The Experience of Young Women Living with Advanced Breast Cancer: A Hermeneutic Phenomenological Study

Author: Debra Lundquist

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Boston College

William F. Connell School of Nursing

THE EXPERIENCE OF YOUNG WOMEN LIVING WITH ADVANCED BREAST CANCER: A HERMENEUTIC PHENOMENOLOGICAL STUDY

a dissertation

by

DEBRA MANNING LUNDQUIST

submitted in partial fulfillment of the requirements

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The Experience of Young Women Living with Advanced Breast Cancer:

A Hermeneutic Phenomenological Study

Debra Manning Lundquist

Chair: Pamela J. Grace Ph.D., RN, FAAN

Abstract

Purpose/Specific Aims: Van Manen's hermeneutic phenomenological method was used to design this study aimed at better understanding the meaning of day-to-day living with advanced breast cancer in young women.

Rationale/Significance of Study: There is a gap in knowledge about the particular needs and daily life experiences of this cohort. Very little data specifically addresses this population. The limited literature that exists suggests that, due to the particular stage of life, their needs differ from those at other life stages as well as those coping with earlier stages of breast cancer. These women have described themselves as being invisible and having to live with the knowledge that their future is uncertain. Thus, this qualitative study is an important initial step in expanding our understanding of what daily life is like for this population.

Sample and Recruitment: Women aged 25–39 with Stage III or IV breast cancer were purposively recruited via private Facebook^{TM} groups specifically for women with breast cancer. The final sample consisted of 12 participants from across the U.S. Incidentally, all were parents.

Data Analysis: Data were collected through two or more semistructured interviews and written journals. Analysis followed van Manen's method of immersion, reading, and rereading, and using manual coding and NVivo software to develop themes to capture the participants' lifeworlds.

Findings: The meaning of their experiences is captured by the overarching theme: *Wearing the mask of wellness in the presence of life-threatening illness*. Five major themes were identified: *Wanting to be known as the person I am, I'm still Mom, Living is more than surviving, Getting through it,* and *Being connected to others.*

Conclusions: Findings highlight that these young women are managing multiple roles and responsibilities despite the ongoing challenges of treatment and symptom management. They feel that their needs and struggles are not well understood because to outsiders they do not look ill. This study provides a base for further research and eventually interventions.

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CHAPTER ONE

STATEMENT OF THE PROBLEM

Background

Nurses have an obligation of care to individuals and society as outlined in codes of ethics and social policy statements (American Nurses Association [ANA], 2010b). This obligation is most critical when persons are in a vulnerable state due to disease or treatment-related factors. Nurse scholars have a professional responsibility to investigate health needs and challenges related to practice populations particularly and society more generally. This is especially important in the case of those who are marginalized or whose healthcare needs are neglected. One such group is that of young women living with advanced breast cancer. This researcher, as a nurse practitioner specializing in oncology, became aware that some of her patients, despite having a diagnosis of advanced breast cancer, continue to live for extended periods of time after curative measures had failed. Some continue to manage full lives in spite of being symptomatic and having a diagnosis that almost certainly harbingers an early death. Busy raising families, working, and juggling many roles and responsibilities, these women are *living with* advanced breast cancer. They are living with advanced cancer but, for the most part, cannot expect cure and may feel they are not given the same attention as others for whom cure is a very real possibility. This phenomenon seems to manifest itself in many ways. For some, *living with* may actually be *enduring* and for others it may be *maintaining normalcy* despite the fact that this time may be anything but their normal. I have seen women come for treatment after work or schedule treatments in such a way that there is minimal disruption to work or family life. Others have made the decision to stop working for a variety of reasons.

Women with metastatic breast cancer have described themselves as being invisible and without a voice and for such reasons should be considered a vulnerable or marginalized group (Danesh, Belkora, Volz, & Rugo, 2014; Novartis Oncology, 2014). The lack of understanding about the experiences and healthcare needs of young women living with advanced breast cancer is introduced in this chapter. A serious gap in knowledge exists about this population's health needs. Moreover, evidence suggests this population will continue to grow, making the problem of how to attend to their needs even more urgent to address. This study specifically explored the experiences of young women between the ages of 25 and 39 who are living with advanced breast cancer. Reasons for undertaking this research study are given. Significance for the discipline, society, and the population is explained, and underlying assumptions and operational definitions for the study are explicated. The chapter concludes with the research questions and a brief rationale for the method chosen to investigate the research question.

Statement of the Problem

While there is a growing body of knowledge about cancer and the experiences of people with cancer, little is known about the particular needs and experiences of young women (less than age 40) living with advanced breast cancer. Advanced breast cancer includes both Stage III and Stage IV (metastatic) disease. The diagnosis is often unexpected and comes at a time when, for most people, much of their lives are before them and are full of promise and expectation. As an advanced practice nurse specializing in oncology, I have heard the stories from some of these women. I have reflected on their experiences and wondered how they can juggle their many obligations in the face of this diagnosis, and I have noted the seeming lack of resources for them. Many struggle with physical and emotional challenges, while trying to maintain as much normalcy in their lives as possible. They are living with, and enduring, a disease that will likely claim their lives at an unspecified and premature time in the future.

A survey of the literature revealed that the challenges and needs of the population of young women living with advanced breast cancer are not well understood. Much of the research focusing on women with advanced breast cancer incorporates a wide diversity of ages and stages. While there may be commonalities in experiences of living with advanced breast cancer, there are likely to be divergent experiences and challenges related to age, life stage, and family responsibilities. To adequately address the needs of young women experiencing advanced breast cancer, we need to better understand their particular challenges, concerns, and experiences of daily living. Given the scarcity of knowledge about this population, there is a clear need to explore, describe, and interpret the day-to-day experience of young women *living with* advanced breast cancer. This is especially urgent in view of existing knowledge about breast cancer and its characteristics and incidence in the United States (U.S.) and globally, as outlined below and detailed in Chapter Two.

Breast cancer. The incidence of breast cancer worldwide is predicted to rise to 2.3 million by 2030 (Ferlay et al., 2010). Cancer survivorship continues to improve due to screening, early detection, and advances in treatment. Currently, there are 3.5 million women and men in the U.S. with a history of breast cancer. Breast cancer is one of the most common cancers in women under the age of 40 (Bleyer et al., 2008; National Institutes of Health [NIH], 2017a) with 7% of all female breast cancers in the U.S. diagnosed under the age of 40 years (Anders & Carey, 2009). In 2015, there were 10,500 cases of invasive breast cancer diagnosed with 1,010 deaths in women less than 40 years old (American Cancer Society [ACS], 2015). Breast cancer is also the leading cause of death in women age 20–39 (Siegel, Miller, & Jemal, 2016). Younger women often have higher grade and more hormone-receptor negative cancers as compared to older women. Additionally, younger women present more often with advanced disease. For these women, 5-year survival is only 39%. The frequency of advanced stage at presentation has increased significantly over the past 30 years in the U.S. (Johnson, Chien, & Bleyer, 2013).

Metastatic breast cancer. At diagnosis, approximately 4–6% of women will already have metastatic disease (Cardoso et al., 2016; Krigel, Myers, Befort, Krebill, & Klemp, 2014; Mayer, 2010; Surveillance, Epidemiology, and End

Results [SEER], 2016), and approximately 30% of women with early stage breast cancer will go on to develop metastatic breast cancer (Harding et al., 2013; Mayer, 2010; Mayer et al., 2010; O'Shaughnessy, 2005). The outlook is not favorable for women with metastatic breast cancer. The focus of care for this group, switches from cure to palliative, controlling symptoms, and improving quality of life (Harding et al., 2013; Krigel et al., 2014). Not all may have access to palliative care resources. Metastatic breast cancer brings uncertainty and significant challenges for women and their families. For some with metastatic breast cancer, day-to-day living may become a struggle to cope and survive. Personal, familial, social, and economic costs also impact these women, as it does society as a whole (DiLascio & Pagani, 2017).

Advances in the treatment and management of metastatic breast cancer have resulted in women living with the disease for longer periods of time with improved quality of life. However, metastatic breast cancer remains incurable for most, despite advances in treatment approaches and understanding of the disease (Harding et al., 2013). These individuals are living longer and their numbers are increasing as a result of improved treatment, yet there is no national database for tracking (Mariotto, Etzioni, Hurlbert, Penberthy, & Mayer, 2017).

Prolonging survival for many women with metastatic disease is possible, but it may require ongoing treatment with uncertain results and accompanying side effects. Unfortunately, treatments, for the most part, ultimately fail to control the disease (Krigel et al., 2014). As the disease progresses, new chemotherapy, hormonal, or biological therapies are introduced to control the disease, but over time, they tend to work for shorter periods and with lowered effectiveness. As a result, many women may experience cumulative side effects and toxicities that require ongoing assessment and management. Additionally, women may need to cope with symptoms related to progressive disease. This often necessitates additional supportive care for problems such as nausea, fatigue, chronic pain, and other debilitating symptoms (Mayer, 2010).

The median survival of approximately 2–3 years has remained essentially unchanged for women with metastatic breast cancer. For those with Stage III (locally advanced breast cancer) disease, approximately 40% die within 5 years (Beishon, 2015). For those with Stage IV (metastatic) disease, approximately 25% will survive for 5 years, and of those patients, approximately 10% will remain alive at 10 years (McClelland, Holland, & Griggs 2015). In the U.S., women with metastatic breast cancer receive an average of four to six regimens of chemotherapy, which potentially leads to additional challenges such as a significant increase in side effects (Kokkonen et al., 2017). Understanding and evidence are limited as to why and to what extent women living with metastatic breast cancer are willing to tolerate treatment-related toxicities in order to extend their lives. Additionally, more evidence is needed to understand their needs for information and support that would help in decision-making and advanced care planning (Harding et al., 2013). All of this is in addition to the existential, familial, and contextual concerns of living with a terminal disease that will cut short one’s life.

Challenges. Women with metastatic breast cancer and their families experience significant challenges related to managing physical symptoms and encountering psychosocial problems that may profoundly affect their quality of life (Mayer et al., 2010). However, there remain few studies that focus specifically on understanding what daily living is like for women with metastatic breast cancer and their families, particularly in light of what is known about the seriousness and burden of this diagnosis. It is quite likely that this population experiences challenges and needs that are significantly different from those of women with early-stage breast cancer; however, a serious gap in knowledge exists about the particular challenges and concerns of this population.

Most current research of women with advanced disease is conducted with groups of women in whom there is a wide diversity in ages. All women with advanced disease face challenges. What is not so well understood is whether the challenges and needs vary based on age group. Better understanding of unique age-related needs and concerns is essential. Generation of knowledge about the particular needs of specific age groups, such as young women living with advanced breast cancer, is required to inform care and improve their quality of life.

Gaps in the knowledge of advanced breast cancer in young women. Young adult women with breast cancer often face a disease that is clinically more aggressive with lower survival rates as compared with those who are older (Korde et al., 2015; Partridge et al., 2014). Diagnosis occurs at a time when they are developing identities, finding their place in the world, establishing careers, developing relationships, and building families (Chen, Parmar, & Gartshore, 2014; Cleeland et al., 2014; Shaha & Bauer-Wu, 2009). In addition, there is limited knowledge about their perspectives regarding issues of mortality (Shaha & Bauer-Wu, 2009). They may have different vulnerabilities than older women to the psychological and emotional burdens of living with advanced breast cancer. Physical and functional challenges may exacerbate emotional burdens that accompany the disease and its treatment. Some scholars have recommended supportive care services to meet the unique challenges of this younger cohort to better understand and provide guidance in managing physical, family, social, and work-related quality of life (Hamer et al., 2017). However, more research is needed to understand these challenges. Data on psychosocial factors specific to the young adult cancer population including educational needs, social and family issues, and employment are lacking (DeRouen et al., 2015; NIH, 2017a).

Current research. There are limited data in general about the association of symptom burden, daily activity impairment, and work productivity in patients with advanced breast cancer (Cleeland et al., 2014) and even less on young women living with advanced breast cancer. Few studies have documented needs and challenges, thus delaying the development of effective interventions to improve quality of life (Chen, Parmar, & Gartshore, 2014; Cleeland et al., 2014).

Emerging research supports the supposition that a significant number of women with metastatic disease feel ignored, invisible, without a voice and misrepresented as the women who have “lost the battle” against breast cancer (Danesh et al., 2014; Novartis Oncology, 2014).

Significance

In a recent European study (Novartis Oncology, 2014) of women living with advanced breast cancer, participants described themselves as “invisible women” who felt isolated from others, health professionals, and society in general in comparison to early stage breast cancer patients. Previous authors have described those living with advanced cancer as experiencing a steady decline in function while having a moderately high level of performance (Lunney, Lynn, Foley, & Lipson, 2003). Others described this population as feeling forgotten and alone, with persistent unrecognized and unmet needs including physical, informational, psychosocial, and existential (Haylock, 2010a, 2010b; Lynn, 2005; Singer et al., 2015).

The limited available research suggests that younger women with advanced breast cancer face unique challenges in their daily lives in addition to sharing some of those suffered by older women (DeSanto-Madeya, Bauer-Wu, & Gross, 2007; Shaha & Bauer-Wu, 2009). For example, they may be building careers, developing long-term relationships, and raising children while also dealing with the challenges of living with an advanced breast cancer diagnosis, concomitant treatment, and existential concerns. Many continue to live, work, and fulfill roles and responsibilities and other commitments for extended periods of time. Some of these women may experience accumulating symptom burden and deterioration of function, while others may remain independent and functional for relatively long periods of time.

In a qualitative study using semistructured focus groups of women with metastatic breast cancer, participants identified major concerns as changes in role functioning, altered relationships, and self-image (Krigel et al., 2014). Certainly, this cohort of women living with metastatic breast cancer, who have described themselves as “invisible” and lacking a voice are among those who may be considered vulnerable and marginalized and should be of special concern to the nursing profession. Research of the multidimensional facets of the experience of living with advanced breast cancer in young adult women is needed to inform educational and supportive interventions.

Recent calls to action. There has been a national response to the challenge of improving the delivery of care to individuals living with advanced cancer. The American Cancer Society (ACS), the Oncology Nursing Society, the National Cancer Institute, and the Institute of Medicine (IOM) have all developed agendas, position statements, and research initiatives to further improve education for both healthcare professionals and patients and to improve access to palliative care. The IOM report “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life” (2015) calls for significant changes in four areas of care delivery: clinician-patient communication and advance care planning, and professional education and development, policies and payment systems, and public education and engagement. Taken together, these recommendations offer a roadmap for progress in caring for people living with advanced cancer that should be person-centered, family-oriented, and evidence-based (IOM, 2015). This study proposes to contribute insights about the experiences of young women living with advanced breast cancer that can underscore the need for further research and the development of interventions.

Purpose of the Study

Because of the scarcity of knowledge about the needs of this population and in line with contemporary understandings that qualitative approaches are appropriate for discerning human experiences of particular phenomena, this study used the hermeneutic phenomenological approach of van Manen (1984; 1990), as explained in more detail in Chapters Two and Three. Van Manen's approach facilitates description of the perspectives of those experiencing a phenomenon to be described within the contexts of their daily lives. The purpose of the study was to describe and interpret the meaning of the phenomenon of young women living with advanced breast cancer from their unique perspective.

Definitions and Assumptions Based on Existing Knowledge

Operational Definitions

Advanced cancer: Cancer that is metastatic or progressive, for which there is no longer curative treatment. People may be receiving noncurative and symptom-management treatments (NIH, 2017b).

Cancer treatment: Surgery, chemotherapy, radiation therapy, targeted therapy or immunotherapy used to treat cancer (ACS, 2017).

Metastatic breast cancer: Breast cancer that has spread beyond the breast to other organs in the body (most often the bones, lungs, liver, or brain). It may also be called stage IV breast cancer (Metastatic Breast Cancer Network [MBCN], 2017).

Noncurative treatment: Chemotherapy, radiation therapy, or surgery used for symptom palliation and for slowing disease progression (ACS, 2017).

Palliative care: Interdisciplinary approach that provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families. Palliative care may begin early in the course of treatment for a serious illness and may be delivered in a number of ways across the continuum of healthcare settings, including in the home, nursing homes, long-term acute care facilities, acute care hospitals, and outpatient clinics (IOM, 2015).

Person-focused care: Care that is respectful of, and responsive to, individual patient preferences, needs and values, ensuring that patient values guide all clinical decisions (IOM, 2015).

Phenomena: Objects and events as they appear objectively or are experienced subjectively. As a research method, “(P)henomenology is the study of structures of consciousness as experienced from the first-person point of view” (Stanford Encyclopedia of Philosophy, 2013).

Phenomenology: A type of inquiry that is aimed at understanding the lived experience in the context of daily life (Creswell, 2013; Lopez & Willis, 2004; van Manen, 1984).

Phenomenon: In this study, is defined as the (day-to-day) experiences of young women with advanced breast cancer. The “essences” of these phenomena emerged from the participants’ written and oral accounts of the phenomena.

Stage III breast cancer: Breast cancer that has extended to beyond the immediate region of the tumor and may have invaded nearby lymph nodes and muscles, but has not spread to distant organs. This stage is considered to be locally advanced breast cancer (National Breast Cancer Foundation, 2017).

Assumptions Made Prior to the Study

1. A young woman living with advanced breast cancer is the most knowledgeable about her experience of living with advanced breast cancer.
2. Some young women with advanced breast cancer continue to manage multiple roles and responsibilities in their lives for extended periods of time even when cure is not possible.
3. Certain essential aspects of the experiences of young women with advanced cancer may differ from those of other age groups experiencing the phenomena of living with advanced breast cancer.
4. Young women living with advanced breast cancer are willing and able to share their experiences with the researcher.
5. The researcher is able to elicit honest information from the interviews

with participants. The interviews with participants would provide insights about essential aspects of the phenomena.

6. A deeper understanding of the experience of living with advanced breast cancer will inform nursing science and lead to generalizable research and eventually the development of person- or group-centered interventions.
7. The nurse researcher can control her knowledge and preconceptions about the experience of young women living with advanced cancer.
8. Themes induced and identified by the analyst from the interpretation of the interview data would be able to inform nursing knowledge for this population.

Aims, Research Questions, and Methodology

Specific Aim

To describe and interpret the essences of the phenomenon of young women living with advanced breast cancer.

Research Questions

1. What is the experience of living with advanced breast cancer for young adult women?
2. What is the meaning of living with advanced breast cancer for young adult women?

Method

Phenomenology was the method choice for this study. It is a method of inquiry derived from philosophical assumptions that there are essential commonalities in human experiences of an object or event—including life-altering events and processes—and can be accessed by those experiencing the phenomena. The following is a description by Willis, Sullivan-Bolyai, Knafl, and Zichi-Cohen (2016):

> A distinguishing attribute of phenomenological research, and its modality of descriptive phenomenology, is the researcher taking the view that the human being is that sort of being who lives through events or life situations that are necessarily shaped and held within one's consciousness pre-reflectively; that is, the human being is the type of being who is able to reflect on his being (p. 1188).

Phenomenology aims to gain a deeper understanding of the nature and meaning of everyday experiences by those who are living them. Hermeneutic phenomenology was determined as the most appropriate method for this study. It is an interpretative approach to inquiry about phenomena as these are experienced and is explained more fully in Chapters Two and Three. Van Manen's method was used to gather and analyze the data. His method was particularly helpful in facilitating the researcher's understanding of the phenomenon of young women living with advanced cancer as it provided a way to "uncover and describe the structures, the internal meaning structures, of lived experience" (van Manen, 1990, p. 10). More detailed reasons for the selection of this particular version of phenomenology are provided in Chapters Two and Three.

Summary

The purpose of the chapter was to outline the significance of this study for nursing knowledge development. An underlying assumption of the study was that nurse scholars have a responsibility to study phenomena of concern for their populations with the intent of improving practice. The contemporary significance of this study, to learn more about the needs and concerns of young women living with advanced breast cancer, was provided in a brief overview of what is known and not known about women living with advanced cancer, in general and young women in particular. Reasons were provided for choosing a hermeneutic phenomenological method as most appropriate given the lack of knowledge about the population. Chapter Two includes an in-depth discussion of the theoretical framework that informed aspects of this study, a thorough and critical review of the pertinent literature related to experiences of living with advanced breast cancer, and what is known and not known about the specific population of young adult women living with advanced breast cancer. Chapter Three details the method and processes used to gather and analyze data. The findings are presented in Chapter Four, and Chapter Five describes the implications related to the findings.

CHAPTER TWO

REVIEW OF THE LITERATURE

The purpose of Chapter One was to outline the problem studied in this project and its significance for the population concerned, nursing, and healthcare more generally. That is, knowledge is lacking about the experience of young women living with advanced breast cancer. It was affirmed that to date very little is known about the experiences of the population of young women who are living day-to-day *with* advanced breast cancer. In Chapter One, it was also argued that this is a particularly vulnerable group who must live with the knowledge that their future is uncertain and that they will ultimately die from their disease. In Chapter Two, the foundation for undertaking the study, as both a clinical and social justice issue, is detailed along with a discussion of what is known and not known about the experiences of those living with advanced cancer, women with metastatic breast cancer, and young adults living with advanced breast cancer.

First, the foundation for the study, aligned with the idea that nurse scholars have responsibilities to further the goals of the discipline, especially as these relate to the researcher's practice area or area of expertise, is discussed. These goals have been articulated by the American Nurses' Association (ANA):

> The protection, promotion, and optimization of health and abilities, prevention of illness and injury, facilitation of healing, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, groups, communities, and populations (ANA, 2017b).

The profession has a moral obligation to promote the individual and societal good related to health through disciplinary knowledge development. Next, an exploration of what is known and not known about this phenomenon, and related phenomena such as living with advanced cancer, are described in detail and critiqued. Finally, the rationale is provided for hermeneutic phenomenology as the best starting point for exploring healthcare issues such as this, where knowledge about the human experience is scant due to the immature state of the science.

Purpose and Goals of Nursing

Nurses serve the public good with knowledge, skills, and expertise (Grace, 2018). Nursing as a profession is responsible to society in the sense that the profession serves a critical purpose in society related to unmet needs. The values and goals of the profession shape the value orientation of the discipline. The profession of nursing uses specialized knowledge and skills developed to address societal needs, and the discipline comprises the inquiry, knowledge development, and prescriptive face of the profession, as described below. These values and goals of the profession have been determined over time by nurse scholars, leaders, and practitioners in response to unmet societal needs. The values and goals are articulated in various documents including codes of ethics (ANA, 2010a; International Council of Nurses [ICN], 2012). Codes of ethics represent the promises that a given profession makes to society about what it holds its members, individually and collectively, responsible for (Grace, 2018).

Ongoing knowledge development and philosophical inquiry are both needed to continue to anticipate and meet the needs of individuals and society and, thus, professional goals. This is the purview of nursing as a discipline. The discipline develops knowledge needed for practice (what the profession does). Donaldson and Crowley (1978) provide a schema for how professions are developed. Each discipline has its own unique syntax (ways of knowing) and substantive structure (content). Yet, healthcare disciplines are not practiced in a vacuum. Interrelatedness exists among various allied disciplines such as those of the healthcare professions. This is important in working with colleagues from other disciplines to advance mutual goals related to the health of individuals and society. Bringing different perspectives to the study of a problem can enhance knowledge development for a population (Dahnke & Dreher, 2011). The profession of nursing is distinguished from other healthcare professions by its purpose, phenomena of concern, unique perspective, knowledge base, and professional responsibilities (Donaldson & Crowley, 1978; Willis, Grace, & Roy, 2008).

The ultimate goal of nursing, as determined over time, is promotion of the human good of health using a nursing perspective. In their 2008 article, Willis et al. reviewed several decades of literature and highlighted the perspective of the discipline as involving humanization of the healthcare environment (Willis et al., 2008). Both the ICN (2012) and the ANA (2010a) describe the goals as including the promotion of health, the prevention of illness, restoration of health, and alleviation of suffering. The goals of nursing drive the ethical principles used in practice; that is, they serve as an anchor for decision-making, whereas ethical principles and theories provide the ability to gain clarity about a given issue or dilemma and important aspects (Grace, 2018). As members of a profession, nurses ideally provide the services that are necessary to individuals and the societies in which they live. The disciplinary aspect of the profession is responsible for ongoing knowledge development both about the profession and its responsibilities and for addressing practice issues. To adequately address practice issues, nurse scholars must concern themselves with anticipating areas where knowledge development is needed and seek to develop this knowledge via research or other sorts of inquiry. Additionally, clinicians, including nurses and physicians who are at the frontlines of care, also have a responsibility to identify gaps in knowledge and care delivery. Ideally, partnerships of clinicians and nurse scholars would provide the mechanism to identify gaps and questions that need to be answered in order to further knowledge development and inform the state of the science about a particular problem.

As an advanced practice oncology nurse and nurse scholar, I have the unique opportunity to reflect on areas of my practice, identify areas of concern, and examine the literature for gaps in knowledge. I worked in a practice that specialized in the care of women with breast cancer. One group, young women with advanced disease, has always concerned me. They are living with a difficult diagnosis at a time when they are developing and establishing their personal and professional identities. I had a unique opportunity as their nurse to have a privileged relationship where they shared intimate details of their lives. It was clear that many were continuing to set both personal and career goals and yet were struggling with symptoms related to disease and/or treatment. Many juggled multiple roles in the context of daily life with a disease that would ultimately cut short their lives. As a nurse, I have a responsibility to treat each individual as worthy of respect and to promote the common good. Therefore, if I, as an advanced practice oncology nurse and nurse scholar with research skills, when I identify an area of my practice about which not much is known, I have an obligation to investigate further. As a nurse clinician and scholar, I am responsible for gaining a better understanding of the implications of these experiences for this population for the ultimate purpose of designing effective interventions. A survey of the literature validated concerns that evidence is strongly lacking about the unique challenges that may be faced by this vulnerable population. Next, the case is made that nursing as a whole has a responsibility to address shortcomings in knowledge related to vulnerable populations and that this is a social justice issue. A review follows, focused on the scant literature related to what is known, and not known, about the particular needs of this population of young women living with advanced cancer.

Social Responsibility of Nursing

As noted, nursing's codes of ethics serve as the profession's promise to the individuals they serve (Grace, 2004). Nurses have a responsibility related to direct care but also a broader social responsibility as articulated in the Codes of Ethics (ANA, 2010a; ICN, 2012). The nursing profession in the U.S. and elsewhere holds itself accountable for identifying and addressing the needs of those made more than ordinarily vulnerable by circumstances or unmet health needs (Sellman, 2005). This is an issue of social justice.

Social justice is concerned with fairness and remedying disparities in care. While a universally agreed upon definition of social justice does not exist, we can recognize injustices that impact the populations we serve, and nurses have a responsibility, indeed a moral obligation, to investigate potential issues of injustice (Grace & Willis, 2012). Social justice is an organizational predisposition in nursing that is central, enduring, and complex (ANA, 2010b; ICN, 2012; Thompson, 2014). This predisposition acknowledges that “nurses share with society the responsibility for initiating and supporting action to meet the health and social needs of the public, in particular vulnerable populations” (Thompson, 2014, p. E21). Nursing practice should focus on any aspect of healthcare and healthcare delivery that disadvantage individuals or groups, including the social determinants of health that the profession can work to correct inequities (Thompson, 2014).

Social Mandate of Nursing

The ANA Social Policy Statement, a contract with the public nursing serves, suggests nurses have a commitment to care that is relationship-based, person-centered, and focused on the biophysical, psychosocial, and spiritual needs for all people, especially those most vulnerable. Nurses have a unique perspective of what constitutes injustice in healthcare and which individuals and groups are at a greater disadvantage (ANA, 2010b). Consequently, women living with advanced breast cancer who have described themselves as “invisible” and lacking a voice, are an especially vulnerable population whose needs should be more fully understood (Novartis Oncology, 2014). The following sections will detail what is known from the literature. First, what is generally known about living with advanced cancer is discussed followed by the experience of young adults living with advanced cancer.

Living With Advanced Cancer

From the accumulated evidence, we know that people are living longer with advanced cancer (locally advanced or metastatic incurable cancer) than in previous decades as a result of improved screening, early detection, and treatment advances (ACS, 2015; Kamal et al., 2011; Salakari, Surakka, Nurminen, & Pylkkänen, 2015). Most are living and receiving care in the community and face psychological, physical, social, emotional, and spiritual issues related to advanced cancer (Kamal et al., 2011; Meier & Beresford, 2008). Some with advanced cancer may experience accumulating symptom burden and deterioration of function, while others may remain relatively independent and functional for longer periods of time.

There is a large and growing body of literature describing diagnosis, treatment, and end-of-life concerns in people with cancer. However, there is a subgroup of people, those living with advanced cancer, in which knowledge about their experience of *living with* advanced cancer is limited. This subgroup incorporates those with a life expectancy greater than 6 months who are not receiving hospice care. The subgroup comprises people who are living longer and who are increasing in number due to improved treatment, yet there is no database to track these individuals. Estimates suggest that 300,000–500,000 people are living with advanced cancer in the U.S.; however, actual numbers may be higher (Haylock, 2010b). Moreover, estimates of life expectancy for this group remain nebulous.

A review of the literature from 2007–2017 related to people living with advanced cancer, demonstrates that existential, physical, and psychosocial needs are included as foci of research. Existential concerns include maintaining hope, meaning, experiences of suffering, spirituality, and happiness (Curtis et al., 2008; Duggleby et al., 2011; Eustache, Jibb, & Grossman, 2014; Hirai, Miyashita, Morita, Sanjo, & Uchitomi, 2006; Koffman et al., 2013; Lethborg, Aranda, Cox, & Kissane, 2007; Morrison, Augustin, Souvanna, & Meier, 2011; Nilmanat et al., 2010; Nilmanat et al., 2015; Nissim et al., 2012; Reinke et al., 2008; Scheffold et al., 2015; Willig, 2015; Wise & Marchand, 2013). Physical and psychosocial concerns include symptom management, decision-making, transitions, and quality of life (Au et al., 2013; Back et al., 2009; Get-Kong et al., 2010; Hopkinson & Corner, 2006; Kamal et al., 2011; Lindqvist, Widmark, & Rasmussen, 2006; Mårtensson, Carlsson, Lampic, 2008; Mehta, Cohen, Ezer, Carnevale, & Ducharme, 2011; Prince-Paul, 2008; Yamagishi et al., 2012; Zhang et al., 2009). Several of the studies, relevant to the current project, are briefly discussed below and are included as they begin to address some of the aspects of living with advanced cancer.

One qualitative study (Burles & Holtslander, 2013) aimed to better understand the lived experience of women with ovarian cancer across the illness trajectory. This study included 16 women between the ages of 37 and 68. The mean age of participants was 52 years. Time since diagnosis ranged from 9 months to 13 years, and participants had varying stages of disease. Five themes were identified and include physical (changes in health status and the body), disruptions in daily activities and relationships, uncertainty, coping, and finding meaning in illness. The essence of living with ovarian cancer was described as "cautious optimism" (p. 442). This study is important in that it offers a description of the lived experience of ovarian cancer. However, the heterogeneity of the sample with regard to age, stage, and length of time since diagnosis is a significant limitation. However, as one of the only studies that began to explore the entirety and complexity of the lived experience from the perspective of daily living, it adds insights of importance to the current study.

Au and colleagues (2013) conducted a cross-sectional study of 198 women with advanced breast cancer receiving chemotherapy in the outpatient setting to identify unmet needs using the Supportive Care Needs Survey Short Form, psychological morbidity using the Hospital Anxiety and Depression Scale, symptom distress using the Memorial Symptom Assessment Scale, and satisfaction with care using the Patient Satisfaction Questionnaire (PSQ-9).

Participants ranged in age from 24 to 81 years old, with a mean age of 53.4 years old. Most commonly identified needs were health system–related, such as continuity of care, informational needs due to poor communication, and psychosocial needs including psychological concerns and sexuality. Limitations of this study included lack of representativeness of the population in that most were patients who received care in a public healthcare clinic. Patients receiving care from private healthcare systems were not included in the study. Additionally, the diverse ages of participants make it difficult to ascertain age-related differences in concerns. As a cross-sectional study, it also was unable to capture how needs may change over time and with disease progression.

Wise and Marchand (2013) used grounded theory method to understand and characterize the strategies and psychosocial conditions that influence how resilient people live with advanced cancer. The sample of 10 participants included seven men and three women. Participants had either advanced lung (n = 7) or advanced colorectal cancer (n = 3). The mean age was 62 years old with a range of 35–82. Participants reported they were living fully in the face of advanced disease, which allowed them to participate in their “ordinary” activities of daily living. Living fully was defined as facing death and also being engaged in life. The strategies identified to living fully in the face of advanced disease included embracing paradox, reframing time, deepening connections, and aligning actions with priorities. The limitations of this study include small sample size, the inclusion of different age groups, homogeneity in terms of race (all Caucasian), and no second interviews.

All these studies are important as they support and begin to identify the ways that some are living with advanced cancer. They also begin to identify challenges that they have faced and strategies that people diagnosed with advanced cancer have used to cope. Yet, the particular experiences of persons with different types of advanced cancer and in different age groups remain unclear. More studies exploring age and disease-specific groups are needed to expand the knowledge base and facilitate tailored supports and interventions.

Moghaddam, Coxon, Nabarro, Hardy, and Cox (2016) undertook a recent systematic review of studies related to the unmet needs of people living with advanced cancer. They identified 23 studies that met the inclusion criteria of focusing on the needs of persons with advanced cancer. Nineteen of the studies were quantitative surveys, and four were qualitative in nature and gathered data using semistructured interviews with individuals or focus groups. Across the studies, the average age of participants ranged from 57 to 75 years old. Fifteen of the studies had a mixed cancer population with the others focused on breast cancer (n = 3), prostate cancer (n = 3), and ovarian cancer (n = 1). The data synthesis from these studies found four primary types of unmet needs: information deficits, preoccupation with worries/uncertainty, symptom-related (pain and fatigue), and loss of function. In addition, there was a significant heterogeneity among the studies in terms of method, coding and reporting of needs, and participant characteristics (Moghaddam et al., 2016). Thus, it is not clear for any specific age group or type of cancer whether there are differences among needs. Moghaddam and colleagues' systematic review highlighted the problem that information is limited about the specific challenges faced by different age groups and/or cancer type, which supported the need for this study.

The review of literature conducted for the study described in Chapters Three and Four of this dissertation highlights that knowledge is lacking about the needs of specific age groups, types, and stages of cancer, and the probability that there are both shared and different needs depending on age, diagnosis, and stage of disease. It is important to study smaller more well-defined populations for the particular needs of these groups to be adequately addressed. This section provided an overview of what is known about living with cancer in general; the next section more specifically reviews the literature on what is known about metastatic breast cancer and its challenges and also supports the need for this current research project.

Women With Metastatic Breast Cancer

Metastatic breast cancer (also called stage IV or advanced breast cancer) is breast cancer that has spread beyond the breast to other organs in the body (most often the bones, lungs, liver, or brain). As the breast is the primary site, regardless of spread to various other organs, it continues to be referred to as breast cancer and is treated as such. On initial presentation of a new diagnosis of breast cancer, approximately 4–6% of women will be diagnosed with advanced or metastatic disease (Cardoso et al, 2017; Krigel et al., 2014; Mayer, 2010; SEER, 2013), Additionally, approximately 30% of women with early stage breast cancer will go on to develop metastatic breast cancer (Harding et al., 2013; Mayer, 2010; Mayer et al., 2010; O’Shaughnessy, 2005). With few exceptions, the focus of treatment for this population switches from cure to controlling symptoms and improving quality of life (Krigel et al., 2014). Metastatic breast cancer brings uncertainty and significant challenges for women and their families. For some with metastatic breast cancer, day-to-day living may become a struggle to cope and survive. There are personal, social, and economic costs that also impact society as a whole (Di Lascio & Pagani, 2017).

Advances in the treatment and management of metastatic breast cancer have resulted in women living with the disease for extended periods and improved quality of life (Mayer, 2010). However, metastatic breast cancer remains incurable for most despite advances in treatment approaches and understanding of the disease (Harding et al., 2013; Mayer et al., 2010). For this current project, a review of research exploring the context of day-to day life for women with metastatic breast cancer was completed. Although the literature remains scant, several studies are highlighted as demonstrating the ongoing gaps in knowledge about the experience of daily life in the context of metastatic breast cancer from the perspective of age.

Day-to-Day Perspective

Treatment advances over the past 10 years have improved short-term outcomes and extended length of life for some women with metastatic breast cancer, even enabling some patients to return to daily activities, including work (Cleeland et al., 2014). However, despite the progress made in extending life and mitigating symptoms, disruptions in functional status and activities of daily living may still occur that are disease- or treatment-related effects (Chen et al., 2014). DeSanto-Madeya et al. (2007) conducted a qualitative descriptive study of daily activity logs written by women with metastatic breast cancer. This study was a secondary analysis of activity logs completed by the control group of a larger study. Members of the control group in that study were asked to keep an activity log of their activities over the course of 4 days. The participant mean age was 52.2 years old. The findings support that some women with metastatic cancer are working and maintaining familial and social responsibilities. Daily activities included maintaining roles and responsibilities, managing households, working, participating in social and community activities, and caring for themselves physically, mentally, and spiritually. They managed all of these activities in the context of living with metastatic breast cancer. This study is important in that it confirmed that some women with metastatic breast cancer are living as they did before their diagnoses. However, the sample included women between the ages of 28 and 79 with a mean age of 52.2 years, and findings were not analyzed in terms of age groups. As a result, more became known about the general needs but not as much about specific needs of the participants. The researchers acknowledged that further research that is focused on the needs of specific age groups is needed. In addition, the authors suggested that further research is needed to better understand the experience as well as the demands and challenges of day-to-day living in all women with metastatic breast cancer (DeSanto-Madeya et al., 2007).

Cleeland et al. (2014) conducted a cross-sectional analysis of baseline patient-reported outcomes in patients with advanced breast cancer. This was an exploratory study to understand patient self-assessments of symptom burden and working productivity in 152 women with advanced breast cancer between the ages of 29 and 85 years. Findings demonstrated that symptom severity and symptom burden were significantly correlated with impairment of work productivity in this group of women. Age was found to be an important factor that affected patient-reported outcomes. Younger women reported higher symptom severity and interference with daily life, worse health-related quality of life, and greater activity impairment than older patients. A limitation of the study was the small number of participants who reported being employed in the workforce (n = 58). Another limitation concerned a lack of information about reasons some women were not employed outside of the home. Further, there was no information about the ages of those employed outside the home, so it is not clear whether there were differences between younger and older women in relation to work.

While the clinical aspects of metastatic breast cancer are extensively studied, there is less research on the personal, psychosocial, and emotional experiences of this disease. From the relatively few completed studies and anecdotally from clinicians, women with metastatic disease have described themselves as feeling isolated and alone. It is noticeable in the media and clinical settings that more attention is directed to the experience of women with early-stage breast cancer and survivors of breast cancer (Mayer et al., 2010). Novartis Oncology (2014) conducted a large European cross-sectional survey that included 20–60 participants in each of nine different countries explored the impact of an advanced breast cancer diagnosis on the psychological, social and economic lives of women and their families. The sample included 158 women with advanced breast cancer, and 146 caregivers. Of the women with advanced breast cancer most (92%) were over age 40, with only 7% younger than age 40. Findings supported that women living with advanced breast cancer have psychological, social, and financial concerns. Concerns included insufficient support and guidance, inadequate information about advanced breast cancer, the need to live in the moment, and fear about an unknown future. Many feel forced by their disease to give up employment or make changes in the number of hours worked or job responsibilities. Forty percent of the participants were employed, but 50% of them had to make changes in their employment: 18% had to give up work entirely, 11% had to decrease their hours, and 9% had to change to a lesser role. They described feeling less able to care for their families and that day-to-day living could be a struggle. A striking finding was that 50% of the women living with advanced breast cancer thought society viewed advanced breast cancer negatively, with only 8% who felt that others treated them normally. Nearly two thirds felt misunderstood and that others did not understand what they were going through, while nearly 40% felt isolated from others who didn’t have advanced breast cancer. Over half were worried about day-to day life as well as the future, and 41% described themselves as depressed, with 37% describing a loss of confidence or sense of self-identity since the diagnosis of advanced breast cancer (Novartis Oncology, 2014). This study provided very important insights into the experience of women living with advanced breast cancer. While the small sample sizes from each country make it difficult to generalize the experience of living with advanced breast cancer, the findings suggest that many of the issues and concerns experienced are shared across countries. However, the small number of women (7%) under the age of 40 makes it difficult to more fully appreciate the experiences of younger women. It remains unclear what specific age-related concerns and challenges they may face in addition to general concerns.

The qualitative study conducted by Krigel et al. (2014) using focus groups explored the lived experiences of women with metastatic breast cancer. The ultimate purpose of the study was to inform the development of interventions to enhance survivorship care. There were 15 participants with ages that ranged from 32 to 75 years, with a mean age of 56.8 years. Only one participant was less than 40 years of age. Participants described a lack of information regarding treatment options and symptom management and a sense of the unknown related to prognosis and survival that all contributed to challenges around uncertainty. The primary theme that emerged was that metastatic breast cancer influenced all aspects of the women’s lives, including changes in role functioning and relationships, the burden of dealing with uncertainty, and the unknown related to prognosis and survival. All these findings influenced the self-identity of the participants. The study is useful in illuminating aspects of the lived experience of metastatic breast cancer from the perspective of older women. However, this study was also limited in its ability to capture the particular experiences of younger women, as only one participant was younger than 40 years old. The question remains unanswered whether and what are the differences in experiences for those at different life stages.

In another qualitative descriptive study of 10 women with advanced breast cancer aged 31–69 years, the experience of altered functional status on their social roles was explored. Results illustrated the adaptive experience of women living with their illness as they reshaped their social roles to fit with their altered functional status and advanced disease (Chen et al., 2014). The mean age of participants was 53.2 years. However, the number of older versus younger women was not reported. The small sample size and wide distribution in age make it difficult to know how the findings relate to younger women with metastatic disease.

A relatively broad and growing body of research involves women with metastatic breast cancer. Areas of study include physical (Chen et al., 2014; Norris, Liu, & Bauer-Wu, 2009), psychological (Mayer et al, 2010), existential (Krigel et al., 2014; Shaha & Bauer-Wu, 2009;), quality of life (Croom, Hamann, Kehoe, Paulk, & Wiebe, 2013; Hamer et al., 2017; Harding et al., 2013; Kokkonen et al., 2017; Luoma & Hakamies-Blomqvist, 2004; McClelland et al., 2015; Soylu, Babacan, Sever, & Altundag, 2016) and supportive care needs (Lam et al., 2014). However, a notable finding of this author's literature review is that all these studies were heterogeneous and undiscriminating with respect to age. In some, older (over 50) was compared with younger (less than 50) although none have looked specifically at young women less than 40 with metastatic disease. Thus, a common problem related to contemporary studies of the experience of metastatic breast cancer, is that samples range in age from 20–80 years old. This wide variation in age makes it difficult to discern whether age-related challenges exist for different groups and what these are. The results of this part of the literature review to understand what is known about women living with metastatic affirms that more needs to be done related to studying age-specific concerns. Some studies have focused on adolescent and young adults living with advanced cancers of various sorts as discussed next. However, the age range of 15–39 years covers too many developmental stages to adequately capture how the needs of adolescents differ from women with family and work responsibilities, as discussed below. Moreover, the state of the science related to young adults living with advanced cancer remains immature in general.

Young Adults Living With Advanced Cancer

The adolescent and young adult (AYA) cohort includes individuals between the ages of 15 and 39 years (NIH, 2017b). This age range incorporates several developmental stages, thus conflating what should be different physical, emotional, and developmental tasks into one set. Even so, understanding is limited of the biologic, genetic, epidemiologic, and psychosocial factors as well as the quality of life implications for this group taken as a whole. Excluding accidental deaths, cancer is the leading cause of death among this age group. There is consensus that research with this population is needed across all aspects of the disease (DeRouen et al., 2015; NIH, 2017a). However, of particular importance to this current study is the population of women aged 25–39 because breast cancer is the leading cause of death in this age group (Siegel et al., 2016). The women in this age group may also be juggling families and multiple roles and responsibilities, and we know very little about their experiences.

Breast cancer is the most common cancer in women under the age of 40 years (Anders & Carey, 2009; Bleyer et al., 2008). In 2015, there were 10,500 cases of invasive breast cancer diagnosed with 1,010 deaths in women less than 40 years old (ACS, 2015). Breast cancer is also the leading cause of death in women age 25–39 years (Siegel et al., 2016). There has been an increase in incidence in metastatic disease among women age 25–39. This increase has been seen across all races and ethnicities especially non-Hispanic White and African Americans and in both urban and non-urban areas. For these women, 5-year survival is only 31%. Younger women often have higher grade and hormone-receptor negative cancers as compared to older women. Additionally, at time of diagnosis, younger women have advanced disease. The frequency of advanced stage at presentation has increased significantly over the past 30 years in the U.S. although the reasons are not yet known and are presumed to be multifactorial (Johnson et al., 2013).

A recent systematic review of 45 studies was conducted by Bibby, White, Thompson, & Anazodo (2017) to examine what is known about unmet needs and care experiences of AYAs with cancer. Most of the studies had considerable variation among ages, types of cancer, stage, and were not limited to diagnosis or treatment. The most common identified concerns included timely and age-appropriate fertility information and information about treatment facilities, and providers with AYA expertise. Another important area identified was age-appropriate emotional support including peer support and ways to enhance well-being.

For the purposes of this current study, this researcher reviewed 10 years of the literature to examine the available evidence concerning the experience of young adult women living with advanced breast cancer. Inclusion criteria required that each source (a) be an empirical study published in English between 2007 and 2017 and (b) involve subjects between 18 and 39 who had a metastatic or advanced breast cancer diagnosis. Because the initial search yielded no studies of young women with advanced breast cancer, inclusion criteria were expanded to include all advanced cancers. The researcher did not expand the 10-year date range in order to focus on contemporary literature in the rapidly changing landscape of cancer care.

Ultimately, the final sample included five articles. Two publications and analyses were conducted using the same sample. Therefore, characteristics of four samples will be discussed. The four samples ranged in size from 10–93 participants. All were described as young adults (YAs) ranging from 18–40 years of age. The mean age across the samples was 31.8 years. The samples were heterogeneous regarding the types of cancer, and all had advanced disease. Three of the samples had greater than one third of the participants with breast cancer (34.4–39.6%). Other cancers included lung, bone, pancreatic, esophageal, sarcoma, nasopharyngeal, ovarian, and mediastinal paraganglioma. Across the four samples, participants were mostly female (66–70.52%) and predominately White (87.1–92.5%).

Four of the five studies were conducted by the same research group, were cross-sectional structured interviews, and were conducted in a single site located in the northeast region of the U.S.. The one qualitative study was conducted in Canada.

The heterogeneous samples were small in size, had very similar patient characteristics, were conducted in the same geographic area, and used instruments that had not been developed or validated in the young adult population. The research teams acknowledged that instrumentation was a limitation in all studies with this population.

The cross-sectional quantitative studies focused on coping (Trevino, Maciejewski, Fasciano & Prigerson, 2011/2012; Trevino et al., 2012), social support and relationships (Trevino, Fasciano, Block, & Prigerson, 2013; Trevino et al., 2014). Two of the studies focused on different aspects of coping. Trevino et al. (2011/2012) used structured interviews to examine the relationship between grief due to cancer-related losses and life disruption due to cancer-related symptoms in 53 young adults with cancer. They found that, for this population, grief may add a unique burden to the cancer experience that is more problematic than physical performance status. The same sample was also asked to identify coping strategies. The relationship between these strategies and psychological distress was examined. Trevino et al. (2012) identified six coping factors: proactive, distancing, negative expression, support seeking, respite seeking, and acceptance coping. These strategies were found to be uniquely related to psychological distress in this group of participants.

Two other studies focused on relationships. One examined the relationship between perceived social support, quality of life and grief using structured interviews with 71 young adults with advanced cancer. The researchers found that higher levels of social support were associated with better quality of life and less grief. They concluded that enhanced social support might also improve psychological well-being (Trevino et al., 2013). The other focused on the therapeutic relationship of oncologist and patient and the impact the relationship may have on suicidal ideation. This study also used structured interviews. There were 93 participants with advanced cancer, and the study concluded that patients with a strong therapeutic alliance with their oncologist had a reduced risk of suicidal ideation (Trevino et al., 2014).

The one qualitative study used a hermeneutic approach to understand the experience of living with advanced cancer. The sample consisted of 10 men and women with different cancers. All had advanced disease. This study identified interrelated themes including “Isolation in multiple dimensions, cancer is inconceivable, developmentally arrested, meaning-making and the problem of time, and staring at mortality” (Knox et al., 2017, p. 402). These findings begin to illuminate the experience of living with advanced cancer. However, the heterogeneous nature of the sample makes it difficult to really understand the experience.

In examining, critiquing, and comparing these five studies, the importance of relationships and their connection to psychological well-being for young adults living with advanced cancer emerged from the findings. Maximizing relationships and promoting social support are important considerations for young adults living with advanced cancer. Both activities are connected to coping and well-being. An additional aspect of coping, grief, is a construct requiring more research. More needs to be understood about all aspects of living day-to-day with a diagnosis of advanced cancer in young adults, including grief.

This review confirmed that evidence is scant, highlighting the immature state of the science for this population of young adults with advanced cancer in general. Much more research is required on all aspects of daily living for this population. Effective targeted interventions aimed at meeting the specific needs of young adults with advanced cancer require a better understanding of the range and nature of challenges faced. So little is known about this researcher’s population of young women with advanced breast cancer that their particular perspectives and experiences need further investigation.

From a clinical perspective, we know that some young women with advanced breast cancer continue to live busy lives despite a diagnosis that threatens their lives. They are busy raising families, working, and juggling many roles and responsibilities. They are *living with* and possibly struggling with advanced breast cancer. Anecdotally, from practice, this phenomenon can manifest in many ways. This researcher, and her colleagues, have encountered those for whom, *living with advanced cancer* may consist of *enduring* and for others it may involve *maintaining normalcy, adapting, or even living each moment as fully as possible* despite the fact that their situations are anything but normal. Given the seriousness of their illness, they would all benefit from having support in terms of treatment and supportive care. In my clinical experience, I have seen women come for treatment after work or schedule treatments in such a way that there is minimal disruption to work or family life. Others have made the decision to stop working for a variety of reasons. For some, it appears they are doing everything they had always done, but the questions remain: "How are they living with this devastating diagnosis? What is this like for them?" and "What don't we know about their experience? How can we intervene in ways that are meaningful?" In today's complex healthcare environment, one wonders what is needed to better appreciate the experience of *living with* advanced breast cancer for young women to adequately address their real needs? Do we understand what it means for them in the context of their daily lives? As a society that focuses on “winners” and “survivors” how does it feel to be one who has not “beaten” cancer? (Mayer, 2010). When a cure is not possible, what then? How can we assure these women’s needs are addressed and they do not feel abandoned? Nursing as a profession has responsibilities to highlight disparities, care for the vulnerable and collaborate with others to rectify healthcare injustices.

Young Women Living With Advanced Breast Cancer

From the literature, it is evident that the experiences of young women living with advanced cancer are not well understood. Research so far has not focused on this population or concerns in their day-to-day lives. There may be experiences shared with other groups living with advanced cancer, but there are also likely to be experiences related to their life stage and expectation that are unique to this population. Only one study was found that focused on understanding the daily experience of women with breast cancer; however, the sample had a wide distribution of ages, and data were collected over 10 years ago (DeSanto-Madeya et al., 2007). Despite the limited research, a contemporary commitment exists among the organizations of different professions to understand and improve the experience of care for individuals with serious illness including advanced cancer (ANA, 2017a; IOM, 2015; National Institute of Nursing Research [NINR], 2016; Oncology Nursing Society [ONS], 2014; Smith et al., 2012). These commitments, highlight the significance of the research undertaken in this dissertation and are discussed below.

Commitment of Professional Organizations

There is a renewed effort on the part of many U.S. organizations to improve the care of people living with serious illness. The reasons for these renewed efforts are many and beyond this current work to delineate in detail. The IOM recommends all patients with advanced serious disease receive palliative care. Palliative care should include access to an interdisciplinary palliative-care team and should be "seamless, high-quality, integrated, patient-centered, and family oriented" (IOM, 2015, p. 10). This recommendation is supported by other national organizations. Survivorship, self-management, and promotion of function for those with serious illness are also priority areas. The position of the ONS is that all patients with cancer should benefit from palliative care, and it should begin at diagnosis and continue throughout bereavement (ONS, 2014). The American Society for Clinical Oncologists (ASCO) has issued a provisional opinion that articulates an emphasis on palliative care for those living with serious disease:

> Substantial evidence demonstrates that palliative care—when combined with standard cancer care or as the main focus of care—leads to better patient and caregiver outcomes. These include improvement in symptoms, quality of life (QOL), and patient satisfaction, with reduced caregiver burden….Strategies to optimize concurrent palliative care and standard oncology care, with evaluation of its impact on important patient and caregiver outcomes (e.g., QOL, survival, health care services utilization, and costs) and on society, should be an area of intense research" (Smith et al., 2012, p. 880).

Additionally, the ANA and the Hospice and Palliative Care Nurses' Association (HPNA) convened an expert panel to identify the state of palliative-care delivery and concluded that "all seriously ill patients and their families, and communities should receive quality palliative care in all settings" and issued a series of recommendations (ANA, 2017a, p. 3). The NINR is also committed to serious illness recognizing that high quality, evidence-based care is critical to maintain quality of life at all stages of disease and should not be restricted to end of life. The NINR supports interdisciplinary research efforts to apply behavioral, biological, and social science strategies to better understand and address the challenges faced by individuals with life-threatening illness and their caregivers (NINR, 2016).

Funding Priorities

The commitment to serious illness is also evidenced in the funding priorities of the ONS and NINR. The ONS Research Agenda provides important and timely direction for research and evidence-based practice. The Research Agenda Team identified eight priority content areas, which include symptoms, survivorship, palliative and end-of-life care, self-management, aging, family and caregivers, improving health systems, and risk reduction. Specific areas in regard to palliative and end-of-life care include research to enhance communication and shared decision-making, issues of access and diversity, models of palliative care delivery, interdisciplinary teams, models for improving palliative care, and professional development and education (ONS, 2014).

The NINR Strategic Plan has four areas of focus: Symptom Science, Wellness, Self-Management, End-of-Life and the Science of Compassion. The Science of Compassion focuses on palliative care and end-of-life science and includes development of strategies to prevent or minimize the symptoms of advanced illness. This also includes support related to emotional, social, spiritual, and decision-making concerns. Development of interventions that address supportive, palliative, and hospice needs across a continuum of services in coordination with individuals, families, and their healthcare teams are also a priority (NINR, 2016).

Clearly, research efforts need to target those living with advanced illness. Such groups can be considered especially vulnerable as a result of the daily physical, psychological, spiritual, and social toll of their disease. They have needs, concerns, and challenges that require focused attention, but we do not always have a complete picture of what these are. This current study focused on young women (age 25–39) with advanced breast cancer and was motivated by the researcher's area of practice. Insights from the study provide a platform for further studies and the development of effective and comprehensive interventions, as discussed in more detail in Chapter Five.

Methodology

A variety of quantitative and qualitative research methods including mixed methods were initially considered as possibly relevant to investigate the phenomenon of women living with advanced breast cancer. However, as the nature of the problem became better defined and the lack of existing research more evident, it was decided that the best method would be qualitative in nature. Simply not enough was known about the experiences of young women living with advanced breast cancer. It became critical to try to understand what it is like for them living day-to-day with this illness.

Qualitative methodology is preferred in those cases where there is a need to better understand aspects of the human condition. When an in-depth exploration is required, phenomenology is the preferable approach (van Manen, 1984; 1990) as discussed in more detail in Chapter Three and below. As Munhall (2012) asserts, qualitative inquiry is the appropriate method to use in seeking to uncover or understand a phenomenon when there is little known.

Across the different qualitative methods, there are several common characteristics of inquiry: natural setting, researcher as key instrument, multiple types of data collection (interviews, observations, and documents), complex reasoning through both inductive and deductive logic, reflexivity, and a holistic account (Creswell, 2013; Munhall, 2012). What differs among them is the purpose of the research and design of the study. For this study, several options were considered for their appropriateness. For example, grounded theory is a good design to use when a theory is not available to explain or understand a process. An explanatory theory is developed from the ground (or data) up as a result of careful data analysis. The theory can in turn inform further research and interventions related to the phenomena studied. Grounded theory allows the researcher to move beyond description in generating a theory (Creswell, 2013). Given the limited understanding of the experience of living with advanced breast cancer, theory generation did not seem possible at this point.

Qualitative description was another design considered for this study. The purpose of qualitative description is to describe and understand aspects of a human experience that are not well understood (Creswell, 2013; Munhall, 1994; 2012). This type of inquiry results in a more superficial description of an experience. “A beginning conceptual or theoretical framework is used to guide and focus the initial interview questions” (Willis et al., 2016, p. 1194). While a qualitative descriptive approach was seriously considered, it was determined unable to provide the necessary in-depth understanding of the meaning of the lived experience desired to answer the study question. Finally, a phenomenological hermeneutic approach was carefully considered and found most appropriate. Phenomenology is a type of inquiry that is aimed at understanding the lived experience in the context of daily life (Creswell, 2013; Lopez & Willis, 2004; van Manen, 1984). Hermeneutic phenomenology allows the researcher to develop an understanding of what it means to live through an experience of which there is limited or no understanding.

There was a clear need to explore, describe, and interpret the day-to-day experience of young women *living with* advanced breast cancer. This knowledge is foundational to further research using a variety of approaches with the ultimate goal of developing person-focused interventions and resources. Therefore, in considering the immature state of the science of the experience of young women living with advanced breast cancer, phenomenology was determined as the most appropriate approach.

Phenomenology

Philosophical Underpinnings

Phenomenology is a method derived from the philosophical movement that sought to understand human consciousness. That is, philosophical phenomenologists such as Husserl and Heidegger were interested in exploring the meaning to human beings of being conscious of their existence in the world. From these ideas, a method of research was developed whereby people could be encouraged to access and articulate the meaning that a given phenomenon holds for them by intentionally focusing on the phenomenon and their experiences of it (Creswell, 2013; Munhall, 1994). The worldview underlying phenomenology includes several assumptions: understanding gained through interpretations of the essences of meaning as these emerge from the data, and there is no single reality because interpretations vary among individuals. Additionally, subjectivity is valued, context is important to know, biases need to be articulated, and ideas can change over time (Cohen, 1987; Cohen, Kahn, & Steeves, 2000; Creswell, 2013).

Hermeneutic Phenomenology

A phenomenological approach to studying a problem or experience is one that assumes human experiences are deep and complex and not always easily accessible to outsiders but may have essential elements that are shared by persons experiencing a given phenomenon. Phenomenological inquiry questions the way humans experience the world and seeks to understand in a richer way the world in which human beings live (van Manen, 1990). The aim of phenomenology as a research method described by van Manen is “the quest to become more human as we search to gain insight into the fullness of living” (Munhall, 1994, p. 303). In uncovering different aspects of the phenomenon, this knowledge can be used to inform interventions, add to theory, or inform the state of the science with the goal of improving the lives of those experiencing the phenomenon of interest. According to van Manen (1990), research is a caring act, where “we want to know that which is most essential to being” (van Manen, 1990, p. 5).

Phenomenology provides the lens to better understand day-to day experiences and shed light on what has yet to be discovered. Hermeneutic phenomenology is one type of phenomenological inquiry that studies the experiences of people in the context of their daily lives. It offers the opportunity for both description and understanding of the meaning of everyday experiences. Both descriptive phenomenology and hermeneutic phenomenology provide approaches to develop knowledge and inform nursing practice.

Three different schools of phenomenological philosophy exist. The first, descriptive phenomenology, is guided by the work of Husserl, who is often referred to as the founder of phenomenology. Husserl was the first to articulate the importance of consciousness. Husserl was interested in exploring the idea that people living their daily lives are conscious of the world and its objects and the effects of the world and its objects upon them. He was interested in the possibility of consciousness and of understanding its essential elements (Lopez & Willis, 2004). In phenomenology, generally, subjective descriptions are considered important for their insights into human behavior and experiences. Husserl defined phenomenology as the science of the essence of consciousness and emphasized the importance of describing conscious experiences and the value of descriptive experiences to the scientific study of human motivation (Spiegelberg, 1975). Phenomena, then, are necessarily experienced and then articulated from the first-person point of view. Husserl argued that anything one encounters in the world is necessarily experienced through one's consciousness. One's life and the world of which one is a part are integrated and inseparable. Consequently, one's consciousness is always intentionally directed towards one's world. As a result, consciousness and the world cannot be viewed separately from each other (Cohen, 1987; Giorgi, 2005; Munhall, 2012; Spiegelberg, 1975). Husserl's project was to show how one could have "objective" knowledge of the essence of consciousness. He proposed that the way to do this is to suspend judgment and set to one side (bracket) presuppositions in order to have a more "objective" perspective on the "mental" objects of consciousness. While some critics have questioned the ability of human beings to suspend all judgments about phenomena, the practice of bracketing preconceptions and biases about the phenomena being studied, has become part of the phenomenological approach to studying human experience (Dowling, 2004). Bracketing allows the researcher to create distance from the experience and to focus on the phenomena as experienced by the subject.

The second school of phenomenology, hermeneutics, seeks to interpret and understand phenomena to uncover hidden meanings and is guided by the work of

Heidegger (Cohen, 1987; Steeves & Kahn, 1995). As a philosophical method, Heidegger was focused on uncovering the meaning of being for humans. One significant difference between the schools of Husserl and Heidegger is the use of bracketing. Heidegger was critical of this aspect, acknowledging that it is not possible, nor worthwhile, to suspend one's beliefs and biases. Heidegger also focused on understanding phenomena in comparison to Husserl, whose approach focused on describing phenomena.

The third approach is guided by what is known as the Dutch school and combines elements of both descriptive and interpretative phenomenology. Van Manen (1990), a scholar in the Dutch school tradition describes phenomenology as a philosophy or "theory of the unique" (p. 7). This approach questions the way humans live in the world and seeks to better understand how people live (van Manen, 1990). This also provides a general understanding of what it means to be human. According to van Manen (1990), this type of inquiry is actually a caring act, where "we want to know that which is most essential to being" in understanding another (van Manen, 1990, p. 5).

Phenomenological research is the study of essences. According to van Manen (1984), essence is the description of the phenomenon. Essences are best understood when "the description reawakens or shows the lived meaning or significance of the experience in a fuller or deeper manner" (p. 1) to the researcher. We come to understand what had been previously unknown, to something that has been revealed and now known. We are able to “see” something in a way that had not been “seen” before.

For van Manen and other phenomenologists, human beings are aware of themselves as living within a context. They are conscious of themselves both as humans existing and also existing in a world of which they are an inextricable part. The essential status and nature of human beings then is that of “being-in-the-world” (Heidegger, 1962, p. 92): People live through their bodies and access the world through their bodies, which also includes the mind and consciousness. Van Manen (1984, 1990) uses the term *lifeworld* to express and understand the essence of one’s “being-in-the-world.” The lifeworld can be understood as the world of lived experience. People are tied to the world in a way that we understand from a holistic perspective in the context of their daily life. Van Manen has identified four interconnected dimensions that make up the whole of the lifeworld (human experience): spatiality (lived space), corporeality (lived body), temporality (lived time), and relationality (lived relation to the other), which will be discussed more fully in the next section. Incorporation of these four aspects is an important part of the process in this type of research. Reflecting on these four aspects helps to uncover meaning around the experience from a holistic perspective. This quest for meaning helps us to also better understand what it means to be human.

The four aspects of the lifeworlds are referred to as the “existentials” (p. 101). Existentials are those entities without which we would have no consciousness of ourselves as living beings. The existentials are fundamental to the lifeworld. The four existentials are spatiality (lived space), corporeality (lived body), temporality (lived time), and relationality (lived relation to the other). Van Manen (1990) acknowledged that the existentials can be differentiated yet not separated; all are essential aspects of living. For example, temporality refers to the time of where people live and is reflected in the past, present, and future. While the relational aspect is essential in the sense that people can't exist without relationships. All of these aspects are needed to have an awareness of being alive and live in the world. Van Manen (1990) described them as forming an "intricate unity, the lifeworld—our lived world" (p. 105).

The spatial lifeworld refers to where one is located but also within the historical context of that time. Corporeality refers to the understanding that we are our bodies and encompasses both the body and mind. This is evidenced by the understanding of the unity of the body and mind in how one experiences things. Temporality refers to the time in which one is living, something that is experienced by all. And lastly, the relational aspect refers to relationships with others in the world (van Manen, 1984, 1990).

Various perspectives on the best approach to phenomenological inquiry have been proposed and discussed. Which perspective is selected depends on the nature of the question and the researcher's assessment of what will work best in uncovering insights about the phenomenon. Two approaches to phenomenology were seriously considered for this study. Giorgi uses a descriptive approach to phenomenology with the aim of capturing as closely as possible the way in which the phenomenon is experienced in the natural setting (Giorgi & Giorgi, 2003). Giorgi's method recommends a small sample to allow for the possibility of multiple interviews. He stresses that it is important for the researcher to develop a sense of the whole experience. Insights gained from the analysis are the incorporated into a description of the experience. In contrast to some other phenomenological approaches, Giorgi does not return to the participants for any interpretation of the findings (Giorgi & Giorgi, 2003: Munhall, 1994).

Van Manen developed a hermeneutic phenomenological approach that offers description and interpretation of phenomena. Hermeneutic phenomenology offers the opportunity for both description and understanding of the meaning of everyday experiences. Additionally, emerging themes are reviewed with participants who become collaborators in the interpretation of the phenomenon. Both descriptive phenomenology and hermeneutic phenomenology provide approaches to develop knowledge and inform nursing practice.

After much consideration and comparison of these two phenomenological methods, this researcher chose van Manen's (1990) hermeneutic phenomenological approach in order to both describe and interpret the meaning of the experience of young women living with advanced breast cancer. This approach provided the opportunity for a fuller and deeper understanding of phenomena. As an approach, it seeks to gain a deeper understanding of the meaning of everyday experiences. It provides explanations through interpretation of the language that human beings use to describe what they are experiencing. Hermeneutic phenomenology offers researchers the opportunity to explore, describe, and develop interpretations of phenomena that are poorly understood in the context of disciplinary goals. This is important to nurse scholars in the development of disciplinary knowledge that can eventually contribute to individual and social good more broadly (Oiler, 1982; Omery, 1983; Streubert Speziale, Alen, & Carpenter, 2003).

Challenges

Challenges that were faced by the researcher included the likelihood that most young women with advanced breast cancer faced unique psychological, physical, social, emotional, and spiritual challenges related to advanced breast cancer. However, those challenges were not well understood. The limited evidence identified concerns in broad strokes across different cancers and different ages, but much more needed to be explored.

There was a clear need to explore, describe, and interpret the day-to-day experience of young women *living with* advanced breast cancer. Phenomenology proved to be the best type of inquiry to understand this particular phenomenon, as detailed in Chapter Four where findings are reported. The goal of this study was to describe the experience of young women living with advanced cancer as it is lived.

Summary

This chapter provided information about the foundation of the study derived from the goals of the discipline. The pertinent literature relating to the experience of living with advanced cancer and the specific experience of young women living with advanced breast cancer were detailed. It was noted that there is a paucity of literature about the experience of young women living with advanced breast cancer. The lack of disease- and age-specific research made it difficult to know the true nature of their everyday experience. Hermeneutic phenomenology was determined as the most appropriate method for an interpretative inquiry of the phenomenon of young women living with advanced breast cancer. Details about the study design, data collection procedures, data analysis, and establishing the study's scientific integrity follow in Chapter Three.

CHAPTER THREE

DESIGN AND METHODS

In Chapter One, a lack of knowledge about the experience of young women living with advanced breast cancer was introduced as a problem, and research questions were identified. In Chapter Two, the foundation for undertaking this study was discussed. As nurse scholars have responsibilities to further the goals of the discipline, an exploration of what is known and not known about the experiences of this population was described and critiqued. Lastly, hermeneutic phenomenology was described, and a rationale was provided for its selection as the best method for accomplishing this study. Phenomenology is especially useful in situations where knowledge about the human experience is scant due to an immature state of the science. This type of inquiry seeks to explore, describe, and interpret life experiences in the context of daily life. Phenomenology was well suited to the investigation of the phenomenon of young women living with advanced breast cancer. This chapter details the method and the rationale for its use in studying this problem. Additionally, study design and research questions, recruitment, sample, setting, data collection procedures, data analysis, scientific integrity, and the timeline are detailed.

Method

The hermeneutic phenomenological approach of van Manen (1990) is well suited to explore this particular phenomenon and to interpret it from the perspective of the discipline and its goals. Van Manen’s approach facilitates the engagement of participants in a personal exploration of the meaning of a phenomenon in a way that allows hidden aspects of their experiences to emerge (Lopez & Willis, 2004; van Manen, 1984). The background and philosophical underpinnings of this approach were reviewed in Chapter Two. A better understanding of the lived experience of young women with advanced breast cancer and the meaning this holds for them was needed for the current study.

Van Manen (1990) identified six research activities that comprise the structure of his approach: (a) turning to the nature of the lived experience, (b) investigating experience as it is lived, (c) reflecting on essential themes, (d) describing the phenomenon of interest through writing, which is an iterative process, (e) maintaining a strong and oriented relation to the phenomenon, and (f) balancing the parts and the whole of the research. These six activities guided the process of data gathering and analysis for the study and are described next.

Turning to the Nature of the Lived Experience

Van Manen (1990) described the starting point of phenomenological research as the identification of something that deeply interests the researcher and then categorizing this area of interest as a true phenomenon, a phenomenon that is different from other phenomena. Phenomenology as research, is derived from the philosophical enterprise of understanding human consciousness; it is about the human experience. “It is a project of sober reflection on the lived experience of human existence—sober, in the sense that reflecting on experience must be thoughtful, and as much as possible, free from theoretical, prejudicial and suppositional intoxications” (van Manen, 2007, p. 12). A lived experience of some phenomenon is the starting point and the end point of phenomenological research. Scholars have noted that the lived experience necessarily has a temporal structure. It is understood reflectively as a past experience rather than as something that can be understood in the moment (van Manen, 1990). For example, when one is asked, “What is the nature of this thing?” it requires reflection of past experience in order to more fully understand it. Van Manen (1990) noted that it is in the reflecting back on experiences that we give meaning to them. The researcher’s work is to help the participant, via the interview process and other methods such as journaling, to reflect on their experiences. Thus, the meaning of these experiences including hidden aspects is brought to the surface of consciousness.

Investigating the Experience as It Is Lived

The lived experience of a phenomenon is both the source and object of phenomenological research. There is a need to explore all of the contextual aspects by searching everywhere in a person’s lifeworld for “lived-experience” material (van Manen, 1990). This material provides important information about the nature of the experience and can include personal experience of the researcher, idiomatic phrases, experiential descriptions from others, protocol writing, interviewing, observing, diaries, journals, and logs (van Manen, 1990).

Personal experience. In phenomenological research, it is understood that the researcher brings his or her own prior knowledge and experience of the phenomenon to the inquiry, as discussed in Chapter One. Reflective awareness of my own knowledge, experiences, and understandings was important. In uncovering meaning of the experience for the participants, my perspective was acknowledged and kept under conscious control.

Idiomatic phrases. These phrases can give further understanding to the nature of experiences. According to van Manen (1990), being attentive to those ordinary phrases can be very informative. The use of ordinary language can provide rich descriptions of the human experience if we are attentive to them. Van Manen refers to these types of phrases as an important source of phenomenological analysis that can hold particular significance in the interpretation of the experience. For example, one common phrase used by participants that captured a particular aspect of living with advanced breast cancer was the expression “running into menopause,” which captured their experiences of abruptly going from being premenopausal to postmenopausal. While another, “doctoring for the rest of my life” captured the sense of being a patient and requiring care for the rest of their lives. When explored further, these phrases provided additional clarity and deeper understanding of certain aspects of the experience.

Experiential descriptions. The emphasis of phenomenological research is always on the meaning of the experiences for the persons experiencing the phenomena. Van Manen (1990) acknowledged that this type of research involves the researcher as “borrowing” the experiences of others to reflect on and come to know “essential aspects of the experience” as meaningful. Knowledge of the meaning of the experience for a given individual can then be compared and synthesized with the accounts of others who are also experiencing the phenomenon, so that essential shared aspects may be uncovered. A description of the phenomenon is just the beginning of the analytic process. What is sought is a deeper meaning of the phenomenon in the context of being human as well as from a disciplinary lens. Participants’ understandings can be gathered in a variety of ways, through interviews, written accounts and journaling, and observation. This study used multiple interviews and journaling to gather data. As an example of the additional complexity that emerges from journaling, participants who used the journals expressed a vulnerability that did not always come through in the interviews. The opportunity to see the participant via Skype™ or FaceTime™ offered another perspective and allowed the researcher to observe nonverbal cues that might not have been discerned via phone.

Protocol writing. The process of writing about an experience provides for the generation of written texts that can be useful in the analysis. Van Manen (1990) cautioned that this is not as easy as it seems. Many people may be reluctant to journal because it is not easy for them. One potential problem is that the task of writing requires the writer to reflect on the experience and, in describing the experience, they may include their own interpretations of the experience. Van Manen suggested the best way is to ask participants, “Please write a direct account of a personal experience as you have lived through it” (p.

65). Participants were given journals in which to write following the first interview. The idea was that they could identify and articulate thoughts stimulated by the interview or additional information that they wished to share. They were not provided specific questions.

Interviewing. For van Manen's (1990) method, interviews are a very important data-gathering strategy. He identified two specific purposes for interviews: (a) as a means of exploring an experience in such a way as to develop a richer and deeper understanding of the phenomenon, and (b) a conversational interview in which the researcher aims to both gather information about the experience and to reflect on the experience with the participant. Thus, the participant-researcher relationship can be both interactive and collaborative. That is, the participant has more of a role than simply providing description. The participant becomes part of the reflective process, reflecting on themes and interpretations that evolve during the analysis. This approach may involve several conversational interviews with each participant. For this study, eight participants had two interviews, and six had a third contact for the purpose of reviewing emergent themes for congruence with their experience of the phenomena of living with advanced cancer.

Observing. Van Manen (1984, 1990) called this aspect of the process "close observation." It requires the researcher to try to "enter the lifeworld" (1984, p. 69) of the participant. Observation in this sense differs somewhat from more traditional types of observation where the researcher strives to maintain distance and objectivity from the subject. Close observation necessitates that I became as close as possible to the subject and her recounting of the experience while still maintaining an orientation of reflexivity that allowed me to step back and reflect on the experience as it was told. This type of data offers a slightly different dimension to the material from that obtained through interviews and the journal writing of participants. For example, nonverbal behaviors such as crying or sighing became part of the data.

Diaries, journals, and logs. Lastly, the use of diaries, journals, or logs provides another rich source of data in the exploration of a phenomenon. Insights may become known to the participant subsequent to an interview. Some participants voluntarily kept a diary, which allowed engaged additional reflection about their experiences. This process added depth and richness to their oral narrative (van Manen, 1984, 1990).

Reflecting on Essential Themes

The purpose of phenomenological research is to try to develop an understanding of the meaning of an experience. Coding of important words and phrases was done initially in order to then identify and consider emerging themes. Van Manen (1990) acknowledged that the researcher's work of reflecting on the data to identify essential themes emerging from the experiences of the cohort is both easy and difficult. It may be relatively easy to "see," or to have an abstract grasp of the experience as described across participants. However, it is more difficult to draw or describe the meaning of an experience. He describes this process as involving reflecting, clarifying, and then making explicit the meaning of the experience. This involves identifying emerging themes that became known as a result of the process of analysis and initial coding. The hermeneutic process includes interpretation in light of disciplinary goals. Van Manen (1990) called themes the “structures of the experience” (p. 79), where the researcher uncovers and develops themes in order to make sense of the phenomenon, which then leads to a better understanding of the meaning of the phenomenon for participants. The meaning is also understood across participants and it is shared in common for this group of participants only. Themes provide a way to understand the phenomenon by describing the experience but also help to give understanding and shape to something that was previously unknown or “shapeless” (p. 88). To clarify this point, van Manen used the metaphor that themes are like “knots in the web of our experiences” (p. 90) that help us to gain understanding of the whole of the experience because we can see how the knots are connected.

For this current project, the development of themes took place over time and is detailed in the analysis section. I immersed myself in the data by listening to the audio recordings and reading through the transcripts multiple times per participant, making notes, writing analytic memos, doing initial coding, and then refining the codes using the participants’ language. As themes started to emerge from this process, they were checked against prior participants’ analyzed transcripts, audio recordings, and journaling (as available). Additionally, the process of reading and rereading the transcripts provided insights about important words and phrases. Coding was done both manually and through use of NVivo 11 qualitative software (QRS International, 2018). Themes were identified after reflection on codes and careful review. They were then discussed with committee members.

Iterative Writing

The act of writing is an important part of the phenomenological research process. Writing "analytic memos," thoughts, and observations throughout the analytic process facilitated the development of language that captured and interpreted the nature of the participants' experiences in a way that revealed meaning (van Manen, 1984, 1990). As van Manen (1984) noted, this process requires a cultivated thoughtfulness and "the totality of our physical and mental being" (p. 68). The process was an iterative one of reflecting, coding, writing, and looking for emerging themes. Diagramming helped with organizing the multiple codes and their relationship to themes.

Maintaining a Strong and Oriented Relation

Using phenomenological methodology was very demanding. It required focused attention on the research question and the phenomenon. This is especially important in studies that research difficult existential experiences (van Manen, 1990). It is easy to lose focus and become distracted from the purpose of the inquiry. The researcher has to remain passionate about the need to understand the phenomenon. A sustained commitment is required.

As noted prior, I have had a longstanding passion and commitment to this population of vulnerable women. This research required intense focus during the interviews as well as when immersing myself in the data. I kept the research questions close at hand as I conducted the interviews. They served as a reminder to remain focused on the phenomenon while also allowing the participant to speak freely about different aspects of the experience. This also prompted further exploration as needed.

Balancing the Research Context by Considering Parts and Wholes

Van Manen (1990) cautioned against getting lost in the process of conducting phenomenological studies. Continual evaluation of the process as well as taking a step back to view the whole is important to keeping everything in perspective. Given the richness and magnitude of data, the many ways one could follow it, and the ease with which one could get "buried in writing" (p. 33), it was important to remain focused on the goal: to uncover the meaning of the experience as it is lived. In this study, I built in several strategies to facilitate focusing on answering the research questions and balancing the different dimensions of the experience within the context of the whole experience. These involved frequent meetings with two of my committee members as well as debriefing with the entire committee as needed. In addition, I debriefed in my field notes journal after each interview and also as needed during the coding and analysis process. The software used to manage the data, NVivo 11, allowed me to document memos and annotations and facilitated easy access to these during the coding process. The program also provides the researcher a capacity to document the process of reflecting, coding, and theme identification in a research journal (QSR International, 2018).

The Experience of the Researcher

The phenomenological researcher's role in the process involves developing a way of seeing the world that is more attentive to everyday events and experiences than would normally occur in practice. For clinicians, the approach results in one becoming more thoughtful, reflective, humanistic, and sensitive to one's own experiences as well as to the experiences of others related to the phenomenon. Munhall describes thinking phenomenologically as making one both "a great researcher and a very understanding person" (Munhall, 2012, p. 116). Thoughtfulness in both speaking and attentive listening is required. A deeper understanding of human beings, what happens to them, and what meaning the experiences of daily life hold for them is gained, and in the process, the researcher evolves. Phenomenology, as the study of the lived experience, is also the study of what it means to be human (Munhall, 1994). Studying the phenomenon of young women living with advanced breast cancer, about whose experience of daily life little is known, was determined to be best studied using hermeneutic phenomenology. As I interviewed participants, and in consultation with my dissertation chair and members of my committee, I became more comfortable with the process, how to probe more deeply, and attend to necessary moments of silence during the interview rather than engage in unnecessary conversation.

Being comfortable with silence or pauses gave the subjects the opportunity to delve deeper in their responses (Munhall, 2012). In the next section, detail of the study design, the population and procedures are provided.

Study Design

This qualitative study, using a hermeneutic phenomenological approach, was conducted to understand the meaning of the experience for young women living with advanced breast cancer. Most participants had two interviews, and some had a third contact to review the themes that had been identified for congruence with their experience with the phenomenon. The following sections detail specifics of this study.

Sampling and Site

A sample of women ages 25–39 with advanced breast cancer (Stage III and IV) was recruited for this study. Some scholars have recommended ranges of 3–25 participants (Creswell, 2013). The ultimate size of the sample was decided based on data saturation; therefore predetermination of the number of participants was not possible (Streubert Speziale et al., 2003). The determination of data saturation is discussed later. Additionally, due to the seriousness of the illness, some of the women were limited in their ability to participate in more than one interview.

Purposeful sampling allowed for the recruitment and selection of individuals who had experienced the phenomenon of interest. It was essential that all participants have the experience of the phenomenon being studied (Creswell, 2013; Munhall, 2012). Inclusion criteria were the following: (a) women age 25–39; (b) diagnosis of advanced breast cancer (Stage III or IV); (c) able to effectively communicate in English; and (d) willing and able to provide informed consent to participate in the study. Participants were excluded if they were receiving hospice care.

All subjects were interviewed at a time convenient for them in a space that assured privacy and minimal interruption. All participants were interviewed via telephone, Skype™, or FaceTime™.

Procedures

Participants engaged in a minimum of one interview and completion of a sociodemographic data form. A blank journal was mailed to each participant with a suggestion that they write additional thoughts that come to mind subsequent to the first interview (van Manen, 1984, 1990). A second interview occurred 2–4 weeks after the first one for all but four participants. Interviews were digitally audio recorded for later transcription by a professional transcriptionist. Field notes, observations, and procedural and personal reflections were documented by the researcher. A descriptive summary of impressions was completed after each interview. Field notes enhanced the transparency of analytic insight and speculation (Willis et al., 2016) and served as discussion points with the dissertation chair and various committee members, including the content specialist.

Recruitment

After receiving Boston College Institutional Review Board (IRB) approval of the protocol (see Appendix A), recruitment flyers were placed in an outpatient clinic waiting room, a patient education center, and on the private Facebook™ pages of two organizations that provide support for women with breast cancer (see Appendix B). One Facebook™ page was a local breast cancer community group, and the other was a national metastatic breast cancer organization. Contact information for the researcher was included on the flyer. Additionally, the researcher followed up monthly with specific contact people to inquire about potential referrals.

Some participants were not able to participate in a face-to-face meeting for various reasons but were willing to participate in phone interviews. For this group, a packet was mailed to an address of their choosing. In the packet were a letter of invitation (see Appendix C), the informed consent document (see Appendix D), the demographic information form (see Appendix E), the journal and two self-addressed envelopes (SAE). Instructions to contact the principal investigator (PI) with any questions about the consent form or the project were included. One of the two SAEs was to be mailed back to the PI with the signed informed consent and the completed demographic information form. Once received, the PI duplicated the signed consent form and mailed the copy back to the participant. Those who used the journal were asked to mail it to the PI after the second interview. The PI photocopied the contents and then returned the journals to the participants.

Upon receipt of the signed informed consent document, the researcher contacted the participant to schedule an interview. The original signed informed consent was kept in the researcher's locked file cabinet, separate from the data. The schedule of events is summarized in Table 1 at the end of this section.

Informed Consent

Before the start of the first interview, a description of the study and consent form was reviewed with the potential participant. Participants had the opportunity to ask questions, clarify information, and change their mind about participating. Participants were informed of potential benefits and risks of participating in the study. They were told they could refuse to answer any questions, and could end the interview and/or withdraw from the study at any time without penalty.

Confidentiality

All data were stored on a password-protected computer, in a secure location, to which only the researcher had access. Measures were taken to minimize the likelihood that emails from prospective subjects could be accessed by others. This was done by frequent checking of the email inbox on the PI's devices. In addition, no one had access to the PI's laptop.

Ethical Considerations

Participants were informed that their participation in the study was strictly voluntary and they could withdraw from the study at any time. They were assured that refusal to participate in the study or withdrawal from the study would not affect their medical care or services or any benefits or rights to which they are entitled. The confidentiality and anonymity of all participants was protected. They were assured that the study results will be published in a way that maintains the privacy of their information. Participants will not be able to be identified in any future publications.

Protection of Human Participants

All steps required by the Boston College IRB to facilitate human subjects' protections and achieve approval for the study to proceed were followed. A description of the study and consent form was reviewed with all potential participants. Participants were informed of the potential benefits and risks of participating in the study. They were told that, given the potential sensitive nature of the conversation, they might feel uncomfortable or anxious when relating their personal experiences. If this became apparent, the researcher would stop immediately. Participants were told they could refuse to answer any questions, and could end the interview and/or withdraw from the study at any time without penalty. A copy of the signed informed consent form was given to participants and the original was kept in the researcher's locked file.

Measures were taken to promote confidentiality. Each participant was assigned an alphanumeric identification code. A master file with the participants' full names, identification number, audio files, and transcripts was kept in a locked file. The researcher was the only person with access to the locked file. The participants were informed that excerpts from the transcripts might be used in professional publications and/or presentations but names would not be associated with the data and personal situations would not be identifiable. Pseudonyms would be used in any publications.

Research Incentives

Time and inconvenience of participants was acknowledged with an honorarium of a $25 gift card.

Data Collection Schedule and Procedures

Table 1

Schedule of Events

	Screening	Initial Interview	Follow-Up	Member Checking
Informed Consent	X			
Inclusion/Exclusion Criteria	X			
Interview		X		
Demographic Information Form		X		
Follow-Up Interview(s)			X	X
Review of Journal			X	

Data Sources

Demographic Information Form

This form was completed by all participants and elicited the following self-reported data: age, date of diagnosis, previous treatment, date of metastatic disease diagnosis, current treatment, marital status, socioeconomic status, level of education, employment, faith tradition, and spiritual practices (see Appendix D).

This information was used to describe the sample and inform the discussion of the findings.

Interviews

All interviews took place via telephone, Skype™, or FaceTime™ per participant preference. Each woman was cautioned to think about whether she could be overheard by family members or others who might be upset by the conversation or whom the participant would not wish to have access to the conversation. Additionally, the hope was that the woman would feel free to talk openly.

Interviews were used to obtain descriptions and personal stories of the experience of living with advanced breast cancer. Interviews allowed for the whole experience to be explored and provided participants an opportunity to share personal stories and concrete examples. Two loosely structured interviews were completed 2–6 weeks apart depending upon participant willingness, desire, or ability. The questions asked were framed in van Manen's postulation that there are four interrelated contextual aspects of human lives that comprise human experience: spatiality (lived space), corporeality (lived body), temporality (lived time), and relationality (lived relation to the other; van Manen, 1990). The first interview was loosely structured according to the "lifeworlds" as described by van Manen.

Initial questions included the following:

1. What is living with the knowledge that you have advanced breast cancer like for you?
2. What is your daily life like? What has changed for you? In relation to how you experience your ability to do things, your sense of time, your health, and relationships?

Additional questions were as follows:

- Can you tell me what the experience of living with cancer is like for you?
- How has this affected you from the perspective of your day-to-day life?
- What is a typical day like for you?
- Does how you feel restrict you?
- Are you able to do everything you want to do? If not, why not?

The initial interview focused on gaining as much of the participant's personal experience of the phenomenon as possible, and it also served to build trust in the researcher. The second interviews built on the first and continued the exploration of their lifeworlds, allowing more data to emerge. These permitted a further reflection on aspects of the first interview and the addition of insights that had not emerged in the first interview but may have been stimulated by it (van Manen, 1984, 1990). The follow-up interview occurred 2–6 weeks after the initial interview. This provided the opportunity for participants to discuss thoughts that may have emerged about the experience after they had completed the first interview. Additionally, a third contact with a subgroup of participants provided the opportunity for them to evaluate how the emerging themes cohered with their experiences of the phenomenon. This was a “hermeneutic conversation” or interpretative conversation, where there was an opportunity for the researcher to discuss her interpretation of the data in light of disciplinary goals and possible interventions. The conversation became more of an interpretative dialogue between the researcher and the participant as they discussed the interpreted meaning of the experience together (van Manen, 1984, 1990).

Journals

Journals were provided to all participants. At the completion of the first interview, suggestions about writing in the journal were made by the researcher. The purpose of the journals was to provide an opportunity for participants to write any additional thoughts that may have emerged subsequent to the first interview and is in-line with van Manen’s method (van Manen, 1984, 1990).

Field Notes

Field notes generally enhance the transparency of analytic insight and speculation (Willis et al., 2016) and help the researcher to control personal biases.

Field notes, observations, and procedural and personal reflections were documented by this researcher in a journal. A descriptive summary was completed after each interview in a “field notes” journal. This journal provided the researcher an opportunity to debrief about the interview, and to reflect on themes and aspects of significance that emerged during the interview. The researcher then transcribed these field notes and uploaded them into the NVivo 11 Software for Mac.

Data Analysis

Descriptive statistics were applied for the background variables: age, race, ethnicity, education, marital status, work status, health rating, cancer stage, current treatment, faith tradition, and spiritual practices. Each interview was professionally transcribed. The researcher verified each transcript with the audio-recorded interview. Transcripts were read several times to develop a fuller understanding of the whole (Vaismoradi, Turunen, & Bondas, 2013).

Data gathering and analysis was conducted concurrently in line with van Manen's method. Also per van Manen (1984, 1990), the researcher became immersed in the data by listening closely to audio recordings of interviews and comparing them with data transcripts and field notes. Reading and rereading along with listening to nuances is critical to the method. The goal of hermeneutic analysis is to provide descriptions that capture and communicate the meaning of the lived experience from the perspective of the participant and interpreted through a nursing disciplinary lens. Analysis began during the interviews and continued as the researcher read through and immersed herself in the data.

First, the researcher listened to and read the texts multiple times, asking herself this: "What statements or phrases seem particularly essential or revealing about the experience being described?" (van Manen, 1984, p. 21). These statements were highlighted. The second approach used line-by-line coding in which the researcher read every sentence, asking, "What does this sentence or statement reveal about the experience being described?" (van Manen, 1984, p.

21). As theme categories were developed, the researcher noted phrases or statements used by participants that seemed especially illustrative. These quotes became part of the written report and were used to provide a richness and fuller understanding of the phenomenon. Additionally, hermeneutic analysis involves a process known as the "hermeneutic circle" of analysis in which the researcher goes back and forth between smaller and larger units of text both within and across interviews to discover possible meanings of the lived experience (Cohen et al., 2000) across participants.

Themes are the "structures of experience" (van Manen, 1990, p. 79). In analyzing the phenomenon, the researcher determined the themes and the existential structures that comprised the experience.

The descriptions became "phenomenologically powerful" when the researcher was able "to see" the deeper significance or meaning-structures of the lived experience (van Manen, 1990, p. 25). Once themes were fully developed, descriptive validity (precise description conveyed by participants) and interpretative validity (accurate description of the meanings participants give to the phenomenon) were reviewed with participants as part of the third contact (Willis et al., 2016).

In addition to the initial manual coding, the researcher also used NVivo 11 Software for Mac, a qualitative data software tool. The software was used to organize and analyze the interviews, journal entries, and field notes. It allowed the researcher to import and analyze transcriptions of interviews, journal entries, and field notes. Information was organized using theme, case, and in-vivo coding. Coding of the data using the software allowed the researcher to categorize and classify data by theme or topic and analyze connections using in-vivo coding, hierarchical coding, and relationship coding. The use of highlighting and coding stripes provided an excellent way to visualize words and themes that emerged from the data. The software also allowed the researcher to keep track of thoughts and ideas through the use of memos and annotations. The researcher used memos to record and store insights, observations, and interpretations and linked them to codes and themes. The researcher was able to ask questions of the data using text search, word frequency, coding, and matrix coding queries, and coding comparison. The software also enabled the researcher to look at various ways of visualizing the data with word clouds and word trees. Additionally, as part of the process of using NVivo 11 software, the researcher used analytic memoing in which the process of exploring and analyzing the data was documented.

Establishing Scientific Integrity

In contrast to quantitative research, the conventional criteria to establish trustworthiness and rigor do not apply to qualitative research. Lincoln and Guba (1985) propose that the traditional quantitative indicators be replaced with credibility (in place of internal validity), transferability (in place of external validity), dependability (in place of reliability), and confirmability (in place of objectivity).

Credibility

Credibility, the truth-value of the study replaces internal validity (Lincoln & Guba, 1985). Techniques to establish credibility include prolonged engagement and persistent observation, triangulation, peer debriefing, negative case analysis, and member checking. Prolonged engagement is concerned with the investment of sufficient time to ensure knowledge of the culture, testing for misinformation, and building trust. This requires the investigator to be sufficiently involved to detect distortions of both the researcher and the participants. Prolonged engagement also builds trust, a process that is time-consuming and essential. Persistent observation adds the element of salience to better understand what is most relevant. This researcher utilized prolonged engagement in building trust with participants. Interviews were typically 60 minutes in duration. Establishing trust occurred in the first interview and was evident at the time of the subsequent interviews. Participants verbalized appreciation about being able to discuss topics that they previously hadn’t discussed with others.

Triangulation uses different sources, methods, and investigators in collecting data. This process involves taking different evidence to illuminate a theme or perspective. One way this is done is when a researcher identifies evidence that documents a code or theme in different sources of data. This involves triangulating information in order to provide validity to the findings (Creswell, 2013). In this study, sources for triangulation included the interviews, participant journals, and field notes of the researcher.

In using negative case analysis, the researcher refines working categories as the research progresses. This involves looking at the evidence and acknowledging that not all of the evidence may fit with a code or theme. In reporting the negative case analysis, a more realistic understanding of the phenomenon is provided (Creswell, 2013; Lincoln & Guba, 1985). This was done by the researcher reviewing her field notes after thoroughly immersing herself in the audio recordings and transcripts. This process allowed the researcher to identify which participants responded differently and then to review their responses in detail to see where the differences were from others.

Member checking gives the researcher the opportunity to check data, interpretations, and conclusions with participants and is both formal and informal (Lincoln & Guba, 1985). Member checking is the “most critical technique for establishing credibility” (Lincoln & Guba, 1985, p. 314). The procedure entails going back to participants to solicit their views of the credibility of the findings and interpretations. It also provides an opportunity for the researcher to assess if the findings merited a phenomenological nod by participants. Nodding may be seen when the participant agrees that the findings have captured the meaning of the experience (Munhall, 2012).

The researcher went back to the participants after themes were identified, interpretations made, and conclusions formulated to determine if the participants agreed with the researcher or not. This provided the participants an opportunity to determine if the findings “made sense” to them. This process was very helpful to the researcher in formalizing the overarching theme and subthemes that emerged from the data.

Transferability

Transferability replaces external validity and concerns the applicability of the study findings. Lincoln and Guba (1985) describe this as “fittingness” (p. 124), the congruence or similarity between two different contexts to understand if the findings of one may be applicable to another. Transferability, as explained by Lincoln and Guba (1985), recognizes the responsibility of the researcher to provide the evidence whereby others can use the evidence to make judgments about the applicability of the evidence to another situation. This requires that a researcher provide sufficient data for evaluation of the findings. The use of thick description is used in conveying the findings. This involves utilization of all types of data in presenting the findings of the study. The findings need to provide everything the reader needs to know to assess and understand the findings (Lincoln & Guba, 1985). For this researcher, thick description included data from interview transcripts, journals of the participants, and field notes of the researcher.

Confirmability and Dependability

Confirmability replaces objectivity or neutrality, as it is known in quantitative research. In the case of qualitative research, the focus is not on the objectivity of the researcher but on the objectivity of the data. The major techniques for establishing confirmability are the use of an audit trail, triangulation, and the use of a reflexive journal. Auditing is a technique to establish dependability and confirmability (Creswell, 2013; Lincoln & Guba, 1985). An audit examines the process and the product of the inquiry. The techniques of triangulation and reflexive journaling are also part of this process. As part of this process, the researcher details thoughts about self and method that arise during a study (Lincoln & Guba, 1985). This researcher maintained a research journal in the NVivo 11 software. Reflexive journaling after interviews and during the process of reflecting and coding helped to also establish confirmability and dependability. Additionally, the researcher met with two committee members regularly to debrief. The researcher also engaged in debriefing with all members of the committee when there was a need to share emerging codes and themes.

Evaluation Criteria Specific to Phenomenological Research

Munhall (2012) proposed evaluation criteria to evaluate phenomenological research for rigor. The criteria are known as the "*One P, Ten Rs"* (Munhall, 2012, p. 523). The "One P" is the phenomenological nod and is the nodding of the participant in agreement when hearing the findings of a study. This nodding indicates the researcher has captured the meaning of the experience for the participant. This was an important aspect of the final interview with participants when the researcher reviewed the findings with them, asking for feedback on the emerging themes and the findings. The "Ten Rs" to evaluate rigor include criteria that evaluate meaning of the study and findings, writing style, greater understanding, and ethical considerations and are described in the next section.

Meaning of the Study and Findings

These evaluation criteria include rigor, resonancy, reasonableness, representativeness, and recognizability, and raised consciousness (Munhall, 2012). *Resonancy* involves asking the participant if the interpretation of the findings makes sense to them. This is also accomplished by member checking; that is, assessing whether emerging themes make sense to the participants. *Reasonableness* is concerned with all aspects of the study. This involves evaluating the research question, method, data analysis, and interpretation. This criterion involves assessing for congruence throughout all aspects of the study. *Representativeness* is determining if the findings speak to the many facets of the lived experience. To evaluate this aspect, it is important to discern if multiple dimensions of the experience are identified. This is accomplished by looking at multiple types of evidence, as is done in triangulation. The criterion of *recognizability* is met when the reader becomes aware of the phenomenon in ways previously not known. This leads to the next criterion of evaluation, *raised consciousness*. This criterion is met when the reader develops new understanding or insights with regard to the phenomenon under study (Munhall, 2012).

Writing Style

Readability is the criterion that assesses the presentation of the study. Evaluation involves a thorough examination of the researcher's presentation of the study and findings to determine if it is clear, understandable, and interesting (Munhall, 2012).

Greater Understanding

The criteria, *relevance* and *revelations*, evaluate the findings. Specifically, they seek to understand if the findings bring us “closer to our humanness, increase our consciousness, enable understanding, give us possible meaning, and guide us in our lives, personally and professionally” (Munhall, 2012, p. 524). Additionally, revelations assess what is now known and the implications of knowing what was previously “concealed or wishes to be concealed” (Munhall, 2012, p. 524).

Ethical Considerations

Lastly, evaluation of the ethical considerations is another criterion for rigor. Presenting a thorough review and discussion of the ethical consideration to the reader is important in determining if ethical concerns have been thoroughly considered and protected (Munhall, 2012).

Summary

This chapter provided the rationale for using hermeneutic phenomenology to study the meaning and lived experiences of a unique population—young women living with advanced breast cancer. Hermeneutic phenomenology proved especially useful in this situation where knowledge about the human experience was scant due to the immature state of the science. Important aspects of the method were discussed, specifically as they pertained to the structure proposed by van Manen. Finally, the procedures and decisions related to the conduct of the study were detailed. Chapter Four details the findings from the study, and in

Chapter Five, implications for further research, practice, education, and policy are provided.

CHAPTER FOUR

RESULTS

In Chapter One, the lack of knowledge about the experience of young women living with advanced breast cancer was introduced and research questions were identified. In Chapter Two, the foundation for undertaking the study, which lies in the idea that nurse scholars have responsibilities to further the goals of the discipline, was discussed. An exploration of what is known, and not known, about the experiences of this population was also described and existing evidence critiqued. Chapter Three detailed the method and why it was chosen to study this problem. The study design and research questions, recruitment, sample, setting, data collection procedures, data analysis, and scientific integrity were also described.

In this chapter, findings from the study are presented. The purpose of this study was to explore the lived experience and its meaning for a sample of young women living with advanced breast cancer. Twelve young women from a variety of areas across the U.S. who were living at home and within their communities participated. Van Manen's (1984, 1990) hermeneutic phenomenological approach guided the study processes as described in Chapter Three. This method was chosen because of its usefulness in uncovering the perspectives and experiences of the participants as they live their daily lives. The demographics of the group are described first, followed by a description of the themes that emerged and that capture the essence of the experience for these women. In Chapter Five, findings are discussed in detail and related to existing literature and implications for further study, practice, and education are described.

Demographic Characteristics of Participants

Sixteen women emailed the investigator in response to the Facebook™ posts that advertised the study. Two were ineligible based on age. Two others did not reply to emails or return consents. Twelve women eventually enrolled in the study (see Table 2). Twelve participated in the first interview, and eight of the twelve participated in a second interview, approximately 2–6 weeks after the first interview. Three participants wrote and returned journals adding important information that was strikingly raw in nature, which augmented the interviews. These data were coded manually and in the NVivo software and analyzed, as discussed in Chapter Three.

Participants ranged in age from 31 to 39 ($\bar{X} = 36$ years; see Table 2). See Appendix E. for the demographic questionnaire. All 12 participants identified as Caucasian (100%), and one identified as Hispanic. This was an educated group with all (n = 12) having completed high school and of those, 25% (n = 3) had completed a 2-year college, 42% (n = 5) completed f4 years of college, and 17% (n = 2) had completed a doctoral or professional degree. More than two thirds (67%, n = 8) worked, more than half (58%, n = 7) worked full-time, one was self-employed with two businesses, two (17%) were homemakers, and two (17%) were on disability. Prior to going on disability, both had worked full-time.

Table 2

Participant Characteristics (N = 12)

	N	%
Age		
31–39 (m = 36)	12	100%
Race/Ethnicity		
Caucasian	12	100%
Education		
Completed high school	12	100%
Completed a 2-year college	3	25%
Completed 4-year college	5	42%
Doctoral or professional degree	2	17%
Employment Status		
Working full-time	7	58%
Self-employed	1	8%
On disability	2	17%
Homemaker	2	17%
Marital Status		
Married	12	100%
Children		
Yes	12	100%
Health Rating		
Good	5	42%
Fair	6	50%
Fluctuating	1	8%
Stage of Disease		
Stage III	2	17%
Stage IV	10	83%
Palliative Care		
Yes	0	0%
No	12	100%
Faith Tradition		
Christian	9	75%
Spiritual	1	8%
No faith tradition	2	17%
Spiritual Practices		
Yes	9	75%
No	3	25%

All were married and had children. Eleven of the participants (92%) had children younger than 12 years of age, and one (8%) had a 14-year-old child. Overall, the health rating of this group was self-described as “fair” (n = 6, 50%)

and “good” (n = 5, 42%), with one participant describing her health as “fluctuating.” Almost all of the sample (83%, n = 10) had stage IV metastatic breast cancer with two women having Stage III disease. Five participants (42%) were initially diagnosed with Stage II breast cancer, and four (33%) were initially diagnosed as Stage III. Three women (25%) were diagnosed with metastatic breast cancer on initial presentation. None were receiving palliative care; one described declining palliative care.

The sample predominately identified as Christian (75%, n = 9), one described herself as “spiritual,” while two other participants (17%) checked the box “no faith tradition.” The majority of participants (75%, n = 9) engaged in some type of spiritual practice including worship, prayer, or both; three women (25%) did not engage in any spiritual practices.

Other Data Sources

The themes and subthemes, as identified from the analysis, are described next and illustrated with direct quotes. Three types of data were used for the analysis as discussed in detail in Chapter Three: (a) face-to-face online interviews that also facilitated interviewer observation; (b) telephone interviews; and (c) journal contents from a subset of three participants who used the pre-supplied booklets to write their thoughts between the first and second interviews. These data were all incorporated in the analysis.

Observation of participants during the interviews occurred for nine participants using Skype^{TM} or FaceTime^{TM}. It was particularly helpful to the analysis to see participants, as they sometimes exhibited nonverbal behaviors that might not have been as well appreciated in the absence to the opportunity for observation. For example, one woman cried silently, wiping the tears from her eyes, allowing the researcher to note the intensity of the emotion being expressed.

Themes

The overall meaning of the experience for these young women living with advanced breast cancer was interpreted using the overarching theme of *Wearing the mask of wellness in the presence of a life-threatening illness*. This overarching theme encompasses the five major themes and subthemes and represents the essence of this phenomenon as described by participants. However, areas of overlap inevitably exist as all are, to a certain extent, inseparable facets of the overall essence of the experience.

Wearing the mask of wellness in the presence of a life-threatening illness represents a multidimensional experience that captures different aspects of the lifeworld of young women living with advanced breast cancer. As a reminder, lifeworld is the whole context of a person's experiences as a conscious being. It has four identifiable but interconnected dimensions: spatiality (living naturally takes place within a fluid space), corporeality (the world is experienced through the senses, which are embodied), temporality (over time), and relationality (connected in important ways to others; van Manen, 1984, 1990).

The five major themes are (a) *Wanting to be known as the person I am,* (b) *I'm still Mom*, (c) *Living is more than surviving*, (d) *Getting through it,* and (e)

Being connected to others. Each theme represents a different facet of the phenomenon. Discernible within each theme are the four elements of the lifeworld further highlighting their essential inseparability except for the purpose of discussion. Each of these five major themes had multiple subthemes. The subthemes are discussed under the appropriate theme (See Figure 1).

Overarching Theme

Wearing the mask of wellness in the presence of a life-threatening illness is defined as follows: The dichotomy of appearing young and healthy to others, and continuing to carry out daily routines including parenting and other relationships while being continually aware of the need to get through living with a potentially terminal or likely terminal illness that will inevitably shorten your their time with your children and others to whom you are connected. Thus the five themes, *Wanting to be known as the person I am, I'm still Mom*, *Living is more than surviving*, *Getting through it,* and *Being connected to others,* are incorporated within the overall meaning of the phenomena of being a young woman and living with advanced cancer.

The overarching theme that was identified, *Wearing the mask of wellness in the presence of a life-threatening illness,* and the five major themes and subthemes begin to capture the meaning of this phenomenon and are described in detail following the figure.

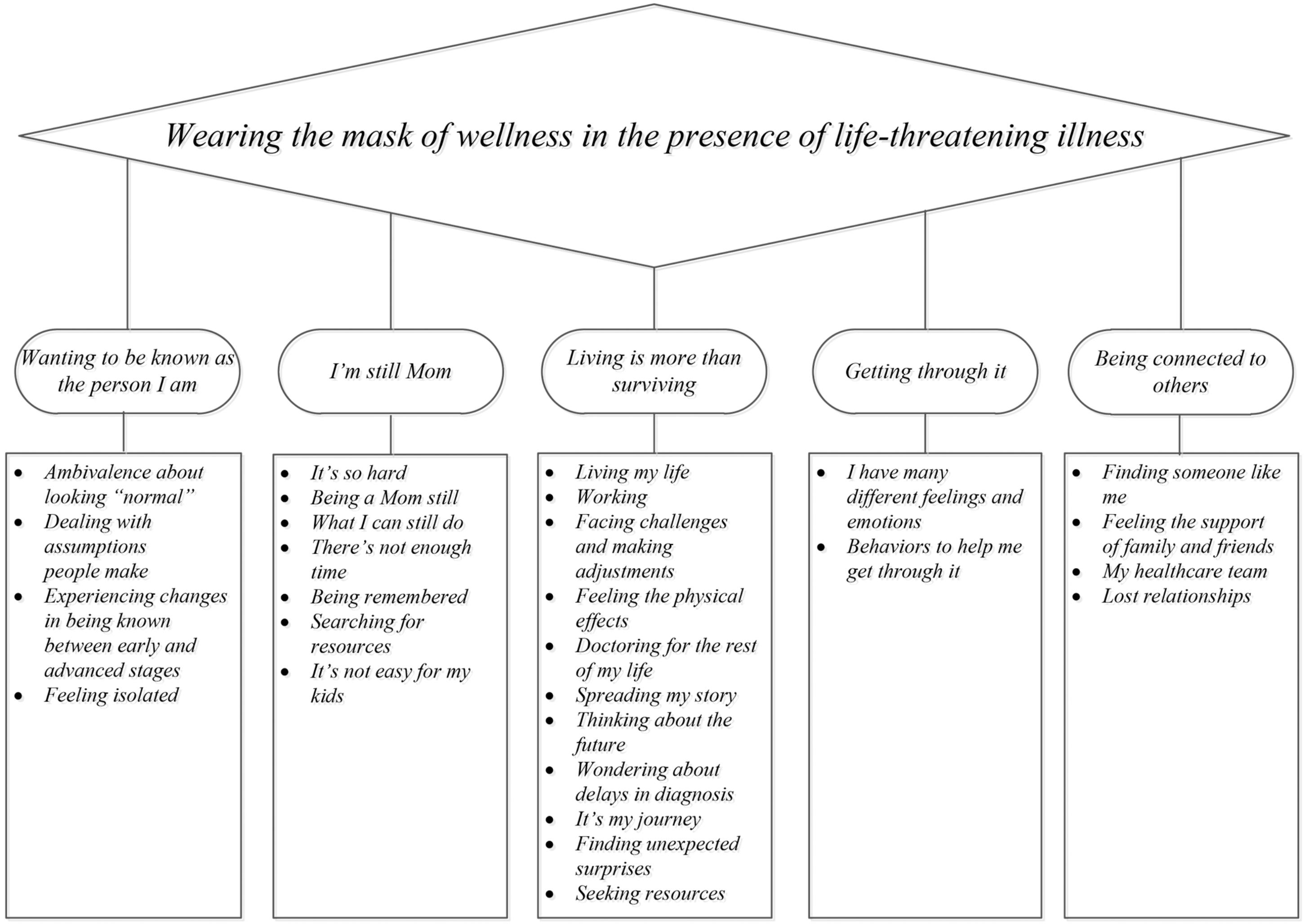

Figure 1. Overarching theme, major themes, and subthemes

Major Theme 1: ***Wanting to be known as the person I am***

Incorporated within the major theme *Wanting to be known as the person I am* are four subthemes: (a) *Ambivalence about looking "normal,"* (b) *Dealing with assumptions people make*, (c) *Experiencing changes in being known between early and advanced stages*, and (d) *Feeling isolated*.

Wanting to be known as the person I am is the ambivalent and sometimes conflictual feeling of wanting to be known in all of one's complexity, including as an individual and as someone who is living with a life-threatening illness. Perceiving others as making assumptions about one's physical or psychological health, as either a person who looks well or as a disease, is isolating. That is, participants wanted to be known as a person with a disease, but also as a person apart from the disease. They talked about looking normal, as opposed to when they were actually getting "curative" treatments and experienced hair and weight loss, pallor and fatigue, and it seemed that this sometimes caused others not to understand or remember what they were actually struggling with on a daily basis. The majority of the participants alluded to this experience of being no longer 'known' in the same way as they had been prior to their diagnosis of Stage III or IV cancer. The desire to be known as a person apart from the disease, but also to be understood as living with this disease is exemplified by Dina, who described it this way:

> *That's one of the things that people don't understand about having Stage IV cancer is I think a lot of people think of the appearance of someone should be bald and super thin and kind of sickly looking. When I tell people "I'll always have Stage IV cancer," they look at me, "No, you don't." I'm like "I look*

> *normal." I know...You can look normal. People don't realize that.*

In addition, for Amy, a 36-year-old mother of three:

> *Well, when people find out I have cancer all the time, I'm told I don't look like I have cancer; because I don't look like I'm dying right this second, thankfully. Because it went to my bones, I got to keep my breasts. Because there's no need to cut them off when it's already out of them* (already metastasized). *And after I finished four rounds of Taxotere, the hair grew back in. So I think it's important that people get educated on the fact that just because I don't look like I have cancer anymore, I still have cancer. And so it's still important socially and for your mental health that people still…I don't want to be treated like a cancer patient.*

Subtheme 1a: Ambivalence about looking "normal." Many spoke about having to revise their ideas of what it meant to look normal causing feelings of ambivalence. Their awareness of looking "normal" to others on the one hand could be a good thing on the other hand when they were having a bad day or felt bad they would have liked people to understand how hard it was for them.

And for Joyce, her perspective about wellness and illness changed when she developed metastatic disease:

> *The first time, it was beating cancer and going in remission and that kind of thing. And it's different now because it's lifelong. It's a chronic thing. And sometimes I think even maybe my husband doesn't understand or grasp when I'm too tired because I don't look sick like I did before. I'm not losing my hair. I'm not throwing up. I'm just hurting a little and a little tired* [laughter] *but it just looks normal.*

There is a tension between feeling good and not feeling good but not necessarily wanting the attention. On one hand, they want to feel known, on the other they wanted to be treated in a way that doesn't box them into the patient role.

> *Part of me is good with the fact that I don't look sick because then I don't get*

> *the pity look, the "I feel sorry for you look." You know what I mean?*

However, getting such acknowledgment as supportive letters could help remind them that they are not forgotten. And for Amy:

> *I don't want to be treated like a cancer patient. I don't want to act like I can't do anything, but the thinking of you, the cards and that kind of stuff, that does really give you a boost in those days where you just feel like "Oh my gosh. I just can't do anything good today…to have a card come in the mail, lifts you up so much, okay. Okay. I can do this. I can do this. And when it stops, it's like, okay. Did they forget me? Did they forget what I'm going …? What's going on? So that's kind of hard…. And little things like that mean so, so much. I try to thank people, but I just cannot explain how much just one little simple—letting me know you're thinking about me or praying for me or—it's really humbling, you know?*

Joyce talked about assumptions people make about her because although she might look well, she is not necessarily feeling well.

> *Some people just pretend like it's not happening. And they'll say the classic like "Oh, you look fine. So I just assume you're fine." So sometimes I feel …like I certainly feel bad, but it's difficult sometimes saying no especially to social engagements. We just can't do it, too much is going on. I'm too tired. So that's a little bit difficult, and I think sometimes people don't understand necessarily how tired you can get on this treatment.*

Subtheme 1b: *Dealing with assumptions people make.* Joan talked about experiencing disbelief from others about her condition. There was a disconnection between the way people view her and the way she actually feels.

> *It's just kind of people look at me almost like I'm faking it. Not faking it, but they look at me in disbelief. If they've never seen me or didn't know what I've gone…don't know what I've gone through.*

This disbelief also led others to make assumptions that weren't true, including people with cancer. There was a sense of being misunderstood by others who were healthy. Many spoke of others making false assumptions and how this made them feel. Inez talked about a waiting room in an oncology clinic and her sense of what people were thinking about her.

> *And so I think they're kind of a little taken aback by it at first because if you look at me, you're like "She doesn't look sick." You know what I mean? She has hair and da, da, da. "What is she doing here?" And then my name gets called and I go back, and then they see me sitting there with my port accessed and they're like "Oh. She's in this too." And I'm just like, "And I've got 11 years' experience* [with metastatic disease]*, so.*

Joan, who at 31 was living with metastatic disease, described her perspective:

> *I feel like I can't be healthy because people think I'm sick, and that's why they're supporting me so much. But that's not the case. People are still just amazingly supportive and seem to be very happy for me that I'm doing so well. If you see somebody who's been going through chemo and lost all of their hair, you're going to hold the door open for them, you're going to let them walk by in front of your car. I mean you're just going to be nicer to them because they're going through something terrible. Where with me, it's like I looked like any normal person, perfectly healthy and fine. When, in all reality, I have terminal cancer.*

For Dina, being 36-years-old and the youngest person in the waiting room was in itself not an easy situation. However, she talked about what actually was worse for her—as she was sitting in the waiting room with her mother, others assuming her mother was the patient:

> *It's weird enough to sit in the waiting room and have 80-year-olds, 90-year-olds, 100-year-olds, 70-year-old people, and I'm the only (young) woman. My mom came with me the other day to get my scan results. And everybody was chatting…my mom's chatty. And everybody was chatting with her and thought she was the patient. I'm like "No, it's me." It's weird enough to sit there…*

Subtheme 1c: *Experiencing changes in being known between early and advanced stages.* Several of the participants were initially diagnosed with an early-stage breast cancer and were able to compare their initial experiences of having early-stage disease and then going on to develop metastatic disease. The accounts reinforced the perceptions, of other participants in the sample, related to looking normal versus looking sick and how others treated them.

> *And now, being on this side of it and not having anything show that there's something wrong, it's kind of frustrating because you want people to know that you don't feel well when you have cancer. It's frustrating, but I mean, it is what it is, I mean, I'm not going to shave my hair off just so people could be like, so what's your deal?"*

There was a new awareness that comes with metastatic disease about life expectancy that they didn't have with early-stage breast cancer. The difference in outcomes, particularly in terms of long-term survival with metastatic disease was unknown for several. For Joan:

> *So, I guess being young and with this…I think probably one of the most frustrating things, is that people just—and even me when I was an early-stager, I had no idea about the 30-month expected lifespan, but people are living longer. My fear was because I thought it was instant death. I didn't realize that there was hope that there's new medicines and stuff like that…*

Joan also spoke to the difference in appearance and awareness of an early-stager (having initially been diagnosed with metastatic disease) versus one with metastatic disease. This perception resonated with the overarching theme of *Wearing the mask of wellness in the presence of life-threatening disease*, as well as the theme of *Know me as the person I am*. There was a struggle of being really known between the person who once was and the person she became living with a life-threatening illness.

> *Living with metastatic, people look at me and like; it was easier when I was first time around, because then I did look sick. Now my hair is long, I smile; try to be more physically active. Some people are like "Oh, she must be fine." I actually had friends think I was cured when I was done. I'm like "you're*

> *never cured." I'm like "Oh my God, I'm like Guys, I'm literally in treatment for the rest of my life. And once treatment stops, try another until….*

Many acknowledged the differences in the treatment approach depending on stage of disease. For early stage breast cancers, there may be a multimodality approach with a myriad of symptoms. However, the treatment has a defined beginning and end. For those living with metastatic disease, treatment often does not have a defined end and this makes it hard both for the person who has it and for those who interact with her. As Dina described:

> *I feel sometimes that, as the metastatic patient, you don't have an end? "What do you mean?" I'm like, yeah. My end is death. Let's not talk about that. Yeah. There's no end to it. I think sometimes that's hard for people.*

This approach to treatment brought an awareness of a new reality. In this new reality, the focus of care shifted from cure to control of disease. Treatments no longer have a discrete beginning and end as they did in the context of early-stage disease. Treatments generally continue until disease progression and then a new treatment may be initiated.

> *In reality, it's like I need treatment more than ever now. So it's just like I look healthy and smile and take pictures, so I must be fine. I must not be going through anything.*

Subtheme 1d: *Feeling isolated.* A sense of isolation was a common experience for participants. They described how the feeling of isolation could be caused by lack of awareness and understanding on the part of others about who they are and what they are living through, and/or from having never met other women who are living with metastatic disease. Alternatively, if participants did know women with metastatic disease, they were older. As Kate explained:

> *I don't have too many women around me that are in the same situation. Most of them are older and their kids are grown up, and I think that's something that would help me that I don't have* [meet someone like me].

Inez poignantly wished she had had someone to turn to who had been or was in her situation:

> *I can go and live "a normal life" without people turning their heads and staring at me, that kind of stuff. But then, when it comes to…I'll be kidding or having a serious conversation with someone, they're like "Well, you look great. You look fine. You're not sick.* (And I think) *How would you know?" And then I open my mouth and say, "Well, when I was 28, I was diagnosed* (with early stage). *And then, 2010* (when I was diagnosed with metastatic disease), *and then I tell them my story and they're like "Oh my gosh. I had no idea." And I'm just kind of like "Well, it's good in a way." But I've been very vocal and very open about my story because if there are people I can help…young women that I can help and be a resource for, or just share my story and encourage someone to stay positive and to do what they have to do with what they have to get through, I'm all for it, you know what I mean, because* ***I wish there was someone like me now when I was first diagnosed because I really didn't have anyone to kind of talk to****. I found a lot of resources and that kind of stuff myself.*

Some, like Inez, wanted to tell their story of being a young woman with breast cancer so that others would not have to feel as isolated. However, some, like Liz, told their stories as a warning to motivate others to be vigilant and try and get an early diagnosis.

> *I wanted people to ask me. I wanted people to be like What's going on with you? But that's just me, because I wanted to spread my story. And if I can spread my story and maybe possibly save somebody's life because of it, maybe this guy will go home and tell his wife to do an exam, and she finds something, that kind of thing.*

Some participants had strategies to mitigate the sense of isolation by stimulating conversations about what it is like to be living with advanced cancer.

Liz hoped that having a visible pink ribbon tattoo would facilitate conversations but was surprised that generally did not and acknowledged how few people had anything to say about it.

> *I also put a pink tattoo on my wrist, and thought maybe that would help people asking questions. And I think in the 5 years that I've had it, I've had maybe a handful of people say something about it.*

The sense of isolation experienced seemed to be magnified by an awareness that advanced cancer underscores the fear of dying. This is particularly challenging when it occurs at a young age, when much of life is still ahead. For Laura, adjusting expectations about lost hopes and dreams while living with her disease was not easy.

> *It's hard when you're a young patient, you're blindsided. So it's a different experience. I mean, I'm sure you're blindsided when you're 65 and you get it too. But at least you've raised your kids, you had your career.*

And for Joan, the reality is that she is one of the many faces of metastatic disease, and recognizes that her "normal" appearance frightens some. This further isolated her from others who began to avoid her because of their discomfort with her situation.

> *Yeah, I have cancer. And they're like "You had?" I'm like "No, I* have *cancer. I'm stage IV. You wouldn't think, right?" And it kind of shocks, they kind of stand back, and I'm like "Yeah, this is what stage IV cancer can look like," and then it almost makes them kind of scared.*

This theme, *Wanting to be known as the person I am,* captures the experience of young women who struggle with the tension between being known as a person with a disease, but also as a person apart from the disease. They talked about looking healthy, *wearing the mask of wellness in the presence of a life-*

threatening illness, while living with the reality that their experiences were anything but normal. They are seeking to be known: They are wearing a mask that gives the appearance of youth, vitality, and good health while, in reality, they struggle with problems that remain "unseen" by others. Many are suffering in isolation, in silence, while still going about their lives; they are looking healthy yet living with the knowledge their time may be short. For Dina, she lives with a difficult reality:

> *But you know what you're probably going to die from and to know that it's going to happen sooner rather than later, what you thought before, it's just a different thing.*

She also realized life is short:

> *You get that understanding that life is short. You're not going to be around, and it's different.*

Major Theme 2: *I'm still Mom*

This theme has seven subthemes that describe different aspects of this essential theme: (a) *It's so hard*, (b) *Being a Mom still*, (c) *What I can still do*, (d) *There's not enough time*, (e) *Being remembered*, (f) *Searching for resources*, and (g) *It's not easy for my kids*. Theme Two is defined as the experience of wanting to be the Mom they were before diagnosis. They see the hardest part of being a young woman with advanced breast cancer was the fact that they are mothers. Being a mother was first priority, but they were hindered in carrying out this role by physical effects, and uncertainty about the future. They also wanted to find supportive resources, create good memories, and protect their children from the collateral damage of their illness. It was clearly the most difficult aspect of the phenomenon of young women living with advanced breast cancer. As Laura described:

> *I mean literally when you're a cancer patient and you have your own kids, the cancer stuff is secondary. You still have to take care of your kids. So in a way, it makes it a little bit easier, maybe psychologically because you still have to live your normal life, but logistically, it's a f***ing nightmare.*

In addition, each of them faced challenges in dealing with diagnosis, treatment and associated side effects. Each of the sub themes are described next.

Subtheme 2a: *It's so hard.* All of the participants reported that the hardest aspect of their experience of living with advanced cancer was their children. For Sarah, upon learning her early-stage breast cancer had progressed, her initial thoughts were about her children:

> *So, of course when they confirmed it was Stage IV, I mean that was really hard. And then the first thing I just said was "I have four babies."*

For Dina, her worries continuously focused on her concerns for her 10-year-old daughter:

> *And the thing I think that makes me most upset is her. I could talk about me and be like Yeah it's me. I'm going to die one day. But it's her that makes me the most upset, I think.*

However, for Laura, there was also irony in that having children forced her to maintain some normalcy in their daily life:

> *I think having little kids you have to just get back to normal. I mean, they need you and they need their normal routine and I find that I don't have a lot to talk about with other young cancer patients who don't have kids because all I talk about is my kids because that's my whole life….The kids don't give a crap. They don't care if you're feeling bad. They don't care if you're bald.*

For Mary, the experience of living with advanced cancer revolved around worries about the effects of her illness on her children and her desire to prepare them for the future:

> *Definitely, definitely hands-down, the hardest thing is the kids. Trying to spend as much time with them and hold them and just love them but still be Mom. They're not gonna go with me. So they're going to have to live the rest of their lives, and I try to still teach them and teach them even more in a shorter amount of time, you know?*

She also worried about how the experience of losing their mother might affect her young daughters. She verbalized fears about her sensitive daughter getting in with the wrong group of friends:

> *I want them to be good people. I want them to be nice people, and I'm not always gonna be here just to tell them that. So, like my older one especially, like I said, she's super sensitive and she's 10 years old and they live in a small town and girls are mean everywhere, but when there's only so many girls then…she is still really struggling to kind of find her space, but I just have this fear that still if something happens in the next couple years that she might get in with the wrong crowd and I might not be there to stop that. And so, yeah. Definitely, hands-down, the hardest thing for me.*

Some compared their experiences to others without children and felt the experience would have been completely different and more manageable. For Laura, it was very clear:

> *I think if I were on my own, if I were a single person without kids, this would be easier for me to deal with. Because the most difficult part is dealing with the kids, for sure as far as that goes.*

Subtheme 2b: *Being a Mom still.* There was a strong desire by all to be seen as mother no matter what might be occurring physically. For Amy, she and her husband both struggled with chronic illness and were firm in their conviction that the children remain their priority despite whatever physical and emotional challenges they faced.

> *This is happening but we're still your parents. We're still going to be here for you. We still love you. It doesn't change anything. It may mean that Mommy needs to sleep more than some mommies. It may mean that occasionally Mommy can't come to something because she's got a doctor's appointment and all. But like I said, we both have really tried to keep the kids a priority of—scheduling appointments and all when they are at school, or they're doing something, so that it doesn't interfere with us being parents.*

Being present to their children was a priority for all of these young mothers. For some, maintaining their role involved continuing to do all of the things they did for their children prior to the diagnosis. This was not always easy. In the case of Amy, she was struggling with symptoms that made speaking difficult at times:

> (Short of breath while speaking) *I mean, it's definitely difficult. You try to keep it…I try to keep a schedule. I try to make sure that I put my kids first, that… I want them to know that even though they've got a Mom who's going through cancer, that I'm still present. I'm still here.*

For those whose children were school age, *I'm still Mom* included activities such as volunteering at school in the classroom or going on field trips, driving their children to and from activities, and being present in their day-to-day life. Many expressed the importance of doing all of the things they had previously done. As Amy shared, this was not always easy and required modification:

> *If they need me, I'm here. I still try to be the one who takes them to their dance lessons. I still try to be the mom who's involved in Girl Scouts, who comes to the school for gardening club and PTO. So it's times of just getting completely worn out, and then just having to say, "While they're at school, okay, I've got to sleep all day today to recover from doing so much other stuff." And then I have a very good village, I would say…"*

Many of the children were silent observers of the changes and happy to have things remain predictable and maintain the rhythm of their family. Mary painfully described how one of her young daughters verbalized her worry in a difficult and poignant question to her:

> *And she* [her daughter] *finally said—and my husband is amazing but he's not me* [laughter]*—So, "How will Daddy ever do all this without you?" And I'm like "Oh, honey." I mean, heartbreaking, and what do you say?*

Subtheme 2c: *What I can still do.* Many focused on behaviors and activities they could enjoy with their children. There was a sense of urgency and desire to do as much as possible, especially if feeling relatively well. For Amy, this focused on preparing her three children for the future:

> *But when you're diagnosed with a terminal illness, you know that minute could come a whole lot faster than you're ready for. And so I try to, in everything that I do, start preparing them. Teaching my 10-year-old how to cook noodles, and how to do certain things, and taking some time that maybe I wouldn't do that at the age she's at now, but I'm going ahead and doing it. So I think it does change some of that, and I try to give them all the experiences that I can so that I get to see them have the experience.*

For Dina, preparation focused on helping to build the relationship between her husband and daughter. She acknowledged her daughter had grown more attached to her since the diagnosis:

> *She wants me around and she wants me there. She's afraid I'm going to be gone and I'm trying a lot to help them foster their relationship because I* will *be gone one day and they're going to need each other, and that's something that's really bothered me lately.*

Several others spoke of their desire to share new experiences with their children. They desired the opportunity to witness and share as many “firsts” as they could. For Amy, one of those firsts included going to a concert with her daughter:

> *I wanted to see her experience getting to try something new, so I said yes. Whereas I might not have done that otherwise because it's a lot. Because it added another night of having to get her somewhere. I want her to be able to try all these different things while I'm here to see her try them. We went to a Luke Warren concert this past year because I wanted to see her go to her first concert. That's something I wanted to see. So I mean, I wish we had a whole lot more money* [laughter] *because I'd love to see so many more things with her. But if it's doable when they ask to do stuff, I do it, because it's like why not? "*

For Sarah, it was to take her four children out of school for the day so they could watch the solar eclipse as a family:

> *The fact that I may not be around for the next solar eclipse and this is a huge memorable experience to spend with my kids, is why I'm taking them out of school, is why I'm trying to find the glasses, so we can share this experience together.*

Subtheme 2d: *There's not enough time.* Almost all with Stage IV disease and none with Stage III spoke of their likely limited life expectancy. They were keenly aware of the 30-month-survival statistics. Sarah tearfully acknowledged that, even if newer treatments could extend her life, it would never be enough time for her:

> *I've taken it as if death's at my doorstep, and they just keep saying I could fight this for many, many years. And I asked her* (the doctor)*, What's many? Two or three* (years)*? Four, five years is not many. My baby will only be 4 at the time. "Three, actually three,"* (she) *said. And I said, **even 10 years is not good enough for me. I need more, obviously.***

Understandably, uncertainty and sense of time were important aspects of the experience of these young women living with advanced breast cancer. This aspect was important to the lifeworld and the existential element of temporality. The next aspect, *Being remembered* was also related to the element of temporality and will now be discussed.

Subtheme 2e: ***Being remembered.*** Almost all of the participants had children under the age of 10 and worried that their children would not remember them. Most had begun to think of things they wanted to do for their children to create memories or leave them something personal including photos and letters. Joyce, the mother of a 3-year-old son had begun to think of possibilities but had not yet done anything:

> *Well, he is only 3.... maybe I'll be here for his whole life, or a lot of it, or maybe I won't, I don't know...I thought maybe I'd handwrite him letters in a book or something just in case, or just for him to have even if I'm still around they'll still be neat to him.*

Joan, an early-stager who had developed metastatic disease while pregnant, had toddler twins. She had begun creating memories and documenting family life through writing and photographs.

> *That's where it's like metastatic cancer has really opened my eyes to creating memories, that the boys are going to remember. I really try to document as much as I can.*
>
> *And as cliché as it is, it's living. Just being grateful for the things you have, try not to dwell on the things that you don't, and just creating those memories and having family around...at least create memories that they can remember us by.*

For Kate, she bought journals but had not started writing:

> *There's no cure as of yet. So I'm still wrapping my head around all of that. I haven't started writing letters or journaling to them yet, but I got the journal kind of things, you know?*

For Joan, there were also positives to the experience and that gave her hope:

> *But I guess the one positive—there's a few positive things out of this whole experience, is that I don't take my life for granted anymore, that I do create memories. And I used to really not take a lot of pictures and stuff, but now I do. So that my boys will be able to have pictures of me when they grow up, and hopefully I'll be taking lots of pictures with them too. That's my hope, but you never know.*

The next subtheme highlights the existential aspects of spatiality and relationality in particular. A lack of resources was identified by participants as an area that needed improvement.

Subtheme 2f: ***Searching for resources.*** Most identified a lack of resources that included supportive care and financial resources. All identified the need for help in talking with their children and having honest conversations. Mary, who presented with metastatic disease after undergoing a whirlwind of tests for excruciating back pain, was surprised to find nothing in the children's literature that helped children understand the metastatic breast cancer experience. As a mother of two young daughters, she immediately went online to look for resources and was upset to find that nothing existed:

> *It's been intense, but we're very, very gently honest with them. In the beginning, when you're diagnosed with any kind of breast cancer, I think you automatically assume mastectomy. You're losing your hair, all the normal kind of cancer things and—so I'm in the hospital on Amazon Prime ordering books for them and it was really hard because in every single book the mom gets better. She gets really sick, she loses her hair, but she gets better. I mean, I have not found anybody* (with) *Stage IV breast cancer in a book. You know?*

For Maria, it was the experience of talking with her nurse about her son's behavior during a chemotherapy treatment that triggered a social work referral:

> *I didn't have anyone to talk to me about how to talk to my kids...they didn't have a social worker come talk to me until I was telling a story to my nurse*

> *about my son kind of acting out and I wondered if it was because of that* (my cancer).

Two participants spoke of their desire to have opportunities as a family to enjoy life experiences. For both, opportunities were limited based on financial considerations. Amy used a Make-A-Wish analogy to explain.

> *I would say if there's one thing that I've noticed that for—and maybe I just haven't found it yet—for families with a parent living with a terminal illness is I wish there were more organizations that helped with being able to go and do some of those experiences. I mean, kind of like the Make-A-Wish thing for children. Kind of a Make-A-Wish for the parents to be able to have an experience with the kids before time is out. So…a lot of the ones that I've seen are like if you feel like you have less than 6 months to live. Well, I don't want to wait until I am in a hospital bed to want to go and take my children to Disney World.*

The identified lack of resources caused challenges in the lifeworld existentials of relationality and spatiality. Participants identified possible solutions that could improve their experience of living with advanced breast cancer while maintaining their role of mother. The final aspect of the theme *I'm still Mom* is the subtheme *It's not easy for my kids*.

Subtheme 2g: *It's not easy for my kids.* The experience of being a mom provides the context of looking at and empathizing with the experience through the eyes of their children. The women were all well aware of the impact of their diagnosis on the lives of those in the family, particularly their children. For Amy, most of her interview focused on the impact of her illness on her children. She described an acceleration of childhood:

> *And my girls, they've had to grow up faster than when they should have, and they're doing a lot themselves. And we try to avoid giving them too much responsibility or even making them feel like they have to do a whole lot. We never wanted that for them before cancer, and we sure as heck don't want*

> *cancer to change our values. We wanted them to be kids; we wanted them to enjoy themselves. And that's what we really try to still push for and aim for, is* ***giving them their childhood****. We don't want to take that away from them. In a lot of ways, cancer's already disrupted that.*

Yet, on the other hand, Dina's 10-year-old daughter expressed a desire to not grow up. This was motivated by her concern for her mother:

> *And one of the things she said is she doesn't want to grow up because if she grows up that means I'll get older and I'll have a longer time with cancer, which means I'll probably die.*

The awareness of an uncertain future was particularly hard for mothers and their children. As the children were beginning to grasp the seriousness of their illness, several expressed the worry that they could not make promises for which the children were searching. For Sarah, it was about not being able to make promises to her daughter:

> *But the solar eclipse was a big deal. Because, of course, the first thing my oldest one tells me is "Mom, you have to be here for the next one in 7 years. You have to be here for the next one." And, of course, that was hard. You put on your brave face, but it's hard to even verbally make that promise because I don't want to ever feel like I've let her down.*

Children of all ages were impacted, and their experiences were described by their mothers. Several described the shift in the levels of responsibility of the children in the life of their family. For Amy, she described how her 10-year-old daughter had assumed more responsibility for the family:

> *But I mean, our girls—because of how long our girls have gone through having parents that are not 100% well—they have grown intuitive as well. I mean, especially our oldest daughter, our 10-year-old. She'll step up and try to take over and take care of her two younger siblings and say, "Leave mommy alone. Leave daddy alone. They need this time." And so, it kind of works.*

And for Maria’s 6-year-old son, there was a desire to protect his mother from others knowing about her treatment-related hair loss:

> *Throughout this, he has said a couple of times, "If you wear the blonde wig everyone's going to know that you're bald underneath." So I tell my son, "It's okay, they love me anyway and they already know that I'm bald underneath. They already know that the blonde hair is a wig.” So he says, "I just want to protect you." So he's really sweet about it.*

All were well aware of the increased emotional burden experienced by the children regardless. Very few of the participants had psychological support in place for their children. Yet, the impact of their mothers’ illnesses took a toll on them. For Mary’s young daughters, there were good days and then days they were simply too worn down from all of it. This was very upsetting for Mary:

> *And my girls have been—it's like a 180. They're so good some days, they're so helpful—just "Mom, don't pick that up, I'll help you. Mom, let me help you with that. Mom, I'll do that." And then other days I think they just get too emotionally worn down and upset that it's like they can't do anything for themselves. They can't do anything to help me out. So it's really hard to kind of see that the—how it affects them so much.*

Inez’s daughter had first watched her mother go through treatment for early-stage breast cancer at a young age and then again at age 9 when her mother developed metastatic disease. Inez described her daughter’s struggles with anxiety:

> *She was four when I was first diagnosed. And so she's superquiet, shy personality, introvert. And so she took it—it was hard on her. And so she developed a lot of anxiety. She didn't want to go to school. She didn't want to even go to my mom's house. When I would have treatment and I would be in the bedroom, she would bring her toys into the bedroom and sit on the floor—“*

The theme *I'm still Mom* captures the experiences of young mothers living with advanced breast cancer with the seven subthemes of *It's so hard, Being a Mom still, What I can still do, There's not enough time, Being remembered, Searching for resources,* and *It's not easy for my kids.* These subthemes represent the four existential aspects of the lifeworld: corporeality, temporality, relationality, and spatiality and are all part of the experience of *I'm still Mom*. Additionally, the emotional toll on these women as they cared for their children while undergoing treatment for a serious illness remained for the most part invisible and hidden behind the mask of wellness.

Major Theme 3: *Living is more than surviving*

This theme has nine subthemes that describe different aspects of this major theme: (a) *Living my life,* (b) *Working,* (c) *Facing challenges and making adjustments,* (d) *Feeling the physical effects,* (e) *Doctoring for the rest of my life,* (f) *Spreading my story,* (g) *Thinking about the future,* (h) *Wondering about delays in diagnosis,* (i) *It's my journey,* (j) *Finding unexpected surprises,* and (k) *Seeking resources*. Major Theme 3 is defined as the experience of trying to live as fully as possible within the constraints of the disease. The participants understood the life-threatening nature of their illness, but there was a desire to talk about it as a warning for others to be vigilant about their own health. However, they have experienced unexpected and positive surprises. This theme paints a picture of what daily life and its struggles are like for these young women as they strive for a sense of normality. They were focused on living with their illness and, for some, living in spite of their disease. Their words illustrated what a typical day looks like in the process of striving for normality. This theme illustrated another aspect of *Wearing the mask of wellness in the presence of life-threatening illness:* working, volunteering, caring for children and families, and engaging in life in many of the ways they did pre-diagnosis. However, despite their busyness, there were still aspects of living with advanced breast cancer that remained hidden from others. The nine subthemes are described and exemplified next.

Subtheme 3a: *Living my life.* All of the participants spoke about day-to-day life. It involved navigating many different aspects including treatment, work, relationships, caring for children, and making choices. All also spoke about the way life "goes on." Life continued despite illness and it was up to the individual to make choices as to how to move forward. For several, there was a strong desire to enjoy life and not let their cancer inhibit them from living the life they wanted to live. For Joan, it was about enjoying life despite the diagnosis of metastatic breast cancer. She was not going to let that get in the way:

> *You know what? I'm not going to stop my whole life. I'm going to live my life. I'm going to enjoy my life.*

For Kate, who at 9 months postpartum was initially misdiagnosed with an early-stage breast cancer and then was found to have metastatic disease. Life was busy. She described her typical day:

> *Well, daily life is very busy, obviously, with two kids, and working, and a husband. And I guess most days I—I mean, obviously, I think of cancer a lot. It kind of crosses my mind a lot, but most days, it's kind of in the back of my mind because I have so much going on in my regular routine daily life that I…it crosses my mind, but I don't sit and dwell on it most days. So I work Monday through Thursday, 8:00 to 4:00, at the dental clinic, and then I come*

> *home and between supper, and bathing children, and household chores…just, it's busy. Busy life.*

After her diagnosis of metastatic disease, Joyce found reality did not catch up with her until she was approaching the 1-year anniversary of her diagnosis. She was busy living her life and acknowledged that life continues despite the cancer diagnosis.

> *The initial day and first couple of weeks were really hard. But then it was just kind of like, I don't know, you just kind of roll on with life. And things didn't really catch up until, like I said, about a year later. And, yeah, I was reliving all that stuff.*

For Linda, a typical day living with metastatic disease involved work, day care, and household responsibilities.

> *But most of the time I manage pretty well. I get up, go to work, and take my son to day care on my way to work. And when I get off work, I go pick him up and we go home and play and make dinner. And then my husband comes home.*

Many acknowledged that life did go on and there was a desire to keep things as normal as possible. In addition, life was more than surviving, it was embracing the “new normal,” living purposely, and enjoying life. For Linda, this meant doing all things she did before her metastatic diagnosis:

> *I mean, I think the whole "Life goes on" thing is a big part of it. If I knew I was going to die in 2 weeks maybe I would have a different plan, or perspective, or routine, but I don't plan on that. So I just keep…I do as much as I can. Rest a little more if I have to, but staying busy and doing the normal things is what makes you…I don't know. It gives you some normalcy and sense of control. Like "Oh. I can still get up and go to work, and act like a perfectly normal person, and just live* [laughter]*." Not just survive.*

Linda also noted that living with metastatic disease was more about choosing to live purposefully, not just surviving:

> *Surviving almost sounds like just the minimal effort, and thriving sounds like you're surviving with this disease, but you're really putting all of your effort into life also. It's not just living. It's living purposefully.*

For Inez, she described living with metastatic disease as thriving:

> *Thriving is the word, we're surviving, but not just surviving, because that sounds like you're just sort of passively living. We're thriving."*

For others, it was more difficult and the physical effects caused by treatment or underlying disease made some days very hard. Sarah, who had several young children sobbed as she described how on some days she struggled in her day-to-day life and acknowledged her husband's role in keeping the household together:

> *I don't understand how women that have to work are able to get up every morning because I can't. And without my husband, this household wouldn't even function on some days.*

And another woman who was receiving neo-adjuvant therapy for Stage III breast cancer, a mother to a 10-month-old and a 3-year-old, acknowledged how difficult life was in a powerful statement:

> *We're hanging on by the skin of our teeth and sacrificing our own needs and our own health.*

Life with advanced breast cancer brought additional new realities: doctors' appointments, scans, and unexpected appointments while also trying to balance the many aspects of daily life. For Amy, who was experiencing worrisome new symptoms that could be indicative of disease progression, described the reality of how hard it could be:

> *It is never-ending trying to figure this out, and control it, and deal with it, and hope that it ends up being nothing, and…so that's why I'm not working right now. And between the pains that the cancer's causing in my bones and just being tired from it to the myriad of doctor's appointments I have right now…because starting tomorrow, I go to the doctor every single day the rest of this week. And then trying to be a Mom, too…so.*

For those with metastatic disease, scans were usually done every 3 months. As a result, life begins to be seen in 3-month increments. For Mary, this added another layer of complexity in an already busy life:

> *And just that that's going to be…it was like another kind of reality check like, This is it. This is how my life is. It's going to be like this every 3 months. And it's so new to us. It seems like it's been a lifetime but it's only been 6 months. And still, with my girls, I'm very involved in the community. I volunteer a lot. And so we're just superbusy. And they're in dance and we actually just decided we're going to raise a pig for the fair. I don't know how that's going to go* [laughter].

A typical day could be exhausting for a variety of reasons. For many, daily life included work, childcare, and familial responsibilities. There was a sense that for some, nothing had changed in the daily routine. By the end of a typical day, Liz was ready for bed:

> *So we'll do dinner like around 7:00. My kid gets in the shower, and then, I get him. I read with him every night as well. He's in bed usually at 8:30. I'm usually in bed by 8:31* [laughter]*, unless it's Sunday, in which case, I stay up and watch The Walking Dead with my husband* [laughter]. *So yeah.*

And she also noted that typical activities haven't changed:

> *I rush really quickly to try and get out of the house, which then would include getting my kid up, getting him dressed and ready, getting his snack bag and lunch bag and my lunch bag, and getting out the door by 7:15* [laughter]. *I commute about an hour to work as well, even though we only live like 14 miles from my office.*

For others, the timing of treatment impacted the ability to remain active due to treatment-related effects; in particular, fatigue. Modifications were often necessary and focused on finding more opportunities to rest. Liz also acknowledged how activities lessened during treatment week:

> *It also all depends on if I'm on my medicine. If I'm on my medicine, I don't feel well, and I usually don't really do a whole lot outside of the house. But if it happens to be a weekend when I'm not on my medicine, it's grocery shopping. It's going to Target. It's getting things done that I couldn't get done the week before when I didn't feel well. It can also include trips to wineries or trips to breweries, fun stuff like that, so yeah, yeah, and taking naps.*

And, for her, a typical weekend included times built in for naps on both days of the weekend:

> *I definitely nap every Saturday and Sunday, and then, it depends on if I'm on my medicine. If I'm on my medicine, I'm tired. I don't feel well. I would love to crawl in bed every single day during that week that I take my medicine. It also depends on how busy I actually am during the day, with working and what not. If it's a busy workday, the next day will be—I will be exhausted and have absolutely no energy.*

Subtheme 3b: *Working.* More than two thirds of the participants worked. For most, working was an important part of their identity and provided some normalcy to their lives as well as being important to their self-identity. Kate, who worked full-time as a dental hygienist, spoke about the financial necessity of working because she carried the insurance, but she also acknowledged that if that were not the case, she would continue to work:

> *I work because, financially, I need to work. I work because I carry the insurance, and I obviously need the health insurance. But if we weren't in the same financial situation and my husband carried the health insurance, I think I would still be working. Maybe not full-time, but I definitely need it to keep in mind other things, get out of the house. Yeah. And, I mean, I enjoy what I do. I mean, I have a lot of friends at work. And, yeah, I definitely think that I would continue to work even if I didn't need to. But I do need to, so—.*

Inez, who has lived with metastatic disease for over 10 years, enthusiastically described her love of work for a cancer nonprofit organization:

> *But I love my job, and unless I'm really sick I'm not quitting.*

Work provided an important outlet and satisfaction in their daily life. For Linda, working made her a better mom:

> *And it's like I love him, but I need my work too. I'm a better mom when I have something else to do. So yeah, for now, this works for us, so we'll continue doing this even though I wish I can do a little more work from home, but I'll deal with this in order to keep my job.*

Two other participants had both worked full-time before making the decision to go on disability. The decision to go on disability was not taken lightly. For Dina, it was the right decision and improved her quality of life both physically and emotionally:

> *I was working full-time and then I went down to part-time. And then I went on disability… Being home has been great since I stopped working. I think working was putting a lot of stress on me that I didn't need to have. And so I've noticed that I feel emotionally and physically a ton better now.*

Liz acknowledged that due to progression of her cancer and the need for chemotherapy, she anticipated leaving her job within a few months of our interview. This created worries about finding a replacement for her position, and she felt responsible about leaving everything "in good shape" while acknowledging she hadn't thought much about the impact on herself:

> *And I knew that I wasn't going to be able to continue working because of the medicine, and being tired, and all that kind of stuff. So I was worried about them finding my replacement. I really haven't taken the time to really sit down and think about the impact that it's having on me… I'll probably work through the end of the year, not necessarily on a full-time basis because when I am taking my Xeloda, it makes me really nauseous, really tired, so I usually*

> *take time off of work when I'm going through that cycle…so yeah. Sometime, at the end of the year.*

Subtheme 3c: ***Facing challenges and making adjustments.*** Most of the participants acknowledged the multiple challenges they faced on a daily basis and how difficult it could be in light of everything else they were already managing. There was both acceptance and resignation about these challenges, which included juggling their many roles and responsibilities, navigating care for their children, caring for the family, self-care, and worry about the long-term effects on the family. For Inez, it involved balancing the many aspects of her life while also worrying about the financial implications. She acknowledged she was fortunate in that she did not have concerns related to her insurance:

> *And then, just trying to think of some other challenges, like balancing the work, the home life, and treatment, you know what I mean? Trying to balance them all to make sure that you're taking time for yourself, but you're also able to care for your family and that kind of stuff. But other than that, challenges, always worrying about finances and that kind of stuff. I mean, I've been lucky to have always had good insurance and not having that issue. But I have friends that have bills out the wazoo, just not having to worry about that is good.*

With the challenges also comes the sense of added responsibility and burden about the effects of their illness on their families with the inability to change or control things. It could be both overwhelming and frustrating. For Mary, living with the knowledge that her life expectancy could be only 3 years forced her to have difficult conversations with her husband:

> *And that's another thing, I guess too. That is knowing that so many people are hurting because of me. And I can't fix it. I can't do anything about it. Yeah. It's hard. My husband is kind of the same way. I think he just pushes it out of his mind and every once in a while it kind of hits in. It's reality. And having to have those conversations. It was a couple months into it and I'm*

> *like "You need to realize what's going on. I'm not being negative, but we're talking 3 years here. You need to learn to be me."*

Several participants also spoke about the modifications they had to make to accommodate the physical effects of living with advanced breast cancer. Life as they had known it before their illness no longer existed and adjusting to the "new normal" required making adjustments to the life now being lived. For Joyce, being a mother of small children added another dimension:

> *So there were modifications I had to make to my lifestyle. And being a mother of little kids, you have to kind of figure out how you're going to do all of that.*

And she also acknowledged that her busy life continued while she was also trying to figure it all out:

> *And you're just so busy with adjusting to the new normal and the treatment schedule and everything that things kind of roll on.*

Subtheme 3d: ***Feeling the physical effects.*** All of the participants spoke at length about how their life was impacted by disease or treatment-related effects. The most common physical effects were pain, fatigue, hot flashes, and "chemo brain" although the treatments themselves could also be grueling for some, with feelings of dread in anticipation of treatment.

For two participants receiving neo-adjuvant chemotherapy for Stage III disease, the treatment-related effects could be unbearable at times. This had significant impact on their ability to navigate and get through day-to-day activities. Maria, who worked full-time and had two small children, had to take a leave of absence from her job. While Laura, who had been diagnosed when she was 9 months postpartum and not working outside of the home, struggled tremendously with the day-to-day care of her two small children. She expressed gratitude that her mother was able to move in to help, but also acknowledged that was a luxury many don’t have.

> *I had trouble navigating my care. When I was on chemo, I was just bedridden for so long, and I just felt so out of it mentally, and I just did not have the capacity. I mean, I couldn't even sit there and play with my kids. I couldn't even triage the information….You're so compromised by the chemo. The chemo ruins your capacity to navigate for yourself. Or it did for me. It really did.*

Anticipation of treatment could add to other physical effects, and the physical effects from anticipation could worsen over time. These effects could include nausea and anxiety. As Inez described it:

> *And then, now tomorrow, I have to go for treatment. And so all day today my stomach's in knots, the dry heave starts and I'm just kind of like, "Oh boy. Here we go again." Just because I'm a person where I'm always on the go. I hate sitting at home, you know what I mean? If I can be out somewhere, I'm going to be out there talking to people, and networking, and doing what I have to do. And so this treatment now just makes me feel like crap. And I'm in bed for 3 days, and I just…I hate it.*

A major concern for some was a change in body image. Despite expressing a desire not to let changes in her body appearance bother her, Inez still struggled to manage her feelings:

> *Just the whole body image too was a big challenge. I was 28, my breasts are lopsided now, and I'm constantly looking at other people to—as women, we do it no matter what, if we have cancer or not, but comparing ourselves to others. And every once in a while, I'll do that, and I'm just like "No, You're alive and you're breathing and look at all this stuff that you've been through in your life. Who cares?" You know what I mean?.... Yeah. Well, definitely the whole hair-loss thing. At first, it was like "Oh my gosh. How am I going to deal with this?" My husband and I weren't married yet. "Is he going to run out the back door when I lose my hair? And how is that going to affect our relationship?”*

Pain. The most common symptom was physical pain of various origins. It was experienced by all of the participants. The pain was either related to bone metastases or treatment-related joint pain from hormonal therapy. For some, the bone pain was unbearable and constant, and invisible to others.

For Amy, who had three young daughters, pain from bone metastases was unexpected and constant:

> *One of the things with the cancer being in my bones—there's something I never knew, bone cancer is extremely painful. So I'm constantly in some type of pain. Like right now just sitting here talking to you my back and left shoulder are about a 2 to 3 out of 10 pain. But it seems like at night it gets worse for some reason. So a lot of times by the time I'm going to bed, my shoulder especially, is an 8 to 10 out of 10.*

Along with the pain, Amy also struggled with other symptoms as well, particularly at night:

> *Every night. And so it's trying to get the rest of my body—because my back always hurts some. Trying to get in a position where it's not hurting so bad that I can concentrate on something else to turn my brain off to go to sleep. They've got me on pain medicine and it helps some but not completely. And I have to take nausea medicine because I'm constantly nauseated for some reason. And so those medicines can help me get to sleep usually, but then I'm constantly waking up, turning over, readjusting, trying to find a comfortable position, trying to get back to sleep again. And that just kind of happens all night.*

The treatment-related joint pain experienced by almost half of the participants was also significant. This pain had an impact on their day–to-day quality of life. Living with this pain became an aspect of their daily life and was normalized and expected. This pain was felt to be more manageable because the alternative of not treating the cancer was not an option. Kate, 33 years old, worked full-time and had two small children. She described her experience with joint pain:

> *I take Arimidex daily, which makes me feel like an 85-year-old woman, but I'll take the side effects over cancer any day…. I do have a harder time, especially in the morning, moving around just from the side effects of the medication. I don't feel that it limits me to anything that I do. I mean, I'm definitely mobile. It just might take me a little bit longer to get going* [laughter]. *Yeah. I feel a little bit older.*

Fatigue. Almost all the participants complained of fatigue that was either treatment- or disease-related. It was something that they were learning to live with and required modifications in their lifestyle to accommodate it. However, many expressed a desire to have more time for self-care and get additional rest but acknowledged that in reality that was usually not possible. It became something that was an expected part of their life that they were learning to live with. For Liz:

> *I've tried really hard to not have it change our life that much, but it really depends on if I'm on my medicine. If I'm on Xeloda, or even when I'm taking the Ibrance, that will take all of my energy away, and it will make me very tired. And during those times, my husband really steps up and he does the cooking. He does the laundry. He does everything so that I can just sit in bed, so that I can just curl up in bed and not move. I think that really the only thing that has changed is during that week when I'm on my medicine.*

For Inez, it was more about doing what she needs to do because she didn’t really have another choice.

> *I mean, just maybe the last couple months, I've been a little bit more…my body's been a little bit more tired. And my staff at work is just kind of like "I don't know how you do it. I don't know how you come to work every day." And I'm just kind of like "Well, I mean, I don't have any other—" You know what I mean? "I don't have any other choice." And plus, if I would just sit at home, my mind would go into a dark place, and I don't want that to happen, so I need to stay busy so I'm not worrying or thinking about myself. and I put the focus on someone else.*

She also wrote about her frustration in her journal:

> *I've had three people ask me how I do it…how do I get out of bed every morning knowing that I live with cancer. And my answer to all three of them…I get out of bed just like you do. I don't know any other way. It frustrates me when my friends say "I don't know how you do it, I would never be able to handle everything like you do" or "you don't look sick"….I have to politely walk away…#isitfridayyet?*

Hot flashes. Not surprisingly, postmenopausal symptoms including hot flashes were experienced by half of the participants. They described the symptoms as varied in intensity. Participants were accepting of them because they felt the benefits of the medication outweighed the unpleasantness of the hot flashes. However, none had tried any type of treatment to diminish this symptom. Several did express how difficult their experience of "rushing into menopause" had been and that it had caught them by surprise.

For Dina, they could be intense and impact her sleep:

> *Between, I don't know if it's the Tamoxifen, the Lupron, or all of it together, hot flashes have—they're pretty intense. And I take, of course, my meds at night. So I don't sleep well because I'm constantly drenched in sweat and then freezing cold, you know?*

For Mary, diagnosed with metastatic disease right from the beginning, she didn't want to stop a treatment that was working because of the hot flashes:

> *I'm not going to just quit because I have hot flashes and maybe a little vaginal dryness because that's just wasting a treatment in my book. Because it's working and there's no progression. My breast tumor has actually shrunk a little bit, but everything else—nothing's grown. Nothing's grown. So I'm not going to quit it because of hot flashes and kind of waste the treatment, which is what, essentially, I feel I would be doing.*

Chemo brain. Half of the participants described struggling with "chemo brain" that was associated with symptoms of forgetfulness and a sense of "fogginess." This symptom also required modifications to daily life. Several identified the need to write things down and to maintain a “To Do” list to keep both themselves and their families organized. Here again, there was a sense of “it is what it is” from the participants. For Joan:

> *I mean, they call it chemo brain sometimes, but I think it's menopause. I think that I can't—sometimes I really can't find the words or I'm real forgetful. I'll put things where they don't belong. And this is all new to me. I have to write things down. I have to make lists.*

Amy had a similar experience with needing to write things down:

> *But I guess a side effect that is new for me is just I have to write everything—I'm really forgetful and real absentminded sometimes. And again, I don't know if that makes it easier to just kind of laugh things off and just stay a little bit calmer if things aren't going exactly as planned.*

Subtheme 3e: *Doctoring for the rest of my life.* All of the participants with metastatic disease talked about how they will be in treatment for life. Several called this aspect “doctoring” to explain the necessity of continued care over time. Many talked about the hope that treatment provided and that there would always be hope for new treatments to emerge. Treatment was viewed as ongoing with no end. For one, the end of treatment was described as “death,” while Dina spoke of the frustration she felt because people in general do not understand that treatment is essentially continuous:

> *And another thing too is, because it's not—people are so unaware of the difference, especially where I live. It's a pretty small community too. They will say, "You got this. I'll come back to you when you're feeling better. I'll come back to you when you're done with treatments." Well, you know what? I'm never going to be done. I'm going to be in treatment forever. I'm going to be doctoring for the rest of my life. And it's just crazy. I was never sick.*

Subtheme 3f: ***Spreading my story.*** Almost all of the women expressed a desire to share their story with others to increase understanding about metastatic disease. This was evidenced by their desire and willingness to participate in this study. Many expressed frustration about the lack of knowledge of the general population as well as healthcare providers. Joan acknowledged she is just one of the many faces of metastatic disease and shared how she developed a desire to educate others because many knew so little:

> *So it's changed me that way where I've become a little bit more like I want to educate people on it. Because I'm like "Yes, I am a face of metastatic, but there are also hundreds of thousands of other women that have different—it just depends on the medication and how long that medication lasts. "I've taken more of an educational role on it. And also realized that I need to do me, I can't help every single person. So I pick and choose my battles.*

For Joan, who first was diagnosed with an early-stage breast cancer, the transition to a metastatic diagnosis was overwhelming. This was a daily reality of the experience of living with advanced breast cancer.

> *Yeah, a lot of people didn't know what it meant to be a stage IV metastatic. People don't understand. Then you go on and Google that, and you start reading about it and it's overwhelming. It's very overwhelming. And I know that a lot of statistics are 5 years old because it takes awhile for statistics to be updated and whatnot but it's scary when you Google metastatic breast cancer. I mean it's scary and I just think—I mean cancer is scary. And I think this year more so than, obviously, in years past.*

It was clear from the interviews that more education and awareness were needed as well as a better understanding of how metastatic disease impacts lives. Many felt that their experience of living with this illness caused them to be more open and share their stories for the benefit of others. Some had become advocates for increased funding and research for metastatic breast cancer, describing the month of October as an opportunity to increase awareness. Some especially criticized the “pink” campaign for breast cancer awareness as focusing on the possibility of cure when cure is not always possible and that this added to their sense of being left out, invisible, or isolated. Dina acknowledged that many do not see the negative side of breast cancer; they only see the positive side. She acknowledges that living with breast cancer is not all pink ribbons and happiness:

> *Everybody looks at the pink ribbon and they're like "Oh, it's a pink ribbon! It's so pretty!" They see the positive, the empowering side of the pink ribbon, and getting the message out, and all that kind of stuff. But people don't see the negative side. People don't see patches of hair falling out. They don't see someone with their face in the toilet throwing up because they just had chemotherapy. People need to see the bad side of it. It's not all pink ribbons and unicorns and happiness.*

Subtheme 3g: *Thinking about the future.* Thoughts about the future were expressed by almost all of the participants. Many expressed worries about the uncertainty of their future. Others described how their situation forced them to change how they looked at the future. Kate spoke about how she changed from being a planner to learning to live more day-to-day:

> *I would call myself a planner, but I think that since my diagnosis I've done a little bit more day-to-day than how I was, just because you kind of have to be that way once you're in treatment and you kind of have to play everything by ear and go day-to-day for a while because it's…Life is not how you had planned it, so you've got to change everything for it. So then you kind of learn to live more day-to-day I think. But, yeah, I'd say I'm kind of both.*

For Joyce, this resulted in less planning and more spontaneity:

> *If I'm physically able and we're financially able to do something we really want to do, then we're probably just going to do it instead of planning for 2 years down the road or whatever. So it's a balance like everything else, and it's definitely shifted over the last couple of years to more of a seize-the-moment type of attitude.*

While for Dina, it was the opposite:

> *I've always been a planner to some extent. I think I was more open to spontaneity before, and I think that I'm pretty…I'll admit I'm pretty closed off to it now. The only spontaneous things I think that I'm usually open for are kid-related things. Unless she says, "Hey Mom, let's go2o hours away," I'll be like "We really have to plan that." But if she says, "Hey let's go down the street to the park." "Oh yeah, sure, let's go." I'm still very much a planner, and it hasn't changed, I mean it's changed just enough to where I think I'm just more of a planner than not.*

For Joan, preparation for the future continued but, rather than taking a long-term approach, her focus became more short-term:

> *You prepare for the future as much as you can. I'm still working and all that stuff. I'm trying to think what my kid will need in the future. But I don't look as much about where do I want to be 10 years from now. I look more about what do I want to be doing next year and then maybe the year after. Not that I won't necessarily be around then, but it's more important to go on and get done whatever I think is important now in case it's—I mean, I say that a lot, but that's how I feel. Just in case.*

And Linda articulated what it felt like to be young and feeling well one day and then suddenly find you are still young and feeling relatively well, yet live with the knowledge that your life will be shortened from your disease:

> *"Well, it kind of like—if anybody else woke up one morning feeling like themselves but 20 years older, and it was like—not that I've lost 20 years of my life but it could be something like that. And so it's like "Okay, I'm not even 40," but it's like I'm more 60 or 70. I'm getting toward the end of my life. Closer to the end than the middle, like I thought. Imagine if you woke up 20 years older but you felt the same way. And so it's like—I mean, anybody can say "Yeah, I could die tomorrow in a car wreck or something." And that's true, but knowing that you're probably going to die 10 years, 20 years sooner than you expected kind of shifts a little bit.*

Uncertainty. Living with uncertainty was another aspect of *Thinking about the future* that was hard for most of the participants. There was a desire to plan and yet, for some, those plans would have to change unexpectedly or be put on indefinite hold. Laura spoke about losing the privilege of not worrying about the future when she was diagnosed with Stage III breast cancer:

> *You just don't know for sure. And that you're always living with that level of uncertainty. It sucks, but the fact is that this level of uncertainty is what everyone lives with, just everyone is not faced with it the same way that a cancer patient who's already been diagnosed is faced with it and can't ignore it. Yeah, it's just something that I had the privilege to ignore before, and now I don't have that privilege."*

And for Liz, disease progression and a new treatment regimen put all of her plans on hold:

> *Yeah. And we had plans for Christmas, and for New Year's Eve, and for trips that we were going to take next year. And everything is on hold right now. It's one thing when you can take a pill every day. You can still do things. You can still go on trips. You can still have a big party or whatnot. But when you start getting into chemo, you're going to lose your hair. Am I going to be throwing up everywhere? Your life is put on hold.*

It is what it is. More than half also acknowledged that *Thinking about the future* also involved an awareness of the current reality over which they had very little control. There was a sense of "it is what it is" and that impacted their ability to plan. The awareness of the reality was also frightening for many and, as a result, important conversations with family members and others were avoided. For Liz, it was about being realistic yet hopeful:

> *I've got three brothers, and so I can see them watching me all the time, but it's like they don't really want to talk about it. I mean, on a list of four, we're* (we were born) *only 5 years apart. So I still see them watching me all the time, but not wanting to actually ask me unless I bring it up. And even then, it's hard to hear. It's bad, but nobody wants to talk about it. And then I don't mean to be negative, and sometimes I think I come off that way in that—I hope that I'm going to be here in 20 years. That's my goal. I also have to be realistic in that, I mean, what does 30% make it? Five years? It might even be less than that. So, yeah. It's trying to be realistic but yet hopeful kind of.*

And for Mary, there was gratitude in the midst of living with a terminal illness:

> *So then, I'm thankful. I'm so thankful that I'm feeling so good. It sounds crazy because it's terminal cancer, but I guess, it is what it is. And there's nothing I can do about it.*

Subtheme 3h: ***Wondering about delays in diagnosis.*** More than half of the participants talked about a delay in either their initial diagnosis or the diagnosis of metastatic disease. It is not clear whether this was due to their age. However, for two of them, bone pain was initially treated as an injury with the typical course of rest and anti-inflammatories and for one, physical therapy. These delays had resulted in them thinking and wondering about how they had impacted their experience. Delays were also associated with feelings that range from shock, a sense of false reassurance, and for others, anger about lack of education and knowledge.

Joyce had been living with terrible back pain that contributed to worsening immobility over time:

> *Yeah, it was really shocking obviously. And the thing about it was…so I had the injury in October, and I was diagnosed then in February, so that's November, December, January…5 months. Five months from injury to diagnosis…*

For Inez, who was approaching the fifth anniversary of her initial early-stage breast cancer diagnosis, excruciating pain led to a trip to the emergency room and an initial diagnosis of kidney stones. When the pain didn't resolve, she returned to the emergency room a week later and was given a shocking diagnosis:

> *And then, right when I was about to hit kind of my 5-year mark, I woke up in the middle of the night with really bad side pain. So I drove myself to the ER,*

> *and they told me I had a kidney stone. So I kind of endured a very long painful week of jury duty. And then, the following Sunday, I believe, my husband and I were grocery shopping, and I almost fell over in pain and I'm just like "You need to take me back to the emergency room…and they told me, Well, it's not kidney stones. You have a tumor three quarters the size of your liver. You have a tumor wrapped around your spine." It's in my ovaries, my pancreas, and in my bones.*

For three of the participants, reassurance about a medical concern led to delays in the diagnosis of *de novo* metastatic breast cancers. This reassurance had given Amy a false sense of security that resulted in her not following up with recommendations for testing:

> *The nurse practitioner who felt it thought the same exact thing as me. She said, "Well, the way this feels, this feels like fibrocystic breast." She went in, gave me an ultrasound order at that time. But, again, because she had said the same thing I was already thinking, I put off having the ultrasound.*

For Kate, she found a lump when she was breastfeeding and was told not to worry about it:

> *And my doctor felt it. He felt that the lump was a milk duct, so he didn't feel that it was anything to be worried about.*

And for Joyce, an early workup was negative, and it was not until she hurt her back 4 years later that the workup eventually revealed metastatic breast cancer:

> *So my diagnosis is sort of atypical. I wasn't showing any real symptoms of breast cancer, but I was having a lot of back pain after I had my second child. So that would've been 4 and 1/2 years ago. And I went in and had X-rays and some stuff done. And they couldn't find really anything wrong on the X-rays.*

Subtheme 3i: *It's my journey.* Almost half of the participants talked about their experience being a journey and that the journey was unique to each of them. For some, their journey involved making choices about how to deal with their cancer, and for others the journey was focused on making adjustments to accommodate treatments or appointments. The rhythm of daily life continued as it had before despite how difficult that may have been for them. The desire to keep things “normal” led to personal sacrifices and accommodations that weren’t always easy. For Inez, a positive outlook was an important way for her to deal with her metastatic disease:

> *And I think probably about, I don't know, a year or two after I had the metastatic recurrence, I kind of thought to myself, I'm just kind of like "90% of this whole journey is all about how you approach it, how you think about it, kind of like your mindset, and then that 10% is just all that nastiness, side effects, and meds, doctor's appointments that you have to deal with." Being in treatment for so long and meeting so many people, you've met people who have had the same attitude as I did, the positive outlook, always looking for the positive. And then, you've seen people who are a little bit negative, or just grouchy and angry, and they didn't make it, you know what I mean? So I'm just always making myself stay positive. I mean, don't get me wrong, I'll have pity parties for myself every once in a while.*

She also described that maintaining life as it had been before diagnosis was how she chose to live her journey:

> *Yeah. I mean, it hasn't changed at all. I mean, throughout my whole journey, I've worked, held a full-time job. I would maybe take off—I'd always schedule chemo to be at the end of the week so I would have to miss minimal work. And, I mean, I would suck it up as much as I could to do family activities and that kind of stuff. So, I mean, my life hasn't changed at all.”*

Subtheme 3j: ***Finding unexpected surprises.*** Three of the participants spoke about unexpected surprises in the midst of a challenging diagnosis. This awareness led to positive changes in living with their disease. For Joan, the silver lining was being forced to slow down a very busy life:

> *We have a very crazy life. It's very hectic. That's kind of the other—if there's any silver lining to this disease, it's that we are slowing down or being forced to slow down.”*

While for Joyce, she was surprised to find the diagnosis refocused her priorities and helped her take better care of herself:

> *And one thing that surprised me was, it wasn't something that was intentional. It wasn't something that I really thought about and charted out. It was just something that kind of came naturally with the diagnosis, like I guess my priorities just came more into focus, I would say, and I just was a lot less willing to give myself away in areas that weren't really, really important to me. So it has changed quite a bit.*

However, a few participants reported a shift in their awareness that others who also look "normal" may be experiencing difficulties that are not obvious. This growth in their awareness also caused some to reflect on whether their assumptions about their view of people as being "normal" were accurate. For Dina:

> *I look at people now and go "They look completely normal. There's a chance they're not completely normal." It changes your perception. It does because I don't know; It's weird on my bad days. On my good days, I like it. On my bad days and I'm feeling like crap and I will look completely normal, it kind of makes me mad because people will assume I feel fine and I'm like "No, I don't feel good today."*

Subtheme 3k: *Seeking resources.* For many living with advanced breast cancer, resources and information were not easily available. Where one was in the treatment trajectory determined the amount of energy they were able to use to search for resources. Laura, who was in the midst of neo-adjuvant chemotherapy, noted she did not have the energy or mental capacity to even begin to think about what she might need. For Dina, who was living with metastatic disease after initially being treated for an early-stage breast cancer, information about disability was not offered or available:

> *But I didn't know about social security, disability. I didn't know about how long—no one really told me about any of that. All I wanted to do was get healthy and go back to work. But I didn't realize, if I would have known what I was going to have to deal with, I would never have gone back there* (to work)*.... It was a great decision. I wish I had done it right from the beginning of my stage IV diagnosis. But yeah, no one told me that. I had no idea I could go on disability.*

Another participant identified the lack of available support groups for young women. Inez was disappointed to find that the support group she went to was not at all helpful, but she used the experience to seek what she needed for support:

> *I went to a support group through the hospital that I was getting treated at, and just had the worst experience of my life…Because I was 28 and so young and, typically, if you think about breast cancer patients, they're women in their 50s and 60s….So topics that they discuss are totally different. They're old and don't really care about what they look like or what they say and where I am—and I walked out of there and I'm just kind of like "Oh my gosh. I'll never go to another support group again" because they were just so negative and just bitching about everything, and I'm just kind of like "Oh my gosh." And then, I encouraged a local organization to start a young adult group. And so they did, and it's been great. We do fun things. We go for hikes. We go to shows, paint your pottery, all that kind of stuff.*

The essential theme *Living is more than surviving* is multidimensional and encompasses the day-to-day experiences of young women living with advanced breast cancer as captured and reported in the subthemes. The participants were maintaining active and busy lives despite a host of treatment- and disease-related effects. All struggled with pain, and most of them also had a combination of fatigue, hot flashes, and chemo brain. The entry into menopause was aptly called "rushing into menopause" by one and really captured the rapid onset of becoming postmenopausal in a body that was not yet 40 years old.

And other areas proved challenging for this group of women. Being in some sort of treatment for the rest of your life was recognized by several and with that came the understanding that life essentially was lived in 3-month increments due to frequent scans.

Major Theme 4: *Getting through it*

This theme has two subthemes that describe the important aspects of this major theme: (a) *I have many different feelings and emotions* and (b) *Behaviors to help me get through it*. This is defined as the experience of coping with advanced breast cancer from both the emotional and behavioral perspectives over time and is a process. The subtheme *I have many different feelings and emotions* includes being overwhelmed, devastation, worry, depression, gratitude, relief, mixed feelings, anxiety, always with me, being a burden, and frustration. The second subtheme, *Behaviors to help me get through it,* includes maintaining normality, doing everything I can, using social media, turning to faith, making choices, worrying about others, enjoying life, grieving, and becoming an advocate. This theme provides a deeper understanding of the complex process of coping and involves a multitude of emotions and behaviors.

Subtheme 4a: *I have many different feelings and emotions.* The experience of *Getting through it* is one that encompasses the many different and conflicting feelings experienced by young women living with advanced breast cancer, which range from devastation to gratitude. This subtheme supports the complexity of the experience and illuminates areas that may be amenable to supportive care interventions.

Being overwhelmed. All of the participants described feeling overwhelmed at different times while living with advanced breast cancer. Sarah described many different emotions that all contribute to feeling overwhelmed:

> *And it can get overwhelming. But it's really hard to just try to focus and try to stay positive. I'm very fortunate, sometimes reading the support groups and being in the support groups does more harm than good. Because you feel for everybody and you understand what everybody's going through, and then you feel guilty for feeling fine when you kind of know what's coming. It's not just scary. It's all the anxiety attacks of how I'm going to die. It's scary in itself.*

Liz had recently learned she would need chemotherapy as her disease had progressed. As a result, she had decided to leave her job. These changes came without warning and had a significant impact on her daily life. She described feeling overwhelmed at the speed at which changes were occurring:

> *Things just kind of progressed a lot faster than what I was planning for. It's just overwhelming, and knowing that I'll probably never have—I'll never work again. Right? It's just kind of that finality of "Oh, crap. I'm done." I don't know. It's almost like it's one step closer to being at the end.*

Feeling overwhelmed occurred at the time of diagnosis and at various intervals thereafter. For those who had been diagnosed initially with early-stage disease and hoped for cure, the diagnosis of metastatic disease was unexpected and incredibly difficult. The awareness that the focus of treatment for the metastatic cancer was no longer of curative intent was shocking for some. For Mary:

> *It was overwhelming. And then I got really—I wouldn't say angry—frustrated, because it's like, those are the things that you did because there is a chance that you're going to get better and you did them. But I'm not going to get better.*

Devastation. Feeling devastated was also common and could come at expected and unexpected moments. These feelings might arise unprovoked in the ordinary moments of daily life when the reality of the situation became more real. For Dina, her initial diagnosis occurred when she was in her 20s:

> *I mean, we would just have days where we were devastated and depressed about it. "Oh, my gosh. I'm going to die before ...." And he would say, "Oh, my gosh. I'm going to be a widower before I'm 30." We weren't even 30 yet.*

Liz acknowledged that her age and where she was in her life in terms of career, family, and relationships made the experience even harder. This is an aspect of this phenomenon that has not yet been well described and is discussed in more detail in Chapter Five.

> *I think that living with metastatic breast cancer is nothing—it's not rare. But most people don't know anybody who has it. So I feel like there needs to be more education or more info, or more attention drawn to metastatic breast cancer. I mean, it's devastating for anybody, obviously, but it's really difficult when you're young. And when you're just starting your career or if you're just starting your marriage or you're trying to have kids. It's such a different world when you're young. And I think a lot of people don't understand that, which is a good thing, obviously. I mean, I don't want people to have the disease. I don't want people to have to deal with it. But I think there needs to be more, I don't know, there just needs to be more outreach, more education, more emphasis, just more about the young people who do get breast cancer.*

Worry. All of the participants talked about feeling worried. For most, worry was with them all the time. Worries ranged from thoughts of recurrence and disease progression to effects on loved ones and future concerns. Many, including Mary, worried about those around her:

> *I'm worried about everybody else around me.*

Liz worried about her husband, her son, and her parents, but didn't say much about worries for herself:

> *It sucks, obviously. So at first, I was really concerned with my husband and how he was going to deal with it. So I was obviously really concerned about my parents as well, how they were going to deal with it. And I have a son who is going to be 8 in November. I was concerned, obviously, for him. We haven't even told him yet just because it hasn't really gotten to that point where he really needs to know. So in the beginning, it was really—I'm worried about everybody else around me.*

She worried about her son and if she would be remembered rather than really thinking about what it meant to her.

> *I really haven't taken the time to just sit down and think about the impact that it's having on me. You sit, and you start thinking about "Well, is my kid—if I die in 2 years, it's like Is he going to remember me?" You know?*

The nature of worry changed with the transition from early-stage breast cancer to metastatic disease and brought awareness that things were now very different. For Joan, the awareness of a potential rapid decline and death was very real:

> *Being an early-stager, I have friends who have gone to stage IV and died within 6 months. I was always afraid of getting to her stage* [stage IV] *because you do think, Am I only going to live 6 months?" Or "Am I only going to do* this*?"*

And for Sarah, a young mother with four small children, it was much more straightforward initially when she was an early-stager.

> *I've taken a different approach to stage IV. Because* [with] *the stage II, I always thought, "Okay, I just got to get through treatment and I'll be fine." It's just a little bump in the road and that'll be my history, and it will be something we talk about later on in life. Then, of course, I was always very worried that it would come back, kind of always in the back of my mind.*

Depression. Most of the participants talked about having feelings of depression. The intensity of depression ranged across participants. Sarah tearfully described the depression that consumed her when she transitioned from early-stage to metastatic breast cancer:

> *But this time it is very scary; there wasn't a light at the end of my tunnel and I've been consumed. I was consumed, and of course, fell into a crazy depression. I was on my phone 24 hours a day, trying to find research and options and inspirational things. Anything. But all I could find was negative. Not what I wanted to hear.*

Dina, who felt relatively well, acknowledged how much harder the emotional aspect of living with advanced breast cancer was when compared to the physical aspects:

> *I mean the physical stuff is hard, sure, but I mean, the emotional stuff that comes with the physical stuff is kind of harder. Most days I'm fine emotionally. I can handle life, and then when the physical stuff hits, I go "That's right, I have stage IV cancer, okay." And I get kind of, I mean, depressed, I guess.*

Despite expressing these feelings, it was apparent that very few of the participants had sought care or support to help with the feelings they were experiencing. Some did not know where to begin to seek supportive resources while others felt they didn't have the time to try to figure it out.

Gratitude. The complexity of feelings experienced by participants ranged from being very hard to manage to more positive and for some, gratitude. Mary described her gratitude for feeling as well as she did despite having a terminal diagnosis:

> *I'm thankful. I'm so thankful that I'm feeling so good. It sounds crazy because it's terminal cancer, but I guess, it is but it is. And there's nothing I can do about it.*

This was an observation that I also noted in the interviews. All of the participants had moments of tears and sadness during the interviews and all but one also expressed laughter at times. The range and intensity of emotions was very powerful. Several acknowledged that being grateful for something in the midst of their lived experience helped them in their daily life. Sarah had the most difficulty during the interview, frequently wiping the tears from her eyes and face as she spoke. She became more hopeful as the interview progressed, and she reflected on the hope and comfort her faith provided her. Joan expressed gratitude for the things she did have and for the opportunity to create memories for her children:

> *So I try to look at it, as jacked up as the whole situation is, I look at it as that we all have a born day and then a death date. And as cliché as it is, it's living. Just being grateful for the things that you have, trying not to dwell on the things that you don't, just creating those memories and having family around.*

Inez was grateful for the support and care she received:

> *So I'm so grateful for all the people who have helped me and just kind of stepped in. So, yeah. So, yes. I've always been on the positive side looking for the good and that kind of stuff.... I'll go to church and stuff. Pray. Pray every night. Thank God for another day on this Earth.*

Participants also expressed gratitude for their participation in this research study. They expressed that having the opportunity to share their story was therapeutic and that it also had several benefits for them. One participant spoke of the therapeutic benefit of using the journal and how she has now incorporated daily writing in the journal. Several expressed relief that others were experiencing similar feelings and physical effects and that made them feel less isolated. All expressed their appreciation I was doing this study. For Laura:

> *Oh, I appreciate it, and I really love that you are doing this study. I think that it's really important. Any study about any disease that anybody can have that's going to kill them is important. It's so very important. So I really love it that you're doing this.*

Inez expressed it this way:

> *Thank you for allowing me to be a part of this and share my story because, like I said, as much as I can, I try to share as much as I can so I can help another Inez, like I was 11 years ago.*

Joan had this to say:

> *I don't feel crazy now for pouring sweat and then being freezing and then having the pain and stuff like that. I hear it in the groups and stuff, but it's hard to pinpoint to a Facebook picture how old people are. During the study, I hear it from you and I'm like "Okay. I feel much better."*

Relief. Several of the participants expressed feelings of relief about aspects of their diagnoses. This was unexpected. These aspects included having information to better understand where they were with the disease, pain relief, and the knowledge they were well cared for. For Joan, the knowledge that she no longer carried the worries about progression was a relief in an ironic way:

> *It's almost like a relief being here. Because I was at an early stage for 3 years, I was so petrified that every ache and pain and wince meant more cancer. So, I guess, messed up as it is in this whole situation, I guess I'm relieved that I finally got here… The end of December will be a year, and I responded really well to chemo.*

She also described that relief came in knowing she was being well cared for as a person with metastatic disease:

> *For me, it really didn't change my mindset because I was always going to be under something. So it wasn't a big shock to me or anything. It was actually almost kind of comforting. Because as my appointment started going farther and farther out, I almost was like "Are they breaking up with me?" I know this is part of the process, but I always had that comfort of being under care and knowing my body better than other people know theirs.*

Mixed feelings. Several participants talked about the range of emotions they have experienced as a young women living with advanced breast cancer. They were aware that emotions often fluctuated based on what was happening in their lives and yet at times they could also be experiencing several emotions at the same moment. Joyce experienced a mixed bag of emotions when she finally started treatment for her metastatic breast cancer and started to feel better:

> *So I mean it was really a mixed bag. It was also somewhat of a relief, I think, because when you're that incapacitated, to have somebody say "All right. This is what's wrong with you. And now we're going to do this. And it should make you feel better." You're just like thank— no matter how bad the diagnosis is, if the treatment's working on a certain level, you do feel some sort of relief at that point too. So I would say that was also a big part of how it felt once I started treatment.*

For Joan, the experience of living with metastatic disease and embracing life was bittersweet; she noted feelings of gratitude and sadness at the same time:

> *So I'm a big one to embrace all these little things. So I did take it all for granted before my cancer. So this is something that is bittersweet and grateful, but sad at the same time.*

The pink ribbon campaign to raise breast cancer awareness and funding can also bring mixed feelings, especially for women with breast cancer who perceived that most of the outreach and research has been aimed at the early-stage population. Mary explained how she felt about it:

> *I've got really mixed feelings about the whole pink ribbon thing, being a metastatic patient. I think, with any metastatic patient, it's sad. It's really, really sad because there is no cure. But on the other hand, it's all I think about. I could talk about it all day every day. This is all I think about. But, I think, people are very hesitant to ask about it. Not wanting to bring it up kind of thing.*

Anxiety. Another emotion common to most of the participants was anxiety. The sense of anxiety was more vague than identified worries. For Kate, living with metastatic disease, working, and caring for two small children, anxiety and difficult thoughts were with her most of the time:

> *I don't know. Some days my anxiety levels are just higher than others, I don't know. Subconsciously, in the back of my mind, I think about it more. Stuff. Worst possible outcomes, I'm thinking of those more. I think. Today I stopped at the pharmacy to pick up my prescription and it was more costly than I expected and anticipated. So then I had a bad afternoon because I was upset to find that I had to take this medication and it's so expensive—and then I just get angry. It turns into a bad day.*

Others talked about their experience with "scanxiety"—their experience of anxiety around scans and waiting for results. For Mary, having scans every 3 months and then waiting for results was not easy:

> *Well, it's scanxiety. We have scans every 3 months, and it was really hard for me. I had them last month, and my tumor markers have been going up, which are not necessarily a dependable indication, but they were pretty kind of steady, very slowly dropping. And then they kind of started creeping up a little bit. I have my scans on Monday and Tuesday. Well, then you have to wait until Friday for the results, and I was a wreck.*

She also described the effect her "scanxiety" had on herself and her children:

> *And, I guess, I do pretty well until this last time I had scans and it was just like, oh, my gosh! I was more anxious than I thought I would be. I had a really hard time that week waiting and so then I'm on edge. So then my kids, obviously, see that or kind of sense that and then they are kind of off. And it just made for a really long week."*

Always with me. Living with advanced breast cancer is also living with the knowledge that it is always with you. This experience has no end for women with metastatic disease. For Joan, that awareness was with her from the moment she woke up until she went to bed.

> *And from the moment I wake up to the moment I go to sleep, there are very few moments when I'm not thinking of it.*

Most described how they kept their thoughts to themselves in order to protect their loved ones from worry. Very few acknowledged the opportunity to share their feelings with a provider or counselor.

Being a burden. Most of the participants described feeling as if they were a burden to their loved ones. For Sarah:

> *I feel like I'm doing a lot of destruction toward my family, that I'm doing a lot of hurt for them, both emotionally, physically, financially. I feel like a burden.*

Kate also kept her feelings to herself to protect her husband and mother:

> *I mostly keep to myself. I feel like a lot of times, I'm the type of person that doesn't want to upset anyone else. So if I talk about it with my husband, I feel like I'm going to get him upset or, if I talk with my mom, I don't want to get her upset. I just kind of keep to myself.*

Laura spoke of keeping feelings to herself to protect her loved ones but acknowledged you cannot keep them to yourself:

> *Do you unload this stuff unto your spouse? Do you unload this stuff unto your mom or your family? No, because you don't want to burden them, but you can't keep it to yourself because if you do, you go crazy.*

Several expressed worries about the burden their illness has caused to the family. Two participants spoke of giving their husband permission to leave them to make their husband’s life easier. Sarah, was willing to sacrifice her own feelings for the greater good of the family:

> *I'm kind of forced to be a burden. I already know I have a burden and I kind of feel like "Well, I'm wanting to release you all from my burden," and then you've got that guilty conscience that you're still hurting them. And that shouldn't even be a concern; my kids should be focusing on after-school activities and extracurricular activities.*

Frustration. Feelings of frustration were common among participants. Frustrations ranged from disease- and treatment-related concerns, to people not understanding what metastatic disease means, to “pink-washing” (support of breast cancer by promoting and selling pink ribbon and “pink” products) and planning for the future. Sarah, a young mom of four, described the frustration of being forced to do things on her bucket list and then live with the knowledge of why her plans had been accelerated:

> *It's frustrating that I'm kind of having to live out on my so-called bucket list items right now, and then kind of not knowing if I'll be able to come back and do this again. You almost can't even enjoy it. So it's definitely a catch or a double-edge sword on that. You plan it, so that you can make these memories. But then, you know why you're planning. You're not planning it to just enjoy yourself and just to go on vacation; you're planning it because you know that you won't be here years later.*

Subtheme 4b: *Behaviors to help me get through it.* All participants spoke about how they coped with their experience of living with advanced breast cancer. Behaviors included maintaining normality, doing everything I can, using social media, turning to faith, making choices, worrying about others, enjoying life, grieving, and becoming an advocate.

Maintaining normality. For many of the participants, trying to keep things as normal as possible was important for them as individuals but also for the life of the family. Keeping the children on schedules, encouraging them to continue their extra-curricular activities and finding time to volunteer or socialize in the community were identified as some of the ways to keep things normal. Many were physically feeling relatively well and said that planning rest periods prior to anticipated events helped them be able to participate. For Joyce, it was the sense that she was living a normal life while also living with metastatic breast cancer:

> *It's nice to be able to, in the greater realm of the world, at this point, live as much a normal life as possible.*

Did everything I could. All of the participants talked about their desire to do everything they could in terms of treatment. As Joan said:

> *I've done everything now; now it's just up to my body. And hopefully, I've done everything that I could.*

For most, this was motivated by concerns for their children and the desire to extend their lives as much as possible. For Amy, this was not a choice, and her decisions carried a heavy responsibility.

> *And just wanting to make sure I'm doing everything right, and the extra pressure of having to make sure I'm here for the kids is also—it's a very heavy responsibility, I guess. It's just doing everything I can. I don't have a choice. I really don't. I can't give up. I can't stop. And that's a good thing. It is definitely a good thing that they're here to push me, because I would have given up already. I would have.*

Social media use. The use of social media was described as a beneficial tool and resource utilized by many of the participants. It was used in many different ways: creating blogs, finding support, offering support, learning more about disease and treatment, and increasing advocacy efforts. Blogs about personal experiences were a source of support for several. For Inez, the opportunity to share her story and get feedback, particularly on difficult days was especially helpful:

> *I mean, telling from day one I put everything out there on social media about myself, and it's so uplifting. I'd be having a bad day and I would just post something, and within 5 minutes, I have all these "You got this,* period*, We're sending prayers your way. Let us know how we can help" kind of thing. And it's just kind of nice that they help me kind of refocus and stay positive and stuff.*

She described her blog as a source of support:

> *I have a blog that I don't keep up with much, but when I'm feeling really down or feeling like I need to write something important, then I will write that out and share with my friends. And I always get good feedback. And I'm a very avid Facebooker, so most of my thoughts do not go unspoken.*

Others used social media for support in the form of online groups. Most did not know anyone in their situation, and they felt very isolated. Finding support from the online support groups was very helpful and decreased their sense of isolation. There was also flexibility in terms of the timing so they could reach out for online support on their own timeline, better accommodating their daily life. Laura described feeling isolated and found support from an online group:

> *So, yes, it's things like that where you wouldn't—because you're isolated, especially a young cancer patient. You're pretty isolated. And those online groups help that.*

Others also used social media as a way to reach out and help others who may be in a similar situation. The opportunity to be able to give back and help others was an important aspect identified by several, including Inez:

> *I don't only do it for myself, but there could be—my neighbor who's on my Facebook friend's page and she's just starting this journey, you know what I mean? So if someone could see it and either reach out to me for a resource or something like that. I mean, I probably get three to four messages through Facebook or text messages a week saying "Hey. My mom was just diagnosed" or "I was diagnosed. Where do I start? How do I begin?" You know what I mean? "What resources are out there for me?" And I love it. I mean, I love being able to help others and just kind of be a resource for them.*

And for Liz, social media provided her the means to raise awareness about young women with breast cancer:

> *I do like talking about it. Even back in 2012, when I was diagnosed, I started a blog. I'm very open to talking about what has happened and what is happening because I think it's very important for people to see that this doesn't just affect older women. It can affect young ones. And when I was diagnosed, nobody in my entire family and my circle of friends had ever known somebody at the age of 33 to get stage II breast cancer.*

Turning to faith. Most of the participants identified a religious tradition and engaged in spiritual practices. They acknowledged the importance of their faith in living with advanced breast cancer. For Sarah, her faith helped her get through it:

> *I never questioned my faith about my situation. I don't blame my faith in my situation, but I look toward my faith to get me through it.*

Others expressed a sense of comfort and strength from their faith. Maria described her approach to treatment as a faith-based approach and used her illness as an opportunity to evangelize in her community and through social media. She also described how her faith grew in the midst of living with advanced breast cancer:

> *I just kind of cried out that I—I don't want to leave now. I want more time. But I think as I'm going through this process, my faith has grown a lot. I'm a really strong Christian. I really believe like this is an opportunity for me to step out and share with others what believing in faith does in the midst of a circumstance that could be fearful. And I think that we all have a story. Right? And if you like, this experience just kind of shows me that you just don't know what other people are going through.*

For Amy, a mother with three small children and struggling with disease-related symptoms, her faith sustained her and gave her hope in the midst of so much uncertainty:

> *My faith. I'm a Christian. I've always believed that there's a lot of people out there who say "Why does God let this happen?" I don't know why God lets it happen, but I do believe that he walks with me. And that no matter what ends up happening or whether I continue to live for 50 more years with cancer or whether I take a turn, and I die way before that, I know that when my time here is over, I have somewhere else that I'm going. That when my time here ends, it's not the ending. I won't just end.*

Liz shared that she and her young son pray together every night:

> *But before bed he and I will pray and he will pray that Mommy's cancer is gone.*

Dina shared a conversation about faith she had had with her 10-year old daughter where she acknowledged that we also need to have a sense of faith in general about people, life, and living life:

> *I think faith helps a lot, and not just speaking about God in general. I'm always telling my daughter—I went and got my last scans not that long ago, and she was upset going to school and I said "You know, you've got to have some faith." And she's like "I believe in God." I'm like "No, no. I mean that's great, but faith. You got to have some faith. You have to believe it's okay. You have to believe it'll be fine. You have to have some faith. And I think that helps a lot if I get down and I'm like "Ugh, this sucks," or, "This is really hitting me hard.*

Trying to find control. The reality that so much about living with advanced breast cancer is out of one's control was a hard reality for many. Finding ways to deal with their feelings around loss of control was important. For Amy, this involved sitting down and praying for help:

> *There's a lot that—my mind spins all the time, "Okay. What if this happens? What if this happens?" And sometimes I just have to sit down and just pray and say "All right, God. Reset my brain. I can't think about everything. There's nothing I can do about this so let's just put this on the back burner for right now. Let's focus on the things where there's something I can do." And that's kind of how I try to get through it. If there's something that I can't control, then I really tried to just kind of not think about it too much and just kind of move onto the things I think that I can have some kind of control over.*

For Sarah, the support of her husband helped her when she was feeling overwhelmed with worry about things she couldn't control.

> *And there are times I can't get myself to do that, so my husband has to step in and say "You can't control that, so quit worrying about it. There's nothing you can do about that right now, so let's not focus on that." And usually, after he tells me that, I can sit there and finally kind of get past whatever's going on and move on to the things that I can control.*

Joan had a very practical approach in how she dealt with her lack of control.

> *Or if I get too focused on how long am I going to live, I just will take everything out of the closet and just completely organize it. Because if I can't control it, I can't control that part, at least I can control the cleaning aspect of things.*

Inez, who had been living with metastatic disease for more than 10 years, found that her control came from making choices about how she was not going to let cancer control her life.

> *And then, just before—kind of like a week before I had graduated from cancer, I woke up with terrible side pain. And to make a long story short, it was cancer in all of my body, and I'm going through kind of the rough chemo and treatment again….You wake up every day with a choice. And say you can either put on your cowboy boots….Or you can, like cancer, kind of take control of your life….And basically, your choice is of putting on your boots or letting the cancer control you. And then your attitude is a big factor in whether you choose to not do much with your diagnosis or do as much as you can to help others.*

Worries. Dealing with worry was the behavioral response to worry that was acknowledged by all in their experiences of living with advanced breast cancer. All expressed worries about many of the different aspects of their life and including disease- and treatment-related concerns, impact on loved ones, and uncertainty about the future. Most worried about those they loved, with less emphasis on worries about themselves. For Liz:

> *So really it has been worrying about those around me, not necessarily myself. I really haven't taken the time to sit down and think about the impact that it's having on me. You sit, and you start thinking about "Well, is my kid—if I die in 2 years, it's like you're going to remember me?" You know?*

One way some dealt with their worries was to keep them to themselves and not share them with loved ones. As Liz described it:

> *I guess I don't talk about that worry with my parents because—I mean, we did kind of talk about it, but my Mom, and she's the opposite of me. "You need to think positive. You're going to be one of those people who live for 20 years, not 5 years."... So in trying to have that kind of conversation with my Mom, she doesn't like me thinking about "Okay. So I need to figure out my will. I need to figure out my trust," that kind of stuff. She's like "I don't want to hear about it. You don't need to deal with that." And I'm like "I do. Even if I wasn't in the position I am now, I still need to figure that kind of stuff out."*

During the interviews, it became clear that the inability to share worries and concerns was to protect others from the reality of the experience. Some acknowledged that their inner thoughts were hard to put into words and sharing them they might cause their loved ones more distress. One is left then to consider the emotional burden of suffering in silence when it comes to not sharing these very private concerns.

Enjoying life. On the other hand, the awareness of an uncertain future was a motivator to enjoy the ordinary and extraordinary moments of daily life. Focusing on the day or the short-term future was one identified action that many acknowledged was important in helping them to cope with their illness. For Linda:

> *I mean, I think the whole "Life goes on" thing is a big part of it. If I knew I was going to die in 2 weeks, maybe I would have a different plan, or perspective, or routine, but I don't plan on that. I just keep—I do as much as I can. Rest a little more if I have to, but staying busy and doing the normal things is what makes you—I don't know. It gives you some normalcy and sense of control. Like "Oh. I can still get up and go to work, and act like a perfectly normal person, and just live." Not just survive.*

Joan focused on enjoying life and not stopping it for cancer:

> *You know what? I'm not going to stop my whole life. I'm going to live my life. I'm going to enjoy my life."*

She also found she wanted to become more fully engaged with others and fully appreciate all of the aspects of daily life:

> *I think it's also I'm trying to get so much more out of my life now. I'm trying to do more things. I'm trying to want to converse with people. I'm trying to really get—when they're asking me about—like our conversation, I'm trying to get out as much information as I can because you never know. So it's like this life is very valuable, which a lot of people take for granted.*

Dina, described having good and bad days. She went on to explain that she sometimes had days when she even forgot she had cancer:

> *When I had my appointments and my scans, and—or if it's a day that I feel really poor, the kind that hits me in the face a little bit. And those are the days that it's a little worse. But if I feel great, I mean, my husband laughs at me but he'll come home, and I'll say "I forgot I had cancer today." And he's like "You did?" And I'm like "Yeah. It was great." And those are the best days, you know?*

For Joyce, enjoying life also included remaining hopeful:

> *But with everything that happened surrounding my diagnosis and having my mobility essentially taken away for a long period of time, I was able to let go a lot, which has been really freeing on a certain level. And it's nice to make plans and to look forward to things, obviously. I mean you might be able to speak to this more than I can, but like hope is what keeps a lot of people going, I think. When they have things to look forward to. And so I think it's important to maintain that. But also, on the other hand, it's a lot if we can do this now so let's do it. It's less about planning for the faraway future and more about seizing the moment if we can.*

And for Linda, it was noticing a changed perspective where she became focused on enjoying as much as she could in the present:

> *And it's just a more mature perspective that, this is life. This is what it is. We'll keep fighting as long as we can but you just can't ignore it completely. Living with cancer is a part of my life. So what you can really do is enjoy your moments now. And again, I'm saying this from a perspective of really strong hope because of my situation.*

Grieving process. In the experience of living life with advanced breast, Dina acknowledged grieving as also part of her coping. She was grieving for lost hopes and dreams while living with the awareness of what she will ultimately die from. This awareness gives an enhanced appreciation of mortality and the value of each day.

> *I'm drawn to people who have had a big loss in their life, like the loss of a loved one. I realized that the friend that I enjoy talking to the most lost her fiancé last year… And I realize she understands me so well. It's amazing how well. And it made me think about how this is all kind of a grieving process for myself. I'm always thinking over my own life. It's interesting…I don't know. I appreciate that you've been doing this because it's also given me a different perspective…. I just think it's the mortality. I think that everybody knows they're going to die. But you know what you're probably going to die from and it's going to happen sooner rather than later than what you thought, it's just a different thins. A lot of people can't relate to that. I mean, I think that's why I relate so well to people who've had loss in their lives. I feel like when you have lost someone in your life like that, you get the understanding that life is short. You're not going to be around, and it's different.*

Becoming an advocate. Living with advanced breast cancer awakened a desire for advocacy among several of the participants. This was an active response to the desire to take charge and become a voice for the cause and raise awareness about metastatic disease. Most acknowledged that prior to their illness, they would not have described themselves as advocates. For some, this desire developed after becoming more aware of the limited education and research for advanced breast cancer. This was particularly striking during some of the interviews that occurred in October, a time known as breast cancer awareness month. Several verbalized frustration that October didn't apply to them, feeling it was more focused on women with early-stage breast cancers. Dina acknowledged that she "hated" October:

> *I've been trying to make friends and to advocate. And I hate October. But October has been keeping me busy to the effect of—just there's a lot in the metastatic community right now of trying to change the conversation for October. And so I've been focusing a lot on that this month. And reaching out on social media to people going "Pink this and pink that." And going "Hey, this is the real issue. Let's focus on this…if your pink is going somewhere that means something, great. If not, then why are you doing it?*

While for Joan, the month of October became her opportunity to start conversations with people about metastatic breast cancer:

> *It's hard not to talk about it even with complete strangers. And October is easier because I feel like I can educate people on purpose. "Hey. So it is breast cancer awareness month and I just want people to know that you can live and go around with stage IV cancer and still be a part of life. It doesn't necessarily mean a straightaway death sentence although it is underfunded." And then I can talk about why we need more resources there and—yeah, it is hard.*

Efforts for some were focused on raising awareness and hoping to make it better for those who may develop this disease in the future, including Dina:

> *Yeah, like "What? How did you not know that?" And a lot of people, "I didn't know around 113 people die every day." I'm like "Yeah. This is the truth. Let's have a little reality check here." So it makes me feel good to get out there and get the facts out there. I mean, if I die from this in the next few years or whenever I do, I want the people who follow, that get this stupid disease, to not have to do the same thing. You get the conversational change, maybe it'll be different and maybe there won't be so much of it.*

Not all were able to engage in advocacy efforts. Joyce acknowledged that given the ages of her children and her need to focus on them, she didn't have the desire to sacrifice time with her family:

> *And I think that if I were older and my kids were older, or if I were a single person who didn't have to take care of my kids, I might be more in that group. But I'm just not willing to sacrifice my family time right now for the activism on that level.*

The theme *Getting through it* focused on the elements of coping with advanced breast cancer and included both emotional and behavioral components. The subtheme *I have many different feelings and emotions* included being overwhelmed, devastated, worried, depressed, grateful, relieved, mixed feelings, anxious, always with me, being a burden, and frustrated. The other subtheme, *Behaviors to help me get through it,* included maintaining normality, doing everything I can, using social media, turning to faith, making choices, worrying about others, enjoying life, grieving, and becoming an advocate. Maintaining a sense of control and living life intentionally to maximize experiences were important aspects of this major theme.

Major Theme 5: *Being connected to others*

Included in the theme *Being connected to others* are four subthemes that describe different aspects of this major theme: (a) *Finding someone like me,* (b) *Feeling the support of family and friends,* (c) *My healthcare team, and* (d) *Lost relationships*. This theme is defined as the experience of being in relationships with others, the desire for new relationships, and changes in relationships that may occur in young women living with advanced breast cancer.

Subtheme 5a: *Finding someone like me.* Most of the participants expressed feelings of isolation. This was the result of not knowing anyone who was living a similar experience of having cancer and being young with children. Several had met older women with metastatic disease but felt they could not relate to them. Kate, who was 33, spoke about how different life was for a 60-year-old, when compared with one in her 30s:

> *I think the only thing that could maybe change is, like I said before, finding a support system. Maybe being able to set you up with somebody. To set you up with somebody that can help you. I know they have—I mean, there have been offers to be able to do that before but, like I said, it's different I think when you're 30 versus when you're 60 and your children are grown up. In the same age group, I guess.*

Others knew of younger woman with early-stage breast cancer and felt the circumstances were entirely different and not relatable. For Dina, she would never have the experience of "ringing the bell" at the completion of treatment:

> *I'm just waiting to just find somebody just to connect with and—and there are a few women in town who have been supersupportive who have breast cancer, or going through it. One woman just went through it for the second time, but again you know it's just—I believe she's like Stage II C and she just finished radiation and all is good, and it looks like they got it all. Superhappy for her. I am very genuinely, honestly happy for her, but it's hard because I'll never ring the bell. I'll never feel that. Feel that relief and joy that I'm done with treatment and this is over. And so to find somebody else who's in that same situation, I'm—hoping though it still happens and I can find a friend.*

The disappointment of not ringing the bell further isolated Dina, and raises the question "are there other aspects of the healthcare experience that unknowingly create isolation?"

Subtheme 5b: ***Feeling the support of family and friends.***

Husbands. All of the participants were married with husbands. The role of the husband in supporting these women varied from one to the other. Most acknowledged their husbands as very supportive and that they were their primary supports. Two participants gave their husbands permission to leave them because of the intensity of the experience and the ways it had changed their lives. Sarah was amazed and grateful that her husband chose to stay. She acknowledged that sometimes it is just so hard and was unsure if she always handles things the "right" way.

> *I would not blame him if he left, because this is a nightmare and he's living it. He continues to live it with me and that's just amazing. And I think it speaks volumes of his character because he doesn't have to, and I've told him he doesn't have to. I've had a legit, not angry, just real concerned conversation with him that this is really hard on me. I don't know how to handle it at times, and I don't handle it the right way a lot of times. So I wouldn't blame you, I wouldn't be mad at you. And just quite honestly, I've told him to leave. I've pushed him away, in a negative approach. I've pushed him away quite a bit and he still stuck around, and I'm forever grateful for him.*

Dina and her husband have had some difficult conversations about the way their lives have been changed because of her cancer diagnosis. She tearfully explained:

> *Oh, it's rough. It's really rough. And being in a marriage is rough too. My husband, the other day, he said "This sucks. This totally sucks. I'm tired of this." I'm like, "I'm tired of it too. What do you want to do? Get a divorce?" He's like "I don't want to divorce you." He's like "But it sucks." I'm like "I know." I can't help that. And it's rough not being able to help him and my daughter. I've always been able to help them, able to help them solve their problems. And this one I can't help with. And yeah, it's rough.*

For Laura, currently being treated with neo-adjuvant chemotherapy for Stage III breast cancer and caring for two small children, described how unprepared she was:

> *Nobody tells you "Look, this is an emotional sh** storm. You're not going to be able to talk to your husband." Who are you going to talk to? Somebody needs to be real about it. The nurses are like "If you feel like you need to talk to someone…" I don't know, I just feel like it's—there needs to be more support for the individual patient from the outset.*

Family and friends. Relationships with family and friends were an important part of the experience of living with advanced breast cancer. For Amy, knowing that no matter what happened to her, her children would be supported and cared for, helped to lessen her worries and provide reassurance.

> *I have such a good family, such a good support system that I know that if something does happen too, my kids are going to be taken care of. That I don't have to worry, "Okay. Is someone going to teach them this? Is someone going to teach them this?" Because I know that there are people that are going to do that. And so, I mean that really helps out.*

The importance of these relationships and support provided were very helpful. Yet, on the other hand, the support could sometimes feel overbearing. For Mary, who worked as a hairdresser and had two young daughters, this was difficult and added an additional dynamic to the situation:

> *My Mom and I are very, very close. And she's a hoverer though, which is funny because that's not how she's always been. And she's constantly "You're working too much. You can't lift that. You can't do that. You need to go home and sleep." I mean, I get frustrated but at the same time I know she's right sometimes. But that's hard.*

While for Liz, the support was not always helpful. Difficult conversations and planning for the future were hard to do.

> *I mean, I definitely don't talk about that worry with my parents because—I mean, we did kind of talk about it, but my Mom, she's the opposite of me. "You need to think positive. You're going to be one of those people who live for 20 years, not 5 years." She's an optimist about this. So in trying to have that kind of conversation with my Mom, she doesn't like me thinking about, "Okay. So I need to figure out my will. I need to figure out my trust," that kind of stuff. She's like "I don't want to hear about it. You don't need to deal with that." And I'm like "I do. Even if I wasn't in the position that I am now, I still need to figure that kind of stuff out.*

Many were well supported and found comfort knowing their families were able to step in and help.

It takes a village. All acknowledged that additional support is needed while living with advanced breast cancer. This support often comes from family, friends and community. For Sarah, with four kids and managing treatment:

> *It really truly does take a village to help to take care of people with this situation. We rely on a lot of people: aunts, uncles, and cousins. Fortunately, we're surrounded by them in a small community, but we've pretty much leaned on everybody at different points, for different things, especially with having four kids.*

Inez found that people really meant it when they offered support:

> *Oh, supersupportive. I mean, there were times when people would drop off meals, and offer to do things with my daughter, and come and clean my house, you know what I mean? And truly mean it too. Not just say it, but truly, truly mean it.*

Kate was surprised to find that support came from people she did not know.

> *I'm from a smaller town, so the community was very helpful during all of my treatments, and a lot of people that I didn't even know were there for me. So that was helpful.*

For most, one of the hardest aspects of the support was acknowledging the need for it. Inez acknowledged that asking for help was really hard and she preferred to be the one offering to help. She used humor to acknowledge that help with food preparation was something she would freely give up.

> *So then, when I'm sick and asking for help or allowing someone to help me has been superhard because I've always just either done it myself or been the one to offer to help someone else. But when it comes to meals and cooking, that's the first thing that's coming out of my mouth because if I can get out of that, then* [laughter]—

Subtheme 5c: *My healthcare team.* Overall, experiences with the healthcare team were positive. There was acknowledgement that the relationship with the physician was important and one that would continue for an uncertain yet extended time. Few spoke of specific nursing experiences. Most recounted stories about their oncologist or surgeon. Dina spoke about her desire to be known by her doctor:

> *And then I see the doctor and she usually just kind of comes in like a whirlwind, and looks like the oncologist you would think of comes in. And I always have to slow her down. I don't know if she has too many patients, or if she's forgetful, or what, but she always looks through her notes while I'm there and I always think "Why don't you look through your notes before you come in here and act like you remember me?" You know what I mean?*

Several identified the need for more supportive services. Most had not met a social worker. Several expressed concern about not knowing how to talk with their children. Some felt very comfortable having the conversations, but others did not. Kate, whose son was 4 when she was initially diagnosed with early breast cancer, found she was struggling to explain her current metastatic situation to her son who was almost 8. The “easier” explanation that had occurred at her initial diagnosis was now more complicated as her son had begun asking more questions. In the midst of her neo-adjuvant treatments, Maria was finally referred to a social worker when she told her nurse about her son’s behavior, not sure if he was acting out because of her illness:

> *I guess the only thing would be that I didn't have anyone to talk to me about how to talk to my kids. Everybody asked me, "Do your kids know?" Or whatever. But they didn't have a social worker come to talk to me until I was telling a story to my nurse about my son kind of acting out and I wondered if it was because of that.*

Laura felt strongly about supportive care provided by a counselor or social worker. She came just short of saying it should be mandatory, but agreed it needed to be funded so that all had access:

> *I would say, the only other thing I can think of is I do think—not that talking to a counselor or social worker should be—it should not be mandatory, but it should definitely be free-funded, and free to the patient, and available in a way that works for the patient. So my hospital had a social worker, but she was performing so many different functions. She was great, don't get me wrong, but she was doing six jobs. I just think that almost every patient could*

> *benefit from talking to a counselor or social worker that specifically knows what the patients are going through. And the navigator is not that person. A navigator is going to be the person who knows the logistics of the medical care.*

Dina, living with metastatic disease, expressed the desire to be known and seen as a person by her oncologist:

> *When you have this thing, you have to have the care forever, I don't want to feel like a patient every time I go in.*

And as Laura pointed out, staff caring for patients may see some of this as routine, yet for the patient, nothing about the experience is predictable:

> *So to the people caring for the patients, all this stuff is routine. You have routine protocols. You have routine chemo regimens. You have a rubric for diagnosis. You have a rubric for staging. It's routine. But to the patient, their life has just been threatened severely with no warning, in most cases, and for a young patient it's even worse—the no-warning aspect is way worse.*

Being a young person with serious illness carries many additional complicating factors including the responsibility of caring for children that may not necessarily be on the radar of the healthcare team. Laura described that the logistics of navigating care in the face of a difficult diagnosis, while also caring for small children, was a nightmare.

> *I mean, if the onus is on the patient to navigate their own care, the patient is so compromised in every way by the suddenness and the severity of the diagnosis. Not just emotionally, the logistics of it, especially in young children; it's just a nightmare.*

Although less focus of the interviews was on experiences with the healthcare team, many identified areas that could be improved. These areas included the desire for a more humanizing experience, improved opportunities for support both for the individuals and their families, and improved access to resources.

Subtheme 5d: ***Lost relationships.*** Four of the participants spoke of the experiences of loss in their relationships. For two, it was the loss of the hope for future children. Joan was pursuing a surrogate pregnancy for embryos she had frozen before her metastatic diagnosis, while Liz, who had one son, considered adoption but in the end did not pursue it.

> *I was pretty sad about it. My husband really wanted to have another child as well, but that's just not how life worked out. It took us a while to get past that. We thought about maybe adoption, and then, that just kind of fell off the list, too. It is what it is. We have a son and that's what's important.*

Two others spoke of the changes in relationships with friends and how living with advanced cancer had affected their friendships. For Sarah, she was cognizant she had lost friends because people didn't know how to handle her diagnosis and that had put a strain on relationships.

> *We've definitely lost some friends. I know it's awkward for people. And, of course, we're not fun anymore. We don't go out. We don't drink. And that's fine. Quite honestly, I don't even care for friends. I have like one or two really good friends, but my focus has always been my family, my kids, and my husband. My best friend is my husband, so I'm worried more about them than anything.*

Dina was trying to develop new relationships because she had lost friends. She stated that some of her friends had disappeared because they were not comfortable accepting her new reality.

> *Been trying to make some friends because a lot of my friends kind of dropped off the face of the earth. I don't know if they were scared, they couldn't deal with the whole dying thing, or—I mean, not that I'm dying. But I know what I'm going to die from likely. I don't know if they could handle it or what, but yeah, I lost a lot of friends, some may still try to contact me occasionally.*

This theme highlights the importance of relationships across many aspects of life. The desire to meet and come to know another living a similar experience was an important aspect of this experience because without knowing others, it became very isolating. Participants experienced support from family, friends, community, and some whom they had never met. The extent of the support was overwhelming for most. Some struggled with accepting the support, yet often didn’t have a choice particularly if it involved helping with the care of their children.

Summary

The overarching theme and major themes presented here begin to characterize the phenomenon of young women living with advanced breast cancer. *Wearing the mask of wellness in the presence of life-threatening illness* captures the experience of appearing young and healthy on the outside while, internally, living with a potentially life-threatening disease and suffering in silence. *Wanting to be known as the person I am* provides an understanding of the essential aspects of being known as a person with a disease and a person apart from her disease. The subthemes support a better understanding of the desire to be known and what some of the challenges are. *I’m still Mom* reflects the desire to still be Mom despite the difficulties and challenges of this experience. The experiences of day-to-day living are captured in *Living is more than surviving* and reflect the multidimensional aspect of this theme. *Getting through it* reflects the emotions and behaviors of living with advanced breast cancer. And lastly, *Being connected to others* reflects the need for and challenges regarding relationships with others while living with advanced breast cancer.

Chapter Five documents a discussion of the findings in relation to what is known and not known, as reviewed in Chapter Two. Limitations of the study are described and implications for further research, practice, education, and policy are detailed.

CHAPTER FIVE

DISCUSSION AND IMPLICATIONS

In Chapter One, lack of knowledge about the experience of young women living with advanced breast cancer was introduced as the problem and research questions were identified. In Chapter Two, the foundation for undertaking the study, which lies in the idea that nurse scholars have responsibilities to further the goals of the discipline, was discussed. An exploration of what is known and not known about the experiences of this population also was described and existing evidence critiqued. Chapter Three detailed the method and why it was chosen to study this problem. In Chapter Four, findings from this study involving twelve participants from different parts of the U.S. were presented. The findings are the result of a phenomenological analysis of the interviews and journals. As a reminder, twelve women participated in the first interview, and eight participated in a second interview approximately 2–6 weeks later. Three participants wrote and returned journals, and six participated in a follow-up telephone call to review and discuss the findings. The overall meaning for these young women living with advanced breast cancer was interpreted as *Wearing the mask of wellness in the presence of a life-threatening illness*.

This chapter documents a discussion of the findings in relation to what was known and not known about the population of young women who are living with advanced cancer. Insights from the study are highlighted and related to the literature reviewed in Chapter Two and to the researcher’s prior understanding of the phenomenon. The discussion is organized in terms of the five themes, *Wanting to be known as the person I am, I'm still Mom*, *Living is more than surviving*, *Getting through it,* and *Being connected to others.* However, as noted earlier, the themes inevitably overlap with each other and are in some ways inseparable from each other and from the overarching theme. The limitations of the study are outlined next with recommendations for future study. Finally, implications of the findings for further research, practice, education, and policy are detailed.

Discussion of Themes

Overarching theme. *Wearing the mask of wellness in the presence of a life-threatening illness* was defined in Chapter Four as the dichotomy of appearing young and healthy to others, while being continually aware of the need to live with a potentially, or likely, terminal illness that will inevitably shorten their lives.

The experience of living for varying periods of time with a life-threatening diagnosis is not an entirely unknown phenomenon for persons; however, we know that the survival periods for people with advanced cancer are longer than in previous decades (ACS, 2015). The review of the literature, discussed in Chapter 2, demonstrated that existential, physical, and psychosocial needs were the foci of most prior research and that studies have begun to address some of the aspects of living with advanced cancer. However, none of these studies focused exclusively on the particular experiences of young women with advanced breast cancer within the contexts of their daily lives. The prior studies are important in that they support and begin to identify the ways that some are living with advanced cancer (Chen et al., 2014; Cleeland et al., 2014; DeSanto-Madeya et al., 2007; Novartis Oncology, 2014). Studies also have begun to identify strategies that people with advanced cancer use to cope with various aspects of their illness, and challenges that they face (Au et al., 2013; Back et al., 2009; Burles & Holtslander, 2013; Wise & Marchand, 2013). Other studies have highlighted needs for supports and resources (Krigel et al., 2014; Lam et al., 2014; Novartis Oncology, 2014; Trevino et al., 2013; Trevino et al., 2014). These findings augment the existing body of knowledge, as discussed below, and add new insights that would not have been possible without a concerted effort to understand perspectives of daily living.

The overarching theme analyzed from these findings, *Wearing the mask of wellness in the presence of a life-threatening illness,* captured the experiences of all of the women. The theme provides a view into the lifeworld of this cohort of women that has not appeared in the literature and, according to the women's accounts, is not well understood by clinicians. As a reminder, a lifeworld, is the whole context of a person's experiences as a conscious being and has four identifiable but interconnected dimensions. The four dimensions of a person's lifeworld are spatiality (living naturally takes place within a fluid space), corporeality (the world is experienced through the senses, which are embodied), temporality (over time), and relationality (connected in important ways to others) (van Manen, 1984; 1990).

This description of the meaning of the overall phenomenon adds to knowledge of what life is like for these women on a day-to day basis. The exploration revealed a heretofore poorly understood tension between how they are perceived and how they actually feel. On one hand, they desire to feel understood and known as one who is living with a life-threatening illness, yet on the other hand, they desire to be treated in a way that does not box them into the patient role. This has important implications for healthcare providers in terms of developing appropriate interventions, approaches, and interactions, as discussed in more detail under "implications." This was especially apparent in those who had been initially diagnosed with an early-stage breast cancer and were undergoing treatment. They "looked" like someone with cancer versus their experience of having metastatic disease where they looked "healthy."

The descriptions and experiences of participants "wearing the mask of wellness" while living with knowledge that the future is uncertain and will likely be cut short is a significant finding and one that merits additional research. This experience of "wearing the mask of wellness" contributes to their sense of isolation and aloneness. The five major themes that were found as aspects of the overarching phenomenon along with select subthemes are discussed next.

Major theme 1: *Wanting to be known as the person I am*. This major theme is the ambivalent and sometimes conflicting feeling of wanting to be known in all of one's complexity, including being known as an individual as well as someone who is living with a life-threatening illness. Nothing was found in the literature alluding to this particular finding, nor about the four subthemes and how they relate. Knox et al. (2017) spoke of an aspect of this experience in their identification of a sense of isolation experienced by young adults living with advanced cancer with the sense of feeling “lost and stranded” (p. 399). Incorporated within the major theme of *Wanting to be known as the person I am* are four subthemes: *Ambivalence about looking “normal”; Dealing with assumptions people make; Experiencing changes in being known between early and advanced stages;* and *Feeling isolated*.

Perceiving others as making assumptions about one’s physical or psychological health, as either a person who looks well or as a diseased person, is isolating because the lack of understanding of their reality can alter the way others think of these women.

That is, participants wanted to be understood as a person who struggles with managing an illness, because they did not always feel as if they could act in ways that match the perception by others that they were healthy. However, they also wanted to be known as individuals in all of their complexity and as different from their disease. They talked about how they now looked “normal,” as compared to how they looked in earlier stages of the breast cancer. At earlier stages when they had been undergoing “curative” treatments that had side effects of hair and weight loss, pallor, and fatigue, they looked ill. Whereas now they were wearing a façade of normalcy that could cause others to forget that they often struggled to live as fully as possible in the face of their diagnoses and likely prognoses.

The “mask of wellness” is similar to the metaphor of the “mask of ageing” where older adults note a disconnection between how they feel and how they appear. Rozario and Derienzis (2009) conducted a qualitative study that examined the metaphor of the “mask of ageing” in older adults. They found that most older adults in their study continued to see themselves as not old even in the face of advanced age with comorbid conditions. In this study of young women, they noted a reverse disconnection: they appeared young and healthy yet internally carried the knowledge of their advanced cancer diagnosis.

This major theme, *Wanting to be known as the person I am*, illuminates the multiple dimensions of the experience that stem from a desire to be known as someone living with illness as well as someone who is an individual apart from the disease. The desire to be known as the person they have become was felt strongly by most. However, they also experienced ambivalence about their appearance as well, having to deal with the implications of incorrect assumptions being made about them by others. This theme was consistent with the earlier work of Knox et al. (2017) who used a hermeneutic approach to understand the experience of living with advanced cancer. Their sample consisted of 10 young adult men and women with different cancers. All had advanced disease. Themes included feeling “lost and stranded,” and themes of being isolated, and having developmental and existential concerns. These themes resonate with those of the current study. The sense of isolation described by the participants in this study included the feeling that people did not understand them or their circumstances.

Their circumstances were seen as different from those who may have been older and yet living with advanced cancer. Most of the participants in this study did not know others in their situation who were managing households, small children, work responsibilities, and existential concerns related to their likely shortened life span.

While the findings of Knox et al. (2017) shed some light on the experience of living with advanced cancer, the heterogeneous nature of their sample makes it difficult to extrapolate to specific populations without further study. The current study supports Knox et al.'s findings by extending and refining the insights related to the specific group of young women living with advanced cancer.

The subtheme *Experiencing changes in being known between early and advanced stages* captures the change in attitudes of others, especially family, friends, and the community at large, toward them between diagnosis of early-stage cancer and later stages. During their earlier stages of cancer and treatments, they perceived that they received more attention and support. However, after being diagnosed with more advanced cancer, they perceived a lessening of interest in them especially over time. This finding supports those from a large European cross-sectional survey that included a total of 158 women with advanced breast cancer. This study explored the impact of an advanced breast cancer diagnosis on the psychological, social, and economic lives of women and their families. Half of the women reported they were viewed negatively because of their advanced cancer stage. They perceived therapeutic efforts and other resources as focused more toward those with early-stage breast cancer. Moreover, this perception led to the participants feeling isolated. Nearly two thirds reported being misunderstood and that others did not understand what they were going through, while nearly 40% felt isolated from others who didn't have advanced breast cancer (Novartis Oncology, 2014).

Participants in this current study also described a sense of isolation in relation to several aspects of their daily experiences and especially since receiving a diagnosis of advanced cancer. This reinforced the findings of the Knox et al. (2017) qualitative study of young adults with advanced cancer. All 10 of the participants described feeling a sense of isolation from their peers. They described this isolation as feeling they did not belong and were no longer understood by their peers. Rosedale (2009) conducted a qualitative study with young breast cancer survivors to describe the experience of loneliness for women more than 1 year after treatment for breast cancer. The findings revealed that the multidimensional nature of loneliness was experienced differently by participants. Factors that contributed to the experience of loneliness included the awareness of mortality, feelings of invalidation from others, an altered sense of identity and connection, and a change in their tolerance of distress. Many of these dimensions were identified by participants in this present study, further supporting the work of Rosedale.

Several of the participants in this study described themselves as having taken on an advocacy role in order to increase awareness about metastatic breast cancer.

I had not expected this but, after speaking with them, I could understand their desire to advocate for themselves and for others living with metastatic breast cancer. A lack of awareness on the part of the public, and even among providers, that this population of women exists and that they are living with advanced cancer was difficult for most of the participants in this study. Some even voiced that their non-oncology providers seemed unaware of many aspects of the advanced breast cancer experience.

The theme *Wanting to be known as the person I am* extends the work done by Knox et al. (2017) and Novartis Oncology (2014) in ways that are meaningful, providing important insights into the experience of young women living with advanced breast cancer. The subthemes further delineate the inner conflict that develops as one who is *Wearing the mask of wellness in the presence of life-threatening illness* and capture the essence of being unknown in the face of illness.

Major theme 2: *I'm still Mom*. Seven subthemes describe different aspects of this major theme: *It's so hard; Being a Mom still, What I can still do, There's not enough time, Being remembered, Searching for resources,* and *It's not easy for my kids.* This theme is defined as the desire to be the mom they were before diagnosis. They see the hardest part of being a young woman with advanced breast cancer is the fact that they are mothers. Being a mother is the first priority, but they are hindered in their parenting activities by physical effects, uncertainty about their future, and worry for their children's future. They also want to find supportive resources, create good memories, and protect their children from the collateral damage of their illness. It was clearly the most difficult aspect of the phenomenon of young women living with advanced breast cancer. There was also a desire to participate in life experiences as a family. This was limited by opportunities as well as financial resources. One participant spoke of her desire to have a Make-A-Wish experience for the family so that children with a parent with cancer could participate with them in experiences that would be meaningful and memorable.

There was also a strong sense that regardless of the physical and emotional effects of illness, these young mothers wanted to do everything to care for their children, be seen as Mom, and engage in as much of life as possible with their children. This theme included acknowledgement of the difficulties inherent in this experience, which were compounded by their worries for their children. They wanted to do as much as they could do both for and with their children while acknowledging there would likely never be enough time to spend with their children. For them, *I'm still Mom* was also about creating memories with their children and documenting them so the children would have tangible reminders of their mothers. Maintaining the role of mother was a priority for all. For some, it meant that cancer came second to being a mother. This also was an aspect where the "mask of wellness" was also apparent. Participants were engaged in activities such as volunteering in the classroom or watching a dance class, and to those around them, they looked healthy and were not distinguished by their illness.

The emergence of this theme reinforces the findings of DeSanto-Madeya and colleagues (2007) that some women with metastatic cancer were working and maintaining familial and social responsibilities. Daily activities included maintaining roles and responsibilities, managing households, working, participating in social and community activities, and caring for themselves physically, mentally and spiritually. The findings of this study extend the understanding of what the familial roles include as mother, caregiver, worker, volunteer, and community advocate. However, no studies were discovered that sought a comprehensive understanding of these dimensions of daily living and their meaning for young women living with advanced breast cancer. DeSanto-Madeya et al.'s (2007) study was a secondary analysis of activity logs that detailed the activities of women with advanced breast cancer between the ages of 28 and 79 years old. Activities were documented over the course of 4 days. As this was a secondary analysis, it did not allow for deeper exploration of meaning nor how participants balanced the many roles and responsibilities that were identified. No studies were found that explored what it means to be a mother in the presence of advanced cancer. Thus, the findings from this current study contribute new insights about the experience of being a mother along with the range of their concerns. Findings point the way for further research to understand how these women can be supported in their parenting role.

Major theme 3: *Living is more than surviving*. Nine subthemes describe different facets of this major theme: *Living my life, Working, Facing challenges* *and making adjustments, Feeling the physical effects, Doctoring for the rest of my life, Spreading my story, Thinking about the future, Wondering about delays in diagnosis, It's my journey, Finding unexpected surprises,* and *Seeking resources*. "Living is more than surviving" is defined as the experience of trying to live as fully as possible within the constraints of the disease. Participants were aware of the life-threatening, probably life-shortening, nature of their illness but did not want this to dominate their daily activities. For this researcher, it was remarkable that some participants described unexpected and positive surprises because of their situation. Some unexpected benefits included being more focused on each day and being more intentional on where to spend time.

This theme gives one a sense of what the daily life of young women living with advanced breast cancer entails. They are focused on living with their illness, making the most of their lives and, for some, remaining engaged and active in spite of their disease. Daily life living with advanced breast cancer is not easy and, for most, feelings of anxiety and depression were part of their experience. Awareness of the many emotional dimensions of this experience is important in order to provide the necessary supportive care to help them flourish in their living with advanced breast cancer. Implications for future research and practice are discussed later; however, a more integrated understanding of the meaning of living day-to-day emerged from the accounts of these women.

Improved survival times and ability to work. Advances in the treatment and management of breast cancer have resulted in improved survival times for some women with metastatic disease and have enabled some to return to daily activities including work (Cleeland et al., 2014). However, due to disease and treatment-related effects, some still experience disruptions in functional status and activities of daily living (Chen et al., 2014). Research involving women with metastatic breast cancer and the effects of the disease and treatment effects upon their daily lives is growing. However, studies have tended to focus on different aspects of the experience including physical, psychological, existential aspects, and supportive care needs. Moreover, as noted earlier, the experiences of this particular population of young women who are living with advanced cancer in what should be the prime of their lives has not been explored. This current study provides a more integrated perspective of the phenomenon of living day-to-day with a diagnosis of advanced breast cancer, specifically as it relates to young women. However, some insights from this cohort of young women may well inform further research for other populations living with advanced cancer. One area for further inquiry is how to support persons living with advanced disease in their work settings.

Cleeland et al. (2014) conducted a cross-sectional analysis of outcomes in women with advanced breast cancer. They found that symptom severity and symptom burden were significantly correlated with impairment of work productivity, with age being an important factor. They found younger women reported higher symptom severity and interference with daily life, worse health-related quality of life, and interference with daily life than older women. The data from the women in this study are supportive of this finding and highlight the need for further study to explore the experience of work in this population. The eight participants in this study who were working all described living with some degree of pain and fatigue that was either treatment- or disease-related. Many also described memory issues that they attributed to “chemo brain” as also having an impact on their work life.

Symptom management and quality of living. These are two additional areas that need more attention for this population of young women living with advanced breast cancer. All of the participants in this study reported that they lived with pain. However, for the nine participants whose interview permitted observation in a virtual face-to-face format via Skype^{TM} or FaceTime^{TM}, pain was for the most part not obvious on their faces or in their bodily positioning. This is another aspect of their experience that needs to be better understood in order to help them manage their pain. Additionally, the hidden nature of the pain further underscores the idea of suffering in silence as part of “wearing the mask of wellness.” However, pain was only one of the symptoms that could interfere with their quality of life. They also described other symptoms including fatigue, “chemo brain,” and hot flashes and other treatment-related physical effects.

This finding, that pain and other symptoms could be disrupting their lives in the context of their social roles and responsibilities, corroborates and extends the work of Chen et al. (2014). Their qualitative descriptive study illustrated the adaptive experience of women living with their illness as they reshaped their social roles to fit with their altered functional status and advanced disease. Thus, these findings provide additional evidence that young women struggle to manage pain, fatigue, and other symptoms for the sake of their children while also living busy lives. In Chen et al.'s study, they described the experience of "adjusting to a new normal" (Chen et al., 2014, p. 196), whereas in this study, many were adding the burdens of illness to their "normal" lives.

Delays in diagnosis. An unexpected finding was that half of the participants reported that there were delays in receiving an accurate diagnosis and, for some, this may have led to their initial diagnosis being metastatic disease. For example, two participants experienced bone pain that was initially treated as an acute injury, with rest and anti-inflammatory drugs prescribed. For another, physical therapy was the recommended treatment. Only when these treatments failed to resolve the issue were they further evaluated, and this sometimes took months. While it is not clear whether these delays were related to their relative youth, their perception was that that some providers made assumptions that delayed timely diagnosis, and they wondered whether earlier diagnosis might have given them a better prognosis. In most of these cases, the young woman presented with a physical complaint and was often reassured it was nothing to worry about.

The major theme *Living is more than surviving* represents how the embodiment of pain and symptoms is experienced over time as they try to carry on their lives, maintain their family roles, and live life as fully as possible within the constraints of their symptoms and existential concerns. It includes how relationships with others can influence their lives positively or negatively. As the researcher who is also a clinician, I found listening to them describe their pain and other symptoms very difficult and somewhat startling. I had not truly grasped the unrelenting temporal nature of their physical and emotional suffering and the efforts they have to make to continue to manage the many demands of family and social life. To them, the pain became an accepted part of their lives.

This theme captures how there is a unity among aspects of the lifeworld. (embodiment, spatiality, temporality, and relationality) for the phenomenon of young women living with advanced breast cancer. Each of the four interrelated existentials is apparent in the individual subthemes, as well as how each aspect influences the others.

Making the transition from early-stage to advanced cancer. This was overwhelming and devastating for participants. Some noted that, although they had understood there was a possibility that the disease might return or progress, they had not really “grasped” this. Others said that they had worried every day about the possibility of developing metastatic disease and what it would mean to them to have those fears realized. Not much is known about this transition, how it is experienced, and what can be done to support persons going through it. The findings from this study related to transitions have wider implications for others who are facing the advance of their disease.

Advocacy and education for others. As a way to derive something positive from their situations and as a way of trying to live as fully as possible, several of the participants talked about their efforts to educate others and advocate for early screening and vigilance. These efforts took various forms. For some, it was education about the number of young women diagnosed with breast cancer, while for others, it was about raising awareness of metastatic breast cancer. Some also talked about the "pink campaigns." They challenge others to think twice about the pink campaign and suggested that first one needs to understand where the money goes before making purchases or giving donations. The advocacy aspect of their experience of *Living is more than surviving* was motivated for some by frustration about the current situation of limited education and research in the hopes they could make a difference for others in the future.

Major theme 4: *Getting through it.* This theme has two subthemes that describe the important aspects of this major theme: *I have many different feelings and emotions* and *Behaviors to help me get through it*. This is defined as the experience of coping with advanced breast cancer from both emotional and behavioral perspectives. The subtheme *I have many different feelings and emotions* includes being overwhelmed, devastated, worried, depressed, grateful, relieved, having mixed feelings, anxious, being a burden, and frustrated. The second subtheme, *Behaviors to help me get through it,* includes maintaining normality doing everything I can, using social media, turning to faith, making choices, worrying about others, enjoying life, grieving, and becoming an advocate. This theme provides a deeper understanding of the complex process of coping and involves a multitude of emotions and behaviors.

As noted in Chapter Two, while the clinical aspects of metastatic breast cancer have been extensively studied, fewer studies have focused on the personal, psychosocial, and emotional aspects of the experience. In a large European study, the impact of an advanced breast cancer diagnosis on the psychological, social, and economic lives of women and their families was explored. In this sample of 158 women with advanced breast cancer, more than half of the women with metastatic breast cancer were chronically worried with just under half of them found to be depressed (Novartis Oncology, 2014).

In this present study, participants identified the need for more support and guidance in navigating their experience of living with advanced breast cancer. One participant described how the emotional aspects of living with advanced breast cancer were much harder to deal with than the physical effects. Most of the participants had not utilized the healthcare system for supportive care. None was receiving palliative care, whereas most if not all would have benefited from these supportive services given the known benefits of palliative care. Those benefits include effects on survival, satisfaction, improved quality of life, and depressed mood (Bakitas et al., 2009; Bakitas et al., 2015; Follwell et al., 2009; Kamal, 2011; Temel et al., 2010).

Major theme 5: *Being connected to others.* This theme has four subthemes: *Finding someone like me, Feeling the support of family and friends, My healthcare team, and Lost relationships*. The theme is defined as the experience of being in relationship with others, the desire for new relationships, and changes in relationships that may occur in young woman living with advanced breast cancer.

This theme highlights the importance of relationships across many aspects of life. There was a conflicting desire to meet other young women experiencing the same phenomenon on the one hand because this would lessen their sense of isolation. However, on the other hand, they would not wish their situation on others. When I shared the findings of the study with six of the participants, they acknowledged that it was a relief to hear that others were experiencing the same thing and it lessened their sense of being alone. This was an unexpected finding of the study in that they expressed the therapeutic benefits in sharing their story and then learning there were similarities in the stories of other participants.

Participants experienced support from family, friends, community, and some whom they had never met. The extent of the support was overwhelming for most. Some struggled with accepting the support, yet often didn’t have a choice, particularly if it involved helping with the care of their children.

Much of the current research has focused on the activities of living with advanced breast cancer but not as much on the relational aspect of living with it. Trevino and colleagues (2013) examined the relationship between perceived social support, quality of life, and grief and found that higher levels of social support were associated with better quality of life and less grief. They concluded that enhanced social support might also improve psychological well-being. The current study supports the finding that higher levels of social support were associated with better quality of life.

The disappointment of not being able to have the experience of "ringing the bell" at the completion of treatment heightened Dina's sense of isolation. Due to the ongoing nature of treatment for metastatic disease, there is no end, thus no reason to "ring the bell." This raises a question about what other aspects of the healthcare experience may unknowingly create additional isolation. Ringing of the bell is meant to be a positive experience and signifies the completion of treatment. As a clinician, this insight stimulated more thought about which other aspects of the healthcare experience might have a similar negative effect. Overall, the participants' experiences with their healthcare team were positive but were not a large focus of our conversations. There was acknowledgement that the relationship with the physician was important and one that would continue for an uncertain yet extended time. Few spoke of specific nursing experiences. As a nurse scholar, this finding was disappointing and caused me to reflect on why this may be the case, especially in a population of women who spent a lot of time interacting with the healthcare system and who would be "doctoring" for the rest of their lives.

Limitations

Limitations of this study are in line with those of other qualitative studies. They include recruitment, selection bias, design, stage of disease, and data collection procedures. The small sample lacked diversity in race and ethnicity. This was a very homogenous sample, with the majority being Christian, well educated, and Caucasian. I was dependent on specialty support groups for recruitment of this particular age group of women who were experiencing the phenomenon. Future studies should focus on exploring the phenomenon of being a young woman who is living with advanced cancer, as experienced by minority women and/or women from other cultures.

Flyers were placed at two comprehensive cancer centers. At one center, they were placed in a patient resource room and, at the other, in a clinic waiting room. However, no one responded to the flyers posted at the two sites. Nor did requested referrals from providers yield participants. Had I had a physical on-site presence, that may have made a difference with providers. I met and reviewed the study with the executive directors of three breast cancer organizations. The flyer was then posted on their Facebook^{TM} pages. Potential participants began to respond to me via email after seeing the post. All who were eligible expressed a desire to participate and received the information packet with the informed consent sent to them. Two potential participants did not return the informed consent, nor did they respond to a follow-up email.

Another recruitment limitation was that in order to access the flyer on social media, participants required a computer or smart phone and Internet access. Women who did not have a computer, smart phone, or Internet access would not have access to the electronic flyer. This limitation of access may be the result of financial constraints. Additionally, it would be another limitation if one did have a computer or smart phone and did not use Facebook^{TM}. The time frame used for interviews and follow-up was a limitation. The schedule of two more interviews, 2–4 weeks after the first interview was not realistic for all participants due to disease- and treatment-related concerns as well as the multiple demands of their lives. Additionally, the 2–4 week interval between the first two interviews also limited the ability to understand changes in the experience for participants as they occurred over time. A more extended timeline may have provided a deeper understanding of changes over time.

All interviews occurred over the telephone, FaceTime™, or Skype™. There was not an option for face-to-face interviews as participants were from a wide geographic distribution. Face-to-face interviews may have provided for different interview experiences.

The inclusion criteria included both Stage III and IV breast cancer. The difference in stages is a limitation for this study because there is a difference in treatment goals for the two stages. The intent of treatment for those with Stage III disease is curative, while for Stage IV disease it is no longer curative. Both stages were included because up to 40% of those with Stage III go on to develop metastatic breast cancer and, in many studies, both stages have been grouped together.

Lastly, I am concerned that there is more to report than could be captured in the discussion but I have tried to portray and discuss the most important aspects of this phenomenon.

The Use of Hermeneutic Phenomenology as a Method

The hermeneutic phenomenological approach of van Manen (1990) was well suited to explore this particular phenomenon and to interpret it in from the perspective of the nursing discipline. Van Manen's approach facilitates the engagement of participants in a personal exploration of the meaning of a phenomenon in a way that allows hidden aspects of their experiences to emerge (Lopez & Willis, 2004; van Manen, 1984).

As a phenomenological study, the aim was to uncover the essential aspects of the experience in order to inform further research and strategies to better meet the needs of this population. This qualitative approach is one that assumes that human experiences are deep, complex, and not always easily accessible to outsiders. However, there are essential elements shared by those experiencing the phenomenon that when brought to light via intentional questioning can be understood in a more nuanced way (van Manen, 1990). In uncovering different aspects of the phenomenon, this knowledge can be used to inform interventions, add to theory, or inform the state of the science with the goal of improving the lives of those experiencing the phenomenon of interest. According to van Manen (1990), research is a caring act, where "we want to know that which is most essential to being" (van Manen, 1990, p. 5).

In addition, the process of using the method and conducting this particular study affected me in ways I had not anticipated. I found myself becoming more aware and attentive to what was being said and not said in conversations with others in daily life. A sense of curiosity to better understand the lived experience of others was cultivated during this work and remains apparent in how I enter into relationships and interactions with others. This was an unexpected benefit for me and will assist me in all aspects of my professional and personal life.

An additional benefit for participants was that they experienced a therapeutic effect in participating. All stated that they found the opportunity to share their story beneficial. One participant also spoke of the therapeutic benefit of using the journal and how she has now incorporated daily writing into her life. Lastly, another therapeutic benefit was identified in the follow-up call to discuss findings. Many expressed relief that others were experiencing similar feelings and physical effects, which they acknowledged made them feel less isolated. Many expressed their appreciation I was doing this study.

This method proved useful in gaining a fuller understand of the meaning of the experience of young women living with advanced breast cancer than had existed prior. This experience was best understood through the unified lifeworld of the four existentials: corporeality, temporality, relationality, and spatiality (van Manen 1984; 1990). The unity of the four existential elements comprise the lifeworld of the phenomenon, and one is not able to separate one from another in the experience of young women living with advanced breast cancer. This is evidenced by the overlapping themes and subthemes within the overarching theme of *Wearing the mask of wellness in the presence of life-threatening illness*.

Implications for Practice, Education, Research and Policy

The insights and findings of this phenomenological study have implications for nursing practice, education, future research, and policy. There are also implications for interdisciplinary work.

Implications for nursing practice. Nurses, ideally, serve the public good by developing and using the knowledge, skills, and expertise needed to meet nursing's goals (Grace, 2018), as discussed in Chapters One and Two. While more research is needed, to build on these insights and design interventions, the findings from this study provide some easily implemented strategies for point of care and advanced practice nurses to use. Young women patients who are known to be living with advanced cancer can be asked about their daily lives, their sense of isolation, supports, and coping strategies and be assisted to obtain necessary resources. Nursing has a particular perspective on persons and their healthcare needs that has been developed over time and in response to societal needs. Willis and colleagues (2008) articulate this perspective in the form of a central unifying focus (CUF) for the discipline. The CUF is as follows: "Facilitating humanization, meaning, choice, quality of life, and healing in living and dying" (p. E32–33). This provides a grounding framework for all aspects of nursing work and is congruent with the idea of "lifeworld" as described previously. The CUF framework is used to organize the practice implications of the findings from this study. The concepts comprising the CUF are interrelated and integrated. Their relationship is described as being like “facets in a diamond” (Willis et al., 2008, p. E36).

Facilitating humanization. Participants in this study expressed a strong desire to be known as a person living with a life-threatening illness as well as a person apart from their illness. This experience was very isolating for several reasons, as described earlier. The theme *Wanting to be known as the person I am* emerged from the data. This theme underscores the desire of the participants to be known as a person in the context of their illness. When taken in the context of the CUF, it becomes very clear that, first and foremost, the individual’s experience of being human and being treated as an individual is essential. Willis and colleagues (2008) define humanization as “human beings’ careful attending to self and each other as relational and experiential in the whole of the unitary human-natural world with all of our unbroken and broken wholeness as human beings” (p. E33).

The participants provided important insights that nurses could incorporate into practice to facilitate humanization for these women. Specific actions included focusing on the person as individual and not primarily as a disease entity. One described the frustration of feeling her doctor did not know her as evidenced by the physician reviewing her chart in front of her at the beginning of an appointment.

Many identified the desire to be known and cared for as a person, particularly because the relationship with their healthcare team was ongoing and expected to last for the rest of their lives. Others identified the need to pull in additional supports to help them in their multidimensional roles including patient, mother, and worker. For some, it was the acknowledgement for more supportive care right from the beginning rather than waiting for a problem to develop. One also talked about the value a phone call made a day or two after a difficult conversation or diagnosis to check in and see how she was doing would be incredibly helpful. It would also have given the individual time to absorb and start to process difficult information. The call would also demonstrate the healthcare team's desire to care in a more personal manner.

Another spoke of things "she never knew." One wonders if it was because she did not feel comfortable asking her provider questions. Or, on the other hand, if there are areas not being addressed in our assessments, are we giving the message that if we don't ask that we are not interested? The ANA Social Policy Statement (ANA, 2010b), a contract with the public that nursing serves, suggests nurses have a commitment to care that is relationship-based, person-centered, and focused on the biophysical, psychosocial, and spiritual needs for all people, especially those most vulnerable. Incorporating all aspects of living with this disease—physical, emotional, psychosocial, spiritual, and sexual—can help us to better understand and know the individual as a person and are critical to improving the care of these women. An important application to practice would be to include questions to assess the dimensions of life that the individual may not easily bring up. For this population, this could include questions related to intimacy, coping with cancer-related losses, and existential concerns that may not be easily apparent and not readily disclosed.

“Ringing of the bell” is meant to be a positive experience and signifies the completion of treatment. As a clinician, this insight stimulated more thought about what other aspects of the healthcare system may have a negative effect on those with metastatic disease whose treatment options are restricted to noncurative palliation. Overall, experiences with the healthcare team were positive but not a large focus of the conversations with participants.

Meaning. All of the participants spoke about changing perspective and meaning in their lives because of their experiences of living with advanced breast cancer. From the perspective of the CUF, meaning is defined as “a human’s arrived-at understanding of life experiences and their significance that comes from processing those experiences” (Willis et al., 2008, p. E34). Meaning is a “basis of human integration of the whole of living and dying and the embodied experience of wholeness” (p. E34). All of the participants in this study shared their experiences around meaning-making and their integration of their *living with* advanced breast cancer in the context of their whole life. Nurses can play a critical role in assessing for meaning and encouraging activities that promote meaning-making.

Choice. All participants acknowledged that they did not have a choice of having advanced breast cancer, but many did acknowledge that they had choices about how they experienced this phenomenon. Choices influenced all aspects of their living both personally and from the perspective of the families, roles, and responsibilities and as members of society. As nurses, it is important to facilitate and encourage persons in this situation to fully understand their circumstances in order to allow for informed decisions about their care. These conversations may also reveal factors that may be influencing treatment decisions. For women in this study, the desire to do everything they could in terms of treatment was often motivated because they had children who were dependent on them. Understanding the additional complexity related to parenting while living with serious illness is an important implication of this study. This could be accomplished by engaging them to discuss their concerns regarding their role as parent in the context of living with serious illness.

The provision of resources and support was identified as lacking by most of the participants, implying that improvements in nursing practice to anticipate patient needs are warranted. This is also an implication for nursing education. This study provides an initial exploration of what some of those resources and supports may be, including supportive care such as symptom management and social service support, and educational materials for the individual as well as age-appropriate materials for their children that are specific to the disease stage. This information provides guidance for nurses in incorporating better education and supportive care

Quality of life. Willis and colleagues (2008) define quality of life as “the value and significance ascribed by individual human beings to their lives, given their changing unitary human-natural world situations (p. E35). Maintaining quality of life while living with advanced breast cancer was an important aspect of their experience. Quality of life was defined differently among the participants; however, a common thread was “living life in a meaningful way.” For all of them, this included being a mother and caring for their children and doing as much as they could to prepare them for the future. For most, working was an important aspect of maintaining quality of life. For others being intentional and enjoying everyday activities and taking every day as it comes contributed to their sense of well-being and quality of life.

Nursing assessment of quality of life is essential for this population. Often, care is focused on treatment-related effects and concerns; however, a broader assessment of how these aspects are effecting quality of life is essential. Incorporating questions to elicit understanding about goals and quality of life is necessary to better care for this population. Nurses caring for this population also have the opportunity to develop a relationship over time, which would facilitate ongoing conversations about the desires and wishes of these women.

Trevino and colleagues (2011/2012) examined the experience of grief due to cancer-related losses and life disruption and found that in the young adult population, grief may add a unique burden that may be more problematic than their physical status. In the current study, some of the aspects of grief and loss and their impact were identified.

Health and healing. Participants described their health as either “good” or “fair.” For those who said “fair” it was more because of their cancer diagnosis. They acknowledged if they were feeling as they did and did not have cancer, their rating would be “good.” Several said that it was the knowledge of having cancer, not how they were feeling, that limited their responses.

Health is defined as “the embodiment of wholeness and integrity in living and dying” (Willis et al., 2008, p. E35), with healing defined as “the multidimensional unitary human-natural world process of restoring bodily experiences (perceptual-physical) of wholeness, meaning, and integrity in living and dying when it is disrupted” (p. E35). Incorporation of these two concepts in the nursing care of young women with advanced breast cancer is essential in order to help them to maximize their living in the face of a life-threatening illness. Understanding the essence of how they want to live their lives, in the context of their illness is an area where nurses can have significant impact.

Living and dying. This concept is defined as “the unitary human-natural world process of coming into existence in a human body in the world and changing until death” (Willis et al., 2008, p. E35). Awareness and understanding of this concept is essential for nurses in delivering care to young women living with advanced breast cancer. For those with metastatic disease, they are living with the knowledge that they will likely die from their disease at a time much earlier than expected. Most acknowledged the average life expectancy of 30 months for those with metastatic disease. This awareness resulted in the experience of enjoying and living their life in ways that were intentional and meaningful. Participants provided insight about some of their behaviors of living with this knowledge. Many expressed a desire to be remembered and focused on creating memories with their children. This is an area of concern that was not something they discussed with their providers. This is an implication that could easily be implemented in caring for young parents with cancer. Initiating conversations to discuss wishes and understand preferences may also influence decision-making and coping strategies. This knowledge is extremely important for nurses who can help facilitate activities and encourage conversations around this aspect of living and dying.

Implications for nursing education. As educators, nurses can influence curriculum and embed within the curriculum discussion about the issues of vulnerable populations and the moral obligation of nursing to uphold our goals and promises to individuals and society. Faculty can prepare nurses to address practice issues and advocate for patients. In particular, education around issues of quality of life, palliative care, and advanced care planning emerged from this study as areas that need to be further developed in curricula. This will ensure that nurses are better positioned to provide care for persons living with life-threatening illness.

Implications for future research. Nurse scholars seek to improve the good of society through research. The disciplinary aspect of the profession is responsible for ongoing knowledge development both about the profession and its responsibilities and for addressing practice issues. To adequately address practice issues, nurse scholars must concern themselves with anticipating areas where knowledge development is needed and seek to develop this knowledge via research or other sorts of inquiry. Additionally, clinicians who are at the frontlines of care also have a responsibility to identify gaps in knowledge and care delivery. Ideally, partnerships of clinicians and nurse scholars would provide the mechanism to identify gaps and questions that need to be answered in order to further knowledge development and inform the state of the science about a particular problem.

The descriptions and experiences of the participants of *Wearing the mask of wellness in the presence of a life-threatening illness* illuminated several important areas of research. It is clear that more research is needed to better understand the experience of being a young adult living with advanced cancer. Initial work has begun, but much more is needed to fully understand the experience and how it may differ from that of older adults. Efforts to better understand the multidimensional coping process for this population is needed in order to design effective person-centered supportive care interventions. In addition, better understanding of the experience of these young adults who are living and engaging in activities in the lives of their communities is important in developing strategies for outreach and education.

For this study, the short time interval between the first two interviews limited my ability to understand changes in the experience for participants as they occurred over time. Ideally, future research should include several more interviews spanning a longer period. This would provide important better understanding of the experience over time.

The current study supports the finding that higher levels of social support were associated with better quality of life. Further research is needed to better understand the effects. This information could then be used to design supportive care interventions to improve their quality of life.

Another area that emerged was the subtheme *Lost relationships*. Trevino and colleagues (2011/2012) examined the experience of grief due to cancer-related losses and life disruption and found that, in the young adult population, grief may add a unique burden that may be more problematic than physical status. In the current study, some of the aspects of grief and loss and their impact were identified. In particular, the experience of losing the ability to have future children and the impact on both partners is of significance and merits further investigation. Other losses, including the loss of friends and relationships is also another area that would benefit from further research.

Ringing of the bell is meant to be a positive experience and signifies the completion of treatment. Discussion around this experience revealed the difficulty that some young women with advanced breast cancer have with this practice in the oncology setting. As a clinician, this was an insight that stimulated more thought about what other aspects of practice may be a negative experience for those whose treatment options are no longer curative. Further research in this regard would be helpful in identifying other ways to acknowledge transitions in care. Overall, experiences with the healthcare team were positive but not a large focus of the conversations with participants. Future research in this area may help to illuminate additional aspects of the experience.

Additionally, given the incidence of breast cancer among young women, the concern about delays in diagnosis, is an important finding that needs further research. Educational efforts including identification of women at higher risk of metastatic disease aimed at primary providers and gynecology colleagues could improve this identified problem.

One participant had declined palliative care because she thought it was the same as hospice care. She did not understand or appreciate the potential benefits of incorporating palliative care into her healthcare. Kumar et al. (2012) measured utilization rates as well as factors that related to the use of palliative care as well as barriers to palliative care. They found 50% of the cancer patients in the outpatient setting had not used any of the existing palliative care services. The participants noted the lack of referral by physicians and the lack of awareness by patients were the most frequently reported barriers (Kumar et al., 2012). A secondary analysis of data of people receiving palliative care demonstrated that many in the community are being referred too late with many unmet needs, further supporting the need for earlier integration of palliative care (Kamal et al., 2011). There is a growing body of research that supports palliative care in the community setting. The known benefits are well established and include beneficial effects on survival, satisfaction, improved quality of life, and depressed mood, and improved caregiver outcomes (Bakitas et al., 2015; Bakitas et al., 2009; Dionne-Odom et al., 2015; Follwell et al., 2009; Kamal et al., 2011; Temel et al, 2010).

Improved access to community-based palliative care programs is needed. This is an area that clearly needs more attention particularly as the benefits of early initiation of palliative care are well known. One is left to wonder if providers are not comfortable with adding palliative care or when advanced care planning conversations are occurring. All of the participants in this study were experiencing multiple physical effects that were for the most part inadequately addressed. One also needs to consider if their age and type of cancer may also have been factors in not receiving palliative care.

Also needed is more research focused on the many roles and responsibilities of young women living with advanced breast cancer. None of the literature reviewed in Chapter Two examined what it meant to be a mother and how the role is actualized, as well as the concerns these mothers carry for their children. The current study highlights and supports the findings of Park et al. (2017), who conducted a qualitative study with both mothers and fathers to describe the experience of living with advanced cancer as a parent. They identified that parents with metastatic disease may have unique palliative care needs that are not well understood. This important area requires further research to understand how to better support parents with serious illness and their children.

As patient advocates, nurses have an opportunity to improve outcomes through practice, education, and engagement in policy initiatives. The clinician, educator, researcher roles offer perspectives to inform policy. The nurse as clinician can offer perspectives from the direct care role to better inform those advancing policy as well as to provide insight into areas of potential research. Researchers can give a perspective provided by the evidence that can inform white papers, position papers, and guidelines. This vulnerable population has identified several areas including the lack of awareness, research and funding for women with metastatic breast cancer. This is a critical area that needs to be addressed at the policy level in order for change to occur.

Implications for policy. A key health policy challenge is developing critical understanding of the significance of this problem. This study begins to provide important insights about the experience of young women living with advanced breast cancer. Nurses have a moral and professional responsibility to society, which benefits the common good. This view and the contract nurses share with society positions them to see where injustices and inequalities are present and to shed light on these areas. Mechanic and Reinhardt (2002) challenge nurses to have a more active role at the policy table given the importance of nursing, its core values, and the high priority that patients place on good nursing care.

Nursing is viewed as one of the most trusted professions, yet it faces challenges to develop a voice at the policy table. Challenges include gender discrimination, decreased ability to realize political potential, or to be taken seriously as a force of change. This stems in part from the domination of nursing by other groups at the table and the profession's identification as a women's profession. Nursing has worked to elevate its professional status, but further work is needed to become more visible in the policy and political arena.

Nurses provide a service related to health and well-being and have a responsibility to address factors that influence individual well-being and health (Grace & Willis, 2012). Nursing is focused on improving the health of individuals and society and has a moral obligation to address injustice. Nurses have a unique perspective of what constitutes injustice in healthcare and which individuals and groups are at a greater disadvantage. And nurses cannot address these issues in isolation. The issues are complex and require interdisciplinary collaboration to challenge injustice and seek solutions in order to provide healthcare that is accessible and affordable to all.

Nursing's role in developing and advancing policy to address vulnerable populations is critical. Engagement in professional organizations such as the ONS and the ANA to advance policy is critical. Nurses are well positioned to actively inform policy and to develop guidelines and position papers to improve care for all.

Summary

The overarching theme and major themes that emerged from the data begin to characterize the phenomenon of young women living with advanced breast cancer. *Wearing the mask of wellness in the presence of life-threatening illness* captures the experience of appearing young and healthy on the outside while internally living with a potentially life-threatening disease and suffering in silence. *Wanting to be known as the person I am* provides an understanding of the essential aspects of being known as a person with disease and a person apart from her disease. The subthemes help to better understand the desire to be known and what some of the challenges are. *I'm still Mom* reflects the desire to still be mom despite the difficulties and challenges of this experience. The experiences of day-to-day living are captured in *Living is more than surviving* and reflect the multidimensional aspect of this theme. *Getting through it* reflects the emotions and behaviors of living with advanced breast cancer. And lastly, *Being connected to others* reflects the need for and challenges regarding relationships with others while living with advanced breast cancer.

This study has explored the phenomenon of young women living with advanced breast cancer. Insights about the phenomenon have been identified and can be applied to nursing practice to better care for this population. Knowledge directly acquired from patient experiences can then be used to design care that will improve the experience of living with advanced breast cancer in ways that are meaningful to the patient. Ultimately, this can lead to innovative interdisciplinary interventions that will improve the experience for young women living with advanced breast cancer.

AFTERWORD

Santiago

The road seen, then not seen, the hillside
hiding then revealing the way you should take,
the road dropping away from you as if leaving you
to walk on thin air, then catching you, holding you up,
when you thought you would fall,
and the way forward always in the end
the way that you followed, the way that carried you
into your future, that brought you to this place,
no matter that it sometimes took your promise from you,
no matter that it had to break your heart along the way:
the sense of having walked from far inside yourself
out into the revelation, to have risked yourself
for something that seemed to stand both inside you
and far beyond you, that called you back
to the only road in the end you could follow, walking
as you did, in your rags of love and speaking in the voice
that by night became a prayer for safe arrival,
so that one day you realized that what you wanted
had already happened long ago and in the dwelling place
you had lived in before you began,
and that every step along the way, you had carried
the heart and the mind and the promise
that first set you off and drew you on and that you were
more marvelous in your simple wish to find a way
than the gilded roofs of any destination you could reach:
as if, all along, you had thought the end point might be a city
with golden towers, and cheering crowds,
and turning the corner at what you thought was the end
of the road, you found just a simple reflection,
and a clear revelation beneath the face looking back
and beneath it another invitation, all in one glimpse:
like a person and a place you had sought forever,
like a broad field of freedom that beckoned you beyond;
like another life, and the road still stretching on.

—David Whyte

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Appendix A: Institutional Review Board Approvals

BOSTON COLLEGE
Institutional Review Board
Office for Research Protections
Waul House, 3rd Floor
Phone: (617) 552-4778, fax: (617) 552-0498

IRB Protocol Number: 17.255.01

DATE: June 13, 2017

TO: DEBRA M LUNDQUIST

CC: Pamela Grace

FROM: Institutional Review Board – Office for Research Protections

RE: THE EXPERIENCE OF YOUNG WOMEN LIVING WITH ADVANCED BREAST CANCER: A HERMENEUTIC PHENOMENOLOGICAL STUDY

Notice of IRB Review and Approval
Expedited Review as per Title 45 CFR Part 46.110, FR 60366, FR, # 6 & 7

The project identified above has been reviewed by the Boston College Institutional Review Board (IRB) for the Protection of Human Subjects in Research using an expedited review procedure. This is a minimal risk study. This approval is based on the assumption that the materials, including changes/clarifications that you submitted to the IRB contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This approval is given with the following standard conditions:

1. You are approved to conduct this research only during the period of approval cited below;
2. You will conduct the research according to the plans and protocol submitted (approved copy enclosed);
3. You will immediately inform the Office for Research Protections (ORP) of any injuries or adverse research events involving subjects;
4. You will immediately request approval from the IRB of any proposed changes in your research, and you will not initiate any changes until they have been reviewed and approved by the IRB;
5. You will only use the informed consent documents that have the IRB approval dates stamped on them (approved copies enclosed).

6. You will give each research subject a copy of the informed consent document;
7. You may enroll up to 15 participants. You may not enroll more than this number of participants without seeking IRB approval. To do so will be a violation of the conditions of IRB approval and, if federal funding is involved in your project, a matter of non-compliance that we must report to the federal government. This could significantly and negatively impact your research.
8. If your research is anticipated to continue beyond the IRB approval dates, you must submit a Continuing Review Request to the IRB approximately 30 days prior to the IRB approval expiration date. Without continuing approval the Protocol will automatically expire on June 12, 2018.

Additional Conditions: Any r*esearch personnel that have not completed an acceptable education/training program should be removed from the project until they have completed the training. When they have completed the training, you must submit a Protocol Revision and Amendment Form to add their names to the protocol, along with a copy of their education/ training certificate.*

Approval Period: **June 13, 2017-June 12, 2018.**

Boston College and the Office for Research Protections appreciate your efforts to conduct research in compliance with Boston College Policy and the federal regulations that have been established to ensure the protection of human subjects in research. Thank you for your cooperation and patience with the IRB process.

Sincerely,

[redacted]

Director
Office for Research Protections

Enclosures

JFC

Appendix A: Institutional Review Board Approvals

BOSTON COLLEGE
Institutional Review Board
Office for Research Protections
Waul House, 3rd Floor
Phone: (617) 552-4778, fax: (617) 552-0498

IRB Protocol Number: 17.255.01

DATE: July 26, 2017

TO: DEBRA M LUNDQUIST

CC: Pamela Grace

FROM: Institutional Review Board – Office for Research Protections

RE: THE EXPERIENCE OF YOUNG WOMEN LIVING WITH ADVANCED BREAST CANCER: A HERMENEUTIC PHENOMENOLOGICAL STUDY

Notice of IRB Review and Approval
Expedited Review as per Title 45 CFR Part 46.110, FR 60366, FR, # 6 & 7

The project identified above has been reviewed by the Boston College Institutional Review Board (IRB) for the Protection of Human Subjects in Research using an expedited review procedure. This is a minimal risk study. This approval is based on the assumption that the materials, including changes/clarifications that you submitted to the IRB contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This approval is given with the following standard conditions:

1. You are approved to conduct this research only during the period of approval cited below;
2. You will conduct the research according to the plans and protocol submitted (approved copy enclosed);
3. You will immediately inform the Office for Research Protections (ORP) of any injuries or adverse research events involving subjects;
4. You will immediately request approval from the IRB of any proposed changes in your research, and you will not initiate any changes until they have been reviewed and approved by the IRB;
5. You will only use the informed consent documents that have the IRB approval dates stamped on them (approved copies enclosed).

6. You will give each research subject a copy of the informed consent document;
7. You may enroll up to 15 participants. You may not enroll more than this number of participants without seeking IRB approval. To do so will be a violation of the conditions of IRB approval and, if federal funding is involved in your project, a matter of non-compliance that we must report to the federal government. This could significantly and negatively impact your research.
8. If your research is anticipated to continue beyond the IRB approval dates, you must submit a Continuing Review Request to the IRB approximately 30 days prior to the IRB approval expiration date. Without continuing approval the Protocol will automatically expire on June 12, 2018.

Additional Conditions: Any r*esearch personnel that have not completed an acceptable education/training program should be removed from the project until they have completed the training. When they have completed the training, you must submit a Protocol Revision and Amendment Form to add their names to the protocol, along with a copy of their education/ training certificate.*

Approval Period: **July 26, 2017-June 12, 2018.**

If you are conducting research using an online survey (e.g. Survey Monkey, Qualtrics), the IRB requires that the approval dates appear on the online consent page of your survey. Please copy and paste the statement below onto your survey:

The Boston College IRB has approved this protocol from July 26, 2017-June 12, 2018 .

Boston College and the Office for Research Protections appreciate your efforts to conduct research in compliance with Boston College Policy and the federal regulations that have been established to ensure the protection of human subjects in research. Thank you for your cooperation and patience with the IRB process.

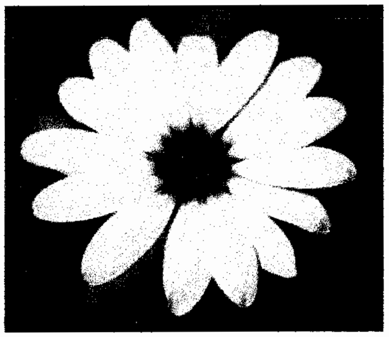
Sincerely,

[redacted]

Director
Office for Research Protections

Enclosures
KR

Appendix B: Recruitment Flyer



Are you a woman aged 25-39 with Stage III or IV breast cancer?

You are invited to participate in a research project being conducted by a nurse researcher at the Boston College Connell School of Nursing. We are doing this study to learn more from younger women like you about experiences living with breast cancer.

If you choose to participate, a nurse researcher will interview you once or twice at a location and time that is convenient for you. The interviews will last no more than an hour. You will also be asked to complete a short survey about yourself. To thank you for your help with this project you will receive a $25 gift card.

If you would like to help and learn more about this project please contact:
Debra Lundquist PhD (c), MSN, RN
978-290-1355
debra.lundquist@bc.edu

Appendix C: Letter of Invitation

Summer 2017

Hello,

Thanks for your interest in this study of young women living with breast cancer being conducted by a nurse researcher at the Boston College Connell School of Nursing.

In this packet you will find a consent form, an information form, a journal and two self-addressed envelopes. If you decide to be part of the study, you will mail the first envelope with the signed informed consent and the completed information form to the nurse researcher using one of the self-addressed envelopes in your packet. You will then be contacted to schedule your first interview. Also, the nurse researcher will mail you back a copy of the signed consent form. After the second interview, you will need to mail the journal to the nurse researcher using the envelope in the packet. If you would like the journal back, you can let me know and I will return it to you.

If you have any questions please contact me by phone at: 978-290-1355 or by email: debra.lundquist@bc.edu

Thanks for your consideration of this study!

Debra Lundquist PhD (c), MSN, RN

Appendix D: Informed Consent

Boston College Consent Form

Boston College Connell School of Nursing
Informed Consent to be in study:
The Experience of Young Women Living with Advanced Breast Cancer: A Hermeneutic Phenomenological Study
Researcher: Debra Lundquist PhD (c), MSN, RN
Adult Consent Form

Introduction

- You are being asked to be in a research study of young women living with advanced or metastatic breast cancer.
- You were selected to be in the study because you are between the ages of 25-39 and have a diagnosis of advanced or metastatic breast cancer.
- Please read this form. You may call me, Debra Lundquist at (978) 290-1355 to ask any questions that you may have before you agree to be in the study.

Purpose of Study:

- The purpose of this study is to understand the experience of living with breast cancer on a day-to-day basis.
- The total number of people in this study is expected to be around 20 women.

What will happen in the study:

- If you agree to be in this study, we would ask you to take part in two tape-recorded interviews each lasting between 30-60 minutes. If you have more information to share after the second interview I may ask if you are willing to take part in an additional interview.
- You will also be asked to compete one form before or after the first interview.
- This form will have information about your age, diagnosis, and treatments as well sections about your daily life.
- You will be given a journal. The purpose of the journal is for you to write additional thoughts as they arise, draw pictures that represent how you feel or use in other ways of your choosing that will help me understand your experience. If you do use the journal we can discuss the contents during the second interview.
- If you are not able to have a face-to-face interview, interviews can take place via telephone, Skype or FaceTime.
- If you are not having a face-to-face interview a packet will be mailed to you with information about the study.
- The packet will have the informed consent form, the information form, a journal and two self-addressed envelopes. There will also be information about how to contact the nurse researcher with questions.
- If you decide to be part of the study, you will mail the first envelope with the signed informed consent and the completed information form to the nurse researcher using one of the self-addressed envelopes in your packet. The nurse researcher will mail you back a copy of the signed consent form.
- After the second interview, you will need to mail the journal to the nurse researcher using the envelope in the packet. If you would like the journal back, you can let us know and we will return it to you.
- If you are not having a face-to-face interview, we will schedule it to happen at a time that is convenient for you when you can talk freely and privately.

Risks and Discomforts of Being in the Study:

- There are no known risks associated with this study. This study may include risks that are unknown at this time.

- If you become upset during the interview or do not want to talk about something, you can refuse to answer the question. You can also stop the interview at any time. The nurse researcher will provide an opportunity for you to discuss concerns and will provide support. Information about local support resources will also be available.

Benefits of Being in the Study:

- The purpose of the study is to understand the experience of living with breast cancer on a day-to-day basis. It is hoped that information gained will help us provide better services in the future.
- There are no direct benefits of being in this study but we hope to better understand what your day-to-day life is like when living with breast cancer.

S

Payments:

- You will receive a $25 gift card after the first interview to thank you for your time and for being in the study.
- All participants will be given the gift card even if the interview is stopped before it is completed.

Costs:

- There is no cost to you to be in this research study.

Confidentiality:

- The records of this study will be kept private. Results of the study will be published in a way that keeps your information private. You will not be able to be identified in any report that we publish. All research records will be kept in a locked file that only the researcher has access to.
- Your name and personal details will be separated from your interview record. The taped recordings of the interview will be assigned an identification number and any personal or identifiable details removed before being sent to a professional transcriber (a person who is trained to make a type-written document from an audio recording). The professional transcriber will type what you have said from the tape recording and send the completed document to me (the researcher) to review as part of the study.
- Your recording will have your identification number only. The recordings will be stored in a locked space and will be destroyed as soon as they have been transcribed (typed up) and verified (reviewed to be sure they are correct).
- Mainly just the researcher will have access to information; however, please note that a few other key people may also be given access in order to make sure the study process is being followed properly. These might include government agencies. Also, the Institutional Review Board at Boston College and internal Boston College auditors may review the research records.

Choosing to be in the study and choosing to quit the study:

- Choosing to be in this study is voluntary. If you choose not to be in this study, it will not affect your current or future relations with the University.
- You are free to quit at any time, for whatever reason.
- There is no penalty or loss of benefits for not taking part or for quitting.

Getting Dismissed from the study:

- The researcher may dismiss you from the study at any time for the following reasons: (1) it is in your best interests (e.g. side effects or distress have resulted).

Care and payment for Injury:

- No physical injury is expected from this study. If you experience emotional distress the researcher will help you access appropriate resources.

Appendix D: Informed Consent

Contacts and Questions:

- The researcher conducting this study is Debra Lundquist PhD (c), MSN, RN. For questions or more information concerning this research you may contact her at 978-290-1355 or by email: debra.ludquist@bc.edu or her supervisor, Dr. Pamela Grace at: pamela.grace.2@bc.edu.
- If you believe you may have suffered a research related injury, contact Debra Lundquist at 978-290-1355 who will give you further instructions.
- If you have any questions about your rights as a person in this research study, you may contact: Director, Office for Research Protections, Boston College at (617) 552-4778, or irb@bc.edu

Copy of Consent Form:

- You will be given a copy of this form to keep for your records and future reference.

Statement of Consent:

- I have read (or have had read to me) the contents of this consent form. I have been encouraged to ask questions. I have received answers to my questions. I give my consent to be in this study. I have received (or will receive) a copy of this form ____ (please check when received).

Signatures/Dates

Study Participant (Print Name and Signature): ________________________________ Date ______

________________________________ Date ______

Subject's Initials___

Appendix E: Demographic Information Form

How would you rate your health at this time? Do you think it is:
_____ Excellent
_____ Good
_____ Fair
_____ Poor

Date of Cancer Diagnosis ______/______/______
Month Day Year

Cancer Stage at Diagnosis
_____ Stage 1
_____ Stage 2
_____ Stage 3
_____ Stage 4

Date of Metastatic Cancer Diagnosis ______/______/______
Month Day Year

Current Treatment
_____ Chemotherapy
_____ Biologic therapy
_____ Radiation
_____ Combination chemotherapy and radiation
_____ Not receiving active cancer treatment

Are you receiving palliative care?
_____ Yes
_____ No

With what faith tradition do you identify yourself with?
_____ Catholic
_____ Mainstream Protestant
_____ Evangelical Christian
_____ Jewish
_____ Muslim
_____ Hindu
_____ Other: ________________
_____ None

Do you engage in spiritual practices?
_____ Worship in a faith community
_____ Pray
_____ Other: __________________
_____ None