Breast cancer and sexual health: the impact of treatment on sexual life, self-concept, relationships, and the intimate partner

https://hdl.handle.net/2144/23820
Boston University
Thesis

BREAST CANCER AND SEXUAL HEALTH:
THE IMPACT OF TREATMENT ON SEXUAL LIFE, SELF-CONCEPT,
RELATIONSHIPS, AND THE INTIMATE PARTNER

by

NICOLINA S. MASCIA
B.A., Dartmouth College, 2015

Submitted in partial fulfillment of the
requirements for the degree of
Master of Science
2017
Approved by

First Reader

David W. Kindelberger, M.D.
Associate Professor of Pathology & Laboratory Medicine

Second Reader

Sharon L. Bober, Ph.D.
Director, Sexual Health Program
Dana-Farber Cancer Institute
Assistant Professor of Psychiatry
Harvard Medical School
DEDICATION

I would like to dedicate this work to my late brother Anthony Mascia. Thank you for always being my biggest fan.
ACKNOWLEDGMENTS

Alyssa Stetson, Sarah Mayer, Kevin Hall
BREAST CANCER AND SEXUAL HEALTH:
THE IMPACT OF TREATMENT ON SEXUAL LIFE, SELF-CONCEPT,
RELATIONSHIPS, AND THE INTIMATE PARTNER

NICOLINA S. MASCIA

ABSTRACT

As breast cancer survival rates increase, quality of life issues should be addressed, specifically regarding sexual health. Breast cancer treatment can lead to sexual dysfunction, alterations in self-concept, body image, self-esteem, and relationship issues which can cause a depressed quality of life. These sexual health issues can also uniquely affect the intimate partner. It appears that a strong relationship and supportive intimate partner can protect against the stressors due to these sexual problems. Addressing sexual concerns, whether physical, psychological, or relational are a clear necessity in managing the care of patients with breast cancer, regardless of partner status, age, or disease stage. Clinicians and medical professionals should address these issues in patient care plans, examinations, and patient education, focusing not only on the patient but also on the couple as a unit. However, there are barriers to communication in regards to sexuality on both the part of the physician and the patient that cause a discrepancy between available resources and patients actually receiving those resources. Developing effective treatment plans and interventions are essential in improving the quality of life in women suffering from physical, psychological, and relational sexual issues due to the management of breast cancer.
TABLE OF CONTENTS

TITLE ........................................................................................................................................... i
COPYRIGHT PAGE ................................................................................................................... ii
READER APPROVAL PAGE ................................................................................................... iii
DEDICATION ......................................................................................................................... iv
ACKNOWLEDGMENTS ........................................................................................................ v
ABSTRACT ............................................................................................................................. vi
LIST OF TABLES ................................................................................................................... ix
LIST OF ABBREVIATIONS .................................................................................................... x
INTRODUCTION .................................................................................................................... 1
SPECIFIC AIMS ..................................................................................................................... 16
PHYSICAL CHANGES – SEXUAL DYSFUNCTION ............................................................... 17
PSYCHOLOGICAL CHANGES ............................................................................................... 26
RELATIONSHIP CHANGES ................................................................................................. 36
IMPACT ON THE INTIMATE PARTNER ............................................................................ 42
BENEFITS OF A SUPPORTIVE PARTNER ........................................................................ 46
SURVIVOR INTERVIEWS – LIFE AFTER BREAST CANCER ........................................... 50
DISCUSSION ......................................................................................................................... 65
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Factors that increase relative risk for breast cancer in women</td>
<td>6</td>
</tr>
<tr>
<td>2</td>
<td>The short term and long term side effects of chemotherapy drugs</td>
<td>13</td>
</tr>
<tr>
<td>3</td>
<td>Sexual function in women on aromatase inhibitors (AIs)</td>
<td>20</td>
</tr>
<tr>
<td>4</td>
<td>Various effects of AIs and Tamoxifen on sexual dysfunction</td>
<td>23</td>
</tr>
</tbody>
</table>
## LIST OF ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AET</td>
<td>Adjuvant Endocrine Therapy</td>
</tr>
<tr>
<td>AI</td>
<td>Aromatase Inhibitor</td>
</tr>
<tr>
<td>ALND</td>
<td>Axillary Lymph Node Dissection</td>
</tr>
<tr>
<td>BC</td>
<td>Breast Cancer</td>
</tr>
<tr>
<td>BCS</td>
<td>Breast Cancer Survivors</td>
</tr>
<tr>
<td>BCSC</td>
<td>Breast Cancer Surveillance Consortium</td>
</tr>
<tr>
<td>BCT</td>
<td>Breast Conserving Therapy</td>
</tr>
<tr>
<td>BR</td>
<td>Breast Reconstruction</td>
</tr>
<tr>
<td>BU</td>
<td>Boston University</td>
</tr>
<tr>
<td>DIEAP</td>
<td>Deep Inferior Epigastric Artery Perforator</td>
</tr>
<tr>
<td>DVT</td>
<td>Deep Vein Thrombosis</td>
</tr>
<tr>
<td>ER-positive</td>
<td>Estrogen Receptor Positive</td>
</tr>
<tr>
<td>FSFI</td>
<td>Female Sexual Function Index</td>
</tr>
<tr>
<td>HR+</td>
<td>Hormone Receptor Positive</td>
</tr>
<tr>
<td>LGBT</td>
<td>Lesbian, Gay, Bisexual, and Transgender</td>
</tr>
<tr>
<td>ME</td>
<td>Mastectomy</td>
</tr>
<tr>
<td>MRM</td>
<td>Modified Radical Mastectomy</td>
</tr>
<tr>
<td>NSM</td>
<td>Nipple-sparing Mastectomy</td>
</tr>
<tr>
<td>PE</td>
<td>Pulmonary Embolism</td>
</tr>
<tr>
<td>PR-positive</td>
<td>Progesterone Receptor Positive</td>
</tr>
<tr>
<td>RT</td>
<td>Radiation Therapy</td>
</tr>
</tbody>
</table>
SERM.................................................................Selective Estrogen Receptor Modulator
SSM ......................................................................................Skin-sparing Masectomy
TRAM ...........................................................................Transverse Rectus Abdominis Muscle
WLE.....................................................................................Wide Local Excision
INTRODUCTION

Breast cancer (BC) is the most common malignancy affecting women within the United States (“WHO | Breast cancer,” n.d.). The incidence of breast cancer in the developing world is increasing due to the increase in life expectancy, urbanization, and adoption of western ways of life (“WHO | Breast cancer,” n.d.). Fortunately, more women are surviving their diagnosis, and breast cancer survivors make up 41% of the entire population of cancer survivors (Candy, Jones, Vickerstaff, Tookman, & King, 2016). With a diagnosis of breast cancer comes a multitude of physical and psychological consequences, often the greatest of these challenges are related to sexual function and sexual self-concept. In a survey conducted by the LiveStrong Foundation in 2010, (24% of the reporting population had breast cancer), sexual functioning and satisfaction were ranked the third most frequently reported concern (“Challenges Reported by Post-Treatment Cancer Survivors in the LIVESTRONG Surveys | What We Do | LIVESTRONG.org,” n.d.). Diagnosis and especially treatment for most cancers can causes issues with sexual function (Sadovsky et al., 2010). However, breast cancer raises specific concerns due to the breasts’ role in feminine sexuality and role as a source of sexual stimulation, eroticism, and pleasure.

Sexual health goes beyond the idea of arousal and orgasm. There are multiple facets of sexual health, including desire, sensuality, arousal, orgasm, satisfaction, pain, and lubrication (Boswell & Dizon, 2015). There are also multiple contributing factors, such as partner status, overall health, body image, psychological health, comorbidities, and intimacy (Boswell & Dizon, 2015). The Diagnostic and Statistical Manual (5th
now identifies dysfunction in sexual health as having three separate, but often interrelated parts: disorders of sexual interest and arousal, difficulty with orgasm, and disorders associated with genito-pelvic pain/penetration (American Psychiatric Association, 2013). One study of 83 breast cancer survivors using the Female Sexual Function Index (FSFI) found that 77% of the subjects qualified for the diagnosis of sexual dysfunction (Maiorino, Chiodini, Bellastella, Giugliano, & Esposito, 2015). Common cancer therapies (chemotherapy, endocrine therapy, surgeries, radiation) can cause changes to a woman’s sexual health and function, resulting in significant alterations in emotional stress (including depression), depressed self-confidence, and negative impacts on personal relationships, most specifically with one’s sexual partner. Sexuality and intimacy has been found to lessen emotional stress and improve the psychosocial response to a cancer diagnosis (Wimberly, Carver, Laurenceau, Harris, & Antoni, 2005). Therefore, it is important to examine the impact of breast cancer treatment on sexual dysfunction and sexual life. Finding the impact of breast cancer treatment on sexual dysfunction, sexual identity, and intimate relationships is crucial for developing effective interventions in order to improve the dysfunctions themselves, self-concept, relationships, and the overall quality of life for women with breast cancer and survivors.

It is an exciting time in history as medicine slowly shifts toward a more whole-person approach. With this shift, it is important to recognize the unique psychosocial changes that come with a breast cancer diagnosis and survivorship. There is a long-standing principle that survival supersedes sexuality, but there is a significant diminishment in quality of life after breast cancer that could lead to sexual dysfunction
and altered sexual self-concept, the concept of self that is formed from one’s own beliefs and the response of others, and self-esteem. In addition, there is a misconception that because women with breast cancer and survivors are typically past middle age, perhaps into menopause, they are no longer interested in sexuality or intimacy. There is also evidence that sexual intimacy has been found to make the experience of cancer more manageable and to assist in the recovery process (Ussher, Perz, & Gilbert, 2012). Therefore, issues with sexual health and identity should be considered as part of the recovery process for breast cancer and should be more openly talked about among patients, clinicians, survivors, and the general public. However, this is not always the case. While there is an availability for treatments (whether effective or not) for sexual dysfunctions and identity issues, there is a huge discrepancy between self-reported need for professional help and actually receiving the care (Kedde, van de Wiel, Weijmar Schultz, & Wijsen, 2013). This could be due to a variety of factors. Health care professionals do not often bring up sexual problems due to time constraints, embarrassment, lack of knowledge on topics, lack of experience, and the inability to provide support (Kedde et al., 2013). It is likewise challenging for patients to mention these topics, perhaps feeling uncomfortable, embarrassed, or fearing judgment. Of more concern, Wilmoth conducted a study of women of an average 50.5 years old with breast cancer and found that women who sought information about the sexual side effects of breast cancer treatment had a more successful adjustment to therapy-related changes (Wilmoth, 2001).
The effects of breast cancer on sexuality are not usually discussed by clinicians, in patient’s care plans, or in patient education. Perhaps this is because sexuality is different for each individual person. Sexuality and sexual expression can be significant for breast cancer patients and their partners as the disease not only causes serious distress and fears but also affects body image, self-esteem, and the ability to express one’s sexuality. Sexual experiences and intimacy can then be sidelined during a time when those acts could be beneficial.

This paper focuses on the impact of breast cancer treatment on sexual life with an emphasis on how the partner and couple’s relationship are affected. There is a lack of research on the intimate experiences of survivorship for the survivor and the intimate partner, post-treatment. This might be due to difficulty identifying participants willing to share their intimate experiences or to the perception that the breast cancer survivor is the only person in the couple impacted by this life-altering illness. Women who have undergone breast cancer treatment can experience sexual problems in the physical domain, psychological domain, and interpersonal domain. Their partner also has difficult experiences unique to their role. Therefore, there are a lot of factors at play in the intimate relationship. However, there is evidence that sexual intimacy can make the experience of cancer more manageable and to aide in recovery (Ussher et al., 2012). This paper suggests that a supportive intimate partner and strong partner relationship, even in the absence of sexual activity, can alleviate some of the distress caused by sexual dysfunction and the corresponding psychological and interpersonal problems. Perhaps, if there is a stable partner relationship, one is able to better battle breast cancer treatment’s
sexual side effects. The patient interviews in the final section of this paper show two survivors sharing a great deal of information regarding their unique struggle with breast cancer, their intimate relationship, and how they were able to live beyond breast cancer.

**Breast Cancer Statistics and Risk Factors**

Breast cancer is the most common cancer among US women, excluding skin cancers, making up 29% of the newly diagnosed cancer cases (American Cancer Society, 2015). A woman in the US has a 1 in 8 lifetime risk of being diagnosed with breast cancer (American Cancer Society, 2015). From 2008-2012, the median age of breast cancer diagnosis was 61, however premenopausal women are diagnosed as well (American Cancer Society, 2015). In 2015, it was estimated that 1,650 women under 40 were diagnosed with in situ cases, while 10,500 of that same under 40 group were diagnosed with invasive cases (American Cancer Society, 2015). That same year, in the 40-49 age category, there were an estimated 12,310 in situ cases and 35,850 invasive cases (American Cancer Society, 2015). For all age groups, there were an estimated 60,290 in situ cases, 231,840 invasive cases, and 40,290 deaths due to breast cancer (American Cancer Society, 2015). These staggering numbers show just how large a problem breast cancer is. Fortunately, however, the mortality rates are decreasing (American Cancer Society, 2015).

Several risk factors are well documented (see Table 1). Familial history increases the relative risk by a factor of two or three (“WHO | Breast cancer,” n.d.). Mutations in genes such as BRCA1, BRCA2, and p53 confer very high risks of breast cancer, but are
rare and account for a small portion of the total breast cancer population (“WHO | Breast cancer,” n.d.).

Reproductive factors associated with prolonged exposure to endogenous estrogens (such as early menarche, late menopause, late age at first childbirth) are some of the most crucial risk factors (“WHO | Breast cancer,” n.d.). Exogenous hormones, oral contraceptives, and hormone replacement therapy users are at a higher risk than non-users (“WHO | Breast cancer,” n.d.). Breastfeeding appears to be a protective factor (Lacey et al., 2009).

Table 1. Factors that increase relative risk for breast cancer in women

<table>
<thead>
<tr>
<th>Relative Risk</th>
<th>Factor</th>
</tr>
</thead>
</table>
| >4.0         | - Age (65+ vs <65)  
|              | - Biopsy-confirmed atypical hyperplasia  
|              | - BRCA1 and/or BRCA2 gene  
|              | - Ductal carcinoma in situ  
|              | - Lobular carcinoma in situ  
|              | - Personal history of early-onset (<40 years) BC  
|              | - Two or more first-degree relatives with BC diagnosed at an early age |
| 2.1-4.0      | - High endogenous estrogen or testosterone levels  
|              | - High-dose radiation to chest  
|              | - Mammographically extremely dense (>50%) breasts compared to less dense (11-25%)  
|              | - One first-degree relative with BC |
| 1.1-2.0      | - Alcohol consumption  
|              | - Ashkenazi Jewish heritage  
|              | - Diethylstilbestrol exposure  
|              | - Early menarche (<12 years)  
|              | - Height (>5 feet 3 inches)  
|              | - High socioeconomic status |
Late age at first full-term pregnancy (>30 years)
- Late menopause (>55 years)
- Mammographically dense (26-50%) breasts compared to less dense (11-25%)
- Non-atypical ductal hyperplasia or fibroadenoma
- Never breastfeeding
- No full-term pregnancies
- Obesity (postmenopausal)/adult weight gain
- Personal history of BC (40+ years)
- Personal history of endometrium, ovary, or colon cancer
- Recent or long-term use of menopausal hormone therapy with estrogen or progestin
- Recent oral contraceptive use

This table shows the factors that increase the risk of breast cancer and their relative risk levels (American Cancer Society, 2015).

In April of 2015, a team of international researchers combined 77 of the common genetic variants into a single risk factor that can be used to improve the identification of women with a high risk of breast cancer (Mavaddat et al., 2015). The factor, known as the polygenic risk score, was built using the genetic data from more than 67,000 women (Mavaddat et al., 2015). The polygenic risk score can be used to place women into various risk categories. A woman in the top 1% was three times more likely to develop breast cancer when compared to a woman with an average polygenic risk score, and women in the bottom 1% had a 70% lower risk (Mavaddat et al., 2015). Results indicated that the polygenic score is as powerful as other well known risk factors, including familial history and breast density (Mavaddat et al., 2015). A sister study found that breast density and the polygenic risk score both contribute independently to breast cancer
risk (Vachon et al., 2015). When the polygenic risk score was combined with the risk stratification tool used by the Breast Cancer Surveillance Consortium (BCSC), which includes history of breast cancer, history of breast biopsy, age, and ethnicity to calculate risk, the performance of the model was improved – putting 11% of women who eventually developed cancer into a higher risk category (Vachon et al., 2015). The team is currently developing a test based on the results with hopes of using it to improve personalized breast cancer screening and prevention. However, future, larger studies are still critical to determine the ability of models to assess risk in the general population. While risk prediction and screening can be used to help improve early detection, it is still crucial to work to improve BC treatment-related issues in order to improve quality of life for those that survive the disease.

**Breast Cancer Treatment Overview**

The following section reviews the four most common treatment options for breast cancer in order to better understand later how treatment can impact sexual dysfunction, sexual identity, self-esteem, and intimate partner relationships.

1. Radiation Therapy
2. Endocrine Therapy
3. Chemotherapy
4. Breast Surgery
Radiation Therapy

Radiation therapy is often needed if the cancer has spread to the lymph nodes or elsewhere in the body. There are two main types of radiation therapy used to treat BC: external beam radiation, radiation from a machine outside the body, and internal radiation or brachytherapy, radiation from a radioactive source inside the body (American Cancer Society, 2016b). Radiation is often used after breast-conserving surgery to help lower the risk of the cancer returning, after mastectomy, and if the cancer has spread (American Cancer Society, 2016b). External radiation, the most common type of radiation, is not typically started until the tissues have healed, and if paired with chemotherapy, it is usually delayed until after chemo is complete (American Cancer Society, 2016b).

Traditionally, breast radiation was given five days a week for 5 to 6 weeks (American Cancer Society, 2016b). Doctors are now using accelerated breast irradiation, giving larger doses over a shorter time (American Cancer Society, 2016b). Side effects of external radiation include swelling and heaviness in the breast, skin changes (ranging from mild redness to blistering and peeling), and fatigue (American Cancer Society, 2016b). Most skin changes subside in a few months, while changes to breast tissue subside in six to twelve months or longer (American Cancer Society, 2016b). Side effects of external radiation appearing later on include: smaller, firmer breasts, issues with breastfeeding, brachial plexopathy, lymphedema, weakness and fracture of the ribs, radiation-related scarring of the heart and lungs (rare), and development of angiosarcoma (very rare) (American Cancer Society, 2016b). Brachytherapy can be used in conjunction with external radiation for women who have had breast-conserving surgery to add extra
radiation to the tumor site. There are various types of brachytherapy: interstitial and intracavitary (American Cancer Society, 2016b). Interstitial brachytherapy involves catheters placed into the area where the cancer has been removed (American Cancer Society, 2016b). Radioactive pellets are placed into the catheters for short periods of time each day and removed; this method is older with more evidentiary support but is not used often (American Cancer Society, 2016b). During intracavitary brachytherapy, a device is put into the space operated on during breast-conserving surgery and is left until the treatment is complete (American Cancer Society, 2016b). It is placed in a catheter with one end protruding out from the breast (American Cancer Society, 2016b). Radiation sources (mostly pellets) are placed through the tube and into the device and then removed (American Cancer Society, 2016b). Treatments are done twice a day for five days, after which the device is removed (American Cancer Society, 2016b). Side effects of intracavitary brachytherapy include redness, bruising, breast pain, infection, break-down of fatty tissue in the breast, weakness and fracture of the ribs (rare) (American Cancer Society, 2016b).

**Endocrine Therapy**

Estrogen receptor positive (ER-positive) and progesterone receptor positive (PR-positive) breast cancer cells grow in response to estrogen and progesterone, respectively. For these types of cancer, endocrine therapy is recommended. Most endocrine therapy drugs work by lowering estrogen levels or inhibiting estrogen receptors on cancer cells,
therefore inhibiting cell growth. It is most often used as adjuvant therapy but can be used as neoadjuvant therapy as well (American Cancer Society, 2016a).

Tamoxifen, a selective estrogen receptor modulator (SERM), blocks estrogen receptors in breast cancer cells. It can be used in women with a high risk of breast cancer to help lower the risk (American Cancer Society, 2016a). Toremifene (Fareston) is another SERM that is used less often and is approved only to treat invasive, metastatic BC (American Cancer Society, 2016a). Side effects of tamoxifen and toremifene include fatigue, hot flashes, vaginal dryness or discharge, and mood swings (American Cancer Society, 2016a). Some women with cancer that has spread to bones may have “tumor flare”, pain or swelling in the muscles and bones (American Cancer Society, 2016a). In premenopausal women, tamoxifen can lead to bone thinning, but in postmenopausal patients, it augments bone strength (American Cancer Society, 2016a). Some more serious, rare complications include developing endometrial cancer and uterine sarcoma in postmenopausal women, blood clots (DVTs and PEs), strokes in postmenopausal women, and increased risk of myocardial infarction (American Cancer Society, 2016a).

Fulvestrant (Flasodex) is a systemic estrogen antagonist. It is used most often to treat invasive breast cancer after tamoxifen and Aromatase inhibitors have stopped being effective (American Cancer Society, 2016a). Side effects (short term) include hot flashes, night sweats, mild nausea, fatigue, weaken bones. It is currently approved only for postmenopausal women (American Cancer Society, 2016a).

Aromatase inhibitors (AIs) stop estrogen production and are most successful for women after menopause (American Cancer Society, 2016a). Letrozole (Femara),
Anastrozole (Arimidex), and Exemestane (Aromasin) are being used to treat BC (American Cancer Society, 2016a). This drug class has fewer severe complications than tamoxifen (American Cancer Society, 2016a). They can cause muscle pain, joint pain, and stiffness, and they can also cause bone thinning in women postmenopause, due to draining the body of estrogen, leading to osteoporosis and fractures (American Cancer Society, 2016a). The current recommendation for premenopausal women with high risk breast cancer is ovarian ablation or suppression and treatment with AIs (Zhang et al., 2016).

**Chemotherapy**

Chemotherapy treats the whole body, not just the breast. It can be administered by mouth or intravenously. There are several side effects of chemotherapy, although women suffer different side effects from different combinations of agents (see Table 2). Not all women with BC need to go through chemotherapy, but it is recommended in some situations: adjuvant (after surgery), neoadjuvant (before surgery), and for advanced breast cancer (American Cancer Society, 2016d). The most common chemotherapy drugs include: Anthracyclines, such as doxorubicin (Adriamycin®) and epirubicin (Ellence®), Taxanes, such as paclitaxel (Taxol®) and docetaxel (Taxotere®), 5-fluorouracil (5-FU), Cyclophosphamide (Cytoxan®), and Carboplatin (Paraplatin®) (American Cancer Society, 2016d). They are often most successful when a combination is used (usually 2 or 3) (American Cancer Society, 2016d). Advanced breast cancer chemotherapy drugs include: Docetaxel, Paclitaxel, platinum agents (cisplatin, carboplatin), Vinorelbine
(Navelbine®), Capecitabine (Xeloda®), Liposomal doxorubicin (Doxil®), Gemcitabine (Gemzar®), Mitoxantrone (Novantrone®), Ixabepilone (Ixempra®), Albumin-bound paclitaxel (nab-paclitaxel or Abraxane®), and Eribulin (Halaven®) (American Cancer Society, 2016d). Advanced breast cancer may be treated with a single drug, but combinations (carboplatin or cisplatin plus gemcitabine) are commonly used (American Cancer Society, 2016d). Chemotherapy drugs are given in cycles, which are commonly 2 or 3 weeks long. Adjuvant and neoadjuvant chemo is given for 3 to 6 months total, depending on the drugs used (American Cancer Society, 2016d).

<table>
<thead>
<tr>
<th><strong>Short Term</strong></th>
<th><strong>Long Term</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>(subside when chemo finishes)</td>
<td></td>
</tr>
<tr>
<td>Hair loss, Nail Changes</td>
<td>Neuropathy</td>
</tr>
<tr>
<td>Mouth sores</td>
<td>Hand-food syndrome</td>
</tr>
<tr>
<td>Loss of appetite or increased appetite</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>Heart damage</td>
</tr>
<tr>
<td>Increased chance of infections</td>
<td>Premature menopause, infertility</td>
</tr>
<tr>
<td>Easy bruising or bleeding</td>
<td>Increased risk of leukemia (rare)</td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
</tr>
<tr>
<td>Diarrhea</td>
<td></td>
</tr>
</tbody>
</table>

There are various short term and long term effects due to chemotherapy drugs that affect many separate body systems (American Cancer Society, 2016d).
Breast Surgery

The type of breast surgery performed depends on: the size of the cancer in the breast, whether it has spread, the size of the breasts, personal feelings, thoughts, wishes (American Cancer Society, 2016c). There are a multitude of breast surgeries – simple or total mastectomy, modified radical mastectomy, radical mastectomy, skin-sparing mastectomy, nipple-sparing mastectomy, lumpectomy or wide local excision surgery, lymph node surgery, and breast reconstruction (or BR, of which there are multiple types) (American Cancer Society, 2016c). During the simple or total mastectomy, the surgeon removes the entire breast including the nipple; the lymph nodes are not removed (American Cancer Society, 2016c). This is the most appropriate option if the cancer is not present in the lymph nodes and if the surgery is done to lower risk of getting breast cancer (American Cancer Society, 2016c). With a modified radical mastectomy, all of the breast tissue, nipple, and lymph nodes in axilla are taken, which is preferred if the cancer is invasive to the lymph nodes (American Cancer Society, 2016c). During the radical mastectomy, the surgeon removes all of the breast tissue and nipple, the lymph nodes of the armpit, and the muscles of the chest wall under the breast (American Cancer Society, 2016c). This is rarely done at present since the modified radical mastectomy is effective and less disfiguring, but is conducted if the cancer has spread to the chest muscles (American Cancer Society, 2016c). With the skin sparing mastectomy, the skin of the nipple, areola, and the area with the tumor are all taken out, leaving behind the rest of the skin to be used for breast reconstruction (American Cancer Society, 2016c). Nipple-

14
sparing mastectomies are similar to skin-sparing surgeries, but the areola is left intact and only the glandular tissue is removed. During a lumpectomy (also known as a partial mastectomy or wide local excision), the surgeon removes the tumor and some surrounding breast tissue. Radiation treatments are likely needed as well with this option (American Cancer Society, 2016c). There are two types of common lymph node surgeries. The axillary lymph node dissection (ALND), during which 10 to 20 lymph nodes from under the arms are removed, and the sentinel lymph node biopsy, where the surgeon finds and removes the lymph nodes where the cancer would most likely have spread to first (American Cancer Society, 2016c). Breast reconstruction (BR) with implants or tissue from the lower abdomen, buttocks, back, or inner thighs can be used to reconstruct the breast after a mastectomy (American Cancer Society, 2016c).
SPECIFIC AIMS

Myths and issues in our society result in barriers to conversations about sexuality in women with breast cancer. One myth in particular is the notion that women with breast cancer and survivors are no longer concerned with sexuality and intimacy. Sexuality and sexual function in a woman with or post breast cancer need to be considered regardless of the woman's age, partner status, and disease stage. One aim of this paper is to present research related to changes in a woman's sexuality, self-concept, and intimacy after the management of breast cancer to provide strategies for clinicians to use in communicating openly about sexuality, as well as to provide loved ones, and intimate partners with support strategies and tools for a similar open communication. Another aim is to present findings related to changes in intimate partner relationships with a focus on the experience of the intimate partner as the primary support system in order to give medical professionals an insight into the struggles of the couple as a unit. The intimate partner provides a unique support system, and the hope is that this paper shows the protective value of a strong relationship and supportive partner against the sexual issues that can arise in association with breast cancer treatment. The aim of this paper is finally to give a research direction for possible treatments for sexual dysfunction, intimacy, and sexuality concerns in breast cancer survivors in order to improve quality of life for these women.
IMPACT OF TREATMENT:

PHYSICAL CHANGES – SEXUAL DYSFUNCTION

While handling guilt, anxiety about the future, and the fear of potential treatment side effects, it is not surprising that sexual problems arise due to breast cancer. Although most cancer causes problems in some area of sexual life, breast cancer is uniquely important to consider due to breasts’ role in feminine sexuality and role as a source of erotic pleasure and stimulation. Breast cancer treatments all have direct and indirect effects related to sexual function (Sadovsky et al., 2010).

Findings show that when compared with healthy, age-matched women, women with breast cancer have less sexual satisfaction and more difficulty maintaining their sexual life (Speer et al., 2005). Each form of treatment may affect sexual function in a different way, but it is of concern that regardless of the type of treatment received, women treated for BC experience sexual dysfunction. This section will present published research on the various areas of sexual dysfunction for each of the major breast cancer treatment options.

Radiation Therapy

Radiation therapy (RT) is a crucial component of therapy for BC patients treated with breast conserving therapy/surgery (BCT) and patients with high risk cancers that necessitate mastectomy (ME), including those women where chemotherapy was chosen in place of surgery (Boswell & Dizon, 2015). RT can result in local breast issues, such as constant breast pain, arm and shoulder pain, loss of flexibility, and lymphedema, which
contributed to depressed sexual functioning (Albornoz et al., 2014; Hidding, Beurskens, van der Wees, van Laarhoven, & Nijhuis-van der Sanden, 2014; Safarinejad, Shafiei, & Safarinejad, 2013). Safarinejad et al. found that treatment with RT had significantly increased risk of lubrication and satisfaction disorders (Safarinejad et al., 2013).

Albornoz et al., found that in women who underwent breast reconstruction (BR), those who had also undergone RT were significantly less satisfied with the breasts and the outcome (Albornoz et al., 2014). The women treated with RT had significantly lower scores for sexual well-being (Albornoz et al., 2014). Despite all of the evidence, it is hard to pinpoint the exact reason for radiation therapy’s negative impact on and contribution to sexual dysfunction and sexual health because it is almost always used in conjunction with other BC treatments in an interdisciplinary manner.

**Chemotherapy**

Many women with BC undergo chemotherapy (often adjuvant chemotherapy). For women who are not yet menopausal, chemotherapy has a risk of chemotherapy-induced ovarian failure and the onset of early menopause, which can cause sexual dysfunction issues (Boswell & Dizon, 2015). Agents such as anthracyclines and taxanes negatively affect general physical functions, reducing interest, arousal, and desire (Boswell & Dizon, 2015). In addition, common side effects of chemotherapy, including fatigue, alopecia, gastrointestinal distress, and myelosuppression, can affect desire and arousal (Boswell & Dizon, 2015). A study in 2010 found that sexual functioning, desire, and arousal all declined significantly following chemotherapy (Biglia et al., 2010). Some
women can experience a relief of changes in sexual functioning after chemotherapy finishes, but Biglia et al. found that these changes persisted at one year following chemotherapy (Biglia et al., 2010). Another study found that chemotherapy was associated with unmet sexual needs, which were reported less than a year from the end of treatment and also more than three years after treatment (Hwang, Chang, & Park, 2013).

**Endocrine Therapy**

Anti-estrogen therapies (including tamoxifen) have large negative effects on sexual and vaginal health (Derzko, Elliott, & Lam, 2007). Anti-estrogen therapies lead to increased endometrial abnormalities, such as more polyps, more hyperplasia, and a higher risk of endometrial cancer (Derzko et al., 2007). They lead to more hot flashes, vaginal bleeding and discharge and cause issues besides genital functioning that affect sexual health, including bladder and bowel difficulties, mobility limitations, and fatigue (Derzko et al., 2007). Consequently, aromatase inhibitors (AIs) have become the premier adjuvant therapy option for postmenopausal women with hormone receptor positive (HR+) breast cancer to prevent recurrence and second primary tumors (Burstein et al., 2014). Beginning endocrine therapy with an AI or switching to an AI after taking tamoxifen has been shown to be significantly better than tamoxifen alone in preventing breast cancer from recurring (Burstein et al., 2014). It is still unclear whether AIs provide a more robust chance of survival than tamoxifen treatment (Burstein et al., 2014). The American Society of Clinical Oncology updated the clinical practice guideline for adjuvant endocrine therapy with HR+ breast cancer in 2014 (Burstein et al., 2014). According to
that guideline, there are options of an aromatase inhibitor (AI) for 5 years or tamoxifen for 5 years followed by 5 more years of an AI (Burstein et al., 2014). Goss et al. (2011) and Cuzik et al. (2014) both showed promising results for AIs used for primary prevention in postmenopausal women at high risk for breast cancer. After such studies, AIs are more often prescribed than tamoxifen for the postmenopausal population (Burstein et al., 2014). Premenopausal women were not able to have AIs because they require non-functional ovaries (Pagani et al., 2014). However, the option of ovarian suppression along with an AI is now an alternative to tamoxifen (with or without ovarian suppression) (Pagani et al., 2014). The current clinical recommendation is to put young women at higher risk on AIs with ovarian suppression, which has profound negative impacts on sexual and vaginal health, including increased hot flushes and vaginal dryness (Zhang et al., 2016). The idea here is that for the higher risk young patients, the benefits outweigh the harms. Three AIs frequently used, exemestane, letrozole, anastrozole, seem to have comparable sexual side effects overall (Hadji et al., 2013; Ziller et al., 2009).

Table 3 shows the various sexual dysfunctions and their prevalence in women treated with AIs (Schover, Baum, Fuson, Brewster, & Melhem-Bertrandt, 2014).

<table>
<thead>
<tr>
<th>Publication</th>
<th>N</th>
<th>Months on AIs</th>
<th>Low sexual desire %</th>
<th>Vaginal dryness %</th>
<th>Dyspareunia %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morales et al. 2004</td>
<td>37</td>
<td>3</td>
<td>68</td>
<td>50</td>
<td>62</td>
</tr>
<tr>
<td>Cella et al. 2006</td>
<td>335</td>
<td>60</td>
<td>34</td>
<td>18</td>
<td>17</td>
</tr>
<tr>
<td>Jones et al. 2007</td>
<td>808</td>
<td>12</td>
<td>58</td>
<td>50</td>
<td>—</td>
</tr>
<tr>
<td>Antoine et al. 2008</td>
<td>14</td>
<td>Unknown</td>
<td>84</td>
<td>88</td>
<td>—</td>
</tr>
</tbody>
</table>
These are the various sexual issues and percentage of women affected will on AIs in publications since 2004 (Schover, Baum, Fuson, Brewster, & Melhem-Bertrandt, 2014).

At least a third of women in most studies reported low sexual desire, vaginal dryness, and dyspareunia. Schover and colleagues do point out limitations that are problematic for understanding these data. It is not clear whether sexually inactive women were excluded or included in the studies. Women not having sex may not be aware of sexual changes (Schover et al., 2014).

Endocrine therapy agents are associated with the onset and/or worsening of menopausal symptoms, including hot flashes, which can negatively impact sexual function and health (Boswell & Dizon, 2015; Morales et al., 2004). 30-40% of women being treated with tamoxifen have sexual complaints, and over 50% of women on AIs report similar sexual problems (Boswell & Dizon, 2015). Women treated with AIs or tamoxifen have similar scores for quality of life, menopause symptoms, hot flashes, and fatigue (Baumgart, Nilsson, Evers, Kallak, & Poromaa, 2013; Cella et al., 2006; Frechette et al., 2013). AIs have been found much more likely to increase vaginal dryness, dyspareunia, and arthralgias than tamoxifen (Castel et al., 2013; Frechette et al., 2013; Morales et al., 2004). In one study by Morales et al., AIs were found to increase

<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>Unknown</th>
<th>51</th>
<th>32</th>
<th>16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oberguggenberger et al. 2011</td>
<td>233</td>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baumgart et al. 2013</td>
<td>35</td>
<td>Unknown</td>
<td></td>
<td>42</td>
<td>62</td>
</tr>
<tr>
<td>Kyvernitakis et al. 2014</td>
<td>181</td>
<td>24</td>
<td>43*</td>
<td>57</td>
<td></td>
</tr>
<tr>
<td>Aiello Bowles et al. 2012</td>
<td>314</td>
<td>Unknown</td>
<td>36</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>Fallowfield et al. 2012</td>
<td>83</td>
<td>24</td>
<td>32</td>
<td>17</td>
<td>13</td>
</tr>
</tbody>
</table>

*Item was reported as “sexual problems” so it may reflect more than low desire.
dyspareunia while tamoxifen decreased sexual interest (Morales et al., 2004). The two agents impact sexual health in differing areas, but both negatively impact sexual health. A more recent study compared postmenopausal women with BC taking either tamoxifen (with or without estrogen) or an AI (with or without estrogen) with age matched women with no history of cancer of two groups, currently taking estrogen and not currently taking estrogen (Baumgart et al., 2013). Sexual activity was similar across all groups (Baumgart et al., 2013). Women on AIs were unsatisfied with their sex life overall (42.4%) and reported significantly less sexual interest (50%) than the tamoxifen-treated group and the two control groups (Baumgart et al., 2013). AI-treated patients had more issues with lubrication (73.9%) and dyspareunia (56.5%) than controls (both taking and not taking estrogen) (Baumgart et al., 2013). Interestingly, tamoxifen-treated patients had more dyspareunia (31.3%) but scored about the same as the control groups in all of the other areas (Baumgart et al., 2013). Orgasmic dysfunction was not statistically different for those taking AIs or tamoxifen (50% and 42%, respectively) (Baumgart et al., 2013). This study’s results suggest that AIs have a greater negative effect on sexual function than tamoxifen (see Table 4). However, this study only used postmenopausal women with or without BC. Morales et al. (2004) found tamoxifen and AIs impacted desire and dyspareunia (respectively), independently of age. This study did, however, show that younger women had increased hot flashes and vaginal dryness with both agents, suggesting there can be age differences in at least those two areas of sexual functioning (Morales et al., 2004).
Table 4. Various effects of AIs and Tamoxifen on sexual dysfunction

<table>
<thead>
<tr>
<th>Sexual Dysfunction Type</th>
<th>% of AI-treated Group Affected</th>
<th>% of Tamoxifen-treated Group Affected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insufficient lubrication</td>
<td>74%*</td>
<td>40%*</td>
</tr>
<tr>
<td>Dyspareunia</td>
<td>57%*</td>
<td>31%</td>
</tr>
<tr>
<td>Orgasmic Dysfunction</td>
<td>50%</td>
<td>42%</td>
</tr>
</tbody>
</table>

*=significant difference from controls

These results from Morales et al. (2004) demonstrate AIs having a greater negative impact in all three areas of sexual dysfunction than tamoxifen.

A study by Schover et al., found that during the first two years of AI therapy, 93% met the specific criteria for sexual dysfunction on the FSFI (Female Sexual Function Index), and 75% reported distress as a consequence of sexual issues (Schover et al., 2014). Almost 25% of women studied who were sexually active at the start of endocrine therapy stopped having sex as a result of these sexual issues (Schover et al., 2014). These women were not investigated throughout and after endocrine therapy so it is unclear whether or not sexual dysfunction remains prominent after therapy has concluded. Further research is needed to find the long-term effect of endocrine therapy on sexual function, which should include studies with premenopausal women. However, research suggests that the majority of women being treated with AIs, the most popular option for endocrine therapy, are experiencing sexual dysfunction in one area or another that is distressing and difficult to overcome.
Breast Surgery

Breast surgery can result in physical changes in sexual function. There is evidence that conserving breast therapy or surgery (BCT) has less of a negative impact on sexual function than simple mastectomies (ME) (Boswell & Dizon, 2015). A prospective study of women with early-stage breast cancer found that post-operative sexual function scores were significantly lower than pre-operative scores in both the mastectomy (ME) and breast conserving therapy or surgery (BCT) group (Aerts, Christiaens, Enzlin, Neven, & Amant, 2014). Compared to their pre-operative scores, significantly more women in the BCT group reported problems with sexual arousal after six months following surgery, while significantly more women in the ME group had problems with sexual desire, arousal, ability to achieve orgasm both six months and one year after breast surgery (Aerts et al., 2014). In the ME group women also reported problems with intensity of orgasm (Aerts et al., 2014). Another study found similar results after evaluating close to 1,000 women over five years following breast surgery (Engel, Kerr, Schlesinger-Raab, Sauer, & Hölzel, 2004). Women who underwent ME had more disruption in their sex lives than those who underwent BCT (Engel et al., 2004). Even more important, while some issues improved over time, issues with sexual functioning did not, plaguing these women for at least five years (Engel et al., 2004).

When it comes to reconstructive surgery, there is conflicting evidence on the impact on sexual dysfunction. Some studies do suggest an improved sexual health associated with breast reconstructive surgery (Atisha et al., 2008; Ganz, 1997). However,
contradicting evidence exists as well. A study by Metcalfe et al. found that women who had ME alone, and ME with either immediate or delayed reconstruction had no significant differences in sexual function one-year post-op (Metcalfe et al., 2012). It is clear that all treatment options for breast cancer cause various types of sexual dysfunction of various degrees of severity. The staggering numbers of women suffering from these distressing issues show the impact that BC treatment can have. It is therefore important to include these risks as part of the conversation surrounding breast cancer treatment and life as a survivor. BC treatment can also understandably affect psychosocial areas including self-esteem and body image. The next section will present research published on these psychosocial changes associated with management of breast cancer.
IMPACT OF TREATMENT: PSYCHOLOGICAL CHANGES –
ALTERED SELF-ESTEEM, BODY IMAGE, AND SEXUAL SELF-CONCEPT

With a diagnosis of breast cancer come various psychosocial issues, and often the greatest of challenges relate to sexual function, body image, and sexual self-concept. Body image is the mental picture of one’s body and is a component of a large concept of self that for many women involves feeling feminine and attractive, although each woman experiences her body differently (Cohen, Kahn, & Steeves, 1998). Research has found that older women experience more body image issues with breast cancer than with gynecological cancers (Gómez-Campelo, Bragado-Álvarez, & Hernández-Lloreda, 2014). A key study done by Pikler and Winterowd found that the more positive a woman’s body image, the better she coped with cancer, and with the better body image came higher levels of self-confidence towards coping with breast cancer (Pikler & Winterowd, 2003). In addition, body image has been found to be correlated with sexual problems (Fobair et al., 2006). It is important to consider the psychosocial effects of breast cancer treatment in order to find interventions for improving self-esteem, body image, and sexual self-concept and perhaps to help remedy sexual problems caused by treatment. While the majority of this type of research focuses on breast cancer surgery, this section presents how each of the common treatments for breast cancer can impact self-esteem, body image, and sexual self-concept.

26
Radiation and Endocrine Therapy

The majority of research on the effects of RT on body image, self-esteem, and sexual self-concept uses participants who have undergone breast surgery (or another treatment option) as well as RT, since this is a common treatment combination. Therefore, it is difficult to find the specific impact that RT has. Albornoz et al. found that women treated with RT after BR had significantly lower scores of psychosocial well-being than women who only had BR (Albornoz et al., 2014). A study by Chang and colleagues found that for women treated with both breast cancer surgery and RT, significantly poorer body image and higher distress was associated with unemployment, when the model was fully adjusted (Chang et al., 2014). In addition, after correcting the model for age, disease stage, present treatment status, and type of breast surgery, higher body image was positively correlated with higher education and family income (Chang et al., 2014). These results, demonstrating that socioeconomic status had an impact on body image and quality of life for these women, further complicates how RT impacts body image (Chang et al., 2014).

Much of the research conducted on women who are undergoing or who have been treated with endocrine therapy for breast cancer in the past focuses on the physical side effects of the treatment, and few studies addressed the psychological impact of endocrine therapy (Rosenberg, Stanton, Petrie, & Partridge, 2015). Kraus’s data shows that distorted body image due to breast cancer treatment is more pronounced if hormonal or chemotherapy is added to the treatment schedule (Kraus, 1999). In this case, however, it is hard to analyze the exact effects of hormone therapy on body image. Aerts and
colleagues found that for women being treated with tamoxifen or AIs, emotional distress was correlated negatively with self-esteem (Ates et al., 2016). For those women, higher self-esteem meant a lower level of emotional distress (Ates et al., 2016). This finding suggests that self-esteem can have a protective effect from emotional distress due to endocrine therapy.

Breast cancer survivors often receive adjuvant endocrine therapy (AET) long-term to reduce the risk of the cancer recurring (Van Londen et al., 2014). In one study on this particular group of women, over 50% of participants were currently experiencing identity and sexual difficulties (Van Londen et al., 2014). A higher number of concerns was associated with the receipt of chemotherapy, suggesting that chemotherapy played an important role in psychological disturbances for these women (Van Londen et al., 2014).

**Chemotherapy**

Cytotoxic chemotherapy causes hair loss and weight gain or loss, which can affect a women’s sexual self-concept and, in turn, their sexual experience (Pinto, 2013). Biglia and colleagues (2010) found that sexual function, desire, and arousal all worsen at one year following chemotherapy for breast cancer. These changes were not associated with a worsening sense of body image (Biglia et al., 2010). However, some studies point to chemotherapy causing a worsening in body image and self-esteem (Fobair et al., 2006; Hwang et al., 2013). Fobair and colleagues found that greater body image issues were associated with hair loss due to chemotherapy (Fobair et al., 2006).
In a larger, recent study of 534 women, Hwang and colleagues found that women who had undergone chemotherapy for breast cancer had a significantly worse quality of life than women who did not have chemotherapy (Hwang et al., 2013). Chemotherapy was associated with depression, unmet sexual needs, and a lower emotional well-being (Hwang et al., 2013). These findings were predominantly reported acutely (less than 1 year from end of treatment) but also appeared to be present later (more than 3 years out from treatment), suggesting a long-term component to the psychosocial effects of chemotherapy (Hwang et al., 2013). However, more research is needed on the long-term effects on breast cancer survivors and their self-esteem, self-concept, and body image.

**Breast Surgery**

BC management has recently been shifting to include considerations for improved quality of life. Although BR and implants may mask breast loss to the outside world, implants are not incorporated into the woman’s body image and does not always help cure her sense of deformity (Al-Ghazal, Fallowfield, & Blamey, 2000). Breast conserving surgeries (such as the wide local excision procedure) are therefore now the premier choice for most patients (“Types of breast cancer surgery | Cancer Research UK,” n.d.). However, this method is not always an available option for some patients, such as those with multiple tumors or widespread ductal in situ carcinoma.

In these cases, mastectomy is preferred since it promises the highest local control of the cancer. However, mastectomies also result in significant changes to body image that cause emotional and psychological stress for many patients (Curran et al., 1998).
Women treated with mastectomy reported life disruptions and significantly lower scores in body image, role, and sexual life (Engel et al., 2004). In any surgery, the cosmetic outcome is important for patient satisfaction.

Breast-conserving surgery is associated with an improved quality of life compared to a simple mastectomy. There have been published studies that have found no difference in quality of life between the two treatment modalities after a long-term follow up, but they have found superior body image in patients undergoing breast-conserving surgery (Jeffe, Pérez, Cole, Liu, & Schootman, 2016). Jeffe and colleagues explained this finding due to the fact that quality of life is affected not only by the type of surgery performed but also by the cancer diagnosis and fear of recurrence (Jeffe et al., 2016).

When it comes to reconstructive surgery, there is conflicting evidence on the impact on psychosocial well-being. Atisha et al., evaluated responses from 116 women who had immediate reconstruction and 57 women with delayed reconstruction. Body image and psychological well-being improved from pre-operative scores (Atisha et al., 2008). The women were thriving regardless of the type of procedure performed. The general psychosocial benefits and improved body image scores continued to be observed 2 years following surgery (Atisha et al., 2008). Metcalfe et al., found that women who had ME alone, ME with immediate, and ME with delayed reconstruction had no significant differences in quality of life, cancer-related distress, body image, anxiety or depression after one year following surgery (Metcalfe et al., 2012). This suggests women need psychosocial support even with reconstruction (Metcalfe et al., 2012).
Much of the research shows changes in body image and self-esteem post breast surgery. In a study by Fobair and colleagues, half of the partnered women experienced two or more body image problems sometimes or at least one problem most of the time following breast surgery (Fobair et al., 2006). The group found that serious problems were rather infrequent, such as feeling self-conscious or embarrassed by their body a lot of the time (reported by 10%), feeling worried about sexual attractiveness (10%), and feeling less feminine (7%) (Fobair et al., 2006). Similar to previous studies, the group found that greater body image problems were reported with mastectomies (Fobair et al., 2006). In a very recent study, Rojas and colleagues studied women who underwent radical mastectomies, skin-sparing (SSM), and nipple-sparing (NSM) mastectomies (Rojas et al., 2017). The NSM group had the least satisfaction with post-operative appearance and lowest median sexual desire (Rojas et al., 2017). While NSM offers the greatest opportunity to preserve the patient’s own skin, the results of this study do not support better body image or greater surgical aesthetic outcome (Rojas et al., 2017). The group suggests that surgeons should be realistic with patients in terms of aesthetic and functional outcomes so that patients can make an informed decision prior to surgery (Rojas et al., 2017).

Markopolous et al. conducted a retrospective study with patients with stage 1 or 2 BC treated with either wide local excision (WLE) and axillary lymph node clearance (breast-conserving or WLE group), modified radical mastectomy without reconstruction (MRM group), or by mastectomy with delayed breast reconstruction (BR group) (Markopoulous et al., 2009). The groups were given two questionnaires, part 1 and 2. Part
1, about body image, was given 12 months after surgery and consisted of yes/no questions, while Part 2 was specific to each type of surgery (Markopoulos et al., 2009). The researchers found that the WLE group had the most satisfaction with treatment overall but reported reduction in sexual willingness, and the BR group reported the least problems in sexual life (Markopoulos et al., 2009). 94% of the WLE group stated they would choose that surgery again (Markopoulos et al., 2009). The majority of the WLE group and many in the BR group were satisfied with their outcomes; over 75% of the WLE group were very satisfied with body image, total cosmetic outcome, and surgical outcome (Markopoulos et al., 2009). The MRM group was the least satisfied with their surgery, body image, and sex life (Markopoulos et al., 2009). The results were consistent with a previous study that found immediate reconstruction produced less distress and a better psychological status compared with delayed reconstruction (Curran et al., 1998). Overall the results showed that breast-conserving (wide local excision) surgery had the least detrimental impact on self-esteem, body image, and sexual life and that delayed reconstruction is better than no reconstruction at all (Markopoulos et al., 2009).

Nano et al. found a significant difference between mean body image score of a mastectomy group (40.73) and the mean scores of the breast-conserving group (44.39), and the BR group (41.99). The ages at diagnosis were oldest in the mastectomy group and youngest in the BR group (Nano et al., 2005). These results suggest that sexuality and body image may be slightly more important for women diagnosed with breast cancer earlier in life (Nano et al., 2005). However, the BR group still had the highest levels of satisfaction (Nano et al., 2005). This group of patients typically has extensive interviews
and counseling before their surgery, possibly influencing satisfaction levels, according to the researchers (Nano et al., 2005). The study also evaluated the surgeries based on the breasts look and feel compared to the original breasts. The BR group reported their breasts looked more similar to the original breasts than the conserving group, and the conserving group reported their breasts feeling more similar to the original breasts than the BR group however (Nano et al., 2005). This may reinforce the finding that 30% of breast conserving surgeries result in significant breast deformities (Dewar et al., 1988; Johansen et al., 2002). The difference in quality of life between the three procedures is hard to say, but this study demonstrated the importance of breast conserving surgeries and BR in maintaining and perhaps improving body image. The highest satisfaction and best cosmetic outcome scores for the BR group demonstrate the superior results that can be achieved with breast reconstruction over conservation surgery.

Al-Ghazal and colleagues (2010) conducted a study to compare psychological aspects and patient satisfaction following WLE, simple mastectomy, and immediate BR. When it came to satisfaction, 91% of the WLE group was very much or moderately satisfied with the cosmetic outcome compared with 80% of the BR group and 73% of the simple mastectomy group (Al-Ghazal et al., 2000). Body image was reported significantly higher by women in the WLE group and lowest in the mastectomy group (Al-Ghazal et al., 2000). Similarly, self-esteem was better in the WLE group and worst in the simple mastectomy group (Al-Ghazal et al., 2000). The wide local excision group had less changes to body image and less extensive disfiguring than the breast reconstruction and simple mastectomy groups, which could have resulted in a higher patient satisfaction
with the cosmetic outcome (Al-Ghazal et al., 2000). Wide local excision is the obvious choice in operative procedures according to this study but is only available for a small group of breast cancer patients. Also of note, Ignacio Arrars and colleagues longitudinally studied premenopausal breast cancer survivors and found that post-mastectomy survivors had a four-fold greater risk of low body image scores, meaning these body image effects due to surgery can last long into survivorship (Ignacio Arraras et al., 2016). Therefore, BR should be offered for all patients that require mastectomy, as it allows for better body image and self-esteem levels and a subsequent higher quality of life.

The type of breast reconstruction has implications for body image and patient satisfaction. Sgarzani and colleagues studied body image and patient satisfaction for women who underwent breast reconstruction with either implants or autologous tissue reconstruction, where the tissue was a deep inferior epigastric perforator (DIEP) flap (Sgarzani et al., 2015). The DIEP group had a significantly higher level of satisfaction with the surgical outcome than the implant group (Sgarzani et al., 2015). The DIEP group also had higher levels on measures of quality of life, including psychosocial well-being, body image, sexual well-being, and physical well-being, but these results did not reach significance (Sgarzani et al., 2015). Yueh and colleagues evaluated patient satisfaction in patients who underwent tissue expander/implant, latissimus, pedicle transverse rectus abdominis muscle (TRAM), and deep inferior epigastric perforator (DIEP) flap reconstructions (Yueh et al., 2010). The DIEP group had the highest general level of
satisfaction (Yueh et al., 2010). Health-related quality of life was identified as a significant covariate influencing patient satisfaction (Yueh et al., 2010). These results suggest that autologous tissue reconstruction appears to have better psychological outcomes than implant reconstruction, with DIEP being the best autologous tissue option.

Sexual self-concept can also be compromised with breast surgery. Wilmoth (2001) conducted a study with 18 women of an average 50.5 years of age to study the sexual side effects of breast cancer treatment. All of the women had undergone breast surgery; 7 women had lumpectomies and 11 women had mastectomies (Wilmoth, 2001). Wilmoth observed “losses” in four areas regardless of the type of surgery performed: “missing parts, loss of bleeding and becoming old, loss of sexual sensations, and loss of womanhood” (Wilmoth, 2001). Wilmoth coined the term “altered sexual self” to describe the adjustment to the sexual side effects of breast cancer surgery (Wilmoth, 2001). For these women, learning to adjust to the new sexual self was the main way to live beyond the cancer (Wilmoth, 2001). Our understanding of the ways breast surgery impacts body image, self-esteem, and sexual self-concept does have significant limitations, as most of the research on sexual self-concept fails to address how psychosocial issues change over time for survivors. Further research is needed to show how psychosocial changes continue later into survivorship.
IMPACT OF TREATMENT:
INTIMATE RELATIONSHIP CHANGES

Historically, research has explored the effects of breast cancer on sexuality and intimacy in regards to women experiencing satisfying sexual activity, their contentment with the frequency of sexual activity, and their physical sexual dysfunction (Wilmoth, 2001). Functionally, sexuality was thought of as penile/vaginal intercourse (Wilmoth, 2001). However, research has shown that sexual intercourse is not the main sexual concern after breast cancer and that sexual satisfaction is not always limited to sexual intercourse (Wilmoth, 2001). The primary focus on physical effects due to breast cancer treatment does not address the influence of the social and relational aspects of sexuality and illness, as well as how the meaning of sex varies to each individual and each intimate couple (Ussher et al., 2012). For breast cancer survivors in partnered relationships, the most important and consistent predictors of sexual health are presence/absence of vaginal dryness, emotional well-being, quality of the relationship, and if partner has sexual problems (Sadovsky et al., 2010). Of those factors, one of the strongest and most consistent predictors of sexual health after breast cancer is the quality of the partnered relationship (Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999). The quality of the relationship has been found to be a stronger predictor of sexual functioning, satisfaction, and desire after breast cancer than the physical damage to the body due to treatment (Alder et al., 2008). A healthy relationship status and supportive intimate partner have
been shown to help a woman cope with cancer (Archibald, Lemieux, Byers, Tamlyn, & Worth, 2006).

Studies have also shown that cancer can have a positive effect on partner relationships by improving intimacy and in turn, bringing the couple closer together (Badr & Taylor, 2009). Unfortunately, however, most research consistently shows the negative impact of breast cancer on intimate partner relationships. Ussher et al., (2012) found that out of 1999 respondents, 24% said their sexual relationship was affected “dramatically”; 26%, “considerably”; 32%, “somewhat”; and only 15%, “not at all.” Many studies show evidence that the diagnosis of cancer can change the relational dynamics between the person with cancer and their life partner, which can in turn affect their sexual life (Gilbert, Ussher, & Hawkins, 2009). A review by Taylor-Brown and colleagues proposes the importance of clinicians’ query about the quality of martial and partner relationships, as it seems to be a main predictor of post-diagnosis marital adjustment (Taylor-Brown, Kilpatrick, Maunsell, & Dorval, 2000). This section will present research on breast cancer treatment’s negative effects in two extremely important areas of intimate partner relationships: sexual intimacy and emotional intimacy.

**Sexual Intimacy**

The research presented in previous sections of this paper show the numerous areas of sexual function and life that are affected by breast cancer treatment. Relationship changes in sexual intimacy are one way to analyze how detrimental these sexual effects of breast cancer treatment can be. One study showed a significant reduction in kissing,
caressing, and sexual intercourse after cancer (Ussher, Perz, & Gilbert, 2015). About half of participants in one study reported disappointment at the loss of sexual intimacy and feelings of inadequacy as consequences of changes in sexuality after cancer (Ussher et al., 2015). A separate study found that 78% of women report a decreased frequency of sexual activity after breast cancer treatment, and 48% report less satisfaction with sex (Ussher et al., 2012). Sixty percent of these women report a decreased satisfaction of intimacy, and 46.5% report a fear of rejection (Ussher et al., 2012). Gilbert and colleagues showed that reports of cessation or a reduction in sexual activities are associated with reductions in sexual satisfaction (Gilbert, Emilee, Ussher, & Perz, 2010).

Hawkins and colleagues found that 84% of partners caring for a person with “reproductive” cancer, including breast cancer, reported a negative impact on their sexual relationship (Hawkins et al., 2009). Cessation of sex or decreased frequency of sex was reported more than half the time by partners (Hawkins et al., 2009). A little less than 20% of partners reported renegotiating intimacy after breast cancer (Hawkins et al., 2009). Other changes in sexuality after cancer were associated with self-blame, lack of sexual fulfillment, and rejection (Hawkins et al., 2009). Sexual well-being is a central component to quality of life, and disrupting intimate relationships can cause significant distress (Mercadante, Vitrano, & Catania, 2010; “The World Health Organization Quality of Life assessment (WHOQOL),” 1995). In the absence of sexual activity, further relationship changes can include changes in emotional intimacy.
**Emotional Intimacy**

Intimacy can be defined as emotional closeness, even in the absence of sexual activity. Perz et al. (2013) questioned patients, their partners, and their health care providers. The group confirmed that clinicians view sexual health most often as physical whereas patients and their partners emphasized emotional intimacy as important and highly valued, even in the absence of a physical sexual relationship (Perz, Ussher, & Gilbert, 2013). Hawkins and colleagues found that one positive consequence of relationship changes was accepting the changed sexual relationship and increasing closeness (Hawkins et al., 2009). A number of participants in a different study reported vastly different relationship changes as a result of sexual changes after cancer: relationship strain or termination and strengthened relationships (Ussher et al., 2015). It is uncertain what factors determine if a couple will grow closer or have increased tension in (or termination of) the relationship after breast cancer and its treatment. Perhaps couples can experience tension followed by a strengthened relationship. Ussher and colleagues hypothesize that the responses of partners took into account a positive bolstering of the relationship (Ussher et al., 2015). These partner responses suggested an acceptance of sexual life changes and persistence of the partner’s interest and desire, which were helpful in adapting and living with the disruption of cancer (Ussher et al., 2015).

Open communication is one area that research focuses on to analyze emotional intimacy. Perz and colleagues position communication as critical to the acceptance of various fulfilling sexual and intimate practices after cancer (Perz et al., 2013). Hawkins and colleagues also discovered that negative changes in sexual function were related to a
reduction in open communication (Hawkins et al., 2009). Similarly, others suggest that higher levels of sexual function were associated with higher levels of sexual open communication (Perz, Ussher, & Gilbert, 2014). In one study, many women reported communication issues, but 7.2% reported an increase in communication (Ussher et al., 2012). Perhaps this was in an attempt to bolster emotional intimacy when sexual intimacy was lacking.

Reis and Shaver proposed a model of intimacy based on the interpersonal process (Reis & Shaver, 1988). This model defines intimacy as a process in which individuals share important and self-relevant thoughts and feelings to another person, and as a result of the other’s reaction, feels that they are understood and appreciated (Reis & Shaver, 1988). This model highlights two key intimate interpersonal actions – self-disclosure and partner responsiveness (S. Manne & Badr, 2008). Manne and Badr evaluated this model for couples where the woman was undergoing breast cancer treatment (S. Manne & Badr, 2008). The couples participated in discussions then subsequently rated four elements of communication: perceived self-disclosure, partner disclosure, partner responsiveness, and intimacy experienced. Interestingly, their results supported the model by Reis and Shaver only for the partner’s self-disclosure; the partner’s self-disclosure was a more important determinant of perceived closeness and emotional intimacy than the patient’s self-disclosure (S. Manne & Badr, 2008). This finding suggests that a patient’s self-disclosure plays a lesser role in maintaining emotional intimacy, while that of the partner’s plays a bigger role (S. Manne & Badr, 2008). The group also observed that a partner’s response, especially self-disclosure, plays a role in patient distress (S. Manne &
Badr, 2008). In this vein, analyzing emotional intimacy and closeness should include evaluation of the intimate partner’s thoughts and feelings. Furthermore, due to the interpersonal nature many changes associated with breast cancer treatment (sexual dysfunction, body image, sexual self-concept, and relationship changes), the majority of aforementioned study findings highlight the importance of assisting couples, not just patients, to manage the difficulties associated with adjusting to life after breast cancer and its treatment. Clinicians and psychotherapists should take into account (and recognize the importance of) the partner and the relationship in order to best remedy any emotional intimacy issues caused by breast cancer management and its impact on sexuality and sexual life.
IMPACT OF TREATMENT ON THE INTIMATE PARTNER

Little research on breast cancer focuses on the unique experience of the intimate partner. However, because intimate relationships are so important to partnered women during and after cancer treatment, delving deeper into the impact of relationship changes experienced by the intimate partner could shed light on how to bolster already strong relationships and correct struggling ones for the benefit of both partners and the patient in particular. In a study by Ussher and colleagues, 1348 participants answered a question on whether their partner experienced any negative consequences due to their breast cancer (Ussher et al., 2012). The most common reports were fear of hurting the partner during sex (52%), lack of interest in sex (37%), difficulties in communication (34%), tiredness (28%), change in role (seeing partner as a patient, 20%) (Ussher et al., 2012). In one early study, Wellisch and colleagues reported spouses had sleep, eating, and work disturbances, all attributed to their wives’ breast cancer (Wellisch, Jamison, & Pasnau, 1978). Spouses reported feelings of being helpless, fearful, and sad (E. Zahlis & Shands, 1991). Spouses also reported finding it hard to watch their wives struggle (E. Zahlis & Shands, 1991). A few men found breast surgery and the disfigurement of the breasts shocking, while others thought it was “not a big deal” (E. Zahlis & Shands, 1991). While there are parallels between the partner and patient’s feelings, there are experiences unique to the partner. Addressing the unique experiences of the partner is not meant to take away the focus from the BC patient or survivor. It is addressed, rather, because the relationships is an important support system for the patient and survivor. If certain areas of distress for the partner are pinpointed they can be addressed early by clinicians and
therapists in order to maintain a strong relationship for both partners. While the patient and partner do experience similar types of distress and fears, the two should not be equated. This section of the paper addresses some unique stressors for the intimate partner in three areas: emotional distress, role changes, and a disordered state of communication.

**Emotional Distress**

Emotional distress is not unique to the intimate partner, but each individual’s experience of this distress is. Significant emotional distress is observed in some husbands of women with breast cancer (Walker, 1997). In a recent study, Kauffman et al. (2016) found that patients and their partners were equally as likely to feel unsupported by their partner, feel down, or depressed (Kauffmann et al., 2016). In a well-known longitudinal study, Northouse and Swain showed that the spouse’s distress level was comparable to the level of morbidity in their wives (Northouse & Swain, 1987). Research consistently reports the fear of recurrence of the breast cancer being one of the main emotional stressors when the woman is in survivorship (Walker, 1997). Some men worried about what the future might bring and their wives’ survival (E. Zahlis & Shands, 1991). There is also greater fear of reoccurrence in male spouses with younger breast cancer surviving wives (Walker, 1997). In this particular study, when the emotional distress was elevated in one partner, the fear of recurrence score was only elevated in the partner in two cases, suggesting there is somewhat of an emotional compensation in the other partner (Walker, 1997). Segrin and Badger found conflicting evidence for emotional compensation (Segrin
& Badger, 2014). They found that breast cancer survivors’ psychological and physical distress is significantly negatively affected by their partners’ stress, and vice versa (Segrin & Badger, 2014). Emotional stress also came from relationship changes. For some men, breast cancer treatment magnified already existing problems in the relationship (E. H. Zahlis & Lewis, 2010).

**Disordered State of Communication**

Communication can sometimes be lessened or disordered in the aftermath of breast cancer (Hawkins et al., 2009; Ussher et al., 2012). In a study by Ussher and colleagues, 7.2% of women described an upsurge in communication, however (Ussher et al., 2012). Studies have reported that male partners of women with breast cancer and survivors avoid discussing their worries with their partner in order to prevent adding to her distress (Sabo, Brown, & MS, 1986; Walker, 1997). Research also suggests that membership (past or present) in a support group was associated with more communication by women with breast cancer and to their male spouses’ greater satisfaction with that communication (Walker, 1997). It is unclear whether communication initiated by the partner or the patient is more beneficial to the relationship, but research does show that open communication is associated with greater intimacy (Hawkins et al., 2009). Regardless of where the deficit in communication lies, this disordered state of communication poses a unique stress on the intimate partner, such that they may not want to share concerns for fear of upsetting their partner or may not have the words to do so.
**Role Changes**

Along with breast cancer and its treatment, there can come a change of roles within the couple. It is likely the spouse will provide the main practical caregiving. Due to the cancer and treatment, the spouse must now provide emotional and practical support at a new, higher level. Hilton, Crawford, and Tarko found two main foci reported by males coping with their wives’ breast cancer and chemotherapy: focusing on the wife’s cancer and care and focusing on the family in order to keep life moving forward (Hilton, Crawford, & Tarko, 2000). Spouses in a study by Zahlis and Shands talked about doing more child care, changing work schedules, and assuming the management of the household (E. Zahlis & Shands, 1991). In one study, expectations from male gender roles guided husbands' attempts to provide emotional support to their wives that was complicated by their understanding of their inability to meet all of their wives' needs (Samms, 1999). Some men also expressed feeling guilty because they could not help their partner more and were critical of their own capability of supporting her (E. Zahlis & Shands, 1991). These studies show role changes for only straight, male partners of breast cancer patients and survivors. Further research needs to be done on LGBT couples with one partner suffering with breast cancer in order to gain a well-rounded view of how gender roles and expectations impact the intimate partner and role changes after breast cancer.
THE BENEFITS OF A SUPPORTIVE PARTNER AND CLOSE RELATIONSHIP

Historically, research has centered around the psychological and emotional impact of caregiving on spouses and the impact of cancer on the general quality of the partnered relationship (S. Manne & Badr, 2008). Unfortunately, much of this research neglects the couple-level perspective; cancer is something that affects the couple, and appreciating this couple-level perspective may be a more useful approach for theoretical and clinical purposes (S. Manne & Badr, 2008). Research shows that partners in fulfilling relationships are conscious of vital functions of their relationship, make purposeful efforts to maintain those in hard times, and try to find opportunities to improve their relationship (S. Manne & Badr, 2008). In that regard, cancer can provide an opportunity for couples to forge a stronger intimate bond (S. Manne & Badr, 2008). Breast cancer and its management, leading to sexual dysfunction and psychological issues surrounding sex, could be problematic for increasing intimacy sexually. However, Manne and Badr suggest a focus on bolstering closeness and adapting to cancer in order to increase relationship intimacy (S. Manne & Badr, 2008).

Manne and Badr (2008) designed an intervention for couples dealing with cancer that centered around communication behaviors. The model proposed that patients and their partners participate in behaviors that either promote or undermine the closeness level in their relationship and that the closeness of the relationship is an important determinant of patient and partner’s psychological adaptation to the experience of cancer (S. Manne & Badr, 2008). They created a model with three processes, collectively called
the “Relationship Intimacy Model”. The three processes include reciprocal self-disclosure, partner responsiveness (feeling understood, cared for, and accepted by the partner), and relationship engagement (S. Manne & Badr, 2008). Their study surveyed 25 couples that completed 5 sessions with the designed intimacy-enhancing intervention, and the results suggest that the model improved patient and partner perceptions of the closeness level in their relationship and reduced both partner’s distress (S. Manne & Badr, 2008). The results suggest that a close relationship, and most likely a supportive and involved partner, can reduce the distress caused by cancer and its management.

Much research supports this claim. A recent study by Borstelmann and colleagues (2015) found that younger women (mean age 35.4 years) with breast cancer and those in un-partnered relationships had more anxiety than women in supportive partner relationships. These findings suggest that partner support plays a role in a young woman’s adjustment to breast cancer, where the supportive efforts by the partner could potentially protect against the impact of stress (Borstelmann et al., 2015). In a study by Winch and colleagues, a supportive partner was found to be instrumental in helping women overcome sexual issues caused by lymphedema, a common side effect of BC treatment, and body image concerns (Winch et al., 2015). Wilmoth found that women with strong intimate relationships adjusted more successfully to the sexual side effects of breast cancer treatment and the subsequent “altered sexual self” (Wilmoth, 2001). Interestingly, one study found that a woman’s perception of her spouse’s support can be just as significant as obvious demonstrations of that support (Wimberly et al., 2005).
As much as a supportive partner has been found beneficial, a non-supportive partner can be detrimental. Multiple studies have found that a non-supportive partner can create harmful disease outcomes and poor psychological and practical adjustment to breast cancer (Chekryn, 1984; Northouse, Dorris, & Charron-Moore, 1995; Peters-Golden, 1982; Nancy Pistrang & Barker, 1992). It has also been found that the partner’s support is of such significance that good support from family and friends does not make up for insufficient spousal support (Coyne & DeLongis, 1986; N. Pistrang & Barker, 1995). Older women (greater than 60 years of age) in difficult, non-supportive partnered relationships, seem to find alternative ways to cope (Sawin, 2012). This finding provides further evidence than older women can cope and deal more effectively with illness, perhaps because they are dealing with other issues related to age and have a wide breadth of life skills and experiences (Crooks, 2001; De & A, 1999; Sawin, 2012).

Because spousal support has been found to be so beneficial for women with breast cancer and survivors to adapt psychologically, researchers sought to investigate what kind of support is perceived as the most helpful. Women often perceive their partners as better supporting instrumentally rather than emotionally, but open communication with the acknowledgement of the cancer and sharing deep feelings with a sensitivity to the partner’s present needs and feelings have been found to aide adaptation to breast cancer (Holmberg, Scott, Alexy, & Fife, 2001; S. L. Manne & Zautra, 1989; Skerrett, 1998). Practicing reciprocal self-disclosure and being emotionally involved and empathetic seem to be partner actions that are beneficial for a women adjusting to cancer (Holmberg et al., 2001; Manne et al., 2006; N. Pistrang & Barker, 1995; Zunkel, 2003).
The following personal interviews show two breast cancer survivors currently in their mid-fifties sharing experiences of their journey and battle with breast cancer. Both women mention intimate and personal details of their partner relationships, and both women acknowledge the importance of having a supportive partner and strong, healthy relationship. The interviews underscore some of the negative effects of BC treatment on sexual function and sexual identity and emphasize the importance of a supportive intimate relationship to alleviate and protect against some of the stressors due to those sexual issues.
SURVIVOR INTERVIEWS: LIFE AFTER BREAST CANCER

The following interviews were conducted in person over the course of two hours and one hour, respectively, at local cafes. Each survivor’s story is different. Each woman had a unique experience and different effects on their sexual lives and relationships. However, both women did experience changes in sexual function, self-esteem, and their partner relationship due to breast cancer treatment. Both women also had strong partner relationships and supportive intimate partners and mentioned that this played an extremely important role in their survivorship. The women both mentioned that cancer likely strengthened their relationship and brought them closer together. For these women, cancer was an opportunity to strengthen an already strong bond with their spouse.

Survivor Interview 1

Pitingolo, Cathy. Personal interview. 12 December 2016.

Interviewee: Carla* name changed for anonymity

Interviewer: Nicolina Mascia

Date and Time: December 12, 2016, 7:00pm

Location: Panera Bread (Gillette, New Jersey)

Background

1. When were you diagnosed with BC and at what age?

I was 41, and the date was July 1, 2004.

2. What type of cancer did you have?
I brought my little paper because I can never remember. It was invasive lobular breast cancer. It was a 5.2 cm tumor, with 8+ affected nodes, ER and PR positive, HER2 negative.

3. What stage were you diagnosed with?

I was diagnosed with (stage) 3+.

4. How was the cancer detected? Breast self exam, clinical exam, mammogram

Let’s see. I have to go by the months. So it was May. I had my normal gynecologist apt. She said I had a clump of fibroids. I didn’t even know; I didn’t feel it. I had a normal mammogram done 6 months prior and that was clear. Then I was showing everybody, and I kept rubbing it. So then it started to hurt. So I went back to my gynecologist, and she had me do a diagnostic mammogram. That was mid June. Then she sent me to the breast surgeon for the diagnosis.

5. Do you have a family history of breast cancer?

Sort of. My mother died of ovarian cancer. Her mother (my grandmother) and sister (my great aunt) died of breast cancer.

6. What were your top three biggest fears?

Well, the first, the biggest one was if I was going to live or die. I had four children under the age of nine - 3 four-year-old triplets and 1 eight-year-old.

7. What was your treatment process? Chemo, radiation, surgery, or a combination?

So I had surgery first, and I had a double mastectomy and a TRAM flap reconstruction in the same surgery. Then I had the chemo. I did ATC is what it
was called. Adriamycin, Cytoxan, and Taxol - ATC. I was also in a clinical study. So I think usually you get the doses of AC once a month for three months, but I got a half dose every other week for 6 weeks. I also got Taxol weekly for four months. Then I had the radiation which started in March. I had 25 rounds, and finished in mid-April. I always remember when I finished radiation because it was a week before my husband’s father died.

**Breast Surgery**

1. **Was this type of surgery the best option for your cancer?**

   For sure. I had the option of doing one breast but decided to do both because of my family history. I also could have gone with implants. A bunch of people I know did the implants, but I’m the only one that went with the TRAM flap. I had enough to work with so that worked for me. She didn’t recommend a lumpectomy (probably because of lymph nodes).

2. **Would you go through this type of surgery again?**

   Yes, absolutely.

   My plastic surgeon was just someone who came into my life and then left. She was amazing. She wanted me to have nipple reconstruction and the tattoo to make me “whole”. She was so much into making people “whole” again. I know a lot of people that never did tattooing or nipple reconstruction. And I guess you just kind of get used to looking the way you do. Now my tattoo is faded the nipple is flattened, which I think is due to weight loss and gain over the years. But I’m glad I did it because she tried to give me the whole picture, my whole body.
1. **Was your reconstructive surgery done at the same time as the mastectomy or as a separate surgery?**

   It was done at the same time. I think I was in surgery for 7 hours. Then I spent four days in the hospital. I was so hunched over until the skin stretched, and I had 4 drains down to my hips. I got lucky and had great nurses that took great care of me. I was in pain for about two weeks. I was wearing everything from my husband’s closet - his underwear, shirts, you know because they were all bigger. I’d walk outside to get a little sun, and I was walking like I was 100 years old, so slowly. The pain was pretty bad for two weeks. I had a C-section, and it was worse than that. I actually think that pain kind of prepared me for it.

2. **How long after surgery until you felt like yourself?**

   Six weeks almost to the day. They told me it would be 6-8 weeks to feel normal again, and I remember it so vividly it was 6 weeks exactly when I started to feel like me again.

3. **Were you happy with the aesthetic outcome of the reconstructive surgery (on a level of 1 to 10, 10 being extremely happy)?**

   Very happy, after the surgery it was a 10/10. After having just chemo, it was still a 10. After radiation, it was like an 8 because it shrunk the one breast smaller.

4. **Did you feel as self-confident following reconstruction as before breast cancer?**
Actually probably more! I was thinner. When I had my triplets I had right breast calcification, and they took a chunk of my breast when removing it. After the reconstruction, it was fixed!

5. **Did you have any complications post-surgery or long-term complications?**

I had a little bit of necrosis in the left breast, where tumor was. It happened within 2 months of surgery, and they think it was the tail of the flap. But we left it. I also had stitches around the left nipple that didn’t heal so they had to re-stitch those.

**Sexuality**

1. **Did you notice any changes in sexual function and sexual well-being following the diagnosis and treatment?**

   Definitely. One of the things they don’t tell you when you have this type of surgery is that you lose all feeling. All that great feeling is now gone; I have no feeling in my breasts. And that was a huge bummer! I was like - well now what do I do? I also had no desire. Most of the time I wasn’t in the mood, and when I wanted to be in the mood, I couldn’t be. I was missing all those cues from my breasts. Sex was also uncomfortable and a little painful.

2. **Did you experience any anxiety about these issues?**

   I tried to pretend those issues weren’t there so we could be intimate, to keep my husband happy. So yes, that was stressful.

3. **If you did notice changes in sexual functioning, how did this affect your relationship with your partner?**
It did. When we did go through those dry spells it definitely made things more tense. But you tried to alleviate it any way you could. It was stressful, and because of the lost feeling, my body didn’t give me those cues. I had the premature menopause symptoms, which made sex uncomfortable, and I couldn’t take any medications for that because they mostly all have estrogen and would have reacted with my cancer since I’m estrogen receptor positive. So you’re stuck trying to figure it out. The intimacy level now though is just completely different. I think it’s more due to the cancer rather than to age.

4. What was the attitude of you and your partner to the sex issues following diagnosis and treatment? How important were the sexual issues to you and to your partner?

I’d say it was more important for my husband. After kids, I was kind of on the down swing of sex anyway. And we’re never alone anyway. But it’s disappointing. It should be easier, unplanned, and unthought-of, but it’s not. The desire is so much less.

5. How did sexuality and sex life changes influence your quality of life?

I’d say it sometimes did, still does. When we aren’t intimate for a while, there’s more tension. Until I give in, and then we’re good (laughs).

6. Have you sought out or received professional counseling for issues with sexuality? If so, please describe.

No, I really just dealt with it. My husband might not have gone. Though, he would probably go if I begged to. I’m just thinking of that movie - Meet the
Fockers. Where Barbra Streisand was the sex therapist. We need that for women. Someone who is just carefree and non-judgmental. They don’t really talk about these issues when you go to the oncologist or the breast surgeon.

7. **Have you sought out or received care from a physician for sexual issues? If so, please describe.**

My gynecologist tried to help with all sorts of remedies. She was a female doctor. My oncologist was an older gay man and talking to him was a little different. He’s the one that told me I couldn’t take anything with estrogen because it would react with the tumor.

**Body Image**

1. **How did the changes in sexuality affect your self-esteem and body image?**

   My self esteem actually didn’t change that much due to it.

2. **How did the effects of breast cancer treatment affect your self-esteem and body image?**

   I think about 2 months into chemo was when it started to go down. All my hair was gone. I spent a lot of money on this beautiful wig - something I’d never do again. I was feeling so blah and was swollen because of the steroids. I had no eyelashes, no eyebrows. I have yellowish skin to begin with, and I was so green/yellow with the chemo. That’s when I felt the most self-conscious. But I just kind of kept going. I was always on the go with my kids making sure they were taken everywhere they needed to go. I wore the wig for only about three months then I went around with scarves and bandanas that my kids bought me.
When I started the taxol my hair started growing back, and I’d say it’s thicker now than pre-cancer. My kids kept me going.

3. Did you experience any anxiety about the changes in your body due to treatment?

   No really. I had preschool aged kids so I kept going.

4. Did you make any changes in wardrobe post mastectomy?

   Nope. Not that I can think of.

Support System

1. What was your most important support system?

   My girlfriends in town. They made sure we had dinner every night, took the kids places. They really went above and beyond to help out. I have 4 sisters and 2 brothers that were important. They were there for me as family, but I really have to give my friends in town more credit.

2. Was spirituality and/or faith important at any point or throughout your journey?

   Oh, all the time. Even now. I’m always a little fearful it could come back.

Partner

1. How did you perceive your breast cancer affecting your spouse/partner?

   I’d say he was mostly frightened. He’s still frightened about it coming back.

   But for the most part it’s behind us. We couldn’t let it control our lives.

2. Were you satisfied overall with your relationship post-treatment for breast cancer?
Yes. Hey, I’m still married to him.

3. **Were you satisfied with your sexual intimacy?** Not really. I had no desire, and when I made the effort, it was very uncomfortable.

4. **Were you satisfied with your emotional intimacy?**

   I’d say so. It probably brought us closer together. It really didn’t cause any relationship stress. I think my husband maybe appreciated life more or life with me more.

5. **Did you have open communication with your partner? If so, how important was communication in your relationship?**

   More communication – when one is stressed out you balance the other out.

6. **If you did have a supportive partner, do you think this played an important role in your fight with cancer? Please explain.**

   Absolutely. It was hugely important. Things can’t remain as they were while you’re dealing with breast cancer. They could be the same eventually, but not while you’re going through it. My husband’s father was also dying at the same time so I’d say I was a big support for him.

**Wrap Up**

1. **What advice would you give to someone newly diagnosed with breast cancer?**

   Firstly, that you could lose feeling in your breasts. That’s important and something no one told me. I guess it really depends on the type of surgery though. If I meet someone who’s having the same surgery as I had, I’d tell them to get a lift chair. I couldn’t really lie down or sit up because of the pain. So I had a chair
that could tilt and lie me down and sit me back up. It helped so much. Also, the wig thing. Don’t spend a lot of money because you don’t really need to. Well, you need it to get started for the self-esteem, but eventually, it becomes easier. Also, take all the help you can get. Don’t think you can do it all on your own, because you can’t.
Survivor Interview 2

Tumolo-Decuollo, Jeannette. Personal interview. 1 December 2016.

Interviewee: Jeannette Tumolo-Decuollo

Interviewer: Nicolina Mascia

Date and Time: December 1, 2016, 3:00pm

Location: Hunterdon Medical Center (Flemington, NJ)

Background

1. When were you diagnosed with BC and at what age?
   I was 47 years old.

2. What type of cancer did you have?
   I had stage 2 ductal carcinoma.

3. How was the cancer detected? Breast self exam, clinical exam, mammogram
   I felt a lump the size of a tennis ball, and went to my gynecologist for a mammogram.

4. Do you have a family history of breast cancer? No, I don’t.

5. What was your biggest fear?
   Really the biggest one was losing my life.

6. What was your treatment process? Chemo, radiation, surgery, or a combination
   I had 7 lumpectomies in 6 years in order to get clean margins. I also had oral chemo for 6 years.
Breast Surgery

1. If you had breast surgery, what kind of surgery did you undergo?
   
   I had 7 different lumpectomies over 6 years.

2. Was this type of surgery the best option for your cancer?
   
   This was the only type my surgeon recommended for me.

3. Would you go through this type of surgery again?
   
   Absolutely. It was a long road for those 6 years, but I would fight again if I had to.

4. Was your reconstructive surgery done at the same time as the mastectomy or as a separate surgery? I didn’t have a need for reconstruction, luckily.

5. Were you happy with the aesthetic outcome of the breast surgeries? I wasn’t unhappy; I just got used to them.

6. Did you feel as self-confident following the surgeries as before breast cancer?
   
   I didn’t have many self-confidence issues at all.

Sexuality

1. Did you notice any changes in sexual function and sexual well-being following the diagnosis and treatment?

   Other than sex taking a backseat for those years, I did not see much change in sexual function or sexual behavior. I can remember it was little uncomfortable for me for a few years, which subsided.

2. Did you experience any anxiety about these issues?

   I was lucky to have support that I didn’t need to be anxious about it.
3. **If you did notice changes in sexual functioning, how did this affect your relationship with your partner?**

None of the issues had any effect on our relationship. He was with me 100% of the way, and although sex occurred less often, it was still a good sexual relationship.

4. **What was the attitude of you and your partner to the sex issues following diagnosis and treatment? How important were the sexual issues to you and to your partner?**

Like I said, he was with me 100%, and sex just took a backseat in our lives for a bit. It really wasn’t an issue.

5. **How did sexuality and sex life changes influence your quality of life?**

I guess it did only slightly though. I’m not sure it was “worse” quality of life in that area, just different. It became a different relationship altogether, and still is. In the grand scheme of our lives, sex just isn’t a worry for us.

6. **Have you sought out or received professional counseling for issues with sexuality? If so, please describe.**

I didn’t have a need to.

7. **Have you sought out or received care from a physician for sexual issues? If so, please describe.**

I didn’t have a need for that either.
Body Image

1. How did the changes in sexuality after breast cancer treatment affect your self-esteem and body image?

To be 100% honest, I had only a few self-esteem or body image issues. I was happy with my body before and after cancer, but it did take a while to get used to the new look, especially since I had 7 different surgeries and each result was a little different. I felt a little like I lost a part of my feminine nature for a while.

2. Did you make any changes in wardrobe post mastectomy?

Not at all. I wore the same things. Maybe I stayed away from the super low cut stuff, but I wasn’t wearing that stuff at my age anyway.

Support System

1. What was your most important support system?

My faith and my husband. He was 100% supportive.

2. Was spirituality and/or faith important at any point or throughout your journey?

Faith was very important throughout the entire time. I grew up Catholic, and faith was important to me as a young child, teenager, and is important even now.

Intimate Partner

1. How did you perceive your breast cancer affecting your spouse/partner?

He was certainly scared. Definitely worried often, especially about it returning.

2. Were you satisfied overall with your relationship post-treatment for breast cancer?
Absolutely! He really was great throughout the whole process. And it was 6 years of it.

3. **Were you satisfied with your sexual intimacy?**

Sex has never really been an issue for me. I’ve always liked it, and even though it doesn’t happen as often, I was lucky enough to still enjoy it after treatment.

4. **Were you satisfied with your emotional intimacy?**

Very- I think we grew closer as a result of the cancer. We had to be strong for each other to make it.

5. **Did you have open communication with your partner? If so, how important was communication in your relationship**

Definitely – it was very important to us. We were very honest about our feelings.

6. **If you did have a supportive partner, do you think this played an important role in your fight with cancer? Please explain.**

I think it played a huge role in getting through things. It’s hard to explain, but it tests your relationship in a big way. If you get through it together, you can do anything.

**Wrap-Up**

1. **What advice would you give to someone newly diagnosed with breast cancer?**

It would definitely be to (1) listen to your doctor, and (2) ask tons of questions!

No question is a stupid question.
DISCUSSION

Fortunately, more and more women are surviving breast cancer. With an increase in survival rates, there should be a shift to bolstering quality of life for these survivors. The findings presented in this paper confirm the many struggles related to sexual changes due to breast cancer treatment physically, psychologically, and interpersonally that can decrease quality of life overall. They highlight the importance of health professionals and support workers recognizing these sexual changes when delivering health education and when developing helpful interventions. Without further studies, it is difficult to determine the interaction of physical sexual dysfunction, psychological issues, and relationship issues due to sexual changes after breast cancer treatment. However, the three areas seem to be interconnected in some way. It seems that when examining sexuality after breast cancer treatment, a woman’s body cannot be dealt with apart from her sexual self-concept and self-image in relation to her intimate partner and society. These factors together are important for living sexually after breast cancer. Therefore, it is important that clinicians approach sexuality from an interdisciplinary standpoint and take into account the physical, psychological, and interpersonal aspects of sexual changes due to breast cancer treatment. It should then stand that psychological interventions intended to reduce stress and improve quality of life after cancer treatment should incorporate elements on sexual health. Likewise, sexual interventions should integrate psychological and interpersonal components. Living beyond breast cancer is not solely about physical sexual interactions, sexual self-concept, or intimate relationships but rather a balance of satisfaction in all
three areas. In addition, the intimate partner’s unique experience should not be neglected, as he or she plays an extremely important role in the woman’s experience with breast cancer and can help the woman to cope with these physical, emotional, and relational sexual changes.

**The Value of Studying Sexuality**

There is a long-standing misconception that because women with breast cancer and survivors are usually past middle age, possibly into menopause, they are no longer interested in sexuality or intimacy. While research has shown that younger women needing breast surgery opt for immediate breast reconstruction, meaning they might care more about sexuality, body image, or sexual life, this does not mean the older women have no concerns about sexuality. Women no longer interested in intercourse can find alternate ways to achieve intimacy, but that should not mean researchers stop looking into sexual dysfunction for the women that are negatively effected. Sexuality is still important for the quality of life of many women who struggle with breast cancer, especially since many of the sexual problems have to do with the intimate partner and the relationship. Distress can come from tension in the relationship due to problems with sexuality and intimacy, further lowering the quality of life for women with breast cancer and survivors. On the positive side, a supportive partner and strong relationship has been shown to help women cope. Likewise, some research shows the positive effect of breast cancer and treatment bringing the couple closer together. However, this should not validate neglecting research on how sexual side effects of treatment negatively affect couples.
Since it is unclear what exact factors predict if a couple will grow closer or have tension, it does not make sense to ignore sexuality in the conversation for all couples dealing with breast cancer, regardless of stage of disease, treatment status, age, race, and sexual orientation.

**What Is a “Supportive” Relationship?**

From the data presented in this paper, it appears that a strong, healthy relationship and a supportive intimate partner could alleviate some of the sexual health stressors due to breast cancer and help the woman to cope. However, the definition of a “good” relationship is different each individual and couple. What works for one couple does not necessarily work for a different couple. This is especially true in regards to sexuality, which has different meanings for each individual. In healthy relationships, each couple develops methods of communication, caring, and supporting in ways that best fit each individual in the couple. It seems that in order for a breast cancer patient or survivor to benefit from a strong, supportive relationship, she must be satisfied with the status and strength of that relationship. There are objective criteria for a good, healthy relationship that could make it difficult to find which specific factors are more likely to help the woman with breast cancer cope, but it is still possible to see the benefits of a supportive, healthy relationship, as long as the woman herself is satisfied with the relationship status. While this paper’s focus is on the sexuality and intimacy effects of breast cancer treatment in partnered relationships, the single women suffering with intimacy issues due to BC should not be neglected.
Clinically Approaching Sexual Function

Sexual dysfunction and issues with sexual health are a reality for many women who have undergone breast cancer treatment. It is important to include issues of quality of life, such as sexual health, in plans for the management of breast cancer and beyond into survival (Boswell & Dizon, 2015). However, the effects of breast cancer on sexuality are not usually discussed by clinicians, in patient care plans, or in patient education. Unfortunately, while there is an availability of treatments (whether effective or not) for sexual dysfunctions and identity issues, there is a disconnect between self-reported need for professional help and actually receiving the care (Kedde et al., 2013). Health care professionals often do not mention sexual problems due to time constraints, embarrassment, or lack of knowledge or experience (Kedde et al., 2013). Patients will often forgo bringing up similar topics perhaps due to feeling embarrassed or uncomfortable. Research does suggest that women who sought information about sexual side effects of breast cancer treatment had a more successful adjustment to sexual changes, yet women are still not seeking or receiving information (Wilmoth, 2001). Perhaps most concerning is that due to a lack of understanding or resources along with the distress of cancer treatment, sexual experiences and intimacy can be sidelined at a time when sexuality could be quite helpful.

Discussing sex and sexuality requires strong patient-doctor connections with open communication and medical understanding. If physicians ask questions about sexual health in their routine questioning, patients may feel at ease and open up about issues
they are facing. Park, Norris, and Bober published a model of communication for patients with cancer based on five A’s – Ask, Advise, Assess, Assist, and Arrange (Park, Norris, & Bober, 2009). Importantly, the group suggests that these issues are tackled in an interdisciplinary manner rather than by a single health care provider (Park et al., 2009).

Addressing sexual function after breast cancer treatment includes delving into a patient’s history and understanding active medical problems and current medications, as many sexual dysfunctions arise from medications, such as beta-blockers, and comorbidities, such as diabetes mellitus (Perez, Gadgil, & Dizon, 2009). It also requires delving into areas of intimacy and sexuality that can be hard to explain or demonstrate, since sexuality and sexual expression are different for each individual.

It is important to note that intimacy can be defined as emotional closeness, even in the absence of sexual activity. Perz and colleagues questioned patients, their partners, and their health care providers (Perz et al., 2013). The group found that clinicians view sexual health most often as physical whereas patients and their partners emphasized emotional intimacy as important and highly valued, even in the absence of physical sexual relations (Perz et al., 2013). Perz and colleagues also found that even though physical sex may not be desired or possible after cancer, relationship satisfaction is attained through open communication and “non-genital intimacy” (Perz et al., 2013). Therefore, medical professionals should not only focus on physical sexual health but also on emotional intimacy and sexuality as it pertains to the couple. Moreover, due to the interpersonal nature many changes associated with breast cancer treatment (sexual dysfunction, body image, sexual self-concept, and relationship changes), clinicians
should support couples, not just patients, to manage the issues associated with sexual changes and to adjust to life after breast cancer treatment. Clinicians and psychotherapists should take into account the partner and the relationship in order to best remedy any emotional intimacy issues caused by breast cancer management and its impact on sexuality and sexual life.

**Further Research**

The literature lacks research conducted on the sexual experience for breast cancer survivors. Further investigation is needed into the lives of survivors five, ten, and twenty years after their breast cancer experience as more people are now surviving the disease. Much of the research done on intimate partners of women with breast cancer is similarly done in the early stages of treatment. Further research is needed on how the intimate partner is affected emotionally, psychologically, and interpersonally over the course of the disease and into survivorship.
REFERENCES


Hadj, P., Ziller, V., Kyvernitakis, J., Bauer, M., Haas, G., Schmidt, N., & Kostev, K.


