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The purpose of this study is to use an integrated biocultural perspective to examine the decision-making processes of young survivors as they navigate breast cancer treatment and reproductive health care options. This retrospective study utilizes a mixed-methods approach that integrates quantitative survey data (Phase I) with interview (Phase II) and focus group (Phase III) narratives from the young survivor community. Grounded theory and biocultural approaches guide analysis and interpretations. Findings reveal how young women engage reproductive and treatment decision-making as biocultural beings, negotiating immediate mortality risks, institutional constraints, and long-term, quality of life concerns and reproductive health values. Recommendations include the integration of women's voices and biocultural approaches into the development of young survivor educational materials and cancer care counseling in an effort to establish a successful shared decision-making model as the clinical standard.

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Reproductive Decision-Making in Young Women Breast Cancer Survivors

by
Courtney Louise Everson

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APPROVED:

Major Professor, representing Applied Anthropology

Chair of the Department of Anthropology

Dean of the Graduate School

I understand that my thesis will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my thesis to any reader upon request.

Courtney Louise Everson, Author

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TABLE OF CONTENTS

	<u>Page</u>
Chapter 1 Introduction.....	1
Chapter 2 Literature Review.....	7
Epidemiology of breast cancer in pre-menopausal women.....	7
Systemic and surgical treatments for young women.....	9
Psychosocial issues faced by young women.....	20
Chapter 3 Methods, Study Population, Study Limitations.....	28
Phase I: Participant Observation and Recruitment Survey.....	28
Phase II: Semi-structured, Open-ended Interviews.....	30
Phase III: Focus Group as Reciprocal Ethnography.....	32
Study Population.....	33
Study Limitations.....	35
Chapter 4 Theoretical Perspectives.....	37
Interpretivist stances and the social construction of disease.....	37
Critical medical anthropology (CMA).....	39
Feminist standpoints.....	40
New biocultural synthesis.....	41
Chapter 5 Results.....	44
Treatment Decision-Making Models.....	45
Theme I: Biology of the Cancer Diagnosis.....	46
Staging of the tumor.....	46
Tumor features.....	49
Prognosis as a critical determinant.....	51

TABLE OF CONTENTS (Continued)

	<u>Page</u>
Theme II: Institutional Constraints.....	52
Breast cancer is an “old woman’s disease” – myth.....	53
Provider’s slant.....	56
Biased options.....	57
Theme III: Sexuality and the Body.....	60
Social and romantic relationships.....	61
Parenting/Childbearing.....	63
Body image: internal/external.....	68
Chapter 6 Discussion, Conclusions, and Recommendations.....	81
Discussion.....	81
Conclusions and Recommendations.....	84
Bibliography.....	87
Appendices.....	98
Appendix A Recruitment Survey.....	99
Appendix B Invitation Script for Phase II.....	103
Appendix C Interview Protocol.....	104
Appendix D Oral Script for Phase III.....	106
Appendix E Applied Intervention.....	107

LIST OF FIGURES

<u>Figure</u>	<u>Page</u>
1. Grounded Theory Schema.....	44
2. Breast Cancer Staging.....	47

Reproductive Decision-Making in Young Women Breast Cancer Survivors

Chapter 1 – Introduction

Case Studyⁱ

Miranda is a 29 year old woman living in a large urban city in the Pacific Northwest. In the last two years, she has graduated from college, was engaged to her amazing boyfriend, Tom, and recently landed her dream job teaching adolescents at an alternative high-school. One Sunday afternoon, she was conducting a breast self-exam and felt a large lump on her left breast at the six o'clock area. She thought: "What is this? Do I have cancer?" She told her fiancée, who assured her all was fine and remarked: "Besides, you're too young to have breast cancer." For peace of mind, Miranda still wanted the lump examined by a doctor. Early Monday morning, she called her care provider for an appointment. Tuesday morning she drove to the clinic at the scheduled time. The clinic performed a baseline mammogram, which showed nothing but young, dense breast tissue. The nurse said: "Well, I doubt it is anything, but if it will make you feel better, we will do an ultrasound." Miranda agreed and at that six o'clock area on her left breast, a dark, irregular round notch appeared. The nurse told her she was ninety-nine percent positive that it was a hemorrhagic cyst or just fibrous tissue, saying: "After all, you're so young that's what we expect." The nurse placed the dopler on the irregular notch, and Miranda could see there was blood flow occurring on the periphery. "I knew, I just knew inside something was wrong." The nurse called the radiologist for further consult. He said: "I would feel a lot better if we went in and aspirated this cyst. I'm pretty sure it's just a hemorrhagic cyst and we'll just go in with a needle and verify, if that's okay." Miranda agreed, "Sure, by all means, go in.". She was by herself and scared. The radiologist tried to aspirate the cyst with a needle, while Miranda watched his movements on the monitor. He was trying to withdraw the fluid, but nothing would come out. At that point, he recommended a corneal biopsy. They took three painful biopsies and sent results to pathology. They again assured Miranda it was likely just a cyst or fatty tissue, sending her to complete her day as planned. Miranda drove across town to attend the training course required for her new job. While on an afternoon break, she was walking to Starbucks for coffee when her phone rang. It was the clinic. She heard the voice on the other end say: "Miranda, this is Dr. Mason and I have some bad news. You have breast cancer." It was a typical February day, raining and cold with the wind howling through the trees. Miranda sat down on the curb, her feet soaking in a puddle, listening, half absent-mindedly, to the doctor as he explained the aggressiveness of the cancer and the urgency with which she much proceed. She thought: "Oh my god. What am I going to do?" Miranda was diagnosed with Stage II breast cancer on February 22, 2006. Her life, as she knew it, would never be the same again.

Breast cancer is the most commonly diagnosed cancer in American women, accounting for 26% of all cancer diagnoses (American Cancer Society [ACS] 2007). It

is also the number one cancer in women of reproductive age, with 5% of all breast cancer diagnoses occurring in women under the age of forty (ACS 2007). Although this sub-population of reproductive-age women remains small in numbers, the unique concerns young survivorsⁱⁱ face are immense and vary with the multiple identities they possess as young female members of society (Brettell and Sarget 2001; Horner and Keane 2000; Inhorn 1994, 2006). For the purposes of this study, the term young survivor is defined as reproductive-age women, eighteen through forty years of age. I use the term to distinguish this sub-population and their unique concerns from their post-menopausal counterpartsⁱⁱⁱ.

In recent years, biomedicine has made significant strides in treatment and early diagnosis, resulting in a current five-year survival rate of 82% for women under the age of forty, for all stages combined (ACS 2007). The improving survival rates have led to an increased focus on survivorship concerns and quality of life after cancer (Bloom et al. 2004; Byar et al. 2006; Cella et al. 2006; Klauber-DeMore 2005, 2006; Langer 2001; Robb et al. 2007). However, this focus has been largely directed at women over the age of fifty who face different survivorship concerns than young survivors. For young women, a cancer diagnosis and increased chances of survival come at grave costs, including body image issues, sexual dysfunction, and the potential for treatment-induced infertility. Ninety percent of young women who undergo treatment are at risk for infertility (Speck-Zulak 2008).

A small body of literature has documented the above reproductive health issues as top survivorship concerns for young women (Bloom et al. 2004; Carrizosa and

Carey 2005, 2006; Dow and Kuhn 2004; Ganz et al. 2003; Grady 2006; Klauber-DeMore 2005, 2006; Murray 2005, 2006; Surborne and Petrek 1997), yet only a handful of research studies have examined the lived experiences of young survivors, and how their unique and shifting reproductive health concerns influence treatment decision-making (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005). Moreover, very few studies have examined the mechanisms by which young survivors negotiate the complexities of the decision-making processes, as they attempt to balance the immediate risk of mortality with long-term quality of life concerns that, for many young women, involve reproductive futures and sexual health values. The lack of attention to these unique concerns and processes has produced an underdeveloped body of educational materials for young survivors.^{iv} This has served as a barrier to fully informed consent and empowerment in treatment decision-making, and Partridge and colleagues (2004) have argued that lack of information in medical decision-making is one of the greatest unmet psychosocial needs of cancer patients.

The current body of literature on the topic of cancer treatment and reproductive health is predominantly focused along two, non-overlapping lines – biological/clinical and psychosocial. The majority of research stems from a biomedical account of the epidemiology of breast cancer and the biological, reproductive and cytotoxic effects of systemic/adjuvant therapies^v (Critchley, Hamish, and Wallace 2005; Knobf 2006; McInnes and Schilsky 1996; Molina, Barton, and Loprinzi 2005). The correlation between treatment and subsequent reproductive and sexual health issues involves three

main variables: breast cancer stage, age at diagnosis, and treatment/dosage type (American Society of Clinical Oncology [ASCO] 2006; Molina, Barton, and Loprinzi 2005). These three variables determine not only the likelihood of reproductive health problems, but also determine the options (including fertility-preservation and breast surgery options) available to mitigate these problems. A secondary subset of research focuses on the psychosocial sexual health effects of cancer. The psychosocial research has primarily examined four concerns: feelings of lost femininity, fear over loss of future/existing family; anxiety over body image and finding/keeping a mate; and problems in sexual function (Nieman et al. 2006; Schover 1999; Schover et al. 1999). The biological/clinical-psychosocial divide in the literature does not fully encapsulate young women's experiences with breast cancer treatment, creating a need for further examination of decision-making processes and the ways women navigate both clinical factors and psychosocial factors.

Decision-making surrounding reproductive health options and cancer treatment is reportedly influenced by biological/clinical, sociodemographic, and psychosocial variables (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Ganz et al. 2003; Nieman et al. 2006; Partridge et al. 2004; Schover 1999; Schover et al. 1999; Thewes et al. 2003; Thewes et al. 2005). However, little is known about the specific factors influencing women's decision making. Existing literature addressing reproductive and sexual health as survivorship concerns reveals three recurring themes in need of further investigation. First, there is a lack of adequate information on reproductive health options provided to reproductive-age breast cancer patients by primary cancer

care providers. Secondly, the mechanisms and processes by which reproductive and sexual health concerns interact with the biological basis of the diagnosis to influence treatment decisions, and vice-versa, are not well documented. Thirdly, there has been a lack of attention to the institutionalized approaches, structural barriers, and power relations that exist in standardized cancer care that influence treatment recommendations, available options, and the ability for care providers to facilitate the decision-making processes of young survivors.

The purpose of this study is to use an integrated biocultural perspective to examine the decision-making processes of young survivors as they navigate breast cancer treatment and reproductive health care options. In an effort to help fill the identified gaps present in current research and educational materials, I use a biocultural perspective, combined with theoretical insights from critical medical anthropology and feminist literature, as a starting point for investigating the mechanisms at play in reproductive and treatment decision-making for young survivors. This retrospective study utilizes a mixed-methods approach that integrates quantitative survey data (Phase I) with interview (Phase II) and focus group (Phase III) narratives from the young survivor community, combined with intensive participant-observation through an extensive internship with the local chapter of Susan G. Komen for the Cure^{vi}. Findings reveal the complex mechanisms by which reproductive concerns influence treatment decisions, including the sociocultural context of women's lives, the biology of the cancer diagnosis, and the institutional constraints that mediate available information and options.

ⁱⁱ All names are pseudonyms given to protect the anonymity of participants. This case study is thus a compilation of stories and details from participants in the study. The case study is used to illustrate the prevalent themes and typical course involved in a breast cancer diagnosis at a young age, as compared to their post-menopausal counterparts.

ⁱⁱ Cancer Survivor, as defined by the National Cancer Institute: An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life.

ⁱⁱⁱ Young Survivor, an emic term/*en vivo* code used by young breast cancer survivors to identify themselves, their peers and their specialized context. Defining young survivor as eighteen through forty years of age is also consistent with the known literature on the topic (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005).

^{iv} Currently, the dominant information targeted at young survivors is web-based in nature, including the Young Survival Coalition and FertileHope. Participants made clear that while these resources are very helpful, they are limited because of their online medium and care providers are often unaware these resources exist, forcing the young patient to take the responsibility of seeking out and trying to incorporate the information into care recommendations that provide little to no flexibility.

^v Systemic/adjuvant therapy: cancer treatment, such as chemotherapy or hormone therapy, used in addition to surgery

^{vi} Komen for the Cure, formerly known as the Susan G. Komen Foundation, is the largest grassroots breast cancer activist group globally, with affiliates in one-hundred and twenty-five U.S. cities and three international branches.

Chapter 2 – Literature Review

The purpose of this study is to use an integrated biocultural perspective to examine the decision-making processes of young survivors as they navigate breast cancer treatment and reproductive health care options. A brief overview of the literature on breast cancer in pre-menopausal, reproductive-age women is provided in order to contextualize the study purpose, to provide the necessary background to understand results, and to identify gaps in the literature that this study will help to fill. In order to achieve these goals, this literature review is divided into three sections: 1) the epidemiology of breast cancer in pre-menopausal women; 2) the systemic and surgical treatment options for young patients; and 3) the psychosocial issues faced by young survivors.

Epidemiology of breast cancer in pre-menopausal women

Studies have documented a difference in the epidemiological patterning of breast cancer in pre-menopausal women compared to their post-menopausal counterparts. Breast cancer accounts for 26% of all cancer diagnoses and approximately 5% of breast cancer cases occur in women under the age of forty (ACS 2007). In 2007, an estimated 16,150 new cases of invasive and 7,640 new cases of *in situ* breast cancer were diagnosed in women under the age of forty (ACS 2007). There was an estimated 2,830 deaths from breast cancer in 2007 in women under the age of forty (ACS 2007). Tumors in young women are typically more aggressive and advanced in nature when diagnosed (Black and Smith 2005, 2006; Choi et al. 2005; Largent, Ziogas and Anton-Culver 2005; Sundquist et al. 2002; Zhou and Recht 2004).

Further, young breasts are characterized by denser breast tissue and constant cell division changes that produce benign (non-cancerous) fibrocystic breast conditions (Black and Smith 2005, 2006; Largent, Ziogas and Anton-Culver 2005). The aggressiveness of the tumor coupled with the increased density of young breast tissue leads to inadequate screening options (as compared to women fifty and older, where mammography effectiveness rates are at 80-90%) (ACS 2007), and later stages at diagnoses (Black and Smith 2005, 2006; Choi et al. 2005; Largent, Ziogas and Anton-Culver 2005; Sundquist et al. 2002; Zhou and Recht 2004). When later diagnosis occurs, more aggressive and less flexible treatment options are standard recommendations.

Due to recent advances in tumor biology research, it is now possible to distinguish between breast cancers of different biological types. High grade tumors (those that present cancer cells of high abnormality, which can lead to a more rapid spread and growth of the tumor) and hormonally responsive tumors (those tumors that grow independent of estrogen and progesterone and thus, do not respond to adjuvant hormonal treatments such as Tamoxifen) are found at higher frequencies in young women (Black and Smith 2005, 2006; Largent, Ziogas and Anton-Culver 2005; Choi et al. 2005). In addition, tumors in young women are more likely to be HER2-receptor positive (HER2 is a growth-promoting protein that is overly expressed in 15-20% of tumors and causes excess breast cancer cell growth and rapid spread of the malignant cells) (American Cancer Society-National Comprehensive Cancer Network [ACS-NCCN] 2007; Black and Smith 2005, 2006). Young tumors are also more likely to

have lymphovascular invasion, meaning that the cancer has spread into surrounding lymph nodes (Black and Smith 2005, 2006; Largent, Ziogas and Anton-Culver 2005; Zhou and Recht 2004).

Tumors in young women tend to be of larger size when diagnosed compared to older women (Black and Smith 2005, 2006; Largent, Ziogas and Anton-Culver 2005; Sundquist et al. 2002; Zabicki et al. 2005). It is hypothesized that the larger tumor size documented in younger women results from the difficulty posed in detecting tumors in young, dense breasts, a lack of standardized and effective screening strategies for women under forty, and the aggressiveness of the tumor biology that results in a rapid growth of presenting tumors (Black and Smith 2005, 2006; Largent, Ziogas and Anton-Culver 2005; Zabicki et al. 2005). These aggressive and advanced characteristics of young breast tumors are associated with poorer overall survival rates (Largent, Ziogas and Anton-Culver 2005), necessitating the need to treat these tumors in an aggressive and emergent manner.

Systemic and surgical treatments for young women

Treatment options available to women diagnosed with breast cancer are broadly divided into surgical treatments (breast conserving surgery, mastectomy) and adjuvant treatments (biological therapy, hormonal therapy, chemotherapy, radiotherapy). Breast conserving surgery (BCS), or lumpectomy, is when only the tumor itself and (potentially) part of the surrounding tissue is removed, while the remaining breast remains intact (Black and Smith 2005, 2006; Lee and Foster 2005, 2006). Mastectomy is defined as the partial or complete removal of the breast (Black

and Smith 2005, 2006; Lee and Foster 2005, 2006). Bilateral mastectomy involves the surgical removal of both breasts, while unilateral mastectomy involves the surgical removal of only the affected breast. Women diagnosed with breast cancer in only one breast may choose a contralateral prophylactic mastectomy, where removal of the other breast as a preventative measure occurs in order to reduce the risk of contralateral recurrence. Studies have not shown a difference in long-term survival rates for women who undergo BCS versus a mastectomy; however, this research has been done primarily with older women. Because the tumor biology differs and due to the increased risk of locoregional recurrence in younger women, these studies remain inconclusive when applied to the sub-population of young survivors. Thus, mastectomies are often the recommended treatment course for younger patients (Black and Smith 2005, 2006; Fisher et al. 2002; Lee and Foster 2005, 2006; Veronesi et al. 2002).

Surgical treatments remain the standard, first line of treatment for breast cancer care in America. Radiotherapy is most often coupled with surgical treatments in an effort irradiate remaining cancer cells left in the breast, chest wall or lymph nodes after surgery (ACS 2007; Carrizosa and Carey 2005, 2006). Radiotherapy relies on high-energy rays to destroy the remaining cells. Additionally, systemic treatments that involve targeted pharmaceutical therapies may be employed when the cancer has spread beyond the breast and nearby tissue (ACS 2007; Carrizosa and Carey 2005, 2006). Systemic treatment may also be recommended to women who do not have evidence that the disease has spread, but who are at increased risk for rapid spread;

when systemic treatment is applied in this way, it is called adjuvant treatment. The two main systemic/adjuvant treatments are chemotherapy and hormonal, or endocrine, therapy. Chemotherapy refers to pharmaceutical drugs used to slow or stop cancerous cell growth (ACS 2007; Carrizosa and Carey 2005, 2006). Hormonal, or endocrine, therapies are those pharmaceutical treatments that block estrogen from binding to estrogen receptor-positive sites of tumors and fueling the growth and spread of the hormonal receptor-positive tumor (ACS-NCCN 2007; Carrizosa and Carey 2005, 2006). Systemic or adjuvant therapy is often coupled with surgical treatments and radiotherapy, depending on the specific prognosis and tumor characteristics of an individual diagnosis.

Recommended treatment courses are a matter of clinical care, and all come with side-effects and late-effects; however, these effects may produce different, or more pronounced, concerns for pre-menopausal women compared to their post-menopausal counterparts (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005). Of particular importance for young survivors are the ways each treatment option/recommendation affects—or is affected by—reproductive and sexual health concerns, and how these concerns and treatment courses affect overall quality of life.

Surgical treatment options weigh heavily on the minds of young survivors, for as young women, the breast is both personally and socially valued (Baucom et al. 2005, 2006). As stated previously, studies show no difference in long-term survival between mastectomy and lumpectomy; however, these studies are inconclusive for

younger women (Black and Smith 2005, 2006; Fisher et al. 2002; Lee and Foster 2005, 2006; Veronesi et al. 2002). Further, because younger women have increased chances of recurrence due to a longer life after cancer (compared to post-menopausal women), care providers may recommend, or younger women may choose, mastectomy at a higher rate (Black and Smith 2005, 2006; Lee and Foster 2005, 2006). Research documents the psychosocial issues that confront women who choose mastectomy, which include concerns over sexuality, body image, and breastfeeding (Black and Smith 2005, 2006; Lee and Foster 2005, 2006). The major issue regarding surgical treatment methods for young women arises in relation to breast reconstruction options and timing, and the interplay with systemic treatment and radiotherapy.

The two main types of breast reconstruction commonly available include implants and the transverse *rectus abdominus myocutaneous* (TRAM) flapⁱ (Lee and Foster 2005, 2006). Breast reconstruction may either take the form of immediate reconstruction, where the surgery is done at the same time as the initial breast removal surgery, or delayed reconstruction, where the surgery is performed at a later date (ACS-NCCN 2007). Implants, either silicone or saline, are a common breast reconstruction option chosen by young patients (ACS-NCCN 2007; Lee and Foster 2005, 2006). Women often elect to have implants as part of immediate reconstruction; however, the risk they face in doing so is that often recommendations for radiotherapy have not yet been determined. If the patient must undergo radiation, the treatment can cause visible damage to the skin covering the implant, resulting in a less-than optimal reconstructive result (Lee and Foster 2005, 2006). Similarly, if a woman chooses

delayed reconstruction and radiotherapy is undergone, the radiation can cause scar tissue at the reconstruction site, making it difficult or impossible for surgeons to optimally perform implant surgery (Lee and Foster 2005, 2006).

TRAM flap, the second common option, may be preferred because it helps to create a natural feel and contour akin to the native breast, and is generally well tolerated in younger women (Lee and Foster 2005, 2006). However, many young women feel the TRAM flap is a less than ideal option due to the physical demands their young bodies face. Because the TRAM flap involves removal of tissue from the transverse *rectus abdominus myocutaneous*, a muscle in the lower part of the abdomen, young women worry about the effects it will have on their ability to exercise and care for young children, who require extensive lifting and carrying (Lee and Foster 2005, 2006). Further, TRAM flap surgery is associated with a relatively long recovery time compared to implants (Lee and Foster 2005, 2006). Confounding the risks and benefits of breast reconstruction surgery is the likely recommendation of chemotherapy. Chemotherapy has a potential to delay wound healing and increase the risk of complications related to reconstruction (Lee and Foster 2005, 2006). Similarly, reconstruction—and any associated complications—may cause a delay in the start of chemotherapy, potentially decreasing a favorable prognosis and chances for survival (Lee and Foster 2005, 2006).

Chemotherapy, while the most common and beneficial of systemic treatments, also remains the treatment course with the greatest impact on reproductive and sexual health. Chemotherapy, and to an extent radiotherapy, involves high levels of gonadal

toxicity, meaning the treatment negatively affects and diminishes gonadal function, and can lead to both infertility and problems related to sexual dysfunction (Roberts and Oktay 2005). Understanding female reproductive biology will allow an understanding of the mechanisms behind these gonadotoxic therapies.

Female reproduction is concentrated in the ovaries where the main purpose is the production of female sex steroid hormones and gametes (Themmen 2005). Female gametes, medically known as oocytes, (popularly known as eggs), mature in the ovaries inside structures called ovarian follicles. The primordial follicle pool refers to the number of primordial (or immature) follicles with immature oocytes waiting for maturation. A woman is born with her entire supply of oocytesⁱⁱ, and she is not capable of substantially producing new gametes. Further, throughout the lifetime of the woman, oocytes are continuously recruited for maturation and growth, but most die in a process known as atresia. Menopause occurs when the follicle pool is completely depleted or when levels of active estradiol are too low to stimulate maturation of remaining follicles (Faddy et al. 1992; Themmen 2005).

The high-dose and combination treatments used in breast cancer care increase the rate of survivorship and concurrently decrease the rate of fertility (Ethics Committee of the American Society for Reproductive Medicine [ECASRM] 2005). The most marked way such cancer treatments impact infertility is through inducing ovarian failure. Certain forms of chemotherapy, when used on the human ovarian tissue, result in significant loss of primordial follicles through ovarian atrophy (Molina, Barton, and Loprinzi 2005). In effect, chemotherapy attempts to kill

cancerous cells, but in the process, may also affect healthy cells and further deplete the oocyte reserve. Cytotoxic agents of chemotherapy negatively combine with the biology of reproduction by diminishing the process of follicular growth and maturation, resulting in oocyte depletion, loss of hormonal production, diminished fecundity, and premature menopause (Critchley, Hamish, and Wallace 2005; McInnes and Schilsky 1996; Molina, Barton, and Loprinzi 2005). Radiotherapy, as it affects fertility in females, operates in a similar fashion. The radiation may penetrate into the ovaries, deplete the primordial follicle pool, and damage ovarian hormone production (Critchley, Hamish, and Wallace 2005).

The gonadal toxicity caused by chemo- and radio-therapy may take two forms, acute ovarian failure and premature menopause. Acute ovarian failure refers to infertility caused by ovarian damage during or immediately after cancer treatment, whereas premature menopause refers to a period of normal ovarian function following treatment, but then an early (before normal menopause) onset of infertility due to ovarian damage from treatment (Sklar 2005). Cancer treatment may cause either type of infertility, and understanding the difference is crucial to developing effective fertility-preservation treatments.

Finally, the extent to which chemo- and radio-therapy affect reproductive functioning is determined by three key variables: 1) dosage; 2) drug class/radiotherapy type; and 3) age of patient/ovarian function prior to treatment. First, the extent to which both chemotherapy and radiotherapy affect fertility is at least partially dose-

dependent, with a higher dosage positively correlated with acute ovarian function or premature menopause (Molina, Barton, and Loprinzi 2005).

The second variable is drug class/radiotherapy type. In chemotherapy treatment, research consistently shows that certain drug classes (otherwise known as drug types) are associated with a much higher probability of resulting female infertility. Drug classes are divided by the type of agent used. Chemotherapy drugs containing alkylating agents are shown to have greater gonadal toxicity (Nieman et al. 2006). Further, certain combinations of drugs are known to affect fertility in varying severity (Nieman et al. 2006). In radiotherapy treatment, this second variable depends on both the dose-schedule and the bodily location of concentrated radiation (Nieman et al. 2006).

The third variable involves age and the correlating ovarian function status prior to treatment. As a woman ages, ovarian reserves continuously deplete. The older the patient, the less oocytes she possesses, and thus the greater the effects of chemo- and radio-therapy (Roberts and Oktay 2005). Younger age seems to offer a protective effect regarding the gonadal toxicity of treatment, as younger women presumably possess a greater follicle pool where any depletion is mitigated by the higher reserve still available (Nieman et al. 2006; Schover 1999; Schover et al. 1999).

Historically, cancer treatment in women utilized a combination of chemo- and radio-therapy, with high dosages and more toxic drugs (known as “heavy” treatment) (Niwa et al. 2005). This approach may stem from a biomedical focus on saving the life of patient, without serious regard to the side- and late-effects. Further, when infertility

as a side-effect of treatment was recognized, a “wait-and-see” approach to fecundity was traditionally employed, where aggressive treatment continued as scheduled and damage to reproductive capacity determined upon completion, leaving women with little to no childbearing options when an unfavorable diagnosis occurred (Nieman et al. 2006). However, with increased survivorship rates and a trend in Western countries toward delayed childbearing (Dow and Kuhn 2004; Grady 2006; Murray 2005, 2006), an acknowledgement of the importance of quality of life and reproductive health, especially fertility, as a top survivorship concern has emerged (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; ECASRM 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005).

In response, fertility-preservation techniques are edging their way into discussions of cancer treatment and care (Nieman et al. 2006). The most common and successful of the fertility-preservation techniques is embryo cryopreservation through emergency in vitro fertilization (IVF)ⁱⁱⁱ (Nieman et al. 2006; Roberts and Oktay 2005). Embryo cryopreservation first involves the process of IVF, where mature oocytes are taken from the woman’s body and fertilized in a petri dish with sperm. The result, if fertilization is successful, is embryo(s) that can be cryopreserved for later use (Robertson 2005).

Although embryo cryopreservation remains the most promising of fertility-preservation techniques, there are multiple limitations young survivors must consider and negotiate as they explore this option. First, the future success of pregnancy utilizing the cryopreserved embryos depends on how many cycles of IVF are

performed. The number of cycles correlates to the quality and quantity of embryos collected – the more available, the more likely the success of future pregnancy when reimplantation occurs. However, because the process of IVF takes time (one to two cycles of IVF are generally possible within a four to six week time period, assuming no complications occur), systemic cancer treatment must be delayed – a consequence that care providers, having a focus on saving the patient’s life, may strongly disagree with (Roberts and Oktay 2005). Unsupportive attitudes on the part of cancer care providers, and a lack of understanding regarding the urgency of fertility-preservation for cancer patients on behalf of reproductive medicine clinics, result in a disarticulation between care providers, leaving the patient to shoulder the burden of coordinated treatment appointments and risk/benefit analysis (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005). Finally, because hormonal stimulation is required in the IVF procedure, safe ovarian stimulation may not be viable for hormonal receptor-positive tumors (Nieman et al. 2006).

Two other limitations are faced by young survivors exploring this fertility-preservation option. First, the procedure is dependent on donor sperm. Younger women are less likely to be married or in committed relationships, and for many young women, even thinking about future children and fertility is a stretch at the time in their life when the diagnosis comes, as their focus may be more on educational and career attainment (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005). The second, and perhaps greatest

limitation, is the financial burden posed by the expenses associated with fertility-preservation. Younger women are again at a disadvantage, as they are more likely to be in a position of lower socioeconomic status with limited financial resources and un- or under-insured.

While not posing the same level of threat to the reproductive health of women, endocrine, or hormonal, therapies also come with a set of risks to the reproductive and sexual lives of young breast cancer patients. The main hormonal therapy used in breast cancer is Tamoxifen, an anti-hormonal agent that blocks receptor sites of estrogen-receptor positive tumors and decreases the risks of recurrence (Dow and Kuhn 2004). Breast cancer patients with hormonal receptor-positive tumors are generally advised to take Tamoxifen for at least five years post-treatment. Pregnancy is contraindicated while on Tamoxifen, and once the regimen is complete, women are at increased risk for early menopause (Dow and Kuhn 2004). A second endocrine therapy, involving aromatase inhibitors, is also effective against hormonal receptor-positive tumors. However, to be successfully used, the patient must be post-menopausal. Thus, for a young survivor to receive this drug (which is increasingly being cited as superior to Tamoxifen), she must make the difficult decision of having a oophorectomy and/or hysterectomy, which will block estrogen from feeding the tumor and force the woman into menopause, allowing her to access the “good drugs” (Dow and Kuhn 2004).

In addition to the fertility threats posed by systemic treatments and surgical options of oophorectomy and hysterectomy, these therapies can also lead to sexual dysfunction as a result of premature menopause and loss of estrogen that is integral to

libido and sexual response (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005). The sudden thrust into early menopause experienced by many young cancer survivors is associated with hot flashes, difficulty in sleeping, decreased sexual drive, and vaginal dryness resulting in painful intercourse (Baucom et al. 2005, 2006). Further, the loss of breasts and other reproductive organs, combined with a decrease in estrogen throughout the body, causes many young women to experience increased anxiety regarding their womanhood, femininity and body image (Baucom et al. 2005, 2006).

Psychosocial issues faced by young survivors

The effects of treatment reviewed above provide the framework for understanding the unique and often heightened psychosocial concerns young patients face with a breast cancer diagnosis. Young women, for example, may face the fertility-related consequences of cancer treatment in a gender-specific way, as a women's societal role heavily relies upon her ability to reproduce (Brettell and Sargent 2001; Horner and Keane 2000; Inhorn 1994, 2006). As such, women may view infertility as a threat to their femininity. Moreover, cancer treatment comes with visual and public side-effects, including loss of hair, breast removal, and drastic weight-loss—effects that threaten women's perceived attractiveness. In combination, these multiple stressors create psychosocial fears over their ability to attract a partner or losing a current mate (Ganz et al.2003; Schover 1999; Schover et al. 1999).

The fear of being unable to attract or keep a mate stems not only from body image insecurity, but also from their newly acquired (in)fertility status. Because

women's cultural roles are highly dependent on their ability to bear and raise children, young patients have cited the strain cancer-related infertility places on current relationships and the (perceived) barrier infertility will cause for future dating (Zebrack et al. 2004). Other survivors cite avoidance of intimate, long-term relationships because of fear of rejection due to their infertility (Zebrack et al. 2004).

Research has also documented the low social and familial support awarded to female reproductive-age cancer patients struggling with infertility issues (Schover 1999; Schover et al. 1999; Zebrack et al. 2004). Losing the dream of having one's own biologically-related child, and losing the ability to experience pregnancy and childbirth, is a well documented, silent struggle among infertile individuals (Layne 1997, 2003; Rothman 1986). When this loss intersects with a cancer diagnosis, young survivors may be told by family, friends, and their biomedical care providers that they should just be grateful (and concentrated) on staying alive—neglecting the feelings of intense loss women are experiencing, further silencing their struggle, and effectively ending any conversations regarding future childbearing and options (Schover 1999; Schover et al. 1999).

Diminished social support is also found in women with one or more children prior to the diagnosis, but who experience secondary infertility, and the associated sense of loss, resulting from cancer treatment. These women have discussed how secondary infertility produces overwhelming grief for the loss of future childbearing, desired birth experiences, and their inability to provide a sibling, or a “complete family,” for their other children. In addition, they are concerned for their current

children, knowing the immediate mortality risk faced (ACS 2007) and struggling with issues of failed motherhood and abandonment (Schover 1999; Schover et al. 1999).

When a young survivor chooses to explore future childbearing, she has two main options, fertility-preservation or adoption. In engaging these two options, additional concerns over conception and parenting arise. Studies indicate that the desire for children is higher among childless individuals than those with one or more children when entering cancer treatment, with 76% of childless individuals indicating desire for children compared to 31% for their already parenting counterparts (Schover et al. 1999). Given the deep desire for future children, fertility-preservation and other parenting options may become high priorities.

As discussed above, fertility-preservation, most commonly embryo cryopreservation through IVF, options come with a complex subset of issues and considerations for young survivors. Similarly, adoption is wrought with legal and social issues unique to young cancer survivors. Studies show that young women are more likely to indicate desire for adoption over fertility-preservation and assisted reproductive technologies (ART), with 62% indicating adoption and only 25% indicating ARTs (Schover et al. 1999).

The greatest barrier young survivors face in trying to adopt is discrimination by public adoption agencies when a history of cancer is known (Nieman et al. 2006; Schover 1999; Schover et al. 1999). The public adoption agencies may feel cancer survivors will make unfit parents, either due to the perceived stress a child puts on already ill bodies or because of the risk of early parental death. Similar discrimination

is found in private adoption agencies where the birth mother is involved in the process of choosing the child's adoptive family (Nieman et al. 2006; Schover 1999; Schover et al. 1999). The expense of adoption poses an additional stressor, as families may already be experiencing financial hardship due to expensive biomedical treatment.

If a woman is able to conceive biologically, the most prevalent and distressing concern manifests as the fear of transmitting genetic risk for cancer to the offspring. Statistics indicate that 39% of childless individuals and 38% of individuals with one or more child worry that their children will have an increased genetic susceptibility to cancer (Schover et al. 1999). Young survivors may experience great concern over genetic transmission in part due to the fact that as young women with an early in life diagnosis, they are more likely to carry the mutations on the BRCA-1 and BRCA-2 genes that are known implicators for increased risk of breast cancer (Black and Smith 2005, 2006). Five to ten percent of women carry mutations on the BRCA genes, and these mutations are most commonly identified in women under fifty (Black and Smith 2005, 2006). The concern over genetic transmission is also the prime motivation for survivors who utilize genetic testing. Many individuals with heritable cancer forms desire reproduction, but will do so only under conditions where the heritable risk is diminished or circumvented. Prenatal diagnostic testing techniques such as Chorionic Villus Samplings (CVS) and amniocentesis may allow detection of heritable cancer genes; however, selective termination is the only subsequent option for circumvention of a positive diagnosis.

Prenatal diagnostic testing is also utilized when women fear that chemo- and radio-therapy damaged their eggs and will produce teratogenic effects in offspring. The fear is further confounded by a prevalent societal gender-bias, where the burden of a healthy child and healthy family lies squarely on women (Brettell and Sargent 2001; Horner and Keane 2000; Inhorn 1994, 2006; Rothman 1993). While very real to young women, the concern is relatively unfounded in light of evidence-based research on this topic, which concludes little to no difference in congenital malformations for children born to cancer-treated mothers (Nieman et al. 2006:273).

A related concern is the risk of pregnancy complications due to cancer treatment. Concerns about pregnancy complications take two forms: the risk of pregnancy complications damaging fetal health and the risk of cancer recurrence due to effects of pregnancy (Fossa et al. 2005). One study revealed that 17% of women were concerned that pregnancy would trigger a recurrence of their cancer (Schover et al. 1999). Standardized biomedical cancer care typically recommends that a woman wait two to five years post-treatment before attempting conception (Calhoun and Hansen 2005, 2006). This recommendation is based on the hypothesis that most cancer recurrences occur within a five year period, and for hormonal receptor-positive tumors, a pregnancy would further increase this risk. If a woman exhibits no signs of recurrence in this time-frame, her recurrence risk decreases and pregnancy may be more advisable. However, the communicating of this recommendation is often unclear for patients, and many women take such advice as indicating that pregnancy increases

absolute risk recurrence at any post-treatment time (Calhoun and Hansen 2005, 2006; Schover et al. 1999).

Another psychosocial concern for young cancer patients involves parenting and rearing of a child after cancer. Among survivors, a marked change in parenting attitudes or perceptions is demonstrated, with 80% of survivors stating that the cancer experience made them better parents (potential or real) (Schover et al. 1999). Many survivors cite the renewed importance of family and children after facing a life-threatening disease, whereas 19% to 24% of survivors express an increased desire for children after facing cancer and their own mortality (Nieman et al. 2006). Survivors feel they will be better parents because of the importance they place on family, their experience in coping with life struggles, and the perceived strength of marriages that survive cancer. Strengthened marriages may not only provide family stability, but the managing of intense, lengthy treatments often means a learned flexibility in gender roles to maintain a viable household. Finally, survivors often cite the ability to raise children as conferring a sense of normalcy back into their lives (Schover 1999; Schover et al. 1999; Zebrack et al. 2004).

A final theme exhibited with young survivors is the importance of information and informed consent (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005). Young women have cited the difficulty of accessing information on reproductive health when a cancer diagnosis is made (Thewes et al. 2003). Women have expressed dissatisfaction with not only the amount (inadequate) of information available, but also with the timing of

information, noting that the information and resources came too late in their treatment to be pursued as viable options (Thewes et al. 2003). Lack of information can cause an additional layer of stress by producing an unclear, often conflicting resource basis from which to proceed with treatment decision-making (Thewes et al. 2003; Thewes et al. 2005). When information is perceived as inadequate or mistimed, lower doctor-patient satisfaction rates and decreased satisfaction with treatment decisions are reported (Thewes et al. 2003). Partridge and colleagues (2004) have argued that lack of information in medical decision-making remains one of the greatest unmet psychosocial needs of patients. Additionally, reproductive health concerns may change over the cancer diagnosis and treatment experience, and there is reportedly very little attention to these shifting concerns by providers (Thewes et al. 2005).

The lack of adequate reproductive health conversations in standardized cancer care approaches is perhaps best evidenced by the low reported rates of informed consent regarding the side-effects of fertility and early menopause. Duffy, Allen and Clark (2005) (n=166) found that only two-thirds of young survivor participants reported a discussion with their care provider regarding menopause, and only one-third recalled a discussion regarding fertility. These rates are consistent with previous studies investigating informed consent and information provision in young cancer patients (Schover et al. 1999).

This literature review has provided the background and information necessary to begin to understand the unique diagnosis and treatment experiences of young survivors. However, missing from the available literature is an analysis of the

mechanisms women use as they negotiate treatment options and, often conflicting, reproductive and sexual health concerns. Current studies (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005) call for a focused investigation of decision-making routes and a qualitative elaboration of themes and concerns prevalent in preliminary research. Through a biocultural approach that documents the lived experiences of young women and their decision-making processes, this research project aspires to meet this call by using findings to inform the development of educational materials, cancer care counseling and clinical standards in an effort to improve the lives and choices of young breast cancer survivors.

ⁱ Other reconstruction options include *latissimus* Flap and *perforator* flap, although these currently remain on the margins for commonly recommended reconstruction options and were not mentioned by any participants in this study.

ⁱⁱ Emerging research (Donnez et al. 2004; Johnson et al. 2004) provides some evidence that females may continue to produce new oocytes over her lifetime under certain circumstances.

ⁱⁱⁱ Additional fertility-preservation options include oocyte cryopreservation, ovarian tissue cryopreservation, GnRH agonists and antagonists, and egg donation and surrogacy (Dow and Kuhn 2004; Grady 2006; Murray 2005, 2006).

Chapter 3 – Methods, Study Population and Study Limitations

This study is retrospective in design and utilizes a mixed methods approach that integrates quantitative survey data (Phase I) with interview (Phase II) and focus group (Phase III) narratives from the young survivor community, combined with intensive participant-observation. I did not analyze quantitative survey results for statistical information, but used them only as a means for contextualizing the study population, and developing and interpreting Phase II and III narrative findings. I used a modified grounded theory approach (Charmaz 2000, 2006) in analyzing interview and focus group texts, and I obtained Institutional Review Board approval for the ethical and non-coercive treatment of research participants prior to the study start.

Phase I: Participant Observation and Recruitment Survey

In Phase I, I relied on the time-honored tradition of participant-observation (Bernard 2006; Creswell 1998; Green and Thorogood 2004; Spradley 1980) with select young breast cancer survivor support groups and breast cancer activist organizations in a large urban city in the Pacific Northwest¹ to gain an ethnographic foundation for research within the young survivor community. I chose the urban locale because it is one of the most demographically diverse areas in the Pacific Northwest with a high concentration of young survivors, facilitating ease of recruitment and increasing the likelihood of multiple perspectives. Participant-observation provided me familiarity with support group and breast cancer survivorship terminology, and assisted me in contextualizing and understanding results from subsequent interview narratives (Bernard 2006).

Further, participant-observation and my work with local breast cancer activist organizations conferred me an “insider” status that facilitated my ability to interact with and be accepted by participants, arguably allowing for a deeper level of data collection to proceed (Bernard 2006). My rapport-building with young survivors through intensive participant-observation also called attention to the false insider/outsider dichotomy feminist researcher Nancy Naples (2004) has recognized. Naples argues that insider/outsider statuses are constructed and fluid, and through recognition of the fluidity, we can challenge the false divide, unmask power differentials between researcher and researched, and engage in self-reflection whereby the co-constructed nature of interviews and ethnographic research is established and made explicit (Naples 2004). The “insider” status I was conferred through my work as a recognized breast cancer activist was consistently constructed and positioned in relation to my concurrent status as an “outsider” because I did not have breast cancer. The constant shift between my insider and outsider positionality, combined with the co-constructed nature of the narratives and deconstructed power relations that followed, aligns well with Naples contention of the false insider/outsider dichotomy.

Phase I also involved dissemination of recruitment surveys (Appendix A) to the young survivor network and support groups, resulting in a volunteer sample of $n=15$. Surveys were disseminated through a two-fold process. First, I attended the monthly young survivor support groups in the urban locale and read an invitation script (Appendix B), orally inviting women to participate in the study. Second, the support group coordinator agreed to disseminate my invitation and survey to the

young survivor support group online list-serve. In total, forty surveys were distributed to young survivors through a combination of in-person and online recruitment; fifteen surveys were returned for a response rate of 37.5%. Surveys were self-administered and took approximately 10-15 minutes to complete. Participants recruited in-person through support group meetings were provided a self-addressed, stamped envelope for survey return. Participants recruited through the online list-serve mailed or emailed back survey responses. Surveys asked relevant demographic, self-reported breast cancer diagnosis information, and reproductive and sexual health questions.

I used survey results primarily to contextualize the study population and to begin to assess the reproductive health concerns of young survivors. Surveys provided a breadth of information that facilitated the development of Phase II interview questions (Bernard 2006; Finan and van Willigen 1991). Most essentially, I used surveys as recruitment tools for the qualitative portion that comprises the bulk of this study. The survey included a portion where participants could self-identify and provide contact information if they were willing to meet with me for an interview. Because the identities of the participants were not known to me as the researcher prior to self-identification, participation was voluntary and presumably without coercion.

Phase II: Semi-structured, Open-ended Interviews

In Phase II, I invited all eligible participants from Phase I who self-identified through the recruitment survey to participate in a semi-structured, open-ended interview (n = 11). Interviews took on average one-and-one-half to two hours to complete and were conducted in a comfortable space chosen by the participant (coffee

shop, home or office). Interviews were guided (Appendix C) by a modified grounded theory approach (Charmaz 2000, 2006; Glaser and Strauss 1967; Glaser 2001) in which I asked a series of open-ended questions and then identified recurring themes in the narratives. I mapped recurring themes into schema or models representing participants' responses and used them to refine research questions and further expand the developing theory. My interview analysis was guided by concept or theoretical saturation (Charmaz 2000, 2006; Glaser 2001) where categories were considered "saturated" when no new details relevant to the developing theory resulted. The ethnographically rich data gathered through interview narratives allowed for a more nuanced and active theory to emerge regarding reproductive decision-making in young breast cancer survivors (Bernard 2006; Creswell 1998; Finan and van Willigen 1991)

Open-ended interviews are also a well-accepted feminist research method because they allow women's voices to be heard in a dynamic conversational style akin to normal social activities, producing categories meaningful to women's lives (DeVault 2004; Harding 2004). Further, semi-structured, open-ended interviews allowed me to elicit illness (Kleinman 1988) and treatment narratives (Sered and Tabory 1999) that are, arguably, an integral part of identity development and are essential for the understanding of researched phenomenon as part of a wider social construction of illness, treatment and health. The sharing of illness or treatment narratives with me as the researcher can also act as a source of empowerment and advocacy for young women survivors (DeVault 2004; Inhorn 1994, 2006; Kleinman 1988; Mathieson and Stam 1995).

I audio-recorded interviews with permission from the participant, transcribed interview texts into Word documents, and analyzed them using a grounded theory approach (Charmaz 2000, 2006; Creswell 1998; Dey 1999). Audio-recording of interviews allowed me to document accurately participants' words (verbal communication), and also to record how their narratives were expressed (non-verbal communication), including tonal changes, pauses, inflections and other signs of emotion like laughing and/or crying. Audio-recordings were supplemented with handwritten notes that I took during the interview, where I noted both key emerging themes and the body language and behavior of participants as they shared their stories. The key themes I identified were translated into a visual schema that delineates interviewee's responses and forms the foundation for my interpretations. Research is therefore "grounded" in the participants' experiences, as interviewees' responses (and not my preconceived expectations) dictate the categories evaluated (Cheyney 2008). In addition, because findings are often returned to communities for comment and critique (see Phase III below), grounded theory approaches have been argued to promote reliability and validity in qualitative research, while remaining meaningful to participants (Barbour and Kitzinger 1999).

Phase III: Focus Group as Reciprocal Ethnography

At the end of each Phase II interview, I orally invited participants (Appendix D) to take part in a focus group discussion of findings with the agreement that I would contact them as soon as preliminary interpretations of interview themes were complete. The focus group lasted approximately two-and-one-half hours and was

conducted at a central location in the meeting room of a local breast cancer activist organization. A total of n=8 women participated in the focus group. The recurring themes identified in Phase II were used as discussion points for the focus group. Participants were provided the opportunity to critique and elaborate upon my proposed categories and emerging theory. The use of focus groups as reciprocal ethnography (Lawless 1992), or “member checking” (Charmaz 2000, 2006), is argued to promote reliability and validity in qualitative research (Barbour and Kitzinger 1999) and is a well-established feminist methodology (Green and Thorogood 2004; Lawless 1992; Wilkinson 2004). I audio-recorded the focus group with permission from participants, and transcribed and analyzed focus group narratives using grounded theory assessment (Charmaz 2000, 2006; Creswell 1998; Dey 1999).

Study Population

I defined study eligibility criteria as women diagnosed with stage zero, one, two or three breast cancer between the ages of eighteen through forty years of age, and who were diagnosed between six months and five years prior to the start of the study. I chose participant population restrictions in accordance with the gender, age and treatment specific requirements of the research purpose and associated questions. I defined reproductive-age women as women ages eighteen to forty (young survivorsⁱⁱ) for the purpose of this study, which is consistent with the known literature on the topic (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005). I determined the stage of breast cancer through self-reporting by the participant. I restricted staging to zero through three

because reproductive options, including fertility-preservation, are only truly viable during these earlier stages. I restricted time of diagnosis to six months to five years previous to the study in keeping with the retrospective or recall nature of the research design. Because the study is retrospective, participants must have already begun treatment decision-making in order to contribute to the study purpose. Because the study focuses in large part on reproductive options, including fertility preservation, I excluded persons diagnosed more than five years previously based on the fact that available reproductive technologies and options have changed substantially in the last five years.

Phase I surveys provided me the demographic information necessary to contextualize the participant population. Key population characteristics were as follows (n = 15): all participants were between the ages of twenty six and forty years of age, for a mean age of thirty-three years; participants represented stages one through three of breast cancer, with stage two occurring most frequently; thirteen participants identified as Euro-American or Caucasian, and two participants identified as Asian American and “mixed” heritage, respectively; all participants self-identified as heterosexual; all participants held a Bachelor’s degree or higher at the time of participation; incomes ranged from \$15,000 to \$100,000; 80% of participants were married or in committed relations at time of diagnosis; 53% had children prior to diagnosis, 13% were pregnant, and 33% were childless; 73% had lymph node involvement; 47% had future pregnancy plans, 40% had completed childbearing, and 13% were unsure; and 20% used fertility-preservation technologies. Surveys indicated

that 74% of participants had reproductive health concerns at the time of diagnosis, but only 20% reported receiving adequate information or resources to address those concerns. Additionally, 33% said reproductive health concerns impacted treatment decisions. The top concerns documented were infertility, pregnancy (current or future) and sexual dysfunction. Survey findings provided me a demographic and psychosocial background for understanding the dominant themes I explore in Chapter Five.

Study Limitations

This study is a pilot project, restricted to a geographically defined area and not representative of the total population of young survivors in the United States. For example, we know little of the reproductive health needs of young survivors in same-sex relationships or how concerns may be differently prioritized for women of lower socioeconomic status. Results may not be generalizable to the larger young survivor community and statistical conclusions or correlations cannot be determined, although results align well with larger, national studies with young breast cancer patients (Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005). Sample size was small, but for qualitative analyses, concept or theoretical sampling was achieved (Glaser 2001). Because I recruited through support networks, the participant population is arguably a self-selecting group, representing higher socioeconomic statuses (those with extra economic and time resources that allow for attendance at support groups and participation in this study) (Partridge et al. 2004).

Results are also subject to recall bias, provided the retrospective design and the stressful, emergent time-period participants were asked to discuss (Bernard 2006;

Thewes et al. 2005). Finally, relations of power must be acknowledged between myself as the researcher and participants as the subjects. In commitment to a feminist research agenda, I employed feminist techniques (DeVault 2004; Harding 2004; Lawless 1992; Naples 2004; Wilkinson 2004) in interviewing, analysis, and publication – including intense rapport building and the co-constructed nature of the research – to help mitigate any resulting power relations and to honor women’s words as valuable knowledge. Additionally, because I am not a cancer survivor, power relations were, arguably, further moderated through the construction of participants as the “experts” on the topic and not me, the researcher. In the pages that follow, I present key findings that emerged from this research design and discuss implications for academic and applied work on cancer care and reproductive health counseling.

ⁱ Because young breast cancer patients remain a small (5%) subset of the overall breast cancer population and details of their stories increase the likelihood of identification, pseudonyms of geographical locations, institutional, provider and patient names are used in an attempt to respect and maintain the anonymity of participants in this study.

ⁱⁱ The term young survivor as used in this study denotes reproductive-age women, ages eighteen through forty, and is used to distinguish this sub-population and their unique concerns from their post-menopausal counterparts.

Chapter 4 – Theoretical Perspectives

The research questions, study purpose and results are situated within medical anthropology and four predominant theoretical frameworks: interpretivist stances and the social construction of disease (Garro 1998; Geertz 1973; Inhorn 1994, 2006; Kleinman 1988; Lupton 2000; Mathieson and Stam 1995; Press et al. 2005; Sered and Tabory 1999), critical medical anthropology (Baer 1990; Singer 1990, 1995; Singer and Baer 1995), feminist standpoints (Brettell and Sargent 2001; Clarke and Olsen 1999; Inhorn 1994, 2006; Layne 1997, 2003; Lee 1997; Lock and Kaufert 1998; Rapp 1999; Rothman 1986; Wilkinson 2007), and the new biocultural synthesis (Dufour 2006; Goodman and Leatherman 1998; Pike and Williams 2006; Worthman and Kohrt 2005). Medical anthropology is the application of anthropological theories and methods to questions of health, wellness, illness, disease, sickness, medicine, and healing (Brown 1998). A medical anthropological approach, coupled with multidisciplinary perspectives, provides the relevant terminology, tools and theories that facilitate development and contextualizing of research results within larger social science paradigms and literature.

Interpretivist stances and the social construction of disease

Interpretivist stances are meaning-centered approaches that facilitate examination of the social processes and constructs behind disease and illness. Geertz (1973) advocates for “thick description,” or a deep, ethnographic account of a phenomenon from the insider (*emic*) point of view, rather than from preconceived structures imposed by the outsider (*etic*) stance. The result, Geertz argues, is a greater understanding of cultural phenomena.

Distinguishing between the concepts of *illness* and *disease* is central to interpretivist stances in medical anthropology. Illness refers to the lived experience of a biological disease and associated pathological problems (Kleinman 1988), while disease refers to the biological structure underlying the pathology or disease at hand (Eisenberg 1981; Kleinman 1988; Kleinman, Eisenberg, and Good 1978; Rosenberg 1986). Illness narratives and explanatory models (Kleinman 1988) are central tools in employing the interpretivist stance. Explanatory models are personal (emic) accounts of sickness, including interpretations of etiology and treatment whereby personal and social meaning is conferred. Explanatory models guide treatment choices and the way an individual interacts with medical institutions and healers (Brown 1998; Kleinman 1988). Explanatory models are collected through illness narratives, which describe the lived experiences of a patient and situate their disease as a socially created, controlled and meaningful process. By eliciting illness narrative and explanatory models, researchers are able to gain rich insight into the social construction of a disease experience, and to develop models and theories meaningful to participants (Garro 1998; Eisenberg 1981; Inhorn 1994, 2006; Kleinman 1988; Kleinman, Eisenberg, and Good 1978; Press et al. 2005; Rosenberg 1986).

Expanding on Kleinman's concept of illness narratives, Sered and Tabory (1999) employ the concept of "treatment narratives." Treatment narratives, they argue, allow exploration and elicitation of the processes and relationships constructing the illness experience in relation to larger medical institutions. This approach highlights the treatment process as a time for identity transformation (Mathieson and Stam 1995; Sered and Tabory 1999). Illness and treatment narratives allow for explanatory models

to emerge in which the social construction of the breast cancer experience for young women can be situated in the context of reproductive health care options and treatment decision-making.

Theoretical refinement of the interpretivist stance is also achieved through the perspective of social constructivism (Lupton 2000:50), where “health, illness, disease, and health care may all be viewed as sociocultural products.” Social constructivism is of further value as it recognizes the importance of discourse in medicine and healing, where discourse is defined as a site of struggles for power and critique. This approach helps to illuminate how various authoritative and alternative discourses (Jordan 1993) (and their associated power struggles) may be inscribed upon and acted out on the human body through the process of embodiment. Embodiment is defined by Lupton (2000:50) as “the lived experience for humans of both having a body and being a body.” Embodiment refers to the dynamic practice in which our bodies are central to identity formation and our interactions with pain, illness, disease, and treatment.

Critical medical anthropology (CMA)

Additional attention is conferred to issues of power, structural inequalities, and institutional barriers through the employment of critical medical anthropology (CMA) (Baer 1990; Singer 1990, 1995; Singer and Baer 1995). Critical medical anthropology examines the core assumptions of a given explanation for a disease in order to uncover biases of a given epistemology. CMA is based on the notion that health is inherently political and that power relationships are fundamental variables in health-related research, policy and programs (Navarro 1984; Singer 1990, 1995). CMA is an additive theoretical perspective that critically examines the political-economic nature of health

and disease, illuminating connections between macro-social, intermediate-social, micro-social and individual levels (Baer 1990; Singer and Baer 1995). CMA assists recognition and transformation of the hegemonic discourse employed in biomedicine where an almost exclusive focus on disease has diminished attention to the lived experience of illness in care, resulting in standard care practices and interventions that are often antithetical to the patient's attitudes and beliefs (Baer 1990; Singer 1990, 1995; Singer and Baer 1995).

Singer and Baer (1995) have also argued for clinical applications of CMA, where they look to effect social and health reform. Singer (1995) proposes two different categories of reform, *systems-correcting praxis* and *systems-challenging praxis*. Systems-correcting praxis are those minor material changes in health care that attempt an often quick-fix solution to a problem, but do not address the underlying institutional and social level foundations that are the ultimate root cause of an issue. Systems-correcting praxis works within hegemonic biomedical discourses, whereas systems-challenging praxis develops alternative discourses to critically examine and demystify underlying assumptions and origins of inequality (Singer 1995). Using the lens of critical medical anthropology allows for critical examination of the construction of breast cancer as a disease in the biomedical and public realms, and an understanding of how power relations and biases influence treatment and reproductive counseling.

Feminist standpoints

Taking an overtly feminist stance in methodology (DeVault 2004; Green and Thorogood 2004; Harding 2004; Lawless 1992; Naples 2004; Wilkinson 2004) and

relying on feminist literature and research allows for recognition and further exploration of gender-inequality and biases, with a focus on politics, power relations and sexuality (Brettell and Sarget 2001; Horner and Keane 2000; Inhorn 1994, 2006). Feminist works on reproduction are especially useful, as they detail the multi-faceted and highly political and social nature of women as reproducers in society (Clarke and Olsen 1999; Layne 1997, 2003; Lock and Kaufert 1998; Rapp 1999; Rothman 1986). Similarly, feminist works on breast cancer (Wilkinson 2007) and the socially and personally constructed definitions of the female breast (Lee 1997) highlight the extremely gendered-nature of breast cancer as a female disease. These works combined help inform interpretations and understanding of qualitative results with a commitment to a feminist discourse.

New biocultural synthesis

The new biocultural synthesis (Goodman and Leatherman 1998) is a theoretical perspective that examines the intricate connections between biology, culture and political-economy. A biocultural perspective allows me to delineate and explore the connections between environment, unequal relations of power, and social and clinical determinants of individual health. Biocultural approaches allow for a more holistic and refined account of a given health phenomenon, moving beyond an exclusively clinical account of disease to understand the social, ecological, and institutional processes at work that produce documented patterns of disease, approaches to treatment and health outcomes (Dufour 2006; Goodman and Leatherman 1998; Pike and Williams 2006; Worthman and Kohrt 2005).

A structural equivalent of the biocultural approach in public health disciplines is the ecological model (McLeroy et al. 1988; Nurse and Edmonson-Jones 2007). The ecological model recognizes and attempts to correct a “blaming the victim” mentality historically prevalent in health promotion interventions (McLeory et al. 1988). This mentality ignores the social and political processes involved in producing individual and population-level health outcomes. This model proposes that attention to and changes in ecological and social environments can more effectively promote positive changes in individual health, and that individual experiences in the wider social and political realms must be recognized for the development of successful policies and health behavior activities (McLeroy et al. 1988; Nurse and Edmonson-Jones 2007).

Biocultural and ecological perspectives facilitate a redefinition and elaboration of what constitutes “health” (Levin and Browner 2005). Health has traditionally been defined as the absence of disease, and biomedical discourse privileges this pathological and clinically-based definition. Biocultural works add to this definition by illuminating the multiple levels and determinants involved in constituting a meaningful definition of health for participants. In doing so, biocultural approaches are, arguably, better able to inform medical care practices and public health interventions by delineating the multiple categories and dynamic processes involved in the illness experience. Biocultural approaches are thus able to more effectively facilitate improvements in patient care, compliance, satisfaction, and outcomes, and decrease disparities in access to care documented through explicit attention to underlying institutional constraints and political-economic realities (Dufour 2006;

Goodman and Leatherman 1998; Levin and Browner 2005; Pike and Williams 2006; Worthman and Kohrt 2005).

The elaborated definition of health that is informed by biocultural works may also include the psychosocial dimension of health, where recognition of psychosocial concerns are seen as integral to overall health and are examined in relation to the social and institutional power structures that support or diminish greater mental health in patients (Pike and Williams 2006). By situating young survivors as biocultural beings, a more nuanced and dynamic picture unfolds that lends itself to understanding decision-making as an active and essential process in the breast cancer experience and in reproductive health more generally.

Together, these approaches produce a broad and nuanced theoretical foundation that can account for the multi-faceted and holistic nature of the young survivor breast cancer experience.

Chapter 5 – Results

The diagnosis of breast cancer for a young patient ignites a complex treatment decision-making process whereby the woman must negotiate immediate survival with long-term quality of life. In listening to women’s narratives, I identified three interrelated themes, with sub-themes, that women engage as they move through treatment courses: 1) Biology of the cancer diagnosis; 2) Institutional constraints; and 3) Sexuality and the body. The grounded theory schema in Figure 1 models the dynamic processes of treatment decision-making and reproductive health in young survivors.

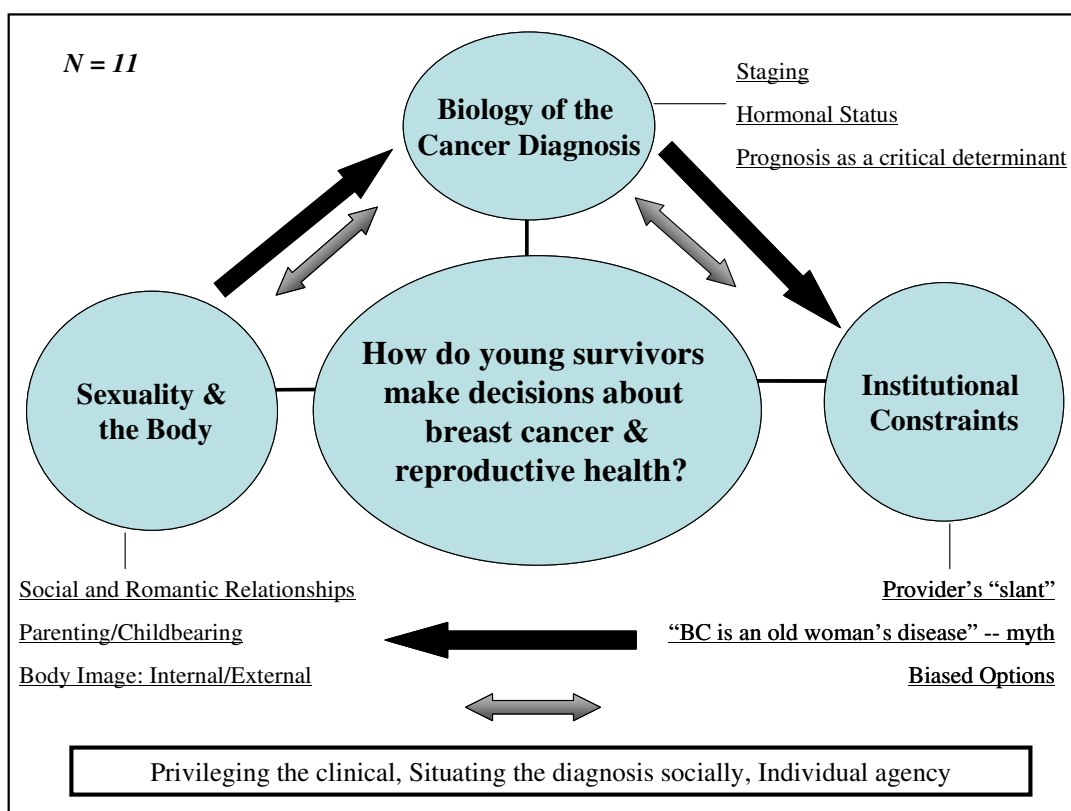


Figure 1. Grounded Theory Schema

Treatment Decision-Making Models

Three primary decision-making models have been proposed to help explain the various pathways patients take in medical decision-making: paternalistic, informed, and shared decision-making¹ (Charles et al. 1997, 1999, 2003). The first, paternalistic, is characterized by complete physician power, whereby the physician controls all aspects of treatment decision-making and the patient is posited as a passive actor with no input other than legal informed consent. Historically, the paternalistic approach dominated medical care, and this remained particularly true for female patients as they were excluded from clinical trials and viewed as a defective form of the male body (Lock and Kaufert 1998; Martin 1987). As consumer activism flourished and the biomedical institution was faced with increasing pressures to abandon paternalistic ways and to involve the patients in their own care, two new decision-making approaches emerged.

Informed decision-making is founded on the basis of patient autonomy; the conceptual foundation is that the physician's role is to provide all the information on available treatment options, the patient will weigh the facts, and make the best decision for her, with no need for physician input. Shared decision-making is characterized by an ongoing, dual interaction between provider and patient, whereby information exchange is bi-directional, with the physician provisioning information on the biological components of the disease and the clinical approaches to treatment, and the patient providing information on her personal values and life context. The shared decision-making approach is held as the gold-standard in the medical literature, and

for young breast cancer patients, it remains the preferred mode of communication and decision-making with providers (Blank et al. 2006; Bruera et al. 2002; Petrisek et al. 1997). Guided by this model, I argue that the biological, institutional and sociopersonal determinants diagrammed in Figure 1 are co-constructed between provider and patient, with particular attention conferred to the political-economic and institutional constraints that affect shared decision-making and posit young women as engaged biocultural beings in treatment decision-making.

Theme I: Biology of the Cancer Diagnosis

While decision-making is certainly more accurately characterized as circular and ever-changing, rather than linear and static, and while individual treatment courses vary widely, the first theme that emerged from analysis is a consistent starting point in the decision-making process that every cancer patient must face. The first theme, the biology of the cancer diagnosis, involves three related sub-themes: a) Staging of the tumor; b) Hormonal status of the tumor; and c) Prognosis as a critical determinant. The biological underpinnings of the disease directly impact the clinical course of treatment recommended, the ability for flexibility and alternatives in treatment options, and the urgency (both real and perceived) with which decisions must be made.

Staging of the tumor

Participants spoke of staging as an initial guide for making treatment decisions. The medical literature cites staging as one of the most important factors for clinicians in selecting and recommending treatment routes (ACS-NCCN 2007). Staging is done using the TNM system and three main biological markers: tumor size (T), lymph node

involvement (N), and whether the cancer has metastasized (M). Figure 2 provides an overview of staging guidelines, as assessed by the American Joint Committee on Cancer. These biological factors are central determinants in decision-making for many patients, as witnessed in their narratives.

<i>Breast Cancer Staging</i>			
Stage	Tumor Size	Lymph Node Involvement (Clinical)	Metastasis
I	Less than 2 cm	No	No
II	Between 2-5 cm	Under arm/same side/not connected	No
III	More than 5 cm	Under arm/same side/connected	No
IV	Not applicable	Not applicable	Yes

Figure 2. Breast Cancer Staging

Participants spoke of the lymph node involvement and how it impacted radiation choices and guidelines. The National Comprehensive Cancer Network (NCCN) (2007) guidelines state that when mastectomy is undergone, complete radiation is recommended when four or more lymph nodes are involved; when three or less lymph nodes are involved, radiation should be considered. Being avid information gatherers, many participants were aware of these guidelines and privileged this clinical information in making treatment decisions. “I wasn’t a borderline case [for radiation]. If you have anything more than four lymph nodes, I think you have to. Given I had so many, [nine positive lymph nodes], I wasn’t a questionable case for radiation and I had maximum areas done” (Julie, 35 years, Stage 3) The NCCN guidelines, however, also created what participants described as a “gray zone” for radiation decisions. Participants argued that the guidelines were based on studies conducted with older breast cancer patients, and not with young patients where the biology differs.

Then the radiation issue came up, and again it was a big question mark area because the standard was more than four lymph nodes, then yes you need radiation independent of a mastectomy; less than four nodes you do not. But this is if you're an older woman, but if you're a younger woman, we don't know (Haley, 28 years, Stage 2).

Further confounding the “gray zone” radiation issue is the fact that often women have to make treatment decisions without fully knowing the extent of the diagnosis. Lymph node involvement is assessed in two forms, clinical and pathological. Clinical is done before any surgery, through physical examination and tests. Pathological is done after the surgery and dissection of lymph nodes with microscopic examination (ACS-NCCN 2007). Pathological staging remains the most accurate method because it is the only way to understand the full extent of lymph node involvement. Participants were thus forced to make decisions about surgery options and systemic therapy without a full pathological work-up. “The lymph node status plays such a big part into what your prognosis is for staging and recurrence. I didn't have my pathological results initially, but you do have to decide” (Julie, 35 years, Stage 3).

Lymph node involvement was particularly stressed in the decision-making context because of the direct influence on breast reconstruction options. Radiation often leaves hard scar tissue at the surgery site that can impede successful reconstruction later (Black and Smith 2005, 2006; Mastaglia and Kristjanson 2001), and if immediate reconstruction is done at the time of initial mastectomy, later radiation can damage silicon implants and the appearance of the reconstructed breast (Lee and Foster 2005, 2006). As Katie explained: “I had a deal with my plastic surgeon. If there was no lymph node involvement at the time of my mastectomy, he

would go ahead and start reconstruction, and if there was node involvement, then he would not” (29 years, Stage 2). As participants juggle this set of “unknown variables,” some choose to move forward with a reconstruction decision and take their chances on the outcome.

I had a bilateral mastectomy with implants, immediate reconstruction. I was taking my chances a little bit because I didn't really know if I was going to need radiation . . . I was just overwhelmed by the choices and I was like, well, this seems like the best decision. If I'm doing one surgery, I might as well do it all. That to me was the easiest decision and it made sense at the time. I'm happy with that decision, although the radiated side doesn't look quite the same, but all in all it works (Julie, 35 years, Stage 3).

Tumor features

A second biological determinant dominant in the decision-making process is presenting features of the tumor. As with lymph node involvement, tumor status directly influences treatment options and flexibility. Tumors are assessed for two main features: hormonal status and HER2 status. There are two hormones, estrogen and progesterone, in women that stimulate breast cell growth and are implicated in many breast cancers when the tumor has estrogen receptor- (ER) or progesterone receptor- (PR) positive sites (Carrizosa and Carey 2005, 2006). Cancer cells with these receptor-positive sites are said to be hormone receptor-positive (ER-positive, PR-positive, or both). Estrogen and progesterone hormones circulate through the blood and bind to receptor sites, fueling the growth of the hormone receptor-positive tumor. Additionally, tumors are assessed for HER2-positive status. HER2 is a growth-promoting protein that is overly expressed in 15-20% of tumors and causes excess breast cancer cell growth and rapid spread of the malignant cells (ACS-NCCN 2007; Black and Smith 2005, 2006).

Hormone-receptor positive tumors directly dictate treatment

recommendations and the ability for reproductive health options, including fertility-preservation. Katja explains:

My tumor was estrogen-receptor positive, so I just saw estrogen as being as much my energy as my enemy. I wanted to get rid of the estrogen, so I decided to do a double mastectomy, oophorectomy, and hysterectomy all at once . . . It was just another treatment essential: you stop the estrogen and decrease the risks of recurring cancer” (34 years, Stage 3).

Mary described a similar decision-making process: “I wanted the cancerous tumor out, badly, and I was ER-positive, so I didn’t see endangering my health further by delaying surgery or adding more hormones to the mix” (39 years, Stage 2).

Although hormonal status can act as the foundation for treatment recommendations and decisions, other participants spoke of how the biological risk of circulating hormones in the blood was outweighed by the reproductive risks and options taken away by aggressive treatment decisions.

Estrogen in my body is unfortunately evil. So I am on Tamoxifen to try and suppress my period. I have a period, but it should be blocking the receptors. I chose to not have surgical removal of my reproductive organs so I can preserve a chance of having another child. I think I’ll probably stick with what I am currently doing. I don’t want to do anything more radical than I have to (Laurie, 36 years, Stage 2).

In addition to hormonal status impacting decisions, so too did HER2 status, especially for aggressive surgery decisions and recommendations, as HER2 is associated with rapid spread and high rates of recurrence. “I think being HER2 positive had a big impact on choosing to take the other breast because it [HER2 tumor] has a higher incidence of contralateral recurrence” (Katja, 34 years, Stage 3). Jocelyn remarked: “I was so high risk. I was HER2, estrogen, and progesterone positive. So

the doctors were really pushing aggressive treatment routes, including taking my ovaries and uterus out” (26 years, Stage 2). In contrast, participants who were triple negative explained that tumor hormonal features played less of a role in treatment decisions. “It [the tumor] was a triple negative, so I felt I had more options relating to fertility-preservation than some” (Beth, 29 years, Stage 2). “I was triple negative, so they [doctors] didn’t care what I did with my reproductive organs” (Holly, 37 years, Stage 1).

Prognosis as a critical determinant

Staging and tumor features combine with other biological factors of the cancer to form a patient’s prognosis, or the predicted course of the cancer and outcome, including recurrence rates. Participants often spoke of how receiving their prognosis created intense and emergent pressures to make what they felt were life or death decisions (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005; Wilkinson 2007). Women discussed in their interviews how decisions felt extremely rushed and options were pushed to the wayside when an unfavorable prognosis occurred. As Julie explained: “Sometimes you wonder like gosh, did I just do too much too fast? But then you look at it and go no, It’s a stage 3 cancer and my prognosis is not good” (35 years, Stage 3). Mary said: “I felt all this pressure from my doctors to make a decision *right this second!* I didn’t have time to look into complementary therapies or alternative routes, let alone anything for reproduction” (39 years, Stage 2).

The urgency imposed from providers and internalized by patients resulted in some participants feeling like they had no choice but to privilege the clinical

information and “kill the cancer,” directly fueling women’s aggressiveness in treatment decision-making. “I wish my prognosis would have been better because I would have felt less pressure to make such hardcore decisions” (Katja, 34 years, Stage 3). Haley described this process: “Receiving your prognosis is like receiving your death report. I look at the graph with my 5-year survival probability and see a grim reaper! I feel guilty for even thinking about eggs and sperm and future children” (28 years old, Stage 2).

Theme II: Institutional Constraints

The clinical/biological focus discussed in the first theme illustrates the hegemonic, biomedical tendency to frame all aspects of breast cancer as a disease (Press et al. 2005), ultimately translating to a “kill the disease,” rather than “treat the person” mentality (Eisenberg 1981; Kleinman 1988; Kleinman, Eisenberg, and Good 1978; Rosenberg 1986). Participants identified institutional constraints that resulted from a disease-dominated focus that limited treatment approaches and silenced the ability to explore alternative routes, including complementary and alternative medicines, or CAMsⁱⁱ.

Women also identified different and often conflicting levels of risk perception and value, especially regarding reproductive health, as an institutional barrier to treatment and shared decision-making. The second theme, institutional constraints, involved three related sub-themes: a) Breast cancer is an “old woman’s disease” -- myth; b) Provider’s “slant”; and c) Biased options. I argue that these institutionalized constraints create a discordance between clinical/authoritative knowledge (Jordan 1993) and patient lived experiences (Charmaz 2000, 2006; Lupton 2000). This

discordance generates a conceptual space where young women are able to challenge dominant medical authority and begin to situate their cancer socially and personally.

Breast cancer is an “old woman’s disease” – myth

While breast cancer remains the most common cancer in American women at 26% of all cancer diagnoses, only 5% of those cases occur in women under forty years of age (ACS 2007). With young women remaining a very small sub-population of all breast cancer patients, a social and institutional bias exists that frames breast cancer as a “disease of aging” (Kasper, Ferguson, and Love 2000; Lantz and Booth 1998).

Screening recommendations and protocols directly reflect this age bias, with all national recommendations for mammography directed at women forty years and older and clinical breast exams recommended only every three years for women under forty (ACS-NCCN 2007). The misconception that young women do not get breast cancer often means ineffective screening and inadequate response when a lump is found in a young woman’s breast (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005; Wilkinson 2007)

Participants spoke at great lengths about their treatment by the medical institution when their lump was discovered.

I had a hardened area in my left breast at least three and half years before I was properly diagnosed. They had done an ultrasound and a mammogram a couple years prior, but they did not follow through with a fine needle biopsy, which was actually what caught it years later (Laurie, 36 years, Stage 2).

“I found the lumps; there were two lumps, two areas of involvement. I found them two years prior and every doctor that checked didn’t do a damn thing . . . They said I

was too young to have cancer and more likely, it was just fibrosis breast tissue”

(Katie, 29 years, Stage 2). Haley echoed a similar story:

I was diagnosed with breast cancer in 2001 and it came as a great shock. In fact, I'd had the lump in both of my breasts for over two years and I was seen by various doctors who told me not to worry about it. . . When I finally did get the diagnosis, I was angry because I felt it could have been diagnosed earlier (28 years, Stage 2).

In addition, even when a lump is taken seriously by one provider, this does not necessarily translate to the outside care facilities the young woman is referred to for further screening.

I had just graduated from college when I found my lump, and I just thought to myself, would I even know what a lump feels like? So I went to my doctor and he checked it out and said, well you're a young woman and you have lumpy breasts. We are not worried about you, and you are way too young for breast cancer. I was 26. They said to just keep an eye on it and come back in a month . . . When I came back, the lump had doubled in size. It was gigantic and getting bigger. They were more concerned and they sent me to have a mammogram, which was definitely more of a struggle than I expected. The lady at the mammography center would not perform the mammogram, saying “You are too young!” And I said “But I have a doctor's order!” which she took from me and called to verify, acting like I was going to get in trouble like a fourteen year old the whole time (Jocelyn, 26 years, Stage 2).

Many participants encountered similar barriers to receiving proper screening and a diagnosis. “I was standing there waiting for the doctor to schedule my mammogram. She actually had this huge argument over the phone with the radiologist because they refused to do a mammogram on me, saying I was too young. It was a huge struggle” (Beth, 29 years, Stage 2). This circulating myth that breast cancer does not occur in younger women directly hampered the decision-making process, as Claire describes: “I do think there is an established bias that this is not a disease that women

under forty have, and because of that, clinicians lack experience with the decision-making process of someone under forty” (34 years, Stage 3).

Participants themselves had often internalized the myth that breast cancer was an old woman’s disease and attributed lumps to normal changes reproductive-age women experience. “I found the lump pretty much when I was pregnant, but I did not go to the doctor right away. I assumed that this was normal pregnancy changes” (Julie, 35 years, Stage 3). Similarly, Claire said:

I found a mass in my right breast and thought it might be a leftover infection [from breastfeeding], like mastitis. I had breastfed my son extensively and thought, ‘Oh yeah, my hormones are just settling down.’ Then I got this infection in my finger and I thought I needed to go to the doctor for my finger and at the same time, I would ask about my breast . . . I delayed for a little bit because as a healthy person, you don’t see the doctor as a priority and as a mom with a young child, well-baby visits come first and yourself second (34 years, Stage 3).

Research documents the power of physician recommendation and reinforcement, showing that patients often mimic the attitudes and behaviors of their care provider (George 2000; O’Malley et al. 2001; Rawl et al. 2000; Richards, Viadro, and Earp 1998; Sassi, Luft, and Guadagnoli 2006). When a care provider views breast cancer as an “old woman’s disease” and does not actively advise screening and follow-up, the patient is more likely to internalize the same attitude. In addition, extensive research documents how women, and especially mothers, carry the burden of family health, often prioritizing their family’s health over their own (Brettell and Sargent 2001; Horner and Keane 2000; Inhorn 1994, 2006).

Provider's slant

Once an accurate diagnosis was made, many participants found their providers to have a “slant” or a “prerogative” in their treatment approach and mentality.

Participants perceived that providers took a very aggressive, time-intense, and toxic approach to treatment recommendations, treating a biological entity and not a social person (Lupton 2000; Press et al. 2005). Providers were oriented toward aggressive treatment to kill the biological disease, and participants found that this medical tendency was exacerbated by their status as a young woman. As Claire said: “No provider wants to lose a patient, let alone a young patient. The litigation and social pressure is too much” (34 years, Stage 3).

Participants' narratives are critical of the institutional approach taken in cancer treatment and the often exclusively, clinically-oriented prerogative providers hold. Jocelyn spoke of the pressures she felt as a young cancer patient to make radical treatment decisions.

I chose to have a bilateral mastectomy in large part because of my age and how afraid all of my doctors were. They kept saying how aggressive the tumor was and how much they were focused on reducing any chance of recurrence and getting rid of the cancer at any cost (Jocelyn, 26 years, Stage 2).

The clinically-oriented stance of providers resulted in many neglecting reproductive health conversations and information sharing with their patients. Haley noted:

I was not told about the side effects to fertility. It was only after speaking with another girl in my support group that I knew to ask my doctor. When I mentioned the infertility issue and the importance of future childbearing for me, my oncologist responded “Oh that's right. Maybe I should have told you something about that, but I'm not really focused on that. I'm focused on aggressive treatment to help you survive cancer” (28 years, Stage 2).

The provider “slant” that participants perceived is summarized well by Beth:

This might be really odd to say, but oncologists have that focus of saving the patient. They're not thinking about anything else but saving the patient. "What can I do to save this patient? I've got to get them surgery. I've got to get them on board with chemo. I've got to get them radiation. We're going to do tumor markers. We're going to do blood testing. I'm going to save this patient." I think a lot of time fertility and reproductive medicine come at the very bottom because when they're thinking about "Oh I've got this patient. She's very young. She's got an aggressive form of cancer. Why is she worried about fertility? I've got to think about saving her life, because if I can't save her life, it doesn't matter about her fertility" (29 years, Stage 2).

The personal preferences of individual providers were also noted by participants. "I really think it [treatment recommendations] depends on the doctor's preference. Some doctors just feel one way is better and sometimes the individual patient's concerns get left out" (Julie, 35 years, Stage 3). This provider prerogative, or slant, is well-documented in the current literature on young survivors and remains one of the top areas of reform for culturally competent cancer care treatment (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005).

Biased options

The highly medicalized and disease-centric focus taken by providers directly translated into what participants identified as biased options and recommendations. Treatment recommendations were considered biased when the clinical course advised was based solely on immediate survival, and did not account for quality of life concerns central to women's decision-making processes.

I think that because their [oncologist's] primary focus is on getting us well, options about childbearing and sexual health are just left out. It would have been nice to have a doctor say 'If you are thinking of future children, these are the concerns and these are your options and here is how it is going to affect treatment.' But no one did and I did not find out until after my treatment was done that chemo could reduce your fertility, drastically – 90% of people don't get it back (Margaret, 33 years, Stage 2).

Katja explained how since reproductive side-effects were omitted from treatment counseling, she felt the treatment recommendations she received were incomplete and biased toward the prerogative of the oncologist, rather than the values of the patient: “No one ever said the chemo might damage my fertility. . . I think they don’t even want to open that door because you’ll have to delay treatment [to undergo fertility preservation] and that goes against their focus of saving your life” (34 years, Stage 3). Mary echoed this institutional constraint, saying: “Everyone is mainly focused on chemo side effects like hair loss and nausea. Nowhere in any of my Cancer 101 information packets did I even see a mention of fertility” (39 years, Stage 2).

The concerns of young patients went beyond fertility, and included sexuality issues that were central to their experience of cancer, treatment decision-making, and long term quality of life (Baucom et al. 2005, 2006; Bloom et al. 2004), yet were rarely addressed by providers. “I wish someone would have told me about the libido effects. No one said that you get totally dry! Most people are like ‘Why are you thinking about sex when you’re having chemo,’ but it is a reality, especially when you’re young” (Claire, 34 years, Stage 3). “It goes beyond fertility, but no one mentioned the sexual dysfunction issues, and this is important to young women” (Mary, 39 years, Stage 2).

The way treatment affected breastfeeding ability and future pregnancy were also important issues for many participants. However, this information was again lacking or absent in discussions on clinical treatment courses recommended by providers. Laurie discussed in her interview her frustration and disappointment with

not being able to breastfeed and the absence of any warning from her surgeon regarding this possibility. Other participants also felt great frustration over the unclear and inconsistent answers they received concerning the safety and viability of future pregnancies (Calhoun and Hansen 2005, 2006). “I heard two years, five years, three years, and never for the recommended time after treatment before I could try to get pregnant. This makes no sense and does not facilitate my decision-making process” (Beth, 29 years, Stage 2). By not fully and clearly disclosing the side- and late-effects of advised treatments, women felt the clinical courses recommended were biased or incomplete, and negated full disclosure and all-options counseling.

Biased options and a focus on the standard approach to cancer treatment may largely result from a “passing the buck” trend (Thewes et al. 2003) participants observed and the fact that breast cancer remains the only female cancer where multiple providers are in charge of your treatmentⁱⁱⁱ. “No one is really in charge of you, so everyone is assuming the other person is taking care of it [quality of life and fertility concerns]” (Katja, 34 years, Stage 3). This trend and the lack of attention to young survivor concerns are inextricably linked to the myth that breast cancer is an “old woman’s disease.” As Claire describes: “I do think there is an established bias that this is not a disease that women under forty have, and because of that, the clinicians lack experience with the decision-making process of someone under forty” (34 years, Stage 3). This myth leads to a lack of information for young survivors, which in turn acts as a barrier to a shared decision-making model (Charles et al. 1997, 1999, 2003).

Sexuality and the Body

The institutional barriers participants experienced created a cognitive dissonance in which their treatment courses were not reflecting their personal values and social body (Charmaz 2000, 2006; Lupton 2000). Participants became avid information gatherers, trying to fill the gap created by this disconnect. Their extensive information-seeking activities fit well with other research on young breast cancer survivors, where individual research and networking are documented as dominant features of young cancer patients, as compared to their post-menopausal counterparts (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005).

As women began to speak with other young survivors, engage multiple medical opinions, and employ multimedia educational materials, they came to situate the cancer diagnosis socially. The third theme, sexuality and the body, documents the unique concerns of young survivors that influence treatment decision-making and highlights the importance of quality of life values they negotiate when faced with a life-threatening disease at a young age. This final theme involves three related sub-themes: a) Social and romantic relationships; b) Parenting/Childbearing; and c) Body image: internal/external. The process of situating the cancer diagnosis socially provides an avenue for young survivors to engage in a form of personal agency (Ahearn 2001; Mankekar 1999) in light of an increasingly medicalized body and political-economic constraints.

Social and romantic relationships

It is well-documented that cancer is a social experience, where a patient's community and network have substantial bearing on the decisions she makes and on her level of satisfaction with the cancer treatment (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Roberts and Oktay 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005; Wilkinson 2007). The relationships that were significant to participants depended on their partner status, their familial context, and the general social milieu that they interacted within on a daily basis.

Partner status at the time of diagnosis can be broadly categorized into two predominant positions: married/committed relationship or dating/single. For all participants, romantic partnerships most clearly influenced their treatment decisions in relationship to the sub-themes of parenting/childbearing and body image. The highly intertwined connections between these sub-themes are explored in more detail later. However, at the most basic level, romantic partnerships largely determine the amount of support, options and "unknowns" that a woman possesses during treatment decision-making. As Julie said: "I've had a husband that's just stepped up to the plate and been so incredibly supportive . . . He would always say 'It's your decision, please don't make any decisions because of me, just for you'" (35 years, Stage 3). In contrast, women without partners commented on the lack of daily support and stability being single meant for their treatment experience.

Just not having anyone to go through those decisions with you. When you're making these decisions, the reality is you are not just making them for yourself in an isolated bubble. Your decisions now affect the rest of your life and your prospects for future relationships (Jocelyn, 26 years, Stage 2).

A clear theme in women's narratives was that romantic relations are fragile and that the life-changing experience cancer constitutes can solidify or break the foundation (Schover 1999; Schover et al. 1999; Zebrack et al. 2004). Katie illustrates this theme in discussing the partnership break-up she experienced following treatment completion:

We'd been together five months when I was diagnosed and we stayed together for a time. After treatment was complete, it pretty much went downhill from there. I think it was just too much. He was a very good caregiver during that time, but I think we established some very strange patterns of interaction that were hard to get out of once I was feeling better (29 years, Stage 2).

Katie's quote speaks to another central topic present in women's narratives about social relationships and interactions during the cancer experience. Participants discussed their feelings about being perceived by others as primarily a patient, or as playing the "sick role" (Parsons 1951).

This social perception conflicted with women's individual perception (or desired perception) of themselves as whole persons (Lupton 2000). Claire summarizes this distinction, saying: "Most people see me as a sick *dying* cancer patient first, with children and a husband second. I see myself as a mother and wife first, and *living* with cancer second" (34 years, Stage 3). This pressure to act like a dying patient first stemmed in part from the endless, fear-based comments received from family and social acquaintances.

Whenever I expressed concerns for quality of life and mentioned the possibility of taking a less aggressive treatment route, friends and family would dismissively say "Let's not worry about it right now. Let's just take care of getting you well. Why are you worried about children or sex? You could die and that is the immediate concern" (Margaret, 33 years, Stage 2).

Jocelyn echoed a similar experience:

I feel like a lot of my friends and family's big focus was on "We have to do whatever it takes to keep you alive," and when I told them my decision to keep my ovaries despite my hormone-receptor positive status, I got a lot of reactions like "What the heck are you doing? I wouldn't make the same decision. I don't support this choice. Why would you put yourself at that risk?" I felt like a lot of my family just didn't get it (26 years, Stage 2).

This discord between social pressures and individual concerns led many participants to try and assert their agency (Ahearn 2001; Mankekar 1999) through strategies where their entire person would be recognized, and not just their disease.

I just didn't want to be seen as sick. I always wore make-up when I went out. I did hats sometimes and some wigs, and I would never leave the house without them because having someone look at you with that 'Oh, poor you, you're sick' look on their face is horrible. So I made a real effort to camouflage myself (Holly, 37 years, Stage 1).

Claire employed the following strategy for personal agency:

My sister, [who was diagnosed with breast cancer around the same time], and I talk about playing the breast cancer card...I don't think it hurts to have big brown eyes and long brown hair and to be the cute little mom with a young child. I always pull out my baby pictures as much as I can because I want everyone to see me as a person and to treat me as a *total person*. And this is even more true when it comes to my oncologist. I tried to be the patient he thought about at night when he put his own children to bed. So you use whatever resources you have, for good or for ill (Claire, 34 years, Stage 3).

Parenting/Childbearing

The romantic and social relationships a woman navigates during the cancer experience tie directly into attitudes and concerns surrounding parenting and childbearing—a dominant sub-theme unique to the young survivor community (Dow and Kuhn 2004; Duffy, Allen, and Clark 2005; Grady 2006; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005;). Well-documented in feminist and anthropological literature are the prevalent pressures of motherhood faced by women

in our society (Brettell and Sargent 2001; Horner and Keane 2000; Inhorn 1994, 2006; Lock and Kaufert 1998; Wilkinson 2007). Women are often posited as self-sacrificing reproducers, a position in which the health of the family and by extension, society, is placed squarely on their shoulders. This attitude is ubiquitous in speaking with participants who have young children at the time of diagnosis.

Children often become a central breaking point for how decisions are made and how the cancer experience is internalized. “I felt like I had to do everything I could, meaning aggressive treatment decisions. I have little kids, how can I not?” (Katja, 34 years, Stage 3). Claire echoed similar concerns: “Already having kids who needed me to be around, that had a lot to do with it. Wanting just to do everything I could even if it meant bad quality of life for me” (34 years, Stage 3). Julie discussed how her existing child affected surgery decisions:

Having children definitely played into my decision making around implants and hysterectomy. I think I chose the implants partially because some of the options [for breast reconstruction] would have involved muscle work, which with a young baby you need your muscles! I also chose the hysterectomy because we already had one child in need of rearing and I wanted to do everything I could to stay alive for him (Julie, 35 years, Stage 3).

This pressure to be the self-sacrificing mother image was even further complicated for Laurie, who was pregnant at the time of diagnosis. “The emphasis was definitely placed on my well-being, but balanced with a concern for my unborn child, as I’m the vessel that the baby is in” (36 years, Stage 2). The pressure was often internalized by participants and overtly expressed by persons in their social milieu. As Holly described: “Ultimately I decided to do the treatment because of fear. It was all

fear. Everybody just kept telling me I was going to die, and I had these two little children and it was all about guilt and fear” (37 years, Stage 1).

Aggressive treatment decisions largely resulted from the pressures participants with young children faced. An additional layer of stress developed in women trying to mitigate and control how their children as individuals were affected by their mother’s cancer experience (Roberts and Oktay 2005).

When a sixty-five year old grandma is diagnosed, it certainly affects her family, but it doesn’t create a new lexicon for the family in the same way. My kids won’t ever know what its like to be in a family where breast cancer isn’t an issue, especially the little one. That’s big (Holly, 37 years, Stage 1).

Katja, who underwent a bilateral mastectomy without reconstruction, explained:

For my kids, it’s so hard when they hit my ribs. They don’t snuggle with me the same way because they bunk their little heads, saying “Why are you so hard mommy? Why aren’t you soft mommy anymore?” They notice, and it’s hard because I have two girls and they are always saying “When I grow up am I going to look like that?” (34 years, Stage 3).

In situations where existing children are a key determinant in the decision-making process, the social and internalized pressure is placed on motherhood and the child’s life first. In contrast, women without children at the time of diagnosis (or those who desired additional children), experience an inverse focus where future childbearing values are dismissed and pressure is placed on saving their own life, no matter the cost. In discussing how her values differed from her oncologist’s recommendations, one young, single participant said:

They were talking about putting me on arimidex, which would mean I would have to have the oophorectomy for it to be effective. That was when I was really really thinking ‘Do I want to have children?’ And I just thought at this time I don’t want to make that decisions, so that’s why I decided not do that, not to go that route. But I got a lot of grief over that decision (Jocelyn, 26 years, Stage 2).

Other participants who had children, but highly valued future children, felt a similar devaluation of their concerns over future childbearing.

[Around the time of the diagnosis], having a 3rd child was the next thing on the fall agenda. We were definitely gearing up for it. Everything was moving in that direction. Then [with the diagnosis] it was definitely like accepting that I wasn't going to have another baby. It was just a lot of crying for myself in the night, because people don't want to hear that. 'You should be worried about your life, not worried about a non-existent baby. That's over for you.' No one was interested in hearing that sadness" (Katja, 34 years, Stage 3).

Feminist authors Rothman (1986) and Layne (1997, 2003) have extensively documented the silent struggle of pregnancy loss and infertility in America, and the profound lack of social support and understanding women experience in their mourning process. Childbearing remained highly valued by many participants, and in spite of inadequate social support, some women chose to undergo fertility preservation. Beth chose embryo cryopreservation. This resulted in a delay in cancer treatment and many painful side-effects. She explained how she came to this decision:

I told the reproductive clinic that even given how bad it was and how much it hurt and how much pain there was, I would do it [embryo cryopreservation] all over again; 10 times over because that was the only way I was going to be able to have a child. A full life for me is a full life with children. If I can't adopt because I'm going to be single because nobody wants me because I have cancer then well, I wanted that opportunity" (29 years, Stage 2).

This quote also speaks to a key theme narrated by many young women without children -- that they often made decisions based on a desire for the future chance (opportunity) of a quality of life that reflected their values (Baucom et al. 2005, 2006; Bloom et al. 2004). "I was triple negative, so she [my oncologist] had me stay on the pill just to keep things working and give me that chance [for future children]" (Katie, 29 years, Stage 2). Mary explained:

Previous to the cancer, I was resigned to not having kids, and I thought at peace with it. But then, confronted with my own mortality, that changed, and I decided I did want a chance. My oncologist and I talked and decided that there was a chance to prop the fertility door open with Zoladex^{iv} and so that's what we did (39 years, Stage 2).

Haley was interested in fertility preservation for the increased options it provided:

You have to understand how your treatment and your decisions now will affect you five, ten, fifteen years down the road. . . For me, I had just turned twenty-eight when I was diagnosed, and I wasn't even going to think about children until I was at least thirty. So to even think about fertility was kind of a stretch, but I decided I wanted to be alive, *and* I want to have a family. The doctors were like "What?! I thought just being alive was good enough!" (28 years, Stage 2).

In trying to socially situate their treatment options and recommendations and to balance quality of life concerns with immediate mortality threats, many young women described how the ultimate decision of whether or not to pursue childbearing options and to delay treatment was based on the "unknown set of variables" and "the big question mark" they juggled. Because these unique concerns of young survivors have traditionally not been incorporated into cancer care counseling and clinical research, the information regarding future pregnancies for young cancer survivors is limited and vague (Calhoun and Hansen 2005, 2006; Surbone and Petrek 1997). Julie explained:

You definitely play with a set of variables you don't know everything about. I felt like there wasn't much data for me on whether pregnancy after cancer was safe. So we [husband and her] just made the decision to be thankful for the beautiful child we had and move on (35 years, Stage 3).

Haley echoed this uncertainty with which decisions must be made: "There is such a big question mark around pregnancy and without the information, I just wasn't comfortable with the risks, so out went the ovaries" (28 years, Stage 2).

Without concise information and a lack of attention to these issues, many participants who were sitting on the fence about future childbearing discussed how the diagnosis made the decision for them. “[Before the diagnosis] we didn’t know if we would have more children. We didn’t think we would want more and this kind of sealed the deal” (Claire, 34 years, Stage 3). “Well, my husband was about 80% sure he was happy with just the one, where I was 80% sure maybe I’d like another child, and when this happened, we both just decided 100% one’s enough” (Margaret, 33 years, Stage 2).

Body image: internal/external

One of the most salient issues connected to the above two sub-themes involves the perception, both public and personal, of women’s body image and their sexuality (Lee 1997; Wilkinson 2007). The complexities and nuances of this sub-theme are revealed in women’s narratives about the way they experience changes in their external body image (breasts and hair loss) and internal body image (the uterus and ovaries), combined with issues of sexuality attached to these biologically and socially constructed body parts.

Body image and sexual health are present in quality of life concerns for all breast cancer patients regardless of age (Figueiredo et al. 2004; Kraus 1999). However, research documents how the weight and burden of these issues is heightened in the young survivor community, and how concerns over sexual health are more likely to impact the treatment decisions of younger women, as compared to post-menopausal breast cancer patients (Avis, Crawford and Manuel 2004; Baucom et al. 2005, 2006; Crandall et al. 2004; Ganz et al. 1998). The increased importance placed

on sexuality and the body for young survivors is arguably a direct result of the interplay between dominant surgical treatment recommendations – that dictate removal of reproductive organs – and the fact that this loss comes at a time in a woman’s life cycle when pressures to attract a life partner and reproduce are centrally valued in personal, interpersonal and social definitions of the woman (Baucom et al. 2005, 2006; Duffy, Allen, and Clark 2005; Klauber-DeMore 2005, 2006; Wilkinson 2007).

One of the most daunting and complex issues tied to a breast cancer diagnosis is the likely loss of the socially and personally valued physical marker of breasts. How participants perceived and coped with their breasts varied based on their current life identities. Katja, who already had children at the time of diagnosis, said about losing her breasts: “That’s [breasts] like a source of confidence, you know. I’m lucky because I got to use them for what they are for [breastfeeding], and that’s always been really important to me, so I think I have less angst about it [mastectomy] than some people” (34 years, Stage 3). Laurie discussed how her inability to breastfeed made her feel like less of a “good” mother:

I wanted to breastfeed so bad, but even though I only had a unilateral mastectomy, the surgery destroyed my ability to breastfeed on my one good breast. I tried very, very hard for two weeks to pump. I tried all the drugs and all the herbs and everything, but I would only get a couple of drops, which I would put in my hand and stick in her [the newborn’s] mouth . . . I went through this mourning process of it’s not going to happen. I just wanted to give her [my daughter] the health benefits, the immunity, the nutrition, ‘breast is best,’ and I couldn’t. And the worst part about it? No one ever warned me that I might not be able to breastfeed. And on top of that, when I couldn’t produce any milk, people started saying it was my fault, that I was not pumping enough (Laurie, 36 years, Stage 2).

Salient *en vivo* codes emerging from women's narratives regarding their breasts and decision-making surrounding a mastectomy included "chopping," "mangled" and "butchered" breasts. Images constructed by women about their mastectomy choices often involved violent and negative associations.

I really, really wanted to keep my breasts. Just not wanting to have your whole body mangled. I have scars. I went from never having had surgery to chopped up and it was just awful. I mean lumpectomy, fine, I can handle it, but taking it [the breast] off is so tragic and then just also to be kind of disgusted at yourself" (Laurie, 36 years, Stage 2).

Regarding her choice to have a bilateral mastectomy without reconstruction, Katja remarked: "No one ever said 'butchery,' but there was some sense that I was destroying my body [by choosing a bilateral mastectomy without reconstruction]. I went from being an attractive young person to scarred up beyond recognition" (34 years, Stage 3).

These images and discourses continued throughout women's narratives. "Your body becomes so butchered. I remember the surgeon saying at one point 'I'm going to put you back together as close as possible and try to keep your life as intact as possible'" (Jocelyn, 26 years, Stage 2). Discussing her decision to have a bilateral mastectomy without reconstruction, Claire said:

It's a lot of surgery to have both a mastectomy and reconstruction. I'm a physically active person and I want to be able to do yoga and not have it hurt. People feel like its not them fighting cancer, but their body is kind of a battle field for the doctors. So I'm in this place where I have to say 'To what degree can I reclaim my body? What control can I exercise? What do I want to give it [my body] a break about?' So I chose not to have the reconstruction. I always say to my mom, if I could have the abracadabra surgery where they could wave a wand and poof! I have breasts back, I would, but that's not reality (34 years, Stage 3).

Women's attitudes about their breasts were also defined in relation to their current romantic relationships. For married women and those in committed relationships, many expressed angst and concern over how their current partner would perceive them, and tried to take into account their partner's preference.

I'm kind of ambivalent about it [reconstruction after bilateral mastectomy], but my husband kind of misses that part of our life. I think if he didn't care, I probably wouldn't get reconstruction, but I felt like I owed it to him to explore it. My options aren't great though, so at this point I've chosen not to go that route (Claire, 34 years, Stage 3).

In discussing her choice to have a lumpectomy versus a mastectomy, Margaret, a married participant, said:

For me, the breast is a source of pleasure and a big part of my relationship with my husband. So that was one of the factors about going with the lumpectomy vs. the mastectomy. My tumor was about 2cm, so I was right on the line to go either way. They quoted me statistics and said it was better to do the mastectomy, but only by about 3%. If you're looking at 2% vs. 5%, I'm going to go with the 5% and keep a little quality of life for me and my husband (33 years, Stage 2).

For other married participants, the choice to have a mastectomy (with or without reconstruction) felt easier because of the security their current partnership provided. Regarding her decision to have a bilateral mastectomy without reconstruction, Katja explained:

Being married helped. I'm not on the market, if I was on the market, oh my god! I would be so depressed. I think that would be the real push to make sure I got breasts back because that's a total confidence booster. I think I have less angst about it than some people because I'm married . . . And my husband kept saying 'It's your decision, it's your decision'. If I had to guess, he would never tell me, but if I had to guess, I got the feeling he wanted me to do it [bilateral mastectomy over unilateral mastectomy], just take them both off because it was scary. They [breasts] betrayed us. And I don't think he could ever see it as a sexual object again. He would be feeling me up and be feeling for lumps! (34 years, Stage 3).

For single women, decision-making regarding breast surgery(ies) was often focused on how it would affect their ability to date and attract a partner at the most basic level. Katie described her experience with entering the dating world after breast cancer.

How do you tell someone they [breasts] aren't real? Do you just wait until the moment of truth, naked in front of a kind of stranger, and when he notices one is big and one is small and kind of lopsided with no nipple do you say, oh by the way? I mean, how do I approach my own sexuality with someone, and when do I tell this person, and how are they going to react? It's certainly not something you want to say right before sex! (29 years, Stage 2).

In discussing her decision to have reconstruction, another young, single participant described how her decision was tied not only to future dating, but also to the recurring theme in narratives of wanting to “return normalcy” to one’s life after cancer (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005). “I felt like I deserved a chance to look normal. I felt like a freak of nature after the mastectomy, and I just didn’t want to feel like that when I had to enter a new relationship later on” (Jocelyn, 26 years, Stage 2). Beth explained how her concerns with dating directly influenced her treatment decisions – decisions that went against the medical advice of her providers:

My oncologist and surgeon advised me along the lines of having a double mastectomy as my best option. But I was 29, and had these big boobs with no kids and no breastfeeding and no partner. I just couldn’t grasp that I was going to chop off my boobs, I just couldn’t. So I went and received a second opinion, and she thought I would have a similar chance in survival if I did the lumpectomy or the mastectomy. I know there is a higher chance of recurrence when you haven’t taken the sick breast off, but that was a risk I was willing to take, and I still have my breasts, and I wouldn’t go back and change it because I’ve maintained a little quality of life with that decision (29 years, Stage 2).

A final factor involved in the decisions surrounding breast surgery and reconstruction was the social pressures, support, or lack of support women felt as they discussed this issue with their friends, family and care providers. Participants discussed how out of all the treatment decisions they had to make, people in their social and familial milieu seemed most opinionated about the decisions regarding their breasts.

I was really ambivalent about reconstruction, but everyone around me was really pressuring me to do it. I think they thought somehow my vitality would be restored if my breasts were back, but it was really frustrating, because they wouldn't be *my breasts* even if I did get reconstruction. A lot of pressure came from acquaintances who were, oddly enough, comfortable talking about my breasts. . . And my doctors were pressuring me to do reconstruction too. I think they came from a place where they wanted to restore me fully, but what I wanted to say was 'I won't feel them after their reconstructed, they won't look the same.' I think doctors feel that they are taking so much away from you with treatment that they just want to give something back, and many see it [reconstruction] as a way of healing. I think it was tied to people's perception that you're too young and they wanted to restore my youth to me. They felt bad that I had to go through this old person's disease at a young age (Claire, 34 years, Stage 3).

Other women felt support from their friends and family regarding their decisions, but often this support did not align with the personal loss a woman felt for the decision she made. Katja, who had a bilateral mastectomy and no reconstruction, said:

Now things are going back to normal, and we're being invited to functions where you have to dress up, and I kind of wish I had reconstruction now. It's mostly about looking good in clothes. Mastectomy bras come up so high that I can never wear anything nice. I just want the freedom to put anything on. Getting dressed when I'm not in my mom t-shirt and jeans uniform takes hours because nothing looks right, and the mastectomy bras have thick straps. When I wear a prosthetic, my friends think I'm crazy. They are like 'You look so good without it!' They question why I am wearing it, but no one can understand what its like to walk around without breasts. And they were never huge and no one ever looked at my chest because I was a mom so no one really notices

anything's different, but *I* notice! There's just no support for that (34 years, Stage 2).

Another young participant shared:

It was interesting meeting friends or family or other survivors who would say [regarding my decision to have reconstruction], "Oh well good because you're a young woman and breasts are important in our society" . . . But while I had support for the decision, it was also kind of lopsided support. I think that how you deal with your body is so taboo. A lot of my girlfriends who had not been exposed to breast cancer in this way, well, after my surgery they didn't really want to talk about it. They were like "It's fine you are going to get fake boobs, but don't talk to us about the mastectomy." It's like trying to talk about a penis with women my age! But I wish the discussion about mastectomy would have been a little more open. I remember I freaked out a week before my surgery because it was the first time I saw a mastectomy. I wish it was a little more out there. I imagined what it looked like, but it was completely different! Then I thought it was weird because when I had my surgery, the first time they were going to take the bandage off the nurse at the hospital was like "You might want to talk to a counselor because your body is going to look different." I was like "This is the only pep talk I am going to get here!" I didn't even want to know how I looked" (Jocelyn, 26 years, Stage 2).

The feminist literature on woman and breasts in American society speaks to the above experiences regarding the socially defined female breast (Lee 1997; Wilkinson 2007). The support women experience overall comes in the form of people wanting to see the young survivor have that aspect of her femininity and youth restored, while disengaging from the realities – multiple invasive surgeries, pain, long recovery times, surgical risks, side- and late-effects, psychosocial distress – surrounding mastectomy and reconstruction.

In contrast to the social involvement garnered with the loss of a breast(s), women described the often silent struggle they experienced as they faced menopausal changes and decisions about reproductive organ loss (oophorectomy and hysterectomy). Menopause remains one of the defining markers in women's narratives

for how their lives changed with cancer, how they experienced cancer and quality of life differently as a young woman, and how early menopause was connected to their sexual health and internal body image.

Making decisions about an oophorectomy or hysterectomy was strongly connected to the hormonal status of the tumor and the woman's general prognosis. Women with hormone receptor-positive tumors are essentially faced with a decision where they must weigh statistical risks and benefits against personal/social risks. Katja explained:

I wasn't doing anything systemic for the hormonal side of my cancer. So I did Tamoxifen [ovarian suppressor] for a couple months and then in July, to get the good drugs, you have to be in full blown menopause. So goodbye ovaries, and I did the uterus too because the doctors were like unless you're going to have a surrogate baby, there's no reason to keep it. Goodbye motherhood, goodbye sexiness (34 years, Stage 2).

Other participants postponed surgical decisions and accepted the statistical risks:

I postponed my hysterectomy for a year, because it was just too much to handle all at once. Like my husband said, my options were between poop, shit or crap! It was just overwhelming, so we decided to delay that decision. Now my year is up and I am facing that decision again. Having a hysterectomy reduces the risk of ovarian cancer too [in addition to breast cancer recurrence], so it's kind of a two for one deal. It's horrible to think about bartering your body parts, but its reality (Margaret, 33 years, Stage 2).

Laurie employed a similar decision-making approach:

I decided to wait and not make the decision about a hysterectomy right away during treatment. And I know I increased my risks, but I am very grateful for that decision because now I feel like at least I have a chance [to have children]. Plus one of my big things is I didn't want to go into premature menopause permanently" (36 years, Stage 2).

These quotes illustrate how women make decisions not simply on statistical probability of risk assessment, but also based on their current and future psychosocial life values (Hunt, Castaneda, and De Voogd 2006; Lysterly et al. 2007).

A dominant personal/social life value expressed in women's narratives, and often privileged in decision-making, involved the (re)definition of womanhood, femininity and the self experienced as both their external and internal body image changed. Women described how the medical approach to disease, rather than personhood, meant a fragmentation of the body and a loss of self-worth; in essence, women began to feel "gender-neutered."

Estrogen remains more than just a pure biological factor, and is intimately connected to women's experience of sexuality. Estrogen was described by participants as a source of vitality and essential to feelings of "womanliness" (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005; Wilkinson 2007).

[Following chemotherapy and during radiation], my ovaries were starting to come back to life and I could feel surges of estrogen. I was like, "I feel great!" And then I was like, "Oh wait, I'm not suppose to feel good. I'm not supposed to feel any libido at all" (Katja, 34 years, Stage 3).

The cessation of hormones for women thrown into temporary or permanent early menopause due to treatment was often described by participants as a loss of "womanly energy."

Menopause was further confounded by the sexual dysfunction menopause causes, which is experienced as uniquely more profound for young survivors (Avis, Crawford and Manuel 2004; Baucom et al. 2005, 2006; Crandall et al. 2004; Ganz et

al. 1998). Women were also often not informed of these sexual side effects, and when informed, they were commonly not provided resources to manage them. Claire explained:

Menopause is such a dirty little secret! I had nooo idea I was going to experience sexual issues after chemo! When I was ready to have sex again, it hurt. That's a big part of our relationship. It kind of felt like our sex life was already under attack since we had a toddler, and we were just getting back into the swing of things and then wham! Cancer happens (34 years, Stage 3).

Katja discussed how she too wished her care providers had more actively addressed the sexual side-effects of adjuvant therapy.

I wish there was more encouragement to the husband when we're sitting there together in the doctor's office. It's like use it or lose it. I think for some men, for my husband certainly, they see you as fragile. 'Just rest' they think. I always have to initiate it. So it would be great if someone told the husband that if the woman is willing, you can help, that's actually a good thing and you aren't going to break her (34 years, Stage 3).

Single participants like Jocelyn face an additional layer of struggle in coping with sexual dysfunction as they re-enter the dating world after cancer.

I definitely experienced sexual dysfunction after chemo. My body went into early menopause and I have a lower sex drive now. I'm in a relationship again and we can talk about it, but it's hard to explain how it's different. It takes longer to get in the mood and It feels different, and I didn't know to expect any of this (26 years, Stage 2).

The silent struggle of loss continued in women's stories, such as Mary's:

I wish someone had said orgasm has nothing to do with menopause. I was crying all to myself because I thought I was never going to have a orgasm again. Then when I started talking to other survivors, I realized it had nothing to do with a post-menopausal vagina. So someone should really address that in chemo 101! (39 years, Stage 2).

Early menopause remained one of the most discussed markers of how cancer changed women's sexuality and internal body image, and concurrently stood as one of the least discussed and taboo topics in treatment counseling.

Finally, women made clear in their narratives that loss of femininity and changing self-definitions of womanliness were a co-constructed result of *both* internal and external body image and sexuality transformations. Feelings of "womanliness" and worth are closely tied to the image of physical beauty so emphasized in our culture (Lee 1997). As Margaret commented:

During the treatment, I was like "I have to wear make-up everyday," because you just feel ugly. You lose your hair and you're going through everything. Everything about your sexual body parts is medical instead of sexual, trying to just keep some integrity about your beauty and I think its something" (33 years, Stage 2).

Feelings about loss of femininity and body image were prevalent regardless of partner status and current children. For married women and those in committed relationships, however, the focus was often more directed toward the surgical decisions surrounding breasts and the sexual dysfunction issues that result from treatment.

Single women, in contrast, often described facing an additional barrier having to do with hair loss and feeling attractive.

Not having hair and not looking like a girl and not feeling like a girl and not feeling cute, thinking 'I'm never going to get a guy now!' I definitely thought about that and thought about my own reasons for wanting to maintain my womanliness. And it's weird how you get so caught up in it all. When I knew I was going to start losing my hair because of the chemo, I was preparing myself saying 'It's okay, it's just hair. It will grow back.' But when I actually lost it, I was bawling and it's just so strange how you do react that way" (Jocelyn, 26 years, Stage 2).

Katie spoke of how her perception of body image and sense of worth changed through the cancer experience.

I think it was really interesting for me because I never had body image issues before. I was pretty much fine and then all of a sudden I was having tons of issues. I think the main thing for me was the hair loss. It was definitely the least favorite part of the whole process, even though that sounds kind of shallow” (Katie, 29 years, Stage 2).

As Beth summarized: “I felt like nobody was going to want me because I had cancer, and you’re bald and you’re sick, and you’re wasting away” (29 years, Stage 2).

Sexuality and the body remains a final conceptual space women negotiate as they move through decision-making processes. Women engage these dynamic processes as biocultural beings, negotiating life-saving treatment recommendations with quality of life concerns and reproductive health values. Their identity as young women, with social and personal pressures to be valuable producers and reproducers, coupled with the diagnosis of a highly gendered, disease of aging, creates a unique position for young survivors; treatment decisions become negotiated terrain between biological determinants, institutional constraints, and social/personal values. Claire summarizes the foundational dilemma facing the young survivor community: “In making treatment decisions, a young survivor balances the need to treat a typically more aggressive or advanced cancer with the potential for a long life ahead” (34 years, Stage 3).

ⁱ There is much debate and inconsistency in the medical literature on how exactly to define these three models. For this analysis, I use definitions developed by Charles and colleagues (1997, 1999, 2003).

ⁱⁱ Many participants spoke of the importance of CAM and holistic healing to the cancer process. This writing cannot do justice to this additional area; future studies with young survivors should address CAM and holism in healing.

ⁱⁱⁱ In ovarian cancer treatment, for example, the gynecological oncologist is trained and manages both the surgical and systemic treatment courses, whereas in breast cancer, the surgeon and oncologist remain two separate providers, often practicing in two separate locales.

^{iv} Zoladex is a hormonal therapy sometimes recommended for hormonal receptor-positive tumors, as it blocks or mitigates the production of hormones in the body that fuel the growing tumor.

Chapter 6 – Discussion, Conclusion and Recommendations

Discussion

A qualitative exploration of young survivors' experiences with breast cancer reveals a nuanced and dynamic picture of reproductive decision-making processes as women engage them in the context of treatment. Mapping participants' responses through a grounded theory schema (Charmaz 2000, 2006) allows for an emerging theory of reproductive and sexual health in the context of a young breast cancer diagnosis. I have argued that women engage decision-making as biocultural beings, negotiating immediate mortality risks with long-term, quality of life concerns that are further mediated by clinical approaches and institutional constraints.

A closer examination of the grounded theory schema (Figure 1) and women's narratives allows for a theoretical construction in which the decision-making process—and the three themes involved, biology, institutional constraints, and sexuality and the body—is constructed and facilitated by conceptual shifts in women's values and cognitive thinking as they move through and between these significant factors. We see in women's narratives how the initial diagnosis is comprised almost exclusively of biological and biomedical information and treatment recourse. Women begin their decision-making process by privileging this clinical information; their cancer is viewed as a disease and pathology that requires highly interventive, toxic and aggressive treatments. This disease-centric (Press et al. 2005) focus, however, often translates into a standardized cancer care approach in which the “patient” is left out of “patient-care” (Mathieson and Stam 1995; Sered and Tabory 1999). The social construction of the illness (Eisenberg 1981; Kleinman 1988; Kleinman, Eisenberg, and

Good 1978; Lupton 2000; Rosenberg 1986) falls by the wayside and with it, options for exploring alternative therapies and values, particularly regarding future reproductive health and other quality of life issues.

The institutional constraints created when the body and disease are defined exclusively within strict biomedical and biological terms creates the first catalyst for young survivors to question their treatment experience and to explore additional values and approaches that, up until this point, were marginalized and pushed to the periphery by a privileging of the clinical. I argue that these institutional constraints create discordance between authoritative knowledge (Jordan 1993) and lived experience (Charmaz 2000, 2006; Lupton 2000), and from this discord, a conceptual space emerges in which young women are able to challenge the dominant medical authority and begin to situate their cancer socially. As this conceptual space emerges, women begin to place an increased amount of importance on the unique reproductive issues explored in theme III, sexuality and the body.

The explanation and articulation of individual concerns are facilitated by participants' active information-seeking activities, and the connections they make with other young survivors and the breast cancer community at-large. As Svendsen (2006:140) writes, "knowledge is both constituted by and generative of social practices." The knowledge young women generate by engaging in this process allows them to situate their cancer diagnosis socially and employ a form of personal agency, defined here as "the culturally constrained capacity to act" (Ahearn 2001:54). By investigating the ways in which women engage, agree and challenge biomedical discourses, we are able to understand how personal agency can be exerted in spite of

institutional constraints. As Mankekar (1999) notes, “resistance and compliance are not mutually exclusive activities.” When participants are able to situate the cancer diagnosis socially, the numerous and often competing factors young survivors balance in their decision-making process create an opportunity for them to engage in personal agency, even when the treatment decisions made are not changed by their exploration of these social and personal values and concerns.

The process of developing a sense of personal agency and empowerment is best facilitated by a return to the shared-decision making model proposed by Charles and colleagues (1997, 1999, 2003). Shared decision-making is characterized by an ongoing, dual interaction between provider and patient, whereby information exchange is bi-directional. The physician provisions information on the biological components of the disease and the clinical approaches to treatment, and the patient provides information on their personal values and life context. I argue that listening to young survivor’s narratives can provide a foundation from which to further develop shared-decision making models for use by cancer care providers and patients. A greater understanding of women’s reproductive and sexual health concerns and values by clinicians may forge the space needed for a bi-directional information exchange to occur, and in effect, the opportunity for institutional constraints and unequal power relations to be critically examined. As a result, solutions that account for the total person may more effectively emerge.

Through women’s narratives, we can begin to understand the importance and role of information in decision-making. Arguably, the most effective form of shared-decision making will result when both clinicians and patients have access to

information on young survivor's reproductive and sexual health needs. As one participant explained:

The doctor's role is to be a source of information for you, so the doctor might have the goal of you surviving cancer, but in my mind that should be independent of what the patient wants. What I mean by that is the patient should be able to say "My fertility is extremely important, and I'm willing to sacrifice my chances of surviving this cancer to increase my chances of keeping my fertility or using some other technique to have a family" . . . the doctors [should] provide the information. This is what the statistics say, this is what your options are, weigh what's important to you so at the end of the day, you feel like you got the best treatment and your treatment reflects what you value (Haley, 28 years, Stage 2).

Information can be a source of empowerment in health and can lead to ensuring that full options disclosure and informed consent are achieved (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005).

Conclusions and Recommendations

Reproductive and sexual health concerns faced in the young survivor community vary with the life context and the multiple identities held at time of diagnosis. Understanding treatment and reproductive health care in young survivors is facilitated by a biocultural approach in which the biological, sociocultural, and political-economic determinants of the breast cancer experience are explored as integrated and dynamic facets of the decision-making process. As we look to affect change in this realm, we must raise these unique concerns in a way that accurately represents the continuum of young survivor concerns:

There are so many different issues. I read about these older women and their issues and they certainly need to be validated and out here, but what about young survivors, single women, working moms, and this and that, and sexuality and body image, and these things in our society, and then add the

breast cancer component and the ovaries and reproduction (Jocelyn 26 years, Stage 2).

A call for action and information dissemination is present in the current literature on young survivors (Baucom et al. 2005, 2006; Duffy, Allen and Clark 2005; Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005), women's words and in the resulting focus group narratives. Results from the focus group session were primarily concentrated in two areas, a strong level of agreement with the theoretical conceptualization developed, and discussion and elaboration of the importance of information for young survivors. Through this latter discussion, participants and I co-developed an applied intervention to assist other young survivors in their cancer care and reproductive health journey. The applied intervention (Appendix E) is a resource sheet outlining questions young survivors may consider discussing with their care provider in balancing reproductive health care options with cancer care treatment recommendations. This resource reflects the words of study participants and is in accordance with previous studies on the preferred information format of young survivors (Partridge et al. 2004; Thewes et al. 2003; Thewes et al. 2005).

Future studies should utilize qualitative and quantitative approaches to further investigate the reproductive health care needs of young breast cancer patients and the decision-making processes involved. In particular, researchers are encouraged to actively elicit diverse young survivor perspectives and to include voices from traditionally marginalized groups (women with same sex-preferences, lower socioeconomic statuses, and those from ethnically and racially diverse backgrounds). Future studies should also examine the perspectives, values and attitudes of cancer

care providers working with young breast cancer survivors. A dual-approach to this topic may prove to be most effective in developing cancer care materials meaningful to young women, in facilitating collaboration between clinicians and patients, and in advancing multi-disciplinary medical teams. Finally, future research should be predicated upon a commitment to social and institutional level change, and to hearing the voices of the young women who have to live in the bodies physicians save and embrace the experience of being “too young to have breast cancer.”

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APPENDICES

Appendix A: Recruitment Survey

1. What is your current age? ____years
2. What race/ethnicity do you consider yourself?
 Latino/Hispanic Origin African American White/Caucasian
 Asian American Pacific Islander Mixed" Heritage
 Other (please specify) _____
3. What was your age at diagnosis? ____years
4. What stage breast cancer were your diagnosed with?
 Stage 0 Stage 1 Stage 2 Stage 3 Unknown
5. Did the cancer spread to your lymph nodes? Yes No Unknown
6. How long has it been since your initial diagnosis? ____months ____years
7. What County was your treatment facility located in? _____
8. What was your insurance status at time of diagnosis?
 Uninsured Private insurance State Assistance Program
 Other (please specify) _____
9. What was your annual household income at time of diagnosis?
 Less than \$15,000/year \$15,000 - \$25,000/year
 \$25,000 - \$50,000/year \$50,000 - \$75,000/year
 \$75,000 - \$100,000/year \$100,000 or more/year
10. What was your highest completed education level at time of diagnosis?
 Less than a high-school degree High-school diploma/G.E.D.
 Associate's degree Bachelor's degree
 Master's degree Doctorate
 Other (please specify) _____
11. What was your marital status at time of diagnosis?
 Single Married
 Committed relationship Divorced/Separated/Widowed
 Other (please specify) _____
12. Did you have any children at the time of diagnosis? Yes No
If yes, what was their age(s)? _____

13. What type of systemic/adjuvant therapy did you receive? (check all that apply)
 Chemotherapy Radiotherapy Hormonal or Endocrine therapy
 Other (please specify) _____
14. Do you have a family history of breast cancer? Yes No
15. Did you know your fertility status at time of diagnosis? Yes No
If yes, which of the following best describes your fertility status at time of diagnosis: Fertile Infertile Other (please specify) _____
16. Did you have plans for future childbearing at time of diagnosis?
 Yes No Unsure
17. Did you have reproductive health concerns regarding cancer treatment at time of diagnosis? Yes No
If yes, what was your top concern?
 Infertility Sexual dysfunction Pregnancy
 Contraception Other (please specify) _____
18. Did reproductive health concerns impact treatment decisions?
 Yes No
19. Before treatment began, were you informed about the possible reproductive/fertility effects of the adjuvant/systemic therapy? Yes No
If yes, who provided you the information?
 Oncologist Fertility Specialist Breast Health Nurse
 Other (please specify) _____
- If yes, how sufficient do you feel the information was in addressing your concerns?*
- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very
Insufficient | Insufficient | Neutral | Sufficient | Very
Sufficient |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
20. Were you provided information/resource on reproductive/fertility options?
 Yes No
If yes, who provided the information?
 Oncologist Fertility Specialist Breast Health Nurse
 Other (please specify) _____
21. Did you utilize assisted reproductive technologies for fertility preservation?
 Yes No
If yes, which ones did you utilize?
 Embryo Cryopreservation Oocyte Cryopreservation

Ovarian Cryopreservation Other (please specify)

22. If treatment is complete, do you know your current fertility status?

Yes No

**Thank you very much for your time, input, and consideration.
It is greatly appreciated!**

Recruitment for Interviews

Yes, I would like to participate in the interview phase of this study. The researcher may contact me to set up an interview time/day using the information below:

Name: _____

Phone: _____

E-mail: _____

Best time to contact me is:

Day(s) of the week _____ Time(s) _____

Thank you!

Appendix B: Invitation Script for Phase II

Dear Breast Cancer Survivor,

I request your assistance in a research project designed to explore young women's decision making processes regarding breast cancer treatment and reproductive health concerns. Currently, there is a lack of information on fertility-related and sexual health concerns of reproductive-age women facing a diagnosis of breast cancer. As a woman diagnosed with early stage (stage 0 – 3) breast cancer between the ages of eighteen and forty years of age, and who was diagnosed within six months to five years prior to the start of the study, I invite you to complete this brief, fifteen-minute survey. Confidentiality is protected and your completion of this survey is considered your implied informed consent. Findings will be published in academic health journals and may be used to develop fertility education materials for use by young female breast cancer survivors and cancer care providers.

If you would like to participate, please fill out the below survey and mail back in the self-addressed, stamped envelope. Thank you!

The bottom portion of the survey contains a spot to fill in your name and contact information. Phase II of this study is an interview phase in which I will interview willing participants who completed a survey in order to elicit their stories on reproductive-decision making in the context of cancer treatment. The purpose is to gain further information on survey findings. If you would like to also participate in an interview, please fill in your contact information. I will contact you to set a time and date for an interview.

If you have any questions regarding this study, feel free to contact the researcher, Courtney Everson, at eversonc@onid.orst.edu. You may also reach my advisor, Dr. Melissa Cheyney, at melissa.cheyney@oregonstate.edu. Thank you very much for your consideration.

Sincerely,

Courtney Everson, BA
Master's Student Medical Anthropology
Oregon State University
270 Waldo Hall
Corvallis, OR 97331
eversonc@onid.orst.edu

Appendix C: Interview Protocol

Interviewer: <u>Courtney L. Everson</u> Participant #: _____ Time: _____ Date: _____

Narrative: Thank you for meeting with me today. This is a very exciting research project and I appreciate your participation. First, I want you to know this is a casual interview. From the survey responses I received back, combined with my experience in this topic and prior research, I have identified various areas in need of further explanation. I have a list of open-ended questions. They will guide the interview, but your responses and what you are comfortable sharing will ultimately determine the direction of the interview. Before we begin, please read over this informed consent form. I encourage you to ask any questions that you may have, and I am more than happy to answer them. Once you feel comfortable with the information and if you agree, please sign it. I will keep the signed copy and you can have this unsigned copy for your records.

- 1) To begin, please describe your breast cancer diagnosis and treatment experience.
- 2) What in your life context influenced your treatment decisions? How so?
- 3) What reproductive health concerns did you have following your initial diagnosis?
- 4) What information, if any, did your primary cancer care provider provide you regarding reproductive and sexual health?
- 5) Were your reproductive and sexual health concerns addressed? If so, by whom?
- 6) How well did the information you received address your concerns?
- 7) Did you want more of anything? Did you seek out additional information? From where?
- 8) Did your reproductive health concerns impact treatment decisions? Why or why not?
- 9) Did you use any fertility preservation techniques, included assisted reproductive technologies (ART)? If so, which ones did you choose and why?

If you did not choose to use them, could you explain why? (What was your experience with the process of ART, especially in the context of treatment?)

- 10) If treatment is complete, do you still have any fertility-related concerns? Do you know your fertility status?
- 11) Finally, what reproductive health information do you feel should be provided to young women breast cancer patients, in what format, and by whom?
- 12) Is there anything else you would like to share?

Thank you very much.

Appendix D: Oral Script for Phase III

I would like to invite you to participate in a focus group discussion on findings from the survey and interview narratives. As soon as preliminary interpretations are formed, I will contact willing participants and set up a day/time for a focus group session that is accommodating to as many participants as possible. As preliminary interpretations may take a while, I want you to know this focus group is likely to not happen until January or February. Would you like to be contacted regarding the focus group discussion?

_____Yes _____No

Reproductive Health & Young Survivors: Unique Questions to Ask Your Medical Team

This publication is intended as a guide for young survivors in communicating with their medical team. Use the back side to take notes and check off each section as you review the questions with your health professionals.

Pregnancy & Childbearing

How will treatment affect my fertility?

- ◆ What are my fertility-preservation options?
- ◆ Do you have a fertility expert on staff or one you could recommend?
- ◆ How do fertility-preservation options impact my treatment options?
- ◆ How do treatment options impact my fertility-preservation options?

Is it possible to have children after cancer?

- ◆ What are the risks of childbearing after cancer treatment?
- ◆ What is the recommendation for how long after treatment I should wait before I try to have a baby?
- ◆ What are my risks for having miscarriages and for future children having birth defects after I undergo cancer treatment?
- ◆ Based on my type of cancer, what are my risks of recurrence if I become pregnant after treatment?

How do I talk to my young children about a cancer diagnosis and treatment?

- ◆ What resources are available for helping my family cope?

How does treatment, including surgery, affect my ability to breastfeed?

Sexuality & Sexual Health

How does cancer treatment affect my overall sexual health?

- ◆ What sexual and sexuality side effects may result from treatment?
- ◆ What resources are available for helping me manage sexual side effects?

What treatment routes are available to ensure successful reconstruction options?

Other Unique Considerations

What are my options for tissue banking?

What resources are available for genetic counseling?

Key Advice From Other YS

1. Take time to make decisions

2. Put together a medical team of professionals you trust

3. You are not alone! Connect with other YS.

4. Be Proactive!

5. Ask questions through the entire process. With each new step comes new concerns.

"IN MAKING TREATMENT DECISIONS, A YOUNG SURVIVOR BALANCES THE NEED TO TREAT A TYPICALLY MORE AGGRESSIVE OR ADVANCED CANCER WITH THE POTENTIAL FOR A LONG LIFE AHEAD"

-YOUNG SURVIVOR

Resources & Notes Page

Resources for Young Survivors

BreastCancer.org

www.breastcancer.org

CancerCare

www.cancercare.org

FertileHope

www.fertilehope.org

FORCE: Facing Our Risk of Cancer Empowered

www.facingourrisk.org

Lance Armstrong Foundation

www.livestrong.org

Living Beyond breast cancer

www.lbbc.org

MAMM Magazine: Women, Cancer and Community

www.mamm.com

PubMed Research Database

www.pubmed.gov

Susan G. Komen for the Cure®

www.komen.org

Y-ME National Breast Cancer Organization

www.y-me.org

Young Survival Coalition

www.youngsurvival.org

Notes

THIS PUBLICATION WAS CREATED FROM A RESEARCH STUDY EXAMINING REPRODUCTIVE DECISION-MAKING IN YOUNG FEMALE BREAST CANCER SURVIVORS. THANK YOU TO ALL THE YOUNG SURVIVORS WHO SHARED THEIR STORIES AND MADE THIS RESOURCE POSSIBLE! THANK YOU TO THE OREGON AND SW WASHINGTON AFFILIATE OF SUSAN G. KOMEN FOR THE CURE® FOR SUPPORTING THE PRINTING AND DISSEMINATION OF THIS PUBLICATION.

QUESTIONS OR COMMENTS? CONTACT COURTNEY EVERSON AT CEVERSON@GMAIL.COM

