Extended Adherence to Adjuvant Endocrine Therapy in Breast Cancer Survivors:
Ritualization of Adherence

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Abstract

Background: Hormone-receptor positive breast cancer survivors traditionally were prescribed adjuvant endocrine therapy (AET) for five years at the completion of definitive therapies. The duration of treatment continues to be explored with recommendations indicating that eight to ten years may be more effective in the prevention of breast cancer recurrence. Non-adherence rates are as high as 50% disruption or discontinuation before the recommendation of the provider. With extended durations of treatment, non-adherence rates will continue to be a challenge, impacting the incidence of breast cancer recurrence in these women.

Aims: 1). Describe the experience of post-menopausal breast cancer survivors as they transition from acute to chronic management of breast cancer. 2). Identify conditions that support or are barriers to adherence to AET in post-menopausal breast cancer survivors. 3). Generate a grounded theory about post-menopausal breast cancer survivors’ decision-making and other conditions that impact adherence.

Methods: Grounded Theory utilizing dimensional analysis was employed. Twenty-one post-menopausal hormone-receptor positive breast cancer survivors, more than three years out from definitive treatment, were recruited. Three Virginia oncology clinics and Facebook support groups were utilized for recruitment. Data collection and data analysis occurred simultaneously. Data-analysis occurred in four phases: initial coding, focused coding, axial coding, and selective coding. Memo-writing was used to support emerging conceptualizations.

Findings: Through this constructivist grounded theory study the central perspective of ritualization of adherence was discovered. Women built a foundation that included arming themselves with accurate information, viewing their breast cancer as a chronic condition, utilizing the support of spouses and healthcare providers, and building a healthy lifestyle as a survivor that led them to divergent paths towards adherence or non-adherence. Non-adherence was facilitated by disruptions to routines and side effects, where-as adherence included a continual recommitment process. They lastly built a means of self-protection that included their belief in the power of the medication, their personal values and belief system, and a consequential message that they were strong enough, which overarched their decision to adhere and fueled the ritualization process.

Conclusion: Throughout this study, participants described the perspective of ritualization of adherence as a way of explaining what conditions and contexts led to adherence and non-adherence in the extended duration of AET use. Based on the findings in this study, nurses and other healthcare providers are able to target specific areas of education and practice in order to improve the experiences and quality of life of post-menopausal breast cancer survivors. Additionally, this study informs researchers and policy-makers in order to target and improve breast cancer survivorship care.
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Chapter 1: Introduction

Hormone-receptor positive breast cancer survivors traditionally were prescribed adjuvant endocrine therapy (AET) for five years at the completion of definitive therapies, specifically surgery, chemotherapy and radiation. The duration of treatment continues to be investigated with recommendations indicating that eight to ten years may be most appropriate (Goss, 2015). Studies reporting non-adherence rates ranged from 7-50% discontinuation before the recommendation of the provider (Camacho, Tan, Alcala, Shah, Anderson & Balkrishnan, 2017; Chim, et al., 2013; Danilak & Chambers, 2013; and Aiello Bowles, Boudreau, Chubak, Fujii, Chestnut, & Buist, 2012) With extended durations of treatment, non-adherence rates will continue to be a challenge, impacting the incidence of breast cancer recurrence in these women.

Concepts

Before examining nonadherence to AET in breast cancer survivors (BCS), the concepts of interest must be defined. A cancer survivor is “one who remains alive and continues to function during and after overcoming life-threatening disease” (National Cancer Institute, 2018); in breast cancer, a patient is considered to be a survivor after a biopsy confirming the presence of cancer in the breast. Medication adherence is the “the extent to which a patient’s behavior, with respect to taking a medication, corresponds with recommendations from a health care provider, and includes therapy initiation, persistence, and execution” (Ursem, et al., 2015, p. 403). Adjuvant therapy is the “additional cancer treatment given after primary treatment to lower the risk that cancer will come back” (National Cancer Institute, 2018). AET, inclusive of drugs such as tamoxifen and aromatase inhibitors, lowers the levels of the hormones estrogen and
progesterone in the body so that cancer cells cannot use those hormones to grow (American Society of Clinical Oncology, 2014).

**Scope of Problem and Impact on Research Priorities**

According to the American Cancer Society (ACS) (2018), there are just over 250,000 new cases of breast cancer diagnosed each year and four million BCS in the United States, with specifically 60,600 breast cancer survivors in Virginia (Cancer Action Coalition of Virginia, 2015), a number that is growing as a result of earlier detection and developing treatments in oncology (Marbach & Griffie, 2011). Additionally, more than 40,000 women and men die each year in the United States (ACS, 2018) and 124.7 per 100,000 die annually in Virginia (Cancer Action Coalition of Virginia, 2015). The mean age of breast cancer diagnosis is 61, with 43% of women being diagnosed after the age of 65. The highest risk of breast cancer recurrence is during the first five years after diagnosis (10.4%), with a spike during years one and two (15.2%) (Colleoni, et al., 2016). Once breast cancer has recurred or metastasized, the treatment options become limited (Ahmed, 2013), making it critically important to focus research efforts on the prevention of breast cancer recurrence.

ACS (2018) has focused its funding and research priorities on innovative ways to improve the lives of cancer survivors, while focusing in on symptom surveillance and disparities. Cancer treatment leads to many side effects including pain, fatigue, and depression. Such symptoms can decrease quality of life, functional status and treatment adherence (2018). The Oncology Nursing Society in concert with the Institute of Medicine’s (IOM) (Nekhlyudov & Wenger, 2014) recommendations on survivorship care have outlined research priorities including “exploring factors associated with the delivery
of quality cancer care to survivors”, in particular exploring specific survivorship groups, as well as, facilitators and barriers to adhering to the prescribed survivorship care (Oncology Nursing Society, 2018). This research aimed to capture through intensive interviewing and grounded theory analysis, the facilitators and barriers of adherence to AET in post-menopausal BCS. This study led a deeper understanding of those who are at risk for decreased adherence, informing interventions that can improve adherence, while decreasing recurrence rates, and ultimately improving the quality of life for these patients.

**Breast Cancer Recurrence**

BCS face a risk of recurrence that increases over time. *Recurrence* is the return of cancer after a period of time that a person is cancer free (National Cancer Institute, 2018). Identifying one’s individual risk of recurrence is based on histological characteristics such as tumor size and grade, lymph node status, age, and hormone status. Additionally, microarray gene expression profiles, as well as, genome sequencing have become commercially available over the last few years making the process of predicting the risk of recurrence much more accurate. Genetic testing can lead to very specific information regarding a patient’s risk of recurrence (Martei & Matro, 2015). AETs have considerably decreased the rates of recurrence among BCS but such therapies come with increased risk and decreased tolerability for patients (Bomeisl, Thompson, Harris, & Gilmore, 2015) to be discussed in further detail below.

**Risk Factors of Recurrence**

Having survived breast cancer, women look for ways that they can modify their lifestyle to prevent the recurrence of their disease. Modifiable risk factors have been
associated with initial breast cancer: alcohol consumption, obesity, lack of physical activity, and diets high in fat or inclusive of soy. Due to the association with initial breast cancer, healthcare providers have discussed such risk factors with their breast cancer survivor patients in order to prevent recurrence, even though little is known about risk factors of breast cancer recurrence (Norman, Potashnik, Galantino, Michele, House, & Localio, 2007). Recent childbirth, age at first childbirth, and oral contraceptive use have been found to be associated with higher risk of recurrence in specific case scenarios. Additionally, hormone replacement therapy has been associated with both breast cancer risk and risk of recurrence, but this result is limited by the study’s observational nature (Brewster, et al., 2007).

Even with incomplete evidence in this area, the American Cancer Society has developed guidelines for all survivors including women with a history of breast cancer to eat fruits and vegetables, exercise regularly, limit alcohol intake and avoid tobacco (ACS, 2015; O’Neill, et al., 2013; Rock, et al., 2012). These recommendations focused on health maintenance, in combination with the continued use of AET as prescribed, may decrease the chance of breast cancer recurrence in hormone-positive BCS (Jankowitz & Davidson, 2013).

**Screening for Breast Cancer Recurrence**

Healthcare providers follow clinical guidelines such as those provided by the National Comprehensive Cancer Network and The American Society of Clinical Oncology regarding surveillance for recurrence in BCS (Runowicz, et al., 2015). Surveillance for breast cancer recurrence is similar to screening for initial breast cancer.
Mammography is the gold standard of imaging after the completion of definitive treatment.

Breast self-examination (BSE) and clinical breast examination (CBE) also continue to be important in the post-breast cancer treatment setting. “Eight to fifty percent of ipsilateral and 18-80% of contralateral metachronous cancers [are] detected by mammography alone” (Schneble, et al., 2014, p. 282). Both the American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN) support annual mammographic follow-up after conservation therapy in breast cancer survivors, however the “optimal interval” of mammographic studies is still widely debated (Schneble, et al., 2014, p. 284). CBE is responsible for detection of about 15% of palpable masses. In addition, CBEs function as safeguards as 10-15% of palpable masses are reported to be missed by mammography. Outside of the metastatic setting, monitoring for cancer recurrence with tumor markers such as CEA or CA 27-29 is not recommended (Schneble, et al., 2014). There are currently no serum tests that screen for breast cancer or its recurrence.

**Health Impact of Recurrence**

Breast cancer recurrence often leads to additional symptoms compared to the first instance of breast cancer as well as a poorer prognosis, including worse physical functioning, fatigue, and quality of life (Wells-DiGregorio, Carpenter, Dorfman, Yang, Simonelli, & Carson, 2012; Thornton, Andersen, & Carson, 2008). Additionally, breast cancer survivors report meeting recommended physical activity guidelines at 70% prior to diagnosis, 39% after breast cancer treatment and only 15% after breast cancer recurrence (Loprinzi, Cardinal, Winters-Stone, Smit, & Loprinzi, 2012). With decreased
physical functioning and motivation towards health maintenance, the health impact of breast cancer recurrence is significant.

**Emotional Impact of Recurrence**

Additionally, after the completion of definitive treatment, it is common that women are worried about the return of their cancer. Fear of recurrence, inclusive of depression, anxiety, and poor quality of life, can persist for many years after the completion of breast cancer treatment (Cruikshank, et al., 2018; Thewes, Bell, Butow, Boyle, Friedlander, & McLachan, 2013). Fear of recurrence may be related to the side effects of AET, unemployment, anxiety, and depression (Corter, Findlay, Broom, Porter & Petrie, 2013). Women tend to feel higher levels of fear of recurrence in the weeks leading up to screening mammograms and decreased levels after a negative test, although the decreased levels are short-lived in nature (McGinty, Small, Laronga, & Jacobsen, 2016). Coping mechanisms and resiliency are areas that continue to be explored to offer protective assistance to cancer survivors and their significant others experiencing psychological distress (Lim, Shon, Paek, & Daly, 2014) such as that which occurs when experiencing fear of recurrence.

**Impact of Recurrence on the Family**

Breast cancer recurrence is a stressful time for families and can lead to worry, distress, and poor health outcomes for all family members, but in particular spouses (Wells-DiGregorio, et al., 2012). One of the most commonly reported complaints of woman with recurrence breast cancer is lack of interest in sexual intercourse (Sarenmalm, Ohlen, Jonsson, & Gaston-Johansson, 2006). Additionally caregivers face a risk of decreased psychological well-being initially when caring for loved ones with breast
cancer recurrence, but over time the continued stress may also result in decreased physical well-being (Northouse, Katapodi, Schafenacker, & Weiss, 2012). The impact of recurrence is far-reaching over women’s and caregiver’s health and emotional well-being. With such an impact, prevention of recurrence through maintenance of AET is critically important.

**Adjuvant Endocrine Therapy Recommendations**

To decrease the risk of recurrence, hormone-receptor positive BCS are prescribed adjuvant endocrine therapy (AET), inclusive of drugs such as tamoxifen and aromatase inhibitors, for five years or more at the completion of definitive therapies: surgery, chemotherapy and/or radiation (Petrilli, Coinu, Cabbidu, Ghilardi, Lonati & Barni, 2013).

Aromatase inhibitors (AIs) are one of the most common types of adjuvant endocrine therapy for post-menopausal women. This family of drugs works by suppressing the hormone estrogen’s production within the ovaries. “Aromatase inhibitors work by blocking the enzyme aromatase, which turns the hormone androgen into small amounts of estrogen in the body. This means that less estrogen is available to stimulate the growth of hormone-receptor-positive breast cancer cells” (Breast Cancer, 2016). The AI family includes anastrazole (Arimidex), exemestane (Aromasin), and letrozole (Femara). While there are choices among the AIs, research has demonstrated similar effectiveness and similar side effects as long as it is taken after menopause. Prior to menopause, AIs may increase the amount of estrogen produced by the ovaries and should not be taken (American Society of Clinical Oncology, 2016).

Tamoxifen is effective in pre- and post-menopausal breast cancer survivors, and may be chosen because of cost, as it is typically cheaper than AIs. Rather than
suppressing the production of estrogen like an AI would, it instead prevents the body from being able to use estrogen (American Society of Clinical Oncology, 2016).

Several large clinical trials were executed examining the extended duration of tamoxifen. The aTTom phase III trial found a 25% reduction in recurrence rates and a 23% reduction in overall breast cancer mortality for women taking tamoxifen for ten years. The ATLAS phase III trial found similar results with a 25% reduction in recurrence when adjuvant tamoxifen was taken for more than ten years as compared to five years (Petrilli, et al., 2013; Azvolinsky, 2013; Inman, 2014). These clinical trials led to the ASCO’s current recommendation that postmenopausal breast cancer survivors “choose among four options: (1) tamoxifen for 10 years, (2) an aromatase inhibitor for 5 years, (3) tamoxifen for 5 years followed by an aromatase inhibitor for up to 5 years, or (4) tamoxifen for 2 to 3 years followed by an aromatase inhibitor for up to 5 years” (Goss, 2015, p. 20).

Problem Statement

Despite known advantages of adherence to AET, studies report nonadherence rates ranging from 13-50% disruption or discontinuation before the recommendation of the provider (Chamacho, et al., 2017; Chim, et al., 2013; Danilak & Chambers, 2013; and Aiello Bowles, Boudreau, Chubak, Fujii, Chestnut, & Buist, 2012). Medication non-adherence leads to poor patient health outcomes and higher costs of care resulting in it being called the “key mediator between medical practice and patient outcomes” (Phillips, Leventhal & Leventhal, 2013, p. 1135). With extended durations of treatment, adherence will continue to be a challenge, impacting the incidence of breast cancer recurrence in BCS. The problem of nonadherence to AET in BCS and the subsequent potential for
increased rates of recurrence has led to this research question: How do post-menopausal breast cancer survivors make decisions about adjuvant endocrine therapy three or more years after the completion of initial treatment? This research study aims to describe the experience of post-menopausal breast cancer survivors as they transition from acute to chronic management of breast cancer, identify conditions that support or are barriers to adherence to adjuvant endocrine therapy in post-menopausal breast cancer survivors, and generate a grounded theory about post-menopausal breast cancer survivors’ decision-making and other conditions that impact adherence.

**Impact and Contribution**

Through dissemination, this program of research has impacted and will impact the quality of life and survival of women with breast cancer (Ahmed, 2013) as nurse researchers better understand women’s experiences, especially their barriers and challenges, in order to develop interventions to help patients make the decision to adhere and manage adherence to extended durations of AET. Adhering to the prescribed AET is the priority of the healthcare team, and this study has unearthed perspectives of women who adhere and those who do not intend to adhere to the recommendation. As indicated by the American Nurses Association (2011), nurses should seek ways to support patients as they make decisions whether they are in accordance with the healthcare team’s recommendations or not. Additionally, as this work is disseminated to colleagues in oncology nursing, adherence interventions may be adapted to improve adherence to treatments in other oncology diagnoses.
Chapter 2. Literature Review

Breast Cancer and Treatment Adherence

While nurses and doctors want to do what is in the best interest of their patients, they must be aware that patients have the right to make autonomous decisions about treatment adherence. The American Nurses Association (2011) regards the role of the nurse as a supporter of the patient’s decision-making (Maly, Umezawa, Leake & Silliman, 2004). While the onus of adherence falls largely on the patient (Tarn, Mattimore, Bell, Kravitz, & Wenger, 2013), providers can act benevolently, relying on research to determine where in a patient’s decision-making process they can enter and offer support so as to provide the greatest chance of adherence in their patients.

Recognizing nonadherence as a problem, the Oncology Nursing Society (ONS) and the American Cancer Society (ACS) in concert with the IOM (Nekhlyudov & Wenger, 2014) have outlined policy recommendations on survivorship care research priorities including “exploring factors associated with the delivery of quality cancer care to survivors,” in particular, exploring the facilitators and barriers to adhering to prescribed survivorship care in specific survivorship groups (ONS, 2018; ACS, 2018). In order to improve the quality of care, understanding the reasons why BCS decide to adhere or not adhere is essential. The literature in this population has focused on symptom severity, health beliefs, and patient-related factors that contribute to adherence and nonadherence behaviors.

**Symptom severity.** Side effects of AET include shortness of breath, dizziness, headaches, joint pain, muscle aches, cognitive and mood changes, fatigue, weight gain, hot flashes, change in libido, increased risk of blood clots, and many more, resulting from
the anti-estrogen properties which cause a side-effect profile similar to that of menopause (Aiello Bowles, Boudreau, Chubak, Fujii, Chestnut, & Buist, 2012). Women report that symptom severity causes disruption and discontinuation of therapy (Ganz, Petersen, Bower, & Crespi, 2016; Kuba, Ishida, Nakamura, Taguchi, & Ohno, 2016; Aiello-Bowles, et al., 2012; Wuensch, et al., 2015; Chim, et al., 2013; Park, Knobf, & Sutton, 2012; Simon, Latreille, Matt, Desjardins, & Bergeron, 2014). In one study, moderate to severe musculoskeletal symptoms were reported in 33-50% of women (Park, Knobf, & Sutton, 2012) and in another study, 11% of women discontinued AET prior to completion of therapy citing joint pain (57%) and treatment-related side effects (30%) (Chim, et al., 2013). Instruments used to measure the physical side effects of AET include the RAND-SF for Health-related Quality of Life (HRQOL), the Beck Depression Index, the Breast Cancer Prevention Symptom Checklist for side effects of AET, the Multidimensional Fatigue Symptom Inventory, the Pittsburgh Sleep Quality Index (Ganz, et al., 2016) and the Brief Pain Index (Chim, et al., 2013). It is clear that symptom severity is an important piece to the nonadherence puzzle, but other contributing factors need to be examined.

Health beliefs. Health beliefs have also been a focus of the literature on adherence to AET, with beliefs about the necessity of the drug (Harrow, et al., 2014), improved communication with the oncologist (Arriola, et al., 2013), weight of the cancer diagnosis, fear of recurrence, and regular follow-up reported as main facilitators of adherence (Simon, et al, 2014). Another study looking at Asian women taking AET found that severity of breast cancer was highly correlated with adherence (Kuba, et al., 2016), suggesting that early-staged breast cancer patients may face more difficulty with
adherence. One study found that 30% of women doubted the efficacy of their AET and 32% reported a lack of knowledge of why they were taking it (Wouters, et al., 2014). Instruments to measure health beliefs included the Beliefs about Medicines Questionnaire, the Self-efficacy for Appropriate Medication Use Scale, and the Perceived Efficacy in Patient-Physician Interactions Scale (Bender, et al., 2014; Kimmick, et al., 2015). Concepts mirrored in the Health Belief Model (HBM) (Champion & Skinner, 2008) are identified here and demonstrate why the HBM is effective for use in exploration of adherence behaviors, discussed further below.

**Patient-related factors.** Patient-related factors are those specific to the patient prior to initiating therapy. One of the greatest predictors of nonadherence was the presence of pre-therapy depression and anxiety (Mausbach, Schwab, & Irwin, 2015; Bender, et al., 2014). Higher physical symptoms, lower self-efficacy, having concerns about their medications, and decreased confidence were associated with intentional and non-intentional nonadherence behaviors (Kimmick, et al., 2015). Medication costs vary for each patient depending on their insurance coverage, but for some, the cost of medication may impact their adherence (Bright, Petrie, Partridge, & Stanton, 2016) and not often examined, one study found that forty-eight percent of women reported practical issues with taking medications such as problems with packaging, logistical complications, limitations in their daily lives and medication interactions (Wouters, et al., 2014). Instruments used to measure patient-related factors included the Beck Depression Inventory-II, Profile of Mood States tension-anxiety subscale, Interpersonal Support Evaluation List, Breast Cancer Prevention Trial Symptom Checklist, the Coin Measure of Economic Hardship, the Brief Fatigue Inventory, Menopause Specific Quality of Life
Questionnaire, Functional Assessment of Cancer Therapy-Taxane Questionnaire, and the Morisky Medication Adherence Scale (Bender, et al., 2014; Kimmick, et al., 2015). Patient-related factors, health beliefs, and symptom severity, as factors of adherence and nonadherence, have contributed to initial interventions in this population.

**Social support.** Social support is defined as “a network of family, friends, neighbors, and community members that is available in times of need to give psychological, physical, and financial help” (National Cancer Institute, 2018). Survivorship care includes complex decision-making that impacts long-term health. Social support, specifically emotional and informational support are positively correlated with self-efficacy in decision-making (Forsythe, et al., 2014). One important decision regarding long-term care of cancer survivors is the decision to adhere to survivorship care. A lack of social support correlated to decreased adherence (Quinn, Fleming, & O’Sullivan, 2016; Chlebowski, Kim, & Haque, 2014;) and may directly and indirectly impact all factors associated with adherence.

**Interventions.** Educational interventions have demonstrated impact on knowledge level, satisfaction, adherence, and HRQOL, but were limited in their results by short follow-up periods (less than six months) (Heisig, et al., 2014; Harbeck, et al., 2013). Park, Knobf, and Sutton (2012) called for an increase in musculoskeletal symptom assessment and exercise-based management of symptoms and von Blackenburg, Schuricht, Albert, Rief, and Nestoriuc (2013) used a cognitive-behavioral intervention to decrease the side effects of AET by mediating patient expectations about therapy. Patients require supportive and educational interventions, but the literature has yet to decide which factors are the most salient to address in this population.
**Important initial studies.** Two studies looked at important aspects of the research problem of interest. In 2014, a thematic analysis probing into the perspectives of post-menopausal women taking AET found that women saw AET as a necessary treatment, experienced unanticipated symptoms, had difficulty making sense of symptoms, had frustration in managing symptoms, and weighed the pros and cons of ongoing treatment (van Londen, et al., 2014). Additionally in 2015, a study in the Netherlands explored health related quality of life for women receiving extended durations (6-8.5 years) of AET, finding that global quality of life was significantly better for those on extended durations of treatment compared to survivors not on extended AET (79.6 vs 64.6; \( p < 0.01 \)) and the general population (79.6 vs 71.2; \( p < 0.01 \)). This effect could be related to the psychological well-being that occurs with extended survival, although the exact reason cannot be determined (Kool, et al., 2015). These studies provide the support for a deeper exploration of the problem of nonadherence to AET in post-menopausal BCS five or more years after initial treatment.
Chapter 3. Methods

This is a qualitative study, utilizing grounded theory to uncover the process by which post-menopausal breast cancer survivors make decisions about adjuvant endocrine therapy three or more years after the completion of initial treatment. This study aimed to describe the experiences of post-menopausal breast cancer survivors as they transition from acute to chronic management of breast cancer, identify conditions that support or are barriers to adherence to adjuvant endocrine therapy in post-menopausal breast cancer survivors and generate a grounded theory about post-menopausal breast cancer survivors’ decision making and other conditions that impact adherence. These aims helped to answer the research question: How do post-menopausal breast cancer survivors make decisions about adjuvant endocrine therapy three or more years after the completion of initial treatment? Medication non-adherence has led to poor patient health outcomes and higher costs of care resulting in it being called the “key mediator between medical practice and patient outcomes” (Phillips, Leventhal & Leventhal, 2013, p. 1135).

Approach

In 1934, George Herbert Mead developed and established symbolic interactionism, which became the theoretical basis of grounded theory (GT) focused on exploring different populations and a method for developing theories to understand human behavior and its social context (Charmaz, 2006). Observation of social interactions is a priority of grounded theory and helps researchers to understand individual behaviors in context (Holloway & Wheeler, 2010). “Pragmatism informs symbolic interactionism, a theoretical perspective that assumes society, reality, and self are constructed through interaction and thus rely on language and communication”
(Charmaz, 2006, p. 7). As researchers, we enter the world of our participants and become a part of it. Through their worlds, we construct theories grounded in the data by our “past and present involvement and interactions with people, perspectives, and research practice” (Charmaz, 2006, p. 10). It is through this symbolic interactionist view that we come to know GT as a theory and methods package of performing qualitative research (Clarke, 2005).

In 1967, Barney Glaser and Anselm Strauss discovered and expanded upon GT. GT allows “identification and description of phenomena, their main attributes, and the core social or social psychological process as well as their interaction in the trajectory of change” (Morse, Stern, Corbin, Bowers, Charmaz, & Clark, 2009, p. 14). GT provides tools to analyze data and develop concepts, although these tools should not be used as a cookbook, as there is no precise formula or recipe to apply to the data every time. It is better to consider GT as a way to think about the data, and thus should not be standardized (Morse, et al., 2009). As opposed to other qualitative methods, GT focuses on the process and actions central to understanding a problem (Charmaz, 2006). “A process consists of unfolding temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks in between” (Charmaz, 2006, p. 10). This method, largely used in sociology, later was introduced and refined in other disciplines. Through the collaboration of Anselm Strauss and Juliet Corbin in the early 1990s, GT methodology was introduced in nursing science (Holloway & Wheeler, 2010). Nursing science continues to use GT today, incorporating modern developments within the method.
In the last couple of decades, GT has shifted around the post-modern turn. This shift has allowed for many perspectives to be analyzed and pulled GT towards a constructivist approach where both the researcher and participant construct the theory together (Clarke, 2005). Elaborations on the method have included dimensional (Kools, McCarthy, Durham & Robrecht, 1996; Bowers, 2009) and situational analyses (Clarke, 2005). Dimensional analysis, passed on largely through oral tradition, is a response that grew from the lack of specific and explicit directions on how analysis occurs in GT. Leonard Schatzman, the first to describe dimensional analysis in 1991, encouraged his students to work at his side so that they could come to understand how the analysis is performed. Working with the students closely ensured that they learned the analysis methods well, but he was still troubled by the inability to articulate how the analysis was done (Bowers, 2009).

Dimensional analysis concludes that experiences have many dimensions and those dimensions have varying values attached to them. It builds upon constant comparative analysis to 1) develop dimensions, 2) assign relative value to those dimensions, and 3) make inferences about those dimensions (Bowers, 2009). Through this iteration of GT, multiple perspectives can be included in the analysis (Bowers, 2009). Perspective, a person’s ability to “see from a standpoint,” was not previously a central consideration of GT. Schatzman believed that any description of an action/situation/thing required an identification of “dimensions and properties” (Bowers, 2009, p. 101), and this process could be done by anyone with research experience or not. This, he believed, was natural analysis and is a very important part of what dimensional analysis entails (Bowers, 2009; Kools, et al., 1996). The focus of dimensional analysis remains the same
as that of GT, developing theory from the data. It is simply that dimensional analysis seeks to make the analysis process more transparent than it previously had been to that point (Bowers, 2009).

**Advantages and Considerations of Using Grounded Theory**

Different from other qualitative methods, GT focuses on the processes and actions central to understanding a problem (Charmaz, 2006). It uses a “structured and systematic” method of collecting and analyzing data (Engward & Davis, 2015, p. 1531) by use of constant comparison and theoretical sampling, unique to GT (Cho & Lee, 2014). Grounded theory could be used to answer this research question because the process of decision making for adherence or nonadherence to adjuvant endocrine therapy remains understudied, which limited the predictive power of the current literature. GT was able to go further than other methods to increase the explanatory and predictive power of decision-making, adherence, and nonadherence in this population (Charmaz, 2006) indicating that a deeper exploration with GT was warranted.

**Methodological Steps**

**Sampling.** The first step in grounded theory is theoretical sampling, which began in a purposive manner. Theoretical sampling, which began after coding the first few interviews, was driven by evolving concepts and theorizing based on comparisons that improved the ability to discover differences among theoretical concepts and “densify categories in terms of their properties and dimensions” (Strauss & Corbin, 1998, p. 201; Stark & Trinidad, 2007). By using theoretical sensitivity, the data was considered conceptually as it was initially analyzed and the criteria of sampling changed to develop theoretical categories in the data. There is a risk that a researcher may become attached
to an initial developing theory and as close-mindedness prevails, theoretical sensitivity may be lost (Strauss & Corbin, 1998). To avoid this risk, a basic question is used for theoretical sampling: “what groups or subgroups does one turn to next in data collection? And for what theoretical purpose?” (Strauss & Corbin, 1998, p. 47). From this question, the initial analysis was reviewed and additional theoretical areas were considered based on what was most important to explore next.

**Data collection.** The next step was data collection, which included individual intensive interviews consisting of 20-30 women recruited from three outpatient oncology clinics. To allow for a greater source of recruitment, social media support groups were used for advertising directly to potential participants and through the administrators of those groups. Phone interviews with audio-recording were available to meet the demand of a larger geographical region. A sample of this size allowed for the best chance of reaching theoretical saturation (Holloway & Wheeler, 2010). Hormone-positive post-menopausal breast cancer survivors were recruited from three outpatient oncology clinics in Virginia utilizing a purposive sampling method. In order to be considered for inclusion in the study, participants must have been:

- Post-menopausal as defined by self-description, age greater than 55, or have completed ovarian ablation.
- Estrogen and progesterone receptor positive
- Completed with definitive treatment (chemotherapy, radiation therapy, and/or surgery) more than three years before starting the study
- Prescribed adjuvant endocrine therapy at the completion of definitive treatment
- English-speaking
Exclusion criteria were:

- Men, as the 1-2% of breast cancer survivors that are men even though they are prescribed AET, are not the primary focus of this initial study
- Pre-menopausal women as the recommended endocrine therapies for this population are different from those of post-menopausal women
- Hormone receptor-negative breast cancer patients as they would not be prescribed adjuvant endocrine therapy
- Experience of recurrence as this study is looking more specifically at the prevention of recurrence
- Women with severe psychiatric conditions that would limit their ability to participate

Data Collection

An initial interview guide was developed with the help of experts in the field with a focus on unbiased, open-ended questions (Charmaz, 2006). First, sensitizing questions were asked to grow an understanding of experiences and subsequent meaning to the participant. Second, theoretical questions were developed based on the first several interviews as differences, connections, and relationships between concepts became more apparent. Third, practical and structural questions provided additional direction for theoretical sampling and theory building, specifically asking questions related to underdeveloped concepts and reinforcement of theoretical ideas. Lastly, guiding questions started out open-ended and became more specific as theoretical ideas became more firm (Strauss & Corbin, 1998). By using open-ended interviews and constant comparison, the researcher could return to the drawing table, analyze developing themes
and return to the field to explore specific conceptual ideas with new or revised interview questions (Charmaz, 2006).

Interviews took place at a location determined by the participant. Three locations were offered as options to the participant: a conference room at the facility where they were recruited from, a private room reserved at the closest library to the participant, or the participant’s home. Interviews were designed to last about an hour, but the space reserved for the interview was booked for two hours each time. This allowed additional time to review the consent form prior to the interview, and accounted for additional time if the interview continued past an hour. The interviews were audiotaped, so as to allow for field notes to be taken. Field notes included the setting of the interview and the participant’s behavior and was analyzed in concert with the other data collected (Holloway & Wheeler, 2010).

As a secondary source of data, literature was reviewed to stimulate theoretical sensitivity and guide theoretical sampling. It posed important research questions that have not been considered such as those regarding the types and frequency of side effects and the impact of fear of recurrence on adherence. The literature was used to verify the data such as that which occurred when investigating the impact of rituals on health behaviors and consider areas that refute their own results. Most grounded theorists believe that existing literature should be a source of comparison and not one of primary data (Holloway and Wheeler, 2010, p. 183).

**Data analysis.** Data-analysis was an ongoing process and began simultaneously to data collection. “Simultaneous data collection and analysis” helped to maintain focus through the data collection to inform “emerging analysis” (Charmaz, 2006, p. 20).
Dimensional analysis was utilized in concert with GT to allow for transparency within the analysis and a further understanding of the multiple perspectives involved in this phenomenon (Kools, et al., 1996; Bowers, 2009).

Interviews were converted into transcribed textual data. Dedoose ©, an analytic software, was used as the platform for analysis. First, data was coded in a line-by-line fashion, beginning with initial coding used in the data expansion phase. Further consideration was given to the basic actions and psychological processes impacting those actions. Coding took on a “language of action,” looking closely at each bit of data and labeling them as actions (Charmaz, 2006, p. 48). This process of coding allowed the researcher to remain open to the data and avoid the temptation to make theoretical leaps in the data prior to completing the analysis (Charmaz, 2006).

Initial codes were based directly on the data and were provisional, and were later refined and collapsed in order to better meet two GT criteria: “fit & relevance” (Charmaz, 2006, p. 54). Each participant interview was coded soon after her interview was transcribed so that interview questions could be adjusted for subsequent interviews to further develop theoretical concepts (Charmaz, 2006). Field notes were recorded during interviews and were analyzed and coded using the same methods that were used for other textual data.

Second, after the data expansion phase described above, a data limitation phase occurred, focused coding, where initial codes were reduced in order to combine concepts that were similar in nature. Second level codes were more abstract and developed through interpretation (Charmaz, 2006). Emerging themes were identified from the data and refined as the process of coding continues.
Third, axial coding occurred, which was the process of identifying emerging categories and exploring relationships between subcategories in the data, linking the data at the dimensional level. According to Strauss and Corbin, “properties are the general or specific characteristics or attributes of a category, [whereas] dimensions represent the location of a property along a continuum or range” (1998, p. 117). To organize into an explanatory matrix, Strauss and Corbin identify *conditions* of the phenomena, the *actions/interactions* of the participants experiencing that phenomena, and the *consequences/outcomes* of those actions and interactions. Axial coding allowed for a frame to be built around the data and provided structure moving forward in the analysis (Charmaz, 2006).

Lastly, selective coding occurred, where the integration of categories ensued and the theory was refined (Strauss & Corbin, 1998). Concepts and their relationships were integrated into various matrices where each major concept was given the opportunity to be examined as the central category. After examining each concept as a central/core category, the explanatory matrix of *ritualization of adherence* was chosen. In this GT analysis, the research team explored core categories in order to link all of the categories of the data together and to develop theories. Developing a grounded theory was the goal of this study and thus integrating concepts was essential to the final product of analysis (Strauss & Corbin, 1998).

The core category was determined as a result of selective coding. After an examination of each concept as the core category, a choice was made. The core category was the one category that pulled the other categories together to “form an explanatory whole” (Strauss & Corbin, 1998, p. 146). Using Strauss and Corbin as a guide,
ritualization of adherence was selected as the core category meeting the criteria below.

Strauss and Corbin have several criteria for choosing the core category:

- All categories must relate to the core category
- It must appear repeatedly throughout the data and exist in most case examples
- The explanation that relates all categories to the core category comes logically and must not be forced
- The name/label given to the core category must be abstract and demonstrate an ability to be used in other research areas/populations
- Through refining the concept, the emerging theory must have “depth and explanatory power”
- The core category must demonstrate an ability to support variations, contradictory cases, and complexities in the data (1998)

Memo-writing occurred during and after coding to fine tune the emerging conceptualizations and fill out developing categories. Memo-writing occurred early, often, and throughout the process of analysis. By analyzing the data frequently as it was collected, theoretical categories emerged and developed during the process of data collection. Making connections and comparisons in the data sparked new interview questions and pointed to new directions theoretically. By iteratively reviewing and revising the coding of transcribed data, all salient themes had emerged from the data and theoretical saturation had been achieved (Charmaz, 2006). Theoretical saturation occurred when enough data had been collected that there were no new “theoretical
insights” (Charmaz, 2006, p. 113). In order to ensure that an adequate amount of high quality data had been collected, several questions were addressed:

- Have enough data been collected to fully understand the contexts, processes, actions and experiences of the participants in the study?
- Have a wide range of views been presented in the data?
- Do the data demonstrate change over time?
- Are there enough data to make sufficient comparisons and analytic categories?
- Have the data reached a point of redundancy (Charmaz, 2006)?

**Dimensional Analysis.** Throughout the methods outlined above, dimensional analysis was woven into the coding and analytic process. In addition to the comparative analysis consistent with GT, dimensional analysis added a few additional layers. Schatzman suggested that the dimensional analysis process should be delayed until the first few interviews are completed so that several initial dimensions could be identified (Bowers, 2009). *Designation* occurred as dimensions were conjured up from the data (Bowers, 2009; Kools, et al., 1996). In many ways, this was similar to the first several steps of coding described above, and the researcher considered what concepts and properties derived from the data were also dimensions of the data. This provided a language that could be used to continue the analysis (Kools, et al., 1996). Second *differentiation* occurred as a value was assigned to each dimension deeming some to have great value and others to have little. By assigning value, distinction occurred between those concepts that had the greatest salience (Morse, et al., 2009; Kools et. al., 1996). Lastly *integration* occurred, as inferences were made about the dimensions, determining
what relationships were present (Morse, et al., 2009). In this final step of analysis, an explanatory matrix was chosen as described in detail above (Kools, et al., 1996). By adding the layers of dimensional analysis to the GT methods described, “both a structure and context for explanation” could be developed (Kools, et al., 1996, p. 317).

**Rigor and trustworthiness.** Glaser and Strauss (1967), have indicated that credibility in GT methods must be based on the detailed examination of data collection, coding and analysis. Within this methodology, several challenges regarding rigor could arise. Whittemore, Chase, and Mandle (2001) describe several threats to rigor in qualitative research including finding truth through multiple lens, how to establish dependable findings when variability presents itself, applying those findings to larger contexts and the avoidance of bias in data collection and analysis.

Furthermore, creativity in qualitative research has value and contributes to exceptional research, but it must be balanced with “reasonable claims, presentation of evidence, and the critical application of evidence.” (Whittemore, Chase, & Mandle, 2001, p.527). Creativity remains important because it guides the researcher towards the discovery of truth, and pushes the researcher past what is known (Whittemore, Chase, & Mandle, 2001).

Several methods were used to establish rigor throughout the study. Rigor carried through from the data collection stage to analysis. Theoretical verification was used by allowing participants to verify various conceptual ideas as they were emerging in the data analysis. Conceptual ideas could be confirmed and additional concepts could be explored. Code lists were collapsed into categories utilizing qualitative software and allowing for a data analysis trail.
In the data analysis stage of the research, a peer analysis team was formed and meetings with the team occurred every two to four weeks through the data analysis period. Prior to the initiation of those meetings, the peer analysis team along with the grounded theory faculty committee member met on a biweekly basis over a 12 week period in order review the techniques of coding and analysis. The peer analysis team assisted with initial coding, data expansion, axial and lastly selective coding. As the explanatory matrix was developed, the peer analysis team met on a more frequent basis to further discuss the placement of concepts throughout the model.

The faculty research team assisted with method verification, providing expert opinions, and overall feedback on the analysis process, research findings and conclusions. Reflexivity was performed through discussions with team/committee members. As a concept arose that needed further investigation due to the potential for bias, the concept was closely examined with the peer analysis team and the grounded theory expert committee member.

In the final two interviews the explanatory matrix was discussed with the participants to provide an additional opportunity for clarification. The participants had the opportunity to discuss concepts more fully and add additional ideas if they presented. After those final interviews, the concepts within the model were more accurately named but the general concepts behind the names remained the same. Through collaboration with the peer analysis team, the faculty research team, and participant verification, trustworthiness and rigor was established within the findings.
Recruitment and Data Protection

The participants were recruited through flyers (see figure 4) hung in the waiting rooms, exam rooms, and restrooms at each clinic. Additionally, Facebook was utilized for recruitment via several public and private breast cancer survivor support group pages. The wording of those posts were similar to that of the wording included on the recruitment flyers. Women who demonstrated an interest in the study through comments or messaging were contacted by phone.

The participants were consented by the PI prior to the interview. They were able to sign the consent form at the time of the interview and received a copy. For participants who chose to be interviewed over the telephone, verbal consent was obtained after the consent form was reviewed with the participant in its entirety. The participants were informed that they would not be paid.

Methods of protecting the participant’s privacy were discussed with them at the time of recruitment into the study. One method used to protect privacy was to allow the participant to choose the location of the interview. By allowing the participant to use the hospital conference rooms or alternatively the participant’s home, the participant could decide what was most comfortable for her. The data collected in the study was handled confidentially. Each transcript was assigned a code number. The list connecting the participant’s name to this code was kept in a password-protected file. When the study was completed and the data had been analyzed, this list was deleted. The participant’s names were not used in any report. The interviews were recorded, and the digital files were kept on a password protected laptop when not in use. The audio files were transcribed into Microsoft Word documents and uploaded into the Dedoose © website.
Interviews were recorded using a voice recorder and then uploaded to a password protected laptop when not in use. It was necessary to record the interviews so that they could be transcribed with accuracy and so that field notes could be taken during the interview. Audio and document files of interviews were kept on a password protected computer while not in use. The Word documents of the transcripts were saved to the password protected computer as well as uploaded to the Dedoose © cloud-based website. The results were reported individually as case examples in most published reports and were also discussed in aggregate.

**Risks and Benefits**

The greatest participant risks were related to confidentiality. Participant confidentiality could not be fully guaranteed, but several strategies were used to protect confidentiality as much as possible. The data was assigned a code number. The list connecting the participant’s name to this code was kept in a password-protected file. When the study was completed and the data had been analyzed, this list was deleted. No names were used in any report. Because of the nature of the data, it may be possible to deduce the participant’s identity; however, there was no attempt to do so and the data was reported in a way that will attempt to mitigate any chance of identifying the participant.

The findings from this study may help to develop future-health interventions that will benefit those in the geographical region of the study as well as other breast cancer survivors in this country. What risk that may have been incurred during the study is balanced by the knowledge that participants were contributing to the body of knowledge about adherence to medications in breast cancer survivors.
Chapter 4. Findings

A grounded theory on ritualization of adherence was generated from the data. When 21 post-menopausal estrogen-receptor positive breast cancer survivors were interviewed, they discussed a spectrum of creating, building, and depending on a ritual that would aid them in adhering to their adjuvant endocrine therapy (AET). Participants spoke of their value systems, particularly their faith in God and their desire to continue living so they could care for their families and do the things they love. In addition to their value systems, viewing breast cancer as a chronic condition, trusting their provider to deliver accurate information about the medications, and the desire to protect themselves from recurrence allowed women to elevate their consistent daily routine to that of a ritual.

The sample was recruited through local oncology clinics and subsequent snowballing (n=13) and through social media support groups (n=8). The age of the women at diagnosis included: ≤ 49 years old (n=12), 50-60 years old (n=8), and ≥ 61 years old (n=1). The recruited sample included women who were diagnosed with various stages of breast cancer: Stage 1 (n=7), Stage 2 (n=2), Stage 3 (n=10), and Stage 4 (n=2). The types of AET prescribed included: Tamoxifen (n=8), Exemestane (n=1), Aromasin (n=1), Letrozole (n=3), Unknown (n=0), More than one type of AET (n=8).

Additionally, 16 women were married and 5 were divorced or never married. All women described themselves as heterosexual or did not discuss sexuality. Race, ethnicity, and socioeconomic status questions were not specifically asked but from the interviews, it can be ascertained that the sample was largely Caucasian and middle-upper socioeconomic status.
During data analysis, attention was paid to wholly understanding the context and conditions impacting the decision to adhere, the process of committing to a ritual of adherence, and the consequences of that process. An explanatory matrix outlining the dimensions of the ritualization of adherence and their relationships is presented (see Figure 1). Using the perspectives of participants, the researcher defined ritualization of adherence as the building and creating of a ritual that aids adherence behaviors that women grow to depend on. It encompasses ideas such as faith in, believing in, and relying on a daily ritual in order to create a sense of control and self-protection. By identifying it as ritualization, the focus can be placed on what elevates a woman’s routine from simply a consistent habit to that of a ritual. Figure 1 demonstrates the explanatory matrix of ritualization of adherence. The upcoming sections will more deeply explore the context, conditions, actions and consequences of the process of ritualization.

After learning about the participants’ disease severity, the process for filling and taking the AET, and the way the medicine made them feel, a hypothetical question was posed, “if the research supported it and your doctor recommended it to you, would you want to/could you continue taking the medication [AET] for the rest of your life?” This question aimed to elucidate two concepts: 1.) the tolerability of the medication over time and 2.) the belief in the power of the medication. These answers provided theoretical guidance for developing the grounded theory.

As the interviews continued, they were packed with detailed examples of ritual building and the beliefs that made that ritual building so important to them. By developing a ritual and being able to depend on that ritual to improve their adherence, they were able to confidently say that they felt protected by the medication. Their ritual
gave them a sense of control in that matter. There was a resounding belief that they would continue to be cancer-free as long as they continued to take the AET the way that it was prescribed. Those women who did not take the medication as prescribed, discussed in more detail below, fell along a spectrum of ritualistic behaviors and belief in the power of the medication as well.

Consequently, the breast cancer, the universe, or God were often described as delivering a “message” to the participants about their life and this played an important role in the central process of the ritualization of adherence. The messages varied from those of advocacy to those of being strong enough to live the life that they always desired to live. Being able to derive meaning from their experience was emphatically described and was reflective of the values/belief systems that initially impacted the decision to adhere and build a ritual.

Central Perspective: Ritualization of Adherence

Ritualization of adherence is conceptually defined as the building and creating of the ritual that aids adherence behaviors that women grow to depend on and involves several steps from the process of filling the medication to the organizational strategies for remembering to take their medications. This process was strongly supported by the belief in the power of the medication to protect them from the recurrence of breast cancer. The medications [AET] provided a “rubber shield” or a “parachute” which empowered women to develop ritualistic behaviors. Specifically without the desire to protect themselves from recurrence and trusting that their providers were up-to-date on the best course of treatment in the use of AET, these women would not be able to develop a ritual that allowed them to take their medication despite barriers such as severe side effects and
disruptions to their routine. Ritualistic behaviors add a layer of self-protection that would otherwise not be present. With the perceived protection from the medication, the habits surrounding their adherence behaviors are elevated from mere daily habits to those of rituals.

**Context of Ritualization of Adherence**

In qualitative research, researchers seek to understand something by “learning what it does, [and] how particular people use it, in particular contexts” (Schwartz-Shea & Yanow, 2012, p. 23). Context refers to those things that are naturally pre-existent prior to the process of decision-making and the development of a daily ritual with adherence behaviors in breast cancer survivors. Several contextual pieces were identified as key underpinnings of the process of ritualization: the values and beliefs that drive a woman’s desire to live, her view of breast cancer as a chronic condition, and arming herself with accurate information about the disease and treatment.

*Values and Beliefs System: Driving the Desire to Live.* Very simply stated, values are what were important to women and thus impact their ability to adhere. For these women, values included making time for what was important to them, faith in God, living a long life, taking care of others, and preserving body image. Values may become more pronounced with diagnosis, but are considered contextual because they are present prior to the diagnosis. Many women described faith in God as a primary belief and value system as demonstrated in the excerpts below:

My relationship with the Lord. Because I know, regardless of the situation, scripture tells me the Lord does everything for my good whether I understand it or
not. So, I have to believe that because when I was diagnosed with cancer. Even though, you know, in the beginning you’ve got the anger the fear you know. After a while it’s like I’ve got to get off my pity pot. This is what’s going on and this is what I need to do. And I just got a peace, I knew the Lord was going, it wasn’t until I came to this point that I knew. I got a peace.

So I just, I really do believe in prayer and having faith that things will be alright. I think that’s impacted me tremendously. I think that would be the biggest [value].

But it is more than just a faith in God that impacts how women make the decision to adhere. It is also about wanting to survive to do specific things in their life, like seeing their children into adulthood, caring for their families or getting back to the things that make them happy. One woman describes just how much she felt that her husband and child needed her and that was her central value.

I just want to see my kids grow up. My husband and I have been together since we were 15. We were high school sweet hearts. I want to grow old with him. So you do what you have to do….My decisions had to be based on what I saw around me, and I didn’t think he was capable of handling my daughter. Because I was on a first name basis with every principal, vice principal, school psychologist. God, she was a handful. So I decided on the Arimidex, and I decided no matter what, if this keeps the beast away, I will take it.

Women perform an inventory of their lives, determine quickly what matters, and then make a choice regarding adherence based on those values. Even women who
choose not to take the medication first consider what is important to them. One participant had to balance her side effects versus her quality of life. Her highest value was placed on what would make her feel the least ill.

But I’ve had these other health problems for close to 30 years. Usually people would rather have cancer because they would die or get better. I was afraid to make myself sicker in those other ways. Everyone was telling me that it didn’t matter. But I had to live with those issues, so. It wasn’t that hard of a decision for me.

Self-reflection often occurred close to diagnosis, but had a lasting impact on decision-making. As demonstrated through the excerpts, women placed value on a multiplicity of things. But despite the differences in where their value was placed, the decision-making process was repeatedly impacted by the values and beliefs that each woman came to the diagnosis with.

*Viewing Breast Cancer as Chronic Condition.* While healthcare providers have viewed cancer as a chronic disease process for many years, patients have long held the belief that cancer was something they could fight and beat so that they could move on with their lives. The duration of the AET prescription is only an introduction into the new normal that is breast cancer survivorship. The participants in this study were in a unique place in time in that the recommendations surrounding the exact duration of AET had recently changed (Goss, 2015) and many providers are skeptical that the recommended durations from the American Society of Clinical Oncology (ASCO) may change again in the future. The researcher posed the question to each participant, “how long did your doctor say that you would need to take this medication [AET]?” Some of the
participants had finished their AET prior to the change in recommendations and thus took five years of medicine. Others taking the medicine initially were told that they would be on it for five years, but their doctor had told them that they would actually continue the prescription for ten years. Others were told it may be longer, with one participant indicating that she asked her doctor if she could continue the medication after ten years and he said that she could.

Well I talked to him, I had bought this book, *the Breast Book* by Susan Love. I talked to him and said I don’t think I should be on it for 5 years, I think I should be on it for 10 years. He said, you know what, you are right, let’s do that. So that’s our plan.

Other women described finding out that they would be on a longer duration of AET.

Well, uh, they said 5 years with a strong probability it would go 10 years.

I started it a year after my diagnosis, so 2012, and it originally when I got diagnosed I believe the research um supported a five year treatment. But actually into my first year of being on the Tamoxifen there was some updated research. And from conversations with my doctor and the cancer board the new recommendations were for that 10 year course completion so that’s what they think would be best for me. So I’m on it for a total of 10 years.

The participants felt protected by the idea of extending the duration of their AET. But despite feeling additional protection, many had conflicted feelings recognizing that they had already tolerated a great deal to arrive at that point.
I think I can. I know quite a few other people that had to switch it um because of their side effects. And I mean blood clots, hospitalizations and stuff like that. And because I haven’t experienced any of that… I feel like this is my comfort, the only thing that I sort of have control over, in hopes that the cancer doesn’t come back. So, I want to stay on it as long as my side effects don’t worsen.

…the Tamoxifen is not great but I know that when I talk to my doctor…when I questioned him probably a year ago and said you know, I’ve been on it a couple of years and I still have all the side effects, the hot flashes, the bone pain, I could go on and on about the side effects. And he said if you go off of it, you will get cancer again. It will come back. So that made me dig my heels in and I’m gonna take it, so I went out and bought myself a little pill sorter so I would make sure that I didn’t forget it.

But despite the recommended longer durations, women and providers alike began to worry about the long-term effects of the medication. Women who once believed that they would be on the medication for five years were no longer able to view their disease as finite.

I have my appointment on Friday so I did have some questions lined up for her to just see. Is it infinity? Do I take it forever? Is there any other damage that could potentially be done to my body? The way I understand the Tamoxifen is that it is an estrogen blocker and if you have estrogen positive cancer and aggressive tumors that came down from high levels of estrogen. To me it makes sense that you would take an estrogen blocker forever. But is it going to kill my liver, is it going to do something else to me. I mean I do need to talk to her about it.
Armed with Accurate Information. As a result of viewing the breast cancer as a chronic condition, women actively sought sources that they believed would provide truthful information about their disease and how to treat it. Primarily, women looked to their providers to explain these things, but in cases where the provider lacked the time or ability to educate, women used other sources to arm themselves with information including discussions with fellow survivors in support groups, the internet, and the packet of information provided by the pharmacist. The information women sought ranged from reliable to inconsistent and untrue. Several women described how they balanced advice from professionals with their own research.

I pretty much listen to my health professionals. Sometimes I’ll do a little bit of internet research. For the most part I find doctors and other health professionals that I trust and go with what they feel is appropriate.

Um, I read the little insert that describes all of the possible side effects. And the oncologist that I worked with…was a female and she was excellent, she would walk through the different blood clot possibilities and different things like that and the warning things to watch for. And I think I was really well prepared for what might happen.

My oncologist and then my own research. Just being pretty anal and being a nurse just doing some of my own research and reading over the side effects. My oncologist is pretty informative and she tries to keep me in the loop as much as she can.
Of the conditions, trust, particularly in the provider was a focus. Trust is reflected in whether women felt like they were armed with the information they needed. More than simply wanting to know about the pill that was prescribed, they wanted to know to what degree it would be beneficial to them. With that context, women could build a ritual based on what they deemed to be the best information, even in the cases of nonadherence. More than one woman addressed how important data and statistics were to their decision-making process.

Statistics. Actually nobody gave me statistics. I found them myself on the internet and I wasn’t happy that I did that… You have to know the statistics, you have to know what your odds are.

I make decisions based on what I believe are medical facts such that I can determine, find out, talking to my doctors, consulting with them. Speaking to family that are in the medical field. I’ve got several nurses in my family. And kind of gathering the facts and then looking at the risk and reward. It kind of goes back to my financial background. Statistics and statistically I felt that I was safe going off the Tamoxifen.

Conditions Impacting Ritualization of Adherence

After establishing the context, it was important to determine what conditions were impacting the ritualization of adherence. Charmaz (2006) defined conditions as “the circumstances or situations that form the structure of studied phenomena” (p. 61). The conditions impacting ritualization are broken down into two main categories: facilitators
and barriers of ritualization of adherence. The details of these conditional factors are described below.

*Facilitators to Adherence.* Facilitators of ritualization of adherence include self-protection and support systems. Self-protection is a mechanism that survivors use to protect themselves physically and mentally from the fear of recurrence and recurrence itself; it was a means of distancing themselves from thoughts of recurrence. Self-protection includes two key dimensions: fear of recurrence and belief in the power of the medication. Women, in an effort to promote a return to normalcy, push the fear of recurrence from their minds in order to focus on their current lives and health maintenance. One woman described several close friends who had been diagnosed about the same time that she had been, who had recently died after a recurrence of breast cancer. Getting close to others with breast cancer had become difficult.

Emotionally it can be really hard. To kind of distance myself a little bit from any new people that are joining. Because last year was so brutal. The thought of another year like last year, you know you have to protect yourself. But unfortunately, I’m someone who likes talking to people. So it’s really hard to not get together with people and talk and try to help them.

Another woman talked about how her appreciation for life allowed her to distance herself from thoughts of breast cancer recurrence.

I don’t live cancer. I feel like I appreciate life more. I think I appreciate being active more than I ever did before. I always thought I had so much time. But we don’t know anymore. I rolled my four wheeler two years ago and broke 2 ribs.
And I thought, now this is something I could die from. There are too many high risk things or we’d all live in a bubble. You have to live.

Avoidance of negative thinking became pervasive for one participant. She felt that if she could think of other things then she could prevent recurrence from surfacing. Additionally, negative thoughts were replaced with concrete, practical prevention methods.

I try to avoid. I don’t look at certain things… I don’t think I focus on it that much, really. I do things that I think will help prevent it from coming back. I take a whole lot of supplements that I never took before. I don’t eat soy. I don’t drink a lot of alcohol. I try to eat organic. So and then, I think well I did the chemo and it killed every cell in my body. I’m good to go.

Many women went on to discuss how much they believed in the medication [AET] they were taking. This was partially based on their trust in the recommendation from the provider and partially based on the safety net that they believed that the medication was providing.

I was nervous to even get off of the pill. And I said to him at that point in time, if it’s doing, if it’s protecting me, why would you take people off of it? But there was a whole medical thing why it doesn’t help really any better. All studies showed that you really don’t need more. So yes, when I got off of that and when he let me go. I was excited and thought wow this is great but yea, it’s a fear that, he was watching me. He was watching over me.
And I felt like it was a great big protective umbrella. And my new oncologist, tried to dissuade me of that thought because he said it’s not that you could never get a recurrence on Tamoxifen, it’s just that it’s reducing your chances and this and that. I was a little disappointed to hear that. I felt like I was wearing a rubber shield.

Women were able to continue their medications with the support of those around them. While friends and communities tend to rally at the time of diagnosis, family, particularly the spouse and also the provider offered the greatest level of support through the medication endurance periods of survivorship and dealing with cancer as a chronic condition. Women felt supported by their providers through education, side effect management, and having their questions addressed.

They were always there when I would call and ask questions. And just be very supportive when I told them how I felt, just with all the pain and you know, that’s what made the doctors say, we’re going to try you on something else. I think they were very supportive. And just asking how I felt, and just being there whenever I called to ask questions.

I just feel that if I have any problems I could call. You know I just feel very comfortable with them. And I know that they will listen to me and help me come to the right decision.

In addition to the practical support that the providers, nurses and office staff offered, husbands and children also listened and offered comfort and support in a way
that only families seemed to know how. Several women described how their husbands and children provided unconditional support.

He was very supportive. My husband was super supportive and my daughters. I felt I had my support system that I needed. And you know if I had something to say, I just said it. And they were here to listen.

He’s a worrier, but he was very supportive. All my kids were very supportive, so. That was really helpful, that was nice.

My husband backs whatever I do. He’ll say comments like she knows her health better than anyone.

Spouses often had to adjust to the side effects of the AET as well, and several women spoke of how those side effects impacted their husbands. Despite feeling the impact of the medication, husbands provided steadfast support. One woman describes how the side effects of the medication made intimacy more difficult.

Oh yea, so much dryness that it’s actually painful. Honestly, my mom’s voice just popped into my head, “You [sic] shrivel up like a prune”, and it’s really brutal. And I had no clue that was going to happen and that was going to come…So it’s been a very literally and figuratively a dry season. But it’s not that I don’t think about it. I totally think about it, and I joke around about it with my husband, but we haven’t really been able to have sex at all really. If I could count on one hand how many times in the last six years that we’ve had sex. Which is sad, but we used to have the most wonderful sex life. We would have sex every day. And it was great so, I feel like it was, we had all of those great
years so we’re going to have a few bad years. And hopefully when we are old, we can be frisky again.

Women discussed how there was less of a need to talk about the impact of the medication to their friends as time went on. It was during later years of survivorship that they leaned into their relationships with their family and providers for the support that they needed to continue.

But now, that it is this far out, I don’t even mention it. Like we have, I’m in a book club, people don’t mention it that much anymore, so. How could I say it is supportive? I guess if I needed to talk, I could. But I just don’t talk about it.

But outside of that, I’m not going to say that they haven’t been there, I just don’t feel like I’ve needed them at this point four or five years down the line of being on it?

*Barriers to Adherence.* There are two primary barriers to adherence that emerged from the data in this study: side effects and disruptions to routine. Although many of the side effects that were reported were not commonly associated with AET, all that mattered was whether the women believed that they were related. Side effects of chemotherapy and aging were intermingled among the most common of the AET side effects reported such as arthralgia, hot flashes, vaginal dryness, and changes in cognition. In terms of disruptions to routine, examples were often related to travel or various other distractions. Several women described their routines and the imperfections within the routines that make them harder to maintain.
Yes I take them every day when I come down for breakfast. The times when I do forget is when I’m away from the house. And that’s difficult for me to remember so I always carry some extras in my purse. So if I remember while I’m out and about, I can take it.

And so if I’ve not filled my tablet boxes and it gets to Tuesday night, I know I’ve not taken my allergy tablets because I start with a sinus headache and sinus pressure. And that gives me a wake-up call, you can’t not take your tablets. You’ve got to buckle down and get back on. So usually it’s only a couple of days.

Additionally, one woman describes how travel created an interference with her ability to adhere.

Actually I think there was a morning, usually when we’re out of town…I’ve forgotten a couple of times. When you are away from home.

The severity of side effects has led to women switching their medications or quitting the medication altogether. Amongst the 21 women who were interviewed in this study, approximately 30 unique side effects were described ranging from hot flashes and arthralgia to urticaria and malaise. The perceived side effects of AET were pervasive in this group of women with one woman unable to persist for more than one day of her prescription and others making it much longer.

I was first prescribed Arimidex and that was just making my muscles and joints hurt so bad. And I guess maybe I took that for…maybe a year or year and half and then I was put on Femara. In all it was 5 years.
First I was diagnosed [sic] an aromatase inhibitor and I immediately had terrible side effects from it. So um, they did give me every single, Arimidex, I tried all of them within probably 2 months, I tried the four that were available. My doctor finally said no, go on the Tamoxifen, you are having too many side effects from the aromatase inhibitors.

I took Tamoxifen for about, I would say about 8 months, but I was having my period. I still had it every 30 days and the Tamoxifen was driving me crazy. I figured between the hot flashes and the mood swings, I was going to come out of this experience alive but alone. Roundabout the 5th or 6th month into, my gynecologist said, just have your ovaries out. And then I spoke to my oncologist and he said good idea. So I had my ovaries out when I was 53 and changed to Arimidex.

Within like seconds of taking it, I turned pale and just felt really awful. And I was supposed to stay on it so that something was fighting the cancer while I waited to get insurance. But instead I took supplements that block estrogen instead of medications.

For many of these women, they were fortunate that another AET drug was available so that they did not have to quit the medications altogether, but many found that the drugs that they were initially prescribed were too difficult to tolerate.

**Actions/Interactions**

Charmaz (2006), defined this part of the explanatory matrix as “actions and interactions”, which are defined as the “participants’ routine or strategic responses to
issues, events or problems” (p.61). The process of ritualization includes two main categories: making the (re)commitment to adherence and building a healthy lifestyle as a survivor. In other words, in order for women to confidently build a ritual that they could depend on, they had to make the commitment to do so, often repeatedly, and want to remain healthy in the years to come.

Ritualization of Adherence. Through this grounded theory, a greater understanding of the decision-making and conditions that impact adherence to AET have been examined. The daily ritual is the routine which the participant uses on a daily basis to remember and reinforce taking their medication. The ritualization of adherence is the building and creating of the ritual that aids adherence behaviors that women grow to depend on. It encompasses ideas such as faith in, believing in, and relying on a daily ritual. By identifying it as ritualization, a focus can be placed on what elevates a woman’s routine from simply a consistent habit to that of a ritual.

One participant described the obsession that she felt about her ritual, “I’m really good. I’m a freak about it. I’ve got a Monday, Tuesday, Wednesday, Thursday, Friday. (Gestures to imaginary pill box).” Other women described their ritualistic methods, “Well I take it at night. So it’s by my bedside table. So I take it off the table. I have a dresser. I take it and put it in on the dresser so that I know that I’ve taken it. If it is not on the dresser, so I switch places.” Another woman described that she “devised a system, I put my medicine in AM and PM and do it for a month at a time because I would forget. I have to be reminded that way. I have to look at what I did in the morning and what I did at night. And have it down according to day or I would forget.” Yet another woman describes her methods, “I have a weekly pill box, so usually on a Sunday, I sit and I do
my pills for the week morning and evening. It’s very sad how many tablets I have to take
every day and it’s the only way I can keep everything in order.” Even more important
than the methods, is the belief in the medication that shows that there is a reason for the
ritual. Women describe how discussions with their oncologists provided them with that
reason to develop a ritual.

When I questioned him probably a year ago and said you know, I’ve been on it a
couple of years and I still have all the side effects, the hot flashes, the bone pain, I
could go on and on about the side effects. And he said if you go off of it, you will
get cancer again. It will come back. So that made me dig my heels in and I’m
gonna take it, so I went out and bought myself a little pill sorter so I would make
sure that I didn’t forget it. I take it every night with a couple of other pain meds
and different medications I need for other things.

If I don’t take it, it’s going to come back is scary. And I know he didn’t say it to
me to scare me, but he to just really boldly spell it out for me. Like look, this is
what we know this medication can do and if you don’t take it, you are headed
back into the infusion room. Basically what he was saying.

The ritualization of adherence has become a part of the daily life of participants,
“Well, I take it about the same time every day about 10 o’clock in the morning. So it’s
after I’ve read the paper and have had my first cup of coffee. And then I’ll have a
second cup of coffee and take my medicine.” Another woman, when asked if she ever
forgot to take her medicine, responded “no, no. They are as regular as breathing.”
Making the commitment to adherence was a decision that for some occurred once and for many occurred over and over. Women want to follow recommendations but may encounter barriers to doing so. By relying on their values, support systems, and desire to protect themselves, they were more confident in the commitment to adherence.

There’s no arguments over my decisions. But I think them through, I think them through. I do what I need to do. I would say that’s what I do.

Um I trust my intuition and trust my intelligence even though it can make you feel like you have Alzheimer’s disease. I trust my intelligence, and doctors who can honor that and see that will say ‘Oh my goodness, you have an amazing knowledge of your health conditions’ and treat me with respect that makes me feel more confident about my decisions.

The commitment to adherence has two decisional-related consequences, either decisional satisfaction or decisional ambivalence. Women reported through the interviews that they were either satisfied with their decisions to adhere or not adhere, or were left questioning their decision. Each participant was asked also about whether decisional regret was part of the commitment to adherence and repeatedly the participants said that they experienced no regret related to the AET related decision-making. Of note, if regret was discussed, it was related to earlier screening and treatment decisions such as those pertaining to surgery and chemotherapy. Those who were satisfied with their decisions described that satisfaction as relief that the decision was over or confident that they had made the right choice.
Pretty good, I think that, I’m sort of, I’m always future thinking. When I’ve made a decision, I’ve usually thought about it for a long time. Um, especially if it is something I was going to plan for. When I have to make a snap decision, I just say well I’m making the best decision that I can based on what I know. And if it doesn’t turn out, it didn’t turn out. I have to forgive myself. It wasn’t perfect. But yea I’m usually pretty confident about the decisions I’ve made.

Usually I feel good. Sometimes it’s one of those things, is it really what I’m supposed to do? Lord, this is what I think I’m supposed to do but if it’s not, I know you are going to block it. And if I still make the wrong decision, I know you can turn it around for me.

I usually feel really good. I usually feel like I’m ready to move forward and let’s do this.

Despite those that felt confident, there were still women who wondered if they made the right choice for the situation. They described decisional ambivalence as questioning or needing the approval of others.

I’m that type of person that questions myself a lot. And I like to talk things through with other people. You know, just because I am a talker. I’m a marketer. I have to talk every day for my job. So um, I do like to talk.

One woman asked her Oncologist to make the decision for her because she was not confident in her own decision-making.

I said, no no no, you decide because I can’t make [this decision], I don’t know.
Building a Healthy Lifestyle as a Survivor. The second important part of the process was building a healthy lifestyle as a survivor. This also tended to be very ritualistic, mirroring behaviors like the daily rituals built by participants for adherence. Women described how they built a healthy lifestyle for themselves after the diagnosis of breast cancer by changing their diets, exercising more frequently or closely following cancer screening guidelines.

I do things that I think will help prevent it from coming back. I take a whole lot of supplements that I never took before. I don’t eat soy. I don’t drink a lot of alcohol. I try to eat organic. So and then, I think well I did the chemo and it killed every cell in my body. I’m good to go.

I’m trying to walk now. Putting the fitbit on. Trying to make sure I get at 13,000 steps a day which I’ve been shy of that because it’s been raining. My cat thinks I’m crazy when I keep walking around the house, keep walking around the house. Um, as far as, I’ve always been not just a junk food eater, but I do like my sweets. But I do try and eat healthy-ish. I’m staying in the Word, keeping in the scripture, my Bible study because that helps me mentally and helps me find the peace also. Um, trying to be aware of my body. You know if something feels different, somethings going on. Trying to figure out what’s going on and acknowledge that if I need to go see the doctor, go see the doctor.

I’m closely watched, I don’t miss doctor’s appointments. I monitor my chest. And again, there were these divets that concerned me, they felt like lumps but they were actually the implant coming through the chest wall. Because the wall
was too thin when they stretched me. But I feel that, I have excellent care, excellent doctors.

Try to eat better. I’ve made a lot of better eating choices and decisions. Since my diagnosis. Exercise, health and wellness. You know I really try to encourage myself and encourage others around me to eating right, and drinking your water, and exercise. I sleep, I try to stay up on my sleep as much as possible. I try to reduce my stress and keep a clear, free mind. I try to go to a spa, just to relax me.

Most women in this sample described how seriously they had taken their health habits since the time of diagnosis. Even those without positive health maintenance habits described that they knew that they should be eating more nutritious foods and exercising. Some women described how they took care of their spiritual and mental health as well. Building a healthy lifestyle as a survivor meant that the survivor engaged in behaviors that improved their health status such as healthy eating, drinking water, exercise, getting rest, managing stress levels, and seeing their healthcare providers for scheduled visits and screening. Women who are eager to improve their lifestyles and health will also do what they believe is best in regards to their medications, by building a ritual to maintain adherence.

Consequences

The consequences of ritualization of adherence fall on the spectrum of behaviors of *adherence* to *non-adherence*, with women describing the cyclical nature of evaluating choices to remain adherent. Often this occurs around the time of screening mammograms and annual doctor visits, where they must again recognize their disease as chronic in
nature. By continuing to monitor for the recurrence of breast cancer, they were reminded to consider what methods they are using to prevent recurrence, including adherence to AET. Ritualization occurs on a spectrum with those participants with a stronger daily ritual having a higher level of adherence with the converse also ringing true.

Additionally the message- I’m strong enough to... presented as an opportunity to focus on themselves, meet new people, or change their current way of living. The diagnosis was an opportunity, and women often described a sense that the breast cancer had delivered a message for them showing their true inner strength as survivors.

Many women were diligent in their adherence to AET and described both the feelings they had about taking their medication and the routines that helped maintain their adherent behavior.

No I never missed more than one and then I would panic.

I don’t remember ever forgetting to take it. And I think maybe because I was on a routine at 7:30, that helped for me to remember to take that pill. Even if I was going to be out somewhere, I would take my medication with me so I could remember to take it at that time.

I’m remembering missing something and if I did, it was immediately the next morning and then again the same night for the next dose. So, I was never without.

No because I devised a system, I put my medicine in AM and PM and do it for a month at a time because I would forget. I have to be reminded that way. I have to look at what I did in the morning and what I did at night. And have it down according to day or I would forget.
Other women were decidedly not adherent to their AET. In these cases, the barriers to taking the medication were described as insurmountable. One woman who was non-adherent due to persistent urticaria for 18 months described that in the end, she felt like the decision to stop was best for her. “No I really feel like I’m doing all the right things. I eat very healthy. I follow the doctors’ orders except for the fact that I stopped the Tamoxifen.” Another felt that with all that was going on in her life, including the loss of insurance, she was not able to continue taking Tamoxifen. For an overly eventful time in her life, it was more than she could handle to continue the prescription.

You know sitting down and going, and for a while I had come off the Tamoxifen, as I said with the hysterectomy and then I was going through the divorce process. I mean that stuff was starting the next year and I lost my insurance and for almost a year I was actually off the Tamoxifen.

Yet another woman described how the medication and the disease caused hormonal side effects that were overwhelming to her.

I had to stop taking the pill when I was diagnosed because the cancer was estrogen-based, there was nothing I could take. So for the first time in a decade, I was menstruating and having hot flashes, right after my diagnosis. I just plunged into hormonal pandemonium.

The final consequence of ritualization of adherence was “the message-I’m strong enough to”, where women realized that after surviving breast cancer and all of its treatments that they were indeed strong enough to do things that they were never capable of before.
No matter what adversity comes. I’m strong, and I am loved, and I will get through it. And you know it’s one of those things of accepting life, and not running from life… So I think just realizing that we all have adversity. It doesn’t matter what form it takes. The thing is to recognize it, go through whatever stages you have to. Get yourself off your pity pot, develop a plan and go for it.

And see what you can gain from it. There’s always got to be something positive in a situation, I feel. So, see what you can gain from that situation and the adversity it never took control of your life. You took control of the adversity.

One woman, after overcoming a breast cancer diagnosis and the difficulties of treatment found the inner strength to make important changes in her life.

Well for me, I was very unhappy in my marriage and I knew after I got the cancer and I was coming out on the other side of it that I had to make a change for me, you know I think for me and a lot of women. If your estrogen is elevated, usually your anxiety is elevated. There is stress, and for many years, a lot of the stress of my personal life was feeding into that. So after going through, I made that decision that I would get a divorce and start making me happy… And I walked out of there that day, I’ve got to become a nurse. I’ve got to go to nursing school and get a divorce.

You know, I got through for this. You got through it, you’re going to continue to get through it and so I love my survivorship….I done been through my storm and I’m getting through my story.
The consequences demonstrated the profound influence of the process of ritualization of adherence on post-menopausal breast cancer survivors. Concluding to adhere or not adhere, and deriving a positive, life-affirming message from their experience will have lasting impacts on the women who have made the commitment to adhere or not.

Through the grounded theory on ritualization of adherence, a greater understanding was gained of the experiences of post-menopausal breast cancer survivors as they transition from acute to chronic management of their disease, the conditions that support and the barriers to adherence of adjuvant endocrine therapy, and the conditions that impact the decision-making process. An explanatory matrix was constructed through the cooperation of the researcher and the participants who survived a breast cancer diagnosis and were prescribed an adjuvant endocrine therapy medication to take in the years after diagnosis. The lives of these women were unique and each of their experiences rich with details about the impact of taking or not taking the AET as prescribed. These findings have informed the researcher’s grounded theory conclusions described in detail in Chapter Five.
Chapter 5. Discussion and Appendices

Discussion

Throughout this constructivist grounded theory study, participants described the perspective of ritualization of adherence as a way of explaining what conditions and contexts led to adherence and non-adherence in the extended duration of AET use. Qualitative research continues to be a necessary foundation to the research in this group of women (Verbrugghe, Vergaeghe, Decoene, De Baere, Vandendorpe, & Van Hecke, 2017; Van Londen, et al., 2014; Bender, et al., 2014), considering the guidelines for medication use in AET is frequently updated based on new evidence (Goss, 2015). By utilizing a constructivist grounded theory approach, a much deeper understanding was gained and the perspective of ritualization of adherence was explored on a broad and comprehensive level.

What we understand now: women take an inventory of their values and beliefs when faced with a life threatening illness and that inventory impacts a woman’s treatment choice. Making the commitment to adhere (or not adhere) and building a ritual for adherence (or non-adherence) meant that a women believed in something. Whether that belief, such as faith in God, led to adherence or non-adherence, women could always go back and explain how their decisions were both guided by and reflective of their values.

With a greater understanding of the information-seeking and healthy-lifestyle building that women participated in during the extended survivorship period, providers can appeal to women in their desire to understand the nature of their chronic disease, the medication that they are prescribed, and what can be done to manage the symptoms of the disease and the side effects of their treatment. As the diagram in figure 2 indicates, it all
begins with the foundation of information. The balance of trust in the patient-provider relationship may improve the chance that women will make the decision to adhere to the prescribed treatment. Women seek statistics and facts to know that they are making the best decision for themselves. After the provider has discussed the most accurate and up-to-date information, they have to rely on the patient to use that information to make the best decision. Autonomy in decision-making for patients continues to be invaluable and women report wanting to have the support of their doctors regardless of what they decide to do with their treatment. Building on the foundation of information-seeking is the reliance on a support system. Women look for support from two main pillars in their lives that they believe will have the greatest understanding of their experience: their spouses, when married, and their providers. They tend to offer encouragement in the health maintenance areas of women’s lives, whereas, the reliance on other support systems fades over time.

Women focus on getting or staying healthy in the period after the acute treatment of breast cancer. Whether it be a focus on exercise, eating right, or seeing their healthcare providers more consistently, women changed their health behaviors to improve their chances of a healthy survivorship. This focus occurred across the board for women both adherent and not adherent to AET. Furthermore, ritualization was individualized and strengthened by the values systems that women come to the breast cancer experience with and the message that they feel that they have received after experiencing breast cancer. It is this idea of strengthening the behaviors with a value system that sets the daily ritual apart from that of simply following a routine. Women
take their ritual seriously, knowing that it provides them with a sense of control and the ability to elicit protection for themselves in a still very unsure period in their lives.

Women who adhere do so because they believe in the power of the medication. This belief is fortified by the information that they sought prior to taking their first prescribed pill, the trust that they share with their provider, and the desire to protect themselves from the recurrence of the disease. Women who do not believe in the power of the medication are unlikely to take it and thus clarifies a necessary piece to the adherence puzzle. Those who believed strongly that the medicine was protecting them from recurrence were quick to defend the choice of putting up with the arthralgia and other side effects that presented during this time. Women felt that the protection they received from AET far outweighed the negative impact of the side effects. But this was not the case for everyone.

There was a spectrum of non-adherers ranging from those that chose to be non-adherent to those who were non-adherent despite the desire to take their medication, which may have been the result of various difficulties. For women who chose not to take their medicine, there was a clear distinction in believing that the improvement in quality of life gained from not taking AET outweighed the protection against recurrence that the medication provided. This led to the divergence in paths and resulted in non-adherence. There are women, however, that fall in the middle of the spectrum, desiring to adhere but not always meeting that expectation for themselves. For these women, disruptions in the routine led to occasionally missing the medication. Women who were traveling or had a sudden change in plans did not consistently have a back-up plan for resuming their medicine at the earliest possible time.
The Foundation

**Viewing Breast Cancer as a Chronic Condition.** Breast cancer has shifted in its status from an acute to chronic disease but now more than previously it is viewed by patients in that manner (Masters, 2013). Ritualization of adherence has many dimensions which build onto each other during the extended duration of survivorship. Across the sample, whether adherent or not, women armed themselves with information. This foundation in the breast cancer survivor’s journey would eventually lead to a divergence where women become adherers, non-adherers, or unstable adherers. Additionally within the foundation is an understanding that the prevention of breast cancer recurrence results in viewing the disease in a chronic manner accepting that they will have to manage their disease for many years. This concept is a shift away from that of cancer being a disease that could be beaten and that survivors would be able to go on living their lives from before diagnosis (Masters, 2013). Women in this study have discussed the new normal that they experience after the initial diagnosis and treatments and how the AET impacts their ability to return to their former self.

Understanding breast cancer as a chronic condition is a dimension of the information with which women arm themselves. With changes in the recommended treatments for adjuvant endocrine therapy (Goss, 2015) and popular media outlets such as Huffington Post and the New York Times (American Cancer Society, 2016; Masters, 2013; Gubar, 2015) referring to breast cancer as a chronic disease, breast cancer survivors have begun to recognize this disease in a chronic fashion as well. This is important because the research involving breast cancer survivors continues to change and recommendations quickly become outdated.
Women come to the breast cancer experience with an understanding that they are in for a “journey” and that the experience will not merely interrupt a year of their lives but potentially much longer (Presutti, et al., 2014). The current study is one of the first of its kind to examine the experiences of breast cancer survivors in the extended duration period of adherence, and it has demonstrated that ritualization of adherence is preceded by an understanding that breast cancer is a chronic condition. Recent literature confirms that women now view breast cancer as a chronic condition (Wertich, 2017; Lo, Packer, Chinna & Quek, 2013) whereas previous literature described how women were split in their view of breast cancer with some seeing the disease as acute and others viewing it as chronic (Rabin, Leventhal, & Goodin, 2004). Knowing that the “journey” may continue on for 10 or more years, women ritualize their adherence behaviors in order to empower themselves with the best chance of taking their medication as prescribed by their providers.

**Armed with accurate information.** An important part to the context of ritualization of adherence is the way that women seek information about their disease. Women armed themselves with information so that they could feel more confident in conversations with their providers about their decision to adhere (or not). As part of the information age, the internet places information, both factual and not, at a woman’s fingertips (Holmes, 2017). Women may use the internet in the event of a brief or discursive appointment with their provider in order to supplement what they discussed. In addition, they discuss variations of decision-making with their providers, from forming their own opinions, to considering their provider’s opinion, to fully allowing their doctor to make decisions on their behalf (Radina, Ginter, Brandt, Swaney, & Longo, 2011).
Arming with information goes far beyond the use of the internet. In the current study, women described feeling that they wanted to know the truth or the facts. They felt most confident about the information discussed with their provider when there was an existing level of trust. In order to ritualize adherence and improve their adherence behaviors, they wanted to know that they were basing their decision on the most accurate information possible. In one systematic mapping review, Brennan, Barnes, Calnan, Corrigan, Dieppe, and Entwistle (2013) explore just how important the connection between trust and information seeking is to the patient and provider. The review goes on to impress that trust must be reciprocal between the provider and patient and that both should be forthcoming in order to achieve better health outcomes (Brennan, et al., 2013). Through the sharing of information based on trust with the provider, women come to understand how AET works within their bodies and will see the importance of taking it as prescribed. The current study verifies the systematic review by reinforcing the importance of trust in information sharing within a specific population of patients, survivors of breast cancer who are prescribed AET. Additionally, this study verifies that information gained from the trusting relationship provides a foundation for women who must make decisions about AET. With this base of understanding, women become ritualistic about adherence behaviors described in detail below.

**Leaning into the Support of the Spouse and the Provider.** The next step up from the foundation of information is a breast cancer survivor’s support system that has many dimensions including practical and emotional support that are critical to promoting healthy behaviors in breast cancer survivors. Peer support is discussed in the literature as a critical pillar for women in the survivorship period (Mirielees, 2017; Taleghani,
Babazadeh, Mosavi, & Tavazohi, 2012; Power & Hegarty, 2010). The current study, found that over time peer support for breast cancer survivors tapered off and the support of spouses and the provider were most instrumental when adhering to AET. The understanding that women most heavily relied on their providers and their spouses for support during the extended duration of medication adherence particularly involving AET is a new and important contribution to knowledge. Emotional and/or practical support is essential with day-to-day occurrences such as eating, medical appointments or reminders for medications. Emotional support is offered by someone close to the patient, who they can confide in and who helps them to reduce their stress level (Kroenke, Kubansky, Schernhammer, Holmes, & Kawachi, 2006). Spouses provide both practical and emotional support. Menopausal side effects have an impact on the spousal relationship, as women report symptoms of atrophic vaginitis: “vaginal dryness, dyspareunia, and irritation of genital skin, pruritus, burning, vaginal discharge, and soreness” (Lester, Pahouja, Anderson, & Lustberg, 2015, p. 50). Those side effects led to changes in the frequency and type of intimacy. Women in the study tended to rely on their spouses and their providers to offer the emotional support required to tolerate those side effects and persist in the prescribed treatment. Very few women described talking to other support people in their lives about those specific and important side effects to the treatment. Additionally, women without a supportive spousal relationship relied heavily on their providers and the staff at their clinics, and when the support from spouses and providers was lacking, adherence to AET faltered. Women with a strong spousal support system and a reliable and trustworthy provider that they could speak to at regular intervals were
able to take the next step of the model: building a healthy lifestyle as a survivor and achieving optimal health through adherence.

**Building a Healthy Lifestyle as a Survivor.** All participants described their decision to adhere or not to adhere in terms of doing what was best for their health. Because of that, this is the final step of the foundation before women take on divergent paths towards adherence and non-adherence.

In the current study, breast cancer survivors described a variety of health behavior changes from exercise, to drinking more water, to trying new health care products and supplements. The current study verifies the current science in this area. Exercise is one of the most commonly described health maintenance habits in breast cancer survivors described in the literature (Hsu, et al., 2012; Terranova, Lawler, Spathonis, Eakin, & Reeves, 2017). Terranova, et al. (2017) reports that while making changes to health habits is often recommended shortly after diagnosis, breast cancer survivors’ adherence to health behavior change is insufficient. The current study found that women were more very likely to adhere to health behavior changes in the extended duration of breast cancer survivorship. Having gone through the experience of a breast cancer diagnosis, women often described feeling strong enough to do things in their life that they were not previously strong enough to accomplish. This mindset seems to be what supports the building of a healthy lifestyle as a survivor. Additionally, women have been informed that modifiable risk factors for recurrence can be addressed through health maintenance such as exercise and dietary intake of fruits and vegetables (American Cancer Society, 2015; O’Neill, et al., 2013). Armed with that information, health maintenance behaviors
have become a central aspect of many breast cancer survivors’ lives and were conceptually verified in the current study.

In the literature, the intensity of frequency and surveillance methods varied by oncologist despite recommendations from ASCO and the NCCN (Margenthaler, Allam, Chen, Virgo, Kulkarni, & Patel, 2012). One study examining health disparities in adherence to survivorship guidelines found that worrying about cancer, financial burden, and stigma about breast cancer may have a negative impact on a woman’s ability to adhere to surveillance methods (Advani, et al., 2017). More than simply changing how they care for their bodies, women in the current study also described how important surveillance for breast cancer and other cancers had become to them and described adherence to the recommendations of surveillance for breast cancer recurrence but were less adherent about screening for other cancers. Maintaining adherence to surveillance for breast cancer recurrence was confirmed in the literature (Risendale, et al., 2016; Tiro, et al., 2015), whereas the idea that women may be less adherent to surveillance for other cancers was not readily discussed. In an effort to protect themselves from experiencing breast cancer again, women focused on their health and building a healthy lifestyle. Women who were following the prescribed regimen of AET, those who sometimes did not follow the regimen, and those who had chosen not to continue AET were commonly linked by their desire to build healthy habits and a healthy lifestyle moving forward in survivorship.

**Divergent Paths Toward Adherence and Non-Adherence**

Up until this point of the model (see figure 2), all women have moved upward on the model building on the foundation of being armed with information, viewing breast
cancer as a chronic condition, having a spousal and/or provider support system, and maintaining a healthy lifestyle as a survivor. These foundational blocks were common across the sample. Figure 2 illustrates how it is at this point in the model where the paths of the women diverge towards adherence and non-adherence. Those women who build a ritual of adherence must first make a commitment to adherence. Whereas those women who are strongly impacted by the barriers are likely to move down a path towards non-adherence.

Nonadherence. C. Everett Koop, a former Surgeon General to the United States was quoted as saying, “Drugs don’t work in patients that don’t take them.” (1985). Non-adherence occurs intentionally about 50% of the time, whereas the rest of the time patients are unaware that they are not taking their medications as prescribed or the regimen of their medications is too complex (Jimmy & Jose, 2011). In the older adult population in particular, medication regimen complexity is high and may impact adherence (Cobretti, et al.,2017; Jimmy & Jose, 2011). Additionally, having a history of breast cancer may lead to non-adherence in other comorbid chronic illnesses. One study found that prior to a breast cancer diagnosis, women tended to be adherent to oral medications 91.4% of the time whereas after a diagnosis, adherence dropped to only 77.9% (Jingyan, Neugut, Wright, Accordino, & Hershman, 2016). Of the women in the study, several were non-adherent in that they did not realize that they were not following the prescribed treatment by their physicians, and others had decided that the barriers to taking the medication were insurmountable.

Barriers to Adherence. The barriers to adherence are perhaps the most heavily discussed area of medication adherence research. In breast cancer survivors, non-
adherence can be attributed to many things including symptom severity, patient-related factors, health beliefs and social support. Symptom severity may be the biggest barrier to adherence in AET. Side effects of AET include shortness of breath, dizziness, headaches, joint pain, muscle aches, cognitive and mood changes, fatigue, weight gain, hot flashes, change in libido, increased risk of blood clots, and many more, resulting from the anti-estrogen properties which cause a side-effect profile similar to that of menopause (Aiello Bowles, Boudreau, Chubak, Fujii, Chestnut, & Buist, 2012). Women often report that symptom severity causes disruption and discontinuation of therapy (Aiello-Bowles, et al., 2012; Wuensch, et al., 2015; Chim, et al., 2013; Ganz, Petersen, Bower, & Crespi, 2016; Kuba, Ishida, Nakamura, Taguchi, & Ohno, 2016; Park, Knobf, & Sutton, 2012; Simon, Latreille, Matt, Desjardins, & Bergeron, 2014).

The current study verifies the literature finding that symptom severity took an incredible toll on the women participating in the study. Even those women who were adherent without missing a pill, still complained of many side effects related to the medication. With the approximately 30 distinct side effects described by women in this study, the perception that the side effect was indeed directly related to AET led women to discuss it as a barrier. Healthcare providers often tried to assuage the concerns about side effects by telling the women that much of what they were describing was not related to the AET at all. In the end, if a woman believed that a side effect or symptom was related to the medication, it was the perception of that impact that counted, extending what we know about side effects and their impact on adherence.

Many patient-related factors were also described in the literature such as pre-existing mood conditions (Bender, et al., 2014; Mausbach, Schwab, & Irwin, 2015),
decreased self-efficacy (Kimmick, et al., 2015) practical and logistical factors (Wouters, et al., 2014), and medication costs (Bright, Petrie, Partridge, & Stanton, 2016). Additionally, in a very recent article exploring adherence in breast cancer survivors in the SEERS database, opioid use was correlated to non-adherence (Tan, Camacho, LeBaron, Blackhall, & Balkrishnan, 2017). Of note, there were several women in the study who were using opioids or other controlled substances for pain and women with pain, particularly at a level that required control with medications, had more difficulty with adherence to AET.

But the most common patient-related factors described in the current study were disruptions to the normal routine. Disruptions impacted women who wanted to adhere but were not always successful. Overall, while it has been discussed in the literature (Wouters, et al., 2014), it is rarely a focus due to the large number of women who report severe symptoms while on the medication. The current study brings “disruption of routine” further into the discussion. Women who are building a ritual for adherence rely on a regular routine to do so. Women who reported regularity and predictability in their daily lives were most able to build a ritual of adherence while adherence rates suffered for those who had consistent disruptions in their routine.

These barriers, both side effects and disruptions to routine, led to the divergence of paths amongst the women in the study. Most women went on to build upon their initial foundation and succeed in taking their medications as prescribed by their providers. Some found the barriers to be overwhelming and either maintained an unstable commitment to adherence or no commitment at all.
Unstable adherence led to a grey zone, where women could not be neatly grouped as adherers or non-adherers. There is a false dichotomy, where women believe that they are one or the other with no room in between. More accurately, these women fell along the spectrum between adherence and non-adherence. Primarily disruptions to the daily routine resulted in a disruption to adherence. The greater the disruptions to the routine, the more consistently women would miss their prescribed medication. These women described themselves as adherent, often not admitting that the disruptions to routine interfered with their ability to adhere. As described above, disruptions to the routine are not heavily described in the literature. This study brought those disruptions into the light and provided a greater understanding of unstable adherence.

**Making a (Re)Commitment to Adherence.** The commitment process involves a decision to adhere. It is a practice that must occur over and over, continually recommitting oneself to adherence. This decision to recommit is driven by the desire to talk oneself into continuing the medicine, believing in its power against recurrence despite the barriers that they have encountered. There is an ambivalence that can occur with wondering whether the medication is worth the difficulties and severities of the side effects. In order to silence the ambivalence, the recommitment process occurs. In the current study, after making the commitment to adherence, women subsequently reported both feelings of decisional satisfaction and decisional ambivalence about AET. Women also reported regret about decisions through their breast cancer journey, particularly those involved with treatment-related decision-making in the acute phase following diagnosis but denied feeling regret over the decision to adhere or not adhere to AET.
Women have the right to autonomy in their decision-making process. Nurses and other providers deliver information and guidance, but a patient has a “right to self-determine a course of action,” (American Nurses’ Association, 2011, p. 1). Despite the woman’s right to change her mind over the course of AET, the current study found that the women who were adherent to AET made a commitment to adhere on a regular basis. It was through this steady recommitment, in silencing their ambivalence, that the ritualization of adherence was built. Those women who made the steady commitment to adhere were likely to feel decisional satisfaction. Of note, whether adherent or not, women who had built their decision on the foundation described and shown in figure 2: accurate information, a support system, and building a healthy-lifestyle were self-assured in their decision-making process. Decisional ambivalence occurred when patients lost their confidence in their ability to take the medication prolonging contemplation about their decision (Konkle-Parker, 2001). Decisional ambivalence led women in the current study to question health decisions and they often described wondering what would have happened if they had made a different choice.

The literature surrounding decision-making in cancer care and other chronic disease populations focuses on the qualities that lead to satisfactory decision-making. Dy and Purnell (2012) found the concept of decision making to include provider competence, provider trustworthiness and cultural competence, patient/surrogate competence, communication and quality information, roles, and involvement (p. 583). The current study found many of those factors to also be of importance particularly provider competence and trustworthiness to both support and provide accurate information. Decision-making involving patients and their treatments is well supported in the
theoretical literature as well. Several theories are provided to describe decision-making as well as to support patients in the choice of healthy behaviors. Two particularly poignant theories are the Conflict Model of Decision-Making by Janis and Mann (Jones, Steeves, Ropka, & Hollen, 2013) and the Uncertainty of Illness Theory (Mishel, et al., 2009).

In the Conflict of Decision-Making model, decision-making is negatively impacted by stress. The amount of risk involved in the consequences, the hope that there may be a better solution, and the pressure of time to make a decision all may precondition a person to various levels of stress and may affect their decision-making styles. The result of the decision is either decisional regret or satisfaction with the health outcome (Jones, et al., 2013). In the current study, women described some of the stressors that impacted their decision-making including side effects and disruptions to the daily routine. These two barriers in particular were most likely to lead a woman away from the commitment to adherence. Women either became unstably adherent, in that they made an effort to adhere but were not always successful in their attempts, or made the decision to stop the medication altogether. Additionally, women described their feelings about their decisions after having made them, although in the current study, decisional regret was not as salient.

The Uncertainty of Illness Theory suggests that by increasing a patient’s access to information, the knowledge level will increase, and so will their ability to discern between certainty and uncertainty. Mishel, et. al. (2009) uses this theory as a guide to manage uncertainty in treatment decision-making in early-staged prostate cancer. In the current study, women built the foundation of their commitment to adherence on their
knowledge level and their access to accurate information adding additional support to this theory. The current study verifies much of what is included in both the Conflict of Decision-Making Model and the Uncertainty of Illness Theory, with the exception of this study’s emphasis on decisional satisfaction and decisional ambivalence over that of decisional regret in this population.

**Ritualization of Adherence.** Daily ritual is the routine which the participant uses on a daily basis to remember and reinforce taking their medication. Ritualization is the building and creating of the ritual that aids adherence behaviors. It encompasses ideas such as faith in, believing in, and relying on a daily ritual. By identifying it as ritualization, a focus can be placed on what elevates a woman’s routine from simply a consistent habit to that of a ritual. In one study of end of life rituals, rituals are described as ranging from “simple to complex, formal or informal, cultural or religious, instructive or constructive, private or public, individual or corporate, one-time or repetitive, passive or active, or rigid or flexible” (Pace & Mobley, 2016, p. 472). Ritualization in the current study occurred after building a foundation that solidified the decision to adhere and after consciously and repeatedly making the commitment to adherence. The rituals were by-in-large, simple, individualized, private, and informal. As demonstrated in figure 2, there is a reflection between a woman’s values and belief systems and the message that they receive after the breast cancer experience. This reflection is made possible by the ritualization of adherence; it is what links the reflection together; in a way, becoming the mirror.

This concept of ritualization drives the science forward. Making the commitment to adherence, as a decision for breast cancer survivors is described in the literature
(Parchman, Zeber, & Palmer, 2010; McGrady, Brown, & Pai, 2016; Jimmy & Jose, 2011), but the ritualization demonstrates the how and the why that takes place after the commitment. It involves confidence, consistency, and sometimes obsession. Rituals provide a sense of security in chaos and “order experiences outside one’s control” (Pace & Mobley, 2016, p. 472). The ritual provides a protective bubble to women who are determined to prevent their breast cancer from recurring. The ritual, whether conscious or subconscious is built onto the previously described foundation for adherence. For some women, the study interviews were the first time that they considered the conditions supporting adherence and the ritualistic nature of their behaviors. In that sense, the ritualization may have been subconscious behavior for the women in this study. The literature goes on to describe what it is about rituals that work. Rituals reduce anxiety and have an impact on people who do not consider themselves to be ritualistic at all. Despite the absence of a causal relationship between a ritual and the protection against a future danger, or future positive impact, performing rituals with the purpose of a desired outcome in many cases is adequate to provide the protection that is desired (Gino & Norton, 2013). Without a causal relationship, the ritual can be reduced to magical thinking, believing that their ritualistic behavior in addition to the adherence itself, is providing additional protections (Carey, 2007). The women in this study regularly described feeling as though their medication was providing a protection from recurrence whereas even with the descriptions of ritualistic behaviors, the women did not always indicate that the behaviors themselves were contributing to their protection, making the rituals at times subconscious in nature.
**Adherence.** Adherence is the “the extent to which a patient’s behavior, with respect to taking a medication, corresponds with recommendations from a health care provider, and includes therapy initiation, persistence, and execution” (Ursem, et al., 2015, p. 403). In 2003, the World Health Organization published a document regarding adherence to long-term therapies in chronic diseases, defining adherence as: “the extent to which the patient's history of therapeutic drug-taking coincides with the prescribed treatment.” (WHO, 2003). These definitions are very similar, even after twelve years of changes in chronic disease management, the difference in the years of publication. Adherence is the culmination of the foundation that has been built. While the paths may diverge for some women, many women in this study were able to successfully build the foundation described in the model in order to adhere to the AET regimen prescribed by their provider.

**Overarching the Adherence Foundation**

Overarching the ritualization of adherence are several protective mechanisms. Self-protection is an important concept in describing what women do to guard themselves physically from recurrence and mentally/emotionally from the idea of recurrence. One way that they protect themselves is by believing in the power of the medication. This is an area where women felt control over their disease process and that served as a mechanism of defense. Also, overarching adherence are the values and belief systems that drive the woman’s desire to live and its reflection in the message that results from their breast cancer experience allowing them to feel strong enough to make important decisions in their lives.
**Self-protection.** In the literature, self-protection is not as prominent as “distress” or “fear of recurrence.” These concepts are interrelated but not interchangeable. Mayo Clinic (2014) describes how as fear of recurrence fades self-protection behaviors increase in an effort to exert control over the disease process. The timeline that women view themselves on in the journey: acute, chronic or cyclical, as well as their emotional representations, and symptom attribution correlate with fear of recurrence (Freeman-Gibbs, Janz, Katapodi, Zikmund-Fisher, & Northouse, 2016). This verifies the findings of this study, where the view of breast cancer as chronic and the symptom/side effect attribution impact adherence to AET. Other studies have attempted to predict the existence of fear of recurrence (Cohee, et al., 2015) and demonstrate its impact on quality of life (Cruickshank, et al., 2018). While women described fear of recurrence throughout the data, they also described how it impacted their behaviors and their desire to protect that which was important to them. While the conceptual idea of “fear of recurrence” is similar to that of “self-protection,” the current study really drives forward the woman’s desire to distance themselves from thoughts of recurrence.

**Belief in the power of the medication.** While not all women in the study believed that the medication would provide protection for them, those who went on to adhere to the medications strongly believed in the power of the medication. Women in this study repeatedly described feeling as though their medication provided a safety net or umbrella protecting them from the potential of recurrence. The literature has previously explored beliefs about medications, for instance, the Beliefs about Medications Questionnaire (BMQ), a validated tool exploring the beliefs about medications for patients with chronic diseases, was tested in the breast cancer population finding that
adherence may be negatively impacted by the concerns that hormonal treatment presents for breast cancer survivors (Hurtado-de-Mendoza, Jensen, Jennings, & Sheppard, 2017). Another study found that fear of recurrence led breast cancer survivors to believe more strongly in the necessity of taking their AET (Corter, Findley, Broom, Porter, & Petrie, 2013). This again demonstrated the strong relationship among fear of recurrence, self-protection, and belief in the power of the medication. The physical act of being adherent to AET was one consequence of this belief, but even women who were not adherent still believed that the medication provided a protection to them when they took it as prescribed.

The Reflection between “Values and Beliefs Systems- Driving the Desire to Live” and “The Message- I’m Strong enough to.” Values are among the antecedents to the decision-making process (Gray & Gibbons, 2007; Hamelinck, et al., 2016; Jones, et. al., 2013; Noone, 2002). Previous research has established this foundation, and through this study, values prominently emerged in regards to the ritualization of adherence in post-menopausal breast cancer survivors specifically. Women discussed values including making time for what was important to them, faith in God, living a long life, taking care of others, and preserving body image.

Women discussed faith in God nearly four times more than any other value. Faith in God was a central value to many of the women in this study. This may be a consequence of experiencing a life-threatening diagnosis such as breast cancer or of the population within the United States in general, where 78% of Americans report believing in God, and 15% more claiming a belief in a higher power (McCormick, 2014). Gall and Bilodeau (2017) report that women use spirituality as a way of making sense of their
breast cancer, helping them to answer the question of “why me.” In this way, having breast cancer was a manifestation of God’s love or will for them. Believing in a higher being promoted a feeling that women are given “direction, guidance, or instruction” which results in the promotion of health habits (Conway-Phillips & Janusek, 2016, p 325). Yet another study found that spirituality provided breast cancer survivors with guidance in their lives, guidance with their efforts to manage their disease, and promoted recovery (Sterba, Burris, Heiney, Baker- Ruppell, Ford & Zapka, 2014). The current study goes further to demonstrate that faith in God in conjunction with other values occurred both as a contextual factor as well as a consequence of the ritualization of adherence. This model helps to bring those values to a full circle encompassing the ritualization of adherence perspective.

Carpenter, Byrnes, and Studts (2011), recognized that these decisions regarding women’s health management are made over and over and thus a more conceptual exploration should be undertaken. The current study more deeply engages women in the values that impact their decisions regarding adherence resulting in a conceptual understanding. In consideration of reflections, the values are not only mirrored in the decision-making process for women, but also in the consequential message received after the breast cancer experience. Women described feeling like the universe, the breast cancer, or God was trying to tell them something on their breast cancer journey. That message helped women derive meaning from the difficult experience they were continuing to go through in the extended duration of adherence.

The Message—“I’m Strong Enough to”. After experiencing breast cancer in an acute sense, women taking AET have had time to allow what they have been through to
sink in. The women in this study ranged in terms of severity of disease at diagnosis, but each explained feeling stronger after having come through the acute period of initial treatment. That feeling of strength led several women to make difficult decisions that they may not have felt strong enough to face prior to diagnosis. Several women described leaving their significant others, one woman went back to nursing school, yet another retired from a high pressure position and moved to quiet home in a retirement community. Each found the strength within themselves with the sentiment that if they were strong enough to go through breast cancer, then they were now “strong enough to____” and each filled in their own answer. A few women claimed that they did not feel they had received a message, but yet through the discussions their lives had changed in various ways, some experiencing changing relationships with children or others choosing to follow a new career focus. So despite claiming that they did not receive a message, they made decisions in their lives that they might not have made prior to their diagnosis. The diagnosis of breast cancer had forever changed them.

In the literature, women make meaning from their breast cancer in different ways. Campbell-Enns and Woodgate (2015) describe that breast cancer causes women to experience distress and sometimes fear which results in “emotional work” in order to cope with the experience (p.112). Documet, Trauth, Key, Flatt, and Jernigan (2012) found that survivors defined themselves as “conquerors” and that having survived cancer gave them a “new appreciation of life” that led to positive changes (p. 313). Yet another study found that survivors needed to envision what their new life would look like after cancer treatment and as they transitioned into a new time of life, filled with potential (Keim-Malpass & Steeves, 2012). The current study reaffirms what is known in the
science, that women make meaning from their survivorship. But I would argue that this
grounded theory analysis adds a layer by closing the circle. In figure 2, the reflection
between the resulting meaning from breast cancer and the woman’s value system is
demonstrated. The meaning that women derive from their experience is directly reflective
of those values demonstrated prior to the diagnosis of breast cancer. That knowledge led
the researcher to both educational and research implications described in further detail
below.

**Limitations**

Recruitment strategies. There were several limitations within recruitment in the
current study. By using passive recruitment strategies, participants were able to decide
whether to contact the researcher to participate, or not, leading to self-selection bias.
This led to homogeneity in the sample of women, which resulted in a higher number of
Caucasian and middle- to upper middle- class women. Charmaz (2006) suggests that it is
important to have a clear understanding of the context that was examined and to be
cautious if attempting to decontextualize the findings (Charmaz, 2006).

Additionally, self-selection into research may have led to a greater number of
women who were adherent to their treatment. Studies that involve medication adherence
have shown that women who consistently take medications as prescribed are more
inclined to participate (Chubak, Boudreau, Wirtz, McKnight, & Weiss, 2013). This was
one of the most difficult limitations to mitigate as the study’s recruitment strategies were
largely impacted by the institutional review board which desired that participants be able
to approach the researcher versus the converse approach. Subsequent studies can be
performed to address this limitation and expand on recruitment of breast cancer survivors targeting a more diverse and less adherent sample.

The findings of this research were contextually bound to the population that was recruited. Recruitment occurred at three different clinics spread over a 100-mile geographical area and recruitment through social media occurred on a national level. The geographical region may have impacted the types of values and beliefs that were described by the participants, as the recruited sample was both specific and homogenous, with the majority of the sample being Caucasian and middle- to upper- socioeconomic status. Including social media allowed for a much larger geographical area to be covered with recruitment. With a predefined population to recruit from (post-menopausal, women, three or more years out from initial diagnosis, and prescribed AET), more specific theorizing could be done for this group but did limit the ability to extend the context to the larger population. Another contextually bound limitation was related to the structural level barriers in AET adherence. For the first half of the interviews, the researcher included a line of inquiry related to practical concerns of medication adherence such as cost and difficulty with filling the prescription. Participants repeatedly dismissed such questions reporting that there were no barriers related to those areas of AET adherence. Having the ability to recruit participants with a lower SES may have led to a greater discussion about these concerns as previous research has indicated the existence of structurally-related barriers (Mackey, Parchman, Leykum, Lanham, Noel & Zeber, 2012; Laba, et al., 2013). Future research will aim to target a more diverse population socioeconomically in order to reduce or eliminate this limitation through
engagement with the healthcare providers in identifying this subsample and utilizing recruitment locations that more readily serve this subsample of women.

Additional limitations occurring after recruitment included a pre-defined demographic collection including age and date of diagnosis, breast cancer staging at diagnosis, types of treatment, and type of AET prescribed. The demographic information did not include a self-disclosure of race or ethnicity, as it was not a central aim within this study, leading to a decreased ability to make comparisons among groups within the sample. It also decreased the ability to generalize the findings to the larger breast cancer survivor population.

Researcher-related limitations. The researcher in this study is a nurse. When patients become participants, as occurred in this study, additional ethical issues could have arisen for two main reasons: an imbalance of power between the researcher and the participant and a vulnerability related to their illness (Holloway & Wheeler, 2010; Lalor, Begley, & Devane, 2007). In this study, the researcher found a balance between respecting the research process and advocating for the participant at the interview’s completion. By meeting with the research team and peer analysis team regularly, the researcher was able to discuss complex relationships and issues with patients, their health needs, and other concerns. Participants occasionally disclosed behaviors that may be negatively impacting their health, and in an effort to protect the participant’s autonomy and confidentiality, the researcher provided an environment free from judgment with active listening so that the participants could feel comfortable to share fully.

The nurse researcher has previously worked with this population leading to a potential for bias resulting from earlier experiences with breast cancer survivors. The key
to mitigating such a limitation is through reflexivity. Additionally, the findings demonstrate a constructivist approach where the participants and the researcher worked together to co-construct the theory and allowed for interpretations based on expertise in the field (Clarke, 2005). Transparency regarding the nurse as the researcher can be included when disseminating the findings with a recognition of the researcher as a co-constructor of the data.

**Implications for Nursing Education, Practice, Research, and Policy**

**Education.** Providers will benefit from understanding the foundation that must be built and the ritualization of adherence process that women undertake in an effort to protect themselves from recurrence. Patient education regarding AET often focuses on an explanation of why the medication is necessary and the potential side effects that may occur (Heisig, et al., 2015), but adherence may improve with more comprehensive teaching. To begin, a longer survivorship appointment should be scheduled at the initiation of AET. Women desire to be provided with accurate information from providers that they trust. Allowing even a twenty minute appointment versus a ten minute appointment will leave time for patients to ask questions and for providers to address concerns.

Secondly, education should be focused on the foundational parts of the ritualization of adherence model. Honest and accurate information about potential side effects, the normality of unstable adherence, and the likely duration of treatment should be discussed. Women may want to discuss what methods have worked for other breast cancer survivors having similar difficulties. Providers should be prepared with concrete ideas that may help women build a ritualization of adherence. The duration of treatment
reinforces the nature of breast cancer as a chronic condition. Additionally, support systems should be examined. Several instruments such as the Perceived Social Support Scale (Li, Yang, Liu, & Wang, 2016) or the Medical Outcome Study Social Support Survey (MOS-SSS) (Kornblith, 2001) have been determined to be valid and reliable in exploring social support in patients with chronic diseases. Others have modified such scales as the MOS-SSS to make them as applicable as possible to their population (Document, Bear, Flatt, Trauth, Macia, & Ricci, 2015). Building a healthy lifestyle as a survivor also begins with education. Appealing to an overall healthy lifestyle will allow women to look at the bigger picture and how AET falls into it.

Thirdly, education reinforcement at a later appointment should be planned. Women in the current study reported having a vague memory of what they learned about the AET at the beginning of the prescribed period. Once the patient has had the opportunity to start the medication, they may develop specific side effects or concerns about the medication and the chronic nature of their disease that they may want to discuss at a later appointment. Women should be empowered by the education that they have received to ask their providers about a back-up plan if their medication becomes intolerable. Another option is to have a provider come to a survivorship support group meeting to address this specific education and reinforcement. If no support group is available through a local community clinic, patients may opt to join a support group via a blog site or social media website. If a patient opts to go this route, the provider should have a discussion about identifying accurate and trustworthy information.

**Practice.** This study has provided implications for nursing practice including opportunities for additional screening of beliefs about medications and assessment of
understanding about medication regimens. Women in the current study reported that the initial appointment where AET was prescribed was cursory. Attention to assessment of specific foundational needs, such as the level of knowledge, support systems, and values and beliefs, will further the relationship of trust with the provider. To assess a patient’s beliefs about medications, the provider can use tools such as the Beliefs about Medication Questionnaire (BMP, cronbach’s alpha 0.71) which explores beliefs about medication harm, overuse, sensitivity, and benefit. While it has not been exclusively tested in breast cancer survivors, it has been tested in other chronic diseases such as hypertension (Alhalaiqa, Al-Nawafleh, Batiha, Masa-deh, & Abd Al-Razek, 2017) and inflammatory bowel disease (Campos, Portela, Sousa, & Sofia, 2016) and may show some benefit in the assessment of breast cancer survivors using AET. Assessing support systems and values and beliefs through open-ended questioning will improve trust as well.

Secondly, support groups should be established physically or virtually to connect breast cancer survivors with each other and the provider, for women who find this helpful. Women may use support groups as a place to share the meaning that they have derived from their experience (Wells, Gulbas, Sanders-Thompson, Shon, & Kreuter, 2013), a concept that was further described in the current study. Whether women are having a positive or negative survivorship experience, utilizing a support group may provide the support of peers desired during this timeframe. Nurses and APNs should be the driving forces behind support groups as they have specialized knowledge of the disease processes, treatments, and experiences of breast cancer survivors.

Side effect management should be centrally discussed in follow-up appointments and the ways in which they overlap with the natural aging process. Women in the current
study tended to minimize their symptom experience but when probed would describe the extent of their discomfort both in terms of arthralgia and the full spectrum of menopausal symptoms. The literature about AET adherence (Aiello-Bowles, et al., 2012; Wuensch, et al., 2015; Chim, et al., 2013; Ganz, Petersen, Bower, & Crespi, 2016; Kuba, Ishida, Nakamura, Taguchi, & Ohno, 2016; Park, Knobf, & Sutton, 2012; Simon, Latreille, Matt, Desjardins, & Bergeron, 2014) and the current study both validate the existence of a wide array of side effects and symptoms. Providers are well aware of these side effects and may minimize them due to their commonplace and may forget that they play a central role in the lives of survivors. Spending a portion of the follow-up appointment addressing concrete methods for treating specific side effects allows women to know that their concerns are being addressed.

**Research.** This study has provided a foundation for additional research in the breast cancer survivorship area. The American Cancer Society places an emphasis on survivorship and quality of life research (American Cancer Society, 2015). Within this study, a greater understanding of the experience of post-menopausal breast cancer survivors was obtained. With this understanding, future research will focus on ways to improve the quality of life of survivors. Based on the findings within this study, breast cancer survivors desire an improved focus on quality of life in symptom management. According to one integrative review, various studies have focused on symptom management in breast cancer survivors looking at cognitive behavioral therapy, exercise interventions, and online-based survivorship research for women who are prescribed AET (Post & Flanagan, 2016). Another review specifically focused on the complementary and alternative (CAM) interventions associated with late-effect
symptoms of breast cancer and its treatment showing that the research indicates that this is a great area of opportunity for nurses caring for women in the survivorship period (Henneghan & Harrison, 2014). Knowing that side effects continue to be one of the most reported reasons for discontinuation of AET despite concerted efforts to help breast cancer survivors manage their symptoms indicates that there needs to be a continual research focus in this area. Larger scale research studies should be conducted on interventions that target the symptoms and side effects that breast cancer survivors are experiencing.

An additional area impacting the quality of life of breast cancer survivors is the need for additional support in the survivorship period. The current study found that women depended most heavily on their spouses and their providers. With the rise of online support groups such as Facebook groups like “Lifting Hearts Breast Cancer Support Group” and “Estrogen Positive Breast Cancer,” women have the ability to virtually connect with others who have similar experiences. Future research should address the impact of online support groups and their efficacy in supporting women through the challenges of adherence to AET.

Additional foci of research should include how to best deliver survivorship care and in what settings that care can be most effectively delivered. Survivorship care is provided through oncology practices, family practices, and survivorship clinics to name a few locations, but little is understood as to which locations provide the most comprehensive care. Additionally, how do various settings for survivorship care uniquely serve underserved or special populations such as high risk patients or those in rural areas? Survivorship care continues to be an under-researched area and simply
understanding the issue of non-adherence to AET in breast cancer survivors is not enough. Research in this area continues to develop and grow leading to new ideas that will improve the quality of life of breast cancer survivors and improve their ability to adhere to their prescribed treatments.

**Policy.** Cancer continues be a burden on public health and it is the responsibility of the government and researchers in the field to address the needs of those with cancer. Based on the findings of this research, future research in this area can address the goals of NCI outlined in figure #3 to integrate policy and research (NCI, 2017). As the research regarding breast cancer survivors continues to expand, nurse researchers will have to consider the broad impact on public health by following national recommendations on research and policy.

Specifically, this study brought to light that the needs of breast cancer survivors continue to change and grow and the current state of survivorship care, particularly in smaller community settings is woefully lacking. The National Comprehensive Cancer Network has established guidelines for the development of survivorship clinics and survivorship care planning. ASCO includes survivorship care among their quality indicators. In addition, the American College of Surgeon’s Commission on Cancer has incorporated survivorship care planning as part of the accreditation process. Despite the support of national organizations, survivorship care has really only gained traction in the last ten years and there is much work in research and policy to be done (ONS, 2014). Despite national organizations driving policy changes, nurses in the clinics and at the bedside can attest to the volume of time involved with survivorship care planning and the disconnect between policies and patient care. With the patient as the focus, research and
policy should address the value of survivorship care planning and look for ways to improve it so that it works effectively for both the patients and their healthcare providers.

**Conclusion**

The problem of non-adherence cannot be viewed as black and white. There are many contextual and conditional factors in the lives of post-menopausal women that contribute to the use of AET. This study brings to light many of those factors. As healthcare professionals, it is easy to assume that if we simply explain the benefits of the medication and treat the side effects as they arise that adherence to the medication would be understood. Women in this study demonstrated that they desire as much accurate information as possible, but that accurate information does not always lead to the decision to adhere and this decision should be respected as a woman’s autonomy to choose her own care. As seen in this study, many times the conditional and contextual factors led to the decision to make healthy lifestyle decisions in other forms such as holistic practices, healthy eating and exercise versus starting or continuing AET. Although, with a foundation of accurate information, a spousal and healthcare provider support system, and a healthy lifestyle, women are likely to make a commitment to their adherence decision. That commitment and recommitment will involve a ritualization of the adherence process for them.

What we have learned about the ritualization process is that it involves a deep desire for self-protection, a mechanism that survivors use to protect themselves physically and mentally from the fear of recurrence and recurrence itself. The overarching self-protection is reflective of both the values that women have prior to diagnosis and the message that they receive after their diagnosis about their inner strength
as survivors. These values include such things as making time for what was important to them, faith in God, living a long life, taking care of others, and body image. The ritualization of adherence provided protection for participants acting as a mirror between those values and beliefs and the consequential message after experiencing breast cancer. The model shown in figure 2, demonstrates that women may feel both decisional satisfaction and decisional ambivalence regardless of whether they choose to be adherent to their medications or not. Recommitment to the AET and adherence behaviors was necessary to quiet the questions that remained for women wondering whether the medication was worth the difficulties and severities of the side effects. In conclusion, to feel most protected by the medication, women built and relied on rituals to best maintain adherence.

This grounded theory analysis has expanded the understanding of the experiences of women who are prescribed AET in the extended duration of survivorship. Opportunities for changes in education, practice, research and policy have been identified as the need for survivorship care continues to grow and the volume of survivors multiplies. One central goal of cancer survivorship care is to increase the number of women who make the commitment to adherence and to assist them in building a ritual of adherence at the time of their initial prescription as to improve adherence for those who desire to be adherent but fail at times to meet the expectation that they will take their medicine as prescribed. By having an understanding of the process of ritualization of adherence, and the many conditional and contextual factors impacting this process, nurses and other healthcare providers are able to target specific areas of education and practice in order to improve the experience of post-menopausal breast cancer survivors.
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Figure 1. Explanatory Matrix of Ritualization of Adherence
Figure 2. Ritualization of Adherence

- **Overarching**
  - **Diverging Paths**
    - **The Foundation**

- **Ritualization of Adherence**
  - Making a Commitment to Adherence
  - Building a Healthy Lifestyle as a Survivor
  - Support Systems - Spousal/Provider
  - Armed with Accurate Information
  - Breast Cancer as a Chronic Condition

- Self-Protection
  - Belief in the Power of the Medication

- Adherence
  - Decisional satisfaction or ambivalence
  - Non-Adherence
  - Barriers
**Figure 3. Opportunities for Cancer Research in Public Health**

1. “Develop and test behavioral interventions that reduce cancer risk (such as smoking cessation, cancer screening, and cancer vaccination programs)
2. Develop and test interventions that improve access to and delivery of cancer care
3. Assess cancer risks associated with environmental exposures so as to inform regulatory decisions to limit such exposures
4. Identify policies and programs that can make cancer care more efficient and cost less
5. Develop better tools and study designs for conducting population-based studies
6. Identify and test methods for more effectively disseminating cancer prevention, risk, screening, prognosis, and treatment information to specific population groups
7. Test ways to meet the needs and challenges of a growing population of cancer survivors”

(National Cancer Institute, 2015)
Figure 4. Recruitment flyer

Seeking Post-Menopausal Breast Cancer Survivors

- Are you a breast cancer survivor?
- Did you receive radiation or chemotherapy more than 3 years ago?
- Did your doctor prescribe you a pill to keep your breast cancer from returning (you do not need to still be taking this pill to participate in the study)?
- Do you want to share your experience as a breast cancer survivor?

Participants in this study will share one to two hours of their time to meet with a nurse researcher to discuss decision-making habits, medication-taking habits, and their experience as breast cancer survivors. Interviews may be completed over the phone or in person at the convenience of the participant. If you are interested in participating, please contact the number or email below.

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