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Molloy College  
The Barbara H. Hagan School of Nursing & Health Sciences  
PhD in Nursing Program

UNDERSTANDING THE LIVED FERTILITY PRESERVATION EXPERIENCE FROM  
DIAGNOSIS TO THE START OF ADJUVANT THERAPY:  
A STUDY OF YOUNG BREAST CANCER SURVIVORS

a dissertation

by  
KRISTINE FERRUCCI-EGAN

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

April 27, 2021

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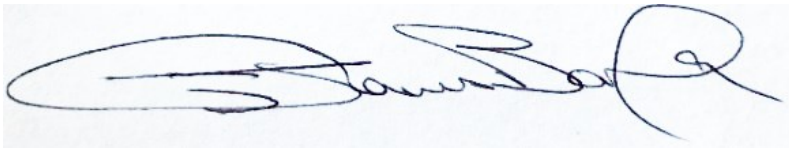
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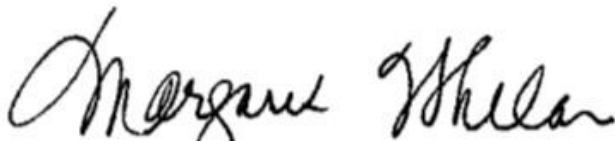
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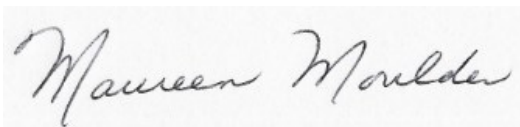
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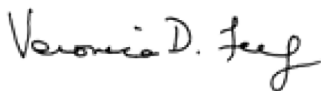
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## **Abstract**

### **Purpose**

The purpose of this phenomenological study was to explore and gain an in-depth understanding of the lived fertility preservation experience of young female breast cancer survivors from diagnosis prior to the start of adjuvant therapy. The knowledge gained from the findings of this study may provide insights for nursing practice, research, and academia.

### **Background**

Premenopausal women often present with later-stage disease and a prognosis far worse than women who develop breast cancer later in life. In addition, this disease in younger women tends to be of a more aggressive biological subtype, with outcomes that are significantly worse than for their older counterparts. The aggressiveness of the disease warrants the use of more rigorous multi-modal treatment approaches that can include surgery, chemotherapy, radiation, and hormone therapy to promote cure and prevent a recurrence. Treatment with chemotherapy can deplete the ovary of follicular stores, leading to menstrual irregularities, ovarian failure, and associated infertility. Preserving fertility is a priority for young cancer survivors, yet there is often little discussion about fertility preservation before the initiation of adjuvant therapy. Preservation of the reproductive potential of these young women is of great importance as it is timesensitive and can be significantly affected depending on the treatment.

### **Research Question**

What is the lived experience of fertility preservation during the post-diagnosis to the pre-adjuvant therapy time period of young women with breast cancer?

### **Methodology**

A qualitative, phenomenological method was chosen to explore the lived fertility preservation experience of young women subsequent to a breast cancer diagnosis. This study utilized the hermeneutic

phenomenological perspective of Martin Heidegger (1962) along with van Manen's (1990) methodological activities. A purposive sample of eight young women were recruited using snowballing technique, and data was collected using in-depth unstructured interviews.

## **Findings**

Five essential themes emerged from the analysis of the data collected. The essential themes developed from the data were: (1) Grateful for Care and Support from Others; (2) Preserving Optionality During Chaos; (3) Overwhelmed with the Amount and Complexities of Medical Information; (4) Unpleasant Symptoms; and (5) Assuring Temporality and Preserving the Now for the Future. The themes illuminated the lived fertility preservation experience of young women. Participants verbalized their experiences, describing both the positive and negative experiences. The meaning of the fertility preservation experience for these women showed that despite the overwhelming, complex, unpleasant, and chaotic environment, participants were empowered by self-determination to preserve their fertility. In doing so, they found hope in protecting their future and were grateful for their network and the support they received. The findings of this study has implications for the nursing profession. Integrating this topic in curriculum for undergraduate and graduate programs will expand the knowledge base for nurses and foster a willingness to openly educate, advocate, and provide evidenced-based nursing care during this critical period.

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## **Chapter I: Introduction**

Survival rates from breast cancer have improved significantly over the past decade. Increased education, early detection, improved technology, and current treatment have widened the scope of attention from not only the treatment of the disease itself but also toward addressing long-term effects such as reproductive concerns (American Cancer Society [ACS], 2018). As a result of this widened perspective, infertility related to cancer treatment has increasingly gained the attention of researchers over the past decade (Lambertini et al., 2016). The targeted population for this problem naturally focused on young women diagnosed with breast cancer who needed adjuvant therapy but had either not yet started or not completed their family. Research suggests that for these young women, the diagnosis and treatment of breast cancer have added complexities and decision-making concerns not experienced by their older counterparts. A diagnosis of breast cancer at any age is a major life event and there is usually an urgency by both the physician and the patient to initiate life-saving treatment. The disease in younger women tends to be more aggressive, warranting more aggressive forms of adjuvant treatment in addition to surgery (Hartman et al., 2011). Initially, the type of surgery followed by adjuvant therapy is decided upon, with the possibility of radiation and endocrine therapy later. However, the literature on the gonadotoxic effects of adjuvant cancer treatment is well established and it is known that adjuvant therapy will most likely cause infertility (American Society of Clinical Oncology [ASCO], 2018).

The opportunity to have children is an important issue for many young breast cancer survivors. Fertility preservation and loss of reproductive potential are primary concerns. Infertility resulting from adjuvant treatment can cause significant distress for women who want to have children (Canada & Schover, 2010; Lambertini et al., 2013). The quality of life for these

women can be impacted negatively if they are left infertile due to the course of adjuvant treatment that they chose or were given (Ruddy et. al., 2014). A survey of young cancer survivors conducted by Schover, Rybicki, Martin, and Bringelsen (1999) revealed that 75% of those without children wanted to have a child in the future. In addition, Schwerdtfeger and Shreffler (2009) analyzed responses of approximately 3000 women from the population-based National Survey of Fertility Barriers and found that women who are involuntarily childless have higher rates of depression and lower quality of life than women who had not experienced infertility.

Young women have a small window of time, from diagnosis to the beginning of the administration of adjuvant therapy, to make important decisions regarding their health status, disease treatment, as well as the added problem of fertility preservation for future pregnancy. The literature shows that the time from diagnosis to surgery ranges from 14 to 42 days, and surgery to the start of adjuvant therapy ranges from a few weeks to 120 days (Chavez-MacGregor et al., 2016; National Quality Forum, 2017; Zhan et al., 2018).

During this short but critical time frame, the choice of doctors, including oncologists and surgeons, both general and plastic (depending upon the type of surgery), need to be decided upon along with decisions regarding the type of adjuvant treatment. With the administration of adjuvant therapy as the standard of care for young breast cancer patients, decisions regarding fertility preservation must be made. Once fertility preservation has been decided upon, the young women must also act upon it. They must choose fertility specialists, have consultations, go for genetic counseling, and start and finish the fertility preservation process all within the short stressful period of time before adjuvant therapy is to begin.

The shock of the diagnosis of breast cancer, combined with treatment challenges and the

real possibility of future infertility, can be overwhelming for these women. A qualitative study using a phenomenological approach was used to explore and understand, from the participants' perspectives, the fertility preservation experience during the time period from diagnosis to the beginning of adjuvant therapy. The aim of this study was "to gain a deeper understanding of the nature or meaning of the everyday experiences of these women as they lived" (van Manen, 1990, p. 9) that period of their lifeworld. The knowledge gained from the findings of this study provided insights for nursing practice, research, and academia.

This chapter identified the phenomena of interest, which is the fertility preservation experience journey of young breast cancer survivors. An overview of the context and background of the phenomena, the purpose, and perceived relevance of the study was discussed. A brief introduction to the chosen research method and the justification for its use was given. The chapter concluded with a discussion on the researcher's biases and beliefs about the importance of the phenomenon, followed by a brief summary of the chapter.

## **Background**

The average age of women diagnosed with breast cancer is 62 (Centers for Disease Control [CDC], 2018). As a result, women under the age of 40 (American Medical Association [AMA], 2014) are not urged to have screening procedures such as mammograms, unless there is a strong family history, pain, discomfort, or a palpable finding. Because breast cancer has historically been referred to as an older women's disease, most young women do not consider the possibility of screening, thus leaving themselves at risk for a more advanced form of the disease when diagnosed. Premenopausal women often present with later-stage disease and a prognosis far worse than women who develop breast cancer later in life. In addition, this disease in younger women tends to be of a more aggressive biological subtype, with outcomes that are significantly

worse than for their older counterparts (Hartmann et al., 2011). The aggressiveness of the disease warrants the use of more rigorous, multi-modal treatment approaches that can include surgery, chemotherapy, radiation, and hormone therapy to promote a cure and prevent a recurrence.

Treatment with chemotherapy can deplete the ovary of follicular stores, leading to menstrual irregularities, ovarian failure, and associated infertility.

Chemotherapy can cause ovarian tissue atrophy with marked loss of primordial follicles. Toxicity can occur through impairment of follicular maturation and/or depletion of primordial follicles. (Camp-Sorrell, 2009, p. 252)

Additionally, delaying conception due to treatment can lead to natural ovarian aging, leaving patients infertile. The effects of the treatment on fertility are a primary concern for many young women newly diagnosed with breast cancer, and for some, it substantially affects decisions about the course of treatment they choose. This, coupled with their diagnosis, contributes to a higher level of distress (Ruddy et al., 2014).

Fertility preservation options available for young women with breast cancer warranting adjuvant therapy depend upon the following factors: age, diagnosis, time available, type of adjuvant treatment, presence of a male partner/sperm donor, and whether cancer has metastasized to the ovaries. According to the ASCO (2018), proven fertility preservation options available are embryo cryopreservation and cryopreservation of unfertilized oocytes. Ovarian tissue cryopreservation and ovarian suppression are also available but are still considered experimental (ASCO, 2018). Embryo cryopreservation is the most effective form of fertility preservation with live birth rates for patients less than 35 years of age at 33%, those 35-37 years of age at 30%, and 25% in patients 38-40 years of age (Tichy et al., 2013).

While preserving fertility is a priority for young cancer survivors, there is often little

discussion about fertility preservation before the initiation of adjuvant therapy (Kim et al., 2011). Studies have suggested there are few discussions among young breast cancer patients and their healthcare professionals regarding fertility preservation. According to a study conducted by Kim et al. (2016), 73% of their 204 participants verbalized that they did not receive adequate information regarding fertility preservation options at the time of their cancer diagnosis.

With the successful implementation of early prevention and new treatment options, young breast cancer survivors can expect long-term survival rates (Waimey et al., 2015). As the population of young breast cancer survivors increases through current effective treatment, there is a substantial need for information, education, and resources targeted specifically for this group. Loss of reproductive potential is of great importance as it is not only time-sensitive but can be significantly affected depending on the treatment. Lambertini et al. (2013) discussed how increasing trends toward delaying pregnancy until later in life may result in the likelihood that some women diagnosed with breast cancer and need adjuvant therapy may have not yet started or completed their family. Young survivors of breast cancer can become pregnant and have children if they have access to the most current evidence-based information about fertility preservation in a timely manner (Meneses & Holland, 2014).

### **Phenomenon of Interest**

The phenomenon of interest for this study was to understand the fertility preservation experiences of young breast cancer patients during the post-diagnosis to pre-adjuvant therapy time period. This study focused on women between the ages of 18-39, who were diagnosed within the past five years (2012-2017).

### **Justification for Studying the Phenomenon**

While treatment for breast cancer has been in place for decades, it has historically

focused on older females. Efforts have been put forth to understand the dynamics and needs of the current rising population of young survivors of breast cancer (Melan et al., 2018). With the increase in this population, there is a substantial need for information, education, and resources targeted specifically for these women. Research has revealed that the needs of young women diagnosed with breast cancer during their childbearing years are not often met and that gaps exist in the education of this population concerning fertility preservation (Duffy et al., 2005; Tiong et al., 2014).

To date, the literature on breast cancer among young women has focused mostly on disease pathology (Anders et al., 2008; Assi et al., 2013; Bharat et al., 2009; Ferzoco & Ruddy, 2015; Rosenberg & Partridge, 2015); treatment options including the short-term effects of adjuvant therapy (ACS, 2018; Rosenberg & Partridge, 2015); the available fertility preservation options (ASCO, 2018); and quality of life post adjuvant therapy with the focus on having children (McCray et al., 2016). Other studies have addressed the lack of discussion, education, and referrals from the physician to the newly diagnosed breast cancer patient regarding fertility preservation (Duffy et al., 2005; Hill et al., 2012; Ruddy et al., 2014; Scanlon et al., 2012).

Even for patients who are informed of fertility risks prior to treatment and have the option to consider fertility preservation, decision making can be difficult and wrought with ambiguity. The lack of data on the precise risk of infertility from treatment and unmet information needs further contribute to patients' feelings of uncertainty (Benedict et al., 2016). At a time of high emotional distress, patients must consider the importance to them of having a biologically related child; their comfort in using fertility preservation that includes religious, cultural, and ethical beliefs; and the opinions and recommendations of healthcare practitioners, partners, and family members (Nass et al., 2015). Decisions are often difficult as the options for

fertility preservation are invasive, can be costly, and may require delaying treatment. The literature is sparse, focusing on the lived experience of fertility preservation in the post-diagnosis to pre-adjuvant therapy time-period of young breast cancer patients.

Limited knowledge is available about this unique experience from the perspective of this group of women, and research is required to gather data that will inform the development of interventions that can aid healthcare professionals to better address the specific needs of this population. It is important to conduct research that is qualitative in nature and specifically from a phenomenological approach in order to gain a deeper understanding of the lifeworld of the women at this critical period. The description of the lived experiences described by these women provided an in-depth understanding of the issues and concerns of fertility preservation during the stressful time between diagnosis and the beginning of adjuvant treatment.

### **Research Question**

The research question for this study was, what is the lived experience of fertility preservation during the post-diagnosis to the pre-adjuvant therapy time period of young women with breast cancer? To gain an understanding of this phenomenon, this researcher posed the following grand tour question to the participants: “Can you please tell me about your experience with fertility preservation during the time period once you were informed of your diagnosis and before you began adjuvant therapy?”

Additional probing questions were utilized to help participants articulate their experiences of the phenomenon. This qualitative study focused on the lived experience of fertility in young breast cancer survivors who received adjuvant therapy. Participants were encouraged to speak freely about their experiences.

### **Purpose of the Study**

The purpose of this phenomenological study was to explore and understand the experience of fertility preservation during the time period after diagnosis and prior to the start of adjuvant therapy for young breast cancer survivors.

### **Definition of Terms**

For the purpose of this study, the following definitions of terms have been adopted:

**Adjuvant Therapy:** The American Cancer Society (ACS, 2018) defines *adjuvant therapy* as additional cancer treatment given after the primary treatment to lower the risk that cancer will come back. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy.

**Fertility Preservation:** The National Cancer Institute (NCI, 2014) defines *fertility preservation* as a type of procedure used to help preserve a person's ability to have children. A fertility preservation procedure is done before a medical treatment such as radiation therapy or chemotherapy, which may cause infertility. Examples of fertility preservation procedures include sperm banking, egg freezing, in-vitro fertilization with embryo freezing, and certain types of surgery for cervical and ovarian cancer. For this study, the fertility preservation period is the time span between breast cancer diagnosis and the first administration of adjuvant therapy.

**Young women/Breast cancer survivors:** The Center for Disease Control (CDC, 2012) defines ages 20-39 years as young adults.

### **Methods of Inquiry**

A qualitative method utilizing a phenomenological design was used to examine the experience of fertility preservation of young breast cancer patients during the short period of time from diagnosis to the initiation of adjuvant therapy. Phenomenology is a philosophy as well as a research method intended to explore the lived experience of the phenomenon (van Manen,

1990). The overall goal of phenomenology is to gain an understanding of the meaning of peoples' everyday lived experiences. Phenomenological research provides insight into an individual's reality and brings one closer to the living world (van Manen, 1990). This study is embedded within a social constructivism worldview, underpinned by the philosophical framework of Martin Heidegger (1962).

This study focused on the participants' description to gain an understanding of the lived fertility preservation experiences of young breast cancer survivors who received adjuvant therapy. A purposive sample of 7-10 women ages 18-39 who were diagnosed with breast cancer and received adjuvant therapy from 2012-2017 were recruited. Participants were obtained through purposive and snowball sampling techniques. Data were collected utilizing unstructured one-on-one interviews between the researcher and each participant. Participants who meet the criteria were interviewed and data were analyzed using the methodological activities of van Manen (1990).

### **Relevance for Nursing**

While a diagnosis of breast cancer is rare in young women, the number of young women being diagnosed and then exposed to adjuvant therapy and later faced with infertility is on the rise (Howlader et al., 2015). With the increased cancer incidence as well as increases in long-term post-cancer survival rates in young women, the use of fertility preservation among this population is growing. In order for healthcare practitioners to better care for and support these women, more research is needed to understand the fertility preservation experience during the short stressful window of time for these women.

Although treatment and survival are the primary focus of both the healthcare provider and patient alike, cancer survivors are living longer, making it vital to consider the quality of life

after treatment, including the possibility of having children. Healthcare practitioners cannot assume that patients will ask about fertility risks and fertility preservation options if they are interested. Young women may be upset and overwhelmed by their cancer diagnosis, or it may not have occurred to them that adjuvant therapy could pose a risk of infertility (Loren et al., 2013).

Nurses are often the most important support system a young breast cancer patient has as they provide communication and reassurance, as well as emotional support. Nurses assist in the coordination of care patients receive from different healthcare practitioners. In addition, nurses discuss and provide education and information regarding treatment, clarify and reinforce treatment options provided by healthcare practitioners, and provide any other information or support that the patient may require (Marriott et al., 2014).

It is important for nurses to be knowledgeable about how cancer treatments affect the reproductive system; the process for each fertility preservation option; the advantages and disadvantages of each method; and which methods may be appropriate for different young women. This knowledge will boost nurses' ability to facilitate the guidance of young women during the decision-making process. However, nurses who advocate for their patients' fertility should be mindful of the young woman's emotional state at the time of diagnosis. There is a multitude of decisions expected, and with the minuscule time frame that is available to have an understanding, counseling may be necessary to assist with the decision of whether or not to attempt to preserve fertility (NCI, 2014). This understanding of these issues can be boosted by listening to the voices of women as they describe their lived world during this experience. Having a window into the physical and emotional turmoil that the young women are experiencing may provide insight into the enhancement and/or development of new care

practices and research by nurses.

The literature supports that young breast cancer patients would benefit from decisions regarding fertility preservation if discussions began as soon as they have received their diagnosis (McCray et al., 2016; Oktay et al., 2018). As a result, newly diagnosed young women require support from a variety of people through their journey, from diagnosis to cure. Increasing awareness of the fertility preservation experiences of young female breast cancer patients among healthcare professionals, and young women themselves, may help increase the number of women receiving proper education and timely referrals to fertility specialists.

According to the literature (ASCO, 2018), while some providers acknowledge the importance of timely education and appropriate referrals to fertility specialists, what is lacking is the understanding of the women's experience, during this short, stressful time period. Lauterbach (2007) stated that "nursing's ultimate goal is to care for people persons experiencing the unfolding life processes by using informed, timely and appropriate care based on human caring and understanding" (p. 217). This is the primary research goal for this study. Examining and understanding the essence of the lived experience of this population provided insights that will enable nurses to better educate and support women in their choice of fertility options during this vulnerable time.

This study adds to the nursing database and body of knowledge as findings provide an understanding of that group of young women's experiences during that short but critical period, from breast cancer diagnosis to the initiation of adjuvant therapy. These insights may help improve how nurses, as well as other healthcare professionals, approach and provide care for young women with breast cancer, who require adjuvant therapy and are interested in having children after treatment. Additional insights from this study may be used to generate educational

resources and create more effective nursing interventions and best practice protocols that will assist in increasing the standard of care tailored to this population. A more comprehensive understanding of attitudes and barriers related to fertility preservation can guide the building of optimal systems that will support effective fertility preservation options, resources, and programs for individuals with cancer.

### **Assumptions and Biases**

The researcher is the primary tool in a qualitative study (Creswell, 2013). It is essential that the personal values, assumptions, and biases of the researcher are clearly expressed from the beginning. This study sought to uncover the essence of the fertility preservation experiences of young breast cancer survivors. This research followed the basic principle of hermeneutics, which meant that the researcher strived to understand and interpret the meanings extracted from the data (Polit & Beck, 2012).

I believe that many young women diagnosed with breast cancer who need adjuvant therapy are entitled to timely and thorough information from their healthcare team regarding treatment and options for fertility preservation. I believe that young women diagnosed with breast cancer who need adjuvant therapy are not receiving timely and sufficient information from their providers to make informed decisions about treatment and fertility options. It is also my belief that if these women are given the information and the opportunity to participate in their future fertility and reproductive decision, the voices of these women will provide an understanding of their experiences and can enhance nursing care and foster additional research focused on fertility preservation and options of this population.

### **Chapter Summary**

Chapter 1 identified that the aim of the study was to understand the lived experience of

fertility preservation of young breast cancer patients during the time period post-diagnosis to the initiation of adjuvant therapy. Justification for conducting this study was articulated and the significance for nursing was given. The researcher's biases and assumptions related to this phenomenon were given. Chapter 2, presented the evolution of the study, understanding the experiences of young breast cancer survivors who received adjuvant treatment and their journey with fertility and reproduction.

## **Chapter II: Evolution of the Study**

The purpose of this study was to understand the lived experience of fertility preservation of young female breast cancer patients from the time of diagnosis to the start of adjuvant therapy. Chapter 1 identified the aim of the study. Chapter 2 describes the evolution of the study by framing the phenomenon of concern was framed in a historical and experiential context (Munhall & Chenail, 2008). An overview of the unique diagnostic and biological characteristics of breast cancer in young women was presented, in addition to the treatment modalities and the impact of these treatments on fertility. This was followed by a critical evaluation of the current knowledge related to fertility preservation options and the physicians' and health care providers' perspectives regarding fertility preservation for this population. The perspective of young female breast cancer patients regarding fertility preservation and future reproduction was also presented. The chapter concludes with a discussion of the experiential context of this researcher.

### **Overview of Breast Cancer**

Breast cancer is a common diagnosis affecting over one million women each year worldwide. It is estimated that in 2019, over 330,000 women will be diagnosed with breast cancer in the United States (NCI, 2018). Approximately one in eight women in the United States will develop invasive breast cancer sometime in her life (NCI, 2014).

### **Unique Characteristics of Breast Cancer in Young Women**

Breast cancer at a young age has unique clinical and biological characteristics that are not observed in older women. Screening and diagnosis, risk factors, tumor biology, and clinical outcomes are somewhat different in the population of young women diagnosed with breast cancer (Assi et al., 2013).

## **Breast Cancer and Age**

Breast cancer in premenopausal women is very rare, affecting 6.5% of women under age 40, 2.7% under age 32, and only 1% under age 30. However, it is still the most frequent cancer in women under 40, accounting for 30–40% of all female cancer in that age group (Fredholm et al., 2009). The average age of women diagnosed with breast cancer in the United States is 62 (ACS, 2018). Approximately 13,000, with the numbers rising, are under the age of 35 (ACS, 2018).

## **Diagnosis of Breast Cancer in Young Women**

Early detection has played a major role in the current fight against breast cancer. However, because the incidence of breast cancer is higher in older women, screening measures such as mammograms, sonograms, healthcare practitioners' breast exams, and the encouragement of self-breast exams are often not consistently offered to younger women (Appleton et al., 2014). Even when some of these screening measures are employed, there are challenges. Mammograms, although routinely done as the first screening procedure, are not as reliable for younger women, as the sensitivity is low due to the density of the breasts of younger women. Researchers have found that ultrasound is superior to mammography in evaluating women aged 30 years to 39 years with symptoms or risk of breast cancer (Appleton et al., 2014).

A study compared these two modalities among women aged 30 years to 39 years who presented for diagnostic breast imaging evaluation for a period of four years. A sample of 1208 cases the authors identified, sensitivity for ultrasound was 95.7%, compared to 60.9% for mammography. In addition, ultrasound examinations found 22 cancers versus only 14 detected by mammography (Lehman et al., 2012). One study found that using mammography contributes to the delay in diagnosis (Gabriel & Domchek, 2010). The recommendation is that U.S. clinical practice guidelines, which currently recommend mammography as the first evaluation in these

women, should be reconsidered (Printz, 2013).

Younger women tend to ignore warning signs such as changes in the skin of the breast, nipple discharge, pain concentrated in one area, and breast lumps, as they may believe they are too young to have breast cancer. Various physiological changes such as breast growth and enlargement, tenderness, and hypersensitivity, darkened veins due to increased blood supply (American Pregnancy Association, [APA], 2018), and parenchymal development that occurs during pregnancy and lactation can further complicate a diagnosis for this population (Lee & Han, 2014).

### **Risk Factors for Breast Cancer in Younger Women**

Breast cancer presents differently in younger women than older women, with a higher risk of relapse and a poorer survival rate (Assi et al., 2013). Decreased physical activity, sedentary lifestyle, and obesity have been identified as common modifiable risk factors for a diagnosis of breast cancer for women of all ages. However, participants enrolled in The Nurses' Health Study showed nearly a 50% greater risk of breast cancer in young women who consume a high animal fat diet (Cho et al., 2003). Research has also identified that exposure to female hormones and long-term oral contraception use can increase young women's risk for breast cancer (Assi et al., 2013).

Non-modifiable risk factors such as family history and genetic mutations (BRCA 1 & BRCA 2) can account for increased risk of breast cancer in women of all ages, but younger women tend to be at greater risk (Assi et al., 2013). Non-modifiable risk factors specific to younger women are young age at diagnosis, advanced maternal age at first full-term pregnancy, and lack of full-term pregnancy (Azim & Partridge, 2014). Younger women who breastfeed have been found to have a decreased incidence of breast cancer (Assi et al., 2013).

## **Tumor Biology**

Evidence indicates that breast cancer in young women is more aggressive and has potentially unique biological features (Azim & Partridge 2014). Tumors tend to be large, of a higher grade, and often with lymphovascular invasion. Aggressive biological characteristics, such as triple-negative or HER2-positive, have also been found to be more prevalent in the younger population (Anders et al., 2008; Assi et al., 2013; Bharat et al., 2009). The appearance of key biomarkers, including endocrine receptors and proliferation markers, appears to be unlike those of older women (Azim & Partridge, 2014).

## **Outcomes of Breast Cancer in Younger Women**

Although currently available treatment is proven successful, breast cancer in young women remains a significant challenge to patients and health care providers. Breast cancer in patients younger than 35 years of age is considered rare but is associated with a poor prognosis. More aggressive tumor biology, delays in diagnosis, and host differences are some factors that likely contribute to the poorer breast cancer outcomes experienced by young women (Rosenberg & Partridge, 2015).

Physicians are quick to adopt the premise that breast cancer is a disease of older women and are therefore less likely or less concerned about fully evaluating younger women for this disease. These factors can contribute to delayed diagnosis (Lee & Han, 2014). Delayed diagnosis due to a low level of suspicion, not only by the patient but also the physician, can lead to more advanced disease once diagnosed, resulting in outcomes that are poorer than that of older women (Lee & Han, 2014). These factors predispose younger women to increased local recurrence as well as metastases that contribute to poorer outcomes. Research has shown that the chance of recurrence (relapse) in younger women is greater, irrespective of aggressive treatment (Anders et

al., 2008; Kollias et al., 1997; Pollan, 2010).

A study conducted on 732 breast cancer patients revealed that patients under age 36 had larger tumor size, more lymph node involvement, and were more likely to be diagnosed at stages II and III versus patients over the age of 36. These findings show significant differences according to age, that tumors arising in younger women are of a more aggressive nature due to biological differences (Assi et al., 2013)

### **Treatment Modalities for Young Breast Cancer Patients**

Treatment of breast cancer is dependent upon diagnosis, the stage, and biological characteristics of cancer. Other considerations are the patient's age, menopausal status, risks and benefits associated with each treatment option, as well as patient preferences (ACS, 2018).

Women diagnosed with later-stage or inoperable breast cancer may be referred for chemotherapy or targeted therapy to try to shrink the tumor, so surgery may be an option. In addition, post-surgery chemotherapeutic agents and/or hormonal therapy may be utilized to prevent or decrease the chance of recurrence (ACS, 2018).

Younger women are more likely to present with a more advanced, aggressive disease than older women. Tumors tend to be of a higher grade and a later stage with unfavorable prognostic characteristics. These tumors are less responsive to conventional therapy, warranting the use of more aggressive treatment (Rosenberg & Partridge, 2015). Treatment options for this population can include a multi-modal approach of surgery, radiation, cytotoxic chemotherapy, ovarian ablation, and hormone therapy, or a combination (Anders et al., 2008). Adjuvant therapy has been widely used to treat young breast cancer patients due to its significant beneficial effects (Rosenberg & Partridge, 2015). This adjuvant therapy uses medications that prevent the growth and spread of rapidly dividing cancer cells both at the tumor site and throughout the body (ACS,

2018), but, this treatment also destroys normal rapidly dividing sex cells. Therefore, although using this multi-modal approach may increase the chance of a cure or decrease the risk of the cancer returning, it can alter or destroy the reproductive potential of the young woman.

### **Common Effects of Adjuvant Therapy**

Some of the most common and well-known short-term side effects of adjuvant therapy are nausea, vomiting, and alopecia affecting women of all ages. The literature has shown that there are very few differences in the short-term side effects from adjuvant therapy between younger and older women. Leukopenia, neutropenia, anemia, stomatitis, mucositis, myalgia, diarrhea, pain/numbness (nerve damage), toe and fingernail weakness, and fatigue are also common side effects that affect women of all ages (ACS, 2018).

Common long-term side effects of adjuvant therapy can include early menopause, weight gain, fatigue, neuropathy, and although rare, cardiac damage (ACS, 2018). Early menopause for young women may harm fertility temporarily or permanently. These oncological treatments at a young age may impair fertility either by direct gonadotoxicity (from chemotherapy), by natural ovarian aging (delaying conception) while receiving treatment, or ovarian aging resulting from endocrine therapy (Ruddy et al., 2014).

### **Impact of Breast Cancer Treatment on Fertility and Reproduction**

Surgery, radiation, and adjuvant therapies, including cytotoxic chemotherapy and estrogen therapy, or a combination of these modalities, are appropriate forms of treatment for this population (Anders et al., 2008). Adversely, the use of this aggressive treatment can alter or destroy the reproduction potential of a young breast cancer patient. According to Sonmezer and Oktay (2004), depending upon age, quantity, and type of therapy, young breast cancer patients who receive adjuvant therapy have a 40-80% chance of losing fertility. The risks of infertility

vary with the treatment chosen. Timely referral to fertility specialists, specifically before receiving chemotherapy, may improve the success of fertility preservation (ACS, 2018; Rosenberg & Partridge, 2015).

### **Fertility Preservation Options**

The evolution of assisted reproductive techniques or fertility preservation over recent years has provided multiple fertility preservation options for young women diagnosed with cancer who need adjuvant therapy. Some fertility preservation options have been established through research while others still remain experimental. Fertility preservation prior to cancer therapy is safe and can often be accomplished without significant or any delay in adjuvant therapy, especially if patients are referred early in the course of their cancer treatment planning (Coccia et al., 2018).

### **Embryo Cryopreservation**

Embryo cryopreservation is an established fertility preservation method that has been customarily used to store surplus embryos after in-vitro fertilization. Since a sperm sample is required for oocyte fertilization, the woman must either have a partner or use donor sperm. Embryo cryopreservation provides a good success rate depending on the number and quality of embryos stored. Although data on pregnancy and live birth rates in cancer patients after the frozen embryo transfer are limited, a live birth rate of 38.7% per embryo transfer is reported for frozen embryo transfer in non-oncological patients younger than 35 years of age (Mahajan, 2015).

### **Cryopreservation of Unfertilized Oocytes**

This procedure may be used for fertility preservation in circumstances where the patient does not have a male partner, does not want to use donor sperm, or has religious or ethical

objections to freezing embryos (ASCO, 2018). Data on pregnancy and live birth rates from oocyte cryopreservation in cancer patients are scarce, so success rates extrapolated from other populations, such as young oocyte donors, have to be used for patient counseling (American Society for Reproductive Medicine [ASRM] Practice Committees of American Society for Reproductive Medicine, 2013).

Although these two options for fertility preservation have decent success rates, there are disadvantages. The process for both options can take two to six weeks for ovarian stimulation and retrieval of eggs, depending upon the woman's menstrual cycle phase at the time of planning and treatment. Only a limited number of oocytes/embryos can be collected/generated in one attempt, which in turn restricts the number of attempts for pregnancy (Mahajan, 2015). Additionally, the cost of an embryo and unfertilized oocyte cryopreservation is not commonly covered by insurance, leaving the patient responsible for the cost. These two options can cost approximately \$15,000.

### **Ovarian Tissue Cryopreservation**

Ovarian tissue cryopreservation for future transplantation is a third option for fertility preservation, although it is still considered experimental (Oktay et al., 2018). This method does not require ovarian stimulation that can cause a delay in starting adjuvant therapy: as a result, the procedure can be performed immediately. However, there is a theoretical concern among the medical community that re-implantation of ovarian tissue can potentially reintroduce cancer cells to women depending upon the type and stage of cancer. The literature, though, supports that there have been no reports of cancer recurrence and that, successful pregnancies have been documented (Loren et al., 2013; Oktay et al., 2018). Kim et al. (2018) reported that as of May 2017, there were 87 live births resulting from ovarian cryopreservation and transplantation.

## **Ovarian Suppression**

The fourth option for fertility preservation is the administration of gonadotrophin-releasing hormone agonists (GnRHa). This method has not been proven to be very effective as a fertility preservation method, and it is only used when traditional methods are not feasible (ASCO, 2018). Although it has not been well established, healthcare providers may discuss it as a potential option but must also include the uncertainty of it as its expected role. According to Oktay et al. (2018), GnRHa may be offered to patients in the hope of reducing the likelihood of chemotherapy-induced ovarian insufficiency or failure.

## **Fertility Preservation Cost**

Access to fertility preservation may be limited by geographic location, specialized reproductive centers, and insurance plan coverage. Insurance does not often cover the cost of undergoing fertility preservation, and for most patients, it is unaffordable. Embryo cryopreservation, the most common method for preserving the fertility of women undergoing cancer treatment, is costly. Currently, the national average in the United States is \$10,000 to \$15,000 per in-vitro fertilization cycle. The cost is dependent on insurance coverage, patient characteristics, and treatment center. This fee does not include implantation and storage costs, which are approximately \$300 annually (American Society for Reproductive Medicine [ASRM] Practice Committees of American Society for Reproductive Medicine, 2019). This procedure requires sperm from a partner or donor. A minimum of two weeks is needed for preparation prior to egg retrieval because it requires ovarian hyperstimulation to create multiple follicles (Nass et al., 2015). In addition, the older a woman is at the time of the procedure, the less likely it is to be successful.

## **Outcomes of Fertility Preservation and Reproduction After Adjuvant Therapy**

Studies reported on the outcomes of subsequent pregnancies after surgery (either mastectomy or breast-conserving surgery) and systemic therapy showed reduced pregnancy rates of 12% to 16% and a significantly lower proportion of pregnancies (3%) in the matched population-based studies. The pregnancy rates after breast cancer treatment for survivors were, on average, 40% less than those for the general population, with studies reporting that only 7% of premenopausal women will remain fertile and less than 5% will be able to conceive after treatment for breast cancer (Gerstl et al., 2018). In addition, the results of two matched cohort studies reporting on the outcomes of subsequent pregnancies after surgery (mastectomy or breast-conserving surgery) and adjuvant chemotherapy showed reduced pregnancy rates of 14% to 47% compared with women who had not received chemotherapy (Gerstl et al., 2018). There is no clear data that indicates these results are impacted by attitudes and knowledge of the provider to the patient.

### **The Fertility Preservation Period**

The window of time to make important decisions regarding health status and disease treatment for a newly diagnosed young breast cancer patient is not only short but also stressful. Research has shown that for optimal survival results, the administration of adjuvant therapy should be no more than 120 days from diagnosis (Chavez-MacGregor et al., 2016; National Quality Forum, 2017; Zhan et al., 2018). As a result, once fertility preservation has been decided upon, the young women must also act upon it.

Upon diagnosis, during the brief window of time before the initiation of adjuvant therapy, the young breast cancer patient must make multiple decisions about her health care. First, she must choose a health care team to provide breast cancer care. A breast surgeon, oncologist, radiation oncologist (if necessary), and plastic surgeon are members of the health care team that

need to be decided upon. Concurrently, the patient must confirm that finances and insurance are appropriate to provide the proper coverage. Multiple physician consultations, bloodwork, additional diagnostic tests, genetic counseling, and decisions regarding the type of surgery and treatment also must be done; next, the patient is scheduled for surgery.

When a young woman chooses to preserve her fertility for future pregnancy, additional steps must be taken. The young woman must research and choose an appropriate fertility specialist, choose a fertility preservation option, ensure insurance coverage or secure finances, and then undergo the fertility preservation process. Preserving fertility in addition to undergoing care for cancer all must be completed prior to the administration of adjuvant therapy. This leaves newly diagnosed breast cancer patients with the time from diagnosis to the start of adjuvant therapy from a few weeks to 120 days (Chavez-MacGregor et al., 2016; National Quality Forum, 2017; Zhan et al., 2018) to complete all of the necessary steps for survival from cancer and the possibility of future pregnancy. A decision of fertility preservation for future pregnancy during this time frame, which is already tight and emotionally charged, can be overwhelming for these young women.

### **Health Care Providers Perspective on Fertility Discussions with Patients**

Fertility preservation is a significant issue for young women with breast cancer; however, not all eligible patients receive education regarding fertility preservation from their physicians or other health care clinicians prior to the start of adjuvant therapy (Banerjee & Tsiapali, 2016). The initial focus of oncologists and healthcare practitioners is plotting out the most successful cancer treatment approach, particularly when treating young women who present with a poor prognosis (Minton & Munster, 2002; Stearns et al., 2006). Concern related to fertility preservation is a distant secondary issue.

Studies have revealed that physicians may be reluctant to discuss fertility preservation with their patients. The rationale offered for this reluctance is that primary importance may be placed on discussing issues regarding immediate or life-threatening issues; concern about fertility preservation can delay the initiation of treatment; physicians' admitted gaps in knowledge related to the topic; providers' level of discomfort with subject as well as providers' knowledge of the exorbitant cost associated with fertility preservation (Banerjee & Tsiapali, 2016; Patterson et al., 2015; Quinn et al., 2009).

Although physicians agree that patients should be educated and referred to specialists in a timely manner, most often, fertility preservation does not take priority over patient survival from the doctors' perspective. The literature has shown that the primary concern of physicians is placed on discussing life-threatening issues rather than future fertility concerns. Knowing fertility preservation can take from two to six weeks to complete, physicians often defer initiating these conversations as they are eager for their patients to begin disease treatment (Patterson et al., 2015). This focus on initiating life-saving treatment often results in many young women feeling that their concerns about fertility and future reproduction are inadequately addressed in a timely manner (Lambertini et al., 2013).

Knowledge gaps seemed to be an influential factor in whether or how physicians discussed fertility preservation with their patients. Many physicians acknowledge that they are not well educated on fertility and fertility preservation and often opt to leave the subject unaddressed. Some physicians report a sense of emotional discomfort in discussing fertility issues with their patients when dealing with the more serious concern of breast cancer. Some physicians have described communications with patients as merely "mentioning" fertility preservation instead of engaging in detailed discussions. Even physicians who routinely discuss

and/or refer patients for fertility preservation admitted they (physicians) did not have the necessary information to be able to engage in an informative in-depth conversation (Quinn et al., 2009).

In addition to concerns about the potential delay in beginning adjuvant therapy that fertility preservation might present, physicians find themselves uncomfortable with the substantial cost associated with fertility preservation. Therefore, they do not initiate the conversation with patients freely (Patterson et al., 2015; Quinn et al., 2009). According to Banerjee and Tsiapali (2016), physicians admitted that they were half as likely to have discussions with women who were over the age of 35 or had already had at least two children, regarding fertility preservation. As a result, fewer than half of physicians routinely refer young breast cancer survivors to fertility specialists.

The ASCO issued guidelines in 2006, which were updated in 2013 and again in 2018, recommending that healthcare providers discuss the risk of infertility with young breast cancer patients who require adjuvant therapy. It was also recommended that physicians refer patients to reproductive specialists as soon as possible (at diagnosis), especially if treatment is expected to affect future fertility. According to the ASCO (2018), the implementation of these guidelines may afford young women the opportunity to have a child after breast cancer treatment.

### **Nurses Perspective on Fertility Preservation**

The American Society of Clinical Oncology (2018) expanded the responsibilities of registered nurses to provide fertility preservation education and counseling for patients of reproductive age undergoing cancer treatment. While care coordination is an integral component of every oncology nurse's job, a specific role of oncology nurse navigator was developed to help address certain barriers to care, including the difficulty navigating the healthcare system, poor

communication, and lack of resources. Additionally, many institutions have included oncology nurse navigator staff to provide education and resources to facilitate informed decision making and timely access to quality health and psychosocial care throughout all phases of the cancer continuum (Oncology Nursing Society, 2019).

As active partners in the counseling and education process, these oncology nurses are uniquely positioned to offer fertility preservation counseling and education for cancer patients of reproductive age. Despite these expanding roles, there still is a dearth of research on current practices and perceptions of the nursing role in fertility preservation. One of the few available studies indicated that many nurses expressed the perception that fertility preservation counseling was important, but it was outside the scope of their practice to provide this education (Keim-Malpass et al., 2018).

### **Patient Perspective on Fertility Preservation Discussions with Healthcare Providers**

The literature shows that many young women are interested in having children after breast cancer treatment and want the subject to be addressed (Partridge et al., 2004). Pagani et al. (2015) revealed that at the time of diagnosis, 94% of young women with breast cancer with a median age of 34 who participated in the study wished to have children in the future. Additionally, 29% of the women who participated in that same study reported they may actually refuse lifesaving treatment for fear they will no longer be able to have children. Young women reported that their concerns regarding fertility and loss of reproduction potential were trivialized by their healthcare provider, who advised they should be more concerned about survival than the potential loss of fertility (Dunn & Steginga, 2000).

Fertility preservation plays a key role in the care of young women with breast cancer (Klemp & Kim, 2012). Although there are multiple fertility preservation options available, the

literature states that less than 50% of young adult cancer patients receive adequate or appropriate education and counseling about fertility and reproduction prior to initiating treatment.

Furthermore, approximately 40% of young adult cancer patients who receive adjuvant therapy were not made aware of the impact that treatment can have on fertility (Duffy et al., 2005; Schover, 1999; Schover et al., 1999; Snyder & Pearse, 2011).

With positive outcomes of current breast cancer treatment, most young women diagnosed with breast cancer can expect to become long-term survivors, making survivorship and quality of life issues important. Literature has shown that quality of life is positive for young women with breast cancer who are able to have children after treatment (Goldfarb et al., 2016). Early referral to reproductive specialists allows for young breast cancer patients to utilize fertility preservation options while avoiding a delay in the initiation of adjuvant therapy.

### **Experiential Context**

As the researcher, this study on the fertility preservation experience of young women diagnosed with breast cancer from post-diagnosis to pre-adjuvant therapy is personal. Six months before my 30th birthday, I was diagnosed with cancer of the left breast. I was newly married, and not too long before I was diagnosed, we were starting to discuss when to start a family.

Along with the shocking news of a breast cancer diagnosis came numerous visits with multiple doctors, many diagnostic tests, blood work, and language that although was not completely foreign to me as a nurse, I still had a difficult time comprehending. On one of the first visits with my oncologist, he referred me to a fertility specialist. He explained that the adjuvant therapy I was going to receive could potentially cause temporary or permanent infertility. I was devastated, not only by my shocking diagnosis but now with this additional life-altering information. Although it was not what I wanted to hear, having to incorporate another doctor and

multiple visits into my already crowded schedule, I am very grateful for the appropriate care provided by my oncologist. After multiple surgeries, months of adjuvant (chemo) therapy, and radiation, fortunately, my battle with breast cancer was over.

After an extensive review of the literature for this study, I have read how many young women are not provided with the proper timely education to make informed decisions about their future fertility. Along with this newfound knowledge, my personal experience was the force behind conducting a study focused on fertility preservation experience during the post-diagnosis to the pre-adjuvant therapy time period of young women diagnosed with breast cancer. Additionally, after examining the literature, it was recognized that there is a gap in the literature pertaining to young women with breast cancer who received adjuvant therapy and their experience with fertility preservation and reproduction. The dearth of literature from the voices of these women provided additional passion and impetus. Having lived through this tumultuous period of my life, I am passionate to uncover the meaning of the experience of women who have lived this experience. Giving these women a voice will facilitate understanding of the lived experience during this critical time period.

## **Chapter Summary**

In this chapter, the evolution of the study was presented. This researcher identified that the current status of the phenomenon, understanding the fertility preservation experience of young women diagnosed with breast cancer during the post-diagnosis to pre-adjuvant time period, was understudied. Emerging research exploring the experiences of fertility preservation in this population is important to ensure that all young women receive education and information in a timely manner to help fulfill their after-treatment goal of having children. The chapter also

presented the situated context of my life experiences that was the driving force for investigating this phenomenon. Chapter 3 details the research methodology utilized in this study.

### **Chapter III: Research and Design**

The purpose of this study was to understand the fertility preservation experiences during the period from diagnosis to the start of adjuvant therapy of young breast cancer patients. This study utilized a qualitative approach of a hermeneutic phenomenological design that is underpinned by Martin Heidegger's (1962) philosophical assumptions. This chapter presented an overview of the research methodology for this study. This overview includes the philosophical basis and research approaches of phenomenology and the researcher's rationale for selecting the approach used in this study. The research procedure was presented. This included the application of van Manen's (1990) methodological activities, the methodical structure chosen to guide this study. In addition, the recruitment and sample selection technique, interview settings, data collection, data management, and data analysis methods and ethical considerations were also detailed.

#### **Introduction to Qualitative Research**

Qualitative research is a process of inquiry that seeks an in-depth understanding of a phenomenon. This method of inquiry is used to understand people's beliefs, experiences, attitudes, behavior, and interactions, and generates non-numerical data. In qualitative studies, the method of interviewing participants until data saturation has been met is significant in gaining an understanding of the perceptions and perspectives of others about a particular phenomenon (Agee, 2009). While the use of qualitative research often implies that documentation is scarce about a phenomenon, this approach is also used to give meaning to statistical evidence (Creswell & Poth, 2018).

The qualitative study enhances the involvement of everyone related to the study. It gives voices to the participants in the study by permitting the participants to share their experiences of

the phenomena of interest. It opens the researcher's eyes to new aspects of the phenomenon being studied. This study used the qualitative research method to give voices to the study participants. As a researcher using a phenomenologist approach, I used the data garnered from those voices to identify common meanings among the participants in order to gain an understanding of the essence of the phenomenon (Pathak et al., 2013).

### **Phenomenology Design**

Phenomenology, although developed under the influence of the German philosopher Edmund Husserl, can be traced back to earlier philosophers such as Immanuel Kant, who supported "transcendental idealism"; the differentiation between phenomena (things as they appear) and noumena (things as they are in themselves) and suggested that we can only really know about the former (Kant, 1929). Kant's transcendental philosophy can be found throughout phenomenology which is considered both a philosophy and a method of research. There are two main perspectives of phenomenology: the descriptive or eidetic approach, and the hermeneutic or interpretive approach.

### **Husserl's Perspective: Descriptive Phenomenology**

Edmund Husserl, a German Jewish philosopher and a mathematician, is recognized as the founder of phenomenology as a philosophy and as a descriptive approach to the research of inquiry (Parse, 2001). Husserl proposed a new approach to scientific inquiry that embraced the lived experience (Moran, 2013). Phenomenology, according to Husserl, is the impartial research of things as they appear. The descriptive approach promotes the investigation of the essence of a person's experience as a new source of knowledge (Husserl, 1962; Leavy, 2011). This was a major paradigm shift from the prevailing idea of that time that observation was the only true source of knowledge. Husserl's philosophical perspective posited that experience, as perceived

by human consciousness, has value and should be an object of scientific study (Lopez & Willis, 2004). According to Husserl, knowledge can be attained through interviews and include observation and active listening of participants in order to capture the essence of the personal experience (Husserl, 1913/1962; Rubin & Rubin, 2012).

Husserl advocated for the exploration of essential structures (essences) of a person's experience as it is lived. Additionally, Husserl embraced the concept of bracketing, which dictated a process of suspending one's beliefs and experiences about the phenomenon under study. A significant aspect of Husserlian phenomenology is that it is essential for researchers to perform the epoche or bracketing. This action requires the researcher to set aside all prior knowledge that was attained from personal experiences, readings, and other secondary sources about the phenomenon being investigated. The belief is that when the researcher effectively brackets or sets aside his/her beliefs, feelings, and preconceived notions of the phenomenon, the researcher can better reach the true essence of the phenomenon of the study (Creswell, 2009). This researcher, having had a personal experience with breast cancer and having to endure adjuvant therapy, took the stance that it is not possible to "bracket" or rid my mind of my experiences and bias.

In order to understand the lived experience of fertility preservation, this researcher adhered to Husserl's perspective that each person's life experience can contribute to scientific inquiry (Husserl, 1962) and that essence and new knowledge can be achieved by eliciting the descriptive experiences of the phenomenon of these young women.

### **Heidegger's Perspective: Hermeneutic or Interpretive**

Martin Heidegger, a former student of Husserl, advanced Husserl's work by developing hermeneutic phenomenology. Although Heidegger (1962) agreed that phenomenology is

descriptive, he challenged some of Husserl's assumptions. Heidegger professed that phenomenology encompasses not only a description of the major concepts and essences but also the meanings of the lived experiences (McConnell-Henry et al., 2009). Therefore, it must also be interpretive or hermeneutical. The word *hermeneutic* is derived from the Greek god Hermes who was responsible for interpreting messages between the gods (Thompson, 1990). "Heidegger's interest was in moving from description to interpretation" (McConnell-Henry, et al., 2009, pg. 8). Heidegger (1962) argued that all description is always already interpretation, which led to the evolution of interpretive, or hermeneutic, research.

Heidegger's focus was on obtaining meaning from being, and he adamantly rejected Husserl's concept of "bracketing." He saw the researcher in the world of the participant being interviewed. Heidegger (1962) professed that it is impossible for the researcher to rid the mind of experiences related to the phenomenon being studied and that personal awareness of the phenomena is essential to phenomenological research. A significant characteristic of the hermeneutic interpretive process of conducting research is that it is not possible for researchers to remove themselves from the research process or the findings of the data (Polit & Beck, 2012). Heidegger describes in his seminal work *Being and Time* (1962), about attempts to interpret being-in-the-world rather than knowing the world. "Being in the world" is another characteristic that distinguishes Heidegger's phenomenology from that of his mentor Husserl.

Heidegger's devotion to ontology and the meaning of being lead him to take the stance that looked at existence itself and the search for understanding (van Manen, 2016). It is the personal belief of this researcher that it is not only important to describe but also to interpret or understand the meaning of the lived experience of fertility preservation for this unique population. Heidegger believed that the world is not separate from understanding the meaning of

“being” but is an essential part. The personal history of this researcher of having had the experience of breast cancer at a young age that required adjuvant therapy can aid in understanding the phenomenon of the study. Additionally, I subscribe to Heidegger’s perspective and belief that it is not possible to “bracket” or rid my mind of my experiences and bias of this phenomenon.

### **Max van Manen’s Perspective**

Max van Manen, a Canadian social scientist and educational philosopher, was introduced to phenomenology, hermeneutics, and human sciences while studying pedagogy in the Netherlands. His works on the human science approach to phenomenology provide some alternatives for nursing scientists facing phenomenological reduction problems and reflect the continuing development of phenomenology as a methodological strategy (Dowling, 2007).

Van Manen’s approach includes both descriptive as well as interpretive (hermeneutic) phenomenological characteristics, and like Heidegger, he does not support bracketing (Dowling, 2007). Van Manen’s methodological approach supplied this nurse researcher with the guidance necessary to conduct the hermeneutic phenomenological study of the lived experience of fertility preservation prior to the initiation of adjuvant therapy for young breast cancer patients.

### **Rationale for Choosing the Methodology of Interpretive Phenomenology**

Knowledge deficits and lack of understanding on behalf of both health care professionals and patients regarding the fertility preservation experience for breast cancer patients are alone disturbing. Factoring in the short critical window of time these patients have for the fertility preservation process helps one to realize the importance of developing an understanding of this phenomenon. The interpretive phenomenological methodology is intended to expose what is hidden in the world that surrounds us (Heidegger, 1962). Phenomenology in nursing research

provides an approach that is consistent with the art, philosophy, and practice of nursing. The foundation of nursing concerns itself with the nature of being, existence, and reality, all of which are immersed within the lived experience. Utilizing this approach was appropriate for conducting this study as it is congruent to nursing practice which embrace wholism. The use of interpretive phenomenology, serves as a method of understanding and describing the essence of the these young womens experiences.

I utilized a qualitative, interpretive phenomenological approach to better understand the essence of the lived experience of fertility preservation. This type of methodology aided in describing the common meaning for individuals on their lived experience throughout the process of fertility preservation before the initiation of adjuvant therapy. Utilizing this methodology, I focused on describing what participants have in common as they experience a phenomenon, then I reduced those experiences with a phenomenon to a description of a universal essence “a grasp of the very nature of the thing” (van Manen, 1990).

### **Integration of van Manen’s Methodological Activities**

Phenomenology aims at gaining a deeper understanding of the nature of the meaning of everyday experiences; thus the motto of phenomenology “Zu den Sachen” means both “to the things themselves” and “let’s get down to what matters” (van Manen, 1990, p. 184). Utilizing van Manen’s (1990) six activities, this researcher attempts to uncover and describe the meaning and structures of the experiences of the phenomenon from the perspective of the participants. This interpretive phenomenological methodology assisted this researcher in finding the essence of the following research question: What is the fertility preservation experience like for young women during the time period from breast cancer diagnosis to the beginning of adjuvant therapy? This study utilized van Manen’s six methodological activities as a guide to conducting

this study. The activities were not performed in a linear fashion but were utilized as a dynamic interplay of one another.

The six distinct activities of van Manen (1990):

1. Turning to a phenomenon that seriously interests us and commits us to the world. This activity requires an unwavering commitment to the phenomenon or research question. This includes conversing, interpreting, and understanding things that are of great significance to the phenomenon. My experience with breast cancer at the age of 29 is one of the driving forces behind my conducting this study. Furthermore, after exploring the literature on young women with breast cancer, I have identified being able to have children after adjuvant therapy as a significant concern for these young women, yet this unique issue is not addressed adequately (Banerjee & Tsiapali, 2016; Benedict et al., 2016; Corney & Swinglehurst, 2013). I kept the research question at the forefront of the research process.

2. Investigating experience as we live it rather than as we conceptualize it. The researcher must be immersed in the world of the experience to understand the nature of the lived experience. As a young breast cancer survivor, I might have experienced some of the same thoughts and emotions as the young women who are interviewed. However, while I am mindful of my own experiences, I attempted to explore the lived world of the participants as they sought to renew their contact with their experience of the phenomenon. I gathered data using interviews, observation, and journaling techniques.

Interviews were used for obtaining the stories of the participants' experiences. Interviews provided me with descriptive data, allowing me to understand the meaning of fertility preservation experiences for young women with breast cancer. Observation was also used by this researcher to observe any reactions or emotions that were not verbalized by the participant

during the interview. Journaling or the taking of field notes was also used as a method of data collection for the interviews. Field notes were taken during the interview process as well as immediately after to capture any additional non-verbal data by the participants or thoughts and feelings by the researcher. Additionally, I provided each participant with a notepad so they could journal any new memories of their experience that they may have failed to share with me. These data-collection strategies were used to investigate the phenomenon under study.

3. Reflecting on the essential themes that characterize the phenomenon. Reflection is a primary means of discovering the essence of the experience. Data generated from the participants' interviews were used to uncover themes. A significant challenge was deciding whether the theme was essential or incidental to the experience. Essential themes are themes without which the phenomenon would not be what it is. This was achieved by the researcher reading and rereading transcripts and field notes, listening to the audio recordings, and reflecting on the data. Assistance regarding the reflection and conclusion of essential themes was sought from committee members. These themes were then reflected upon to gain an understanding and essence of the fertility preservation experience of young women with breast cancer.

4. Describing the phenomenon through the art of writing and rewriting. Writing is a reflective component of the phenomenological method. Phenomenological writing is not just writing the report. Writing is essential in every phase of the project: "To write is to reflect; to write is to research" (van Manen, 2016, p. 20). Throughout the research process, I wrote and re-wrote the data gathered from the participants. This process helped me to reflect upon the gathered data and assisted in illuminating the meaning of the phenomenon of the study.

5. Maintaining a strong pedagogical relation to the phenomenon. A phenomenology is a research approach in which requires that the researcher stay devoted to the phenomenon

under study to avoid being diverted. This researcher established and maintained a strong and oriented relation to the phenomenon. I attempted to keep the participants focused on expressing their lived experience with fertility preservation. This was achieved by redirecting the participant back to the research question posed. This researcher remained oriented by being active in the research process. This entailed being in the world of the participant, active listening, and observing participant behaviors.

6. Balancing the research context by considering parts and whole is the sixth research activity. It was important that this researcher remained focused from the beginning and continued to stay focused throughout the research process regarding what this study sought to uncover and understand concerning this phenomenon. The research design and construction of the study was clear and focused. It is possible to lose focus during the research process amid the multiple layers and the process of identifying themes. As a result, I took a step back, reviewed my work, and looked at how each part contributed to the whole. This researcher maintained the focus of the phenomenon of fertility preservation itself and continually worked toward the goal of understanding that lived experience of this unique population.

## **Research Procedures**

This qualitative study was conducted utilizing the interpretive (hermeneutic) phenomenology methodology of inquiry. This study was guided by Heidegger's philosophical framework and van Manen's six methodological activities. In order to understand an experience from the perspective of the participants, the major data-gathering method was primarily in-depth interviews with participants (Creswell, 2009). The aim of this study was to gain an understanding of the essence of the lived experience of fertility preservation of young women diagnosed with breast cancer who received adjuvant therapy.

## **Participant Sample**

In-depth, unstructured, face-to-face interviews were used to capture the voices of young breast cancer patients who experienced fertility preservation within the past five years.

Participants must have been diagnosed with breast cancer and experienced fertility preservation prior to the initiation of adjuvant therapy (Creswell, 2009). Inclusion criteria consisted of participants being at least 18 years of age, and the ability to speak, read, write, and understand the English language to adhere to the chosen methodology. To decrease the chances of participant bias, family, friends, and acquaintances of this researcher were excluded. Using in-depth interviews required that participants must be able to articulate their fertility preservation experience prior to the initiation of adjuvant therapy. Participants who met the criteria were asked to participate in this research study.

## **Recruitment**

The purposive sampling method had been selected based upon this research study's aim to understand the lived experience of fertility preservation of the young breast cancer patient who received adjuvant therapy. This researcher used face-to-face interaction at support groups to solicit potential respondents. Personal referral and snowball sampling methods were utilized to contact additional potential participants. Institutional Review Board (IRB) approved flyers (Appendix A) were posted in public locations where health care and supportive services for the young breast cancer population are provided.

## **Setting**

The data collection and interview process was conducted in the participants' natural setting of choice, for example, the participant's home or a private office or room at their provider's site. This maintained authenticity regarding human behavior and allowed for the most

comfortable situation for the participant as possible. The participant and the researcher mutually agreed upon the interview schedule, location, and space for the interview.

### **Protection of Human Subjects**

It is the ethical obligation of the researcher to protect the participants and to safeguard their identities as well as their shared experiences. Approval was obtained from Molloy College IRB. This study posed no significant ethical issues and was conducted in accordance with Good Clinical Practice (DeRoy, 2004), the Declaration of Helsinki (World Medical Association, 2013), and the Molloy College IRB rules and regulations. Informed consent (Appendix B) was obtained from the participants prior to the interviews and for the audiotaping.

The informed consent (Appendix B) was used to explain the study's purpose and procedures in simple terms before participants enter into the study. The consent form contained a comprehensive description of the research study to enable the participant to determine whether she wanted to participate in this study. In addition, this researcher explained in simple terms and answered any questions the participant had regarding the study procedures before the participant entered into the study. Informed consent (Appendix B), appropriate signatures, and dates on the document were established prior to the beginning of each interview. All research was conducted in accordance with the IRB procedures at Molloy College.

This study aligned with the Nuremberg Code, which is focused on the protection of human subjects in a research study. Participants were informed before and throughout the study that their participation is voluntary. Participants were made aware that they may stop the discussion at any time, reschedule, or withdraw at any time without any adverse consequences. Any information they may have contributed may also be excluded if they so choose. Their refusal or discontinuation at any time will be without penalty.

The participants were asked to participate in one to three interviews lasting approximately 45 to 60 minutes per interview. Participants were assigned pseudonyms of the participant's choice to assure confidentiality. Participants were made aware at the beginning of each interview that they will be audiotaped and verbal consent will be obtained. Each participant's signed informed consent (Appendix B) was kept in a secure and locked location apart from the transcripts and audio tapes where only this researcher had access.

As the researcher is the primary data-collection tool in a qualitative study (Creswell, 2013), it was essential that I clearly expressed my personal values, assumptions, and biases at the outset of this study. The phenomenon of interest is the fertility preservation experiences of other young women diagnosed with breast cancer. As a young breast cancer survivor, personal perception of those experiences can be brought to this study. To establish trust between the interviewer and interviewee, each participant was provided with a brief disclosure of my history with breast cancer. Participants were made aware of local counseling and or supportive services such as Adelpi NY Statewide Breast Cancer Support & Hotline and Cancer Care, Inc. These services are free of charge to the public and can be accessed by any participant in the event that recalling a particular experience evoked an emotional response.

### **Data Collection**

Active asking and engaged listening are methods of interviewing that are appropriate when a researcher is focused on a particular phenomenon requiring an understanding from those being interviewed (Rubin & Rubin, 2012). The use of in-depth interviews allowed this researcher to ask questions and use probes for details and clarity when collecting data. The utilization of this type of open-ended, unstructured, one-on-one interview process in a private space of the participants' and researchers' choosing facilitated openness and increased engagement. It guided

the conversation and allowed the participants the ability to discuss the areas of importance to them. This enabled participants to voice their experiences unconstrained by any perspective of the researcher or past findings (Creswell, 2013). This process placed the participant in the center of the interview and recognized each participant as the expert of her own experience (Rubin & Rubin, 2012). Prior to beginning each interview, this researcher explained the purpose of the study, the inclusion criteria, and the participant's role in the study. A short script describing my strong relationship with the phenomena was utilized and shared with each participant (Appendix D). Written informed consent (Appendix B) was then obtained. Participants were asked to complete a short demographic form (Appendix C) related to the current age, marital status, age of diagnosis, income level, and insurance status at the time of diagnosis. The unstructured interview questions were formulated to meet the needs of the research methodology (Salzmann-Erikson, 2013).

Interviews were conducted in person, with one interview conducted via telephone. All interviews were audio-recorded lasting about an hour each, and field notes were taken during and immediately after the interview. Field notes were used to document how participants reacted during the interviews and assisted the researcher to synthesize and further understand the context of the data (Polit & Beck, 2012).

### **Data Management**

Following each interview, audio files were transferred to a secure internet network and a password-protected personal computer. Recordings were password secured, transmitted to, and secured by a reputable professional transcription company. The researcher and a professional transcription service transcribed the interviews verbatim. Transcripts and field notes are kept in a secured, locked filing cabinet or password-secured computer file. All external storage media,

paper memos, and field notes of the interviews, as well as any hard copy material, were stored in a locked file cabinet. This researcher retains all flash drives, journals, and transcripts for a period of seven years. This researcher shared material relating to this study with only the members of the dissertation committee.

## **Data Analysis**

The NVivo computer system that supports qualitative research was used for this study to manage data during collection and analysis. NVivo was used to organize and store the interviews, notes, memos, and journal entries and assisted the researcher in creating a final analysis of the data (QSR International, 2018). In addition to the NVivo computer system, this researcher utilized Interpretative Phenomenological Analysis, a qualitative approach that aims to provide detailed examinations of personal lived experience, in which the researcher is attempting to make sense of the participant, trying to make sense of what is happening to them (Smith et al., 2009). The data were read and re-read and coded in an attempt to establish themes. This analysis included listening, observing, judging, challenging, reflecting, and looking for bias from the participant and as well as the researcher.

## **Rigor**

Trustworthiness in qualitative research, according to Lincoln and Guba (1985), is established by four criteria, including credibility, dependability, confirmability, and transferability. This framework provided the researcher with a foundation to establish rigor in this study. These steps were utilized for data collection and analytical methods were used to maintain rigor and trustworthiness (Polit & Beck, 2012).

Credibility was established by portraying a true picture of the phenomena by finding confidence in the data from the participants of the study. Lincoln and Guba (1985)

acknowledged that credibility involves two aspects: first, carrying out the study in a way that enhances the believability of the findings, and second, taking steps to demonstrate credibility in research reports. Prolonged engagement will assist in establishing a rapport and building trust, which will yield rich data. Member checking, discussing emerging themes with participants to see if they align with their experiences, will also aid in ensuring that participants' meanings were understood. This researcher interviewed participants and then read and reread and reflected on the transcripts until a sense of closure had been met. Additionally, debriefing with the members of the dissertation committee assisted in establishing credibility.

The second criterion this researcher adhered to in this framework is dependability (Lincoln & Guba, 1985). This criterion references the stability of data over time and conditions ensuring that the data for the phenomenon are accurately documented and portrayed. To establish dependability, I kept detailed documentation of interviews, field notes, and memos as an audit trail for authentication.

The third criterion established was confirmability, which refers to objectivity in establishing a similarity in the accuracy of the data between two or more autonomous individuals. The goal of this criterion is to validate that the results represent the findings provided by the participants and that the researcher does not invent the interpretations of those results. This researcher utilized the "audit trail" an in-depth description of how the researcher collected and analyzed the data from the start of a research study to the development and reporting of findings. This researcher reconciled data collected from audiotapes, field notes, and transcripts to ensure dependability and confirmability.

The fourth criterion this researcher established is transferability, which was ensured by providing a rich account of the data collected. This entailed describing not only the context of the

interview but also participant behaviors so the experiences become meaningful to readers. To ensure consumers can evaluate the applicability of the data in contexts, this researcher provided adequate descriptive data (Polit & Beck, 2012).

Trustworthiness and the utilization of the findings from the voices of the participants' life-world experiences was attained by orientation, strength, and richness of their stories. This researcher involved herself in the world of participants' stories to establish orientation. Strength was achieved by the text representing the understanding of the meaning expressed by the research participants through their stories. Richness was established by the quality of the text that describes the meanings as perceived by the participants (van Manen, 1990).

### **Risks Associated with the Study**

There were no research-related risks anticipated with this study. It is possible that some participants may have felt tired from talking for an hour. Psychological discomforts were not experienced by the participants even though the nature of the phenomenon is an intimate issue being studied. This researcher has extensive professional experience dealing with young women (patients) with breast cancer and utilized this in making an earnest effort to protect the participants in this study. Although the role of the nurse researcher in a qualitative study is to gather, analyze, interpret data, and report the findings, it may become difficult to maintain the primary role of the researcher. This researcher self-identified as both a nurse and researcher and ensured that each participant understood that my interaction with them was solely that of the researcher.

### **Limitations**

Several potential limitations were identified by this researcher prior to conducting this study. Potential limitations of this study were the participants' degree of willingness to disclose

their experiences. Fertility preservation and breast cancer are both sensitive topics that people may have a difficult time discussing. Due to the sensitivity of this topic, participation in this study might have been extremely challenging for young women, especially if they remain childless despite their efforts. Another limitation that may have arisen was the process of recruitment via inter-personal relationships and the snowball method. These two methods might not have produced the number of participants desired or participants who met the criteria for this study. A possible limitation was that due to the exorbitant cost of fertility preservation, the available population may be skewed towards those of higher education and income level. Another potential limitation is it would be challenging for young breast cancer survivors to be willing to participate in this study if they participated in fertility preservation prior to the initiation of adjuvant therapy. Participants who met the criteria may not have wanted to participate because both breast cancer and fertility preservation are sensitive topics and having to recall the experience may have caused emotional trauma for the participants. Trust was needed to gain access to potential participants. The researcher conveyed explicitly that the interest of this study was to better understand the fertility preservation and reproduction experience of young breast cancer survivors who received adjuvant therapy.

### **Summary of the Chapter**

The purpose of this phenomenological study was to examine the lived fertility preservation experience of young breast cancer patients prior to receiving adjuvant therapy. This chapter presented an overview of the philosophical bias, research approaches of phenomenology, and the researcher's rationale for selecting the research method used in this study. The research procedure guided by van Manen's methodological activities was discussed. The protection of human subjects, recruitment and sample selection technique, and interview settings were

presented. In addition, the procedure used for data collection, data management, and analysis were also detailed. The chapter concluded with an articulation of the procedure for maintaining rigor and a discussion of the potential risks and limitations of the study. Chapter four presented the analysis and findings of the study.

## **Chapter IV: Findings**

The purpose of this phenomenological study was to explore and understand the experience of fertility preservation during the time period after diagnosis and prior to the start of adjuvant therapy for young breast cancer survivors. This chapter presented a descriptive summary of each of the stories and provided an in-depth description of the data collection and data analysis. Findings and essential themes that emerged as a result of data analysis were also presented in this chapter.

### **Detailed Description of the Participants**

Prior to the interview, each participant completed a demographics survey (Appendix C). The survey collected data on age, ethnicity, year and age diagnosed with breast cancer, county of residence, marital status and level of education at the time of diagnosis, employment, household income, insurance status, and whether or not there were children at the time of diagnosis (see Table 1). The demographic information obtained provided the study with a more in-depth illustration of each participant, thus enhancing the understandings of their lived experiences.

The study sample consisted of eight young women between the ages of 18 years to 36 years of age who within the last five years experienced fertility preservation prior to receiving adjuvant therapy subsequent to a breast cancer diagnosis. Three of the participants were married, one was in a serious relationship, and four participants were unmarried. One of the participants had one child at the time of her breast cancer diagnosis.

**Table 1: Demographic Chart**

ID/ Pseudonym	Age	Race/ Ethnicity	Year Dx	Age Dx	Marital Status	Employed	County of Residence	Insured	Children @ diagnosis
TC	29	Caucasian	2019	28	Married	Yes	Nassau	Yes	0
AJ	20	Caucasian	2017	18	Not Married	Yes	Nassau	Yes	0
EG	21	Caucasian	2017	19	Not Married	Yes	Nassau	Yes	0
EF	33	Hispanic	2017	31	Not Married	Yes	Queens	Yes	0
ND	37	Caucasian	2015	33	Serious Relationship	Yes	Nassau	No	0
LS	23	Caucasian	2019	22	Not Married	Yes	Nassau	Yes	0
KJ	36	Caucasian	2018	35	Married	Yes	Queens	Yes	0
MJ	37	Caucasian	2016	34	Married	Yes	Nassau	Yes	1

**Data Collection**

Interviewing is an approach utilized in hermeneutic phenomenological research to collect information with the purpose of cultivating a deep understanding of the phenomenon of interest (Husserl, 1913/1962). This study relied on the memory and critical reflection of the participants to interpret and understand rather than to just explain. Therefore, the hermeneutical approach is appropriate when posing the research question “Can you please tell me about your experience with fertility preservation prior to the start of adjuvant therapy?” During the interview process, young women who underwent fertility preservation prior to breast cancer treatment shared their personal experiences by way of their story. Personal interaction with the participants along with

their stories allowed for this researcher to gain an insight into the participants' lived experiences. Interviews were conducted between January 2020 and March 2020. Prior to each individual interview, participants were contacted via email, telephone, or in person for the purpose of screening for inclusion criteria. Once inclusion criteria were met, each participant and this researcher mutually agreed on a time and meeting place for the interview.

Prior to the start of each interview, the approval letter from Molloy College IRB (Appendix F) was shared with each participant. The nature, purpose, and respective role of the study were explained. Each participant was assured that confidentiality would be maintained, as each participant would be identified by a pseudonym of their choice to protect their identity and preserve their privacy. Upon dissemination of this information, written consent was obtained from all participants (Appendix B). Permission to record interviews was obtained from each participant by explaining it was necessary for the accuracy of the data. Additionally, each participant was informed that any identifiable information collected would be removed from the data.

All interviews, except for one, took place face to face in a mutually agreed upon location for the participant and researcher. One interview took place via telephone due to participant/researcher scheduling. For this participant, the consent form was emailed to the participant and the signed document was returned via a secure password-protected (encrypted) email prior to the interview. To further maintain the privacy and protection of this participant, I received her call while in a private room with the door closed; she was in her living room, home by herself, waiting for her husband to get off work. Prior to each interview, a script (Appendix D) acknowledging my strong relationship with the phenomena was shared with each participant.

Each interview began using the open-ended question, "Can you please tell me about your

experience with fertility preservation during the time period once you were first informed of your diagnosis and before you began adjuvant therapy?” In addition, attention and conversational management probing questions (Rubin & Rubin, 2012) were used such as:

- What supported or hampered your decision?
- Describe your experiences with your family, spouse, significant other, and friends during this time period.
- Can you think of any physical, emotional, or even spiritual aspects of your fertility preservation experience from back then until now?
- Describe any challenges you may have experienced with the fertility preservation process.
- What is important for nurses and healthcare providers to be aware of when providing care to young breast cancer patients who may want to preserve their fertility?
- What advice related to fertility preservation would you have for a young woman newly diagnosed with breast cancer?
- Is there anything else you would like to share about the fertility preservation process?

Probing questions were available but hardly ever utilized because the participants spoke freely and comprehensively about their fertility preservation experience (Appendix E). The length of the interviews was approximately 35 minutes to one hour long. All of the participants were enthusiastic and willing to openly discuss their experiences. Each participant was asked at the end of each interview, “...is there anything else you would like to share?” All of the participants declined and said they did not. At the conclusion of each interview, participants were

thanked again for their time and willingness to share their experience.

Two digital recorders were used throughout each interview in anticipation of allaying any technical issues. Upon conclusion, each interview was transferred to a personal computer using a secure password-protected system only available to this researcher. Immediately following each interview, field notes were made of the interview process and of any observations. These field notes were included as part of the data collected. Field notes were recorded in a notebook dedicated to this research study. All interviews were transcribed verbatim. Transcripts were vetted to remove any names, locations, or other forms of identification.

Participants' information, recorded interviews, hard copies of transcribed interviews, observations, and field notes are kept in a locked file cabinet where only this researcher has access. All information related to this research study including transcripts, recordings, digital files, and notes are all secured and will be retained for the period of time as specified according to the Molloy College IRB regulations.

### **Descriptive Summaries of the Participants and Their Stories**

The following descriptive summaries are brief reconstructed life stories (van Manen, 1990) that reflect my observations of each participant in conjunction with an overview of her lived experience descriptions. Each participant is referred to by the participant's self-chosen pseudonym to protect confidentiality. Each participant shared her experience in detail without much, if any, probing or prompting from this researcher.

#### **Participant 1: TC**

TC was a 29-year-old Caucasian female who was diagnosed with breast cancer in 2019 at the age of 28. TC discussed her experience with me via telephone. She called at the scheduled time and I was in a private room with the door closed. TC was home in her living room waiting

for her husband to come home from work. TC was working full-time with the company she is currently employed with now. She explained that prior to her breast cancer diagnosis, she was a very healthy person and was very disciplined when it came to her doctor appointments. TC reported having a planned appointment with her gynecologist in May where everything was fine. Two weeks away from her wedding day, she discovered a lump in her breast (in early July) when performing a breast exam in the shower. She went to the breast surgeon who said it was a fibroadenoma and that she should “go enjoy your wedding.” TC noticed upon returning from her honeymoon the lump got larger. At that point, she showed her mom and decided to get a second opinion. She went to another surgeon whom her mom has used before. The new doctor reviewed the report from the first doctor and said that while she agreed with the first doctor, she recommended that a biopsy be done. TC received a call from the doctor requesting that she come in because the biopsy came back cancerous. TC explained that the doctor was so shocked that she had never viewed a mass on an MRI, Sonogram, and mammogram that looked nothing like cancer yet actually turned out to be positive, in all her years of being a surgeon. She took blood to test for the BRCA gene, which took weeks to find out. The doctor was so shocked that she wanted to test TC’s DNA to make sure the pathologist did not make a mistake and give her someone else’s results. TC explained that she along with her family were on their hands and knees for five days praying that this was a mistake, hoping it was a big mix-up. The doctor finally called, and she said, “It was your tissue: Stage 2A ductal carcinoma.”

TC was diagnosed with breast cancer in August after returning from her honeymoon. TC described that as she was adjusting to married life, she was faced with having to come to terms with her new diagnosis. She stated her doctor informed her she was going to need chemotherapy and that the chemotherapy may cause her to not be able to have children. He said that if she

planned on having kids in the future, she should see a fertility specialist. She stated, “It was just too much.” TC also stated that “as the doctor was telling me I needed to freeze my eggs, I was barely listening to him”. She said she was told to “do (freeze) embryos since we were married: it was horrible.”

TC explained that she worked for a great company (she is currently still with the company) with excellent medical benefits and that the fertility preservation procedures were covered. However, medications for the fertility preservation process/procedure were not covered. TC was referred by her fertility doctor to the Livestrong Fertility Program, which donated one cycle of fertility medication.

Now called Livestrong Fertility, the program is dedicated to helping men and women diagnosed during their reproductive years better understand cancer-related risks to their fertility and access discounted fertility preservation services and free medication. Additionally, Livestrong Fertility provides access to medical professionals with equational resources to improve patient-provider communications and tools to implement systemic change that can lead to better care (<https://www.livestrong.org/what-we-do/program/fertility>).

TC continued, “And here is my new husband having to give me like ten shots a day for like two weeks to try to grow my eggs. Then I had to go there every two days for them to look at my eggs and then had egg retrieval.” TC explained that they [the specialist] were able to “retrieve 20 eggs, which are like an incredible amount.” She further explained that eight eggs were fertilized, giving them eight embryos, but unfortunately, two died on day three, leaving six frozen embryos. TC also stated, “If I have to say, the hardest thing of this entire process was that fertility preservation and being in menopause at 30 years old; it was horrible, it was horrible.”

## **Participant 2: AJ**

AJ is a 20-year-old Caucasian female who was diagnosed with breast cancer in 2017. A few days before her 19th birthday, AJ discovered a lump in her breast while putting on a towel after her shower. AJ said she mentioned something to her mom who said she should see a gynecologist. Since this was actually her first visit to a gynecologist, AJ chose to go to the doctor her mom uses. This doctor recommended an ultrasound because she did not want AJ to be exposed to the radiation from the mammogram. After the ultrasound, the doctor wanted AJ to do a mammogram anyway, so she did. The radiologist recommended that AJ have a biopsy, which she did the next day. AJ said a few days later, which she said “felt like an eternity,” she got a phone call telling her the biopsy came back positive and that she had cancer. AJ explained that she was on the phone with the doctor who was giving her all sorts of instructions, but once she got off the phone, she had no idea what the doctor had said and she did not write any of it down. She decided to call her back and sit there with her mom so they could get all the information. She made appointments with multiple surgeons and oncologists for different opinions. AJ stated she was provided with multiple options for surgery, but, because of her young age, she decided on a lumpectomy with breast conservation. AJ then went to the oncologist who said with the type of cancer she had, she would need chemotherapy. She explained that even though she believed she might need to have chemotherapy, it was still devastating for her to hear. AJ reported that it was only upon her return to her gynecologist that both she and the gynecologist realized that the oncologist did not bring up or address the issue of fertility preservation. It was the gynecologist who then explained how the chemotherapy may interrupt the normal function of AJ’s ovaries. AJ was upset that the oncologist never mentioned anything about the loss of fertility due to the medication. AJ, as a result, chose to change her oncologist. The oncologist she ultimately chose

did explain the fertility risks involved with having chemotherapy and recommended that she see a fertility specialist. He recommended a fertility doctor in the city who she went to see. AJ explained how it was “weird” sitting in a fertility specialist’s office with her mom because everyone else was sitting there with their significant others. She discussed that she was there for about two hours talking to the doctor. She explained that she was told she would have to inject herself every day to stimulate and grow the eggs in her ovaries. She said she was told that once the eggs were big enough, the doctor would be able to perform the egg retrieval process. AJ explained that she was concerned that the medication she would need to take to help stimulate her ovaries is estrogen and her cancer was estrogen receptive. She said, “So it kind of made me think, do I really want to put that in my body? And I asked him about it.” She said the doctor assured her that the literature he has read showed there has not been increased cancer when estrogen is given because the amount is similar to what one’s body would produce. She said with that information, she decided to go ahead with it. She explained that she did not want to be left without any options. The doctor wanted to draw blood and do a transvaginal ultrasound, but AJ had to get approval from her insurance company before she could start. AJ’s insurance did not cover the medication, so she was referred to Livestrong. She explained that she was so happy she was referred to them. They supplied her with the two weeks of medication she needed to stimulate her ovaries and grow the eggs. Because AJ’s insurance was taking forever to approve the procedure, her oncologist agreed to her pushing her treatment back two weeks so she could preserve her fertility. Once she finally received approval, the medication was sent to her house. AJ’s mom had volunteered to give her the medicine. She explained that her mom said she really did not like doing it, but she felt bad and wanted to help. So, they would alternate administering it. Once AJ started the medication, she had to go into the doctor’s office multiple times a week

for bloodwork and ultrasounds to be able to monitor her hormone levels and the size of the follicles. She explained that she had bruises all over her arms from them taking blood, and after a while, they started to have problems trying to access her veins. She said her stomach was sensitive from the shots every day and that she was bloated all the time. Once the eggs were big enough, she went in for her egg retrieval. AJ reported that her mom accompanied her for this procedure. She said her boyfriend felt bad not going, but he said he didn't want to see her uncomfortable afterward, so he came to her house for when she got home. AJ described the difficulty the providers had in gaining intravenous (IV) access because she had had so much blood taken over the previous few weeks. When AJ woke up from the surgery, she was told the doctor was able to retrieve 20 eggs. Once AJ felt well enough, she was escorted home by her mother. She said she felt "ok just a little tired." The doctor called her later in the day to let her know that 14 of the eggs were mature enough to be frozen.

### **Participant 3: EG**

EG is a 21-year-old Caucasian female who was diagnosed with breast cancer one week before her 19th birthday. At the time of her diagnosis, EG was single, living at home, and working a full-time job. EG reported that one morning, her parents woke her up at 7a.m. saying the doctor called and recommended that she have a biopsy of a mass that he noticed on a scan she had done a few days prior. A few days later, the biopsy results came back as invasive ductal carcinoma.

EG explained how the next week or so was filled with doctors' appointments. The doctor gave EG the name and number of a surgeon and an oncologist. She reported her doctor told her that she was going to need surgery and probably chemotherapy. EG stated, that "First of all, I couldn't think past the fact that I have cancer. Then I was told that I was probably going to need

chemotherapy. I really felt like this was not all happening. I felt like it was like some bad dream that I was waiting to wake up from. Nope! Not a bad dream although I wish it were.” EG discussed that although there was a lot that needed to be done, those next few weeks are a blur to her. She explained that she made appointments with the doctors she was referred to but also went for second opinions. She ultimately chose the surgeon her doctor recommended but then chose a different oncologist. EG explained that because of her diagnosis, she opted to do a bilateral mastectomy. Because she was thinking of reconstruction as well, her surgeon recommended she see a plastic surgeon to get all the important details and information about when to have it done and the options for reconstruction. EG explained how she chose a plastic surgeon and an oncologist within a few days of one another. She said the oncologist explained that since the cancer was invasive that she would need chemotherapy. EG stated, “I’m thinking, okay, this is a lot to process, but then he tells me that the chemo I would be on could, not definitely would, but could prevent me from having children in the future, and for me, that was just not an option. It was kind of like something in the back of your mind you don't really want to think about, but you're forced to. For me, the option not to have kids was not an option.” With this information, EG made an appointment with a fertility specialist and then onto another for a second opinion. She explained how this all started on a Wednesday morning and by the next Wednesday, she had a surgeon with a plan for surgery, a plastic surgeon with a plan for reconstruction, and an oncologist with a breast cancer treatment plan in place. Then she was researching and choosing a fertility specialist. EG explained how initially the fertility specialist wanted to put her on a drug called Lupron. He said it would put her ovaries to sleep so they wouldn't be working so hard as her body was trying to heal itself from the chemotherapy. But he also said Lupron was not a sure thing as it was still experimental as the sole fertility preservation method. EG said then he [the

fertility specialist] explained if she just did Lupron, there would not be any type of invasive procedure. He said his feelings were because she was so young, he thought her ovaries would bounce back so she wouldn't have to go through the whole fertility preservation process. EG explained that after listening and processing all of this, she decided to go ahead with the traditional fertility preservation method (i.e., egg retrieval, and either freeze her eggs or embryos). She said she wanted to make sure that she at least had an option to try to have kids. She did not want to chance going into menopause if the Lupron didn't work. EG also commented on how unusual it was being at a fertility clinic with her parents while most people were there with a husband or significant other. EG said the staff at the fertility clinic were great and they worked well with her, but it was still kind of awkward. They tried to make her feel as comfortable as possible, but the whole situation was awful. It started with bloodwork and an ultrasound. The nurse then told her that medication would be sent to her house and it had to be kept in the refrigerator. Before she left, the nurse showed her and her mom where and how to inject the medication. This was done every night for approximately two weeks. In addition to the injections, she had to make trips to the fertility clinic daily for bloodwork and ultrasounds so they could see how her ovaries were progressing. That schedule changed to every other day for a few days and then went back to every day. Once the eggs were large enough, it was time for the egg retrieval. EG explained the procedure, how she was poked at to try to get someplace to put an IV, after her arms had been beaten up for the last two weeks trying to get blood. Once the IV was in place, she was given medication to fall asleep. She explained how the next thing she knew she was groggy, her stomach hurt, and she just wanted to go home and go back to sleep. Once she was awake, the doctor came in to check on her and said they were able to retrieve 19 eggs. EG decided to freeze her eggs since she had just turned 19. She said, "I didn't think it was

appropriate for me to freeze an embryo made with someone else's sperm." The doctor called EG later in the evening; they said they were able to freeze 14 of the 19. They said those were pretty good numbers. EG said she was very glad that part was all done and that she really would not want to wish having to do that on her worst enemy. EG had the egg retrieval done on a Thursday and the following Monday, she had a bilateral mastectomy. She explained that since she healed pretty well and quickly from the surgery, she started chemotherapy two weeks after surgery.

#### **Participant 4: EF**

EF was a 33-year-old Hispanic female who was diagnosed with breast cancer in 2017 at the age of 31. At the time of her diagnosis, EF was not married and was working full-time. EF stated she found a lump and went to the doctor. The doctor then sent her for an ultrasound. The doctor performing the ultrasound decided to biopsy the lump while she was there. EF stated, "All I can remember thinking and saying to myself is that this couldn't be happening." Two days later, the results came back that the lump biopsied was cancer. EF was referred to a surgeon and to an oncologist. During the visit with the surgeon, EF decided on a bilateral mastectomy. EF then went to her oncologist appointment where she was informed that with the type of cancer she had, she was going to need chemotherapy and possibly radiation. The oncologist also informed EF that the chemotherapy may affect her ovaries because of her advanced age and that if she were thinking about having children in the future, that she may want to look into fertility preservation. She said she didn't think that she was that old, but according to her doctors, from a reproductive perspective, she was on the older side. EF verbalized that she had a hard time processing all of this. She said she honestly felt like Charlie Brown when the teacher was speaking and all she heard was "blah blah blah."

EF only had time for one cycle of egg retrieval as she needed to start chemotherapy as

soon as possible, especially since she was already delaying starting chemotherapy for a week in order to preserve her fertility. EF stated she had insurance that covered the cost of the fertility preservation procedure, but it did not cover the medications or the monthly/yearly cost of storage. EF was referred to the Livestrong Fertility Program, which donated one cycle of medications to her. EF explained how the drugs were sent to her house with instructions on how to self-administer them. She explained how never in her life did she think she would be doing something like this. EF stated, “I look back and wonder how I made it through all of this.” EF injected herself morning and night with hormones to stimulate egg production. Once the medication started, she had to make trips to the fertility clinic either every day or every other day to monitor her ovaries and hormone levels. EF stated the doctor explained the risks of the medication and procedure to EF as minimal but the side effects of the drugs could be brutal, and according to EF, he was right. EF explained that she was in immense pain all of the time, that her ovaries hurt, she was constipated, and always very tired. She had bruises all over her arms and hands from where they were trying to get blood samples either every day or every other day. Her stomach was extremely sore from the daily injections. EF stated that she was glad the medication she was injecting was only for two weeks as “I don’t know how much more of it I could have taken.”

EF explained how the egg retrieval only took about 20 minutes. She was given an IV injection to relax her; she also reported that gaining IV access was almost impossible as all her veins had been previously poked. They then gave her a local anesthetic and that was the last thing she remembered. When she woke up, she saw the doctor standing there and he asked how she was doing. EF reported she was told the first words out of her mouth when she woke up were, “I’m great; thank you, doctor, for giving me hope to be able to have children in the future.”

She was told that the doctor was able to retrieve 16 eggs and would let her know how many of them were mature enough and could actually be frozen. After recovering from the procedure, EF went home and just sat for a while. She said she remembered letting out a big sigh, thinking, “Ah I’m done. And then it hit me, I still had to do chemo and then surgery and reconstructive surgery.” EF was informed that evening that 12 of the eggs were mature enough to freeze. EF started chemo a few days later. She explained how it felt it went on forever, but “Let me tell you; chemo was nothing compared to fertility preservation.” “Here I am a few years later and I’m still working on piecing myself back together. The great part is, no matter how long it takes me to get myself together, I know I still have options.”

#### **Participant 5: ND**

ND was a 37-year-old Caucasian female who was diagnosed with breast cancer in 2015 at the age of 33 years old. ND was single but in a serious relationship and she worked full-time at the time of her diagnosis. ND said one of the first things she was told after her breast cancer diagnosis (by a friend of hers who was also diagnosed with breast cancer) was not to forget to think about fertility. ND explained how everyone kept asking what she was going to do about fertility planning. Was it something she was going to think about? Was she going to freeze her eggs? ND explained that at that point, she had no idea where to go with it. She explained how the boyfriend she had at the time of diagnosis is the boyfriend she is still with now. ND discussed how the crazy part other than being so young to be diagnosed with breast cancer was the time frame. Everything seemed to happen at lightning speed. The time frame from diagnosis until what to do with fertility was about two weeks. ND explained that although she had no insurance coverage, she did not even think about insurance coverage for any of that. She discussed how she never had any health problems and was not trying to even think about having a family, so this

was not even a thought. Within two weeks of her diagnosis, she and her boyfriend sat down with the fertility specialist. She explained that they had to make some really quick decisions on what they were going to do with their future. ND went on to describe how tough it was because she was also dealing with the heartache of having cancer. She explained that at that point, she really could not see the future because of her cancer diagnosis. She explained how it was so much to wrap her mind around. She was just diagnosed with breast cancer and worrying about whether or not she was going to live or going to die, and then thrown into what is she going to do about her future. She explained how she kept worrying about her future and if she was going to have one. She said that her boyfriend told her she had to stop worrying about the whole cancer thing and focus on what had to be taken care of right now. ND explained that her fertility specialist knew she had no insurance, so he put her in touch with the Livestrong program. She was provided with two weeks of in-vitro fertilization medication, which she said was enough because that's really all the time she had to do all of this. ND explained that after two weeks of medication administration, she went back to her for egg retrieval. ND said, "So here we are on our way to the fertility clinic; they call me and tell me I had to pay \$7000 upfront for the egg retrieval. Thank goodness I had the money up front, but I can't imagine people that don't necessarily have that amount of money to do it." She went through with the egg retrieval and had to make tough decisions as to whether they were going to freeze eggs or embryos. They were told the eggs don't thaw as well as embryos, so they had to make quick decisions on what to do. They opted to freeze embryos. ND explained that shortly after the egg retrieval, she started chemotherapy. She also discussed that after she went through all of that, she later found out she will never be able to carry kids. The reason she said was that her breast cancer was hormone related so there is a risk there if she were to ever become pregnant that cancer could come back. And right now, almost

five years later, she is still on medications to help subside the estrogen. She still also has monthly injections as part of her cancer treatment.

ND explained that with all of that, she cannot really carry her own kids. ND and her boyfriend are at the stage where they are contemplating if they are going to start a family and what does that look like? Is it surrogacy? Is it adoption? Do they not have kids? She explained how they have had the opportunity to confide in a lot of people who have gone through all of this through support groups. She said, “They are at that point where they are doing research to find out the best road for them.”

#### **Participant 6: LS**

LS was a 23-year-old Caucasian woman who was diagnosed with breast cancer at the age of 22. She was not married and worked full-time at the time of her diagnosis. LS explained that fertility treatment was the hardest thing that she has ever had to do, even harder than what she had to do for her breast cancer. When LS was told that the treatment of chemotherapy for breast cancer could interfere with the normal function of her ovaries, she wanted to do something. LS was informed that some people, especially those who are young who have chemo, can “bounce back,” but other people are just stuck in early menopause for the rest of their life. The doctors also told LS that because she was really young, they believed that her ovarian function has a good chance of returning to normal, but there is really no way to tell. LS was also informed that there is not much research out there on this because there are not that many 22-year-olds in the world that have breast cancer. The oncologist treating LS initially wanted to start chemotherapy right away but then said he would not be too upset if she delayed chemotherapy for a week or two in order for her to be able to preserve her fertility. LS went with her family and boyfriend to the fertility specialist where they spent two hours talking to the doctor. She explained how

everyone had their own set of questions that they felt they needed to ask, even though it was not about them.

LS went on to discuss the fertility preservation process. The doctor told her she would have to inject herself every day to stimulate and grow her egg follicles in the ovaries. She explained that once the follicles are big enough, they were able to go in and extract the eggs. LS went on to explain that she was trying to figure out the best option. Freeze embryos? Freeze eggs? Or not do anything and just hope that everything works out later? She explained how she was told using frozen eggs has a lower chance of turning into an embryo and that embryos have a higher chance of survival after thawing. LS was in somewhat of a serious relationship at the time but immediately eliminated embryos because she and her partner had only been dating for a little over a year. She was still in college and he had just graduated and started his job, and until this happened, they were not thinking about their future like that. LS explained how she felt like she could not use some random sperm and that she did not like the idea of freezing embryos and not using them in case her body did go back to normal. LS said she felt that if she chose to freeze her eggs, that they are just eggs, not embryos. She said that, in her mind, it is like when the eggs in her body are not fertilized every month, they just go away and that an embryo is a little bit more permanent. She went on to say how this was a lot to think about at the age of 22 in addition to worrying about cancer and cancer treatment.

Before LS could go any further, she had to get approval from her insurance company. Her insurance covered the whole process, but they were taking forever to approve everything. She was supposed to start chemo but spoke with her oncologist to let him know what was going on. He agreed to let her push the start date back an additional week. She finally got approval and the medication was sent to her house. There were all sorts of directions on how to mix and

administer the drugs. A family friend who was a nurse offered to give her the shots. She explained how she was really not too happy having to “stab me multiple times a day with these needles, so I was so happy when she agreed to give them to me. This poor thing would come over every evening and give me the shots.” LS described how after starting the medication, she had to go to the doctor’s office multiple times a week for bloodwork and ultrasounds to be able to monitor her hormonal levels and the size of the follicles. She had bruises all over her arms from them taking blood. After a while, they were having problems trying to get blood. She explained how her stomach area was bruised and in constant pain from the shots. She was bloated all the time and did not feel like eating much. LS discussed how everything with this entire process was extremely time-sensitive. Even for the shots, the days and times for the blood work and the ultrasounds were all time-sensitive. Even the retrieval surgery was on a certain day at a certain time. When that day came, the health care workers experienced difficulty trying to place an IV since she had had so much blood taken over the last few weeks. Finally, they were able to get it placed and gave the medicine to put her to sleep. She explained that when she woke up from the surgery, she was told they were able to retrieve 24 eggs. They said they would let her know later in the day how many were mature enough to freeze. When she felt ok enough, they let her go home with her mom. She said she felt okay, just a little tired and sort of beat up. She worked from home the next few days. LS explained that the doctor’s office called later that evening and informed her that out of the 24 eggs that were retrieved, 11 of them were mature enough to be frozen. She explained that she is incredibly happy with her decision to freeze eggs. She said it gave her plenty of opportunities for the future. LS also said if she was lucky enough to have her body go back to normal, then so be it; if not, at least she knows that she has options. LS said, “Looking back on it now, I’m not really sure how I was able to manage, but I did. It was

a lot to process and deal with all at once, but you got to do what you got to do, right?”

### **Participant 7: KJ**

KJ was a 36-year-old Caucasian woman who was diagnosed with invasive breast cancer at the age of 35. KJ was married and worked full-time at the time of her diagnosis. Once she received her diagnosis, she spoke with her primary doctor who recommended she see a breast surgeon and oncologist. He then asked her thoughts and plans on having a family. “I told him that we had just recently discussed starting a family.” The doctor told KJ she should probably also make an appointment with a fertility specialist. KJ stated she could not imagine why and then thought, now? Why now? KJ said all she kept thinking about was her diagnosis, no thoughts about a family. KJ questioned why she would have to see a specialist, and did it really have to be right now? She explained how she had a lot of other things going on at the time. The doctor explained that the type of cancer she was diagnosed with is often treated with chemotherapy, which can suppress ovarian function, and since she was already 35, she is considered old from an obstetrics point of view. KJ explained that it was way too much information being given and that she could not process it all and that she could not think straight. The whole thing was very overwhelming. First the diagnosis, then the number of doctors and doctor visits. KJ said, “Do you know my primary also asked if I was thinking of reconstruction? I didn’t even know what I was going to do about surgery, let alone reconstruction. He said if I were going to have some sort of reconstruction, that that would be done at the time of surgery, so I would need to make an appointment with a plastic surgeon.” She said he also informed her that this really needs to happen now. KJ claimed that all the decisions about surgery and reconstruction, the type of treatment for breast cancer, and decisions about family planning were extremely overwhelming to her. She explained how her husband and family were very supportive and went with her to

appointments, but ultimately, this was all her decision and it was very overwhelming. KJ said, “Honestly, I think if I had some time to really sit and think about all of the information I was being given it wouldn’t have been so bad; well yeah, I think it still would have been bad, but I wouldn’t have had the feeling of drowning on top of it.” She explained how she had so many decisions to make in such a short amount of time, all while being remarkably busy. The oncologist wanted to start chemotherapy right away to try to shrink the size of the tumor before surgery, but then after speaking with her surgeon, they decided it would be best to have surgery first, then treatment. KJ explained how now she had to make some quick tough decisions about fertility preservation: “Do I not want to do it and risk the possibility of not being able to have children? Do I do it and then just see how things go?” She said she spoke with her husband for a while about it, but they finally had to come up with a decision since the surgeon and fertility specialist wanted it done before surgery. They decided to go ahead with fertility preservation just to have options. Options were extremely important to the couple. Once the decision was made, the fertility specialist contacted the insurance company to see if the procedure was covered. It was, but the medication was not covered. The doctor referred KJ to Livestrong who provided her with the medications necessary to be able to move forward with the procedure. KJ explained how upset she was with the insurance company because the medicine was not covered. She said, “either cover it or don’t.” Once approved by Livestrong, the medicine was sent to her house. KJ began the two-week process of injecting medication into her stomach. KJ recalled that after the third day, she had no desire to do it anymore. Her stomach was so uncomfortable, sore, and she started to get black and blue. Her husband would give her the shots when he was home at the time, but he worked all hours, so sometimes it was not possible. Once she started the medication, she had to go to the fertility specialist’s office at least every other day, if not more, for

bloodwork and ultrasounds to see how the eggs were growing. Once the eggs were large enough, she had to go in for egg retrieval. They put an IV in her arm and gave her medicine to fall asleep. She woke up in a recovery room-like setting with her husband next to her in a chair. The doctor came in and told them he was able to retrieve 18 eggs and that they were being fertilized as he was speaking to them. He said he would give daily reports about how the embryos were doing and then when the time to freeze then came, he would let them know how many. Once KJ was feeling up to it, her husband took her home. KJ explained how she went home and just collapsed on the couch. She said, “All I wanted to do was sit. He was trying to get me to eat something, but I just did not feel like it. I just wanted to sit. I kept thinking about what I had just been through, and it really upset me.” She explained how this was just a lot to deal with. The next day the doctor called and said that all the eggs were fertilized, but one of them did not make it overnight. The doctor called daily and gave updates about how many embryos they had, and on the 4th day, he called and said that 13 were okay enough to be frozen. KJ and her husband have 13 embryos that will be available in the event she does go into early menopause from the chemotherapy. KJ explained that she was a little worried because she knows not all of them thaw well but thinks 13 is a good number. KJ said, “Like I said, it gives us options.”

#### **Participant 8: MJ**

MJ is a 37-year-old Caucasian woman who was diagnosed with breast cancer at the age of 34. MJ was married and worked part-time at the time of her diagnosis. She and her husband were getting ready to go away for the weekend, just the two of them; she explained how they needed some time to themselves. MJ’s mom was going to watch their child. She explained that she went to take a shower to get ready to go and found a lump in her breast. She said she was alarmed and began examining the entire breast. She was going to say something to her mom and

husband but didn't want to ruin the whole weekend, so she "blew it off" since they were getting ready to leave. She tried to put it in the back of her mind, but every so often, it would pop up and she would get worried, but she still kept it to herself. She explained how they had a nice time and really enjoyed themselves. MJ said she was glad she didn't say anything because that was the last nice time they have had since. She said they came home and obviously the lump was still there, so she made an appointment with her OB/GYN and told her husband. He was upset she did not say anything before, but he said he understood why. MJ went to see the doctor who recommended a sonogram because "I was still too young for a mammogram." After the sonogram, they decided to do a biopsy. MJ said, "Yep, it was positive. All I can remember thinking is, this can't be happening. I have a little one; this really can't be happening." She was immediately referred by her OB/GYN to a breast surgeon. The breast surgeon discussed all the surgical options and provided her with information about how to make a decision that works for her. He then asked MJ if she had any children and what her plans were for the future when it comes to having a family. She explained that she could not imagine what he was talking about and why he, as a surgeon, wanted to know. She said she was a little annoyed since she felt like he was almost prying into her personal life. Once he explained why he was asking, she said she kind of felt a little bad about her initial reaction. She explained to the doctor that they already had one child but had recently been thinking about and discussing the possibility of becoming pregnant again. The surgeon explained that if they were thinking of more children that she should see a fertility specialist, especially because there was a good chance she would need chemotherapy. MJ explained that she was shocked at what she was being told. The surgeon recommended she see an oncologist because he said from the report of the biopsy that, in his experience, patients diagnosed with ductal carcinoma insitu as he called it, usually need

chemotherapy. He referred her to a fertility specialist and an oncologist. MJ repeated, “All I kept thinking was, this can’t be happening.” She made appointments and went to see both doctors within a few days of one another. She explained that the surgeon was right; she was going to need chemotherapy. The oncologist was happy that the surgeon mentioned family planning and that she had already had an appointment with a fertility specialist because it was something he was going to suggest. MJ said that when they left his office, she sat down in the car and let out a big sigh. She really could not believe all that was happening in such a short amount of time.

“So, let’s see, it was approximately two weeks from the time I noticed the lump in my breast. I had already been to three doctors, had a sonogram, had a biopsy, been diagnosed with breast cancer, told I needed surgery, told I needed chemotherapy, told I would need to do fertility preservation if I wanted to have any more children, which we did, so I still had to see a fertility specialist. My head was spinning. Way too much to process in a short period of time.”

MJ then went to a fertility specialist. He recommended that given her family situation, meaning that she was already married, that she and her husband should freeze their embryos. He suggested that she have it done as soon as possible, so that she was not trying to heal from surgery while injecting medications for two weeks, and then undergo the egg retrieval procedure. MJ’s surgeon and oncologist were okay with her delaying her treatment about two weeks for the fertility preservation process. MJ stated that her health insurance covered the whole process. The plan was for daily injections for two weeks. Sometimes her husband helped, but for the most part, she did it on her own. She reported that her abdomen was painful and tender with large ecchymotic areas due to daily injections and the sudden enlargement of her ovaries. She reported that she was really tired. During this time, she had to take daily trips to the fertility doctor for bloodwork and ultrasounds. MJ’s mom would assist by providing childcare while she went to the

fertility doctor. MJ explained that her husband was working, so they felt he should take the time off when she went in for the retrieval and for surgery instead of when she went in for routine blood and scans. MJ said that “after two weeks of torture, you know when I was injecting the medication, I had the egg retrieval. Although the procedure was described to me, I was still not prepared for it.” She explained that her husband was able to be in the room until they gave her the medicine to go to sleep. The nurse placed an IV in her arm after sticking her several times and gave her “a little bit of fluid.” Once the doctor came in, her husband had to leave and she was given medication (propofol) to put her to sleep. MJ said that it burned and that “They actually called it the Michael Jackson drug.” She said the next thing she knew she woke up to the nurse standing over her, asking how she was feeling. MJ explained that she was a little tired and sore but all in all was okay. They brought in her husband and had him stay by her side. Once she was awake, the doctor came and explained to both of them that he was able to remove 12 eggs and all of them fertilized. He explained that they would let the embryos grow a couple of days, and once they get to a certain point, they will freeze them. He promised to call and give updates. MJ said every time the phone rang, she would run, hoping he was going to give an update. After a few days, the doctor called and said that 2 of the embryos had not survived and there were 10 left. He then explained that the embryos that survive over the next few days would then be frozen. He promised her that he would call once he had the number of embryos that were able to be frozen. He called again in 3 days and said there were 9 embryos that were going to be frozen. MJ said she was relieved. She felt that that was a good number. At the time, they were only thinking of maybe having one more child, but this at least gave her and her husband options. She explained that she was very glad this was over. She said the poking and prodding really got to her after a while. Once this was done, it was a big sigh of relief, but then she had to refocus and

move back to treating her cancer. She remarked it was weird that she had gotten so wrapped up in the fertility preservation process that she almost forgot about her cancer diagnosis. MJ and her husband are letting nature take its course and they are going to try to get pregnant on their own, but if that does not work, they at least have the option of using the frozen embryos.

### **Summary of the Participants' Stories**

Eight young women shared their personal experience with fertility preservation subsequent to a breast cancer diagnosis with this researcher. Although all eight participants came from diverse backgrounds, different environments, and their experiences with breast cancer were different, the stories of their fertility preservation experience were all too similar. They verbalized how stressful it was because there was so much occurring at once and that it was a lot to process. These young women voiced how difficult it was to make so many life-altering decisions in such a short amount of time. They expressed the physical and emotional discomfort they experienced during those few weeks while they were going through the fertility preservation process.

### **Data Analysis**

Data analysis in qualitative research is the process of systematically scrutinizing, searching, and arranging the interview transcripts, observation notes, or other non-textual materials that the researcher accumulates to gain an understanding of the phenomenon. The process of analyzing qualitative data involves systematically categorizing the data while simultaneously making sense of enormous amounts of data. This process is then followed by identifying significant patterns and finally drawing meaning from data (Wong, 2008).

The practice of listening to interviews while simultaneously reading and rereading transcripts occurred multiple times between March and July 2020. This afforded me the

opportunity to submerge myself in the data to understand the essence of the lived fertility preservation experience of these women. Memoing was utilized for any thoughts or feelings that arose related to my personal experience while assisting in making leaps from the data collected to essential themes. This process helped to focus on and understand the participants' lived experiences.

Van Manen's (1990) six methodological activities were employed to guide the study and to analyze the participants' data regarding their individual experience with fertility preservation subsequent to a breast cancer diagnosis.

The first of six activities described by van Manen (1990, p. 31) and used in this study is *turning to the nature of lived experience*. This first activity is utilized to make sense of some aspect of the human experience and explore an aspect of human existence. Van Manen defines phenomenological research as a deep questioning of a phenomenon and that "it is always a project of someone: a real person, who, in the context of particular individual, social, and historical life circumstances, sets out to make sense of a certain aspect of human existence" (1990, p. 31). In essence, this first activity involved the evolution of the research problem and the phenomenon of interest, and the formulation of my research question.

A diagnosis of breast cancer in younger women tends to be more aggressive, warranting more aggressive forms of adjuvant treatment in addition to surgery (Hartman et al., 2011). However, the literature on the gonadotoxic effects of adjuvant cancer treatment is well established and it is known that adjuvant therapy will most likely cause infertility (American Society of Clinical Oncology [ASCO], 2018). There is a small window of time, from diagnosis to the beginning of the administration of adjuvant therapy, for these women to make important decisions regarding their health status, disease treatment, along with the added problem of

fertility preservation for future pregnancy. During this short but critical time frame, the choice of doctors, along with decisions regarding the type of adjuvant treatment, needed to be made. With the administration of adjuvant therapy as the standard of care for young breast cancer patients, decisions regarding fertility preservation must be made quickly and hence the research question, “Can you tell me about your experience with fertility preservation prior to the start of adjuvant therapy?” While analyzing the data, I continually referred to that research question, to ensure the methods being utilized were appropriate to answer the question.

Phenomenological research focuses on the establishment of a renewed contact with the fundamental experience. Van Manen (1990, p. 31) posed that the second activity is *investigating experience as we live it rather than as we conceptualize it*. During this phase, the researcher vigorously delves into the phenomenon. For this study, the phenomenon of interest was the lived fertility preservation experience of young women diagnosed with breast cancer. This, according to van Manen, is where the phenomenon is captured through methods of investigation such as an interview or focus groups. With the purpose of understanding the phenomena, it was necessary to enter the lives of those who have lived the experience. To achieve this goal, I chose to conduct unstructured interviews with eight young women who experienced fertility preservation prior to the start of adjuvant therapy. These women provided this researcher with rich in-depth descriptions in their own words of their experience with fertility preservation. The experiences of each of these women were gathered to gain an in-depth understanding of fertility preservation prior to adjuvant therapy. As I listened to the women’s descriptions, I attempted to live, learn, re-live, and re-learn the experiences as illustrated to me by the participants.

Activity three, *reflecting on the essential themes*, involves the process of analysis, that is characterized by reflectively bringing into focus that which is ordinarily obscure (van Manen,

1990). It is the researchers' reflective grasp of the significance of the experience to the phenomena. This researcher operationalized this phase by repeatedly listening to the recordings of the interviews. Once the transcripts were available, I began reading and rereading the transcripts of the interviews. I then went back and listened to the recordings while reading the transcripts multiple times to understand and grasp the units of meanings or emerging themes of the phenomenon. The repetitious process of listening, reading, and rereading occurred simultaneously and allowed this researcher to dwell with the data in order to begin to gain an in-depth understanding of the fertility preservation experience of these women. Statements and/or phrases were categorized together to form the beginnings of sub-themes and emerging themes that evolved to give meaning to the phenomena.

Van Manen (1990) describes phenomenological themes as the “experiential structures that make up an experience” (p. 79), and that thematic analysis is the process of uncovering themes from the text of the descriptions. He posed that there are three methods for isolating thematic statements in data analysis. These methods are the detailed reading approach, the selective or highlighting approach, and the wholistic approach. This study utilized a combination of the selective or highlighting approach and the detailed reading approach to extract the themes. The “detailed reading approach” (van Manen, 1990, p. 93) was used during the first iteration. This approach compelled the researcher to look at every sentence or cluster of sentences transcribed and to ask the question, “What does this sentence or collection of sentences reveal about the phenomenon, the fertility preservation experience of the participants?” Each transcript was analyzed, allocating words or phrases to each sentence or cluster of sentences as they emerged.

The preliminary analysis consisted of systematically analyzing each interview separately

and then analyzing the interviews together or according to van Manen (1990), going from the ‘parts to the whole’. Words and phrases, reflecting similar ideas of the phenomenon, used by the participants were categorized. Through these categorized ideas, keywords began to be developed. Through novel ideas, reading and re-reading of the data, listening to the transcripts, and dwelling with the data, keywords were identified and further developed into concepts that became sub-themes (van Manen, 1990).

### **Emerging Themes**

The purpose of this study was to answer the research question, “What is the lived fertility preservation experience prior to the start of adjuvant therapy?” In this study, the participants described their experience with fertility preservation prior to the start of adjuvant therapy. Based on the analysis of the data gathered through individual interviews, seven emerging themes related to the research question were developed

- Experiencing unpleasant symptoms
- Physically and emotionally drained
- Overwhelmed/information overload
- “Blurring of time” with past, present, and future
- Understanding and trying to make sense of the complexity of health care information
- Importance of creating opportunities
- Grateful for connection

#### **Experiencing Unpleasant Symptoms**

In this study, many of the participants described some of the unpleasant symptoms they suffered during the fertility preservation experience including (1) black and blue arms; (2) black and blue abdomen; (3) bloated, swollen, and sore; (4) constant poking and prodding; and (5)

emotionally and physically drained. The participants discussed these five unpleasant symptoms as common and significant factors related to their fertility preservation experience.

**Black and Blue Arms.** Many participants verbalized they experienced black and blue arms as a result of the daily or every other day bloodwork they needed to have done. EF stated that there were “trips to the clinic every other day for blood work and ultrasounds...Bruises from trying to get blood.” EG stated that she was “picked at for an IV after my arms were beaten up for the last two weeks trying to get blood.” According to AJ, she endured “injections every day...Go to the office multiple times a week for blood work and ultrasounds...I had bruises all over my arms from them taking blood...Started to have problems trying to get to my veins...They put in an IV, which was really hard since I had had so much blood taken over the last few weeks.” LS stated, “I had bruises all over my arms from them taking blood...After a while, they were having problems trying to get blood.”

**Black and Blue Abdomen.** Participants in this study expressed how they experienced a black and blue stomach as a result of the daily injections they had to endure. MJ said that: “I had to self-inject for two weeks...My stomach was sore it became black and blue.” According to LS, “My stomach area was bruised and in constant pain from the shots.” KJ commented on the two weeks of injecting medication into her stomach. “After the third day, I had no desire to do it anymore...My stomach was so uncomfortable, sore, and I started to get black and blue.” AJ stated that her “stomach was sensitive from the shots every day.” Both EG and EF also explained that their abdomen hurt and was sore as a result of the daily injection of medication they had to endure.

**Bloated, Swollen, and Sore.** Although some of the participants did not specifically verbalize they were bloated, swollen, and sore, they all felt some sense of being and feeling

uncomfortable. LS described that “I was bloated all the time and I didn’t feel like eating much.” While EF discussed how her “stomach was sore, ultrasounds were brutal, all veins had been poked, so much pain.” She also mentioned that her ovaries hurt, and she was constipated and tired.

**Constant Poking and Prodding.** Most of the participants verbalized that there was constant poking and prodding during their fertility preservation experience. EF verbalized that the “ultrasounds were brutal...All veins had been poked, so much pain.” EG explained that her mom was willing to administer the medication and stated that: “The nurse showed me and my mom where and how to inject the medication every night for two weeks...Daily trips to the clinic for blood work and ultrasounds.” According to KJ, “My husband would give me the shots when he was home at the time...Once I started the medication, I had to go to the fertility specialist’s office at least every other day, if not more, for bloodwork and ultrasounds to see how the eggs were growing.”

LS stated, “I had to go to the doctor’s office multiple times a week for bloodwork and ultrasounds to be able to monitor my hormone levels and the size of the follicles...It took them a while to place an IV since I had had so much blood taken over the last few weeks...There was no good place to put an IV...Finally, they were able to get it placed and gave me the medicine to put me out.” MJ verbalized that “while I was giving myself the medication, I had to take daily trips to the fertility doctor for bloodwork and ultrasounds ... After the two weeks of torture, you know, when I was injecting the medication...the nurse placed an IV in my arm after sticking me a number of times and gave me a little bit of fluid.”

### **Physically and Emotionally Drained**

The participants conveyed a sense of being physically and emotionally drained. EF

describes her experience of her ovaries hurting, that she is constipated and tired. While EG said “physically and emotionally draining,” AJ verbalized, “great this is over” but then she went on to state, “It hit me like a ton of bricks; I still had more to go through.” KJ stated, “I went home and just collapsed on the couch. All I wanted to do was sit. He was trying to get me to eat something, but I just didn’t feel like it; I just wanted to sit. I kept thinking about what I had just been through and it really upset me. This was just a lot to deal with.” MJ echoed, “We left his office; I sat down in the car and let out a big sigh. I really could not believe, one, all that was happening, and two, in such a short amount of time.” LS added, “This was a lot to think about at the age of 22, in addition, having to worry about my cancer and cancer treatment, it’s a lot to process.” TC reiterated, “I can’t believe I am going through something like this...This whole thing sucks...Honestly, you beat cancer and now you have to deal with this; it’s like it is never-ending.”

### **Overwhelmed/Information Overload**

Research findings in this study indicated that the participants reported being extremely overwhelmed. This was a reoccurring theme that was captured in their rich descriptions as the participants verbalized experiencing extreme difficulty hearing and processing the amount of medical information being delivered in such a short amount of time. The term “overwhelming” was a reoccurring theme throughout all the interviews. As a result, the following sub-themes emerged related to the emerging theme: Overwhelmed/information overload; short amount of time to process important information; sense of drowning, head spinning; extremely difficult time; overwhelmed.

EF explained “I was extremely overwhelmed, but I didn’t have time to be overwhelmed... Too much information too quick.” KJ added, “Did I mention it was

overwhelming? I was extremely overwhelmed ... All I have to say is it was way too much information being given and then to process it all, I could not think straight ... The whole thing was overwhelming.” EG verbalized that she “could not believe all of the doctors and visits I had to go to and quick .... It was like a whirlwind.” To this MJ added, “too much to process, the head was spinning.” ND stated that it was “really tough because I was still dealing with the heartache of ‘I have cancer.’”

### **“Blurring of Time” with Past, Present, and Future**

Participants described how complicated the time period was while they were going through fertility preservation as (1) difficult few weeks, (2) felt like it was never ever ending, (3) couldn’t see a future, (4) taking it day by day, and (5) speed of light. TC describes how “fertility preservation was the hardest thing of this entire process. ... The next week was a blur.” EG added, “Although there was a lot that needed to be done, the next few weeks were a blur.”

### **Understanding and Trying to Make Sense of the Complexity of Health Care Information**

In this study, all the women verbalized the experiences of multiple doctor visits with new and important information being provided with every visit. They repeatedly verbalized that they experienced difficulty trying to make sense of the enormous amount of important medical information being provided to them with each doctor visit. Six sub-themes were linked to the emerging theme of understanding and trying to make sense of the complexity of health care information; (1) importance of knowledge and understanding, (2) translating knowledge into action, (3) importance of information, (4) communication with healthcare professionals, (5) changing information, and (6) decision-making challenges.

EG explained, “The doctors called and said that the scans I had recently showed a mass...The doctor said “you need to go for a biopsy...the doctor called a few days later and ‘I

found out that it was cancer.” She [Doctor] gave me the name and number of a surgeon and an oncologist...I did make appointments with the doctors I was referred to, but I also went for second opinions...My surgeon recommended I see a plastic surgeon...The oncologist told me that I needed chemo. Now onto another doctor; you know the fertility specialist. The fertility specialist said...then he explained...”

AJ expressed the same feelings and added, “I went to my mom’s gynecologist; this was actually my first visit to a gynecologist. She said she wanted an ultrasound because I was too young for a mammogram. After the ultrasound, the doctor wanted me to do a mammogram anyway...I made an appointment with a surgeon and an oncologist. Actually, I made appointments with a few doctors for different opinions.”

Similarly, EF stated, “I found a lump and went to the doctor...At the time of the ultrasound, the doctor there decided to do a biopsy of the lump...my doctor called and said that the lump that the doctor biopsied was cancer...He referred me to a surgeon and an oncologist.” KJ verbalized, “first the diagnosis, then the number of doctors and doctor visits...I had to go to the fertility specialist’s office at least every other day.”

MJ articulated, “My OB/GYN referred me to a breast surgeon who I went to see immediately...He explained that if I was thinking of more children that I should see a fertility specialist...He recommended I see an oncologist...He said from the report from the biopsy that in his experience patients diagnosed...with DCIS as he called it usually need chemotherapy...He referred me to a fertility specialist and an oncologist.”

LS communicated, “My oncologist initially wanted to start chemotherapy right away but then said he would not be too upset and agreed to me delaying my chemotherapy for a week or two in order for me to be able to preserve my fertility.” TC conveyed, “We went to another

surgeon ...The new doctor got the results from the other doctor I went to three different oncologists, three different surgeons. As soon as they said chemo, I was shocked.”

Overall, participants in this study felt that with each new doctor visit, there was an enormous amount of important information being provided. Participants verbalized that they experienced difficulty comprehending the information.

### **Importance of Creating Opportunities**

The participants in this study articulated that the ability to at least try to be able to have children was important to them. Most of the participants used the word “options.” The three sub-themes that have evolved are related to the emerging theme: the importance of creating opportunities/choosing to reclaiming power/taking control. Choosing life/choosing the future is (1) creating opportunities for the future, (2) preventing restriction on the future, (3) investing in the quality of life for the future. LS commented: “I do feel that I am lucky that I am being given this option...When I was told that the treatment of chemotherapy for my breast cancer could mess up my ovaries, I said I wanted to do something.”

Like LS, MJ had similar feelings. She said: “At the time, we were only thinking of maybe having one more child, but this at least gave us options.” These feelings were supported by statements from other participants such as KJ, EF, AJ, and EG. KJ stated: “We decided to go ahead with fertility preservation just to give us options. That was very important to us; options.”

According to AJ, “The doctor assured me that the literature he has read shows there has not been an increase in cancer when estrogen is given because the amount is similar to what your body would produce. I decided to go ahead with it. I didn’t want to be left without any options.” EF echoed those feelings and stated, “The great part is no matter how long it takes me to get myself together, I know I still have options.” EG added, “For me, the option

not to have kids was not an option. I wanted to make sure that I at least had an option to try to have kids.” Although TC did not use the word “options,” she stated, “If I have to say the hardest thing of this entire process was that...fertility preservation, it was really horrible. In hindsight, thank God, thank God we did that.”

Overall, the emerging theme of the *importance of creating opportunities* was common among most if not all the participants. Participants verbalized that it was important for them to have options about being able to have their own children in the future. The opportunity of having the option to have children in the future appeared to be an indicator of perceived improvement in participants' quality of life.

### **Grateful for Connection**

Participants in this study verbalized that the support and help they received from family and friends was important and assisted them along in their journey. A few of the participants verbalized that the nurses or health care workers at the doctor's office were helpful and supportive. Sub-themes that evolved related to the emerging theme thankful for helpers are (1) supportive network, (2) connections, (3) relationality. In addition to the support each participant verbalized they received, they all described in detail the assistance received with administering the daily injections.

TC verbalized, “My new husband had to give me like 10 shots a day for two weeks. We didn't even have the wedding pictures back and here is my husband giving me shots.” AJ verbalized how “My mom had volunteered to give the medicine to me so we would alternate. She said she really did not like doing it, but she felt bad and wanted to help...My mom came with me to the procedure, my boyfriend felt bad, but he said he didn't want to see me uncomfortable afterward, so he came to my house when I got home.” EG articulated that “the

staff at the fertility clinic were great and they worked well with me, but it was still kind of awkward...They tried to make me feel as comfortable as possible but the whole situation was awful...It started with bloodwork and an ultrasound...before we left the nurse showed me and my mom where and how to inject the medication.” LS added, “I was really not too happy having to stab myself multiple times a day with these needles, so I was so happy when she agreed to give them to me...This poor thing would come over every evening and give me the shots...My sister, my mom, my dad, and my boyfriend, it was like I had an entourage all came with me to my fertility doctor appointment...We were there for hours talking to the fertility doctor.” KJ and MJ conveyed the same feelings. KJ voiced, “My husband and family were very supportive and came with me to appointments...He was trying to get me to eat something, but I just did not feel like it. I just wanted to sit...I would just like to say that I could not have gotten through all of that without the love and support of my husband and family. It is really such a hard thing to go through and I thank God they were there for me.” MJ added, “I had to self-inject for two weeks. Sometimes my husband helped me, but for the most part, it was me...My mom watched my little one while I went.” ND stated, “I still also have monthly injections for my cancer treatment...I go see the fabulous nurses who give me the shots.” In addition, participants who received medication from Livestrong were grateful for the services they received.

Assistance and support from family, friends, and health care workers was a similarity that was conveyed from each participant. Each participant specifically verbalized how they had assistance with administering the daily injections. Participants expressed a sense of gratitude for those who assisted them through their journey.

### **Essential Themes**

During the final iteration, the quest was to use phenomenological reflection to attempt to

grasp the essential meaning, the essences, of the fertility preservation experience of these women. Themes integral to the research questions were developed during the final iteration. As the researcher, I again immersed myself into the transcripts, field notes, memos, and emerging themes, regularly referring to the research question. I went back and forth observing for similarities and differences. I condensed and regrouped themes and identified where they could be merged to form essential themes. Essential themes, according to van Manen (1990), are when individuals are able to grasp and understand the “lived quality and significance of the experience in a fuller or deeper manner” (p. 1990). Upon identification of essential themes, I again referred to the research question to ensure the identified themes answered the research question. These five essential themes were identified: grateful for care and support from others; preserving optionality during chaos; overwhelmed with the amount and complexities of medical information; unpleasant symptoms; and assuring temporality and preserving the now for the future.

### **Essential Theme 1: Grateful for Care and Support from Others**

All the participants expressed gratitude for those who assisted them on their journey. Nearly all the participants verbalized assistance from family members while a few discussed how the health care providers were important during this difficult time. Family members were acknowledged for not only providing emotional support but also assisting in “providing medical care” such as administering injections and accompanying participants to the facility for their egg retrieval. KJ stated, “I would just like to say that I could not have gotten through all of that without the love and support of my husband and family. It is really such a hard thing to go through and I thank God they were there for me.” Health care workers were recognized as instrumental in not only assisting in the education and administration of the injectable

medication but also providing the participant with emotional support. LS, ND, and EG verbalized how health care workers provided significant support and help during their experience. EG articulated that “the staff at the fertility clinic were great and they worked well with me, but it was still kind of awkward...They tried to make me feel as comfortable as possible.” While ND stated, “I still also have monthly injections for my cancer treatment...I go see the fabulous nurses who give me the shots.”

A few of the participants benefited from the generosity of Livestrong, a foundation that provides services such as medication for cancer patients who are trying to become pregnant. TC stated, “They (fertility doctor) actually got me all of the shots donated through Livestrong; it’s a fund for women with cancer.” KJ added, “My doctor referred me to Livestrong. Have you ever heard of it? They were great; they provided me with the medications I needed to be able to move forward with this procedure.” These support systems were influential and made such a significant impact and assisted participants during their difficult journey. After going back and forth between each participant's transcript, dwelling with the raw data, and analyzing the emerging themes the theme of *grateful for connection* evolved into an essential theme of *grateful for care and support from others*.

### **Essential Theme 2: Preserving Optionality During Chaos**

All participants in this study strongly expressed that the option to have children in the future was important to them. While they verbalized they had trouble trying to make sense of the enormous amount of important medical information being provided to them with each doctor visit, what they did know was that they wanted to secure the opportunity to have children in the future. Once again, I went back to the recordings and transcripts while referring to the research question, this time in conjunction with the two emerging themes: *Understanding and trying to*

*make sense, and importance of creating opportunities* were merged to form the essential theme *preserving optionality during the chaos*. This theme captured the participants' efforts to gain some measure of control over their situation, and for them, the decision for fertility preservation gave them some measure of control.

According to AJ, "I remember her giving me all sorts of instructions and me saying "okay" but after I got off the phone, I had no idea what she said, and I didn't write any of it down. Should have had my mom sit with me, but I didn't. I had to call her back and sit there with my mom so we could get all the info... This upset me, as the oncologist never mentioned anything like this to me. As a result, I chose to change my oncologist. The oncologist I ultimately went with did explain the fertility risks involved with having chemotherapy." EF added, "I made an appointment with my doctor to discuss the next steps. He referred me to a surgeon and to an oncologist. When I went to the surgeon, we discussed the surgery options available, and I decided on a bilateral mastectomy... As I was trying to process all this information, my oncologist then said the chemo may affect my ovaries and that if I was looking to have children in the future, that I may want to look into fertility preservation... And here I am a few years later, and I'm still working on piecing myself back together. The great part is, no matter how long it takes me to get myself together, I know I still have options." TC echoed, "So that is, it was really horrible. In hindsight, thank God we did that."

### **Essential Theme 3: Overwhelmed with the Amount and Complexities of Medical Information**

Most participants in this study indicated they were overwhelmed. They described how

with each new doctor visit came more essential information. The sense of being overwhelmed was due not only to the enormous amount of important medical information that was being provided but also the fact that they needed to be able to understand and process all of it to make life-altering decisions for their future.

EF and KJ utilized the terminology of being overwhelmed by all the doctor visits and information. EF stated, “I was extremely overwhelmed, but I didn’t have time to be overwhelmed...Too much information too quick.” KJ added, “Did I mention it was overwhelming? I was extremely overwhelmed...All I have to say is it was way too much information being given and then to process it all, I could not think straight. The whole thing was overwhelming.”

ND added that “Within two weeks of me being diagnosed, we sat down with the fertility specialist...We had to make some really, really quick decisions on what we were going to do with my or actually our future...I think that was really tough for me because again I was dealing with the heartache of I have cancer but then figuring out what to do with the future, I guess...And at that point, I really couldn't see the future because I had a cancer diagnosis. EG referred to her sense of being overwhelmed as a whirlwind. EG “could not believe all of the doctors and visits I had to go to and quick...It was like a whirlwind.”

To fully capture the essence of this experience as described by the women, the theme of overwhelmed/information overload was renamed *overwhelmed with the amount and complexity of the medical information*.

#### **Essential Theme 4: Unpleasant Symptoms**

All the women who participated in this study experienced some sort of unpleasant symptom related to their fertility preservation experience. Most specifically explained that they

were black and blue from the needles, whether it was from the medication they needed to inject or as a result of the daily blood work they had to endure. EF, EG, AJ, and LS all verbalized how their arms became black and blue as a result of the daily or every other day bloodwork they needed to have done. EF stated, “Bruises from trying to get blood.” AJ added, “They put in an IV, which was really hard since I had had so much blood taken over the last few weeks.” Most of the women explained how their abdomen were bruised and sore from the medication that was injected daily and sometimes twice a day. MJ verbalized that: “I had to self-inject for two weeks. ... My stomach was sore it became black and blue.” According to LS, “My stomach area was bruised and in constant pain from the shots.” KJ explained that she had two weeks of injecting medication into her abdomen. Both EG and EF also conveyed that their abdomen hurt and was sore as a result of the daily injection of medication they had to endure.

LS and MJ both stated that it was extremely difficult to try to place an IV for their egg retrieval procedure. MJ said, “It took them a while to place an IV since I had had so much blood taken over the last few weeks .... There was no good place to put an IV.... Finally, they were able to get it placed and gave me the medicine to put me out.” MJ verbalized the “The nurse placed an IV in my arm after sticking me a number of times and gave me a little bit of fluid.”

This essential theme, *unpleasant symptoms*, captured the physical discomfort that was an integral part of this fertility preservation experience for these women.

### **Essential Theme 5: Assuring Temporality and Preserving the Now for the Future**

The concept of time was threaded throughout the women’s descriptions. They spoke of not enough time, a short window of time, the blurring of time, instances of blurred time, and enough time for only one cycle of egg retrieval. This reoccurring emphasis on time was merged with the emerging themes of “blurring of time with past, present, and future” and “the

importance of creating the future” to form the essential theme of *assuring temporality and preserving the now for the future*.

*Temporality* as described by van Manen is,

lived time that is subjective time as opposed to clock time or objective time. It is the time that appears to speed up when enjoying ourselves or slow down when we feel bored. What I have encountered in the past now sticks to me as memories or as forgotten experiences that somehow leave traces on my being.

<http://www.phenomenologyonline.com/inquiry/methods-procedures/reflective-methods/guided-existential-reflection/temporal-reflection/>

Although the participants did not dwell on their past, they verbalized that their need to preserve the future after their breast cancer diagnosis was what led them to endure the fertility preservation process.

Temporality, according to van Manen, also speaks of the future; as he states “The past changes itself, because we live toward a future which we already see taking shape, or the shape of which we suspect as a yet secret mystery of experiences that lie in store for us.” This was especially significant for participants TC and ND as both women endured the fertility preservation process only to find out that the type of cancer they were diagnosed with was receptive to hormones, which means that pregnancy would probably not be an option in their future. TC stated, “I might not be able to carry my own baby because of the fear of recurrence ... Not enough research to prove either way... We’ve been talking about potentially using a surrogate, but it sucks.” ND added, “So we chose to do embryos just because we knew at this point it wasn’t going to be a quick next year thing; it is going to be a future thing, so we did that... So anyways after that, I had chemotherapy and after all of that, I quickly found out I will

never be able to have kids and the reason why is...My breast cancer was hormone related so there is a risk there if I were to ever become pregnant that cancer could come back.” The other women still hold onto the possibility that the process they endured, while delaying their life-saving breast cancer treatment, would one day in the future allow them to have children.

The question posed by this study was: What is the fertility preservation experience during the post-diagnosis to the pre-adjuvant therapy time period of young women with breast cancer? The five essential themes — grateful for care and support from others; preserving optionality during chaos; overwhelmed with the amount and complexities of medical information, unpleasant symptoms, and assuring temporality and preserving the now for the future —captured the essence and meaning of the experience and provided the answer to the research question.

### **Rigor**

In this phenomenological study, rigor was operationalized using the framework put forth by Lincoln and Guba (1985), consisting of credibility, transferability, dependability, and confirmability. This framework provided this researcher with the foundation to gain an understanding of the lived fertility preservation experience of young women subsequent to a breast cancer diagnosis. These steps were utilized for data collection, and analytical methods were utilized to maintain rigor and trustworthiness (Polit & Beck, 2012).

Credibility, the accurate description of participants' lived experience was achieved in this study through the use of unstructured interviews, audio taping, and memoing. This researcher interviewed the participants, listened to, read, and reread, and reflected on the transcripts to gain an understanding of the participants' experiences. Additionally, this researcher met frequently with the chairperson of the dissertation committee to establish credibility. This was utilized to minimize any misrepresentations that may emerge from the data.

Transferability, the next criterion was ensured by providing a rich account of the data collected. To ensure transferability, the context of the interviews, as well as the participants' behaviors, were described in detail so that the experiences are meaningful to readers. Field notes and memoing were utilized in conjunction with the context of the interview to ensure adequate descriptive data were provided.

Dependability, referring to the stability of data over time and conditions (Lincoln & Guba, 1985), was established during this study by accurately documenting and portraying the data for the phenomenon. This was achieved by having detailed documentation of the interviews, field notes, and memoing. This information can be used as an audit trail for authentication.

Lastly, confirmability, referring to objectivity in establishing a similarity in the accuracy of the data between two or more individuals, was achieved as this researcher was able to validate that the results represented the findings and were not a fabrication of the results. The "audit trail" was used in conjunction with the audiotapes, filed notes, memoing, and the transcripts to assure confirmability.

## **Chapter Summary**

This chapter described the data analysis process, significant words, concepts, the essential themes of the phenomenon, and the experience of young women who experienced fertility preservation subsequent to a breast cancer diagnosis. An overview and summary of the research findings, significance to nursing, as well as recommendations for further research are discussed in Chapter Five.

## Chapter V: Discussion

The purpose of this study was to understand the fertility preservation experience of young women subsequent to their breast cancer diagnosis. This chapter began with a summary of the findings and integration of the findings with current literature. The strengths and limitations of the study were discussed, followed by a discussion of implications for nursing practice, research, education, and health policy. Chapter Five concluded with recommendations for future nursing research and the researcher's reflexivity.

An extensive review of nursing literature, related to breast cancer of young women, treatment for breast cancer in young women, and the fertility preservation process was conducted. A review of the nursing database CINAHL and EBSCO using keywords *breast cancer, young women, fertility preservation, and adjuvant therapy* between the years 2010-2020 yielded approximately 14 articles. Most of these addressed pathophysiology and treatment management, and only one article addressed participants' attitude and experience (Hill et.al., 2012). This search highlighted the gap in the literature on studies focused on the fertility preservation experience of this unique population.

This study focused on the lived fertility preservation experience of eight young women who were diagnosed with breast cancer and were scheduled to have adjuvant therapy as part of their treatment. All participants were from the New York area and self-described as being between 18 and 39 years of age. Face-to-face interviews except for one phone interview was conducted. All interviews were digitally recorded and transcribed verbatim. Five essential themes developed from the data were: (1) Grateful for Care and Support from Others; (2) Preserving Optionality During Chaos; (3) Overwhelmed with the Amount and Complexities of Medical Information; (4) Unpleasant Symptoms; (5) Assuring Temporality and

Preserving the Now for the Future. The data collected were rich in detail, illuminating the fertility preservation experience of these young women. Participants verbalized their experiences, describing both the positive and negative experiences.

### **Reconciling Findings with Current Literature**

A literature search was performed after the data analysis was conducted and the essential themes generated, to identify if any new literature was published after the original review of the literature and to determine whether there was a linkage between the essential themes and current literature. This search revealed there are no new studies exploring the lived fertility preservation experience of young women diagnosed with breast cancer. The linkage of the essential themes with the current literature follows.

### **Preserving Optionality During Chaos**

Findings from this current study support those of Dagan et al. (2017), who investigated the experience of fertility preservation counseling and decision making. The focus of that study was to identify potential counseling patterns among 16 young women between the ages of 24 and 38 who were diagnosed with breast cancer 1 to 5 years prior to the interview. Emphasis was placed on the importance of options and how patients were able to make decisions that had an impact on their future and quality of life. Dagan et al.'s (2017) findings revealed that unlike the passivity and dependency women have toward their care providers in other areas of breast cancer treatment, decisions related to fertility preservation constituted an area of personal autonomy and served as an important coping mechanism for young breast cancer patients. In this current study, the participants reported that they considered the decision regarding whether to undergo fertility preservation as one of the only decisions that were truly theirs to make during this chaotic time. This allowed them a certain amount of control over the present and future happenings. Similar to

the findings by Dagan and colleagues, participants in the current study saw the decision and activities around the fertility preservation process as a temporary "escape from the disease situation, eventually contributing to lower decisional conflict and regret. From this perspective, FP may be construed as a symbol of control over one's life in a situation that robs the young women of nearly all their autonomy" (p. 2426).

### **Grateful for Care and Support from Others**

The participants in this study experienced gratitude for the care and support they received from others. This experience has been identified in the literature. Hauken and Larsen (2019), in their study about the support system of young adults during their cancer treatment, identified the following two themes that emerged from their data: *my partner was my rock-or not* and *my family stood by me-or not*. These themes described the social support the participants did or did not receive from their significant others. Most described their significant other as the most important and supportive person during their treatment. Additionally, Ellingsen et al.(2013), in their study of exploring the experience of time by patients who were at end of life, reported that support during a difficult time is essential. *Receiving time, taking time* is an essential theme that emerged from their participants' experiences. This theme described how receiving care without having to ask for it revealed the giver's sensitive, generous heart to those participants. Participants of that study described both positive and negative experiences regarding assistance from family members. Overall, those participants described that their family, especially their parents, provided them with the help and support they needed during their treatments. These findings are similar to the current study where one participant verbalized that her husband of only a few weeks was administering her fertility preservation injections. Another's mother took on the role of nurses, companions, and caregivers. The current study also showed occasions

where partners chose to “not be there” because of their own apprehension in being present during some of the health care procedures. The findings of the study illuminate that the participants’ major source of a private social network were their partners and close family members. This echoes the findings of the earlier studies by Ellingsen et al. (2013) of the significant roles played by partners, spouses, and family members during this experience. However, in this current study, the participant also experienced support from nurses and Livestrong. The essential theme of *grateful for the support of others* was repeated throughout many of the participants' descriptions where they verbalized gratitude for the support from their family members and others.

### **Assuring Temporality and Preserving the Now for the Future**

Temporality or lived time, according to van Manen (1990), is “subjective time as opposed to clock time” (p 104). The concept of *time* was threaded throughout all the participants’ descriptions. These women explained that time played an important role throughout their experience. Most of the women described that there was not enough time to make important decisions; they only had a narrow window of time for the fertility preservation process, and they explained how the time from their diagnosis up to and through the completion fertility preservation process was like a “whirlwind” as one participant called it. This theme, as verbalized by participants of this study, resonated with the findings from the phenomenological study of Ellingsen et al. (2013), whose study described the embodied experience when living with a severe incurable disease. One identified theme from that study was *listening to the rhythm of my body, not looking at the clock*. This theme captured how the disease depletes the strength and energy from patients, which makes everything slow down and makes everyday tasks, such as getting dressed, take more time, essentially making it feel as if the time is going faster. This resonates with the essential theme that emerged from this study; assuring temporality and

preserving the now for the future.

### **Unpleasant Symptoms**

Pain at the injection or blood draw site, bloating, fatigue, abdominal pain, and black and blue arms and stomach were a few of the unpleasant symptoms the young women verbalized. They articulated that these symptoms began once the medication for the fertility preservation process was initiated. Injections for some were twice a day every day for approximately two weeks. In addition, there were the daily or every other day blood work and the frequent transvaginal ultrasounds. As they continued with their medication regimen, some of the participants explained that their abdomen hurt as a result of either the daily injections or the enlarging of their ovaries due to the hormones they were injecting. Others verbalized that they were fatigued and had no desire to eat. A study conducted by Sarenmalm et al. (2007) identified common and distressing symptoms that occur with recurring cancer. The results from the 56 women who participated in that study revealed that women with recurrent breast cancer suffer from “multiple, concurrent, and interrelated symptoms of illness, anxiety, depression, and fatigue” (p. 24). Women in the study conducted by Sarenmalm et al. (2007) verbalized that they experienced pain, lack of energy, and lack of appetite. “The majority of the participants experienced a very high prevalence of symptoms, between 10 and 23 symptoms of illness” (p. 33). These results echoed the type of symptoms as well as the multiple concurrent symptoms experienced by the young women who participated in this phenomenological study.

### **Overwhelmed with the Amount and Complexities Medical Information**

News of a breast cancer diagnosis can be devastating, overwhelming, and can inflict stress and suffering on the patient. Participants expressed a sense of being overwhelmed with all the important medical information being delivered at a swift pace during a stressful time. Most of

the participants utilized the word “overwhelmed” frequently during their interview when discussing a large amount of important complex medical information they were receiving. The study conducted by Jensen et al. (2013) reveals that approximately three-fourths of adults are overwhelmed by cancer information, a construct that has been labeled cancer information overload. Jensen and colleagues define *cancer information overload* as feeling overwhelmed by the amount of cancer-related material in the information environment. According to Jensen et al. (2013), information overload posits that highly arousing content (e.g., information about cancer) strains already limited storage and processing capabilities, resulting in overload. Overload triggers other negative reactions such as increased fatalistic thinking and decreased intentions to engage in cancer-related behaviors.

Participants of this research study described that information pertaining to their cancer diagnosis, cancer treatment, surgery, adjuvant therapy, and fertility preservation was being “spewed” at them all while they were dealing with the “heartache of having cancer,” as one of the participants ND stated. The experiences described by the women in this study echoed those of the participants of the study conducted by Jensen et al. (2013) in that they were “overloaded” with cancer-related information.

## **Linking the Essential Themes to Nursing Theory**

### **Theory of Accelerating Change**

The concept of *time* and participants' thoughts about their future was threaded throughout all the interviews. Many discussed the narrow window of time to undergo fertility preservation. They verbalized that the time from diagnosis up to and throughout their procedure was like a whirlwind. During this turbulent time, they were also trying to make decisions about their future. Martha Rogers's Theory of Accelerating Change is necessary for understanding the essential

theme, Assuring Temporality and Preserving the Now for the Future, that emerged from the participants' interviews. “Rogers derived the theory of accelerating change to illustrate that the only “norm” is accelerating change” (Smith & Parker, 2015, p. 240). Rogers also discussed that people experience faster environmental motion and that it is common for people to experience time as rapidly speeding by (Smith & Parker, 2015). Incorporating this theory into practice for this population may assist in providing appropriate care for the patient.

One shared experience that emerged from the data collected was that the participants felt a sense of loss of control about their diagnosis and disease management, yet were empowered by their fertility preservation decision. Participants explained that there was so much necessary important medical information being provided in such a short amount of time, all while trying to manage a cancer diagnosis. The essential themes, *preserving optionality during chaos* and *overwhelmed with the amount and complexities of medical information*, were generated from the data analysis and echoed Rogers’ concept of accelerated change.

### **Theory of Power as Knowing Participation in Change**

Barrett’s Theory of Power and Knowing Participation in Change is derived from Martha Rogers’s Science of Unitary Human Beings (SUHB). Although “Rogers did not write about power in the SUHB, she did emphasize that human beings can knowingly participate in change” (Barrett, 2015, p. 496). Power, according to Barrett (2015), “is the capacity to participate knowingly in change by being aware, making choices, feeling free to act intentionally and involvement in creating change” (p. 498). Perusing literature along with the integration of her thoughts, Barrett identified four concepts of power: awareness, choices, freedom to act intentionally, and involvement in creating change. “Power is being aware of what one is choosing to do, feeling free to do it, and doing it intentionally” (p. 498).

Upon the diagnosis of breast cancer, the participants of this study verbalized that they were inundated with medical information and education about treatment for their cancer diagnosis. They also expressed that the option to have children in the future was essential. While they verbalized that they had trouble trying to make sense of the enormous amount of important medical information being provided to them with each doctor visit, what they did know was that they wanted to secure the opportunity to have children in the future. The feeling of a loss of control is difficult for young women with breast cancer. However, having the ability to decide to have options and be able to choose their future for these participants was reassuring.

### **Theory of Self-Care Deficit**

Accepting help from significant others, family, friends, and health care professionals was another concept that was threaded throughout the participants' experiences. They expressed that help, even in the form of education and support, was of significant value during those trying times. These women verbalized how spouses, parents, friends, and healthcare professionals were administering their fertility preservation medication to them via injection. Others stated that family members accompanied them to their doctor appointments and even to their egg retrieval procedure. Many voiced that they would not have been able to get through this trying time without the help and support of not only their family and friends but also the health care professionals.

Dorothea Orem's Theory of Self-Care Deficit is based on the belief that each patient has a need for self-care in order to maintain optimal health. Orem's theory also states that the goal of nursing is to enable the patient or members of the patient's family to meet the patient's self-care needs (Orem, 2001). Participants in this study verbalized that nurses provided education as to where, when, and how to administer the fertility preservation medication. According to Orem,

patients will benefit from appropriate nursing interventions when a health situation inhibits the ability or creates a situation where their abilities are not sufficient to maintain their own health and wellness. Nursing action concentrates on the appropriate identification of the deficit, then implementing interventions appropriate to meet the needs of the patient (Orem, 2001).

Integrating the essential theme, *grateful for care and support from others*, with the *theory of self-care deficit* can promote the opportunity for nursing to become more involved in the education, care, and support of this unique population.

### **Theory of Unpleasant Symptoms**

The theory of unpleasant symptoms sought to improve the understanding of the symptoms experienced in a variety of circumstances while providing valuable information for developing effective resources to prevent, improve, or manage unpleasant symptoms and their adverse effects (Lenz et al., 1997). The theory of unpleasant symptoms posits that patients often experience the occurrence of multiple synonymous and interrelated symptoms. The symptoms have physiological, psychological, and situational antecedent factors. These precipitating factors may include age, illness, treatments, emotional state, and the social support of the patients (Lenz et al., 1997). According to the theory as put forward by Lenz and colleagues, these symptoms are hypothesized “to affect a person’s functional and cognitive performance, and performance.... reciprocally affects the symptom experience and may also change the antecedent’s factors” (p. 19).

All the women who participated in the current study stated that they experienced multiple unpleasant symptoms related to their fertility preservation experience. Most of the participants described that their arms and stomach were black and blue from the needles from either injecting the daily fertility medication or the daily blood work they had to endure leading up to the egg

retrieval, with an IV placed for the egg retrieval procedure. Others verbalized that they were bloated, swollen, sore, had abdominal pain associated with the maturing of the follicles/eggs, and they did not feel like eating much. One participant reported that her ovaries hurt, and she was constipated and fatigued most of the time.

Participants verbalized they experienced a sense of being physically and emotionally drained and that the whole experience was a lot to deal with. LS said, “This was a lot to think about at the age of 22 in addition having to worry about my cancer and cancer treatment; it’s a lot to process.” The overriding precipitating factor was coping with their breast cancer diagnosis in addition to responding to the emotional whirlwind of complex decision making related to cancer treatment and fertility preservation.

### **Implications of the Study**

Exploring the lived fertility preservation experience of young women subsequent to a diagnosis with breast cancer offers insight into the tribulations faced by this unique population. Findings from this study have implications for the healthcare profession, nursing education, and nursing practice as they could help to raise awareness and a greater understanding of the lived fertility preservation experience prior to the start of adjuvant therapy. By understanding specific aspects of the fertility preservation experience, the findings of this study provide valuable information to patients, as well as to healthcare providers, especially nurses.

### **Implications for Nursing Education**

Given the findings of this study, women who experience fertility preservation prior to adjuvant therapy would benefit from a nursing profession that is evolving to include fertility preservation as part of the standard of care. This can be promoted through several methods. First, develop a curriculum focused on fertility preservation and integrate it into the current

undergraduate curriculum. Second, develop a curriculum and protocol focused on the fertility preservation process to educate graduate-level nurses, many of whom go on to be primary care providers, on how to provide both physical and emotional care for this population.

Fertility preservation for cancer patients requires a multi-disciplinary team that can consist of physicians, nurses, nurse practitioners, clinical health psychologists, and social workers. Nurses, however, play an integral role in the process by providing most of the assessment and education (Murray et al., 2016). The literature has shown that nurses do not have adequate training and knowledge on not only the fertility preservation process but also the physical and emotional symptoms that are associated with it (King et al., 2008). Failure on behalf of nurses to discuss fertility preservation leaves their patients at a disadvantage during a critical time and ultimately for their future. Developing and promoting a curriculum focused on fertility preservation, fertility preservation options and the process, and patients' experience with the process will highlight the importance of this topic and ensure that nurses have the concepts and language to transfer their learning into the practice arena.

Formulating a process to educate nurses on how to develop and utilize a plan of care related to patients undergoing the fertility preservation process will better prepare nurses for discussion, education, and the provision of appropriate care during this unsettling time. Providing education and establishing a standard of care will equip nurses with the tools they need to promote meaningful conversation, generating a better understanding of fertility preservation and patient outcomes.

### **Implications for Nursing Practice**

This study illuminated the lived fertility preservation experience of young women diagnosed with breast cancer. The findings of this research revealed that the use of fertility

preservation among patients diagnosed with breast cancer during their childbearing years provides patients with a sense of hope for their future. Ongoing education and support for nurses will ensure that young women will benefit from improved information regarding their reproductive needs. Indications for practice include increasing fertility preservation awareness, as it is fundamental in developing comfort with this area of nursing.

Literature has shown that nurses experience difficulty initiating and discussing fertility preservation with their patients. According to Wright et al. (2018), “Nurses experienced a perceived lack of knowledge resulting in avoidance of raising fertility issues” (p. 2867). Nursing staff provides front-line education and support. Therefore, it is essential that nurses be cognizant of the vital role they play during the fertility preservation process and to understand that the role is comprised of education, their hands-on involvement during the fertility preservation process, as well as physical and emotional support. Accordingly, the literature and findings of this current study show that nurses need to be equipped with the information and knowledge so they are comfortable speaking with patients once fertility preservation becomes a possibility.

### **Implications for Nursing Policy**

While the focus of this study was not to address health care policy, participants’ experiences along with the integration of the literature indicated there is a need for continued understanding and support in health policy. According to the New York Department of Financial Services:

New York Insurance Laws 3216(i)(C)(i), 3221(k)(6)(C)(v)(II), and 4303(s)(3)(E)(ii) require as of January 1, 2020 coverage for standard fertility preservation services for individuals when a medical treatment will directly or indirectly result in “iatrogenic infertility” which is an impairment of fertility by

surgery, radiation, chemotherapy, or other medical treatment affecting reproductive organs or processes.

[https://www.dfs.ny.gov/apps\\_and\\_licensing/health\\_insurers/ivf\\_fertility\\_preservation\\_law\\_qa\\_guidance](https://www.dfs.ny.gov/apps_and_licensing/health_insurers/ivf_fertility_preservation_law_qa_guidance)

Many women are still not afforded the opportunity to take advantage of this as they are not properly informed about their options.

The women in this study were able to undergo fertility preservation prior to this law being revised because either their insurance carriers covered most or all the fertility preservation process or they had the finances to afford the procedure. For some of these women, the challenge they faced was obtaining medication through their insurance carriers. Those who did not have their medication covered were referred to Livestrong through their physician and were able to have a cycle of medication donated. With the revision of these laws, medications, although they may be “generic,” are now required to be covered.

As breast cancer in young women of reproductive age rises (CDC, 2018), coupled with positive fertility preservation outcomes, there has been an increased use of fertility preservation. This situation warrants further education for nurses. According to Lacewell, 2019 the New York Department of Financial Services has been advised that nurses typically discuss the fertility preservation process with cancer patients; therefore, nursing deserves funds from the federal government to support the integration of education courses with a focus on fertility preservation.

### **Implications for Research**

The findings from this study contributes to the evidence and research related to the fertility preservation experience of young women subsequent to a breast cancer diagnosis. Although the number of women being diagnosed with breast cancer at an early age is on the rise

(CDC, 2018), the population is small and there is little research available. Given that most women diagnosed with breast cancer have passed childbearing years, research on the fertility preservation experience is lacking. Examination of the lived fertility preservation experience of young women subsequent to a breast cancer diagnosis is pertinent given the growing population and awareness of meeting the needs of these young women.

### **Recommendations for Future Nursing Research**

The findings of this study could serve as a basis for other studies in the area of fertility preservation as there is a lack of research, not only of young breast cancer patients but also of those who experience fertility preservation. Results from this study suggest that additional research is warranted. Recommendations include looking at a different population, utilizing a more diverse sample, and replicating this study in other regions of the United States.

The participants of this study are from a background where they all had access to finances or insurance and could afford fertility preservation. The experience of the participants may or may not be similar to those from different socioeconomic and educational backgrounds. With the revisions of the New York Insurance Law requiring large groups insurance policies to cover three cycles of in-vitro fertilization there would be a significant benefit to conducting another study on fertility preservation, as the population having access to the preservation process may increase and become more diverse. According to Lacewell, 2019:

Because not all insurers currently cover in-vitro fertilization (IVF), coverage is only available to employees of certain employers, or to those who can afford to pay out-of-pocket. Mandating IVF coverage would make the service more widely available to all, regardless of a person's employer, marital status, sexual orientation, gender identity, or socio-economic status. (pg. 1)

Utilizing a diverse sample from different socioeconomic and educational backgrounds will make the topic stronger for future research.

Because this study was conducted in the Northeastern United States, replicating this study in an alternate region of the United States may yield different patient experiences. Alternate regions of the United States should include areas similar to New York, where it is mandated by law that fertility preservation is covered by the patient's insurance. Utilizing states that mandate fertility preservation is covered may yield a larger population with diverse backgrounds to study.

Literature focusing on not only young women diagnosed with breast cancer but also their experience with fertility preservation subsequent to the diagnosis is lacking. Given the dearth of literature, additional research focusing on this unique population is warranted. It would be beneficial to learn even more about the experience from the participant's perspective. Conducting a study utilizing the relationship between the essential themes that emerged from this study could aid healthcare professionals to provide appropriate education and care to patients.

## **Limitations**

Homogeneity of the sample may have been a limitation of the study. Participants were all from New York City or Long Island, New York. They were all financially stable as they were either working full-time themselves or had a significant other who was working and had the finances to afford the procedure. Moreover, the recruitment process may have been a limitation of this study as the participants were not of a diverse population. Participants were recruited through interpersonal relationships and snowball method as well as a cancer support group. Lastly, this researcher's novice skill level with interviewing participants may have also limited the richness of the data collected.

An additional potential limitation of this study is the sensitivity of the subject. Fertility preservation is an extremely sensitive topic. Having to endure fertility preservation as a result of a breast cancer diagnosis adds to the sensitivity of this topic and may have deterred young women from participating in the study.

## **Reflexivity**

A personal experience with a diagnosis of breast cancer during their childbearing years has always made me ponder what the lived fertility preservation experience would have been like, had I chosen to endure the fertility preservation process. Personal experience, along with a significant lack in research, focused on not only breast cancer in young women but also the lived fertility preservation experience, which was a driving force for this study. The participants' interviews were very moving, and I felt somewhat of a connection to each one as they described their lived experience. Each time I listened to the recordings and dwelled with the data, I felt like I was back actually conducting the interview.

Conducting interviews with these women was an enlightening experience. Participants often began their interview with how they were diagnosed with breast cancer, causing me to reflect on my own experience with my diagnosis. Like myself, these participants experienced many struggles managing their breast cancer diagnosis but then had the added stress and management of fertility preservation. Although each participant had their own unique experience, there were many similarities. I am genuinely grateful for their willingness and openness to share their experiences.

## **Participants**

This study illuminated the lived fertility preservation experience of young women subsequent to a breast cancer diagnosis. Eight willing participants shared their unique stories,

allowing this researcher to gain an understanding of their experience. The participants were polite, eager to discuss their experience, and resourceful, making the interviews fascinating to conduct. The participants in this study are strong women who survived not only the experience with fertility preservation but also their battle with breast cancer. It takes an even stronger woman to relive both of those experiences while discussing them as a participant in a research study. Although it was difficult at times to listen to the experiences of these women, as it resonated with my own past experiences, I was honored to conduct this study.

## **Conclusion**

Because few women under the age of 39 are diagnosed with breast cancer, many of the complications that go along with the diagnosis in that age group, such as fertility preservation, are overlooked. Fertility preservation for a 62-year-old woman, which is the average age of a breast cancer diagnosis in the US is not a concern ([http://seer.cancer.gov/csr/1975\\_2017/](http://seer.cancer.gov/csr/1975_2017/)). Realizing that age for not only the disease but the potential complications that can be associated with the treatment needs to be addressed to improve the quality of life for those who are undergoing this process.

The purpose of this phenomenological study was to explore the lived fertility experience of young women subsequent to their breast cancer diagnosis. The findings of this qualitative study illuminated the lived fertility preservation experience as described in the words of young women subsequent to a diagnosis with breast cancer. With 62 as the median age of diagnosis of breast cancer for women in the US, very little research has focused on breast cancer among young adults, let alone complications that may accompany it. Understanding the meaning of the lived fertility preservation experience of young women prior to initiating adjuvant therapy may drive future research focusing on this unique population and thereby help provide appropriate

healthcare. This is accomplished by providing health care professionals with education and a better understanding of the fertility preservation experience.

Data for this study were collected using unstructured, audio-recorded interviews of the experiences, thoughts, and feelings of the fertility preservation experience of young women subsequent to a breast cancer diagnosis. This study was interpreted through the lens of Heidegger's philosophical perspective and van Manen's methodological activities. Eight willing participants shared their stories, allowing this researcher to understand their experiences. From the women's rich description of their lived experiences, the five essential themes that have emerged are: grateful for care and support from others; preserving optionality during chaos; overwhelmed with the amount and complexities of medical information, unpleasant symptoms, and assuring temporality and preserving the now for the future. These themes capture the essence of the experience and the answer to the research question.

The need to learn even more about this population is essential. Changes to the way we inform, educate, and support these young women must be implemented. These findings may be helpful in influencing public policy in the financing of the fertility preservation process. Findings may also be used to influence health care professionals better understand and provide care for this unique population.

## References

- Agee, J. (2009). Developing qualitative research questions: A reflective process. *International Journal of Qualitative Studies in Education*, 22(4), 431-447.
- American Cancer Society. (2018) Cancer Facts & Figures 2018.  
[www.cancer.org > cancer-facts-and-statistics](http://www.cancer.org/cancer-facts-and-statistics)
- American Medical Association. (2014) <https://www.ama-assn.org>
- American Pregnancy Association. (2018) Skin changes during pregnancy.  
[www.americanpregnancy.org](http://www.americanpregnancy.org)
- American Society of Clinical Oncology. (2018) ASCO Guidelines.  
<http://www.asco.org/survivorship-guidelines>
- Anders, C. K., Hsu, D. S., Broadwater, G., Acharya, C. R., Foekens, J. A., Zhang, Y., ... & Blackwell, K. L. (2008). Young age at diagnosis correlates with worse prognosis and defines a subset of breast cancers with shared patterns of gene expression. *Journal of Clinical Oncology*, 26(20), 3324-3330.
- Appleton, D. C., Hackney, L., & Narayanan, S. (2014). Ultrasonography alone for diagnosis of breast cancer in women under 40. *The Annals of The Royal College of Surgeons of England*, 96(3), 202-206.
- Assi, H., Khoury, K., Dbouk, H., Khalil, L., Mouhieddine, T. & El Saghir, N. (2013). *Journal of Thoracic Disease*, (S1) 5 2-8.
- Azim, H. A., & Partridge, A. H. (2014). Biology of breast cancer in young women. *Breast Cancer Research*, 16(4), 1-9.
- Banerjee, R., & Tsiapali, E. (2016). Occurrence and recall rates of fertility discussions with young breast cancer patients. *Supportive Care in Cancer*, 24(1), 163-171.

- Barrett, E. (2015). Barrett's theory of power as knowing participation in change. *Nursing Theories and Nursing Practice*, 495-508.
- Barrett, E. (2015). Barrett's theory of power as knowing participation in change. (Smith, M., & Parker, M.), *Nursing Theories and Nursing Practice* (pp. 495-507). Philadelphia: F. A. Davis Company. ProQuest Ebook Central <https://ebookcentral.proquest.com>
- Benedict, C., Thom, B., N. Friedman, D., Diotallevi, D., M. Pottenger, E., J. Raghunathan, N., & Kelvin, J. F. (2016). Young adult female cancer survivors' unmet information needs and reproductive concerns contribute to decisional conflict regarding post-treatment fertility preservation. *Cancer*, 122(13), 2101-2109.
- Bharat, A., Aft, R. L., Gao, F., & Margenthaler, J. A. (2009). Patient and tumor characteristics associated with increased mortality in young women ( $\leq 40$  years) with breast cancer. *Journal of surgical oncology*, 100(3), 248-251.
- Butcher, H. K. & Malinski, V. M. in Smith, M. & Parker, M. (2015) *Nursing theories and nursing practice* (5th ed.). Philadelphia: F.A. Davis.
- Camp-Sorrell, D. (2009, November). Cancer and its treatment effect on young breast cancer survivors. In *Seminars in oncology nursing* (Vol. 25, No. 4, pp. 251-258). WB Saunders.
- Canada, A. L., & Schover, L. R. (2012). The psychosocial impact of interrupted childbearing in long-term female cancer survivors. *Psycho-oncology*, 21(2), 134-143.
- Center for Disease Control. (2012). What are the risk factors for breast cancer? [www.cdc.gov > cancer > breast > basic\\_info > riskfactor](http://www.cdc.gov/cancer/breast/basic_info/riskfactor)
- Chavez-MacGregor, M., Clarke, C. A., Lichtensztajn, D. Y., & Giordano, S. H. (2016). Delayed initiation of adjuvant chemotherapy among patients with breast cancer. *JAMA Oncology*, 2(3), 322-329.

doi: 10.1001/jamaoncol.2015.3856.

Cho, E., Spiegelman, D., Hunter, D. J., Chen, W. Y., Stampfer, M. J., Colditz, G. A., & Willett, W. C. (2003). Premenopausal fat intake and risk of breast cancer. *Journal of the National Cancer Institute*, 95(14), 1079-1085.

Coccia, P. F., Pappo, A. S., Beaupin, L., Borges, V. F., Borinstein, S. C., Chugh, R., ... & Shead, D. A. (2018). Adolescent and young adult oncology, version 2.2018, NCCN clinical practice guidelines in oncology. *Journal of the National Comprehensive Cancer Network*, 16(1), 66-97.

Corney, R. H., & Swinglehurst, A. J. (2014). Young childless women with breast cancer in the UK: a qualitative study of their fertility-related experiences, options, and the information given by health professionals. *Psycho-Oncology*, 23(1), 20-26.

Creswell, J.W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Thousand Oaks, CA: Sage.

Creswell, J. W. (2013). *Qualitative Inquiry & Research Design: Choosing Among Five Approaches* (3rd ed.). Los Angeles: SAGE Publications

Creswell, J.W. & Poth, C.N. (2018). *Qualitative Inquiry and Research Design Choosing among Five Approaches*. (4th ed.). Thousand Oaks, CA: SAGE Publications, Inc.

Dagan, E., Modiano-Gattegno, S., & Birenbaum-Carmeli, D. (2017). "My choice": breast cancer patients recollect doctors fertility preservation recommendations. *Supportive Care in Cancer*, 25(8), 2421-2428.

De Roy, P.G. (2004). Helsinki and the Declaration of Helsinki. *World Medical Journal*, 50(1), 9-11.

Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological

- approaches. *International Journal of Nursing Studies*, 44, 131-142.
- Duffy, C. M., Allen, S. M., & Clark, M. A. (2005). Discussions regarding reproductive health for young women with breast cancer undergoing chemotherapy. *Journal of Clinical Oncology*, 23(4), 766-773.
- Dunn, J., & Steginga, S. K. (2000). Young women's experience of breast cancer: Defining young and identifying concerns. *Psycho-oncology*, (9), 137-146.
- Ellingsen, S., Roxberg, Å., Kristoffersen, K., Rosland, J. H., & Alvsvåg, H. (2013). Entering a world with no future: A phenomenological study describing the embodied experience of time when living with severe incurable disease. *Scandinavian Journal of Caring Sciences*, 27(1), 165-174.
- Ferzoco, R. M., & Ruddy, K. J. (2015). Unique aspects of caring for young breast cancer patients. *Current oncology reports*, 17(2). 1. ). <https://doi.org/10.1007/s11912-014-0425-x>.
- Fredholm, H., Eaker, S., Frisell, J., Holmberg, L., Fredriksson, I., & Lindman, H. (2009). Breast cancer in young women: Poor survival despite intensive treatment. *PloS one*, 4(11), e7695.
- Gabriel, C. A., & Domchek, S. M. (2010). Breast cancer in young women. *Breast Cancer Research*, 12(5), 1-10.
- Gerstl, B., Sullivan, E., Ives, A., Saunders, C., Wand, H., & Anazodo, A. (2018). Pregnancy outcomes after a breast cancer diagnosis: a systematic review and meta-analysis. *Clinical breast cancer*, 18(1), e79-e88.
- Goldfarb, S. B., Kamer, S. A., Oppong, B. A., Eaton, A., Patil, S., Junqueira, M. J., ... & Gemignani, M. L. (2016). Fertility preservation for the young breast cancer

- patient. *Annals of Surgical Oncology*, 23(5), 1530-1536.
- Hauken, M. A., & Larsen, T. M. (2019). Young adult cancer patients' experiences of private social network support during cancer treatment. *Journal of Clinical Nursing*, 28(15-16), 2953-2965.
- Hartmann, S., Reimer, T., & Gerber, B. (2011). Management of early invasive breast cancer in very young women (< 35 years). *Clinical Breast Cancer*, 11(4), 196-203.
- Heidegger, M. (1962). *Being and time*. Malden, MA: Blackwell Publishing.
- Hill, K. A., Nadler, T., Mandel, R., Burlein-Hall, S., Librach, C., Glass, K., & Warner, E. (2012). Experience of young women diagnosed with breast cancer who undergo fertility preservation consultation. *Clinical Breast Cancer*, 12(2), 127-132.
- Howlader, N., Noone, AM., Krapcho, M., Garshell, J., Miller, D., Altekruse, SF., Kosary, CL., Yu, M., Ruhl, J., Tatalovich, Z., Mariotto, A., Lewis, DR., Chen, HS., Feuer, EJ., Cronin, KA. (2015). SEER Cancer Statistics Review, 1975-2012, *National Cancer Institute*. [https://seer.cancer.gov/archive/csr/1975\\_2012/](https://seer.cancer.gov/archive/csr/1975_2012/)
- Husserl, E. (1913/1962). *Ideas: General Introduction to Pure Phenomenology* (W. R. B. Gibson Trans.) New York: Macmillan. (German original, 1913)
- Jensen, J. D., Carcioppolo, N., King, A. J., Scherr, C. L., Jones, C. L., & Niederdeppe, J. (2014). The cancer information overload (CIO) scale: Establishing predictive and discriminant validity. *Patient Education and Counseling*, 94(1), 90-96.
- Kant, I. (1929). Critique of pure reason. 1781. *Modern Classical Philosophers*. Cambridge, MA: Houghton Mifflin, 370-456.
- Keim-Malpass, J., Fitzhugh, H. S., Smith, L. P., Smith, R. P., Erickson, J., Douvas, M. G., ... & Duska, L. (2018). What is the role of the oncology nurse in fertility preservation

- counseling and education for young patients? *Journal of Cancer Education*, 33(6), 1301-1305.
- Kim, S., Klemp, J., & Fabian, C. (2011). Breast cancer and fertility preservation. *Fertility and sterility*, 95(5), 1535-1543.
- Kim, S., Lee, Y., Lee, S., & Kim, T. (2018). Ovarian tissue cryopreservation and transplantation in patients with cancer. *Obstetrics & Gynecology Science*, 61(4), 431.
- Kim, J., Mersereau, J. E., Su, H. I., Whitcomb, B. W., Malcarne, V. L., & Gorman, J. R. (2016). Young female cancer survivors' use of fertility care after completing cancer treatment. *Supportive Care in Cancer*, 24(7), 3191-3199. doi:10.1007/s00520-016-3138-x.
- King, L., Quinn, G. P., Vadaparampil, S. T., Gwede, C. K., Miree, C. A., Wilson, C., ... & Perrin, K. (2008). Oncology nurses' perceptions of barriers to discussion of fertility preservation with patients with cancer. *Clinical Journal of Oncology Nursing*, 12(3), 467-76.
- Klemp, J. R., & Kim, S. S. (2012). Fertility preservation in young women with breast cancer. *Journal of Assisted Reproduction and Genetics*, 29(6), 469-472.
- Kollias, J., Elston, C. W., Ellis, I. O., Robertson, J. F. R., & Blamey, R. W. (1997). Early-onset breast cancer—histopathological and prognostic considerations. *British Journal of Cancer*, 75(9), 1318-1323.
- Lacewell, L. (2019). New York State Department of Financial Services: Report on In Vitro Fertilization and Fertilization Preservation Coverage. p. 1-11  
<https://www.dfs.ny.gov> > [dfs\\_ivf\\_report](#)
- Lambertini, M., Anserini, P., Levaggi, A., Poggio, F., & Del Mastro, L. (2013). Fertility counseling of young breast cancer patients. *Journal of thoracic disease*, 5(Suppl 1), S68.

- Lambertini, M., Del Mastro, L., Pescio, M. C., Andersen, C. Y., Azim, H. A., Peccatori, F. A., ... & Anserini, P. (2016). Cancer and fertility preservation: international recommendations from an expert meeting. *BMC Medicine*, 14(1), 1-16. doi:10.1186/s12916-015-0545-7.
- Lauterbach, S. S. (2007). Meanings in mothers' experience with infant death: Three phenomenological inquiries: In another world; five years later; and what forever means. *PL Munhall (Ed.), Nursing research: A qualitative perspective*, 4, 211-238.
- Leavy, P. (2011). *Essentials of transdisciplinary research*. Walnut Creek, CA: Left Coast Press Inc.
- Lee, H. B., & Han, W. (2014). Unique features of young age breast cancer and its management. *Journal of Breast Cancer*, 17(4), 301.
- Lehman, C. D., Lee, C. I., Loving, V. A., Portillo, M. S., Peacock, S., & DeMartini, W. B. (2012). Accuracy and value of breast ultrasound for primary imaging evaluation of symptomatic women 30-39 years of age. *American Journal of Roentgenology*, 199(5), 1169-1177.
- Lenz, E. R., Pugh, L. C., Milligan, R. A., Gift, A., & Suppe, F. (1997). The middle-range theory of unpleasant symptoms: An update. *Advances in Nursing science*, 19(3), 14-27.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
- Livestrong (2020). <https://www.livestrong.org/what-we-do/program/fertility>
- Loren, A. W., Mangu, P. B., Beck, L. N., Brennan, L., Magdalinski, A. J., Partridge, A. H., ... & Oktay, K. (2013). Fertility preservation for patients with cancer: American Society of Clinical Oncology clinical practice guideline update. *Journal of Clinical Oncology*, 31(19), 2500. doi:10.1200/JCO.2013.49.2678
- Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: Their

- contributions to nursing knowledge. *Qualitative health research*, 14(5), 726-735.
- Mahajan, N. (2015). Fertility preservation in female cancer patients: An overview. *Journal of human reproductive sciences*, 8(1), 3. doi:10.4103/0974-1208.153119
- Marriott, M., Masino, K., & Casella, G., (2014). CNE: Breast Cancer Care gets personal. *American Nurse Today*, 9(10).
- McConnell-Henry, T., Chapman, Y., & Francis, K. (2009). Husserl and Heidegger: Exploring the disparity. *International Journal of Nursing Practice*, 15(1), 7-15.
- McCray, D. K., Simpson, A. B., Flyckt, R., Liu, Y., O'Rourke, C., Crowe, J. P., ... & Valente, S. A. (2016). Fertility in women of reproductive age after breast cancer treatment: practice patterns and outcomes. *Annals of Surgical Oncology*, 23(10), 3175-3181.
- Melan, K., Amant, F., Veronique-Baudin, J., Joachim, C., & Janky, E. (2018). Fertility preservation healthcare circuit and networks in cancer patients worldwide: What are the issues? *BMC Cancer*, 18(1), 1-9.
- Meneses, K., & Holland, A. C. (2014). Current evidence supporting fertility and pregnancy among young survivors of breast cancer. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 43(3), 374-381.
- Minton, S. E., & Munster, P. N. (2002). Chemotherapy-induced amenorrhea and fertility in women undergoing adjuvant treatment for breast cancer. *Cancer Control*, 9(6), 466-472.
- Moran, D. (2013). Introduction to phenomenology (2<sup>nd</sup> Rev. ed.). London: Routledge.
- Munhall, P. L., & Chenail, R. J. (2008). *Qualitative research proposals and reports: A guide*. Jones & Bartlett Learning.
- Murray, A., Chrisler, J. and Robbins, M. (2016). Oncology nurses report positive attitudes but list numerous barriers to discussing fertility preservation with adolescent and young

- adult cancer patients. *Clinical Journal of Oncology Nursing*, 20(4), 93-99.
- Nass, S. J., Beaupin, L. K., Demark-Wahnefried, W., Fasciano, K., Ganz, P. A., Hayes-Lattin, B., ... & Smith, A. W. (2015). Identifying and addressing the needs of adolescents and young adults with cancer: Summary of an Institute of Medicine workshop. *The Oncologist*, 20(2), 186.
- National Cancer Institute. (2014). Fertility Issues in Girls and Women with Cancer. <http://www.cancer.gov>
- National Quality Forum. (2017). Fertility preservation and breast cancer. <http://www.qualityforum.org/>
- Oktay, K., Harvey, B. E., Partridge, A. H., Quinn, G. P., Reinecke, J., Taylor, H. S., ... & Loren, A. W. (2018). Fertility preservation in patients with cancer: ASCO clinical practice guideline update. *Journal of Clinical Oncology*, 36(19), 1994-2001.
- Oncology Nursing Society. (2019). <https://www.ons.org/articles/research-agenda-oncology-nursing-society-2019-2022-executive-summary>
- Orem, D., (2001). *Nursing Concepts of Practice*. St. Louis: Mosby
- Pagani, O., Ruggeri, M., Manunta, S., Saunders, C., Peccatori, F., Cardoso, F., ... & Partridge, A. H. (2015). Pregnancy after breast cancer: Are young patients willing to participate in clinical studies? *The Breast*, 24(3), 201-207.
- Parse, R. R. (2001). *Qualitative inquiry: The path of sciencing*. Jones & Bartlett Learning.
- Partridge, A. H., Gelber, S., Peppercorn, J., Sampson, E., Knudsen, K., Laufer, M., ... & Winer, E. P. (2004). Web-based survey of fertility issues in young women with breast cancer. *Journal of Clinical Oncology*, 22(20), 4174-4183.
- Pathak, V., Jena, B., & Kalra, S. (2013). Qualitative research. *Perspectives in clinical*

*Research*, 4(3). doi:10.4103/2229-3485.115389

Patterson, P., McDonald, F. E., Zebrack, B., & Medlow, S. (2015, February). Emerging issues among adolescent and young adult cancer survivors. In *Seminars in oncology nursing* (Vol. 31, No. 1, pp. 53-59). WB Saunders.

Polit, D.F., & Beck, C.T. (2012), *Nursing Research. Generating and Assessing Evidence for Nursing Practice* (9th ed). Philadelphia, PA: Lippincott Williams & Wilkens.

Pollán, M. (2010). Epidemiology of breast cancer in young women. *Breast Cancer Research and Treatment*, 123(1), 3-6.

Practice Committee of the American Society for Reproductive Medicine. (2013). Fertility preservation in patients undergoing gonadotoxic therapy or gonadectomy: a committee opinion. *Fertility and Sterility*, 100(5), 1214-1223.

Practice Committee of the American Society for Reproductive Medicine. (2019). Fertility preservation in patients undergoing gonadotoxic therapy or gonadectomy: a committee opinion. *Fertility and Sterility*, 112, 1022-1033.

Printz, C. (2013). Ultrasound better than mammography for women younger than 40 years with symptoms of breast cancer. *Cancer*, 119(6), 1118-1118.

<https://doi.org/10.1002/cncr.28012>

QSR International (2018). *NVIVO*. Retrieved from: <http://www.qsrinternational.com/nvivo/what-is-nvivo>

Quinn, G. P., Vadaparampil, S. T., Lee, J. H., Jacobsen, P. B., Bepler, G., Lancaster, J., ... & Albrecht, T. L. (2009). Physician referral for fertility preservation in oncology patients: a national study of practice behaviors. *Journal of clinical oncology*, 27(35), 5952-5957.

- Rosenberg, S. M., & Partridge, A. H. (2015). Management of breast cancer in very young women. *The Breast*, 24, S154-S158. doi: 10.1016/j.breast.2015.07.036.
- Rubin, H. J., & Rubin, I. S. (2012). *Qualitative interviewing: The art of hearing data*. Sage Publications
- Ruddy, K. J., Gelber, S. I., Tamimi, R. M., Ginsburg, E. S., Schapira, L., Come, S. E., ... & Partridge, A. H. (2014). Prospective study of fertility concerns and preservation strategies in young women with breast cancer. *Journal of Clinical Oncology*, 32(11), 1151.
- Salzmann-Erikson, M. (2013). IMPAD-22: A checklist for authors of qualitative nursing research manuscripts. *Nurse education today*, 33(11), 1295-1300.  
doi:<http://dx.doi.org/molloy.idm.oclc.org/10.1016/j.nedt.2013.03.010>
- Sarenmalm, E. K., Öhlén, J., Jonsson, T., & Gaston-Johansson, F. (2007). Coping with recurrent breast cancer: Predictors of distressing symptoms and health-related quality of life. *Journal of Pain and Symptom Management*, 34(1), 24-39.
- Scanlon, M., Blaes, A., Geller, M., Majhail, N. S., Lindgren, B., & Haddad, T. (2012). Patient satisfaction with physician discussions of treatment impact on fertility, menopause and sexual health among pre-menopausal women with cancer. *Journal of Cancer*, 3, 217.
- Schover, L. R. (1999). Psychosocial aspects of infertility and decisions about reproduction in young cancer survivors: a review. *Medical and Pediatric Oncology: The Official Journal of SIOP—International Society of Pediatric Oncology*, 33(1), 53-59.
- Schover, L. R., Rybicki, L. A., Martin, B. A., & Bringelsen, K. A. (1999). Having children after cancer: A pilot survey of survivors' attitudes and experiences. *Cancer*, 86(4), 697-709.
- Schwerdtfeger, K. L., & Shreffler, K. M. (2009). Trauma of pregnancy loss and infertility among

- mothers and involuntarily childless women in the United States. *Journal of Loss and Trauma*, 14(3), 211-227.
- Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. Sage Publications, London.
- Smith, M., & Parker, M. (2015). *Nursing theories & nursing practice*. Philadelphia, PA : F.A. Davis Company
- Sonmezer, M., & Oktay, K. (2004). Fertility preservation in female patients. *Human reproduction update*, 10(3), 251-266.
- Snyder, K. A., & Pearse, W. (2011). Discussing fertility preservation options with patients with cancer. *Journal of the American Medical Association*, 306(2), 202-203.
- Stearns, V., Schneider, B., Henry, N. L., Hayes, D. F., & Flockhart, D. A. (2006). Breast cancer treatment and ovarian failure: Risk factors and emerging genetic determinants. *Nature Reviews Cancer*, 6(11), 886-893.
- Thompson, J. (1990). Hermeneutic inquiry. In L.E. Moody (Ed.), *Advancing nursing science through research* (p. 223-280). Newbury Park, CA: Sage.
- Tichy, J. R., Lim, E., & Anders, C. K. (2013). Breast cancer in adolescents and young adults: A review with a focus on biology. *Journal of the National Comprehensive Cancer Network*, 11(9), 1060-1069.
- Tiong, V., Rozita, A. M., Taib, N. A., Yip, C. H., & Ng, C. H. (2014). Incidence of chemotherapy-induced ovarian failure in premenopausal women undergoing chemotherapy for breast cancer. *World Journal of Surgery*, 38(9), 2288-2296.
- Van Manen, M. (2016). *Researching lived experience: Human science for an action sensitive pedagogy*. Second Edition. Routledge. Ontario, Canada: The Althouse Press.

- Van Manen, M. (1990). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing*. Routledge. California: Left Coast Press.
- Waimey, K. E., Smith, B. M., Confino, R., Jeruss, J. S., & Pavone, M. E. (2015). Understanding fertility in young female cancer patients. *Journal of Women's Health, 24*(10), 812-818.
- Wong, L. P. (2008). Data analysis in qualitative research: A brief guide to using NVivo. *Malaysian Family Physician: The Official Journal of the Academy of Family Physicians of Malaysia, 3*(1), 14.
- World Medical Association. (2013). World Medical Association Declaration of Helsinki: Ethical principles for medical research involving human subjects. *Journal of the American Medical Association, 310*(20), 2191-2194.
- Wright, E., Norton, W., & Geary, M. (2018). Nurses' experiences of undertaking fertility-related discussions with teenagers and young adults with cancer: An interpretive phenomenological analysis. *Journal of Advanced Nursing, 74*(12), 2860-2870.
- Zhan, Q. H., Fu, J. Q., Fu, F. M., Zhang, J., & Wang, C. (2018). Survival and time to initiation of adjuvant chemotherapy among breast cancer patients: A systematic review and meta-analysis. *Oncotarget, 9*(2), 2739.

## APPENDIX A: Recruitment Flyer

### Fertility Preservation Experience Study

#### Fertility Preservation Experience Study

Be a part of an important Fertility Preservation Experience research study.

The purpose of this study is to understand the meaning of the lived fertility preservation experiences prior to the start of adjuvant therapy of young women diagnosed with breast cancer.

Are you a young woman who had fertility preservation subsequent to a breast cancer diagnosis between 2012-2017?

Do you want to share your experiences with fertility preservation?

If you answered Yes to these questions, you may be eligible to participate in a research study focusing on the fertility experience of young breast cancer survivors.

Your participation would involve 1-3 audio-taped interviews, lasting 1-2 hours with the researcher.

A follow-up contact is requested for you to validate or clarify your interview analysis. You may choose to do that by telephone, email or in person. It should take no more than 30 minutes.

The purpose of this study is to interpret the meaning of the lived fertility preservation experiences prior to the start of adjuvant therapy of young women diagnosed with breast cancer.

If interested, please contact:

Kristine Ferrucci-Egan MSN, RN

PhD Doctoral Candidate

Barbara H. Hagan School of Nursing at Molloy College

1000 Hempstead Ave, Rockville Centre, New York, 11570

[Kferrucci-egan@lions.molloy.edu](mailto:Kferrucci-egan@lions.molloy.edu)



Date \_\_\_\_\_

Dear

Thank you for your interest in this study. I am a nurse researcher in the Barbara H. Hagan School of Nursing at Molloy College conducting research for my doctoral dissertation.

The purpose of this research is to understand the lived fertility preservation experience prior to the start of adjuvant therapy of young women diagnosed with breast cancer.

Individuals are asked to participate by providing 1-3 in-person interviews at their convenience that last from 1-2 hours each. These will be audio-taped and transcribed with your permission. A follow-up contact is requested for you to validate or clarify your interview analysis. You may choose to do that by telephone, email or in person. It should take no more than 30 minutes.

Your personal information is kept confidential. The information from all the study participants is reviewed as a collection of experiences. A final write-up of the results of this study will be made available to all participants, as desired.

Please feel free to contact me for any questions about the study and ways of participating. I can be reached directly at: Email: [Kferrucci-egan@lions.molloy.edu](mailto:Kferrucci-egan@lions.molloy.edu)

Sincerely,

Kristine Ferrucci-Egan, MSN, RN

PhD Doctoral Candidate

Barbara H. Hagan School of Nursing at Molloy College

1000 Hempstead Ave, Rockville Centre, New York, 11570



## APPENDIX B: Written Informed Consent

### Informed Consent

**Title of the study:** Understanding the Lived Fertility Preservation Experience From Diagnosis to the Start of Adjuvant Therapy: A Study of Young Breast Cancer Patients

**Researcher:** Kristine Ferrucci-Egan MSN, RN  
PhD Doctoral Candidate Barbara H. Hagan School of Nursing  
Molloy College  
1000 Hempstead Ave,  
Rockville Centre, New York, 11570



My Name is Kristine Ferrucci-Egan and I am a doctoral student conducting a study at Molloy College in the School of Nursing. I am conducting a study on the fertility preservation experience of young breast cancer survivors. I am reaching out to young women between the ages of 18-39 who had the experience of fertility preservation subsequent to a breast cancer diagnosis during the period 2012-2017, and are willing to participate in this study. The driving force behind this study is my experience as a young breast cancer survivor. I am asking you for your permission to interview you about your experience with fertility preservation. This study is expected to improve the understanding of health care providers and clinicians who care for patients who are caring for patients faced with fertility preservation issues

**This consent form will explain:**

The purpose of the study and what your participation will entail.

**Purpose of the study:** To understand the lived fertility preservation experience prior to the start of adjuvant therapy of young breast cancer patients.

**Description of the procedures/methodology:** You will be asked to participate in one to two interviews about your fertility preservation experience which will take approximately 45-60 minutes each in a mutually agreed upon location. You will also be asked to fill out a brief demographic form prior to the interview, which will take no more than 5 minutes. Interview(s) will be audio-recorded and your personal information will be kept confidential and will only be

shared with the members of my committee. A follow-up contact is requested for you to validate or clarify the analysis of your interview. You may choose to do that by telephone, email, or in person. It should take no more than 30 minutes. A final write-up of the results of this study will be made available to you if desired.

**Foreseeable risks or discomforts:** There are no known or foreseeable risks to participating in this study. However if at any time you feel uncomfortable discussing your experiences, you may choose to stop the interview and restart at another time if you wish. I will provide you with a list of local supportive services that you can access at no cost to you in the event you feel you need it. You may also withdraw from the study if you wish without any consequences.

**Possible benefits of the study:** There are no direct benefits to you from participating in this research study. However, this research may lead to insight into understanding the lived fertility preservation experience from diagnosis to the start of adjuvant therapy of young breast cancer patients.

**Voluntary Participation/Withdrawal:** Your decision as to whether or not to take part in this study is voluntary. If you decide to take part in the study, you may withdraw at any time. Any information you have contributed may also be excluded. Your refusal to participate or discontinuation of participation at any time is without penalty.

**Cost:** There are no costs to participate in this study.

**Confidentiality:** You will be identified only by a pseudonym. This signed consent will be kept separate from your demographic survey. I may publish the results of this study. Your name and or any identifiable information will not be used in the publication. Files containing electronic data will be encrypted and password protected. Each participant's signed informed consent will be kept in a secure and locked location apart from the transcripts and audio tapes where only this researcher will have access.

**Audiotapes during the study:** In order to obtain an accurate account of your experience interviews will be audio taped, with your permission. Tapes will be labeled with the pseudonym and will be kept locked in this researcher's files. You may, at any time, review your audiotapes. The audiotapes will be reviewed by this researcher and transcribed to review for this study.

Contacts for questions about the research:

Kristine Ferrucci-Egan, MSN, RN or [Kferrucci-egan@lions.molloy.edu](mailto:Kferrucci-egan@lions.molloy.edu)

Or my academic advisor and Dissertation Committee Chairperson Dr. Judith James-Borga  
[jjamesborga@lions.molloy.edu](mailto:jjamesborga@lions.molloy.edu)

Barbara H Hagan School of Nursing, Molloy College  
1000 Hempstead Ave  
Rockville Centre, NY 11754  
516-323-3000

An explanation of the procedures to be utilized for this study, in which I have voluntarily agreed to participate, has been offered to me. All of my questions and concerns regarding this study have been addressed to my satisfaction. It has been explained to me and I understand that the information collected will be held in confidence, and that my personal information will not in any way be identified. I understand that additional information about the study results will be provided, upon conclusion of the study, at my request. I know that I am free to withdraw from this study without penalty at any time.

The above information has been provided to me (check one) \_\_\_\_\_ In writing \_\_\_\_\_ Orally

Signature of subject \_\_\_\_\_

Date \_\_\_\_\_

Signature of researcher \_\_\_\_\_

Date \_\_\_\_\_

Complete the following if you wish to receive a copy of the results of this study:

NAME: \_\_\_\_\_ (Typed or printed)

ADDRESS: \_\_\_\_\_ (Street)

\_\_\_\_\_ (City) (State) (Zip)

e-mail \_\_\_\_\_ Phone \_\_\_\_\_



## APPENDIX C: Demographics Questionnaire

### Understanding the Lived Fertility Preservation Experience From Diagnosis to the Start of Adjuvant Therapy: A Study of Young Breast Cancer Survivors Demographic Questionnaire

This questionnaire is designed to help the researcher gather information. Your replies are optional. All information is confidential and will be compiled without any individual identifiers.

Pseudonym (name to be used in the study that is not your real name) \_\_\_\_\_

Age: \_\_\_\_\_

Race/Ethnicity:

- African American or Black \_\_\_\_\_
- Asian / Pacific Islander \_\_\_\_\_
- Hispanic or Latino \_\_\_\_\_
- Native American or American India \_\_\_\_\_
- White \_\_\_\_\_

What year were you diagnosed with breast cancer? \_\_\_\_\_

How old were you at the time of your diagnosis? \_\_\_\_\_

Where do you reside?

- Rural \_\_\_\_\_
- Suburban \_\_\_\_\_
- Urban \_\_\_\_\_

Marital Status at the time of diagnosis:

- Single \_\_\_\_\_
- Separated \_\_\_\_\_
- Divorced \_\_\_\_\_
- Widow \_\_\_\_\_
- Committed relationship \_\_\_\_\_



Highest Level of Education at time of diagnosis:

- High school\_\_\_\_\_
- College\_\_\_\_\_
- Graduate school\_\_\_\_\_.

Were you employed at the time of your diagnosis? Yes \_\_\_\_\_ No \_\_\_\_\_

What was your household income at the time of your diagnosis?

\$12,500-\$25,000 \_\_\_\_\_

\$25,001-\$50,000 \_\_\_\_\_

\$50,001-\$100,000 \_\_\_\_\_

\$100,001-\$150,000 \_\_\_\_\_

\$150,001-\$200,000 \_\_\_\_\_

Above \$200,000 \_\_\_\_\_

Were you insured at the time of your diagnosis? Yes \_\_\_\_\_ No \_\_\_\_\_.

If you were insured did your insurance cover:

- Fertility specialist\_\_\_\_\_
- Consultation\_\_\_\_\_
- Medications\_\_\_\_\_
- Lab work\_\_\_\_\_
- Ultrasounds\_\_\_\_\_
- Egg retrieval\_\_\_\_\_
- Egg Fertilization \_\_\_\_\_
- Embryo Transfer\_\_\_\_\_
- Egg or Embryo storage\_\_\_\_\_
- \_\_\_\_\_

Did you have children at the time of diagnosis? Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, please list the gender and age of each child (do not give their names)

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## **APPENDIX D: Script**

Hello, My name is Kristine Ferrucci-Egan. I am a Registered Nurse and currently enrolled in the Ph.D. program with Molloy College in partial fulfillment of the requirements for the degree of Doctor of Philosophy. The focus of my research study is the lived fertility experience of young women diagnosed with breast cancer who received adjuvant therapy.

As the researcher, this study on the fertility preservation experience of young women diagnosed with breast cancer from post-diagnosis to pre-adjuvant therapy is personal. Six months before my 30th birthday I was diagnosed with cancer of the left breast. I had a mastectomy of the left breast and underwent both adjuvant therapy and radiation. On the advice of my oncologist, I consulted a fertility specialist however I did not go through with the process. As a result, I have always wondered what that experience might have been like so I would appreciate it if you would share your experience with me.

## APPENDIX E: Reaserch Probes and Questions

Understanding the Lived Fertility Preservation Experience From Diagnosis to the Start of  
Adjuvant Therapy: A Study of Young Breast Cancer Survivors

### Interview Questions



The purpose of this study is to examine the lived fertility preservation experience of young breast cancer patients prior to receiving adjuvant therapy. To understand the essence of this phenomenon participant interviews will be conducted utilizing a phenomenological perspective. This type of methodology aids in describing the common meaning for individuals on their lived experience throughout the process of fertility preservation before the initiation of adjuvant therapy.

#### Research Question:

What is the lived fertility preservation experience of young breast cancer patients from the time of diagnosis to the start of adjuvant therapy?

#### Grand Tour Question:

What were your fertility preservation experiences from the time of your diagnosis to the start of adjuvant therapy?

As participants proceed with the descriptions of their experiences, this researcher may ask specific follow-up questions to probe or clarify the descriptions. The following are samples of probing questions that may be used:

- What educational resources were you provided with?
- What supported or hampered your decision?
- Can you describe experiences with your family, spouse, significant other, and friends during this time period.
- Can you describe any physical, emotional, or spiritual aspects of your fertility preservation experience?
- Describe any challenges you may have experienced with the fertility preservation process.

- What is important for nurses and healthcare providers be aware of when providing care to young breast cancer patients who may want to preserve their fertility?
- What advice related to fertility preservation would you have for a young woman newly diagnosed with breast cancer?
- Is there anything else you would like to share about the fertility preservation process?



## **APPENDIX F: Molloy College IRB Approval**

Study Title: Understanding the Lived Fertility Preservation Experience from Diagnosis to the Start of Adjuvant Therapy: A Study of Young Breast Cancer Patients

Approved: January 6, 2020

Approval No:11050701-0106

Dear Dr. Borga and Ms. Egan:

The Institutional Review Board (IRB) of Molloy College has reviewed the above-mentioned research proposal and determined that this proposal is exempt. It is considered an EXEMPT category 45 CFR 46.104(2)(2) per the requirements of Department of Health and Human Services (DHHS) regulations for the protection of human subjects.

As per 45 CFR 46.115(b) and 21 CFR 56.115(b) require that all IRB records be retained for at least 3 years, and records relating to research which is conducted be retained for at least 3 years after completion of the research.

Please note that as Principal Investigator (PI), it is your responsibility to be CITI Certified in both the Responsible Conduct of Research and Human Subjects Research and to submit the evidence in order to conduct your research. Remember, all consents and recruitment flyers for any research protocol need to have Molloy IRB dated stamps of approval. To obtain the official stamp, please contact Ms. Gina Nedelka ([gnedelka@molloy.edu](mailto:gnedelka@molloy.edu)) to arrange a time to meet with her in her office in Kellenberg-Room 009. You will bring one clean consent (of each consent

and/or assent) and any recruitment flyers to the meeting with Ms. Nedelka for IRB dated stamp of approval. You then make copies of stamped materials and use those copies for recruiting and consenting.

You may proceed with your research. Please submit a report to the committee at the conclusion of your project.

This acknowledgement expires within three years-unless there is a change to the protocol.

However, the IRB requires an annual ongoing report of your exempt protocol (the application for ongoing/continuing review) is available on the IRB web page.

If there is a proposed change to the protocol, it is the responsibility of the Principal Investigator to inform the Molloy College IRB of any requested changes before implementation.

A change in the research may change the project from EXEMPT status and requires prior communication with the IRB.

Sincerely,

Patricia A. Eckardt, PhD, RN, FAAN

Chair, Molloy College Institutional Review Board

Professor, Barbara H. Hagan School of Nursing

[peckardt@molloy.edu](mailto:peckardt@molloy.edu)