners mastectomy altered bodies systematic review	I	Systematic Review	Men were distressed by their partners bodily alterations leading to high complex and emotional coping mechanisms	Sample characteristics were limited. Findings from western world's predominantly white men middle-class, well-educated
Sun et al., 2018	<i>n</i> = 12 qualitative studies: women 30-77	Summarize qualitative studies exploring the impact of losing the breast in women breast cancer survivors.	Mastectomy, body image, breast cancer identity.	I	Meta-analysis	Losing breast regarded as disfigurement causing discrepancy in self and societal images: Themes changes in identify and coping with changes in identify.	Need to develop personalized care plan for women who are going for mastectomy who may have high risk of developing negative perceptions of losing the breast.
Fergus et al., 2015	<i>n</i> = 80 heterosexual couples	Patients and their male partners who participate in the Couplelinks program will demonstrate significant improvement on several measures of the relationship.	Psychosocial adjustment, psychological interventions	II	Randomized controlled trial	Couplelinks is the first internet-based intervention to improve psychological interventions	New program
Manne et al., 2016	<i>n</i> = 302 women and their spouses	To evaluate the efficacy of the 2 types of couple-focused group interventions on couples' psychological functioning.	Relationship functioning, psychological functioning	II	Randomized control trial	Analyses indicated that anxiety, depressive symptoms, and cancer-specific distress declined, and positive wellbeing improved.	High rate of study refusal. High rate of couples who dropped from the ECG and SG conditions before the groups began. Spouses were men.

Author	Sample	Research question/ Aim	Concepts	Level	Methodology	Major findings	Limitations
Nicholaisen et al., 2018	<i>n</i> = 198 recently diagnosed breast cancer patients and their partners	Evaluate the effect of a psychological attachment-oriented couple intervention for breast cancer patients and partners in the early treatment phase.	Breast cancer; couples; coping	II	Randomized control trial	No significant effect of the HiH intervention cancer-related distress. The results suggest that most couples can cope with cancer-related distress in the context of usual care	Selection bias in the enrollment Attrition throughout the study may have influenced the results, and the initial participation rate of 26% may have decreased the generalizability of the findings.
Carr et al., 2019	<i>n</i> = 21	To identify patients' support needs after BR from partners.	Breast cancer	III	Exploratory	Four support needs were identified and were composed of elements of instrumental, emotional, and informational support	The sample of participants was drawn from a limited geographic region and, indeed, from a specific healthcare organization
Duggleby et al., 2014	<i>n</i> = 110 surveys	To examine the relationship of the quality of life of male spouses of partners with breast cancer with the following factors: (a) demographic variables (b) levels of hope (c) self-efficacy, loss and grief of male spouses, and (d) quality of life	Male spouses Breast cancer	III	Cross-sectional	Hope, self-efficacy, feelings of guilt, age, and their partners' quality of life were significantly related to quality of life of the male spouses of women with breast cancer	None identified

Author	Sample	Research question/ Aim	Concepts	Level	Methodology	Major findings	Limitations
Duggleby et al., 2015	<i>n</i> = 105 caregivers	To describe the types of transitions experienced by male spousal caregivers of women with breast cancer and the strategies used by male spouses to deal with these transitions and (b) examine factors related to their quality of life	Partner, breast cancer, mastectomy	III	Cross-sectional	The male caregivers with higher quality-of life scores reported higher hope and lower caregiver guilt scores.	The sample was older with middle-class incomes. Male spouses with poorer health and lower incomes may have produced different results.
Fang, Lin et al., 2015	<i>n</i> = 135 women	1) To understand the relationship between women's marital coping efforts and body image as well as sexual relationships and (2) to test a hypothesized model suggesting that marital coping efforts have a mediating effect on the relationship between body image and sexual relationships among breast cancer survivors	Relationship, breast cancer	III	Cross-sectional	Body image, marital coping, and sexual relationship were found to be significantly correlated with each other	The causal relationship was only speculative rather than confirmed because of its cross-sectional, correlational design. The sample size of this study seemed to be small,

Author	Sample	Research question/ Aim	Concepts	Level	Methodology	Major findings	Limitations
Favez et al., 2017	<i>n</i> = 61 participants	To investigate expressed emotion (EE) in couples facing breast cancer in the immediate post-surgery period.	Breast cancer, partners, immediate post-operative period	III	Observation	Both partners expressed overt and covert criticisms; women expressed more overt criticisms than did their partners	Small sample size, being video recorded in the FMSS was an unacceptable condition for some patients and the nature of the disease may attenuate the expression of criticisms.
Fenech et al., 2022	<i>n</i> = 144 survivors and partners	Examined the daily, within-person links between attempted and perceived partner responsiveness and subjective sleep.	Breast cancer, partners	III	Longitudinal	Survivor and partner reports of partner responsiveness were associated with own subjective sleep, perceived partner responsiveness was associated with improvements in one's own sleep.	Sample was mostly homogeneous in its sociodemographic data and recruited from a single site. Causal effects cannot be determined.
Frost et al., 2011	<i>n</i> = 269 women	To evaluate the long-term consistency of satisfaction with contralateral prophylactic mastectomy (CPM) and adverse psychosocial effects as well as to explore the effect of informed decision-making, personality traits, and quality of life (QOL) on satisfaction.	Mastectomy	III	Longitudinal	Most adversely affected were body appearance (31%), feelings of femininity (24%), and sexual relationships (23%)	Retrospective perspective in which women are asked to identify how CPM has affected psychosocial aspects of their life. 55% return rate on the second follow-up survey

Author	Sample	Research question/ Aim	Concepts	Level	Methodology	Major findings	Limitations
Kuo et al., 2018	<i>n</i> = 105 partners	Examined the influence of partner involvement in decision-making for breast reconstruction (BR) on women's body image and post-BR decision regret.	Partner involvement, mastectomy	III	Cross-sectional	Showed that the amount of medical information women obtained was directly related to body image and decision regret, while body image also directly influenced decision regret.	The low willingness to participate of those with post-BR complications or those who had poor relationships with their partners. Selection bias.
Shapira et al., 2018	<i>n</i> = 103 women <i>n</i> = 39 partners	To investigate partners of women who had undergone a mastectomy and their levels of adaptation	Rescue answer partner adaptation	III	Cross-sectional	Risk reducing mastectomy is a significant event in the process of adapting to life at risk for hereditary cancer partners relate to adaptation and carriers this study is cross-sectional is not quantitative	Bias toward those who seek out support groups flawed recruitment method results not generalizable sample size of partners was smaller
Yeung et al., 2019	<i>n</i> = 176 husbands	Quality of life (QoL) among husbands of breast cancer survivors was associated with their stress and coping processes.	Breast cancer, partners	III	Cross-sectional	Reducing husbands' caregiving burden, increasing their marital satisfaction, helping reevaluate the negative impact of breast cancer, and reducing barriers for expressing emotions and concerns may increase their sexual well-being.	Cross-sectional study where the tested relationships were correlational but not causal. The non-random sampling and self-selection bias might compromise the generalizability of the finding.

Author	Sample	Research question/ Aim	Concepts	Level	Methodology	Major findings	Limitations
Blais et al., 2014	<i>n</i> = 70 couples	Identify key information components that would be the basic content of a brief informational intervention, developed from a population perspective	Breast cancer Couples Spouses/education	IV	Quantitative	Provided validation of the relevance, from the viewpoint of women and their spouses, of the message content to be part of a brief informational intervention	Three focus groups each for women and spouses. Second, we did not ask participants to suggest additional relevant messages, although a new idea—that of creativity.
Brown & McElroy 2018	<i>n</i> = 68 survivor's	Explored sources of stress and support experienced by sexual and gender minority (SGM) breast cancer survivors and the impact of treatment on their lives	Mastectomy	IV	Quantitative	Need for research on the physical and emotional effects of breast cancer treatment on SGM breast cancer survivors and exploration of the social support needs and experiences of SGM breast cancer patients and their partners	This sample is comprised of survivors who self-selected into the study and who were accessible to recruitment through connection to some facet of the LGBTQ community. The small sample size may have resulted in inadequate statistical power.
Christensen, 1983	<i>n</i> = 20 couples	To evaluate the effects of a structured couples treatment program on the cycle social discomfort following a mastectomy	Mastectomy couple breast cancer	IV	Quantitative	Provided a structured protocol for the clinician working in this area the protocol reduces depression in the patient emotional support for both and increases sexual satisfaction in both partners	Sample population differed from what has been previously discussed in the literature the selection criteria may account for some differences

Author	Sample	Research question/ Aim	Concepts	Level	Methodology	Major findings	Limitations
Chronopoulou et al., 2016	<i>n</i> = 33 couples	To investigate the caregivers' burden of mastectomized women	mastectomy women husbands' caregiver burden	IV	Quantitative	Couples' anxiety and depression tend to resolve over time although husbands expect greater burden three months after spouses' mastectomy	None provided
Clarjis et al., 2022	<i>n</i> = 116 caregivers	To evaluate the care-related quality of life in caregivers of breast cancer patients, to assess its association with breast cancer patients' health-related quality of life (HRQoL), and to identify its potential predictors.	Breast cancer, quality of life	IV	Quantitative	Most caregivers experienced some or a lot of fulfillment and support when needed at six versus twelve months	Low response rate, the lack of socio-demographic characteristics of caregivers prevents to precisely describe the cohort that was studied.
Decker et al., 2012	<i>n</i> = 65 patients and their partners	To develop and evaluate the feasibility of a brief intervention to attenuate the incidence of psychosexual morbidity within the dyad secondary to the diagnosis and treatment of breast cancer.	Intimacy, sexual functioning, and dyadic adjustment.	IV	Quantitative	Data examined for significant differences at three time points on each variable and, when no differences were found, they were combined for the comparative analyses with the questionnaire-only group	Not designed as a randomized, controlled efficacy trial, and the available resources limited the number of participants Recruitment also was a challenge and random assignment was not used

Author	Sample	Research question/ Aim	Concepts	Level	Methodology	Major findings	Limitations
Jabłoński et al. 2018	<i>n</i> = 50 women	focuses on how women see themselves and experience an intimate relationship with a partner	breast cancer mastectomy body self and self-acceptance	IV	Quantitative	Differences were obtained between the entire group of women after mastectomy and the control group of women and three aspects of the utilized questionnaire by the acceptance manifesting femininity and experiencing an intimate relation with a partner.	Partners not utilized in this study open
Mauer et al., 2016	<i>n</i> = 25 male participants	Identifies the concerns and perspectives of male romantic partners regarding their unique decisions	Male partners cancer sexuality	IV	Quantitative	participants reported relationship changes regarding intimacy attraction and Communication	Small sample size, the study design creates bias, participants were recruited due to importance you were more likely to have had a dedicated relationship or perhaps more likely to answer.
Schmidt et al., 2017	<i>n</i> = 10 in each group	Explored the individually perceived significance of the breast among patients with and without breast reconstruction and its correlation with postoperative satisfaction.	Mastectomy and postoperative	IV	Quantitative	Breast of a woman fulfills a variety of intrapsychic and interactional functions	Small sample size. The retrospective assessment could have led to a bias of the results

Author	Sample	Research question/ Aim	Concepts	Level	Methodology	Major findings	Limitations
Archer et al., 2018	<i>n</i> = 6 women	the role of others in supporting younger women who opt not to reconstruct their breast post-mastectomy.	Mastectomy, breast cancer	VI	Qualitative	Participants reported reaching a more accepting view of themselves. A product of the support provided by others, the forging of their new sense of self and the successful navigation of challenges over time.	The sample size is small yet consistent with the IPA approach. Women's age, sexual orientation and relationship status should be considered in future research.
Catania et al., 2019	<i>n</i> = 8 partners	To investigate the experiences of male partners of female breast cancer patients who had undergone surgery and oncological treatment and who were still raising children	Breast surgery, men's experience	VI	Qualitative	Participants emphasized the difficulties they faced in trying to juggle work and family responsibilities while offering support to their partners, a task they felt ill-prepared	Small sample size
Cheng et al., 2018	<i>n</i> = 8 couples	Reports on the embodied experience of women with breast cancer considering post-mastectomy delayed breast reconstruction	Breast cancer; body image; decision-making	VI	Qualitative	Embodiment thus played a significant role in women's decision-making. Other psychosocial factors, however, may compete with embodiment motivations.	Small sample size. Responses might be affected by volunteer and selection bias.

Author	Sample	Research question/ Aim	Concepts	Level	Methodology	Major findings	Limitations
Fasse et al., 2017	<i>n</i> = 18 couples	To gain a better understanding of the couples' decision-making process for BR	Cancer surgery heterosexual	VI	Qualitative	The analysis revealed 11 major themes. The two most salient ones were 'external influence' and 'implication of the partner'	Representative nature of the sample consisted of participants who had volunteered to take part in the research. Results concerned couples who have good and long-standing spousal relationships.
Gürsoy et al., 2017	<i>n</i> = 16 partners	To acquire a deeper understanding of male experiences on the emotional and social impact of their partners' mastectomy and chemotherapy-induced alopecia	Mastectomy, breast cancer	VI	Qualitative	The changes in the partners' physical appearance after mastectomy and chemotherapy affected males differently in psychological, emotional and social terms	The study was carried out with volunteer participants whose wives had undergone treatment for breast cancer in the Eastern Black Sea region. Does not address the experiences of men from other geographical regions or young men.
Lamore et al., 2019	<i>n</i> = 10 interviews, with five couples	To explore couples' experiences of mastectomy and breast reconstruction decision-making, the month following the mastectomy.	Breast cancer; Breast reconstruction; Couple	VI	Qualitative	Partners were supportive and protective. The women in their decision to have or not a breast reconstruction	Small sample size
Loaring et al., 2015	<i>n</i> = 8 couples	Upon couples' experiences of breast cancer surgery, and its impact on body image and sexual intimacy.	Breast cancer; male partners following mastectomy	VI	Qualitative	Findings illustrate the positive acceptance that partners may express toward their wives' postsurgical bodies.	Small sample size

Author	Sample	Research question/ Aim	Concepts	Level	Methodology	Major findings	Limitations
Mackenzie, 2015	<i>n</i> = 36 women	Examine women's experiences of enablers and constraints to physical activity participation after being diagnosed with breast cancer.	Breast cancer, partner support	VI	Qualitative	Social enablers and constraints particularly partner support and gendered identity were powerful in framing women's participation	The sample is weighted women from higher socioeconomic status in fluent English. Recruited through cancer and breast cancer in organizations.
Nasiri et al., 2016	<i>n</i> = 26 individuals	To define ways in which men adjust to their wives' breast cancer and to present an appropriate model in this respect	Men breast cancer support	VI	Qualitative	Men's adjustment to their wives' breast cancer occurs during three stages confrontation with the disease, disorganization of and struggled to reorder family life	Isfahan city used, findings cannot be generalized, and sample focused on Iranian husbands
Paul et al., 2014	<i>n</i> = 13 semi structured interviews were	to better understand the support needs and resources of sexual minority women breast cancer patients.	Support needs, breast cancer, sexual minority women	VI	Qualitative	Theme themes emerged support groups, family of origin support and partner support	Sample was younger than the median age 30, predominantly white, majority Jewish living in New York. Findings may not be generalizable to other groups women
Rubin & Tanenbaum, 2011	<i>n</i> = 13 lesbian and bisexual women	Explore sexual minority women's lived experience of mastectomy and reconstruction for treatment of breast cancer.	Breast cancer Mastectomy Decision making	VI	Qualitative	Participants were acutely aware of and reflective of potential readings of breast reconstruction in relation to gender identity and feminist body politics.	Sexual identity is not the only necessarily influence on a woman's decision. Majority of women

Author	Sample	Research question/ Aim	Concepts	Level	Methodology	Major findings	Limitations
Shaffer et al., 2021	<i>n</i> = 20 partners	Assessed the perceptions of female breast cancer survivors, intimate partners of breast cancer survivors, and breast cancer oncology providers about how an Internet intervention for couples may address breast cancer-related sexual concerns.	Breast cancer, partners	VI	Qualitative	Survivors and partners tended to express interest in some individualized intervention private from their partner, although they also emphasized the importance of opening communication about sexual concerns within the couple	Interpretations of findings are limited given the demographics. The samples of survivors and partners tended to report being in long-term relationships.
Shaffer et al., 2022	<i>n</i> = 29 couples	To help refine guidelines, we examine breast cancer survivor, partner, and oncology provider perspectives about including partners in discussions about cancer-related sexual side effects.	Breast cancer; couples	VI	Qualitative	Findings suggest future clinical guidelines should emphasize that incorporating partners into clinical discussions about sexual concerns is important for many breast cancer patients.	Study sampling was not based on the research question. E, findings are not necessarily representative of preferences differing by race, culture, healthcare access and literacy, and sexual orientation
Yoshimochi, et al., 2018	<i>n</i> = 10 partners	To understand the experience of partners of women with breast cancer	breast cancer caregivers' oncology nursing	VI	Qualitative	The partners experience emotional distress caused by the fear of losing their partners before suffering they demonstrated willingness to provide care comfort and to support the woman.	the selection of partners of women with breast cancer who attended a health care Center for rehab after mastectomy. Did not interview partners who did not want to care for their partner.

Theoretical Framework

Whittemore and Knafl's (2005) theoretical framework was used to guide this integrated review as this method enabling a complete understanding of the phenomenon of interest.

According to Whittemore and Knafl (2005), integrative reviews allow the researcher to evaluate both quantitative and qualitative evidence, as well as theoretical literature, to provide a comprehensive summary of a subject. This framework was used to analyze diverse sources to understand the lived experiences of intimate partners of a person who has undergone a mastectomy. Whittemore's and Knafl's (2005) five stages of review were used: (a) problem identification, (b) literature search, (c) data evaluation, (d) data analysis, and (e) presentation.

Analysis

Data analysis was comprised of four stages using the Whittemore and Knafl (2005) framework. Data reduction included categorization of data from each article in a matrix according to information in the following areas: author and year, sample, research question/aim, concepts, methodology, level of evidence, major findings, and limitations of the study (see Table 1). In the data display stage, data extracted from each article were placed in a matrix to enhance visualization of patterns and relationships, and to facilitate comparisons. The data comparison stage involved an iterative examination of data; comparisons were made across the different studies to identify differences and similarities between the themes. In the conclusion stage, patterns, and relationships as well as differences and similarities were identified and raised to a higher level of abstraction and verified with primary data. A comprehensive matrix was used to abstract the data. Headings included the keywords: author and year, sample, research question/aim, concepts, level of evidence, methodology, major findings, and limitations of the

study to make contrasts and comparisons, noting relations between variability and finding intervening factors.

Results

The review included one meta-analysis as the highest level of evidence. The meta-analysis review was the basis for this literature review as it showed that breast cancer survivors experienced both negative and positive impact of losing the breast (Sun et al., 2018). One systematic review looked at breast cancer in transgender patients and recommendations regarding long term follow-up (Stone et al., 2018). The other systematic review reviewed articles on men's experiences post-mastectomy with the oldest article being over 10 years old (Rowland & Metcalfe, 2014). Five randomized control trials (RCTs) are included in this integrated review. Three of the four RCTs investigate the partner and the patient as a couple and aim to have both participate in an intervention designed to help the couple adjust to breast cancer (Fergus et al., 2015; Nicolaisen et al., 2014; Nicolaisen et al., 2018). The fourth RCT explored improving family functioning and quality of life (Çol & Kiliç, 2019). The fifth RCT looked at couples' psychological and relationship functioning (Manne et al., 2016). The literature review includes nine quantitative reviews. Jabłoński et al. (2018) focuses on how women see themselves and experience an intimate relationship with a partner. The next quantitative review considered the husband's psychological distress and the role strain he experiences after his wife had a mastectomy (Chronopoulou et al., 2016). Two quantitative articles examined the partner's well-being and changes in sexuality after a partner lost a breast (Ghizzani et al., 2018; Mauer et al., 2016). Brown and McElroy (2018) used a quantitative design to review the needs of sexual and gender minority breast cancer survivors. They found that participants reported that their needs for cancer-related social support was not met for themselves or their partners (Brown &

McElroy, 2018). Participants reported feeling uncomfortable discussing same-sex relationships in non-LGBT groups (Brown & McElroy, 2018). The next four quantitative reviews included an original study and looked at the relevance from the viewpoint of women and their spouses (Blais et al., 2014; Christensen, 1983; Clarjis, 2022; Decker et al., 2012; Schmidt et al., 2017).

Eleven reviews including cross-sectional, exploratory, observational, and longitudinal reviews were included in this integrated review. Shapira et al. (2018) used a cross-sectional design to investigate partners of women who had undergone a mastectomy and their levels of adaptation. Three of the studies emphasize quality of life (Duggleby et al., 2014; Duggleby et al., 2015; Yeung et al., 2019). One of the cross-sectional studies expressed emotion and couple satisfaction (Favez et al., 2017). Two other cross-sectional studies explore body image, sexuality, and depression (Carr et al., 2019; Fang, Chang, & Shu, 2015; Fang, Lin et al., 2015). The last cross-sectional design reviews partner involvement in decision-making and partner responsiveness (Fenech et al., 2022; Frost et al., 2011; Kuo et al., 2018).

Fourteen qualitative reviews are included in this integrated review. One study emphasizes decision-making after breast surgery (Archer et al., 2018; Fasse et al., 2017; Lamore et al., 2019). Three studies discuss varying types of support provided by men (Catania et al., 2019; Gürsoy et al., 2017; Nasiri et al., 2016). Three studies discuss the needs of sexual minority women (refers to people whose sexual orientation is not heterosexual, lesbian, gay, bisexual, and LGBT) post mastectomy (Mackenzie, 2015; Paul et al., 2014; Rubin & Tanenbaum, 2011). The 2011 article published by Rubin & Tanenbaum is included in this review of the literature as there is limited research in this area of sexual minority women. The final four studies address emotional distress, coping, body image concerns, and sexual functioning of men whose loved

one underwent a mastectomy (Cheng et al., 2018; Loaring et al., 2015; Shaffer et al., 2022; Yoshimochi et al., 2018).

Informational, Instructional and Emotional Support

Breast cancer diagnosis and treatment has created several concerns facing the patient-intimate partner couple. Research has shown that as partners and their loved ones' work through their experienced challenges such as lack of communication, intimacy concerns, and a decrease in their satisfaction of their relationship, they become equipped with the necessary tools to be successful throughout this difficult journey (Zimmerman, 2015). Blais et al. (2014) aim to identify important components of a brief informational intervention designed to empower couples facing breast cancer and to validate the acceptability of these components. The informational interventions are developed to address building communication, practical considerations, life as a couple, and sexuality (Blais et al., 2014).

Social Support

Support offered through a support group is identified as a major theme in over 50% of the studies reviewed. Fergus et al. (2015) used an online support group that improved coping among the couple. Manne et al. (2016) performed an RCT and learned support groups allow partners to observe empathy, validate their concerns and hear first-hand the type of support desired during this most challenging time. Fang, Chang, and Shu (2015) show that partners provide essential support among women with breast cancer. The results of this study support the authors' hypothesis that partner empathy decreases depressive symptoms indicating that women receive greater empathy from partners. Thus, partners play a significant role in reducing women's distress as they learn and practice empathetic skills in support groups with their mates.

Social support expressed through instrumental and emotional avenues from partners appears to be important contributions to a successful journey toward adjusting to breast cancer and its treatment (Zimmerman, 2015). In a cross-sectional, mixed methods design involving 48 spouses of newly diagnosed women with breast cancer, the spouses describe changes in their relationships in communication, roles, and their hopes (Duggleby et al., 2015). This same study reported that male spouses experienced disruptions in their sleep, eating habits, and ability to work (Duggleby et al., 2015). A lack of open and constructive communication for the couple may contribute to concerns about sexuality and depression (Ghizzani et al., 2018). In another cross-sectional correlational design study, spouses reported their quality of life improved as hope increased (Duggleby et al., 2014). Thus, it is important to maintain hope that the treatment and diagnosis will be positive and communicate this positivity with the partner.

Support should be provided in the early phases of the disease and treatment, focusing on social, psychological, and spiritual needs. It is extremely important to involve the main caregiver who is often the intimate partner (Ghizzani et al., 2018). In a qualitative study by Yoshimochi et al. (2018), men expressed willingness to provide care, comfort, and support to women through treatment. The ability to express sensitivity and recognize when the woman experiences distress was also significant finding. Mackenzie (2015) observed in a qualitative study of 26 Australian women that interconnections between social and individual factors provided intimate partner support, which is optimal for achieving quality cancer care. An area neglected in the literature was the support for sexual minority women. Sexual minority women require partner support when faced with breast surgery. In one qualitative study, Brown and McElroy (2018) explored sources of stress and support experienced by sexual minority breast cancer survivors and the impact of treatment on their lives and found there was a need for appropriate social supporters

for patients and partners of breast cancer treatment. In another qualitative study, Paul et al. (2014) gathered four themes for the support needs and resources of sexual minority women: the value of support groups, social support resources for same-sex partners, support for the partner, and family. To evaluate the needs of heterosexual women, Carr et al. (2019) performed a qualitative study and found that women expressed four support needs: access to information, help with daily tasks, emotional connection, and being understood. In viewing partner's needs, male partners prefer the use of their own internal resources and informal supports (Cheng et al., 2018).

Communication

Communication between the partner and the person who has experienced a mastectomy is a common theme represented in this integrated review. Women's perceptions of their partners' empathy allow them to feel understood and valued and played a significant role in reducing women's stress (Fang, Chang, & Shu, 2015). Loaring et al. (2015) performed a qualitative study and found that women experienced "avoidance" during the interview when answering questions as a couple. However, the couple did concur on the need to communicate more clearly to build their relationship. Another study has shown that partners can find it difficult to cope, and communication can lessen the partners anxieties (Rowland & Metcalfe, 2014). Favez et al. (2017) found that structured interventions targeting communication in couples reduce distress and increase coping skills. To determine if these same issues were prominent among different ethnic groups, a later study investigated the Chinese culture and determined that improving couple's communication when openly discussing private concerns may be helpful for the partners in understanding the concerns of women.

Additionally, intimate partners could use empathy to help reduce body image discomforts (Fang, Lin et al., 2015). In a relationship, the spouse is usually the most frequented source of support. However, the spouse can be affected as much as the patient while facing breast cancer but may feel that they are unable to speak freely of their concerns (Blais et al., 2014). Huynh et al. (2022) suggested that clinicians are open to instruction, and that patients are eager for education as it will assist to normalize their sexual health and reduces anxiety in discussing, provides an opportunity for further questions, and helps improve communication with partners. Throughout the breast cancer experience, couples react as an emotional system rather than as individuals, and their communication is pivotal in dealing with breast cancer and its treatment (Blais et al., 2014).

After a mastectomy, intimate partners can experience sexual difficulties and communication difficulties (Lamore et al., 2019). Communication and intimacy-based interventions are essential yet remain overlooked for cancer survivors and their partners Shaffer et al., 2021). Shaffer et al. (2021) revealed themes suggesting partners placed immense importance on providing emotional support and communicating.

Decision-Making

This integrated review presents three articles that found decision-making was involved in breast cancer and treatment. Factors guiding the experiences of partners regarding the decision-making process for breast surgery are not very well understood; however, a minimum amount of information on the topic is available in the literature (Fasse et al., 2017). Shapira et al. (2018) found that partners are integral to the decision-making process when considering a genetically necessary mastectomy. In a different study, Kuo et al. (2018) found that support of the partner was not significant in decision-making, yet it was advisable to decrease feelings of regret. Two

studies indicated that being in a relationship influenced the decision-making process for breast surgery (Ghizzani, et al., 2018; Fasse et al., 2017). In addition to physical care, the social-emotional support of caregivers has a positive effect during decision making and processing (Clarjis et al., 2022). As a result, the decision to undergo mastectomy or not remains a decision that both the intimate partner and their loved one experience.

Emotional Responses

Four studies explored an emphasis on the male partners' emotional, informational, and instructional support in this integrated review. In one study, male partners wanted information on dealing with emotional and psychological distress (Cheng et al., 2018). In another qualitative study with this same focus, the authors learned that men's experiences of emotional and social support impact their partners' post-mastectomy and improved relationship (Gürsoy et al., 2017). In some cases, participants were concerned with the recurrence of the cancer and the patient's unexpected demise (Catania et al., 2019). Thus, a crucial concern that is pertinent includes the emotional responses among partners and their loved ones. Favez et al. (2017) carried out a cross-sectional design and discovered lower couple satisfaction as partners refrained from negatively expressing feelings and then displacing those feelings onto their partners.

Body Image

Women are concerned with how their partners see them; breasts often symbolize femininity, and these feelings are exacerbated in women who feel their bodies have been mutilated with breast surgery (Fang, Chang, & Shu, 2015; Gürsoy et al., 2017). In one investigation, research supports that a mastectomy can disrupt a woman's physical appearance and create distress (Ghizzani et al., 2018). In this integrated review, several studies reported that women experience body image concerns (Fang, Chang, & Shu, 2015; Fang, Lin et al., 2015;

Loaring et al., 2015). Problems with body image seem to persist up to 2 years postoperatively, with over 50% reporting problems with their scars and appearance (Frost et al., 2011). The perceived level of social support offered by others has been associated with improved psychological adjustment for women with breast cancer. Partners play an important supporting role for women with breast cancer as they navigate through their diagnosis and treatment and adjust to their post-cancer lives (Archer et al., 2018).

The women who described prominent levels of partner support experienced a smoother and expedited adjustment regarding intimacy. This supports earlier research that linked partner support with greater relationship satisfaction and couples' experiences of intimacy after mastectomy (Loaring et al., 2015). Fang, Chang, and Shu (2015) found that as women are affected by breast cancer, surgery, and other treatments such as hormone therapy and/or chemotherapy, they often experience body image problems. They additionally found that marital coping efforts have a mediating effect on the relationship between body image and sexual functioning. In a study of four couples, Loaring et al. (2015) determined there was a shift in the view of the body among the couple. Women had feelings about the attractiveness of their bodies, while men emphasized their interest in their partners regardless of the loved one's body. In contrast, Fang, Chang, and Shu (2015) found no significant relationship between empathy from a partner and body image. Changes in sexuality occur in patients with breast reconstruction in addition to the altered body image through lack of sensation in the breast and inhibition of the partner to touch the mastectomy area (Schmidt et al., 2017).

Distress

Research has shown that women who have undergone a mastectomy can suffer psychological burdens, yet there is little mention of the partner's experience of burdens and

psychological stress (Chronopoulou et al., 2016). The burden of caregivers has continued to grow, and caregivers feel obliged to provide care to their loved ones (Clarjis et al., 2022).

Previous studies demonstrated that husbands experience role strain when trying to carry out their usual roles at home and work, which often places strain on relationships with partners and may lead to marital strain (Fang, Chang, & Shu, 2015; Favez et al., 2017). Distress is one strain that men experience, especially when it comes to thoughts of loss of their spouse. Manne et al. (2016) discovered interventions that focused on relieving anxiety, decreasing depressive symptoms, and decreasing cancer specific stress while promoting positive well-being for couples. In another study, Nicolaisen et al. (2014) found that their interventions reduced cancer related distress.

Mauer et al. (2016) also reported that men had concerns regarding the lifespan of their partner. In a later study, Yoshimochi et al. (2018) performed a qualitative study and learned that men experienced emotional distress caused by the fear of losing their partner. The devastation associated with loss of a partner is an area for further research.

Finances

A financial burden may occur for the couple experiencing a breast cancer diagnosis. The person experiencing the mastectomy may be unable to work, resulting in a decrease in finances to support their family. Nasiri et al. (2016) performed a qualitative study and found that Iranian men experienced disorganization of their family life, with their major concern being financial challenges associated with the breast cancer treatment. Men must adjust to varying degrees of life changes post-mastectomy and financial worries is just one area of concern. Catania et al. (2019) performed a qualitative study and learned that men faced financial challenges and felt the need to provide for the family. Thus, financial burden is an experience that men may face post-mastectomy of their intimate partner.

Empathy

The importance of emotional and instrumental support from partners of breast cancer patients is supported by recent literature that shows partner support can minimize the impact of changes in a woman's body image and on the number of depressive symptoms she experiences (Fang, Chang, & Shu, 2015). The literature review found that some spouses of patients with cancer described themselves as helpless and incompetent and required more information regarding their partners' breast cancer to assist them on this difficult journey (Fasse et al., 2017). This lack of being able to express empathy could result in a couple deciding to go their separate ways. In one report, women reported that their partners did not provide support during their breast cancer journey, which resulted in separation from their spouse (Mackenzie, 2015). In this same study, a participant shared that she felt her husband experienced more life stressors and changes than she experienced, while another participant felt her partner wanted to be supportive, but it was too much for him and he grew angry. The male partner often provides emotional and practical support, but they did have difficulties recognizing when their support was needed. Thus, it is critical to recognize the stress and symptoms that lead to the wives' depression.

Couples

According to the literature, couples who attend support groups that target health preservation, problem-solving, and communication improve the caregiver's quality of life (Ghizzani et al., 2018). Çol and Kiliç (2019) performed an RCT that focused on assessing the effects of a training program and counseling program of women and their spouses. They found that training and counseling programs structured with health promotion model positively influenced the ability to solve financial and moral problems, open communication, and equal distribution of roles.

Intimacy

Intimacy concerns may have arisen during diagnosis and treatment of breast cancer, which can often lead to sexual dysfunction if not properly addressed. Shaffer et al. (2022) suggests that partners have reported difficulty discussing sexual concerns, describing reactions to physical changes and fear of hurting their partner (Shaffer et al., 2022). The quality of intimate relationships is related to higher sexual satisfaction, improved body image, and overall adaptation to the disease (Ghizzani et al., 2018). The intimate relationships reflect a fundamental relationship centered around partner responsiveness. During this process one partner discloses personal feelings and information to their partner who then responds in verbal and non-verbal ways to be responsive (Fenech et al., 2022). Intimacy depends strongly on the degree to which the partner responds to feeling understood, validated, and cared for (Fenech et al., 2022). Partner responsiveness and communicating verbally and non-verbally are key determinants of intimacy and can accumulate over repeated interactions to contribute to more broad evaluations of a partner being supportive, trustworthy, and loving (Fenech et al., 2022). Fang, Chang and Shu (2015) identified four factors that were influenced by women's partners: sexual difficulties, sexual performance, sexual esteem, and sexual intimacy. Several of the studies reviewed shared these themes. In one study, the breasts of women were associated with psychosocial issues and sexual identity, sexuality, maternity, attractiveness, and femininity (Jabłoński et al., 2018). The partners expressed feelings of being estranged from their loved ones as well as discomfort with the breast surgery. They additionally expressed that touch and sexual intercourse eventually took on a new meaning. Another study reported difficulty in developing sexual relationships with men. Fenech et al. (2022) found that perceived partner responsiveness is a key determinant of intimacy as it contributes to partner supportiveness, trustworthiness, and a loving relationship.

Women experienced less intimacy, fear, and tension in their intimate relationships with their partners after having a mastectomy (Jabłoński et al., 2018).

Nasiri et al. (2016) learned that men experienced loneliness as they felt neglected by their spouse, lack of understanding from others, and worry about their partner. In a similar study, Mauer et al. (2016) performed a quantitative study of 25 male partners and found that 24% were less intimate. The authors further learned that the partner's loss of breast sensation was a concern in 36% of participants and the need for physical attractiveness for their partner was only experienced in 18% of participants. Thus, research indicates that attractiveness is not the main concern when it comes to male participants. In a recent study by Ghizzani et al. (2018), the authors recommend that the couple participate in an intervention that improves communication, intimacy, and harmony. During the intervention, the couple spends time creating physical intimacy. Findings implied that reducing husbands' caregiving burden, increasing marital satisfaction, helping them to reevaluate the negative impact of breast cancer, and reducing barriers of expressing emotions and concerns may increase their sexual well-being.

Caregiver Roles

Breast cancer not only affects women, but also decreases family functioning and quality of life for their spouses who often fulfill the role of care giver (Çol & Kiliç, 2019). Nasiri et al. (2016) revealed that most husbands accepted that their wives were no longer able to engage in household chores, so they performed chores to show empathy and love. Similarly, Chronopoulou et al. (2016) performed a quantitative longitudinal study and found that husbands experience significant strain following their spouse's mastectomy related to their roles as a caregiver. Engaging caregivers during the treatment of breast cancer and optimizing the communication

between provider, patient, and caregiver may lead to better patient outcomes and breast cancer care post mastectomy (Clarjis et al., 2022).

A later study by Loaring et al. (2015) performed a qualitative study consisting of eight semi-structured interviews among four heterosexual couples and found the need to offer psychological support for women and their partners surrounding sexual intimacy and body image. Access to therapeutic support can help maintain physical and verbal relational dialogue between the woman and her partner. These studies discuss the experiences of the caregiver role and how the partner remains an integral part throughout the cancer process.

Coping

Coping was addressed in the literature as an experience of the partner supporting a person who has experienced breast cancer and treatment. In a cross-sectional study, Fang, Lin et al. (2015) found women's experience of connectedness to their significant others contributes to their self-concept development. The findings also indicate that a woman's sexual relationship may be addressed by focusing on couple interaction rather than individual coping. Sun et al. (2018) found changes in a woman's identity; additionally, coping with these changes helped them to live with this change (Fergus et al., 2015; Sun et al., 2018). Fergus et al. (2015) developed an online program designed to guide mental health professionals and couples cope throughout the breast cancer process. Additionally, Shapira et al. (2018) performed a cross-sectional study and found that partners of women undergoing risk-reducing mastectomy are more satisfied with their relationship and cope better than their partner.

Gaps in the Literature

Several gaps were identified in the literature review. The loss of the breast, whether identifying as male or female, is a difficult and challenging experience that should involve

intimate partner support. One of these gaps surrounded the support needs of sexual minority women in comparison with heterosexual women. Four reviews identified the need to explore this underserved area. One study identified a lack of exploring lesbian women's experiences of their partner's altered body image as a result of a mastectomy and subsequent reconstructive surgery due to breast cancer (Rowland & Metcalfe, 2014). A second study identified experiences of partners in same-sex relationships and women's attitudes and concerns about males with breast cancer as a gap (Mauer et al., 2016). Recently, Stone et al. (2018) performed a systematic review of the literature regarding transgender relationships that involved breast cancer. The study documented reported an increase of cases of female to male breast cancer, which led to research recommendations for screening for cancer at a person's birth. Another recommendation suggested that transgender men undergo an annual chest exam over the age of 50 (Stone et al., 2018). Few studies assessed sexual orientation and made efforts to include sexual minority women (SMW) in this systematic literature review. Further research is needed to explore the experiences of SMW with racial or ethnic differences. As more transgender patients are seeking surgical options including cross-sex hormone therapy, it is critical that transgender women are taught the importance in breast screening including mammography and ultrasonography to embody their female identity (Stone et al., 2018). Research in breast cancer of the transgender population is limited and even more so in the area of their intimate partners' feelings regarding the experience of breast surgery (Stone et al., 2018).

To date no published study has considered specifically how the partners' quality of life is affected by the types of transitions that accompany caregiving for a spouse with breast cancer, and how they deal with these transitions (Duggleby et al., 2015). Other gaps exist when the person undergoing a mastectomy wants the partner present but lacks the ability to explain what is

needed. The partner desires to be present but often struggles with how (Fasse et al., 2017). Negative communication can occur in both partners, and women are more likely to address criticisms than their partner. Targeting communication in couples facing cancer throughout phases of treatment has been shown to be effective in reducing distress and increasing coping skills (Favez et al., 2017).

Many of the studies reviewed interviewed the partners together as a couple rather than individually, which could have censored the responses in front of the partner (Fasse et al., 2017; Favez et al., 2017). This process fails to capture the needs of the individual partner. Additionally, interviewing couples together does not allow the intimate partner to speak freely without fear of hurting the partner's feelings if they are candid. There is limited information regarding how partners of post-mastectomy individuals perceive their partners changes related to the results of their breast surgery. Thus, knowledge of men's experiences during the partner's breast cancer diagnosis and treatment can be helpful as other partners are faced with similar challenges regarding breast cancer treatment (Catania et al., 2019; Gürsoy et al., 2017; Mackenzie, 2015). Partner involvement is recognized as important in reaching optimal care, thus research is needed to understand the effects of perceived partner support on breast cancer survivors (Mackenzie, 2015).

Discussion

Even though partners of individuals with cancer described themselves as helpless and incompetent, studies found that emotional and practical support were present. Examples of this support included accompanying their partners to medical appointments, managing the home, putting a greater emphasis on their quality of life, and building sexual relationships with partners (Fang, Lin et al., 2015; Favez et al., 2017). These are just a few of many examples of support for

the intimate partner that express their concern and help to their partner. The synthesized findings in this integrated review are significant as the intimate partner takes an active role in caring and supporting their partner post-mastectomy. After the intimate partner is equipped with the necessary information regarding sufficient caring for their loved one, the intimate partner can then assist through coping strategies and supportive information to function as the main support person during this emotional and challenging time.

Limitations of the Review

This integrated review has several limitations. The review includes literature published from the last 9 years from 2014-2022. As the literature is limited in the transgender population, an article was included from 2011 to capture information about this population. No information was found concerning the male patient who has undergone a mastectomy and the support of his intimate partner. The sample composition is comprised of primarily Caucasian, well-educated, and primarily heterosexual couples. Most spouses were men, and all patients were women. The articles that discussed couples interviewed the participants together instead of individually.

Raw data analysis was undertaken by one person which can reduce the range of possible interpretations. Much of the current research assessed focuses on the couple facing breast cancer surgery. The sample characteristics of the studies are also limited as a majority of the studies reported findings from predominantly White, middle-class, and well-educated couples. Articles that were not published in the English language were excluded because of lack of access to translation services. No articles were produced with the utilized search terms that located research pertaining to the male partner who had a mastectomy and the experiences of the female partner. Therefore, further research should be conducted to explore the experiences of intimate partners of a person that has undergone a mastectomy.

Relevance to Clinical Practice

The findings of this integrated review highlighted a wealth of information regarding experiences of male partners and spouses of patients who have undergone a mastectomy. The articles reviewed and synthesized did provide information that can be generalized to men, yet there remains a gap in including intimate partners experiences after their loved one had a mastectomy. Several areas were identified that could be used to implement programs in the healthcare arena to offer support for intimate partners. To ensure that these programs address the intimate partners' needs, there must be an opportunity to understand their experiences.

Summary

This integrated review provides descriptions of partner support for a person who has undergone a mastectomy by synthesizing primary research studies. A wealth of information is available concerning the experiences of a person who has experienced a mastectomy. This research has since been used to develop interventions and programs to assist the person that has undergone a mastectomy. There is a need to understand the experiences of intimate partners as they too are affected by breast cancer and the results of a mastectomy of their loved one. The perceptions and understanding from the experiences of the intimate partner can contribute to positive emotional, physical, instrumental, and social support that can be used in continuing to demonstrate support of a person who has undergone a mastectomy.

CHAPTER III

METHODOLOGY

Procedure for the Collection and Treatment of Data

A descriptive phenomenological approach was chosen for this study as the literature lacked the lived experiences of intimate partners who have cared for individual's post-mastectomy in the post-operative phase during the last 5 years. Identification of factors that facilitate intimate partners' ability to provide care and support for their partners allowed the opportunity to understand multiple factors that influence the ability to provide optimal caregiving (Duggleby et al., 2014). Edmund Husserl's concept of descriptive phenomenology involves the following four steps: bracketing, intuiting, analyzing, and describing. In examining the lived experiences of the intimate partner, the researcher used bracketing to allow openness to meanings of the phenomenon associated with the lived experience of intimate partners, and to extract significant meanings to understand and define the phenomenon (Polit & Beck, 2021). Colaizzi (1978) believed that the success of phenomenological research was dependent on utilizing questions that gained lived experiences distinct to theoretical explanations (Edward & Welch, 2011). Thus, qualitative methods are useful in exploring and understanding the lived experiences of an intimate partner of someone that has undergone a mastectomy.

Setting

The participants were recruited from two support organizations: Reconstruction of a Survivor (ROS) and Facing Our Risk of Cancer Empowered (FORCE). ROS is a non-profit breast cancer organization sponsoring several services for women diagnosed with breast cancer and survivors of breast cancer, located in Houston, Texas. FORCE was founded in 1999 to fill the information void for individuals and families with hereditary cancer and to help them

advocate for themselves. The organization has become an unequalled source of research, advocacy, support, and information regarding risk management, prevention, and awareness. The FORCE headquarters is in Tampa, FL. Participants were recruited from anywhere over the 50 states through online presence.

The location, date, and time of the semi-structured interview (see Appendix A) were mutually agreed upon by the participants and the investigator to allow for a private and confidential conversation, either in-person or via Online platform (if not local).

Population and Sample

A criterion sample was used to obtain rich descriptions of the lived experiences of intimate partners of a person who underwent a mastectomy. According to Morse (2000), the ideal sample size of a phenomenological study in which one has a large amount of data for each participant is six to 10 participants. In this study intimate partners were invited to participate. Semi-structured interviews (see Appendix A) ensued until saturation was met at 13 participants. Eligibility criteria for participation in this study included being the intimate partner or spouse (male or female) of a person who underwent a mastectomy. The participants were between the ages of 18 and 75 years of age. The participants were those who wanted to share their experience of the care/support that they provided to a loved one after a mastectomy. Participants needed to be willing to commit to a semi-structured interview (see Appendix A) that was approximately 60 minutes in length.

The sample size goal for this dissertation was up to 30 participants, including the participants from the pilot; saturation was reached at 13 participants using criterion sampling. Data saturation means the researcher identified categories and themes and continued

interviewing new participants until the new interviews no longer provided additional or new data into the category and/or theme(s) (Creswell, 2007).

Participants were recruited from ROS and FORCE support organizations. The researcher contacted the director of both organizations and informed them about the study to gain support and access to these establishments. Recruitment flyers (see Appendix B) were placed on a table at support group meetings and the leader of the support group announced a study taking place that was voluntary and without incentives at the ROS organization. Participants who were out of state were recruited via the organization's website. The directors posted the recruitment flyer (see Appendix B) on the websites of ROS and FORCE. The recruitment flyer (see Appendix B) also included the PI name and contact information, the goal of the study, and the eligibility criteria. Participants who were interested in participating were asked to contact the PI directly by phone or email for more information. Once contacted, the PI used the telephone script (see Appendix C) and determined if the participant met the inclusion criteria. If the participants were still interested in participating after speaking with the PI, a mutually agreed upon time was established for the interview to take place. The participants had a choice of face to face or via online meeting. At the face-to-face meeting, the consent form (see Appendix D) was provided, explained, and then signed by the participant. If the meeting was online, then the PI would email the consent form (see Appendix D) immediately before the interview began and the participant would return the form to the PI, then the interview began. The demographic information form (see Appendix E) was completed by the PI at the time of the interview.

Protection of Human Subjects

The Institutional Review Board (IRB) approval form at Texas Woman's University approved the research study in August 2018 (see Appendix F). The PI completed the Protection

of Human Subjects module as required by Texas Woman's University and adhered to the IRB's current rules and requirements in completing this study.

The potential risks included the possibility of feelings of distress by the participant, loss of confidentiality, loss of time, and fatigue. If distress was noted, the researcher or participant had the option to stop the interview. The participant was also given the choice to skip the questions that they did not feel comfortable answering. As none of the participants shared experiencing emotional discomfort during the interview, the researcher did not provide additional resources for distress.

Another potential risk was loss of confidentiality. At the beginning of the interview, the researcher explained that all dialogue and participant's identification would be kept confidential. Audio recordings, all data/transcripts, and all consent forms (see Appendix D) and the demographic information forms (see Appendix E) were retained in a locked file cabinet in the researcher's home to which only the researcher had the key and access to the information. The researcher transcribed the audio recorded tapes and stored the audio tapes and transcriptions in the locked cabinet in the researcher's home. Only the researcher had access to the transcripts. The researcher removed all names and identifying information from the transcripts and coded appropriately.

Loss of time was another potential risk of participation in the study. All participants were informed of the maximum time commitment, which was no longer than 60 minutes. The participant was notified to set aside 60 minutes for the interview prior to the actual interview. No compensation was offered for participation. Lastly, fatigue was a potential risk as the participant was asked to converse in an interview that could tire them due to the length of the questions.

The original consent forms (see Appendix D) were locked securely and separately from the data. To ensure anonymity, participant numbers were substituted for the participants' names, and any information that participants provided was password-protected and encrypted. Participant identifiers were kept separate from the audiotapes and typed transcripts and were not disclosed in any publication or presentation of findings. Audiotapes were erased once they were transcribed, and the analysis was completed. Transcripts will be kept on file for 5 years in the researcher's home in a locked cabinet, and they will then be shredded and disposed of to protect confidentiality. The participant was informed that they were able to stop the interview and/or take a break at any time they chose. Information regarding distress was available to the participants if they verbalized at any time, they felt stress or discomfort.

Data Collection

The ROS and FORCE agencies posted the recruitment flyer (see Appendix B) on their websites and made them available at support group meetings. Interested participants contacted the PI to set up a confidential interview in-person or via online meeting program. Two individuals elected face to face interviews and due to a pandemic the remaining 11 participants were interviewed online using a meeting program. Participants were informed of the research study via telephone using the telephone script (see Appendix C). The participant received and reviewed the consent form (see Appendix D) in its entirety by email immediately before the interview began. The participant then returned the consent form (see Appendix D) and the interview was completed. On the two occasions when the interview took place in person, the PI reviewed the interview process and obtained informed consent at the time of the scheduled interview. Each interview was confidential and followed a semi-structured interview guide (see Appendix A). At the beginning of the interview, the researcher introduced oneself and shared

with the participants the reasons for conducting the study, answered any questions, and informed them that they could skip any question or stop the interview at any time. The interview began with the first interview question and continued. Verbal probes asking for clarification were used, such as, “Can you give me an example?” “Can you explain more?” and “What do you mean by that?” Some verbal cues such as “oh,” “that is right,” “I got what you mean,” ah,” and “I see” were also used when a conversation needed promoting. Following the interview, each participant was thanked for their time and interest. Field notes were taken after each interview to capture a wide range of information from the participants and to ensure all important observations occurring during the interview, such as nonverbal behaviors, were documented (Polit & Beck, 2021). Participants were notified that interviews would not have any identifiable data to maintain confidentiality. All participants were assigned a participant number that linked them to their interview. The participant numbers and recorded interviews were kept in a locked file cabinet in the home of the researcher on a laptop computer. Participants were informed that their participation was completely voluntary, and they may discontinue participation in the study at any time. Interviews were conducted in private to ensure the participants were comfortable and able to speak openly about their experiences, thoughts, and feelings. All interviews lasted no longer than 60 minutes and proceeded until all interview questions were processed. Each interview was audio-recorded and transcribed verbatim as soon after the interview as possible, and field notes were taken with each interview, noting observations, e.g., emotions, smiles, tears, pauses, and any other pertinent non-verbal behaviors such as “um,” “hmm,” and “uh.” Silent periods, smiles, and facial expressions were examples of some observed behaviors that were documented in the field notes immediately after the interview. Demographic information form (see Appendix E) was obtained through a paper and pencil questionnaire that included

information on age group, gender, race, marital status, and educational level, either during the interview or pre-interview. All recordings, signed consent forms (see Appendix D), and completed demographic information forms (see Appendix E) were stored confidentially in the investigator's home office in a locked file cabinet and the PI was the only individual with access to the locked file cabinet.

Data Analysis

Colaizzi's (1978) analytic method was utilized to analyze the data of this descriptive phenomenological design. Data analysis occurred concurrently with data collection. Colaizzi's (1978) method consists of seven steps:

1. Read and reread all protocols to acquire a feeling for them.
2. Review each protocol and extract significant statements.
3. Spell out the meaning of each significant statement (e.g., formulate meanings).
4. Organize the formulated meanings into cluster of themes.
 - a) Refer these clusters back to the original protocols to validate them.
 - b) Note discrepancies among or between the various clusters, avoiding the temptation of ignoring data that do not fit.
5. Integrate results into an exhaustive description of the phenomenon under study.
6. Formulate an exhaustive description of the phenomenon under study in as unequivocal a statement of identification as possible.
7. Ask the participants about the findings thus far as a final validating step.

In this study, Colaizzi's (1978) method was applied in the following manner (Edward & Welch, 2011). First the researcher read and reviewed the transcribed audio-taped interviews. The participants' transcripts were transcribed verbatim using NVivo, a qualitative data analysis

software. Each interview was transcribed with a professional transcription service and saved into Microsoft Word Software. The transcripts were analyzed line by line and then initial coding was conducted by highlighting key words, phrases and sentences that were repeated throughout each transcript and writing codes in the margins of the transcripts. These initial codes were then collapsed into common categories. These categories were generated by grouping similar codes together. The categories were then grouped together to create the final themes. Direct quotes from participants were used to illustrate the themes and to link them to the intimate partner experience. Next, the researcher extracted significant statements and used those statements to form meanings. The researcher then clustered the formulated meanings into themes to identify the lived experience of the intimate partner of a person who had undergone a mastectomy. At that point, the researcher reviewed each transcript and determined if any pertinent information was missing. The researcher then analyzed the clusters of significant statements and carefully captured themes. During this step, the researcher also noted any discrepancies among or between the clusters of meanings after an additional review of the transcript. New themes were carefully categorized and those themes that did not fit were discarded. Themes were used to capture the essence of the lived experiences of intimate partners. The researcher continued to interview participants until saturation was reached. The researcher reviewed the themes for commonalities and significant responses from participants that addressed the lived experiences of the intimate partners. Lastly, representation and visualization were used to present a narration of the essence of the experiences and noted in tables, figures, and notations to further understand the phenomenon.

The researcher completed a pilot study of three participants. Two of the intimate partners were same sex partners and the third participant was a male spouse. One of the individuals was

interviewed in person (prior to the COVID-19 pandemic) and the other two were interviewed via an online meeting platform. Moving forward, all participants were interviewed online. In the first interview, the participant was very talkative and engaged in the conversation. At times, the participant seemed to take the lead role. A lesson learned was to adhere to the script and as the participant deviates from the designated topic, gently redirect to obtain all the needed information in the 60 minutes allotted for the interview. The first interview took more than 90 minutes and the researcher had to redirect to end the interview. The researcher learned that the list of resources needs to be available at the close of the interview and shared with the participant. This would allow the participants to have the needed resources as they deemed it necessary post interview. Another challenge was gaining the availability of the participants. The researcher was very flexible with scheduling the interview; however, one of the participants was extremely busy and changed the meeting more than three times. While this was frustrating to the researcher, the researcher was more than happy the participant did not back out of the study due to unavailability. Moving forward the researcher requested three dates and times of availability to allow for more flexibility. The interviews were very enlightening and offered much information. The researcher transcribed the three interviews verbatim and determined that a professional transcriptionist would be needed.

Strengths and Challenges

The study findings can help guide critical areas for healthcare promotion and support in intimate partners due to the increasing prevalence of breast cancer and mastectomy procedures. The interviews were conducted in the participants' primary language (English), which enabled the researcher to elicit rich, in-depth personal stories from intimate partners about their experience of caring for a person who has undergone a mastectomy. The sample included

intimate partners with varied, but primarily higher, educational levels. The short time commitment allowed the participant to not be interrupted drastically by the interview. The researcher remained flexible and was able to continue interviewing participants until saturation was reached. Challenges included use of online platform, which creates roadblocks to the establishment of trust between PI and participants. The researcher perceived, in general, less connection between the PI and participant, which may have been less had the interviews taken place in a face-to-face manner. In some cases, this was not the most private for some participants who had individuals in their home. They had to stop the interview and find a more private area to continue. More participants may have been recruited if an in-person interview was possible as many do not prefer to utilize online platforms for such intimate details to be shared. However, a much broader geographic area could be covered due to the online platform.

Rigor

In order to establish and enhance trustworthiness, the researcher evaluated and engaged in several strategies related to credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Credibility refers to confidence that the findings and interpretations of the research data is true (Polit & Beck, 2021). It is also defined as the extent to which the interpretations reflect the participants' lived experiences. The researcher considered if the results reflected the intimate partners' experiences and context in a believable manner. To ensure credibility was achieved, the researcher reminded participants that they were free and safe to answer the questions. Prolonged engagement with participants and the use of a semi-structured interview guide (see Appendix A) with open-ended and probing questions encouraged open dialogue which enabled participants to provide rich descriptions of their lived experience of being an intimate partner of a person who underwent a mastectomy. To establish credibility, the

researcher engaged in in-depth conversations and a thorough review of participant transcripts during data collection. Member checking was used to ensure the meaning of their lived experience as the intimate partner of a person that underwent a mastectomy was captured and interpreted correctly. Member checks mean the data and interpretations are continuously tested as they are arising from the participants, and it is part of the collaborative process of discussing findings with participants as themes emerged. The researcher then reviewed the transcripts to ensure that they were accurate, and the richness of the participants responses were extracted and reviewed. Transferability refers to the extent to which the qualitative research might resonate with others rather than being generalizable to similar settings (Polit & Beck, 2021). The researcher facilitated transferability by providing sufficient descriptions and using purposeful sampling. The researcher provided rich thick descriptions of the intimate partners' experiences, results, data collection, context of the study, and themes (Munhall, 2012).

Dependability refers to the reliability of data over time and conditions. The PI recorded the precise methods for data collection, analysis and interpretation and provided adequate contextual information about each piece, so that the study could theoretically replicated by other researchers and generate consistent results (Polit & Beck, 2021). Detailed accounts concerning methodology, data collection, and analysis were maintained to achieve dependability.

Confirmability ensures that the data represent the information participants provided directly and that the researcher did not change this data or interpret incorrectly (Polit & Beck, 2021). Accuracy, relevance, and meaning of the data are essential in mastering this criterion. The researcher incorporated the participants' voice by analyzing how the participant responded to the questions, thus eliminating the researcher's biases, motivations, or perspectives. The researcher listened without adding any of their own feelings in the interview. The researcher accounted for

all pauses and unspoken words within the transcription of the interview. In transcriptions of the interviews, pauses and sighs were noted to capture the emotion of the participants for relevance, accuracy, and understanding of the significance of what was shared.

The researcher established authenticity of the data collected and the data analyzed by using validation. The researcher did not generalize about particular people, settings, and times, and observed for threats such as sampling bias and validity concerns. To ensure valid research, the researcher aimed to ensure that the research was based on trustworthiness and external reviews. This was completed by utilizing data, extensive excerpts from transcripts, to enhance the quality of the study and extractions of themes. Descriptive validity was documented as the researcher noted accurate, factual description of what was heard, felt, and observed. The researcher utilized interpretive validity to present an accurate account of the meaning of significant statements of the participants.

Summary

A descriptive phenomenological approach utilizing feminist inquiry was used to collect data for this qualitative study. The potential participants were recruited through the use of recruitment flyers and purposive sampling was used to recruit intimate partners in two support organizations, FORCE and ROS. The consent forms were reviewed prior to beginning the interview and anonymity of the participants were a priority to the PI. The study followed the rules of the IRB in order to ensure the proper consent and privacy of the participants. Each participant was assigned a participant number to avoid potential loss of anonymity. Data were collected through the use of a semi-structured interview guide and a demographic form. Qualitative data analysis was completed using the seven steps of Colaizzi's data analysis (1978) model. Colaizzi's (1978) data analysis method was employed to analyze the participants'

transcripts. Multiple methods of rigor for a qualitative study were employed to demonstrate rigor and ensure results accurately depicted the lived experienced of intimate partners of someone that underwent a mastectomy.

CHAPTER IV

RESULTS

Analysis of Data

The purpose of this study is to understand the lived experiences of the intimate partner who provided support post-operatively to a person (male or female) who underwent a mastectomy during the post-operative phase within the last 1 to 5 years. Numerous studies have explored the experiences of women who have undergone a mastectomy; however, there are few studies concerning the lived experiences of the intimate partner. This chapter presents the data analysis and findings of this study. Demographics are described, and key findings or themes are identified and explored. The data collection and analysis were ongoing, and the process of identifying significant statements began after the first interview.

The data analysis followed Colaizzi's (1978) seven-step method of phenomenological data analysis. In this method, all recorded interviews were transcribed and read several times to gain what was most meaningful in the responses; these were identified as significant statements. In reviewing each of the transcripts, significant sentences, quotes, and phrases were identified that pertain to the lived experiences of those who provided support to their intimate partner who had undergone a mastectomy. The significant statements were then grouped into larger units of information. These meaning units were then gathered from the sentences, quotes, and phrases to formulate themes common to all the participants' transcripts. The results were used to describe an in-depth description of the lived experiences of intimate partners who had provided support for a partner who had undergone a mastectomy. Methodological rigor included interviewing individuals who experienced being the intimate partner of a person who underwent a mastectomy. The interviews were recorded and transcribed. Other forms of data analysis were

observations of the individuals and notes that were taken throughout the interviews. In beginning the data analysis, the PI bracketed past experiences. In this process, the PI provided a description of experiences relating to the self and attempted to remove the self from the situation so that the focus could be on the participants' reflections. The data were then grouped into codes, themes, and categories. Rigorous data collection and data analysis included the construction of a table with all the responses and their associated formulated meanings. Horizontalization, the second step of phenomenological data analysis, involves listing every significant statement relevant to the topic. The PI accomplished this step by identifying a list of nonrepetitive, nonoverlapping statements that have equal worth. After themes were identified, a textural description of what the participants in the study reported was evaluated for rich, thick data, and verbatim examples were included from participants. Next, the PI reflected on the setting and context in which the phenomenon was experienced, known as structural description. Then an overall description incorporating both textural and structural descriptions were used to develop the essence of the intimate partners' lived experiences.

The descriptive phenomenological process developed by Husserl (1962) involved: bracketing, intuiting, analyzing, and describing (Polit & Beck, 2021). This process involved reflection on the investigator's reactions to the data and was based on the investigator's experiences and knowledge of the research topic. The descriptive process involved detailed description of ordinary conscious experience of everyday life as people experience it. The PI depended on describing what participants heard, saw, believed, felt, remembered, decided, evaluated, and acted on regarding their experiences. Rigor was facilitated by triangulation in which data collection occurred at different points in time over 4-5 months from participants with different experiences and viewpoints.

The method of collecting data was participant interviews utilizing a semi-structured interview guide. During the interview process, the interviewer listened, took notes, encouraged candor, and bracketed personal views. Interviews were initially held in person; however, the interviews were then moved to an online platform due to a pandemic. During this initial phase, the PI applied probing questioning techniques during interviews with the intent to collect more rich and thick data. These initial actions guided further collection of data and interviews that led to more profound and richer understanding of the participant's experiences. The pace of interviewing participants was limited to no more than one a day so that data from each interview could be reviewed and considered before proceeding with additional interviews. Additionally, compiling information requires the PI to be focused, which requires time to regenerate between interviews. The PI began by providing the intent of the interview and shared that if, at any time, distress or emotional stress developed, the participant could stop the interview. The PI shared that information about resources was available if distress was experienced. The PI was careful not to become involved emotionally with the participants to maintain meaningful and trustworthy data. The data was recorded using an audio recorder, detailed notes, and observation of the participant's nonverbal behavior were noted during the online platform interview. The PI transcribed the first two interviews and learned that it took more than 4 hours per interview. Thus, the interviewer used software, Sonix, to transcribe the remaining interviews which proved a more efficient use of time. Each participant's transcript was carefully labeled with an identification number and the interview date. The interview data were stored on the personal laptop in a password-protected file on the interviewer's computer. During the interviews, the interviewer created a respectful environment that encouraged participants to speak freely and openly. As data collection and analysis continued, additional probing questions were used to

obtain thick data. Semi-structured interviewing continued until data saturation occurred and no new emerging themes developed. Once all interviews were completed, the transcripts were read and reread to discover other subtle themes that were not initially identified.

The first step of Colaizzi's (1978) phenomenological data analysis was for the PI to provide a full description of their own experience with the phenomenon. In this step, the PI attempted to set aside their own experiences and focus on the information provided by the participants in the study. Next, a list of significant statements and phrases that seemed essential to how the participant was experiencing the phenomenon was created, which involved coding to generate as many conceptual codes as necessary to fit the data. The PI began analysis by scrutinizing the data carefully and becoming completely immersed in the data. The PI accomplished this task by reading and rereading the transcripts to better understand the meaning and significance of the phenomenon. After the PI became familiar with the data, clusters of themes emerged. These themes were validated by referring to the original transcripts. At this point, any discrepancies were identified and corrected. The PI reviewed the transcriptions for accuracy and ensured that the data was verbatim. The PI also listened critically and was careful to insert any nonverbal cues that were recorded during field notes. The PI classified, organized, and made the data more manageable. During this process, the PI developed a category scheme and coded the data using a software program, NVivo. NVivo provided an organized storage file system so that the PI could easily locate the material. The PI was able to review the information line by line in NVivo to accurately generate the meaning of the sentences and ideas. The PI then used Microsoft OneNote to categorize ideas to develop a list of nonrepetitive meaning statements that did not overlap. The researcher carefully read the data and clustered concepts, ideas, actions, and events associated with the participant's experience, extracted significant statements, and

grouped them into four themes and nine subthemes. Lastly, the PI developed textural and structural descriptions to describe the essence of the intimate partner's lived experience.

Description of the Sample

A total of 13 participants were interviewed for this qualitative descriptive study. Three of the 13 participants served as the pilot group to determine the interview protocol and the validity of the semi-structured interview guide. The pilot participant responses were included in the data analysis and results. The 13 participants included in the final sample were English-speaking intimate partners that lived in various parts of the United States. The participants were recruited through purposeful sampling. The participants were recruited through two support organizations: ROS and FORCE. Both support organizations provide support to multiple services for women who are diagnosed with breast cancer and their survivors. ROS was located in Houston, TX and FORCE was located in Tampa, FL. In using FORCE, participants could be recruited from anywhere over the 50 states through Skype or an online platform. Participants were recruited through fliers posted on the website and social media sites of both these organizations. The flyers were specifically seeking intimate partners of a person (male or female) who had undergone mastectomy. The participants were comprised of two females and 11 males. The participants who were interviewed reported the following races/ethnicities: Caucasian (69.2%), Hispanic (23.1%), and Black American (7.7%). Ages ranged between 25 and 75 years of age. Marital status consisted of (23.1%) single and (76.9%) married. The education level of the participants was (92.3%) with a bachelor's degree and (7.7%) with a master's degree. The participants were interviewed between February 2018 and June 2020 (see Table 2).

Table 2*Frequency Distribution of Participants*

Categories	Sample (n)	Frequency (%)
Age		
25-34	4	30.7
35-44	3	23.1
45-54	5	38.5
55-64	0	0
65-75	1	7.7
	13	100
Gender		
Male	11	84.6
Female	2	15.4
	13	100
Ethnicity		
White	9	69.2
Black	1	7.7
Hispanic	3	23.1
	13	100
Relationship Status		
Single	3	23.1
Married	10	76.9
Total	13	100

Findings

This study aimed to answer the research question: What are the lived experiences of the intimate partner who provided support post-operatively to a person (male or female) who underwent a mastectomy during the post-operative phase within the last one to five years? The following semi-structured questions was an instrument used to interview the participants in order to collect data that would capture responses of the participant's lived experiences to answer this

research question. The PI utilized the probes to ignite the conversation and to extract rich, detailed information from the participants. The participants were encouraged to speak freely and share their experiences in their own words. Throughout the interviews, the PI listened and observed the participants for verbal and nonverbal responses that also were recorded and documented.

1. What role did you play in caring for your spouse or partner during the post-operative phase?

Probes

- What did you do?
- What made it easy or hard?
- Is there anything that stands out in this post-operative phase?

2. What outcome did you expect from the surgery?

Probes

- How did you feel about the surgical outcome post-operatively?

3. Did your feelings for the patient change during the post-operative phase?

Probes

- How did your feelings change over time?

4. What emotional support did you receive?

5. Did you feel equipped to be a caregiver upon leaving the hospital post-surgery?

6. Did you and your spouse or partner communicate regarding what she/he needed?

Probes

- Would you please explain?
- Did your spouse or partner tell you how she/he was feeling during this time?

7. What support did you feel you offered during this process?

Themes

The analysis of the participants' narrative revealed four main themes and seven subthemes that were related to and impacted by the main themes. The development of key themes was a nonlinear process that involved the PI returning to the transcripts and participant notes to determine if the ideas and patterns fit. The PI was then able to refine the themes as necessary. Verbatim quotations were used as textual descriptions of the participants' experiences. The four main themes and seven subthemes were:

Theme 1: Initial responses

Subtheme: Shock

Subtheme: Pride

Theme 2: Aesthetics

Subtheme: Fearing the unexpected

Subtheme: Changes in physical appearance

Subtheme: Burdens of surgery

Theme 3: Communication through it all

Subtheme: Reassurance and supportiveness

Subtheme: Lack of support for intimate partners

Theme 4: Resilience

Theme 1: Initial Responses

The first theme that emerged encompassed initial responses to the surgical procedure. The participants described how they felt upon first visualizing the breast area post-surgery. The initial responses of a mastectomy can be an overwhelming experience for both the person

undergoing the procedure as well as the intimate partner. The initial responses that emerged were shock and pride.

Subtheme 1: Shock

A subtheme of shock emerged in interviewing participants. Participants shared that even though they felt like they had prepared themselves, they still were in shock. Although the participants tried to prepare themselves ahead of time, what they expected and what they saw were not in alignment. While this was a trying time for all, the intimate partner knew that something had to be said to let their partner know that everything was okay.

So, I knew what I was expecting to see. She showed me pictures. I had done research on my own. I knew what I was going to see. But when those bandages came off, I was shocked ...because. I saw this on the person that I cared deeply for. And that's the thing like, oh, my goodness, what did we do? Is this really the right thing to have done? So, I knew what I was going to see, but I didn't know what I was about to see would have ever prepared me for it. (P. #8)

I knew that there were gonna be incisions. I knew that could be a difference in (Name) chest area. Like, I knew all these things going forward. And I think, (Name) and I expected these things, too. But that's what kind of hit us both when, you know, there was nothing there. I think that took the emotional toll initially. And then (Name) like I said, she stayed in good spirits and moved forward. (P. #9)

Participants initially believed they would be able to prepare themselves post-surgically, yet what they expected was not always what they experienced, thus leaving feelings of shock. As most of the participants had educational backgrounds in post-secondary school, the commonality was they were used to researching and preparing themselves, just as they had throughout school.

The participants found despite their attempt to prepare through techniques they were used to, such as either reading articles or searching the internet for pictures, the participants realized that there was no amount of research that would prepare for what awaited. Once they saw their loved one with a body alteration, they quickly experienced this unexpected shock. The theme of shock indicated that time is needed to adjust to a major surgical alteration. Regardless of the degree of preparation, feelings of reality quickly set in, including the realization that it is not possible to be prepared for the alterations in the partner's body following a mastectomy.

Subtheme 2: Pride

The decision to have a mastectomy is not an easy decision. The participant shared after seeing what their partner had undergone post-mastectomy, they took pride in their partner for making the decision to have a mastectomy as a lifesaving manner to eradicate the breast cancer. Participants acknowledged feeling proud of their partner for being able to endure losing a breast to survive and having to carry on without a part of their body, which can be a major psychological concern post-surgery. Yet, participants realized their partner's decision to undergo a mastectomy was not easy, and after they saw what their partner experienced post-surgery, they felt proud of their partner for surviving what they had experienced and what experiences were likely yet to come.

It was again pride. I was even more attracted to her, if that was even possible.... I couldn't believe, you know, (name) always been a very strong individual. But it's another thing to look in the face of someone and say, I'm going to have a surgery. And it's not because I'm sick, but it's because I could get sick and it could take considerable years off the life that we wanted.... I was so proud of her and I knew that this was gonna be a rough road and I knew that there were gonna be so many speed bumps along the way. But

I was just so incredibly proud that she was willing to take this step. So that we can continue to live the life that we have. (P. #9)

Just seeing her go through it. This just made me like proud of her. I don't feel like it really changed my feelings, but I guess I felt more proud of her. (P. #2)

I remember sitting in the waiting room and I'm just the worst pessimist in the world and what? why aren't they coming out here? Why aren't they done yet? Why is it? I'm the worst, sitting there by myself and it's just terrible and you know, I remember when I got to see her again. It was just a relief, and I was very proud of her in that moment. (P. #10).

Although feelings of fear, despair and defeat were possible, feelings of pride ensued.

Participants realized during one of the most trying events of their partners' life that a positive could be found. Post-surgery participants voiced being able to finally see and speak to their partner, and the first words they shared was being proud at the victory of undergoing an unimaginable loss. No one wants their partner to experience a mastectomy, thus, it is at this lowest point in their partners' life that they feel a sense of pride in the struggle that their partner faced and overcame.

Theme 2: Aesthetics

A second identified theme was aesthetics. Many of the participants discussed their experiences related to how their partner saw their own breast area post-mastectomy. The participant's reaction to the appearance of the chest area is included in this theme. Searching for the right words to say to a loved one following a mastectomy can be a difficult process.

Participants shared that it was hard to view the chest area, that they felt uneasy, and that the image of the chest area stayed with them even after the initial shock was gone. Intimate partners

experienced their own feelings and were faced wondering how to share their feelings without coming across as uncaring.

I was very sad for her. Was trying to understand what it feels like. I don't know if it was about me at that point, it was mostly about her. I think it was just sad for her to see herself like this. But then, I understood why she did it. (P. #10)

I mean just different, you know. And I fought for a word, that I felt when looking at the place where a breast once was. I feel bad, you know, that she has to go through all of this. You know, I would trade places in a second, if it was possible. (P. #13)

It's a little upsetting to see. (Long pause) Injured, basically. Oh, kind of hard to remember now, because she's had various things done a number of times...Uh (pause) that part is concerning, it's like when you're dealing with cancer. It seems a minor thing to be bothered by an incision or the way something looks. Obviously, the alternative is a lot worse. So, it didn't really bother me so. And, she still has scars, but that's ok. (P. #4)

After the mastectomy, both partners undergo an experience that can only be understood and described by those who have experienced the loss. These responses allowed for the interviewer to develop a sense of the participants' experiences.

Subtheme 1: Fearing the Unexpected

Several of the participants discussed at length their fear of the results following the mastectomy. Many times, when faced with a mastectomy, the person undergoing the procedure will seek pictures or secondhand information from others to understand how their breast will look following the procedure. With this self-research, they often share this information with their intimate partners, which intensifies their fear also. Even in the highest-quality mastectomies, other variables, such as prior or impending radiation, quality of the breast skin (amount of stretch

marks), size of the breast, prior surgery, amount of ptosis, or “sagging,” and other medical issues, play a tremendous role in how the breast tissue will heal (Breastcancer.org, n.d.). One participant recalled fearing that his wife would have results similar to his mom’s surgery that occurred years ago. Another participant went on to share how uneasy he was because of what he heard regarding the poor outcome of the mastectomy and implants.

I remember my father telling me that my mother had reconstruction in 1985. I think it was such a long time ago. He said it looked a little like dorsal fins. That's how he described it, like on the back of a whale or a dolphin, you know, like they were not normal and she had the same procedure as my wife with the flap, they just, they didn't look normal he would tell her that but that was 30 plus years ago. So, I was afraid going in and I had first opted for implants because of that. (P. #12)

I was pleasantly surprised and excited for her with the direct implants. You know, with the mastectomy and the implants, there’s a lot of horror stories out there with, you know, bad work. You know, the implants not sitting right, being lopsided, being, you know, different size and, you know, just some bad horror stories out there that, you know, both my wife, as you know, came across you know, from her support groups and what not. (P. #5)

You know as far as the mastectomy, you know, not sure if it was going to look right off the bat. How is the reconstruction going to turn out, without worrying about how things are going to change or her being affected as she continues at treatment. (P. #8)

Fear of the unexpected played in the minds of participants as they attempted to visualize what was to come post-mastectomy. These feelings intensified as they were shown pictures of the possibility of what their partners’ chest area could look like following the mastectomy. This

unexpected fear plagued their minds and became an area of great concern as they wanted the best outcome for their partner.

Subtheme 2: Changes in Physical Appearance

When someone mentions that a person is undergoing a mastectomy, a main focus often is how the breast area will look with the breast is no longer there. Participants expressed their experiences regarding how they felt about their partners' changes in physical appearance following the mastectomy. While some had partners who opted for no surgical intervention following the mastectomy, others decided on reconstructive surgery. These quotes provide insight into what the participants were experiencing when they reflected on their partner's physical appearance following the mastectomy, indicating variability in responses.

No, I didn't really, didn't see any difference. Like I said, besides the nipple being gone.

She looked the same. It didn't make her any different. I just, you know, a little bit of physical appearance. So, I didn't really have any different feelings about it. (P. #7)

My wife wanted to look more natural I am so happy that she didn't do the implants and they look (pause) they look fabulous, other than one is smaller than the other. (P. #12)

While some of the participants described feeling comfortable with their partner's physical appearance, another participant described a much different experience.

I mean, it looked a little bionic, in my opinion..... To be honest with you. No, I just think (pause) I just think it just didn't look very good. My wife is very lean. And so, you know, when you stretch the skin, it just doesn't look natural. And she's very tall and thin. So that's why it didn't look great. (P.#10)

The participants reflected on their experience of the breast following the mastectomy. When it comes to sharing and being candid, it is not always easy. The participants were able to voice their opinions candidly regarding the physical appearance following their partner's mastectomy. While many had positive experiences, it is important to understand that not all experiences are the same.

Subtheme 3: Burdens of Surgery

The issue of a mastectomy can be a burden for the couple to endure. The combination of the mastectomy with other issues that the partner may have to experience, such as reconstructive surgery, chemical imbalances, physical and mental changes, and other unexpected complications, may create a sense of burden on the intimate partner. Thus, the third subtheme apparent in several participants was the burden of surgery. These participants reflected on their experiences.

I think the chemical imbalance was very challenging to deal with.... I think trying to just be there for her as she was going through the changes in her body and mentally, emotionally and spiritually. All that stuff.... No, I don't think so, I think was upset, I was angry of like the whole thing, of the situation we're in. But I was trying to separate that between her and the decision that was made. She had to do that. (P. #10)

So basically, you know, the initial mastectomy, the reconstruction and then the hysterectomy was basically, three major surgeries in less than six months. We're still kind of establishing that new normal at this point. I mean, it's only been a year and a half since everything went down. (P. #8)

As one participant recalled, despite how his wife felt, he just wanted her to be okay. She said she felt less of a woman because of the breast removal, so we had a talk about it and let her know that wasn't the most important thing, the most important thing was she

was okay. And it just overall, it was the breast we were able to get through, but medications they put her on...caused a lot of vaginal dryness... bothered her more because of the fact that it caused her sexually, not to be sexually active. (P. #3)

I feel bad, you know, that she has to go through all of this. You know, I would trade places in a second if it was possible.... (P. #13)

It is challenging to see a partner undergo a mastectomy. When complications arise, it puts additional strain on the intimate partner relationship. These experiences from participants indicated that changes in physical appearance were considered as decisions were made following the mastectomy. While a couple of the participants did not mind that the breast was altered, it remained vitally important to be able to speak candidly of experiences in order to heal.

Theme 3: Communication Through It All

Another theme that emerged while interviewing participants was communication through it all. Many participants discussed how important communication was throughout the entire process. Participants described the need to make communication a priority to be able to voice their feelings, stressors, intimacy, and what they are experiencing day to day. While several participants discussed how difficult it was to communicate, others discussed how easy communication was in their relationship. As couples communicated, they realized how they were able to discuss sensitive subjects and allow each other to be heard, which strengthened their relationship.

I think it was such a difficult time. We often talked about how we felt in the process, and we made it a priority to talk And, you know, to prevent like any like depression or stress that we might feel. So, yeah, and we always talk about things. About our feelings or

what's going on in our lives? We always have little discussions, so I feel like it was it wasn't any different talking about this, about how it made us feel. (P. #2)

I think some (pause) some things like, you know (pause), about being intimate, I think takes a little while to get out. But I think eventually, she does get everything off of her chest. She's open most of the time... I think that sometimes just keeps her from wanting to be intimate. I definitely try to reassure her that, you know, that nothing's different. (P. #7)

Well, we had we went to a lot of therapy with our therapist. He really helped us quite a bit to try and put things in the right place. Work through things mostly for me. And a lot of you know, with those tools that we had talking, communicating. We just sort of grew together and worked, worked it through. I don't think we're done. I don't think it's not a sprint. I think it's a journey that you go through. Yeah. We're still working through some things. (P. #11)

There are times that she has communicated to me explicitly and honestly about how she felt. And you just need to add those times. You know, I sit back, listen, truly listen, not just hear, listen to her and try to understand, you know, exactly what she's trying to relate to me with regards to those things. Some of it is emotional (P. #8).

The experience of losing a breast is an emotional process, and it would be difficult to understand unless going through the process. The participants described increased communication during these times that was open and honest and included listening intently to each other. It may not be a topic that is easy to bring up or discuss, yet it is vital to the intimate relationship to discuss those concerns for each other's benefit. Several of the participants spoke about how important it was to try to understand the challenges that were faced with undergoing a

mastectomy. As challenges were presented, communication was important to allow each person's feelings, positive and negative, to be voiced. The ability to communicate openly and freely allowed the couple to work on areas of their relationship that were problematic.

Subtheme 1: Reassurance and Supportiveness

As the interviewing ensued, a subtheme of reassurance and supportiveness emerged. The participants discussed the need to provide reassurance, and this involved being supportive of their partners. Even though they often felt unsure of the outcomes and found themselves frightened, lonely, and in disbelief, they knew they had to provide reassurance and supportiveness to their partners under the circumstances.

The crazy thing is they act like it was minor. And there's nothing minor about having a mastectomy, having to lose one of your breasts. There's nothing minor about that.

Nothing! So I was there to let her know she could do it. (P. #1)

I have a very close connection to my breasts. So, I definitely understand. And if I was to ever look down and only see one, it would freak me the fuck out. Excuse my French, but it definitely would.So sitting in her chair and being like, OK, being alone, I understand it. The alone part, I can never say I understand losing your breasts. I don't understand going to treatment. I can't. I can only be the person on the outside looking in and try to make a comparison to my life, that I understand and everybody can do that. (P. #1)

For some time, mastectomies have been a one-day procedure. The individual has the breast surgically removed and is usually sent home the next day. The major part of the surgery is the aftermath following the surgery, and this participant was clearly able to share the experiences that were shared with the intimate partner as they faced struggles throughout the healing process.

She was more concerned about how I felt than how she felt. I mean, she was thinking that I was the one that would be bothered by it, which I wasn't, because I helped take care of the area. And so, we talked about it. But we'd like to say we worked through it. Like I told her, it doesn't really bother me because the breast doesn't make a woman. That's why I don't mind.... The only outcome I wanted was to make sure she was okay. Cause like I said the mastectomy is really not a big deal to me and she's been through enough surgeries and chemo. (P. #3)

Another participant shared the experience of helping his partner to see the bigger picture of why they chose the mastectomy and his continued reassurance and support.

Anything that we need to talk about, we're going to talk about now. Now, (Name) might hold back a little bit when it comes to her, but reassurance on that end always helps. And I think once I opened to how I thought about this whole thing, that let her have the same level of openness. (P.#9)

Other participants exhibited reassurance and support by offering encouraging words, being positive, and letting their partner know they are not alone and can get through this difficult time.

You know, still caring for her, still, you know, supporting her emotionally. You know, cheering her on during this whole process, you know, kind of being a cheerleader for her.

(P. #5)

Dealing with a mastectomy is an emotional and daunting time. The support provided by these intimate partners allowed reassurance in letting the person undergoing the mastectomy know they were not alone. They provided emotional support, positivity, and emphasized to their partner that life and health are more important than the removal of a breast.

Subtheme 2: Lack of Support for Intimate Partners

Participants were able to share their experiences of a lack of emotional support for themselves. One subtheme that was significant among participants was difficulty finding resources for them during this process that could provide them emotional support, which left them feeling excluded. A couple of the participants mentioned that they attended a support group with their spouses. They described feeling that this was not a support group for partners and that they felt excluded. When this area was explored, male participants explained that it was difficult to talk about their loved one who underwent a mastectomy with anyone else.

It's a (pause) it's a man problem. It's a cultural problem with our men. That it is the woman's problem. It's not a man's problem. That's something that we're not comfortable talking about.... Oh my God, I had no idea what the hell I was going to go through. I had no one to reach out to and say hey man. I just kind of went in blind....It's weird. I mean, I'm not blaming my wife when I say she did the best she could but that's not her role in that situation. I don't go asking for it. I don't necessarily put it out there where it's obvious to everyone that, Hey man, I might need an arm around me at this moment. Oh so partly that's on me. And that's a pattern throughout most of my adult life is I'll just do it myself not like I don't need anybody's help....I could have used more support, to be perfectly honest with you. Yeah, but it wasn't available. (P. #12)

As far as for myself, I really mean, I worked through it on my own. I mean, I understand what, you know, what my wife was going through and my goal was just to make sure she was fine. I wasn't too much worried about myself at times like I said, I was able to talk to (Name), That's who I reached out to. If I had something to talk about to (Name) who was always there if I had a question. But mainly, just for myself and my dad before he passed

and I talked to my dad about it, but other than that. That's the emotional support for me was my father and talking to (Name), without them I'm not sure how I could have made it. (P.#3)

I think. I think being able to talk about it with like minded individuals, perhaps male individuals, would have helped. But there's really nowhere to go. There's like no real organization or group where you can go to as a male to talk about these things. I mean, I, I think that's the value of it. If there was one. I mean, that's.. I think that's the point of therapy, to be able to share and be vulnerable, to get the most out of it. Otherwise, why would you go and then (pause) You know, I, I have a ton of guy friends, but no one's ever gone through a similar situation that I have. So it's hard for them to relate. I mean, I think getting sympathy is one thing, but truly understanding what is going on is another if you've never been in that situation before. (P. #10)

I felt neglected multiple times, just like everybody was worry and like I am not selfish. I'm so selfless. But everybody was. So how's (name) And send (name), my love and (name) this. And we'll there's (Name),you need anything? Well, what about me?

Sometimes I need to cry too. Sometimes I need someone to talk to. Sometimes I just want to sit in silence. I didn't get the support that I would have wanted, but I was strong enough to get through it. (P. #1)

Theme 4: Resilience

Resilience was a significant theme voiced in several of the interviews. Not only did the participants express their resilience, they also described the resilience of their intimate partners. The participants shared that their intimate partners had been through so much in their journey, from learning they needed a mastectomy to undergoing the actual procedure. Participants

described how they gained strength, how they watched the strength exhibited by their partners, and how proud they were of their partners. Undergoing a mastectomy is a difficult and unsettling surgical process to endure. It can affect both the intimate partner as well as the individual who is undergoing the surgery. Participants shared that standing by their partners' side provided them with the opportunity to understand the strength in their partner. One of the participants described his wife's strength as "not even really broken, but just beaten."

I just got more proud of her. You know, it's one thing to you know, I know (Name) is a strong person, but it's another thing altogether to actually see the progression, you know, from I'm already a strong person to being mildly not even really broken, but just beaten. But then just to come right back and bounce back from everything and adhere to, you know, the post-operative plan and never deviate it's credible. It was just cool to see her flex all of the strength that she had. It was very cool. (P. #9)

Another participant was amazed at how his wife bounced back just a few days after surgery. He observed that even though she was not sharing how she felt through the experience of losing a breast, she remained physically active and resilient through it all. The participant had been married to his spouse for 10 years, and he said he knew she was a strong person but never knew how strong until now.

To see how her, the way her body bounced back. You know, just a couple of days after surgery and then, you know, two days after getting our drains out, you know, the way her body is just bounce back is just amazing to watch. You know, she was she was resilient during the whole thing. And then, you know, as soon as she got her drains out, who's up moving around and being active and not letting you know the whole situation, you know,

kind of give her an excuse to just sit around like she's often moving in and making sure that, you know, she's still, you know, active throughout this whole thing. (P. #5)

Another participant discussed that his intimate partner has challenges committing to decisions. During one of the toughest decisions imaginable, he witnessed how strong she had been through the entire process mastectomy process.

I would only say that she sometimes has trouble committing to making decisions on relatively minor things and to be honest, she had a little trouble making this decision here and thought about not doing it even up to the last minute just canceling it and I understand the stress and everything that goes with that, but she really just went to it. She attacked it, she has a very low tolerance for pain, and it could be a little difficult to deal with her sometimes when she's in pain, and she's just a soldier through this whole thing. It was truly heroic. (P. #12)

Another participant described several trials that he and his intimate partner experience, such as living in China, the loss of his sister to breast cancer, and his wife undergoing a hysterectomy and a mastectomy. These difficult experiences have strengthened both him and his wife.

I think in generally like getting (silence) I don't know if this falls into the category that you're asking about. But just in general, like dealing (silence) with having perspective on life and dealing with situations. Having dealt with the death of my sister and going through these surgeries and just sort of like... because before that we lived in (uh) we actually lived in China for three years. So, we had perspective on just like the difficulties of life that are there. A lot of things that may drive people crazy, but for us we're like no

big deal. You know, we lived in China, we've been through surgeries. We had loved ones die. I think it's like little things that bother others bother me less. (P. #11)

Other participants commented that the mastectomy and watching a partner undergo cancer treatment is not easy, yet they received strength in observing their partners tenacity.

Other than my wife's strength to continue on, because, like I said earlier, is that because of the mastectomy and the removal of the lymph nodes, she had been doing a lot of chemo and a lot of radiation that I think I couldn't have done, but she was able to go through that and still keep faith. So (pause) for me, I thought that was that was the main reason. She had.. she had the chemo. She had the chemo. Let's see with her, they did the chemo first and then the radiation then she had the surgery, if I'm not mistaken.... Yeah. I think so, because you never realize how strong, you know in my case, my wife was until she had this surgery and it was (silence), It was amazing to see how she managed to go through this. (P. #3)

I got my strength through her strength. (P. #2)

When faced with difficult life situations, problems, and stress, the decision has to be made to run from the problem at hand or stay and fight. Each of these participants shared experiences in which they stayed and fought. Through their experiences and observing the experiences of their partners, strength was their reward.

Summary of the Findings

The purpose of this study is to understand the lived experiences of the intimate partner who provided support post-operatively to a person (male or female) who underwent a mastectomy during the post-operative phase within the last one to five years. Data from a sample of 13 participants revealed four main themes which were initial responses, aesthetics,

communication through it all, and resilience and seven subthemes. The demographic information of the study participants was comprised of 69.2% Caucasian, 23.1% Hispanic, and 7.7% Black American intimate partners. The ages ranged between 25 and 75 years of age. This chapter provided research findings on these four themes, which were resilience, aesthetics, communication through it all, and initial responses and seven subthemes: shock, pride, fearing the unexpected, changes in physical appearance, burdens of surgery, reassurance and supportiveness, and lack of support for intimate partners.

The participants discussed their initial responses to the mastectomy. Some participants described feeling shocked while others reported feeling a sense of pride for their partner. Participants shared their feelings concerning the aesthetics of the mastectomy, their fear of the unexpected, and the burdens of the mastectomy. Despite this challenging surgery, the participants were able to communicate throughout the entire process. Many participants expressed the need to provide reassurance and supportiveness throughout the astounding changes, while participants discussed not having the support, they needed throughout the mastectomy journey. Finally, participants interviewed were open and shared that although this was a difficult situation, they tried remained confident despite the number of challenges faced and remained resilient. Chapter 5 will provide a summary, discussion of findings, nursing implications, limitations, conclusions, and recommendations for further studies.

CHAPTER V

RECOMMENDATIONS AND CONCLUSIONS

Overview of the Literature

In an overview of the literature, it was consistent that studies focused on both couples together instead of providing emphasis solely on the partner. Secondly, a number of the partners in the literature referred to a male partner or spouse which would leave out others that are not included in this limited description. An extensive literature review indicated that partner support is important in enhancing psychological well-being, expediting recovery, and improving acceptance of new body image of the partner who has undergone a mastectomy was reviewed (Carr et al., 2019; Rowland & Metcalfe, 2014). Other studies examined the importance of intimate partners participating in aspects of care during the post-operative phase of a mastectomy. These aspects consisted of positive communication, expanding their roles, coping with stress, problem-solving, and effective responsiveness (Ghizzani et al., 2018; Jabłoński et al., 2018; Rowland & Metcalfe, 2014). Additionally, these studies found that an appropriate training program provided positive effects on family functioning and quality of life (Ghizzani et al., 2018; Jabłoński et al., 2018; Rowland & Metcalfe, 2014). Lastly, Catania et al. (2019) reported that diagnosis, treatment, and survival processes associated with breast cancer not only affected patients but impacted spouses who are often responsible for maintaining the primary caregiving role.

Few studies have focused on the in-depth experience of the intimate partner whose partner has undergone a mastectomy. This study aims to understand how intimate partners' own needs influence their partner's needs, how they support their partner, and how they can cope effectively during this post-surgical phase. The results of this study can be used to suggest how

nursing practice may be enhanced in providing holistic needs of those undergoing mastectomies while incorporating supportive care to include their intimate partner. In completing a study based on intimate partners of those that have undergone mastectomies provided an opportunity to gain insight from a population that has rarely had the opportunity to share their experiences.

Summary

This qualitative study aimed to explore the lived experience of intimate partners of a person who underwent a mastectomy in the postoperative phase. The research question of this study was: What are the lived experiences of the intimate partner who provided support post-operatively to a person (male or female) who underwent a mastectomy during the post-operative phase within the last one to five years? The reasons a mastectomy would be necessary, and the complexity of emotions experienced by the intimate partner following the procedure were also discussed. The intimate partner must deal not only with being a caregiver but also with the distress of the physical changes of their partner, lack of coping mechanisms, and lack of resources from support systems during such a complex and challenging experience.

Review of Methodology

In an attempt to understand intimate partner's experience of their partners' mastectomy a descriptive phenomenology approach was utilized which originated with Husserl (Husserl, 1962). Colaizzi's (1978) phenomenological research process was used for data analysis to conduct an in-depth analysis of each participant by focusing on meaning and understanding of subjective phenomena of the intimate partners. A semi-structured interview guide was developed and used for data collection in virtual interviews of participants were conducted and perused until saturation was met. Colaizzi's (1978) method depends upon rich first-person accounts of their lived experience which was derived from the interviews. The researcher discussed

Colaizzi's (1978) method of data analysis, in which the researcher identifies meanings relevant to the phenomenon that arise from a careful evaluation of the significant statements provided by participants. A description of the pilot study involving three participants was discussed. Finally, a discussion ensued on the role of the principal investigator and how experiences and knowledge of the subject matter would be part of the analysis process.

A discussion of how data was organized and synthesized using meanings, themes, and an exhaustive description of the essence of the phenomenon was derived utilizing Colaizzi's (1978) phenomenological data analysis. The emerging themes specific to the research question and their participant origin were reported and described. Verbatim quotations from the participants' transcripts that substantiated and provided credibility to the four themes and seven subthemes were incorporated into the descriptions as well.

Descriptive phenomenology provided the philosophical framework to explore the lived experiences of intimate partners of those who have undergone a mastectomy in the postoperative phase. Purposive sampling was used to recruit intimate partners in two support organizations, FORCE and ROS. Data analysis was completed using the seven steps of Colaizzi's data analysis (1978) model. Colaizzi's (1978) data analysis method was employed to analyze the participants' transcripts.

The final sample size encompassed purposive sampling of 13 participants who were intimate partners of a person who underwent a mastectomy and cared for the person in the immediate post-operative period. Participants were eligible for this study if their partners had undergone a mastectomy, they were the primary caregiver for their partner and wanted to share their experience and they were in an intimate relationship. The participants were eligible if they were between the ages of 18 and 75 years of age. Interested individuals contacted the researcher

and appointments were set up to meet in person or via virtual platform based on participant preference. The participants' confidentiality was protected by the use of participant numbers where relevant in this study. Demographic details that could identify the participants were omitted from the collected data and only aggregated demographic data are presented. The risks and benefits of the study were explained to the participants in a consent form and discussed verbally with them prior to obtaining signed consent for the interview to be carried out. The participant returned the consent form in person or emailed it to the researcher prior to beginning. Participants were offered information to address distress if the interviews stirred up emotions that were distressing and they felt that they required further help. Permission was obtained from participants to audio record the interview, and they were assured that they had the right to withdraw their participation at any time. Furthermore, they were informed about who had access to the recordings and transcripts and the length of time these were going to be kept. Pilot interviews were carried out with three of the participants and full transcripts prepared. This proved useful to adjust the sequence of prompting questions and determine the approximate interview length. In the actual study, each interview lasted between 60–90 min and was audio recorded to facilitate careful exploration of the participants' experience. During the interview, short field notes were taken in order to record non-verbal behaviors that could not be captured by the recording process.

Overview of Themes

Data analysis involved manually deriving emergent themes from each transcript. The researcher attempted to be as accurate as possible to the participants' words by being as explicit as possible about the text interpretation. Therefore, it was essential to explore the original transcript and elicited themes over and over again to enhance authenticity as much as possible.

When this process was repeated with each transcript, the researcher looked for connections between emergent themes to form clusters. The results were presented together with direct excerpts from the transcripts in order to bring the participants' experiences to life.

The following main themes and subthemes emerged:

Theme 1: Initial Responses

Subtheme 1: Shock

Subtheme 2: Pride

Theme 2: Aesthetics

Subtheme 1: Fearing the unexpected

Subtheme 2: Changes in physical appearance

Subtheme 3: Burdens of surgery

Theme 3: Communication through it all

Subtheme 1: Reassurance and supportiveness

Subtheme 2: Lack of support for intimate partners

Theme 4: Resilience

Methodological Rigor

Methodological rigor was a way to establish trustworthiness in the findings of this study. It allowed for consistency in the methods that were utilized. Lincoln and Guba (1985) suggested utilizing four criteria to establish trustworthiness. The four criteria applied in this study to ensure the rigor of qualitative findings were credibility, dependability, confirmability, and transferability.

Credibility refers to confidence in the truth of the data and how the information is interpreted and involved carrying out the study in a way enhanced that the results were believed

and embarking on steps to demonstrate credibility in research reports (Polit & Beck, 2021). It is also defined as the extent to which the interpretations reflect the participants' lived experiences (Lincoln & Guba 1985). The researcher's engagement with the participants and the use of a semi-structured interview guide with open-ended questions allowed for participants to provide rich descriptions of their experience of being a partner of a person that underwent a mastectomy. The researcher further gained credibility in engaging in in-depth conversations with the participants during data collection.

The next criterion is dependability. Dependability refers to ensuring that the information is reliable over time, thus using the same participants and circumstances would yield the same data.

Confirmability refers to congruence between two or more people concerning the data's accuracy, relevance, or meaning (Polit & Beck, 2021). This criterion ensured that the results of this study were those of the participants and the researcher did not alter the information that was provided by the participants. The findings represented the participants' own voice of the information obtained regarding their lived experiences. The results, data collection, and the context of the study were provided. Transferability was presented by the researcher utilizing direct quotations to represent participants' experiences and to illustrate themes.

The fourth criterion, transferability refers to the potential for extrapolation, meaning the findings can be transferred to other settings or groups (Polit & Beck, 2021). The researcher provided sufficient descriptive data so that others can transfer data in other settings or groups. Findings reflected the participants' viewpoints and were not influenced by any bias of the researcher. To ensure transferability of this qualitative study, thick descriptions of the partner's lived experiences of their partner undergoing a mastectomy.

Discussion of Findings

Initial Responses

It was a difficult experience for participants to see their partners for the first time after the surgery, but they emphasized that it was more important that their significant others were healthy than the fact that they did not have breasts and hair. Participants in this study discussed their initial responses which they described as shock and pride. A major consensus among the participants was that they attempted to prepare themselves for the aftermath of life postmastectomy yet found that this was difficult to accomplish. Through the entire experience of breast cancer, the participants in this study reported that they could not truly prepare for the tough challenges associated with this health crisis. One of the first feelings described was that of shock. Participants shared that from the first moment that they were allowed to see the chest area where the breast once resided was a shock. Participants shared that they could not find words to say even after ensuring that they were “prepared” for the procedure. Research had been completed and participants knew what the area was going to look like from previous photographs and from frequent searches on the internet, but they still had a feeling of shock. One participant recalled when “it hit me.” He looked there at the chest area and “nothing was there.” Participants then shared they would be the caregiver and they were shocked by the collective impact of all elements.

Intimate partners discussed their feelings of pride for their significant partner and what they had undergone after the mastectomy. Participants shared that even such a devastating surgical intervention that had the ability to leave partners emotionally scared, there was a sense of pride. Participants verbalized feeling proud that their partner for handling the situation with

such pose. One participant shared “when she had lost so much, I just recall being so proud of her.”

Aesthetics

The second theme that emerged was aesthetics. The breast area is associated with psychosocial issues and attributes such as sexuality, attractiveness, and femininity (Jabłoński et al., 2018). After the mastectomy, the intimate partner described their experience of seeing the surgical area as difficult. This reaction was a common experience among intimate partners in the study. Surgical treatment of breast cancer with a mastectomy involves a sensitive area of the body in terms of physiology, aesthetics, and emotions and participants shared how they felt when they looked at the surgical area. Some mentioned a lack of self-confidence and lack of participation in their intimate relationship.

Three subthemes of aesthetics were identified in this current study. The first was fearing the unexpected. The participants in the current study discussed how they felt when they did not see what they expected to see after the mastectomy. Intimate partners in this study were concerned about the horror stories they heard from others concerning the unattractive physical appearance of the area. This was closely related to the next subtheme: changes in physical appearance. While some found it to be a challenge to see the new breast area post mastectomy, other intimate partners shared that it was not a problem, and that they did not see any differences in the look of their significant other. As the third subtheme, burdens of surgery, emerged that some participants experienced a positive change in their relationship and said it had become stronger because of their significant other’s health crisis. Often a combination of surgical interventions and treatments may be necessary in the treatment of cancer, creating numerous changes in the body. These can leave the patient physically and physiologically drained, which

can create burdens for the intimate partner following the surgery as well. The intimate partner was faced with the decision of what to say, how to say it, and generally how to assist their significant other as these complications arose.

Communication Through It All

The third theme identified was communication through it all. Participants discussed that they realized how they were able to discuss sensitive subjects and allowed each other to be heard, which strengthened their relationship. In this study, participants discussed the need for freedom to express themselves to their intimate partner without fear of retribution or being viewed negatively for openly sharing their feelings. The combination of reassurance and supportiveness was identified as one of two subthemes. As the person who underwent a mastectomy experiences fear, anxiety, anger, despair and disturbances in body image, thus, encouragement through understanding, reassurance, and supportiveness was required to advance through the treatment process which strengthened the intimate partner relationship (Fang, Chang, & Shu, 2015; Gürsoy et al., 2017). The participants in this study verbalized taking the time to listen with intent to understand and make a conscious effort to offer open and honest communication. This dialogue allowed the lines of intimate conversation to flow even in the darkest situations. Participants mentioned the importance of knowing the right thing to say or when to say it is a skill that is learned through trial and error. Participants shared that recalling the need for the mastectomy as a life-saving measure reminded them to be supportive, reassure their significant other, and remain understanding during difficult situations.

The next subtheme identified was the lack of support available for intimate partners. Participants discussed their wish for someone they could talk to about their experiences; however, no support groups were available for intimate partners. Intimate partners often

experience a ‘double role.’ On one side, they may suffer from their own psychological distress, and on the other side, they are the main source of support for their distressed partner. With these challenging roles intimate partners need an outlet to discuss their feelings and gain insight from others in similar situations.

Resilience

The final theme identified was resilience, defined as the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioral demands (American Psychological Association, n.d.). Fang, Chang, and Shu (2015) found that conflict is related to mood disturbance and that confronting directly, rather than withdrawing from, differing opinions will increase a couple’s resilience in committing to the relationship. As patients are faced with fears and distress related to cancer and treatment options, their ability to openly discuss these feelings with their partner made it easier to adjust when their intimate partner was positive, attentive and responsive which made their relationship become more resilient (Fergus et al., 2015). After withstanding the traumatic loss of a breast, resilience was the one characteristic that was consistent among participants and their partners. Participants shared that they were able to overcome the difficult challenges of observing their partner losing a breast by being supportive, confident, and encouraging. They discussed being able to display their resilience and stay focused on providing social support and care throughout the difficult process.

Conclusions and Nursing Implications

In conclusion, the participants interviewed shared their lived experiences of caring for their partner that underwent a mastectomy. Participants found that being able to openly and honestly communicate with their partner was a key factor in being supportive through the

surgical phase. In communicating, participants were able to share their feelings. They were also able to communicate regarding how they felt regarding aesthetics following the mastectomy, obtaining the support needed and being resilient through this difficult surgical intervention. Intimate partners play a key role as they are often the main person that cares for the person undergoing a mastectomy. Thus, the intimate partner requires a means to exhibit their support as well as a means to be supported.

Results of this study will help healthcare professionals understand the experiences of intimate partners during the health crisis associated with mastectomy. They will also prove useful in planning the psychosocial care for both patients and their families. Furthermore, this study will contribute to developing nursing initiatives to assist intimate partners in acknowledging needs, accepting expression of feelings regarding the new diagnosis and treatment, and identifying way for both partners to provide support. Finally, understanding the intimate partners' lived experiences will provide development of more effective support systems for them during the diagnosis, treatment, and long-term care of their significant other. The results of the current study have highlighted several themes that form the basis for future planning for interventions to support intimate partners such as improving communication and problem solving, as well as contributing data for development of support groups for intimate partners.

Many significant others have identified their partner as their most important source of support. The breast cancer diagnosis introduces individual and relationship challenges for both patient and intimate partner. In this study, participants perceived that their partner who underwent a mastectomy leaned more to them for needed support. These challenges can bring a couple closer together or create a wedge in the relationship, induce serious distress, and

negatively influence successful relationship coping throughout the cancer journey (Zimmerman, 2015).

The findings of this study suggest that the intimate partner remains resilient through the breast cancer journey. In interviews, participants discussed their most difficult experiences and how they expressed resilience. Exemplifying resilience provided the person undergoing a mastectomy and their intimate partner to find ways to exhibit dedication and strength through the difficult challenges in which they are faced.

One nursing implication would be including behavioral sex therapy to assist both patients and intimate partners with physical intimacy concerns following the mastectomy. Medical professionals should be involved in providing resources to couples who may experience sexual dysfunction and may be too embarrassed or reluctant to voice their opinions about such a sensitive topic.

Another nursing implication would be to identify organizations to spearhead efforts to disseminate programs and resources for intimate partners of those who underwent a mastectomy. These programs should be internet-based support as well as face to face. Examples of these programs would include the following: social support groups, online therapy for psychosocial/physical symptoms, and online systems integrating information, support, and coaching services. Social support groups would focus on the intimate partner. In this study, many of the intimate partners indicated that they were not made a part of the care experience. While they were invited to join the support group with their partner, the experience they noted was focused mainly on the individual undergoing cancer and/or mastectomy and not the intimate partner. Intimate partners need an avenue to discuss their feelings with others who have experienced situations similar to what they have experienced to encourage them to speak freely.

It is important to identify factors that promote greater engagement. Leslie et al. (2022) found that customizing interventions to meet needs and providing personalized feedback were associated with greater retention and found that providing qualitative feedback by telephone or face-to-face were preferred. The importance of including telephone messages is further supported by evidence that the messages and self-care advice are the components most used by patients with low social support, thus could also be proven to be just as helpful with intimate partners. For those who prefer face-to face meetings in a support group, this would also be a viable option. The programs could be centered around what to say and how to say it, but it is necessary to remain optimistic and be flexible within the program. Such programs should be offered world-wide with flexible schedules so those in need of support would have accessibility whenever needed. A program in which there is 24/7 access to speak with someone face-to-face or online would be beneficial from someone who understands what it is like to be an intimate partner of someone who underwent a mastectomy and is willing to speak openly and honestly about the experience. Additionally, a program that facilitates intimate partners to develop their communication skills would also be a positive experience in that it would share techniques for intimate partners to be able to share feelings openly without fear of hurting their partners feelings.

Practicing listening skills would be useful in understanding what is being said. Participants felt they should always have the answer. Yet, many times, what is needed is the art of listening openheartedly to shed light on the situation. Health care professionals should be aware of the benefits and drawbacks of varying support resources, so they advise appropriately (McCaughan et al., 2017).

The current study provides information about the lived experiences of participants, which can assist in development of interventions for nurses to implement that can address the needs of intimate partners. Future recommendations should focus on effective nursing and psychological interventions that target the needs of the intimate partner rather than just the person that has undergone a mastectomy. Interventions should promote how intimate partners can be supportive and how they can share their expectations after the mastectomy. Support can be provided in several manners. Examples of offering support include listening to others, exploring online resources, and in person communities in which sharing similar experiences can be accomplished. These communities may offer ongoing events and provide an atmosphere that is inviting to the intimate partner. The participants in the current study shared that they wanted to feel comfortable sharing their inner most feelings without fear of being looked down on for having feelings that others may view as right or wrong. They also shared they wanted an outlet to share with others that had experienced similar situations. Understanding the lived experiences of intimate partners post-mastectomy can be an opportunity to gain vital information in building a more cohesive relationship while the intimate partner works through living with a partner that has undergone a mastectomy.

Limitations

While the researcher intended to maintain the required details of this study, there were still a number of limitations that could strengthen the study. Firstly, this study was carried out with participants who were intimate partners of those that were attending meetings at FORCE and ROS, which were just two support groups resulting in selection bias as intimate partners were recruited only through partners at support groups who received a flyer from their partner. This study addressed the experiences of intimate partners within the United States, thus

spreading the area to recruit subjects may yield different results. It may be possible that the duration of the interviews was too short in length. Each interview was approximately one hour in length. Allowing for a longer interview may yield more rich data. The sample size of this study was small, consisting of 13 participants and having a larger sample size would be able to relate the data found to a larger population. Another limitation could have been that the interviewer was female, which could have led to some discomfort for the male participants. Including a male interviewer may possibly elicit more responses and allow male participants to respond more freely with information about their experiences. This study explored the experience of intimate partners who were between the ages of 18 and 75 years of age. The age range could also be a limitation as experience of participants may not represent the experience of those individuals who are outside this age range and who could have been at a different life stage when their companion underwent a mastectomy. Hence, these findings are specific to this particular age group. The need for a mastectomy among those with varying sexual orientations should be acknowledged and included in the study. One same-sex participant was recruited in this study, which is not representative of the entire population. So, conducting a study in which most of the participants are same sex would provide information that is generalized to that population. The semi-structured interview guide should be altered to include more questions on sexual and intimacy questions to gain a sense of how the sexual relationship was affected by the surgical intervention. The sample size should be increased in number and use a more diverse population of participants. As 69.2% of the participants were of the Caucasian ethnicity, the results of the study cannot be generalized to the entire population, thus there is a need to expand the study to a variety of ethnicities. Lastly, all interviews should be conducted in person as to include the

personalization of being in person. The researcher planned in the initial phases of this study to conduct face to face interviews, but virtual interviews became necessary due to a pandemic.

This research study was carried out with intimate partners of those who have undergone a mastectomy and who were recruited from two support organizations, FORCE and ROS, designed primarily for a person experiencing a mastectomy. The participants in this study were in relationships of 12 months or longer with the person who required a mastectomy. In other studies, intimate partners have been underrepresented and more information was needed about their lived experiences of being in an intimate relationship with someone that underwent a mastectomy. Four themes and seven subthemes emerged from the study. The themes were initial response, aesthetics, communication through it all, and resilience.

Intimate partners exhibited their strength not only through watching their significant other in difficult situations but in providing support to them during these difficult situations. The participants discussed their lived experiences of understanding, strength, and resilience during those difficult situations.

The relevant literature emphasized that patients with breast cancer can experience changes in body image, self-concept, emotions, behavior, family dynamics, and roles. The importance of a woman's breast can have a dramatic impact upon body image, and depending on the woman, the loss of a breast through mastectomy will have multiple meanings and can trigger conflicting emotions. Thus, the intimate partner is challenged with what to say, how to react, and how to be supportive in such a devastating time. Participants in this study discussed being fearful of the results of the mastectomy. Participants reported that they expected changes, but some felt they could have never prepared themselves for the experience postmastectomy. While some participants related, they did not note any differences, others had a difficult time with the

aesthetics of the breasts post mastectomy. Other participants conveyed that the combined effects of the surgery and side effects of medications left their significant others with a decreased libido. This often left the participants searching for the right words or manners to comfort their significant other during this most difficult time. In a previous study, men interviewed felt empowered at work but helpless at home in the face of cancer and its treatment. Many felt inadequate in their roles as caregivers and wished they had a template to guide them through the process and help them share their experiences (Fergus & Gray, 2009). In the current study, intimate partners reported that their experiences regarding showing their support included being in the moment and having difficult conversations regarding the challenges and feelings that they experienced to initiate conversation and be able to speak openly.

A need exists for the continued assessment of the knowledge and understanding of intimate partners to gain their perspectives regarding the needs of their significant others post mastectomy. According to the literature, supporting programs for couples that target health preservation, problem-solving, and communication skills improve caregivers' quality of life. The current study aligned with the literature in that when the caregiver has significant improvement in coping and suggested the benefit of support has positive implications for both the patient and the intimate partner (Ghizzani et al., 2018). In continuing to research intimate partners' their needs influence how they view their significant other's needs, how they provide support, and coping effectively post mastectomy.

Recommendations for Future Studies

The findings from this research study have implications for future studies. Healthcare personnel are in unique positions to offer support to a person undergoing a mastectomy and their intimate partner. Acknowledging the various emotions experienced at the time of breast cancer

diagnosis and treatment options can allow health care professionals to understand what patients and intimate partners are seeking in their current provision of care. Participants in the current study identified that they did not receive any information post-mastectomy concerning providing intimate partner support and communication. Thus, a study focusing on providing needed educational programs or sessions can be provided and evaluated to determine which programs will best equip participants with detailed information to assist their loved ones following a mastectomy. It was often difficult for intimate partners to address their needs to their significant other as they did not want to burden them with “their feelings when the person undergoing a mastectomy was having such difficult feelings of their own,” so often times intimate partners expressed just keeping to them self. Participants expressed having initial responses consist with shock and pride. So, conducting a study that would allow evaluation of the best avenue for expression of initial responses would provide additional information for the intimate partner to understand their feelings and how to best share such feelings with their loved one.

Another study can address the need to have continued communication. Thus, utilizing a study involving counseling techniques with the intimate partner could be beneficial. This would allow an opportunity for the intimate partner to discuss their deepest concerns freely without judgement. In the current study, participants discussed the need to have someone they were able to confide in concerning their experiences, yet it was not available. It is also important that future research addresses the needs of intimate partners who are separated, divorced, or widowed following their significant others’ fight with breast cancer and mastectomy. This study may be aimed at understanding and being able to cope with loss. Studies have indicated that cancer survivors have positive attitudes toward internet-based interventions thus this same study may prove beneficial to intimate partners (Alberts et al., 2018; Durosini et al., 2021). A future study

can also seek to determine how psychosocial internet-based interventions are associated with intimate partners regarding the aesthetics of their partner that has undergone a mastectomy. Finally, a study should explore the needs of intimate partners coming from different socioeconomic, cultural, and ethnic backgrounds for the best opportunities of inclusion during the surgical support process.

Summary

This study examined the lived experience of intimate partners of a person that has undergone a mastectomy using a descriptive phenomenological approach. The findings indicate that the lived experiences of intimate partners surround four major themes which include and cohabitating women, adolescents, and college age women. This study included intimate partners and revealed new areas of research for new studies. Additionally, clinical implications were highlighted that may help determine how intimate partners can be more involved throughout the surgical journey.

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APPENDIX A

SEMI-STRUCTURED INTERVIEW GUIDE

1. What role did you play in caring for your spouse or partner during the post-operative phase?

Probes

- What did you do?
- What made it easy or hard?
- Is there anything that stands out in this post-operative phase?

2. What outcome did you expect from the surgery?

Probes

- How did you feel about the surgical outcome post-operatively?

3. Did your feelings for the patient change during the post-operative phase?

Probes

- How did your feelings change over time?

4. What emotional support did you receive?

5. Did you feel equipped to be a caregiver upon leaving the hospital post-surgery?

6. Did you and your spouse or partner communicate regarding what she/he needed? Probes

- Would you please explain?
- Did your spouse or partner tell you how she/he was feeling during this time?

7. What support did you feel you offered during this process?

8. What role did you play in caring for your spouse or partner during the post-operative phase?

Probes

- What did you do?
- What made it easy or hard?
- Is there anything that stands out in this post-operative phase?

9. What outcome did you expect from the surgery?

Probes

- How did you feel about the surgical outcome post-operatively?

10. Did your feelings for the patient change during the post-operative phase?

Probes

- How did your feelings change over time?

11. What emotional support did you receive?

12. Did you feel equipped to be a caregiver upon leaving the hospital post-surgery?

13. Did you and your spouse or partner communicate regarding what she/he needed? Probes

- Would you please explain?
- Did your spouse or partner tell you how she/he was feeling during this time?

14. What support did you feel you offered during this process?

APPENDIX B

RECRUITMENT FLYER

Study for Partners of a Person having Underwent a Mastectomy

Be part of an important study aimed at Partners of a person (male or female) that underwent a Mastectomy

- *Are you the partner or spouse of a person that has underwent a mastectomy?*
- *Are you between 18 and 75 years of age?*
- *Do you want to share your experience of the care/support you provided after your loved one had a Mastectomy?*

If you answered YES to these questions, you may be eligible to participate in a partner support study focused on the partner of a person that underwent a Mastectomy.

The purpose of this research study is to understand perceived partner support of a person that underwent a Mastectomy. Benefits include the opportunity to share your experience post-Mastectomy of your partner. Participants will be interviewed by a doctoral student that has been approved to collect research at Reconstruction of a Survivor and Texas Woman's University.

This study is being conducted In person at Reconstruction of a Survivor 2617C, #224, Holcombe Blvd., Houston, TX 77025 or via Skype as preferred by the participant.

Please call Torina Lane, RN at (713)816-9543 for more information.

APPENDIX C

TELEPHONE SCRIPT

Hello, My name is Torina Lane, I am a doctoral student at Texas Woman's University and have been given permission by Dr. Bennett with Reconstruction of a Survivor to recruit participants for this research study as well as the Director of Facing Our Risk of Cancer Empowered. The purpose of this research study is to understand how partners perceive the support they provide to a person that has undergone a Mastectomy. Benefits include the opportunity to share your experience that you have undergone, in a private and confidential environment. You may choose to be interviewed in-person at Reconstruction of Survivor or via online meeting. Please understand that this interview is confidential and no identifying information will be shared concerning your interview.

May I screen you for eligibility with 3 questions?

- Are you the partner or spouse of a person that has underwent a mastectomy
- Are you between 18 and 75 years of age?
- Do you want to share how you provided partner support following Mastectomy surgery?

If you have answered yes to these questions and are eligible to participate. What do you prefer in-person interview or an interview via online meeting? I am happy to schedule a day and time that is best time for you, what would you like? Please note that your responses will be audio recorded only. You will not be recorded for either interview.

There are no incentives in participating in this study. I do appreciate your time and consideration in participating in this research study.

APPENDIX D
CONSENT FORM
TEXAS WOMAN’S UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Title: Understanding Perceived Partner Support of the Person who Underwent a Mastectomy

Investigator: Torina Lane RN.....tt@twu.edu 713/816-9543

Advisor: Peggy Landrum, Ph.D.Plandrum@twu.edu 713/794-2176

Explanation and Purpose of the Research

You are being asked to participate in a research pilot study conducted by Torina Lane RN a Ph.D. student at Texas Woman’s University. The purpose of this research is to evaluate the perceptions of partner support of persons that underwent a mastectomy. The study aims to understand the spouses or partners lived experiences of a person that underwent a mastectomy and the care they provided in the immediate recovery phase.

Research Procedures

For this study, the investigator will conduct individual interviews using participants of Reconstruction of a Survivor Support group, located at 2617 W. Holcombe Blvd., #224, Houston, TX 77025. You will be given the option of a face-to-face interview or Skype Interview based on preference. If you request a face-to-face interview, a private room will be used at the Reconstruction of a Survivor local office and where privacy will be provided for the interview. You will be recruited by the founder of the organization on a volunteer basis of partners that have a person that underwent a mastectomy. The interview will be audiotaped. The purpose of audiotaping is to provide a transcription of the information discussed in the interview and to assure the accuracy of the reporting of that information. Your total time commitment in the study will be approximately 120 minutes.

Potential Risks

Potential risks related to participating in the study include emotional discomfort during the interview. If you experience emotional discomfort regarding the questions, you may stop answering any of the questions at any time, or you may stop the interview. If you feel as though you need to discuss this emotional discomfort with a professional, the investigator will provide you with a resource list of additional assistance.

Another possible risk to you is the release of confidential information. The investigator will use your information for the purposes of the research study. Confidentiality will be protected to the extent that is allowed by law. The interview will take place in a private location or via Skype with only the participant and investigator present. No names will be used on the audiotape or the transcription. Only the investigator will have access to the recording. The audiotapes, hard copies of the transcriptions, and transcription text files will be stored in a locked filing cabinet in the investigator's home. The tapes and transcription text files will be erased and the hard copies of the transcriptions will be shredded within 5 years. The results of this study will be used to present the findings of this pilot study to Texas Woman's University Defense committee.

The researcher will try to prevent any problem that could happen because of this research. You should let the researcher or support staff know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participant Initials

Page 1 of 2

Participation and Benefits

Your involvement in this research study is completely voluntary, and you may discontinue participation in the study at any time without penalty. There are no financial benefits associated with participation. The only direct benefit of this study to you is that at the completion of the study a summary of the results will be mailed to you upon request. *

Questions Regarding the Study

If you have any questions about the research study you may ask the researcher; her email and phone number are at the top of this form. If you have questions about your rights in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research at 713-794-2840 or via e-mail at IRB@twu.edu. You will be given a copy of this signed and dated consent form to keep.

Signature of Participant

Date

The above consent form was read, discussed, and signed in my presence. In my opinion, the person signing said consent form did so freely and with full knowledge of its contents.

Signature of Investigator

Date

* If you would like to receive a summary of the results of this study, please provide an address to which this summary should be sent:

APPENDIX E

PARTNER DEMOGRAPHIC FORM

Partner Demographic Form							
Instructions: Check the appropriate response on the form by using the number next to the selected response.							
Age Group	<input type="checkbox"/> (1) 18-24	<input type="checkbox"/> (2) 25 – 34	<input type="checkbox"/> (3) 35 – 44	<input type="checkbox"/> (4) 45 – 54	<input type="checkbox"/> (5) 55-64	<input type="checkbox"/> (6) 65 – 75	
Sex:	<input type="checkbox"/> (1) Male	<input type="checkbox"/> (2) Female					
Race:	<input type="checkbox"/> (1) Hispanic/Latino	<input type="checkbox"/> (2) American Indian	<input type="checkbox"/> (3) Asian	<input type="checkbox"/> (4) Black	<input type="checkbox"/> (5) Pacific Islander	<input type="checkbox"/> (6) White	<input type="checkbox"/> (7) Other
Marital Status:	<input type="checkbox"/> (1) Single	<input type="checkbox"/> (2) Married	<input type="checkbox"/> (3) Divorced	<input type="checkbox"/> (4) Widowed			
Education Level	<input type="checkbox"/> (1) No schooling completed	<input type="checkbox"/> (2) Some high school	<input type="checkbox"/> (3) Some college; no credit	<input type="checkbox"/> (4) Trade, Vocational, Technical	<input type="checkbox"/> (5) Associates	<input type="checkbox"/> (6) Bachelor's	<input type="checkbox"/> (7) Masters or above
Cancer Diagnosis of person that underwent mastectomy: _____							
Date Person underwent mastectomy: _____							
Duration of care and/or support provided: _____							
Specify when you were involved in post-operative phase: _____							

APPENDIX F

INSTITUTIONAL REVIEW BOARD APPROVAL FORM



Institutional Review Board

Office of Research

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<https://www.twu.edu/institutional-review-board-irb/>

DATE: September 30, 2022

TO: Ms. Torina Lane
Nursing - Houston

FROM: Institutional Review Board (IRB) - Houston

Re: Extension for The lived experiences of the intimate partner of a person who underwent a mastectomy (Protocol #: 20203)

The request for an extension of the IRB approval for the above referenced study has been reviewed by the TWU IRB (operating under FWA00000178). This study was originally approved on August 27, 2018 and has been renewed. Approval for this study expires on September 21, 2023.

If applicable, agency approval letters must be submitted to the IRB upon receipt prior to any data collection at that agency. If subject recruitment is on-going, a copy of the approved consent form with the IRB approval stamp is enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study.

Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any unanticipated incidents. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Paula Clutter, Nursing - Houston
Dr. Peggy Landrum, Nursing - Houston