

HOW SPIRITUALITY AND FATIGUE INTERACT TO AFFECT QUALITY OF LIFE IN
PATIENTS WITH METASTATIC BREAST CANCER

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by
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HOW SPIRITUALITY AND FATIGUE INTERACT TO AFFECT QUALITY OF LIFE
AND DISTRESS IN PATIENTS WITH METASTATIC BREAST CANCER

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ABSTRACT

The cognitive theory of stress and coping by Lazarus and Folkman can explain how individuals cope with a stressful chronic illness, specifically metastatic breast cancer (MBC). If an individual appraises their MBC as stressful and concludes that they have the coping resources and ability to use them, they may effectively cope with and adapt to the stressor. Spirituality may be an important coping mechanism for patients with MBC, while symptoms of fatigue may lead to increased risk of developing psychiatric comorbidities such as depression, anxiety and panic disorders, eating disorders, substance abuse disorders, and somatization disorder. The limited number of studies conducted on the topics have examined relationships between spirituality, fatigue, QoL, and/or distress (i.e., symptoms of stress, anxiety, and depression) among patients and survivors of cancer, as research on patients with MBC is limited. This present study aimed to fill the gap in the literature by examining whether an interaction exists between spirituality and fatigue that affects QoL in the long term. Specifically, this project aimed to examine whether levels of spirituality would interact

with fatigue to predict QoL over two periods of data collection. It was hypothesized that the combination of low fatigue and high spirituality would predict the highest levels of QoL. The sample consisted of 25 patients with MBC who were recruited from an MBC clinic in the Midwest. Measures consisted of data collected from participants' electronic health records (EHRs) and from self-report validated questionnaires. Due to low statistical power attributed to a small sample size, hypotheses were modified so that analyses could focus on bivariate correlations instead of the originally planned upon linear regressions, although power was still limited. Therefore, it was hypothesized that spirituality would be positively related to QoL and negatively related to fatigue, while fatigue would be negatively related to QoL. Findings indicated that Spiritual Peace, Spiritual Faith, and total spirituality were positively associated with Emotional QoL. Spiritual Peace was positively associated with Functional QoL, and Functional QoL was significantly negatively associated with fatigue. All other associations did not reach statistical significance based on *p*-values. Implications, limitations, and further directions are discussed.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Education, Social Work and Psychological Sciences have examined a dissertation titled “How Spirituality and Fatigue Interact to Affect Quality of Life in Patients with Metastatic Breast Cancer” presented by Anahi R. Primgaard, candidate for the Doctor of Philosophy degree, and certify that in their opinion it is worthy of acceptance.

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CONTENTS

ABSTRACT.....iii

LIST OF ILLUSTRATIONS.....viii

LIST OF TABLES.....ix

LIST OF ABBREVIATIONS.....x

Chapter

1. INTRODUCTION.....1

 How Spirituality and Fatigue Interact to Affect Quality of Life in Patients with
 Metastatic Breast Cancer 1

2. REVIEW OF THE LITERATURE.....3

 Chronic Illness and Difficulties 3

 Stress and Coping 4

 Transactional Model of Coping and Chronic Illnesses..... 8

 Summary..... 37

 Hypotheses..... 41

3. METHODOLOGY.....44

 Participants..... 44

 Procedures..... 45

 Measures 52

 Planned Data Analysis 55

4. RESULTS.....57

 Data Analysis Conducted..... 57

 Modified Power Analysis 62

Normality Assumptions and Descriptive Statistics.....	63
Scale Reliability	64
Participants.....	65
Covariate Variables.....	68
Exploratory Associations Between Clinical Variables and Predictor and Outcome Variables	68
Bivariate Correlations for Study Hypotheses	72
Summary	75
5. DISCUSSION.....	77
Planned Hypotheses	77
Modified Exploratory Hypotheses	77
Lessons Learned.....	85
Implications.....	85
Limitations	86
Conclusion	88
APPENDIX.....	90
A. Measures.....	90
REFERENCE LIST.....	93
VITA.....	109

LIST OF ILLUSTRATIONS

Figure	Page
1. The Transactional Model of Stress and Coping.....	7
2. Study Procedures for New Patients.....	50
3. Study Procedures for Patients who were Retrospectively Recruited.....	51
4. Breakdown of Participant Recruitment Process and Eligibility at Times 1 and 2..	61
5. Sensitivity Analysis for Bivariate Correlations Using G*Power (Faul et al., 2009).....	63

LIST OF TABLES

Table	Page
1. Participant Characteristics and Clinical Variables.....	66
2. Correlations Between Clinical Variables and Predictor and Outcome Variables....	71
3. Descriptives and Correlations Between Predictor and Outcome Variables (<i>N</i> = 25).....	72

LIST OF ABBREVIATIONS

Estrogen Receptors = ER

Electronic Health Records = EHRs

Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being = FACIT-Sp-12

Functional Assessment of Cancer Therapy Scale-Breast Cancer = FACT-B

Functional Assessment of Cancer Therapy-General Scale = FACT-G

Hospital Anxiety and Depression scale = HADS

Human Epidermal Growth Factor Receptor 2 = HER2

Initial Cancer Diagnosis = ICD

Metastatic Breast Cancer = MBC

Progesterone receptors = PR

Psychological Well-Being = PWB

Spiritual Attitude and Involvement List = SAIL

Spiritual Index of Well-Being = SIWB

Spiritual Well-Being Scale = SWBS

Quality of Life = QoL

CHAPTER 1

INTRODUCTION

How Spirituality and Fatigue Interact to Affect Quality of Life in Patients with Metastatic Breast Cancer

The cognitive theory of stress and coping by Lazarus and Folkman (1984) can explain how individuals cope with a chronic illness. Based on this model, if an individual appraises an event as stressful (e.g., symptoms of chronic illness) and concludes that they have the ability to handle the stressful event, then they may be able to effectively cope with and adapt to the event. One chronic illness of focus is cancer, specifically advanced, terminal breast cancer, also known as metastatic breast cancer (MBC). Spirituality may be an important coping mechanism that patients with MBC use when adapting to the life threat of cancer and cancer-related stress (Laubmeier et al., 2004). In contrast, fatigue may lead to increased risk of developing psychiatric comorbidities such as depression, anxiety, and panic disorders, eating disorders, substance abuse disorders, and somatization disorder (Sharpe & Wilks, 2002).

This dissertation project examined past research to determine how spirituality and fatigue individually and in combination influence quality of life (QoL) in patients with MBC. In addition, methodological issues related to research design and the measurement of spirituality, fatigue, and QoL were reviewed while also including an overview of MBC and patients' common symptoms, needs, and difficulties. A review of the literature found that a limited number of studies have examined relationships between spirituality, fatigue, QoL, and distress including symptoms of depression and fatigue among patients and survivors of cancer, including breast cancer and much less likely, MBC. It is unknown whether

spirituality decreases fatigue and symptoms of depression and anxiety or whether it improves QoL in the long term. The present study aimed to fill part of this gap in the literature by examining whether an interaction exists between baseline levels of fatigue and spirituality that affects QoL in the long term. It was hypothesized that baseline levels of spirituality would interact with baseline symptoms of fatigue to predict QoL over time, such that the negative relationship between fatigue and QoL would be weaker for patients with MBC high in spirituality compared to their counterparts low in spirituality. However, hypotheses were later modified following the discovery of a smaller pool of eligible participants (i.e., one or fewer new patients with MBC in two weeks) leading to a smaller than anticipated sample size. The modified exploratory hypotheses examined the cross-sectional relationships between 1) spirituality and social/family well-being; 2) spirituality and emotional well-being; 3) spirituality and functional well-being; 4) fatigue and social/family well-being; 5) fatigue and emotional well-being; 6) fatigue and functional well-being; and 7) fatigue and spirituality. Therefore, longitudinal associations and interactions were not examined.

CHAPTER 2

REVIEW OF THE LITERATURE

Chronic Illness and Difficulties

Illnesses are considered to be chronic when they are prolonged, do not resolve spontaneously, and are rarely, if ever, completely cured (Dowrick et al., 2005). Chronic illness is the main reason patients seek healthcare in developed countries, and it is the main cause of death worldwide. Within the United States, six in ten adults have one chronic illness, which includes heart disease, cancer, chronic lung disease, and diabetes, among others (“About chronic diseases,” 2020). Chronic illnesses may limit daily activities and lead to disability or death. Compared to adults living without a chronic illness, adults living with chronic illness may experience more symptoms of depression and lower levels of self-esteem (Huurre & Aro, 2002). The emotional aspects of chronic illnesses may be overlooked when considering medical care, which may lead to difficulty diagnosing depression in patients with chronic illness who may need treatment (Turner, 2000). Patients who develop new symptoms when their chronic illness was once stable may experience emotional distress. Chronic illness is often associated with numerous other psychological and physical concerns. These often include shoulder/neck pain, back pain, limb pain, tiredness/weakness, and sleeplessness (Molarius & Janson, 2002).

For emotional problems, people with chronic illness may experience fatigue, which is the subjective symptom of malaise, aversion to activity, and/or objectively impaired physical or mental performance (Sharpe & Wilks, 2002). Symptoms of fatigue include a lack of energy, sleeping more than usual, feeling tired even after sleeping, and a loss of interest in the things one normally enjoys doing (“Fatigue: A side effect of treatment,” 2020). One study

found that symptoms of fatigue were positively related to symptoms of pain and perceived stress among a sample of patients with fibromyalgia, arthritis, or inflammatory bowel disease, which are common chronic illnesses ($N = 1280$; Hirsch & Sirois, 2014). Aside from physical and emotional concerns, advances in medical research and health care have extended life expectancies for individuals living with chronic illness, which in turn have brought new problems such as long-term costs of treatment and medical surveillance (Turner, 2000). Furthermore, these secondary stressors may exacerbate stress and emotional difficulties.

Stress and Coping

Coping involves cognitive and behavioral efforts to manage internal and/or external demands of the person-environment situation that an individual appraises as stressful or exceeding their resources (Lazarus & Folkman, 1984). Based on the transactional model of stress and coping, if an individual appraises an event as stressful and without the ability to control the event or the environment, they may use problem-focused or emotion-focused coping. The type of coping method used will lead to either positive or negative outcomes, or further coping efforts. Therefore, the two main functions of coping include managing emotional stress (i.e., emotion-focused coping) or changing the person-environment relationship by removing or altering the stressor (i.e., problem-focused coping; Lazarus & Folkman, 1987). See Figure 1 (Turner-Cobb & Hawken, 2019, pp. 229-236) for a detailed figure of the transactional model of stress and coping (Lazarus & Folkman, 1984). Problem-focused coping is most likely to be used when an individual perceives that something productive can be done to change the stressor, while emotion-focused coping may be more

likely used when one feels that the stressor must be endured (Carver et al., 1989; Folkman & Lazarus, 1980).

Types of problem-focused coping include active coping, planning, and seeking social support. Active coping consists of taking active steps to remove or change the stressor to minimize its effects (Carver et al., 1989). Planning is thinking about how to cope with a stressor using action strategies without executing the plan. Seeking social support occurs when an individual seeks assistance from others for advice, moral or emotional support, venting, sympathy, or understanding.

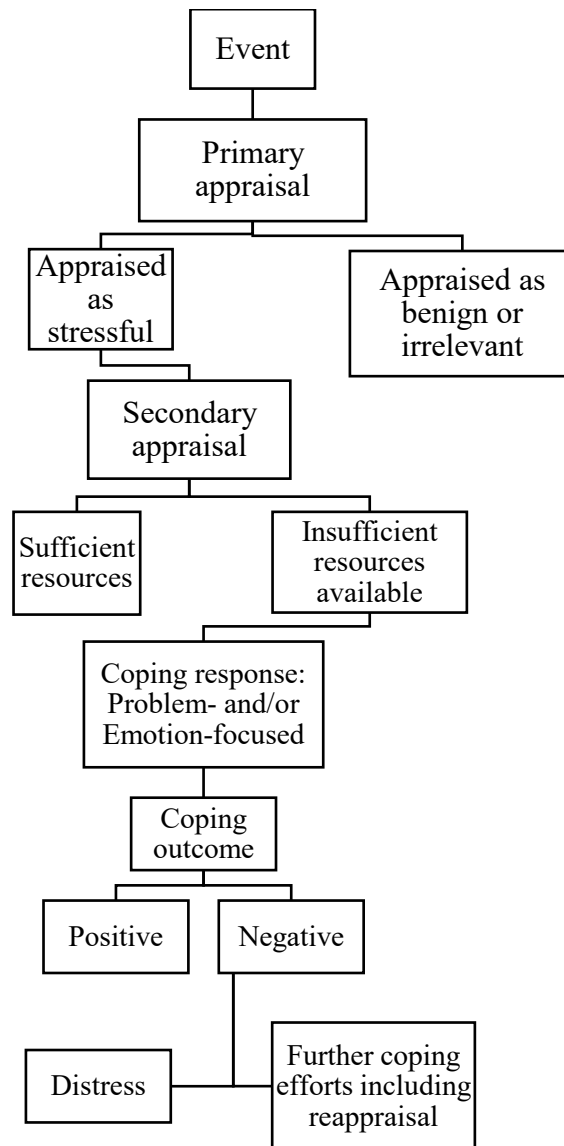
Emotion-focused coping strategies include positive reappraisal, denial, acceptance, and turning to religion (Carver et al., 1989; Folkman & Lazarus, 1980). Positive reinterpretation and growth, or positive reappraisal, is used to manage distressing emotions instead of dealing directly with the stressor. Denial consists of minimizing or ignoring a stressor, and possibly refusing to acknowledge that it exists. Acceptance is the opposite of denial in which an individual accepts the reality of a stressor. Turning to religion can be a source of emotional support in which one prays and finds comfort in a religion, a God, or some other higher power. However, religion can also be a form of problem-focused coping when an individual turns to others within their religious community to solve a problem that causes stress (Krägeloh, et al., 2010).

Spirituality and religiosity are separate concepts, which may or may not be related in all individuals (Tanyi, 2002). The former involves the search for meaning in life and the latter involves an organized entity with rituals and practices surrounding a higher power or God. Zinnbauer et al. (1997) found that both concepts were related to church attendance and frequency of prayer, but the association was stronger for religiosity. Spirituality was

described by participants in more personal terms, such as having a relationship with God or a higher power, while definitions of religiosity included both personal beliefs and organizational/institutional beliefs and practices (i.e., belonging to a church, attending church, and committing to an organized religion's beliefs system).

Figure 1

The Transactional Model of Stress and Coping



Note. Adapted from *Stress and Coping Assessment* (pp. 229-236) by J. Turner-Cobb and T. Hawken, 2019.

Transactional Model of Coping and Chronic Illnesses

The transactional model, or the cognitive theory of stress and coping (Lazarus & Folkman, 1984), can be used to explain how individuals cope with a chronic illness (see Figure 1). Appraisals are cognitions and perceptions of the ever-changing relationship between an individual and their environment in regard to one's well-being, so an appraisal is an evaluation that can affect one's mood. There are two overarching types of appraisals, which are called primary and secondary appraisals. Primary appraisals consist of determining whether an environment poses a threat to one's well-being while secondary appraisals consist of evaluating one's coping strategies. Furthermore, primary appraisals consist of appraisals that are irrelevant, benign-positive, and stressful. An appraisal can be evaluated as irrelevant if it does not cost or benefit the individual in any way. A benign-positive appraisal is one that can be seen as beneficial to one's well-being, such as if it preserves or enhances emotions of joy, love, happiness, etc. A stressful appraisal includes the concepts of harm/loss, threat, and challenge. In harm/loss concerns, an individual has experienced either an injury or illness, damage to their self- or social-esteem, or the loss of a loved one. In threat concerns, one anticipates harms or losses to one's well-being, while being able to use anticipatory coping, and emotions consist of fear, anxiety, and anger. In challenge concerns, one mobilizes coping efforts to focus on the potential for growth and it can include emotions of eagerness, excitement, and exhilaration.

On the other hand, secondary appraisals consist of an evaluation of what might and can be done during a stressful situation, so it is a process in which one evaluates their coping options and determines the likelihood that one can apply a given coping method along with the likelihood that it will accomplish one's goals.

This transactional framework by Lazarus and Folkman (1984) argues that appraisals mediate the response to stressful events, such that a stressor influences an individual's appraisals of the event and the individual will appraise their ability to handle the stressful event by evaluating their coping skills, such as inner and outer resources (Lazarus, 1999). Additionally, the model says that coping is an important mediator of the relation between stressful events and positive adaptation (Lazarus & Folkman, 1984). Therefore, if an individual appraises an event as stressful and concludes that they have the ability to handle the stressful event, then they may be able to effectively cope with and adapt to the event.

As mentioned, the cognitive theory of stress and coping by Lazarus and Folkman (1984) can be used to explain how individuals cope with a chronic illness. Patients may rely on their symptoms as a subjective indicator of the progression of their chronic illness (O'Neill & Morrow, 2000). This may include subjective feelings, inability to engage in daily tasks, and levels of fatigue. These differing variables affect the way in which individuals cope with and/or choose their coping strategy based on their appraisal of their illness. For example, individuals with chronic illness may appraise their illness and ever-changing symptoms as stressful and have concerns related to life threat that affect their well-being (Laubmeier et al., 2004), but the use of an effective coping method may allow them to positively adapt by decreasing negative emotions.

Cancer

One chronic illness of focus is cancer. Cancer occurs when abnormal cells grow uncontrollably and spread throughout the body, which may lead to death (American Cancer Society, 2021). Although the causes are not fully understood, several factors are known to

increase the risk of developing cancer, including tobacco use, excess body weight, unhealthy diet, lack of physical activity, family history, and genetic susceptibility.

Globally, there were nearly ten million deaths attributable to cancer in 2020 (“Cancer,” 2021). Cancer survival varies based on the cancer type and stage and age at diagnosis (American Cancer Society, 2021). Relative survival is the proportion of people who are alive five years post-diagnosis divided by the proportion of people of similar age, race, and gender that would be alive in the absence of cancer. The five-year relative survival rate for all cancers ranges from 39% to 68% among White people and from 27% to 63% among African Americans. These differences in relative survival rates by race may be caused by disproportionate rates of poverty and systemic discrimination that may reduce African Americans’ access to cancer screening, early detection, and high-quality treatment.

Breast Cancer

Breast cancer can originate in different areas of the breast, such as the ducts, the lobules, or the breast tissue (“Types of breast cancer,” 2021). The cancer can also be invasive or non-invasive. Invasive breast cancer means that the cancer has spread to the surrounding breast tissues. There are four stages of breast cancer, which are determined by the cancer’s characteristics, such as size, presence or lack of hormone receptors, and whether it has spread to healthy tissues inside the breast or other areas of the body such as the lymph nodes (“Breast cancer stages: 0 through IV,” 2020). The most common system used to stage breast cancer is the American Joint Committee on Cancer’s TNM system that is based on tumor size and whether it has spread into nearby tissue (T), whether it is in the lymph nodes (N), and whether it has spread to other parts of the body beyond the breast such as the lungs, bones, liver, or brain. Breast cancer cells can have hormone receptors, or proteins called

estrogen receptors (i.e., ER+) or progesterone receptors (i.e., PR+). If the cancer is ER+ or PR+ then the cancer cells may receive signals from estrogen or progesterone that could promote cancer growth (“Hormone receptor status,” 2020). The cancer can be ER+ or ER- as well as PR+ or PR- (Meng et al., 2016). Approximately two out three breast cancers test positive for hormone receptors. The human epidermal growth factor receptor 2 (HER2) is a gene that can lead to the production of a protein called HER2, which are receptors on breast cells (“HER2 status,” 2020). In approximately 10 to 20 percent of breast cancers, the HER2 gene works improperly, creating too many copies of itself and HER2 receptors, which are called HER2 gene amplification and HER2 protein overexpression, respectively. This process makes breast cancer cells grow faster and be more likely to spread in the body compared to cancers without this, called HER2- breast cancers. These characteristics, including cancer stage, hormone receptor status, size, and spread of the cancer influence the type of treatment that a patient with breast cancer is given.

Risk factors for developing breast cancer include modifiable and non-modifiable risk factors (American Cancer Society, 2021). The strongest risk factors include increasing age and being born female. Other non-modifiable risk factors include inherited genetic variations (e.g., BRCA1 or BRCA2 genes), a personal or family history of breast cancer, certain benign breast conditions (e.g., high breast tissue density), a long menstrual history, high levels of estrogen or testosterone, recent use of hormonal contraceptives, and not having children or having children after age 30 years. Potentially modifiable risk factors include weight gain after age 18 years, being overweight or obese, the use of menopausal hormone therapy, alcohol consumption, tobacco use or smoking history, and physical inactivity. Breast cancer is not limited to women; for men, the lifetime risk of getting breast cancer is about 1 in 833

(“Key statistics for breast cancer in men,” 2021). In 2021 in the United States alone, approximately 284,200 new cases of breast cancer will be diagnosed, and more than 44,130 deaths attributable to breast cancer are expected (American Cancer Society, 2021) this year.

Metastatic Breast Cancer

When breast cancer has spread to another part of the body, most commonly the liver, brain, bones, or lungs, it is classified as MBC (“Metastatic breast cancer,” 2021). Tests to diagnose MBC include blood tests, X-rays, whole-body bone scans, magnetic resonance imaging, computerized tomography scan, positron emission tomography scan, biopsies, and removal of fluid from an area in the body (“Treatment of stage IV [Metastatic] breast cancer,” 2020). On average, 30% of women diagnosed with early-stage breast cancer will develop metastatic disease (Redig & McAllister, 2013). For those who receive an initial diagnosis of MBC, they are classified as “de novo metastatic;” this means that they did not find the disease until it had already spread outside of the breast. Recurrent breast cancer means that the cancer has returned after a period of time in which the cancer could not be detected.

Systemic/drug therapies are the main form of treatment for patients with MBC, which work to shrink or slow the growth of tumors, improve symptoms, and help patients live longer (“Treatment of stage IV [Metastatic] breast cancer,” 2020). Treatment for MBC tends to stop working after some time, so if the cancer no longer responds to a treatment regimen, different combinations of drugs may be used. Systemic therapies include hormone therapy, chemotherapy, targeted therapy, and immunotherapy. Hormone or endocrine therapy is given to patients with hormone receptor-positive breast cancer. This type of treatment stops hormones from attaching to estrogen and progesterone receptors so that it stops or slows

cancer growth (“Hormone therapy for breast cancer,” 2019). Chemotherapy consists of anti-cancer drugs that are injected into a vein or given by mouth in order to enter the bloodstream and reach cancer cells in the body (“Chemotherapy for breast cancer,” 2019). MBC is usually treated with single chemotherapy drugs but some combinations of chemotherapy may still be used. Chemotherapy is the main form of treatment for patients with hormone receptor- breast cancer. Targeted drug therapies enter the bloodstream as chemotherapy does, and in some cases they may work even when chemotherapy does not (“Targeted therapy for breast cancer,” 2021). Targeted therapies for patients with HER2+ cancers include medications such as Herceptin, Perjeta, and Kadcyla, and chemotherapy that targets HER2 may be used in combination. Targeted therapies for patients with HER2- cancers include Olaparib and Talazoparib among others. Immunotherapy is the use of medicines that stimulate the nervous system to identify and destroy cancer cells more effectively (“Immunotherapy for breast cancer,” 2020). These medications include Keytruda and Tecentriq.

Common side effects of treatment for MBC include fatigue, nausea, vomiting, hair loss, loss of appetite, diarrhea, weight changes, joint stiffness, hot flashes, vaginal discharge or bleeding, and an increased risk of broken bones (“Breast cancer - Metastatic - Types of treatment,” 2021). Rare side effects of treatment include cataracts, blood clots, and cancer of the uterine lining in women. Side effects that patients experience depend on the individual, the type of drugs used, and the dose and schedule of the drugs used.

Survival rates for MBC have substantially improved with the introduction of new medications as the median survival rate for recurrent MBC increased from 21 months in 1990 to 38 months in 2010 (Caswell-Jin et al., 2018). The survival rates for MBC have increased in equal magnitude for both de novo and recurrent diagnoses as well as both ER+ and ER-

MBC (Caswell-Jin et al., 2018). For de novo MBC, the median survival rate increased from 20 months in 1990 to 31 months in 2010. MBC prognoses vary from person to person, but the five-year relative survival rate is at approximately 28% (“Survival rates for breast cancer,” 2021). This is in contrast to the 86 to 99% five-year relative survival rate for stages 0 to III breast cancer that has not metastasized. A small percentage of patients with MBC survive ten years or more, as one statistic estimates that more than 11% of women diagnosed with MBC between 2000 and 2004 under the age of 64 years survived for ten years or longer (Mariotto et al., 2017). Additionally, younger women diagnosed with de novo MBC have a higher survival rate compared to women diagnosed at an older age.

Symptoms of MBC may include pain in the chest or other areas of the body (e.g., bone), difficulty breathing, nausea, loss of appetite, headaches, and confusion (“Metastatic breast cancer symptoms and diagnosis,” 2018). The symptoms of MBC can differ based on the location of the cancer. Patients with MBC may experience high levels of stress that may be attributed to their MBC diagnosis and treatment that can far exceed their coping abilities in line with the transactional model of stress and coping (Lazarus & Folkman, 1984). The diagnosis and treatment of MBC are likely perceived as stressful events. As Manning-Walsh (2005) explained, a breast cancer diagnosis is a major stressor that may exceed one’s ability to cope, and thus may negatively affect QoL. Additionally, the course of cancer and its treatment may lead to repetitive, cumulative trauma (Rodin, 2018). Patients’ QoL may decrease because of the effects of cancer treatment, physical changes, stressors within interpersonal/social relationships, and the emotional impact of cancer (Rippentrop et al., 2006). Physical symptoms may present as a result of the illness; this, with the combination of treatment’s side effects may affect patients’ mood (Turner, 2000). Even mild forms of

depression may reduce patients' motivation to follow treatment plans and cope with pain. As more and more patients with breast cancer survive past treatment, the focus of care has shifted from acute treatment-related side effects to long-term effects that affect QoL (Ferrell et al., 1998).

Common Concerns and Needs. It is important to understand patients' common concerns and unmet needs in order to examine their ability to cope with a cancer diagnosis. Lu et al. (2020) examined 47 journal articles to summarize past qualitative research on the information needs of patients with breast cancer. One of the three themes that emerged was a need for information about cancer prevention, etiology, diagnosis, clinical manifestation, treatment, prognosis, impact and resumption of normal life, scientific research, and social assistance. One study found that patients who had younger children often talked about the lack of information available for their children (Gould et al., 2006). For example, they needed targeted information on how to guide their communication about breast cancer with their children because they had difficulty finding age-appropriate information. Lu et al. (2020) stated that the findings can help inform health professionals and information service providers on how to help patients with breast cancer receive the information necessary to cope with cancer. Similarly, Rainbird et al. (2009) described the needs of a sample of 246 patients with advanced, incurable cancer in Australia and differentiated between needs and problems. The study showed that patients with advanced, incurable cancer have high levels of unmet needs, especially within the domains of psychological and medical communication/information needs.

The specific needs were highest in dealing with a lack of energy and tiredness, coping with fears about the cancer spreading, and coping with frustration at not being able to

do the things one used to do (Rainbird et al., 2009). Surprisingly, almost all ($n = 234$, 95%) participants reported that they experienced some level of need for help (e.g., low, moderate or high). More than a third of participants reported a moderate/high level of need for help on the psychological and emotional domain (39–40%); and 31 to 35% reported moderate/high needs on the medical communication/information domain. The most prevalent moderate/high needs ranged from 15 to 22% in the symptom domain and 10 to 30% in the financial domain. Among the remaining domains, moderate/high needs ranged from 10 to 15% (financial 11–12%, spiritual 11–15%, and social 10–13%). Within the psychological/emotional domain, 39% reported moderate/high needs dealing with concerns about family's fears and worries. Within the functional/daily living domain, 30%, 15%, and 10%, respectively, reported moderate/high needs with dealing with doing work around the house, getting assistance to do usual work, and getting assistance with preparing meals. Within the symptoms domain, 22% and 16%, respectively, reported moderate/high needs with dealing with a loss of appetite and coping with difficulty eating or swallowing. Therefore, these results show that patients with advanced cancer have a wide range of unmet needs, and thus it would be worthwhile to examine how psychosocial needs change over time.

One study interviewed patients with cancer in order to describe their symptom experience. McCarthy et al.'s (2000) study described the dying experience of patients with cancer over the last six months of life. Their sample consisted of patients with metastatic colon cancer ($n = 319$) or advanced non-small cell lung cancer ($n = 747$) who died within a year of study entry. The initial interviews were conducted during the first week of the index hospitalization after study entry (between days two and seven). Patients and their caregivers were interviewed again during week two between days six and 15 or at hospital discharge.

The third follow-up interviews were completed at two- and six-months post-enrollment to collect information on current functional status, symptoms, preferences for care, and financial impact of the illness on the family. Lastly, caregivers were interviewed within four to ten weeks following the patient's death. They found that patients experienced functional decline, worsening severity of illness, and poorly controlled severe pain and confusion during their last six months of life. They also found that even though patients with cancer prefer comfort care as they near death, many died experiencing severe pain, but they were only moderately affected by symptoms of anxiety and depression. Researchers posit this is possibly because patients had accepted that their death was imminent.

Additionally, during the last six months of life, patients and their families experienced significant financial burdens because of end-of-life care, and as patients approached death they increasingly relied upon their families to provide care (McCarthy et al., 2000). So, by the time the patient had died, more than 40% of caregivers reported that a family member had to quit work to care for the patient, nearly one-third of families lost a major source of income, and 25% lost most or all of their savings. Also, patients who died around index hospitalization seemed to have worse physiological functioning and greater functional impairment compared to those who survived the index hospitalization but died within a year. Most patients were highly functional with fewer than one physical impairment until about the last month of life, and severe pain was the most prevalent symptom during the last 6 months of life, but sometimes adequate control of severe pain can lead to increased confusion or loss of consciousness. They explored whether patients who expressed a preference to die rather than be confused were more likely to experience severe pain, but they found no association between pain and preference to avoid confusion. In sum, their results indicated that patients

with terminal cancer may experience high levels of poorly controlled pain and confusion and moderate levels of symptoms of anxiety and depression as they near their last months of life.

Fatigue. Fatigue is one of the most common side effects of breast cancer treatment (“Fatigue: A side effect of treatment,” 2020). Fatigue can be commonly associated with psychiatric diagnoses such as depression, anxiety and panic disorders, eating disorders, substance abuse disorders, and somatization disorder (Sharpe & Wilks, 2002). Manir et al. (2012) found that 83% of participants in their sample of patients with breast cancer reported experiencing fatigue during chemotherapy or radiotherapy ($N = 64$), and there was a decrease in fatigue after completing treatment. Although researchers only sampled patients with Stage I to III breast cancer, this shows how fatigue related to cancer treatment affects patients undergoing breast cancer treatment. In a systematic review, Prue et al. (2006) found that cancer-related fatigue was present both during and after cancer treatment within several studies with patients with varying types of cancer, including MBC. Based on the associated comorbidities, fatigue can have a major impact on patients’ QoL. For example, fatigue has been found to be related to psychiatric diagnoses such as depression, anxiety and panic disorders, eating disorders, substance abuse disorders, and somatization disorder (Sharpe & Wilks, 2002).

Cancer-related fatigue is different from fatigue present in the general population. Specifically, cancer-related fatigue is more severe and more disruptive (Cella et al., 2002). As previously described, fatigue is related to poor mental health and decreased QoL. Patients with breast cancer experiencing fatigue have reported symptoms of pain, depression, insomnia, and social and cognitive dysfunction that have negatively affected their QoL (Ruiz-Casado et al., 2021). One study found an increase in fatigue scores in patients with

Stage IV breast cancer compared to other stages (Lewis et al., 2014), therefore patients with more advanced illness may experience more fatigue. However, the literature shows that a multidisciplinary healthcare team can help patients with cancer manage symptoms of distress and fatigue associated with their illness (Lu et al., 2020; McCarthy et al., 2000; Rainbird et al., 2009).

End of Life Conversations. Patients with MBC often experience high levels of stress (Manning-Walsh, 2005; Lewis et al., 2014) that may be managed with the help of healthcare providers. According to Tyrrell et al. (2020), dealing with terminal illness involves preparing for death and attempting to minimize symptoms. They proposed that healthcare providers may feel as if their job is done as they can no longer heal the patient, and they may drop out of the patient's care. This can lead patients and their family to feel as if they have been abandoned by the healthcare team. Therefore, it can be helpful to have a palliative care team to provide counsel, administer comfort care, deliver emotional support, and empathize with both the patient and the family. In other words, it may be beneficial to have end-of-life conversations between patients and their healthcare team. However, Rodin (2018) described how psychosocial care is under-resourced compared to other aspects of cancer care, and acute stress disorder (ASD) and posttraumatic stress disorder (PTSD) may occur at disease diagnosis and/or recurrence, and depressive symptoms may occur at progression of disease and/or at metastatic/advanced disease.

There may be barriers to discussing end-of-life conversations between patients with MBC and their health care team. For example, there may be a mismatch between patients' information needs and the information they receive. Snyder et al. (2007) found that patients were most interested in receiving information about their cancer, treatments, and care

coordination, while health professionals were more focused on providing information about symptoms and side effects. Other potential factors can include physicians' personal discomfort with death and dying, lack of personal responsibility among colleagues, or lack of experience with the subject; while for patients, barriers can include reluctance to speak about end-of-life, language barriers, or younger age (Granek et al., 2013). Healthcare providers may also refrain from initiating end-of-life conversations because of perceived patient or family factors such as believing that family members may wish to protect a patient from 'painful' information, or because of differing religious or cultural factors between providers and patients (Travers & Taylor, 2016). Initiating end-of-life conversations early on has been shown to be related to less aggressive care, greater use of hospice or home-health services, and improved patient health outcomes and satisfaction with care (Travers & Taylor, 2016).

Spirituality. One element of holistic care for patients with MBC is to address the role of spirituality in coping with their diagnosis. Spirituality is a multidimensional construct (Tanyi, 2002), which can be explained as a combination of existential well-being (i.e., finding nonreligious meaning and purpose in one's life) and religious well-being (i.e., finding harmony with God or a higher power; Laubmeier et al., 2004). Spirituality may be an important coping mechanism when adapting to the life threat of cancer and cancer-related stress. It can motivate patients to achieve their optimal physical and emotional well-being (Tanyi, 2002). Spirituality may be an important factor in helping patients with cancer adjust to their illness as it may provide meaning and comfort (Burkhardt, 1989). Patients with terminal cancer who identify as moderately to very spiritual may be more likely to feel at peace, calm, and accept their illness at end of life compared to patients who consider

themselves slightly spiritual or not spiritual at all (Mack et al., 2008). Therefore, spirituality may be integrated into the transactional model of coping by Lazarus and Folkman (1984).

There is no universally agreed upon definition of QoL, but it may be more accurately measured using separate domains (Teoli & Bhardwaj, 2023). QoL may consist of at least four domains including spirituality; the three other dimensions are physical, psychological, and social well-being (Ferrell et al., 1998). As previously mentioned, religiosity and spirituality are separate concepts, which may be related to health outcomes, including other domains of QoL. For example, Rippentrop et al. (2006) found that spirituality and religiosity were both positively related to overall QoL (i.e., physical, functional, social, and emotional well-being), while spirituality explained more variance in QoL among a sample of patients with hematologic cancer (i.e., cancer affecting the blood, bone marrow, and lymph nodes). Few studies have examined the relationship between spirituality and QoL in patients with cancer, much less among patients with MBC. The following studies show how spirituality or spiritual well-being have shown to be cross-sectionally, positively related to QoL (e.g., Manning-Walsh, 2005; Visser et al., 2009) and how spirituality may be an effective coping mechanism in adjusting to a cancer diagnosis. This literature review focuses on the use of spirituality as a coping mechanism instead of as outcome such as spiritual well-being may be perceived, therefore, I will use the umbrella term of spirituality.

First, Khoramirad et al. (2014) conducted a cross-sectional study using 80 Muslim women with breast cancer in Iran to determine relationships between sleep quality, spirituality, and religious activities. They used the Spiritual Well-Being Scale (SWBS; Paloutzian & Ellison, 1982) to measure spirituality. The SWBS consists of 20-items on two subscales measuring religious and existential well-being with items ranging on a scale from 1

(*strongly disagree*) to 6 (*strongly agree*). Scores are summed and range from 20 to 120, with higher scores indicating higher levels of spirituality. The religious well-being scale consists of ten items that determine an individual's relationship with God, and the existential well-being scale consists of ten items that determine an individual's relationship with other individuals and the world. The internal consistency reliability of the scale was found to be acceptable at $\alpha = 0.74$ (Khoramirad et al., 2014). Researchers found no significant cross-sectional correlations between sleep quality, religious activities, and spirituality (i.e., religious and existential well-being), and they did not include a measure of QoL. However, they found that patients who agreed that they get personal strength and support from God and who believed in some real purpose for their life had better quality of sleep. It may be argued that sleep quality is an aspect of physical QoL. The lack of significant results may be attributable to the small sample size and lack of sufficient statistical power.

Similarly, Laubmeier et al. (2004) cross-sectionally examined spirituality among a sample of patients with mixed types of cancer ($N = 95$). Participants were recruited from hospitals across different areas of the United States. Most of the sample (96%) identified as White, 2% identified as African American, 1% identified as Hispanic, and 1% identified as Asian. Sixty-four participants identified as female and 31 identified as male, and the mean age of participants was 58.5 ($SD = 10.8$) years. Patients' cancer diagnoses were as follows: 23% prostate, 16% breast, 14% ovarian, 11% endometrial, and 36% other including uterine, colon, cervical, and lung cancers. Participants' religious affiliations varied widely: 41% were Protestant, 39% Catholic, 7% Jewish, 3% Agnostic, 2% Atheist, 1% Buddhist, and 7% reported other religious affiliations. The study aim was to examine whether spirituality was associated with positive benefits, including good QoL, in patients with cancer regardless of

perceived life threat, or whether spirituality would be a buffer only among patients with high levels of perceived life threat. Participants completed a survey that consisted of demographic questions, a scale that measured patients' levels of perceived life threat and distress, and the SWBS (Paloutzian & Ellison, 1982) as a measure of spirituality. Cronbach's alpha for the SWBS was not reported besides explaining that the internal consistency reliability was good (Laubmeier et al., 2004). Participants also completed the Functional Assessment of Cancer Therapy-General Scale (FACT-G; Cella et al., 1993) as a measure of QoL over the past seven days. The FACT-G consists of 27 items on four subscales: Physical, Social/Family, Emotional, and Functional Well-Being. An example of an item is, "I worry about dying," with response options ranging on a scale from 0 (*Not at all*) to 4 (*Very much*). Scores for each subscale are calculated by summing items into a total score, multiplying the sum of the item scores by the number of items, then dividing by the total number of items answered, which provides the subscale scores. Subscale scores are then summed to calculate a total score ranging from 0 to 108, with higher scores indicating better QoL. The questionnaire was validated using patients currently receiving treatment for Stage III or IV cancer. In Laubmeier et al.'s (2004) study, Cronbach's alpha was reported to be good at $\alpha = .89$.

Researchers found that spirituality was negatively related to distress in the form of symptoms of anxiety and depression and positively related to QoL among their sample of patients with cancer (Laubmeier et al., 2004). Surprisingly, there was no association between spirituality and life threat, but high levels of spirituality were associated with less distress and symptom severity regardless of levels of perceived life threat. Therefore, spirituality may be a protective buffer that allows patients with cancer to better cope with symptoms of anxiety and depression regardless of perceived threat to one's life. Researchers suggested that health

care providers assess levels of spirituality in patients with chronic illness to help them deal with adverse psychological effects related to their illness.

The relationship between spirituality and QoL has also been examined in the context of mediating variables. Manning-Walsh (2005) hypothesized that the relationship between symptoms of distress and QoL would be mediated by religious/spiritual support and social support among patients with breast cancer. At the time of the study, there were no studies found in which religious/spiritual support and social support were included as mediating variables. Manning-Walsh surveyed 100 female patients with breast cancer using a questionnaire that included a measure of distress and the breast cancer version of the Functional Assessment of Cancer Therapy Scale (FACT-B, version 4; Cella et al., 1993) and the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp-12; Brady et al., 1999; Cella et al., 1993; Peterman et al., 2002) as measures of QoL. The FACT-B consists of 37 items ranging on a Likert-type response scale from 0 (*not at all*) to 4 (*very much*). The FACT-B contains the subscales included in the FACT-G (Cella et al., 1993) plus the breast cancer subscale. It consists of five subscales that ask about physical, social/family, emotional, and functional well-being and breast cancer over the past seven days. Both a total score and subscale scores for physical well-being, functional well-being, and breast-cancer can be used. An example of an item is, "I am content with the quality of my life right now." The FACIT-Sp-12 consists of three dimensions: Meaning, Peace, and Faith. There are twelve total items that ask about spiritual aspects such as meaning, peace, and faith over the past seven days. An example of an item is, "I feel a sense of harmony within myself." Response options on a Likert-type scale range from 0 (*Not at all*) to 4 (*Very much*). Two items are reverse scored. Subscale scores are calculated by summing the individual item scores in each

dimension, multiplying by four, then dividing by the number of items answered in the respective subscale. Total scores are calculated by summing the three subscale scores. Higher scores indicate higher levels of spirituality. Total scores range from 0 to 48, while possible subscale scores range from 0 to 16 for each of the three subscales. However, in this study Manning-Walsh (2005) combined total scores from the FACT-B and FACIT-Sp-12 instruments into a composite score measuring QoL with Cronbach's alpha equal to .93, which was excellent.

Results showed that participants reported moderate levels of distress, including fatigue (85%), altered mood (83%), insomnia (77%), dissatisfaction with appearance (77%), and decreased ability to concentrate (68%; Manning-Walsh, 2005). Additionally, none of the demographic variables (e.g., age, annual income, education, and church membership) was found to be significantly related to QoL. Mediation results showed that cross-sectionally, social support outside of one's religious congregation partially mediated the relationship between symptoms of distress and QoL, while religious/spiritual support neither mediated the relationship between distress and QoL nor was it related to QoL. Therefore, social support from family members and friends may be an important coping resource for patients with breast cancer. Manning-Walsh concluded that further research should examine the relationship between religious/spiritual support and QoL, especially in the context of symptoms of distress and at more than one time point as the study was cross-sectional. Additionally, further research may benefit from a better measure of religious/spiritual support as Manning-Walsh explained that spiritual support may not have been adequately captured.

In a study of survivors of various types of cancer, Johannessen-Henry et al. (2013) sought to determine the extent to which spirituality and faith are associated with distress and

positive mental adjustment. They surveyed 1043 survivors of cancer at one time point using a questionnaire that measured spirituality and faith using a Danish-translated version of the FACIT-Sp-12 (Brady et al., 1999; Cella et al., 1993; Peterman et al., 2002); they used both a total score for the full scale and the subscale score of the faith dimension. They also included three single items that they developed to measure faith, including “I believe in a God with whom I can talk.” The Danish-translated scale and faith items were not validated. Majority of participants were female (76%, $n = 802$), the mean age was 58 years old (ranging from 43 to 72), and most were survivors of breast, colorectal, gynecologic, prostate, or hematological system cancers (78%, $n = 816$).

Johannessen-Henry et al. (2013) found that spirituality was associated with less total distress and increased mental adjustment to cancer, including less anxious preoccupation and helplessness-hopelessness, and more fighting spirit. Of note, spirituality was not significantly related to fatigue-inertia. Scoring high on the faith subscale was related to less distress and anxious preoccupation, and more vigor-activity and fighting spirit. Among the three single faith items, results showed that those who believed in a God had more anxious-preoccupation and cognitive avoidance than those who did not believe in a God; those who believed in a God they could talk to had higher levels of tension-anxiety, vigor activity, and fighting spirit; lastly, having experiences related to God was related to more tension-anxiety, confusion-bewilderment, and vigor-activity, but also related to less cognitive avoidance and significantly more fighting spirit. Johannessen-Henry et al. (2013) argued that patients who are distressed by their cancer and have poor capacity to adjust may be less capable of engaging in meaning, peace, and faith, which are components of spirituality. On the other hand, those who experience anxiety and poorer adjustment to cancer may experience a

comforting relationship with a God or other higher being. They also explained that better differentiation between spirituality and the faith dimension of spirituality may explain more of how cancer survivors cope with their illness. The cross-sectional nature of the study limits causation as one cannot know the direction of the relationship; however, these conclusions imply that spirituality and its components may have both positive and negative effects on mental adjustment and distress related to cancer.

Spirituality and Fatigue. Past research has shown spirituality to be cross-sectionally, positively related to QoL (e.g., Manning-Walsh, 2005; Visser et al., 2009) and cross-sectionally, negatively related to symptoms of distress (Laubmeier et al., 2004), while symptoms of fatigue may be negatively related to QoL (Lewis et al., 2014). Spirituality has been suggested to be important for adapting to the life threat of cancer and cancer-related stress (Laubmeier et al., 2004), which should be negatively related to symptoms of fatigue as it may be a buffer or protective factor. In other words, spirituality may influence the experience of chronic pain or fatigue (Baetz & Bowen, 2008) by potentially decreasing these symptoms. The following studies describe the relationship between spirituality and symptoms of fatigue in patients with cancer or respiratory failure. Few studies have examined the relationship between spirituality and fatigue, therefore, research involving patients or caregivers of patients with any type of chronic illness were included.

Lewis et al. (2014) cross-sectionally surveyed 200 patients undergoing active cancer treatment to assess levels of spirituality and fatigue during cancer treatment. They measured fatigue and spirituality using the FACIT Fatigue Scale (Yellen et al., 1997) and the FACIT-Sp-12 (Brady et al., 1999; Cella et al., 1993; Peterman et al., 2002), respectively. The FACIT Fatigue Scale consists of thirteen items that measure levels of fatigue during daily activities

over the past week using a five-point Likert-type response scale ranging from 0 (*Not at all fatigued*) to 4 (*Very much fatigued*). An example of an item is, “I have trouble starting things because I am tired.” Scores are summed, ranging from 0 to 52, with higher scores indicating higher levels of fatigue. For this sample Cronbach’s alpha was not provided, but it was reported to be excellent at $\alpha = .96$ in a sample of patients with cancer and anemia (Lewis et al., 2014; Yellen et al., 1997). Head and neck and gastrointestinal cancers consisted of 26.5% ($n = 53$) of the sample, 19% ($n = 38$) breast cancer, 18.5% ($n = 37$) genitourinary cancers, and the remainder constituted 9.5% ($n = 19$). Of these, 11.5% ($n = 23$) had Stage IV cancer.

Mean spirituality scores were found to be significantly higher in females compared to males, and lower with higher stages of cancer (Lewis et al., 2014). All 200 patients reported experiencing fatigue, while those with Stage IV reported higher levels of fatigue. Therefore, results suggest there are greater levels of fatigue in patients with Stage IV cancer compared to other stages. Lewis et al. also found a negative relationship between levels of fatigue and spirituality, and spirituality was a significant primary negative predictor for fatigue scores, followed by stage of disease, and gender. Therefore, this study shows how there may be a negative cross-sectional relationship between levels of fatigue and spirituality.

Lewis et al. (2014) contended that spirituality and fatigue are important for assessing QoL in patients with cancer in order to determine patients’ coping abilities in the disease trajectory. Despite this, they did not include QoL as an outcome variable in their study. The researchers argued that it is unknown whether patients with cancer who have low levels of fatigue are more spiritual, or whether patients with high levels of fatigue are less spiritual.

Fatigue can influence every part of a person’s life including physical, psychological, and social well-being, and spirituality, but fatigue is often under-assessed and under-

addressed (Lewis et al., 2014). Fatigue has been shown to be an indicator of distress, and spirituality has been shown to affect fatigue in patients undergoing cancer-directed treatment. However, future studies should explore different aspects of spirituality such as faith, meaning in life, and peace and its relationship to distress in longitudinal studies as they did not examine the subscales of the FACIT-Sp-12 (Brady et al., 1999; Cella et al., 1993; Peterman et al., 2002) over more than one time point. This information may shed light on the strength of the relationship between spirituality and fatigue to determine whether patients with cancer who have high or low levels of fatigue should be encouraged to engage in spirituality to decrease distress related to cancer, in this case said levels of fatigue.

Similarly, Richardson Gibson and Parker (2003) conducted a correlational study to describe the psychological effects of using inner resources, specifically spirituality (e.g., sense of coherence, hope, and spiritual perspective) by African American survivors of breast cancer ($N = 162$). This population is generally exposed to major life stressors but individuals continue to have high levels of psychological well-being (PWB), as explained by the Gibson Model of Inner Resources. Therefore, PWB may be seen as an indicator of QoL in African American survivors of breast cancer. Additionally, the Model suggests a link between sense of coherence, hope, spiritual perspective, and PWB, which are said to be intercorrelated and independently positively related to PWB. Symptoms of PWB were measured using the Psychological Well-Being Subscale, Quality of Life-Breast Cancer Version (Ferrell et al., 1998). The questionnaire consists of 22 items using a response scale ranging from 0 (*Worst outcome*) to 10 (*Best outcome*). An example of an item is, “How difficult is it for you to cope today as a result of your treatment?” Mean scores are calculated by summing the number of items answered and dividing by the total of all items within the subscale. Higher scores

indicate higher levels of PWB. For this sample researchers reported Cronbach's alpha to be excellent at $\alpha = .91$ (Richardson Gibson & Parker, 2003).

The results showed that few participants experienced nausea ($n = 14, 8.6\%$) or vomiting ($n = 11, 6.8\%$) and 85 (52.5%) experienced fatigue (Richardson Gibson & Parker, 2003). Spiritual perspective was not related to PWB, while sense of coherence and hope were independently related to PWB. An indirect effect was found between spiritual perspective and PWB through hope. That is, spiritual perspective was positively related to hope while controlling for the effect of PWB, and hope was positively related to PWB while controlling for the effect of spiritual perspective. Thus, participants used hope with spiritual perspective to influence PWB. Sense of coherence and hope were positively related; hope and spiritual perspective were positively related; and sense of coherence and spiritual perspective were positively related as well. Although researchers did not include fatigue in the model despite more than half of participants reporting experiencing fatigue, these findings emphasize the need to assess inner resources before conducting individual or group treatments to treat psychosocial distress associated with breast cancer. Future research should examine how fatigue affects hope, PWB, and spiritual perspective or spirituality.

Szatkowska and Sołtys (2018) cross-sectionally surveyed 55 caregivers of patients with chronic respiratory failure who used home mechanical-ventilation. The aim of their study was to determine whether social support and spirituality would buffer the effects of caregiver burden, including daily life fatigue. They described how fatigue consists of subjective discomfort and tiredness that is related to a decrease in well-being. Study procedures included completing a questionnaire at one time point, which included the Polish-translated version of the Spiritual Index of Well-Being (SIWB; Daaleman & Frey, 2004) as a

measure of spirituality, and the Daily Life Fatigue Questionnaire (DLFQ; Urbańska, 2010) as a measure of daily fatigue. The SIWB consists of twelve items on a five-point Likert scale and two subscales: Self-Efficacy and Life Scheme. An example of an item is, “I am far from understanding the meaning of life.” Scores are summed to calculate a total score ranging from 12 to 60, with higher scores indicating higher levels of spirituality. In this sample, Cronbach’s alpha was reported to be good at $\alpha = .85$ for the whole scale, .87 for the Self-Efficacy subscale, and .85 for the Life Scheme subscale (Szatkowska & Sołtys, 2018). The DLFQ (Urbańska, 2010) consists of eight items per each of the three subscales: Physical Fatigue, Mental Fatigue, and Social Fatigue; response options included “yes” or “no.” For this Polish-translated questionnaire, items, response options, and information about scoring could not be found. In Szatkowska and Sołtys’ (2018) study, Cronbach’s alpha was reported to be good at $\alpha = .85$ for the whole scale, and .71-.86 for the subscales.

Results showed that social support was not correlated with fatigue (Szatkowska & Sołtys, 2018). As expected, overall spirituality and scores on the life scheme dimension of the SIWB were negatively related to physical, mental, and social fatigue. In stepwise multiple regression analyses, higher levels of both dimensions of SIWB were not related to decreased levels of general daily life fatigue and mental fatigue. Only the self-efficacy SIWB dimension was related to lower levels of physical fatigue. Neither dimension of the SIWB was related to levels of social fatigue. Therefore, among caregivers of patients with chronic illness, spirituality may buffer against the effects of daily life and mental fatigue. A limitation of the study is that they did not survey patients themselves, therefore, future research should examine whether the results hold in patients with chronic illness, and specifically whether spirituality protects against or minimizes the effects of fatigue and measures of QoL.

As a mini meta-analysis, Visser et al. (2009) reviewed 40 studies that examined associations between spirituality/meaning in life and well-being/QoL among patients with cancer. Most of the cross-sectional studies (31 out of 36) found a positive relationship between spirituality and well-being, even among studies that controlled for sociodemographic and cancer-related factors. The four longitudinal studies showed mixed results between spirituality and well-being. Within one of those cross-sectional studies, Brady et al. (1999) showed that patients with cancer, HIV, or AIDS who scored high on spirituality also had high levels of enjoyment of life, regardless of levels of pain or fatigue using the FACIT-SP-12 (Cella et al., 1993; Peterman et al., 2002) as a measure of spirituality, and using the FACT-G (Cella et al., 1993) as a measure of QoL and fatigue. High levels of fatigue were defined as a rating of 3 (*Quite a bit*) or 4 (*Very much*) on the FACT-G item, "I have a lack of energy." Therefore, patients with high symptoms of fatigue but high levels of spirituality reported high levels of contentment with life. This shows how spirituality may buffer against the effects of fatigue to contribute to good QoL among patients with cancer.

In a related study, Lo et al. (2011) cross-sectionally examined spirituality among 747 patients with various types of cancer in Canada. They hypothesized that religion or other belief systems, self-esteem, social relatedness, and freedom from physical suffering shape spirituality. They used the FACIT-Sp-12 (Brady et al., 1999; Cella et al., 1993; Peterman et al., 2002) to measure spirituality, but they did not measure symptoms of fatigue. The authors confirmed their theoretical model in which spirituality is positively related to religiosity, self-esteem, and social relatedness, and it is negatively related to physical suffering (Lo et al., 2011). Furthermore, religiosity, social relatedness, and the physical burden of disease were

significantly related to spirituality. They argued that it may be necessary to determine the sources of spirituality in order to develop and assess clinically relevant interventions and to determine who should deliver the interventions within the health care system.

Years later, Visser et al. (2018) tested the hypothesis that spirituality would reduce the influence of cancer-related fatigue, pain, and perceived life threat on distress in two studies in the Netherlands. The moderator variable was spirituality, which was measured using the Spiritual Attitude and Involvement List (SAIL; Jager Meezenbroek et al., 2012). The SAIL consists of seven subscales; however, the subscale Trust was not used due to questionable validity. The six subscales that were included consisted of Meaningfulness, Acceptance, Caring for Others, Connectedness with Nature, Transcendent Experiences, and Spiritual Activities. The response options range from 1 (*Not at all*) to 6 (*To a very high degree*) for four of the subscales, while the response options for the remaining three range from 1 (*Never*) to 6 (*Very often*). Seven mean scores were calculated for each of the subscales with higher scores representing increased spiritual involvement. Symptoms of fatigue were measured using the four-item Dutch version of the Checklist Individual Strength (Alberts et al., 1997). The four items asked whether participants felt tired, were easily tired, felt well, or felt physically exhausted on a six-point scale ranging from 1 (*Not at all*) to 6 (*To a very high degree*). One item was reverse-scored, and a total score was calculated with higher scores representing higher symptoms of fatigue. Pain was measured using a visual analog scale ranging from 1 (*No pain at all*) to 7 (*The worst pain imaginable*). Symptoms of distress were measured using the Dutch version of the Hospital Anxiety and Depression scale (HADS; Spinhoven et al., 1997). The HADS consists of fourteen items on two subscales that measure symptoms of anxiety and depression, which sum up to a total score with higher

scores representing higher symptoms of depression and anxiety, or distress. In addition, participants provided demographic information and completed measures of perceived life threat and serious life events.

The first study was cross-sectional in nature and it included 209 individuals with cancer (Visser et al., 2018). The second study was longitudinal, therefore a separate sample of 240 individuals with cancer completed the questionnaires at three separate time periods. Participants completed the first survey at baseline (i.e., Time 1), six months later they completed the same survey (i.e., Time 2), then they completed the survey at an additional six months from Time 2 (i.e., Time 3). All individuals who participated in both studies were being treated for cancer with curative intent at the time of the study. The data were analyzed with both marginal effects plots and regression analysis to determine whether there was a moderating effect of the spirituality subscales on the relationship between fatigue, pain, and perceived life threat on distress.

Results showed that none of the six spirituality subscales significantly interacted with pain or fatigue in study one (Visser et al., 2018). However, symptoms of fatigue were shown to be significantly related to increased distress. High scores on the Acceptance, Connectedness with Nature, Transcendent Experiences, and Spiritual Activities subscales appeared to buffer against symptoms of pain and fatigue on distress, however, these effects did not reach statistical significance. Additionally, scores on the Caring for Others subscale appeared to be unrelated to pain or fatigue on distress, while high scores on the Meaningfulness subscale appeared to increase symptoms of pain and fatigue on distress. There were only two significant moderation effects found, which were included in the second study. The first was the buffering effect of Meaningfulness on the relationship between

change in fatigue and distress scores from Time 1 to Time 2. The second statistically significant moderation effect was an aggravating effect of Caring for Others on the relationship between change in perceived life threat and change in distress from Time 1 to Time 2 and from Time 2 to Time 3. Overall, Visser et al. state that the effects were small but present for a large proportion of the sample. They concluded that, as described by James and Wells (2003), spirituality may influence mental health by allowing individuals to experience life as meaningful and accept negative and positive aspects of life that can help one reappraise symptoms of fatigue as a part of cancer or life. Therefore, spirituality may help one reappraise fatigue to reduce or not cause additional distress. Visser et al. argued that they may have found little evidence that spirituality may reduce the influence of pain, fatigue, or perceived life threat on distress due to using a poor measure of distress that is too broad. Another limitation is that a total spirituality score was not used, therefore, it is unknown whether the combination of the spirituality subscales moderates the relationship between fatigue, pain, and perceived life threat on distress related to cancer.

Only a handful of studies have used spiritual interventions to evaluate the effects of increases in spirituality on patients' QoL, and even fewer have included fatigue. For example, Kestenbaum et al. (2017) evaluated the feasibility of chaplain-delivered spiritual care with 31 patients with advanced cancer receiving outpatient palliative care. They specifically focused on the effects on patients' spirituality, religious and cancer coping, and psychological and physical symptoms. Following three chaplain sessions, they found an increase only on the Faith subscale of the FACIT-Sp-12 (Brady et al., 1999; Cella et al., 1993; Peterman et al., 2002) at Time 2. They did not report mean total FACIT-Sp-12 scores; they reported mean scores for the three subscales of Meaning, Peace, and Faith pre- and post-

intervention (Kestenbaum et al., 2017). There were no significant changes for either physical symptoms or several of the psychological measures. Although this study examined changes in spirituality over time, they did not measure symptoms of fatigue.

Similarly, in a randomized controlled trial, Wyatt et al. (2012) studied patients with Stage III or IV breast cancer diagnosed with and without distant metastasis ($N = 385$) for the purposes of identifying differences in levels of health-related QoL, including functioning, symptoms, and spirituality. The two experimental groups included reflexology ($n = 95$) and lay foot manipulation ($n = 95$), and the control group consisted of care as usual ($n = 96$). Foot reflexology consists of pressure stimulation of specific reflex points in the feet that are believed to map on to and affect corresponding organs in the body (Song et al., 2015). Lay foot manipulation was reported to be superficially similar to reflexology (Wyatt et al., 2012). The remaining participants were assigned to two test groups ($n = 99$), which were included in the final data analysis. Health-related QoL was measured using the subscales and total scores of the FACT-B (Cella et al., 1994). Spirituality was measured using the spirituality subscale of the Long-Term Quality of Life Instrument (Wyatt & Friedman-Donze, 2003). The subscale consists of eleven items rated on a five-point scale that are summed to calculate a total subscale score with lower scores reflecting higher levels of spirituality. The current study did not report the internal consistency reliability coefficient for the subscale, but Cronbach's alpha was found to be good at $\alpha = .87$ in a prior study (Wyatt et al., 2012; Wyatt & Friedman-Donze, 2003). Fatigue over the past day to a week was measured using the Brief Fatigue Inventory by Mendoza et al. (1999), which consists of nine items rated on three response scales: 'yes' or 'no,' from 0 (*No fatigue*) to 10 (*As bad as you can imagine*), or from 0 (*Does not interfere*) to 10 (*Completely interferes*). An example of an item is "Have you felt

unusually tired or fatigued in the last week?” Scores are summed with higher scores indicating higher levels of fatigue. Cronbach’s alpha was reported to be more than .95.

Wyatt et al. (2012) found no differences between patients with and without distant metastasis on fatigue, sleep quality, anxiety and depressive symptoms, or spirituality at baseline and at five and 11-weeks post-randomization. However, after controlling for age, comorbidity, type of treatment, and time since cancer diagnosis, patients with distant MBC had worse physical functioning and more pain compared to patients with local/regional metastasis. The researchers summarized that most differences between patients with and without distant metastasis were physical, as emotional and spiritual QoL outcomes were unrelated to metastasis so patients with MBC may have adapted emotionally and spiritually but may need help managing physical symptoms. Based on the results of this study, healthcare providers may be an important resource in helping patients with MBC manage physical symptoms.

Summary

Research shows that patients with terminal cancer often report unmet needs, mental symptoms of distress, and physical symptoms that can be managed with the help of their healthcare team (Lu et al., 2020; McCarthy et al., 2000; Rainbird et al., 2009; Wyatt et al., 2012). Specifically, patients may experience functional decline, worsening severity of illness, high levels of poorly controlled pain and confusion, fatigue/lack of energy, and moderate levels of symptoms of anxiety and depression as they near their last months of life (McCarthy et al., 2000). With the transactional model of stress and coping in mind (Lazarus & Folkman, 1984), patients with MBC may experience high levels of stress that may be attributed to their MBC diagnosis, terminal prognosis, and treatment. Individuals’ coping

abilities may be ineffective when dealing with MBC-related stress, potentially leading to negative outcomes including increased symptoms of anxiety and depression that may contribute to a worsening of QoL. On the other hand, some individuals may be able choose and utilize certain coping strategies to buffer against cancer-related stress.

Spirituality is one resource that patients with MBC may use to minimize the effects of their diagnosis on fatigue, and to increase QoL. Spirituality has been measured using questionnaires such as the SWBS (Paloutzian & Ellison, 1982), the FACIT-Sp-12 (Brady et al., 1999; Cella et al., 1993; Peterman et al., 2002), the SIWB (Daaleman & Frey, 2004), the four-item Dutch version of the Checklist Individual Strength (Alberts et al., 1997), the spirituality subscale of the Long-Term Quality of Life Instrument (Wyatt & Friedman-Donze, 2003), and the SAIL (Jager Meezenbroek et al., 2012). Fatigue has been measured using the FACIT Fatigue Scale (Yellen et al., 1997), the DLFQ (Urbańska, 2010), the Brief Fatigue Inventory by Mendoza et al. (1999), the four-item Dutch version of the Checklist Individual Strength (Alberts et al., 1997), the FACT-G item, “I have a lack of energy,” and the Dutch version of the Checklist Individual Strength (Alberts et al., 1997). QoL has been measured using the FACT-G (Cella et al., 1993), the FACT-B (Cella et al., 1993), the FACIT-Sp-12 (Brady et al., 1999; Cella et al., 1993; Peterman et al., 2002), and the Psychological Well-Being Subscale-Quality of Life-Breast Cancer Version (Ferrell et al., 1998). All these instruments have been shown to have good internal consistency reliability based on Cronbach’s alpha coefficients, and they appear to be valid measures of their constructs in the context of patients or caregivers or patients with cancer or other chronic illnesses. For example, many of the instruments, including the FACT-G, FACT-B, and the FACIT-Sp-12, consist of more than one subscale that allow for the measurement of multiple

dimensions of a construct. The questionnaires are brief which means they allow for a quick, efficient way to obtain large sample sizes that qualitative interviews could not provide, in addition to making it easy to conduct quantitative data analyses with scoring information readily available. However, there are drawbacks to relying on self-reported questionnaires. For example, participants may be subjected to biases such as the social desirability effect or the halo effect that can influence participant responses when filling out the questionnaires. Mono-method bias can occur when relying on a single method of measurement, however, it would be difficult to obtain insight into patients' cognitions and perceptions of spirituality, fatigue, and QoL by relying on any other method. A potential limitation of this bias could be that significant associations could be non-significant.

The handful of studies that have examined relationships between spirituality, fatigue, and QoL in patients with cancer have found that spirituality may be cross-sectionally, positively related to QoL (e.g., Manning-Walsh, 2005; Visser et al., 2009) and fatigue may be cross-sectionally, negatively related to QoL although this was not tested in the study (Lewis et al., 2014). Furthermore, Johannessen-Henry et al. (2013) found that spirituality was cross-sectionally, negatively related to total distress, but positively related to mental adjustment to cancer, including having a less anxious preoccupation among survivors of cancer. Of note, spirituality was not cross-sectionally associated with less fatigue-inertia. They argued that patients who are distressed by their cancer and have poor capacity to adjust may be less able to engage in spirituality. Relatedly, Laubmeier et al. (2004) found that spirituality was cross-sectionally negatively related to distress in the form of symptoms of anxiety and depression and positively related to QoL. This means that spirituality may be a buffer that minimizes symptoms of anxiety and depression and increases QoL. In contrast to

those findings, one study explained that among caregivers of patients with chronic illness that require home ventilation, engaging in spirituality may have minimized the effects of daily life and mental fatigue, but not social fatigue (Szatkowska & Sołtys, 2018).

Lewis et al. (2014) argued that fatigue and spirituality are important for assessing patients' QoL and ability to cope with cancer. In the short-term, spirituality may be negatively related to fatigue, although this relationship was not tested in their study. Additionally, the longitudinal relationship between spirituality and fatigue is unclear as it is unknown whether engaging in more or less spirituality decreases distress related to high and/or low levels of fatigue over the long term. Although not specifically mentioned by Lewis et al., spirituality may be a moderator variable that buffers against symptoms of fatigue and improves QoL. For example, Brady et al. (1999) reported that spirituality may have enabled individuals with cancer, HIV, or AIDS to endure high levels of fatigue and pain to preserve a capacity to enjoy life. Relatedly, among caregivers of patients with chronic respiratory failure, Szatkowska and Sołtys (2018) proposed that spirituality may buffer against the effects of daily life and mental fatigue.

Only one study was found in the literature that included spirituality as a moderator variable. Visser et al. (2018) conducted a cross-sectional and a longitudinal study that explored whether six spirituality subscales of the SAIL (Jager Meezenbroek et al., 2012) would reduce the influence of fatigue on distress. Results showed that none of the six spirituality subscales significantly interacted with pain or fatigue in the cross-sectional study; however, two significant moderator variables were found in the longitudinal study. First, the Meaningfulness subscale was found to buffer the relationship between change in fatigue and distress scores from baseline (i.e., Time 1) to follow-up (i.e., Time 2). Second, there was an

aggravating effect of the Caring for Others subscale on the relationship between change in perceived life threat and change in distress from Time 1 to Time 2 and from Time 2 to Time 3. Of note, Visser et al. did not include a total spirituality score as a moderator variable, and they did not include QoL as an outcome variable.

Therefore, these mixed findings in the literature that focused primarily on cross-sectional relationships indicate that longitudinal research is needed to show the direction and strength of the relationships between spirituality, fatigue, distress, and QoL (Johannessen-Henry et al., 2013; Lewis et al., 2014; Manning-Walsh, 2005; Szatkowska and Sołtys, 2018; Visser et al., 2009). The literature is missing information about the relationship between spirituality and fatigue predicting QoL, particularly in the long-term and among patients with more advanced stages of cancer. It is unknown how this relationship may change over more than one period of time while patients are undergoing treatment for MBC. Additionally, research is needed to examine the relationships between spirituality as a moderator variable interacting with fatigue to predict QoL. These long-term relationships may be clarified when spirituality as a moderator variable is taken into account.

Hypotheses

Based on past research showing a relationship between spirituality and QoL dimensions, studies are needed to examine the interconnections between spirituality, fatigue, and QoL. As mentioned previously, treatment for MBC tends to stop working after some time, so if the cancer no longer responds to a treatment regimen, different combinations of drugs may be used (“Treatment of stage IV [Metastatic] breast cancer,” 2020). This means that patients with MBC may experience drug changes over time. This can be potentially stressful, along with the fact that each time a cancer progresses it becomes less likely to

respond to treatment. Additionally, as the disease progresses MBC hormone receptors may change from positive to negative, which is called conversion of ER or PR (Meng et al., 2016). Conversion ER or PR from positive to negative was shown to be associated with worse overall survival compared to patients who did not have a change in ER or PR status in Meng's retrospective study of a sample of 627 patients with MBC. Most studies examining spirituality/meaning in life and well-being among patients with cancer have been cross-sectional (Visser et al., 2009), so it was deemed worthwhile to study these relationships over two periods of time to assess how they may change while patients are undergoing treatment for MBC. It was anticipated that the two periods of data collection would be able to capture changes in treatment and/or hormone receptor conversion for MBC patients, which may have decreased QoL and increased distress. Therefore, the two time periods were hypothesized to allow for examination of all study variables over time.

Thus, the study planned to test the following hypotheses:

1. Hypothesis 1: Spirituality would interact with fatigue to predict QoL in the form of social/family well-being over time.
 - a. Spirituality at Time 1 would interact with fatigue at Time 1 to predict social/family well-being at Time 2 (controlling for Time 1 social/family well-being). Specifically, the magnitude of the negative relationship between fatigue and social/family well-being would be lower for those high in spirituality (compared to their low spirituality counterparts).
2. Hypothesis 2: Spirituality would interact with fatigue to predict QoL in the form of emotional well-being over time.

- a. Spirituality at Time 1 would interact with fatigue at Time 1 to predict emotional well-being at Time 2 (controlling for Time 1 emotional well-being). Specifically, the magnitude of the negative relationship between fatigue and emotional well-being would be lower for those high in spirituality (compared to their low spirituality counterparts).
3. Hypothesis 3: Spirituality would interact with fatigue to predict QoL in the form of functional well-being over time.
 - a. Spirituality at Time 1 would interact with fatigue at Time 1 to predict functional well-being at Time 2 (controlling for Time 1 depressive symptoms). Specifically, the magnitude of the negative relationship between fatigue and functional well-being would be lower for those high in spirituality (compared to their low spirituality counterparts).

CHAPTER 3

METHODOLOGY

Participants

The sample was recruited from the Saint Luke's Koontz Center for Advanced Breast Cancer in Kansas City, Missouri. Participants consisted of patients with MBC who completed an intake questionnaire at their initial consultation at the Koontz Center. Patients were referred to the clinic following a diagnosis of MBC. Inclusion criteria for participating in the study consisted of: 1) Having a diagnosis of MBC, 2) Having been contacted for participation in the study within six weeks of an initial appointment at the Koontz Center, 3) Being 18 years of age or older, and 4) Being able to read and comprehend English. Based on the eligibility criteria, patients with MBC may have received an MBC diagnosis prior to their intake appointment and may have received a second opinion at the Koontz Center. Others could have transferred their care to the Koontz Center after receiving care at a different institution.

A statistical power analysis was conducted using Faul et al.'s (2007) G*Power program. This analysis showed that using six predictors (i.e., Spirituality, Fatigue, Spirituality interacting with Fatigue, and three possible covariates, including the Time 1 outcome variable) and anticipating a medium effect size with .80 power, a sample size of 99 would be needed. This sample size recommendation included having the *p*-value set at .017 to correct for family-wise error. According to Cohen (1992), a sample size between 134 and 97 is recommended to have 0.80 power to detect a medium effect using six predictors; these recommendations are based on alpha levels of .01 and .05, respectively. Because G*Power

allows the user to set a specific p -value for the exact test to be conducted, a sample size of 99 was planned for this project.

Before recruitment started, we anticipated some declines to participate in the study from prospective participants. Although participation rates are quite high in other studies at this clinic (K. M. Harry, personal communication, March 3, 2022), I planned to over-recruit by 10% in order to collect data from at least 99 participants. To reach this goal, I anticipated needing to approach at least 109 participants at Time 1 to achieve my desired sample size of 99. Furthermore, I anticipated some attrition from the study between Times 1 and 2. Because study attrition at this site is fairly low (K. M. Harry, personal communication, March 3, 2022), I anticipated needing to over-recruit by at least another 10% to account for participant attrition. Therefore, I planned to recruit at least 120 participants at Time 1 to be able to collect data from 99 participants at both Times 1 and 2. Before recruitment started, there were on average two new patients a week at the Koontz Center, so Time 1 data collection was anticipated to take 14 months. Follow-up data collection was anticipated to take another 2 months, which would bring the entire data collection period to approximately 16 months. However, we knew this timeline could be reduced depending on how many participants were retrospectively enrolled to the study once data collection started.

Procedures

All new patients with MBC complete an intake questionnaire at their initial appointment at the Saint Luke's Koontz Center for Advanced Breast Cancer. At their initial appointment, patients see a multidisciplinary team that includes a medical oncologist, social worker, dietician, licensed psychologist, and physical therapist. The team meets to discuss each case and then the patient meets with the medical oncologist to discuss their

comprehensive treatment plan. Patients can schedule follow-up appointments with any discipline as needed. Patients have the option to complete the questionnaire electronically on their patient portal in advance of their appointment, or they could complete a hard copy in the clinic on the day of the appointment. For consenting patients, responses in this questionnaire were used as data in the study. The Saint Luke's IRB approved study procedures, which were forwarded to the University of Missouri-Kansas City IRB through a Request to Rely on the Saint Luke's IRB. The university IRB approved the request to rely on the Saint Luke's IRB protocol; therefore, all study materials and procedures were approved by the respective IRBs.

A brief overview of the study procedures is depicted in Figures 2 and 3. Although all patients at the Koontz Center are asked to complete the intake questionnaire, I had to first recruit them to the study to be considered participants. This was done by contacting participants via phone before or after their initial appointment, or in person at their intake appointment or at a follow-up appointment. This included several patients who had previously completed the intake questionnaire within the past six weeks of the start of data collection as they were considered eligible to participate. Once the study was approved by the IRBs, patients who had recently completed the intake questionnaire within the six-week window of the Time 2 data collection period were contacted to participate in the study. These patients were then retrospectively enrolled in the study if they consented to participate. I reviewed the Koontz Center schedule twice a week through the electronic health records (EHRs) system to determine whether there were any eligible participants to contact via phone or in person at their initial appointment.

Before enrolling in the study, participants provided written consent which included consent to access their EHRs after hearing about the study procedures and agreeing to participate in the study.

Eligible participants were provided with information about the study, which included an informed consent form with an embedded authorization form to access medical information from their EHRs. If participants agreed to participate, they returned their signed consent forms, which included their contact information such as phone number and personal email address if not already found in the EHRs. In order to maintain participant confidentiality, participants were assigned identification numbers. However, an Excel sheet with participant names, identification numbers, and contact information was stored on the Saint Luke's network drive in a private folder that could only be accessed by individuals who have been granted access. If participants had not already completed the intake questionnaire at home before the initial appointment on their Saint Luke's patient portal, they were asked how they would prefer to complete it. Participants who wished to complete a paper copy of the intake questionnaire were given a hard copy of the questionnaire on site in an exam room. Participants who completed the intake questionnaire through their Saint Luke's patient portal at home before arriving to their initial appointment only had to sign the consent form. The mySaintLuke's (MSL) patient portal, which is also the system used to access EHRs, is secure and encrypted (Epic, 2021). Epic uses various technical safeguards to protect the confidentiality of patients' personal information including supporting Transport Layer Security/Secure Sockets Layer certificate technology and encryption. Participants were asked their preferred method of completing the follow-up questionnaire with the option of completing it online via email/REDCap, a phone call, a hard copy mailed to their home, or

onsite at the Koontz Center. REDCap servers are located in a local data center at the University of Missouri-Kansas City, all web-based information transmission is encrypted, and the system was developed around HIPPA-Security guidelines (Harris et al., 2009; UMKC Center for Health Insights, 2022)

The intake questionnaire took approximately fifteen minutes to complete. Once completed, the intake questionnaire was reviewed by staff for the intake appointment then placed in a locked cabinet in a private office on site. All hard copies of intake questionnaires and informed consent forms are kept in a locked cabinet in a private office on site. Intake questionnaires that were completed at home before the appointment through MSL were extracted from MSL patient portals by research staff and entered into an Excel sheet which included all other participants' questionnaire data. Intake questionnaire data were entered in this Excel sheet using identification numbers in place of patient names. Similar to the patient identification Excel sheet, questionnaire data was stored on the Saint Luke's network drive in a private folder that could only be accessed by individuals who have been granted access. The baseline data collection date was considered the date of intake questionnaire completion for Time 1.

Six weeks from completion of the first intake questionnaire, or at Time 2, participants completed the follow-up questionnaire through their preferred method of completing the questionnaire. The six-week follow-up was chosen as patients meet monthly with the oncologist at the Koontz Center, and new patients may have a better understanding of whether their treatment for MBC was working at the time of the second questionnaire. Additionally, patients may have undergone scans to determine if the treatment was working. Participants were contacted by phone before receiving the Time 2 questionnaire as a

reminder. If a participant chose to complete the follow-up questionnaire online via REDCap, they were sent a link to their personal email address to complete the questionnaire. If a participant preferred to complete a paper copy of the follow-up questionnaire at home, I mailed the questionnaire to their home along with a return envelope and pre-paid postage stamp. Participants also had the option to complete the follow-up questionnaire via a phone call, which was set up a week ahead of the six-week follow-up. Lastly, if a participant opted to complete the questionnaire in person at the clinic and if they had an appointment scheduled within the time frame, I gave the participant either a hard copy of the questionnaire, or they could have chosen to complete the questionnaire through REDCap on an iPad onsite. A total of up to three reminder phone calls and/or emails were placed for Time 2, and each participant was given up to ten days to complete the questionnaire. Participants were considered lost to follow-up if they did not respond to the three reminder phone calls and did not complete the Time 2 questionnaire.

Figure 2

Study Procedures for New Patients

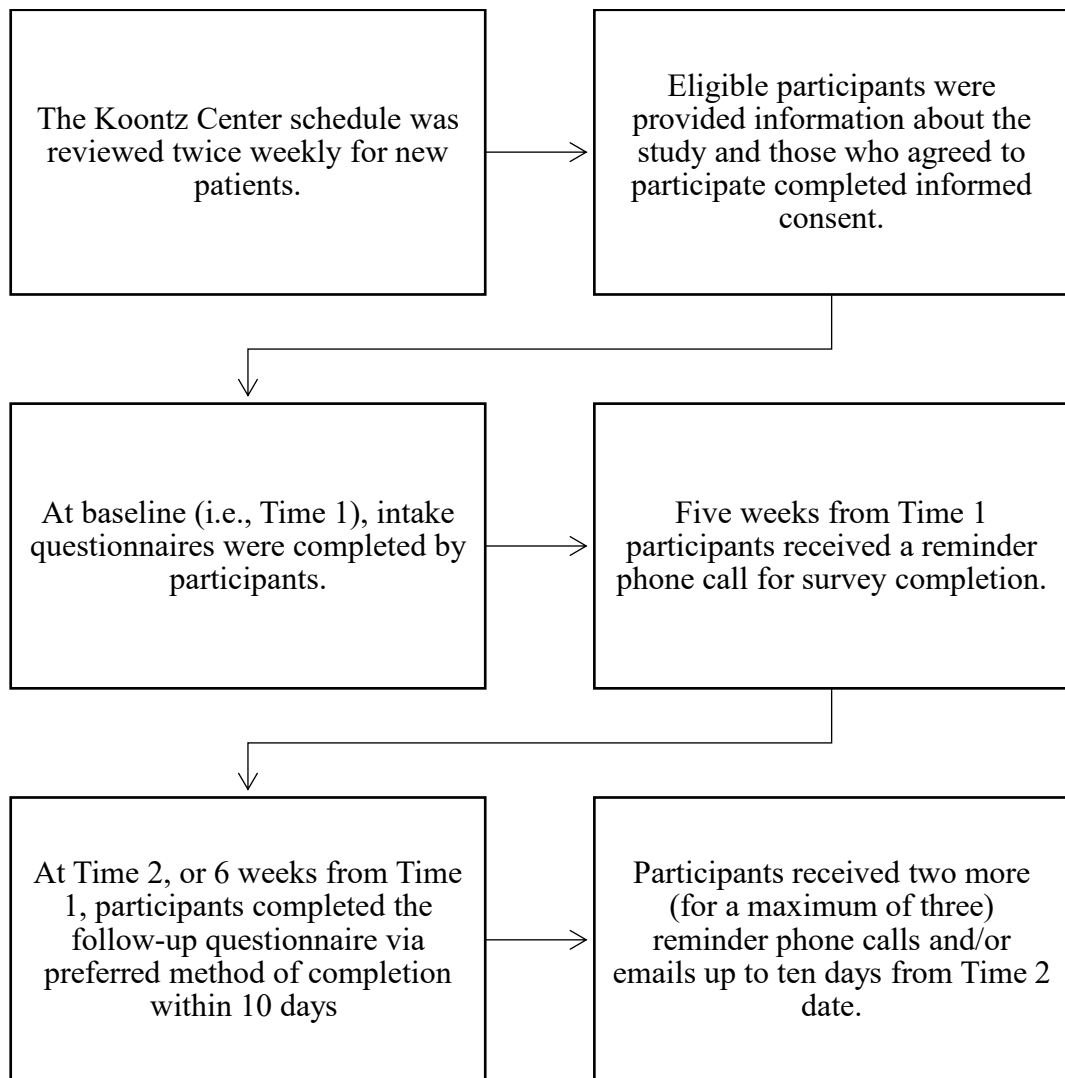
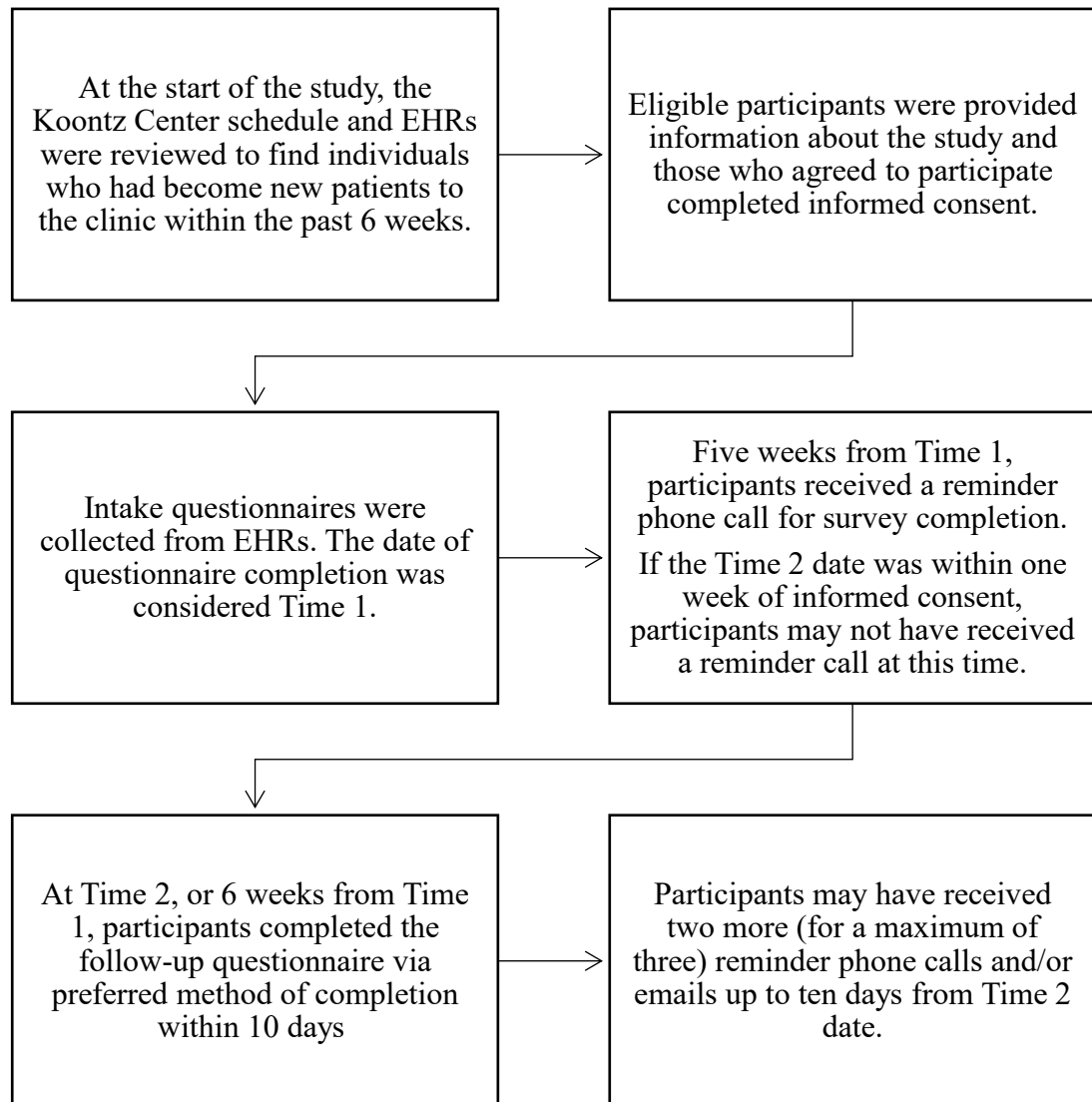


Figure 3

Study Procedures for Patients who were Retrospectively Recruited



Measures

Measures from this study consisted of data collected from participants' EHRs and from self-report validated questionnaires. These questionnaires are already a part of the existing intake questionnaire packets that are used for standard care. Data were collected from EHRs at Times 1 and 2, or at baseline and at six weeks from completion of the first questionnaire.

Data collected from EHRs included participant age and date of birth, religious preference, gender, initial cancer diagnosis (ICD) stage, date of ICD, days since MBC diagnosis, and treatment response. Treatment response was defined as whether the patient was responding to treatment based on chart review from the perspective of clinic staff. This variable was dichotomized into responding to treatment versus not responding to treatment. If patients' cancer had not been responding to treatment, their treatment was changed to a second- or third-line of treatment. If patients' cancer was responding to treatment they would not have experienced a change in medication. These data are referred to as *clinical variables*. In order to contact participants for the follow-up questionnaire, personal phone number and email address information were also collected, and this information was stored in a private folder on the Saint Luke's private server.

The self-report questionnaires included measures of spirituality, fatigue, and QoL at both Times 1 and 2. At Time 2, the self-report questionnaires included additional demographic questions. The demographic questions asked for ethnicity/race, relationship status, education, occupation, religious preference, spiritual preference, religious background and behaviors (RBB), perceived treatment response, and tolerance of treatment side effects; see Appendix A. Spiritual preference, religious preference, and RBB would be treated as

quantitative, continuous variables. The Religious Background and Behaviors (RBB) Questionnaire Items were taken from Connors et al. (1996). The first item was coded from 0 to 4, and the remaining items were recoded by subtracting 1, then all items were summed to calculate a total score. Relationship status was dichotomized into single versus partnered (single, divorced, and widowed were considered “single,” and those who were married or partnered were considered “partnered”). Similarly, employment status was dichotomized into employed (employed full-time or part-time) or unemployed (unemployed, retired, or on disability). Perceived treatment response was dichotomized based on patients’ perception of responding to treatment (“strongly agree” and “somewhat agree”) versus perceiving oneself not responding to treatment (“somewhat disagree,” “strongly disagree,” or “not sure/do not know”). Lastly, treatment tolerance was dichotomized based on tolerating treatment side effects (“strongly agree” and “somewhat agree”) versus not tolerating treatment side effects (“somewhat disagree,” “strongly disagree,” or “not sure/do not know”).

Spirituality (Moderator)

Levels of spirituality were measured using the FACIT-SP-12 (Brady et al., 1999; Cella et al., 1993; Peterman et al., 2002). The questionnaire consisted of three dimensions: Meaning, Peace, and Faith. There were 12 items in total that asked about spirituality, meaning, peace, and faith over the past seven days. An example of an item is, “I feel peaceful.” Response options fell on a Likert-type scale that ranged from 0 (*Not at all*) to 4 (*Very much*), and two items were reverse coded. Subscale scores were calculated by summing the individual item scores in each dimension, multiplying by four, then dividing by the number of items answered in the respective subscale. Total scores were calculated by summing the three subscale scores. Possible total scores ranged from 0 to 48, while possible

subscale scores ranged from 0 to 16 for each of the three subscales with higher scores indicating higher levels of spirituality. The questionnaire has shown high internal consistency reliability ($\alpha = .87$) among a sample of patients with cancer, HIV, or AIDS (Brady et al. 1999) and among a sample of patients with Stage III breast cancer in Indonesia ($\alpha = .87$; Komariah et al., 2021).

Fatigue (Predictor)

Symptoms of fatigue were measured using the FACT-B item (Cella et al., 1993), “I have a lack of energy.” This item originated from the Physical Well-Being subscale of the FACT-B, and it has been used as a measure of fatigue in the past (Brady et al., 1999). The item measured symptoms of fatigue during daily activities over the past seven days using a five-point Likert-type response scale that ranged from 0 (*Not at all*) to 4 (*Very much*). In the past, high levels of fatigue have been defined as a rating of 3 (*Quite a bit*) or 4 (*Very much*).

QoL (Outcome)

For this study, the Social/Family, Emotional, and Functional Well-Being subscales of the FACT-B (Cella et al., 1993) were used to measure three forms of QoL over the past seven days. Response options for all subscales ranged on a five-point Likert-type scale from 0 (*Not at all*) to 4 (*Very much*). Scores for each subscale were calculated by summing items into a total score then multiplying the sums by the number of items in the respective subscale, then dividing by the total number of items answered in each subscale, which provides three subscale scores. The Social/Family Well-Being subscale consisted of seven items. An example of an item is, “My family has accepted my illness.” Possible scores ranged from 0 to 28, with higher scores indicating better social/family well-being. The Emotional Well-Being subscale consisted of six items, and five of those items were reverse

coded. An example of an item is, “I am satisfied with how I am coping with my illness.” Possible scores ranged from 0 to 24, with higher scores indicating better emotional well-being. The Functional Well-Being subscale consisted of seven items. An example of an item is, “I am enjoying the things I usually do for fun.” Scores ranged from 0 to 28, with higher scores indicating better functional well-being. Internal consistency reliability for the Social/Family and Emotional Well-Being subscales has been reported to be lower than the acceptable range at .69 for both with a sample of patients with Stage III or IV breast cancer (Brady et al., 1997). In the same study, internal consistency reliability for the Functional Well-Being subscale was found to be good at .86.

Planned Data Analysis

Data were planned to be analyzed using IBM SPSS Statistics (Version 29; 2022). Before testing the hypotheses, the data would be screened for missing data and meeting normality assumptions. Descriptive statistics would be run to confirm that data were not missing at random. Histograms, scatterplots, boxplots, and Q-Q plots would then be created to determine whether the predictor and outcome variables were normally distributed and to identify any existing univariate or multivariate outliers. An exploratory factor analysis would be conducted to determine whether items on the FACIT-Sp-12 (Brady et al., 1999; Cella et al., 1993; Peterman et al., 2002) loaded on one, two, or three factors. If items loaded on a single factor, total scores would be used for data analyses; if items loaded on two factors then two subscale scores would be used; and if items loaded on three factors then three subscale scores would be used. Internal consistency reliability for the Social/Family, Emotional, and Functional Well-Being subscales of the FACT-B (Cella et al., 1993) would be evaluated. If the reliability coefficients were found to be below the acceptable cut-off, an exploratory

factor analysis would be conducted to determine an acceptable factor structure/subscales to use. Bivariate correlations and independent samples *t*-tests between demographic variables, clinical variables (e.g., stage, time since diagnosis), and study variables would be run to determine which, if any, would be included as covariates. Continuous covariates would be chosen based on having statistically significant bivariate correlations between both predictor and dependent variables. Dichotomous covariates would be chosen based on having statistically significant *t*-tests on both predictor and dependent variables. Three separate hierarchical linear regression analyses would be used to test whether the mean-centered interaction between spirituality and fatigue would predict high levels of QoL in the form of social/family, emotional, and functional well-being. The main effects for spirituality and fatigue, and three or fewer covariates would be included in each regression. Covariates would include the Time 1 outcome variable and possibly two demographic variables. The significance level (i.e., the *p*-value) would be set at .017 using the Bonferroni Correction to correct for family-wise error (i.e., $\alpha = .05$ divided by the number of tests estimated, which is three). If a significant interaction term was found in a regression model, the relationship between fatigue and the relevant outcome variable would be plotted based on level of spirituality: high versus low. Overall, it was predicted that spirituality would serve as a buffer, attenuating the negative relationship between fatigue and QoL.

While these were the analyses planned for the hypotheses outlined at the beginning of the study, for reasons detailed later in this document, I was not able to complete these analyses. Rather, given the data collection challenges I faced and the resulting small sample size, I focused on exploring descriptive statistics of clinical, demographic, and study variables, as well as on bivariate correlations among the variables collected.

CHAPTER 4

RESULTS

Data Analysis Conducted

In the midst of data collection, I experienced fewer than anticipated eligible participants at the Koontz Center for Advanced Breast Cancer and low response rates at Time 2 (56%, $n = 14$ responded to Time 2 questionnaires; see Figure 4). Before data collection started, there were approximately two new patients with MBC a week at the Koontz Center. Once data collection started there were one or fewer new patients in two weeks. This unexplained change may have possibly been due to fewer individuals being diagnosed with MBC and/or due to the oncologist seeing fewer patients as he decided to have more research days and fewer clinic days.

In an attempt to recruit from a second local hospital, I spoke to a fellow researcher in a different, local hospital. From September 2021 to September 2022 there were only seven patients with Stage IV breast cancer new to that cancer clinic (personal communication, September 27, 2022). They see a lot of patients with Stage III breast cancer. Since there were so few eligible patients at this site, it was decided not to recruit at a secondary location.

It was decided to halt data collection in the present study after twelve months and only run analyses using the Time 1 data due to the low enrollment numbers. There were 26 participants who consented to participate in the study. However, one participant was excluded due to only answering 16 items, which were not of interest to the current study. The final sample size consisted of 25 participants at Time 1. Due to the low sample size, in addition to only analyzing the Time 1 data, it was decided to exclude testing interaction

effects in hierarchical regressions and to focus on bivariate correlations. Therefore, the modified exploratory hypotheses are as follows:

1. Modified exploratory Hypothesis 1: There would be a positive association between spirituality and QoL in the form of social/family well-being.

Specifically:

- a. There would be a positive association between the meaning subscale of the FACIT-Sp-12 (i.e., spiritual meaning) and social/family well-being.
- b. There would be a positive association between the peace subscale of the FACIT-Sp-12 (i.e., spiritual peace) and social/family well-being.
- c. There would be a positive association between the faith subscale of the FACIT-Sp-12 (i.e., spiritual faith) and social/family well-being.
- d. There would be a positive association between total spirituality and social/family well-being.

2. Modified exploratory Hypothesis 2: There would be a positive association between spirituality and QoL in the form of emotional well-being. Specifically:

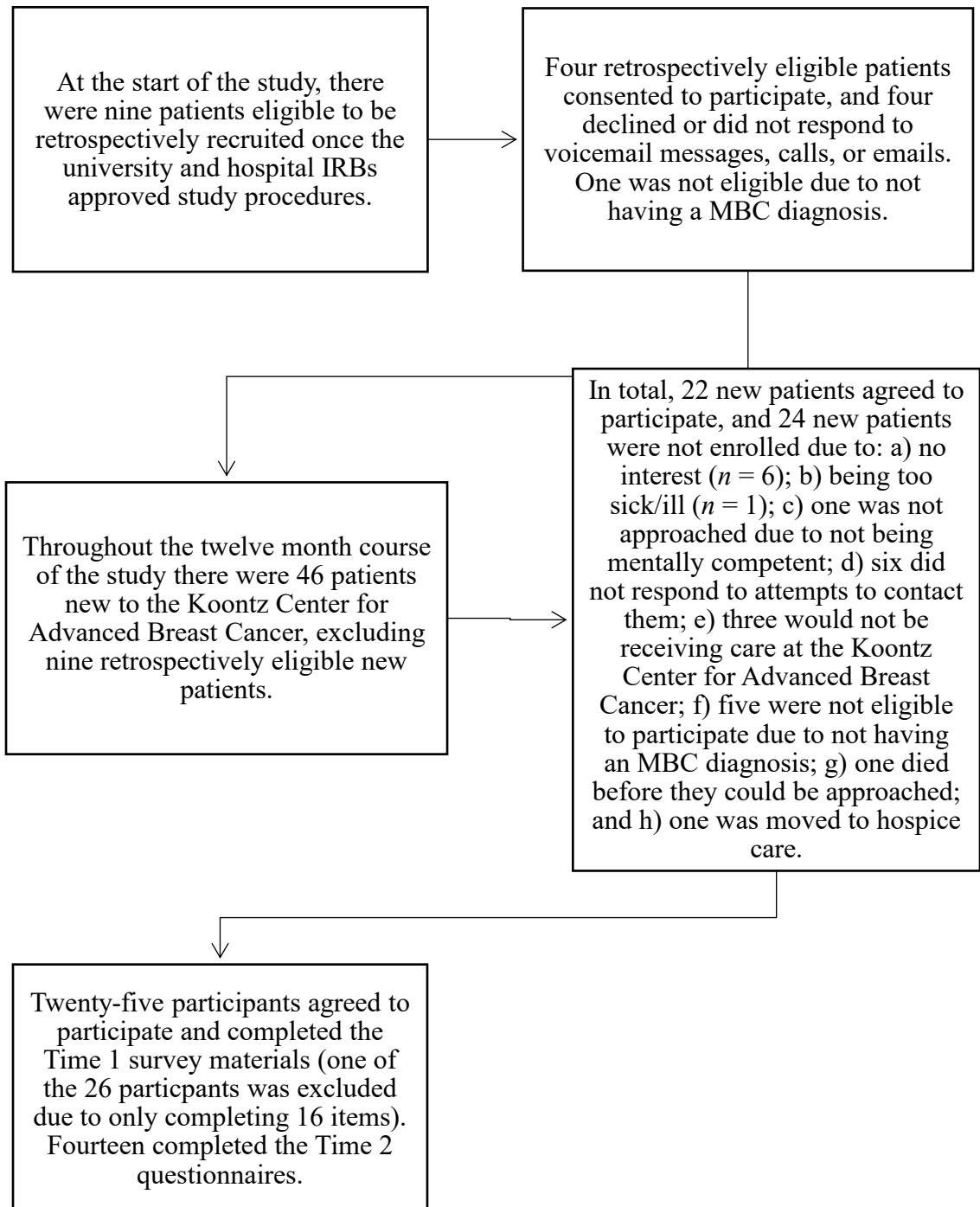
- a. There would be a positive association between the meaning subscale of the FACIT-Sp-12 (i.e., spiritual meaning) and emotional well-being.
- b. There would be a positive association between the peace subscale of the FACIT-Sp-12 (i.e., spiritual peace) and emotional well-being.
- c. There would be a positive association between the faith subscale of the FACIT-Sp-12 (i.e., spiritual faith) and emotional well-being.
- d. There would be a positive association between total spirituality and emotional well-being.

3. Modified exploratory Hypothesis 3: There would be a positive association between spirituality and QoL in the form of functional well-being. Specifically:
 - a. There would be a positive association between the meaning subscale of the FACIT-Sp-12 (i.e., spiritual meaning) and functional well-being.
 - b. There would be a positive association between the peace subscale of the FACIT-Sp-12 (i.e., spiritual peace) and functional well-being.
 - c. There would be a positive association between the faith subscale of the FACIT-Sp-12 (i.e., spiritual faith) and functional well-being.
 - d. There would be a positive association between total spirituality and functional well-being.
4. Modified exploratory Hypothesis 4: There would be a negative association between fatigue and QoL in the form of social/family well-being.
5. Modified exploratory Hypothesis 5: There would be a negative association between fatigue and QoL in the form of emotional well-being.
6. Modified exploratory Hypothesis 6: There would be a negative association between fatigue and QoL in the form of functional well-being.
7. Modified exploratory Hypothesis 7: There would be a negative association between spirituality and fatigue. Specifically:
 - a. There would be a negative association between the meaning subscale of the FACIT-Sp-12 (i.e., spiritual meaning) and fatigue.
 - b. There would be a negative association between the peace subscale of the FACIT-Sp-12 (i.e., spiritual peace) and fatigue.

- c. There would be a negative association between the faith subscale of the FACIT-Sp-12 (i.e., spiritual faith) and fatigue.
- d. There would be a negative association between total spirituality and fatigue.

Figure 4

Breakdown of Participant Recruitment Process and Eligibility at Times 1 and 2



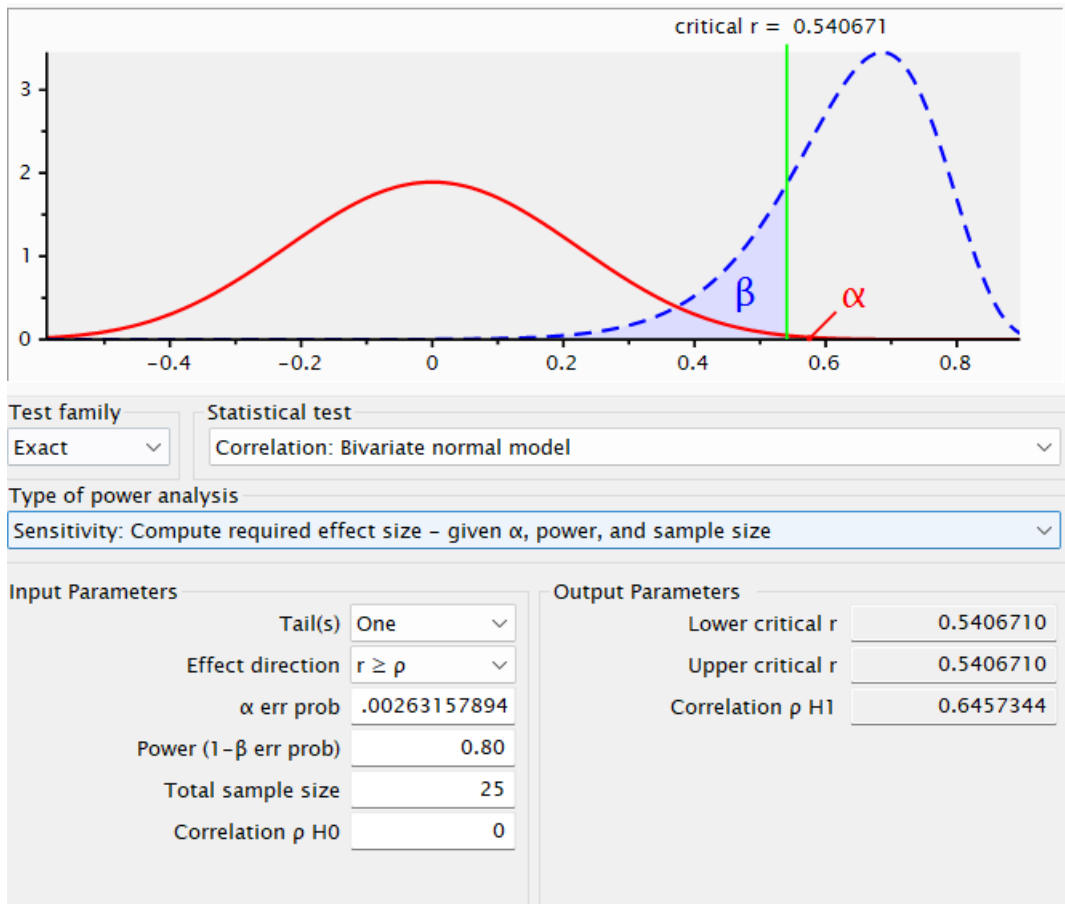
Modified Power Analysis

As mentioned in the previous section, due to low response rates and low enrollment numbers, the data analysis plan was modified to exclude the Time 2 data. Since the alpha level was adjusted, the large number of correlations should not increase Type I error. As the spirituality variable was reported as both a total score and three subscale scores, this resulted in 19 total bivariate correlations. It was decided to correct for family-wise error using the Bonferroni correction, so the significance level set was set at approximately .003 (alpha of .05 divided by 19 is approximately .003). Using G*Power (Faul et al., 2009), it was found that with two-tailed correlations expecting a moderate effect size of .30 with power equal to .80 and the p -value set at approximately .003, sample size of 158 is recommended. The current project is severely underpowered with a sample size of 25 and its inferential results should be interpreted with caution.

A sensitivity analysis was run using G*Power (Faul et al., 2009). See Figure 5. Results of that analysis revealed that a minimum value of .54 for Pearson's r would need to be achieved in order to detect a statistically significant result with a sample size of 25, power of .80, and alpha level set at approximately .003. This means that an R^2 value of .29 would be detectable, which is a large effect according to Cohen's (1988) effect size standards for correlations. Therefore, any correlation below $r = .54$ may not be detected, which means that small and medium effects may not be detectable due to the low statistical power.

Figure 5

*Sensitivity Analysis for Bivariate Correlations Using G*Power (Faul et al., 2009)*



Normality Assumptions and Descriptive Statistics

Data were analyzed using IBM SPSS Statistics (Version 29; 2022). First, the data were screened to determine if the assumptions of normality were met. Descriptive statistics were run to examine histograms, Q-Q plots, scatterplots, skewness, and kurtosis. Results showed that the data were approximately normally distributed. Standardized variables and Q-Q plots did not reveal any extreme outliers. Additionally, the data were found to be missing completely at random. Little's test (1988) for data missing completely at random showed that

the null hypothesis could not be rejected ($p = 1.00$). It was found that 5 items were missing 4 to 28% of data; therefore, it was decided to use multiple imputation to impute the few missing cases. Clinical variables and demographic questions at Time 2 were used as predictors for the multiple imputation process, but missing values for these variables were not imputed. Only 14 (56%) of participants completed the Time 2 questionnaires. As previously mentioned in the methodology section, clinical variables included participant age and date of birth, gender, stage at initial cancer diagnosis, days since MBC diagnosis, and clinical treatment response. The demographic questions at Time 2 asked for ethnicity/race, relationship status, education, employment status, religious preference, spiritual preference, RBB, perceived treatment response, and tolerance of treatment side effects; see Appendix A.

Data were re-checked for meeting assumptions of normality following multiple imputation. It was found that data were approximately normally distributed and data analysis proceeded.

Scale Reliability

Internal consistency reliability for the Social/Family, Emotional, and Functional Well-Being subscales of the FACT-B (Cella et al., 1993) were evaluated. Cronbach's alphas were .73, .82, and .80; respectively. Based on Taber's (2017) standards, scale reliability for the aforementioned subscales was deemed good, reliable, and fairly high; respectively. An exploratory factor analysis was planned if the reliability coefficients were found to be below the acceptable cut-off to determine an acceptable factor structure/subscales to use. Based on recommendations for a sample size between 100-250 by Catell (1978) and Gorsuch (1983), it was determined that it would not be possible to conduct an exploratory factor analysis for the QoL subscales.

Since the FACIT-Sp-12 (Brady et al., 1999; Cella et al., 1993; Peterman et al., 2002) has been analyzed using subscale scores and/or total scores in past studies (Lewis et al., 2014; Lo et al., 2005; Manning-Walsh, 2011; Kestenbaum et al., 2017), it was originally planned to conduct an exploratory factor analysis to determine whether items loaded on one, two, or three factors/subscales. However, the sample size needed to conduct the analysis was insufficiently small. Therefore, it was decided to use three subscale scores and one total score for the FACIT-Sp-12 since it was not possible to determine the correct factor structure/subscales to use. The Cronbach's alpha for the FACIT-Sp-12 showed that the reliability of a total score was supported ($\alpha = .92$), as well as that of three subscale scores: Meaning: $\alpha = .75$; Peace: $\alpha = .94$; and Faith: $\alpha = .91$. Scale reliability was judged to be strong, good, excellent, and strong; respectively (Taber, 2017).

Participants

As aforementioned, participants consisted of 25 patients diagnosed with MBC who were receiving care at Saint Luke's Hospital and the Koontz Center for Advanced Breast Cancer at the time of the study. See Table 1 for participant characteristics.

Table 1*Participant Characteristics and Clinical Variables (N = 25)*

Variable	<i>M(SD)</i>
Age (years)	60.32(10.13)
Days Since MBC Diagnosis	1089.67(1280.48)
Religious Background and Behaviors	29.86(14.92)
	<i>n(%)</i>
Relationship Status	
Single	2(8%)
Married	14(56%)
Partnered	1(4%)
Divorced	5(20%)
Widowed	3(12%)
Education	
Less Than High School	--
High School or GED	--
Some College or Trade School	4(16%)
Postsecondary/Associate's	1(4%)
Bachelor's	5(20%)
Graduate/Professional Degree	4(16%)
Employment Status	
Employed Full-Time	8(32%)
Employed Part-Time	4(16%)
Unemployed	1(4%)
Retired	10(40%)
Disability	2(8%)
ICD Stage	

IA	2(8%)
IB	2(8%)
IIB	2(8%)
IIIB	1(4%)
IIIC	2(8%)
IV	3(12%)
Perceived Treatment Response	
Strongly Agree Treatment is Working	7(28%)
Somewhat Agree Treatment is Working	2(8%)
Somewhat Disagree Treatment is Working	--
Strongly Disagree Treatment is Working	--
Not sure/do not know	5(20%)
Treatment Tolerance	
Strongly Agree Treatment is Tolerated	3(12%)
Somewhat Agree Treatment is Tolerated	7(28%)
Somewhat Disagree Treatment is Tolerated	2(8%)
Strongly Disagree Treatment is Tolerated	1(4%)
Not sure/do not know	--

Note. MBC = Metastatic Breast Cancer. ICD = Initial Cancer Diagnosis.

Eleven participants did not complete the Time 2 questionnaires so some demographic information was unavailable for 44% of participants. Some of the missing data was able to be found on EHRs (i.e., age, sex, relationship status, and employment status). All participants identified as female, and all but one participant identified as White (the remaining participant identified as African American/Black, 4%). Ages ranged from 39 to 77 years, with an average age of 60.32 years. Ten (40%) participants were categorized as single, and 15 (60%)

were categorized as partnered. Thirteen (52%) participants were categorized as unemployed and 12 (48%) were categorized as employed. As for religious preference, 10 (40%) participants identified as Christian, 4 (16%) Catholic, 3 (12%) Protestant, 2 (8%) non-Denominational, 1 (4%) Agnostic, 1 (4%) Baptist, 1 (4%) Intensely Spiritual New Age, 1 (4%) Lutheran, and 1 (4%) Unity. Nine (36%) self-identified as very spiritual, 2 (8%) not at all spiritual, 2 (8%) slightly spiritual, and 1 (4%) identified as moderately spiritual.

Among 11 participants (44%), date of ICD stage ranged from 2010 to 2022, and date of ICD stage was not available on EHRs for 14 (56%) participants. Days since receiving an MBC diagnosis at the time of the initial Koontz appointment ranged from 12 to 3,914 days ($n = 9$, 36%), with an average of about 1,090 days. Date of MBC diagnosis was unknown for 16 (64%) participants. As for clinical treatment response, 3 participants passed away during the course of the study, and 6 others were placed on a second or third line of treatment, so 15 participants (62.5%) were categorized as not responding to treatment by clinic staff.

Covariate Variables

It was originally planned to include covariate variables; however, they were no longer necessary as regression analyses would not be conducted. This was due to low statistical power and a small sample size. Bivariate correlations and independent samples *t*-tests were still analyzed to show the relationship between clinical variables and predictor and outcome variables. See Tables 2 and 3 for these results.

Exploratory Associations Between Clinical Variables and Predictor and Outcome Variables

Bivariate correlations between clinical variables and predictor and outcome variables are shown in Table 2. Participant age, highest education level achieved, ICD stage, and days

since receiving an MBC diagnosis were all unrelated to predictor and outcome variables including fatigue, total spirituality and subscale scores, and the three QoL subscales. Total spirituality and spiritual faith scores were strongly positively associated with levels of RBB ($r = .82, p < .001$; $r = .80, p < .001$; respectively). However, scores on the Meaning and Peace subscales were not significantly associated with levels of RBB ($r = .73, p = .003$; $r = .59, p = .03$; respectively). Spiritual Preference (e.g., identifying as not at all spiritual) was positively associated with levels of Spiritual Faith ($r = .78, p < .001$), but the association with total spirituality was not statistically significant ($r = .69, p = .006$). Correlations between Spiritual Preference and Spiritual Meaning, Spiritual Peace, and the three different forms of QoL were not statistically significant either (see Table 2). It is important to note that several of the aforementioned correlations were large, but did not reach statistical significance, as with levels of RBB and emotional QoL ($r = .49, p = .08$). However, the sample size for some of these analyses was as low as $n = 9$ so statistical power was decreased for these analyses.

Independent samples *t*-tests were conducted between dichotomous clinical variables and predictor and outcome variables. Results showed no differences on predictor or outcome variables (i.e., fatigue, spirituality subscales and total scores, and QoL subscales) between participants who were single (i.e., single, divorced, separated, or widowed) versus those who were partnered (e.g., partnered or married). Similarly, there were no differences between participants who were diagnosed with de novo MBC ($n = 3$) compared to those who were diagnosed with MBC following a cancer recurrence ($n = 9$) on any of the predictor or outcome variables. Individuals who were employed either full-time or part-time reported lower levels of fatigue ($M = 2.85, SD = 1.07$) compared to individuals who were unemployed [$(M = 1.83, SD = 1.19)$; $t(23) = 2.24, p = .04$].

Since religious preference (e.g., identifying as Christian) was not dichotomized, one-way ANOVAs were conducted to determine whether there were any differences on outcome variables within groups based on participant religious preference. There were no statistically significant ANOVAs, so further analyses were deemed unnecessary (i.e., independent samples *t*-tests).

As for clinical treatment response, participants whose cancer responded to treatment reported lower functional QoL on average ($M = 13.33, SD = 4.55$) compared to those who were not found to respond to treatment [$(M = 20.54, SD = 5.95), t(22) = -3.35, p = .002$]. It is important to note that mean differences were more than one standard deviation apart, which is a large difference. In contrast, there were no statistically significant differences found between participants who perceived their cancer was responding to treatment, versus those who were unsure whether their cancer was responding to treatment on any of the predictor or outcome variables. Similarly, there were no statistically significant differences found on any of the predictor or outcome variables between participants who perceived that they tolerated/were able to manage their treatment side effects, compared to those who reported they could not.

Table 2*Correlations Between Clinical Variables and Predictor and Outcome Variables*

Variable	Age	Education	ICD Stage	RBB	Spiritual Preference	Days Since MBC Diagnosis
Fatigue	.24	.06	.84	-.21	-.13	.39
Meaning	.20	.28	.16	.73	.45	.12
Peace	.21	-.34	.42	.59	.45	-.57
Faith	.08	-.09	.28	.80*	.78*	-.49
Total Spirituality	.18	-.10	.37	.82*	.69	-.48
Social/Family QoL	.16	-.17	.33	.44	.32	-.03
Emotional QoL	.14	-.20	.43	.49	.43	-.72
Functional QoL	-.08	-.02	.25	.15	.22	-.19
<i>n</i>	25	14	12	14	14	9

Note. Education = Highest education level achieved. ICD = Initial Cancer Diagnosis. RBB =

Religious Background and Behaviors Questionnaire Items (Connors et al., 1996).

* $p < .003$

Bivariate Correlations for Study Hypotheses

It was decided to focus on exploratory bivariate correlations at Time 1 to answer the modified study hypotheses. See Table 3 for correlation results. Statistical power was judged to be low for both planned and modified hypotheses. Effect sizes were also examined through the use of CIs and R^2 s for each hypothesis as the adjusted p -value to detect significant correlations was low.

Table 3

Descriptives and Correlations Between Predictor and Outcome Variables (N = 25)

Variable	1.	2.	3.	4.	5.	6.	7.	8.
1. Fatigue	--	--	--	--	--	--	--	--
2. Meaning	-.39	--	--	--	--	--	--	--
3. Peace	-.56	.58*	--	--	--	--	--	--
4. Faith	-.35	.42	.64*	--	--	--	--	--
5. Total Spirituality	-.51	.72*	.89*	.88*	--	--	--	--
6. Social/Family QoL	-.17	.50	.28	.25	.37	--	--	--
7. Emotional QoL	-.26	.48	.76*	.61*	.75*	.38	--	--
8. Functional QoL	-.77*	.42	.63*	.34	.54	.34	.40*	--
<i>M</i>	2.36	13.48	10.01	11.12	34.61	23.16	5.21	16.36
<i>SD</i>	1.22	2.65	4.10	5.09	10.00	3.93	15.12	6.21

* $p < .003$

Modified Hypothesis 1

The hypothesized relationship between Spiritual Meaning and Social/Family QoL was not significant due to the adjusted alpha level ($r = .49, p = .01, 95\% \text{ CI } [.12, .74]$). Data did not show a significant association between Spiritual Peace and Social/Family QoL ($r = .28, p = .28, 95\% \text{ CI } [-.13, .61]$), or between Spiritual Faith and Social/Family QoL ($r = .25, p = .24, 95\% \text{ CI } [-.16, .59]$). Similarly, there was not a significant association found between total spirituality and Social/Family QoL ($r = .37, p = .07, 95\% \text{ CI } [-.03, .67]$). Therefore, Hypothesis 1 was not supported. Furthermore, only the CI for the correlation between Spiritual Meaning and Social/Family QoL did not include 0, and it is unlikely that the other three associations would be significant. In addition, the R^2 value for the correlation between spiritual meaning and social/family QoL was .24.

Modified Hypothesis 2

The relationship between Spiritual Meaning and Emotional QoL did not reach statistical significance ($r = .48, p = .02, 95\% \text{ CI } [.10, .74]$). Further results showed a strong positive association between Spiritual Peace and Emotional QoL ($r = .76, p < .001, 95\% \text{ CI } [.52, .89]$), and between Spiritual Faith and Emotional QoL ($r = .61, p = .001, 95\% \text{ CI } [.28, .81]$). Lastly, the association between total spirituality and Emotional QoL was found to be statistically significant ($r = .75, p < .001, 95\% \text{ CI } [.50, .88]$). Overall, hypothesis 2 was partially supported. In addition, based on the 95% CIs the four correlations are significant, and the R^2 values are .23, .58, .37, and .56 for the associations between Emotional QoL and Spiritual Meaning, Spiritual Peace, Spiritual Faith, and total spirituality, respectively.

Modified Hypothesis 3

A positive association was found between Spiritual Peace and Functional QoL ($r = .63, p < .001, 95\% \text{ CI } [.31, .82]$). The association between Spiritual Meaning and Functional QoL was non-significant ($r = .42, p = .04, 95\% \text{ CI } [.03, .70]$). There was no significant association found between Spiritual Faith and Functional QoL ($r = .34, p = .10, 95\% \text{ CI } [-.06, .65]$). The relationship between total spirituality and Functional QoL was not statistically significant, either ($r = .54, p = .01, 95\% \text{ CI } [.18, .77]$). Hypothesis 3 was partially supported. Since all but one of the 95% CIs for the correlations did not include zero, these can be said to be statistically significant based on this statistic. The R^2 values were .40, .18, and .29 for the associations between Functional QoL and Spiritual Peace, Spiritual Meaning, and total spirituality, respectively.

Modified Hypothesis 4

There was no significant association between fatigue and Social/Family QoL ($r = -.17, p = .41, 95\% \text{ CI } [-.53, .24]$). The CI crossed zero, so the correlation was non-significant. Hypothesis 4 was not supported.

Modified Hypothesis 5

The relationship between fatigue and Emotional QoL was found to be non-significant ($r = -.26, p = .20, 95\% \text{ CI } [-.59, .15]$). The CI crossed zero, so the correlation was non-significant. Results did not support Hypothesis 5.

Modified Hypothesis 6

Results revealed a strong negative association between fatigue and Functional QoL ($r = -.77, p < .001, 95\% \text{ CI } [-.89, -.54]$). The CI did not include zero, so the correlation was

statistically significant. Therefore, Hypothesis 6 was supported. Additionally, the R^2 value was equal to .59.

Modified Hypothesis 7

Spiritual Peace and total spirituality were not associated with fatigue ($r = -.56, p = .004, 95\% \text{ CI } [-.78, -.21]; r = -.51, p = .01, 95\% \text{ CI } [-.75, -.14];$ respectively). Spiritual Meaning and Faith were not significantly associated with fatigue ($r = -.39, p = .053, 95\% \text{ CI } [-.68, .01]; r = -.35, p = .09, 95\% \text{ CI } [-.65, .05];$ respectively). Therefore, Hypothesis 7 was not supported based on p -values. However, since the 95% CIs for the correlations between fatigue and Spiritual Peace and total spirituality did not include zero, they can be said to be statistically significant. The R^2 values were .31 and .26 for the associations between fatigue and Spiritual Peace, and fatigue and total spirituality, respectively.

Summary

The study hypotheses were modified to account for the small sample size. Among the modified exploratory hypotheses, overall results based on p -values showed that only hypothesis 6 was fully supported. Hypotheses 2 and 3 were partially supported. Hypotheses 1, 4, 5, and 7 were not supported. This means that spirituality in its various forms (i.e., Spiritual Meaning, Peace, and Faith, and total spirituality) was not significantly associated with Social/Family QoL.

However, Spiritual Peace, Spiritual Faith, and total spirituality were strongly positively associated with Emotional QoL. Spiritual Meaning was not significantly associated with Emotional QoL, but the aforementioned associations were statistically significant.

As hypothesized, Spiritual Peace was positively associated with Functional QoL. Spiritual Faith and Meaning and total spirituality were unrelated to Functional QoL.

Fatigue was not significantly associated with Social/Family and Emotional QoL. Of the three types of QoL, only Functional QoL was significantly, strongly negatively associated with fatigue. Lastly, Spiritual Meaning, Peace, and Faith and total spirituality were not associated with fatigue.

CHAPTER 5

DISCUSSION

Planned Hypotheses

This study planned to examine the interaction between symptoms of fatigue and levels of spirituality at baseline and its relationship with three different forms of QoL at follow-up six weeks from baseline. The three forms of QoL consisted of levels of Social/Family QoL (Hypothesis 1), Emotional QoL (Hypothesis 2), and Functional QoL (Hypothesis 3). However, the sample size was lower than anticipated ($N = 25$) so due to low statistical power and low response rates at follow-up, it was decided to only analyze Time 1 data and adjust the hypotheses. Despite using bivariate correlations instead of hierarchical linear regressions, statistical power remained low.

Modified Exploratory Hypotheses

In addition to focusing on cross-sectional baseline data, the hypotheses were modified such that the interaction between symptoms of fatigue and levels of spirituality would not be examined due to the small number of study participants. Additionally, since exploratory factor analyses could not be conducted, levels of spirituality were examined in four different forms: Spiritual Meaning, Spiritual Faith, Spiritual Peace, and total spirituality (i.e., the combination of Meaning, Peace and Faith).

The first, second, and third modified exploratory hypotheses examined the relationships between 1) levels of Spiritual Meaning; 2) levels of Spiritual Peace; 3) levels of Spiritual Faith; 4) levels of total spirituality and 1) levels of Social/Family QoL; 2) levels of Emotional QoL; and 3) levels of Functional QoL. The fourth, fifth, and sixth modified hypotheses examined the relationships between symptoms of fatigue and 1) levels of

Social/Family QoL; 2) levels of Emotional QoL; and 3) levels of Functional QoL. The seventh hypothesis examined the relationships between symptoms of fatigue and 1) levels of Spiritual Meaning; 2) levels of Spiritual Peace; 3) levels of Spiritual Faith; and 4) levels of total spirituality.

Spirituality and Social/Family QoL

Results showed that levels of spirituality (i.e., Spiritual Meaning, Peace, and Faith, and total spirituality) were not significantly associated with levels of Social/Family QoL. Therefore, Hypothesis 1 was not supported. However, relying on the CIs, it can be said that 24% of the variance in levels of Social/Family QoL could be explained by levels of Spiritual Meaning, which is a moderate effect size according to Cohen's (1988) effect size standards for correlation coefficients.

Research has found that within a sample of 242 patients with cancer, including 194 (81%) with breast cancer, those who were partnered showed a positive association with total levels of spirituality as measured by the FACIT-Sp-12 (Brady et al., 1999; Cella et al., 1993; Peterman et al., 2002) compared to those who were single (Barata et al., 2022). Although the FACT-B (Cella et al., 1994) was included in the study, researchers did not report whether individuals who were partnered also reported higher levels of Social/Family QoL compared to patients who were single. It would make sense that individuals who were partnered would experience good Social/Family QoL especially if said partner acted as a caregiver. Researchers did find that at baseline, higher levels of spirituality were associated with better Social/Family QoL, but baseline levels of spirituality were unrelated to changes in levels of Social/Family QoL (Barata et al., 2022). Increases in levels of spirituality over time, however, were associated with improved levels of Social/Family QoL at seven and 13 weeks,

and decreases in spirituality levels over time were associated with worsened levels of Social/Family QoL.

More specifically, post-hoc analyses in Barata et al.'s (2022) study showed that higher baseline levels of Spiritual Meaning, Peace, and Faith were significantly associated with higher levels of Social/Family QoL over time. Further research needs to be conducted to determine whether there exists a positive association between levels of spirituality and Social/Family QoL within a sample consisting solely of patients with MBC. A study with a larger sample size may reveal positive relationships between spirituality in its various forms, besides solely Spiritual Meaning, and levels of Social/Family QoL, unlike the lack of associations found in the present study.

Spirituality and Emotional QoL

Levels of Spiritual Peace, Spiritual faith, and total spirituality were strongly positively associated with levels of Emotional QoL which supported the second hypothesis. Levels of Spiritual Meaning were not associated with levels of Emotional QoL, but the aforementioned associations were statistically significant based on *p*-values. When examining the 95% CIs, levels of Spiritual Meaning, Spiritual Peace, Spiritual Faith, and total spirituality explained 23%, 58%, 37%, and 56% of the variance in levels of Emotional QoL, respectively. These effect sizes ranged from moderate to large.

These significant associations confirm the results found in the literature. In Barata et al.'s (2022) study, they found that higher levels of spirituality at baseline were associated with better levels of Emotional QoL at baseline and at seven and 13 weeks. Patients with low levels of spirituality at baseline showed low levels of Emotional QoL at baseline that remained worse over time, despite slight improvements, compared to patients with higher

levels of spirituality at baseline. Additionally, post-hoc analyses revealed that higher baseline levels of Spiritual Meaning, Peace, and Faith were significantly associated with higher levels of Emotional QoL over time. The present study should be replicated with a larger number of participants to achieve more accurate statistical estimates.

Spirituality and Functional QoL

As hypothesized, levels of Spiritual Peace were positively associated with levels of Functional QoL. Levels of Spiritual Faith, Spiritual Meaning, and total spirituality were unrelated to levels of Functional QoL. Therefore, Hypothesis 3 was partially supported based on *p*-values. Relying on 95% CIs, all correlations aside from the correlation between levels of Spiritual Faith and Functional QoL did not include zero. This means that levels of Spiritual Peace, Spiritual Meaning, and total spirituality explained 40%, 18%, and 29% of the variance in levels of Functional QoL, respectively. These were large, small, and moderate effect sizes, respectively.

These results partially confirm Barata et al.'s (2022) study. They found that at baseline higher levels of spirituality were associated with better Functional QoL at baseline and over seven- and 13-weeks' time. Furthermore, low levels of spirituality at baseline were associated with worse levels of Functional QoL at baseline that declined over time. Post-hoc analyses showed that higher baseline levels of Spiritual Meaning, Peace, and Faith were all significantly associated with higher levels of Functional QoL over time. Based on those results, the present study should be replicated with a larger number of participants to achieve more accurate statistical estimates with sufficient statistical power.

Fatigue and Social/Family, Emotional, and Functional QoL

Symptoms of fatigue were not associated with levels of Social/Family and Emotional QoL. Of the three types of QoL, only levels of Functional QoL were significantly, strongly negatively associated with symptoms of fatigue. This means that Hypotheses 4 and 5 were not supported, but data supported Hypothesis 6 based on *p*-values. Examining 95% CIs confirmed these results, as only levels of Functional QoL showed a significant association and explained 59% of the variance in symptoms of fatigue. This was a large effect size.

According to the literature, fatigue can significantly impair individuals' (i.e., patients with cancer and patients in general) QoL (Given, 2008; Ruiz-Casado et al., 2021; Sharpe, 2002). It can also affect patients' normal ability to function (Given, 2008). A cross-sectional study of 240 patients with Stage I to III breast cancer in Spain revealed that symptoms of fatigue were correlated with levels of functional health-related QoL (Calderon et al., 2019). In a much larger study of 954 patients with varying types and stages of cancer, including breast (26%) and Stage IV diagnoses (31%), Gupta et al. (2007) found cross-sectional, negative associations between symptoms of fatigue and patient satisfaction with health and functional, social and economic, and family QoL. Based on these results, it makes sense that levels of Functional QoL were negatively related to symptoms of fatigue in the present study as functional well-being may be conceptually similar to satisfaction with health and functional QoL. It is important to add that patients who were employed either full- or part-time reported lower levels of fatigue compared to those who were unemployed. Good functional well-being, or functional health status, consists of being able to perform daily activities that fulfill basic needs, usual roles, and help maintain health and well-being (Skube et al., 2018). With

this in mind, it makes sense that patients with higher levels of fatigue were more likely to be unemployed.

On the other hand, it is not surprising that levels of Social/Family and Emotional QoL were unrelated to symptoms of fatigue due to the high statistical power needed to detect these effects in the current study. Gupta et al. (2007) had a much larger sample size that may have helped to reveal the associations between symptoms of fatigue and patient satisfaction with family QoL. Similarly, Calderon et al. (2019) found that symptoms of pain and fatigue were significantly negatively related to levels of social health-related QoL. It is important to add that symptoms of fatigue had a larger effect on levels of social health-related QoL compared to symptoms of depression and pain.

As for levels of Emotional QoL, Calderon et al.'s (2019) study showed a negative association between symptoms of fatigue and emotional health-related QoL. Overall, their results suggest that physical symptoms (i.e., fatigue, nausea, and pain) had smaller effect sizes than psychological symptoms (i.e., pessimism or depression) with levels of QoL. One can hypothesize that with a larger sample size in the present study, results would have revealed a significant association between levels of Emotional QoL and symptoms of fatigue. This relationship may have had a small effect size that was not detectable with the current statistical power, unlike the large effect found between symptoms of fatigue and levels of Functional QoL. It is also possible that symptoms of fatigue may be related to levels of Emotional QoL in a different way, however. For example, Given (2008) found that emotional reactivity was associated with the experience of symptoms of fatigue among patients with cancer. According to Given, emotional reactivity includes feelings of instability and irritability, which were not exactly measured in the present study. Further research may

reveal significant associations between symptoms of fatigue and levels of Emotional QoL, specifically among a larger sample of patients with MBC.

Spirituality and Fatigue

Levels of Spiritual Meaning, Peace, and Faith and total spirituality were unrelated to symptoms of fatigue. Therefore, Hypothesis 7 was not supported based on *p*-values.

However, since the 95% CIs for the correlations between fatigue and Spiritual Peace and total spirituality did not include zero, they can be said to be statistically significant. The R^2 values were .31 and .26 for the associations between levels of fatigue and Spiritual Peace, and fatigue and total spirituality, respectively. These are both large effect sizes.

The primary reasons for the lack of significant associations may be the small sample size and low statistical power. It may be tempting to assume that using a single item to measure fatigue could have led to the lack of associations; however, there was a fairly large amount of variation within patient responses in the fatigue item ($\sigma^2 = 1.49$; min. = 0; max. = 4). Additionally, in Gupta et al. (2007)'s study there was a statistically significant negative association between symptoms of fatigue and patient satisfaction with psychological and spiritual QoL. Most importantly, Gupta et al. measured symptoms of fatigue using the fatigue subscale from the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (Kaasa et al., 1995), which consists of only three items. They also had a very large sample of 954 patients, which shows that it is possible to detect a wide range of responses on the three fatigue items used.

As previously mentioned in an earlier chapter, levels of spirituality have been shown to be cross-sectionally, negatively associated with symptoms of fatigue among patients with various types and stages of cancer (Lewis et al., 2014). Research has also shown associations

between fatigue and various forms of spirituality. For example, Grossoehme et al. (2020) surveyed 126 adolescent patients with various types of cancer and found that levels of Meaning and Peace were negatively associated with symptoms of fatigue. Also, patients with higher symptoms of anxiety, depression, or fatigue were more likely to report lower levels of Meaning, Peace, and feeling God's presence daily. Similarly, Chen et al. (2019) examined the association between peaceful acceptance and fatigue within a sample of 106 patients with various types and stages of cancer, including 51 with breast cancer (48.1%). It can be argued that peaceful acceptance in the cancer experience is conceptually similar to levels of Spiritual Peace. Findings showed a negative association between peaceful acceptance and symptoms of fatigue, such that those with higher levels of peaceful acceptance reported fewer symptoms of fatigue. Furthermore, when controlling for symptoms of depression, anxiety, and stress, symptoms of fatigue were shown to be negatively associated with illness acceptance. Most important to the present study, levels of peaceful acceptance were shown to partially mediate the relationship between symptoms of a) depression, b) anxiety, and c) stress and symptoms of fatigue. Since Grossoehme et al.'s (2020) study used a sample of adolescents, and both their and Chen et al.'s (2019) study did not focus on patients with MBC, follow-up research is needed to determine whether results are replicated. More specific to Chen et al.'s study, further research is needed to determine whether levels of Spiritual Peace, Faith, and Meaning function as mediator or moderator variables between symptoms of fatigue and levels of QoL, as neither were tested in the present study. As evidenced in an earlier chapter, it is more likely that levels of spirituality moderate the relationship between symptoms of fatigue and levels of QoL (Lewis et al., 2014; Szatkowska and Sołtys, 2018; Visser et al., 2009). Overall, further research is needed with a larger sample

of patients with Stage IV breast cancer to reveal any associations and interactions present between symptoms of fatigue and levels of total spirituality and Spiritual peace, Meaning, and Faith.

Lessons Learned

There are several lessons to be learned from this study. Patients with MBC may be difficult to recruit as there may be fewer eligible patients, and many may be too ill to be willing and/or able to participate. However, I found that patients were more likely to consent to participate in the study if they were approached in person in comparison to phone calls as many did not answer my phone calls or respond to voicemail messages. If patients do agree to participate, they may become too ill to respond at follow-up time periods or they may pass away. Therefore, a qualitative study that naturally requires a smaller sample size may be more feasible than a follow-up quantitative study when conducting a study with patients with MBC.

Implications

The results of the present study show that even with the small sample size, Functional QoL was negatively related to fatigue, and there were positive relationships between different forms of spirituality and QoL among patients with MBC. However, relying on the CIs showed that there were small, moderate, and large effect sizes despite the small sample. It is not surprising that the small effects were not detectable with null significance hypothesis testing, or *p*-values, given the low statistical power based on the sensitivity test conducted using G*Power (Faul et al., 2009). However, CIs showed that there were smaller effects that were found to be non-significant. Further research is necessary to study the relationships between these topics, whether through quantitative or qualitative research methods.

Qualitative methods may be more feasible as they require a smaller sample size, which this study shows that it is difficult to recruit a large sample size of patients with MBC. One option for a qualitative study could be a structured clinical interview over two periods of time to examine how levels of spirituality, QoL, and fatigue may influence each other and/or change over time. These clinical interviews could provide rich information and further insight into patients' minds in contrast to Likert-type response scales.

Although it is preemptive to suggest interventions should be conducted, results still show that patients reported engaging in spirituality and experiencing fatigue. Therefore, health care members (i.e., nurse practitioners, physicians, psycho-oncologists, etc.) should identify whether patients need referrals to appropriate resources, such as pain management, physical therapy, psycho-oncology, or chaplain services as patients may not ask for additional support.

Limitations

There are several potential limitations to the current study. Data were collected at a center that specializes in treatment for MBC, which is the only center in the Kansas City metropolitan area. Majority of patients at the Saint Luke's Koontz Center for Advanced Breast Cancer identify as White and female, which may not be representative of all individuals who are diagnosed with MBC who receive care at other hospitals or MBC centers. In this study, all patients identified as female and all but one patient identified as White—one patient identified as African American/Black. Although most patients with MBC identify as female, results may be generalizable to only patients who identify as White and female which limits external validity.

A second potential limitation is that there may be drawbacks to relying on self-reported questionnaires for the study. For example, participants may have been subjected to biases such as the social desirability effect or the halo effect that can influence participant responses when filling out the questionnaires. There is also mono-method bias that can occur when relying on a single method of measurement. It is also a potential limitation that fatigue was measured using a single item, which limits statistical power due to the limited variability compared to other measures that consist of multiple items. The item may not encompass all aspects of cancer-related fatigue, as previously mentioned cancer-related fatigue is more disruptive and severe compared to fatigue in the general population (Cella et al., 2002). It is important to note that there may be restriction of range on the spirituality measure based on patients being recruited from the Midwest. Individuals in the Midwest may be culturally conservative and support traditional values such as love for God and family, which may affect their spirituality (Sellers, 2001). The Koontz Center for Advanced Breast Cancer is located within a faith-based hospital, so patients may be more spiritual or religious compared to patients receiving care from non-faith-based centers or clinics.

The small sample size is an additional limitation with possibly the biggest impact. Due to the insufficient sample size, an exploratory factor analysis could not be conducted on the spirituality and QoL subscales. This means that items could have loaded on different factors/subscales than what was used in analyses. The small sample size may have also made it difficult to detect small effect sizes due to low statistical power. Since participants have a form of terminal cancer, this may have contributed to low response rates at follow-up as not all completed the Time 2 questionnaire. The sample size greatly decreased at Time 2 due to participant attrition. However, even if the participant attrition had not occurred at Time 2, it

still would not have been possible to examine longitudinal changes due to the larger sample size that was needed for those sets of analyses. As previously mentioned, the inferential results should be interpreted with caution.

Conclusion

The literature review revealed that further research is needed to examine the direction and strength of the relationships between spirituality, fatigue, and QoL (Johannessen-Henry et al., 2013; Lewis et al., 2014; Manning-Walsh, 2005; Szatkowska and Sołtys, 2018; Visser et al., 2009). In the present study using patients with MBC, modified hypotheses tested using *p*-values showed that only Hypothesis 6 was fully supported, while Hypotheses 1, 2, 3, and 7 were partially supported, and Hypotheses 4 and 5 were not supported. The only significant associations included the positive associations between Emotional QoL and Spiritual Peace, Spiritual Faith, and total spirituality; the positive association between Spiritual Peace and Functional QoL; and the negative association between Functional QoL and fatigue. This means that spirituality in its various forms (i.e., Spiritual Meaning, Peace, and Faith, and total spirituality) was not significantly associated with Social/Family QoL; Spiritual Meaning was not significantly associated with Emotional QoL; and Spiritual Meaning, Spiritual Faith, and total spirituality were not significantly associated with Functional QoL. As for fatigue, it was not significantly associated with Social/Family QoL, Emotional QoL, or spirituality in its various forms.

Alternatively, focusing on CIs shows different results as more associations were revealed to be statistically significant. For example, 24% of the variance in Social/Family QoL could be explained by Spiritual Meaning, while 23%, 58%, 37%, and 56% of the variance in Emotional QoL could be explained by Spiritual Meaning, Spiritual Peace,

Spiritual Faith, and total spirituality, respectively. As for Functional QoL, 40%, 18%, and 29% of the variance was explained by Spiritual Meaning, Spiritual Peace, and total spirituality, respectively. Associations between fatigue and spirituality showed that the R^2 values were .31 and .26 for fatigue and Spiritual Peace, and .26 for fatigue and total spirituality. Among the three different forms of QoL, only Functional QoL showed a significant association with and explained 59% of the variance in fatigue. Overall, effect sizes based on R^2 values ranged from small, moderate, to large.

Further research should focus on qualitative methods of data collection as the data may provide more in-depth information with a smaller sample size needed. This is important as patients with MBC may be difficult to recruit and retain over two time periods.

APPENDIX

A. Measures

Demographic Questionnaire Including the Religious Background and Behaviors

Questionnaire Items (Connors et al., 1996)

Please answer the following questions.

What is your race/ethnicity?

- White
- Hispanic/Latino
- Black/African American
- Indigenous American/Alaska Native
- Native Hawaiian/Pacific Islander
- Asian
- Mixed race
- Middle Eastern/Southwest Asian
- Other/specify: _____

What is your current relationship status?

- Single
- Married
- Partnered
- Separated
- Divorced
- Widowed
- Polyamorous
- Other/specify: _____

What is the highest level of education you have achieved?

- Less than high school
- High school or GED
- Some college or trade school
- Postsecondary/Associate's
- Bachelor's
- Graduate/professional degree

What is your current employment status?

- Full-time
- Part-time
- Student
- Unemployed
- Medical leave
- Retired
- Disability

What is your religion?

- Protestant
- Catholic
- Christian
- Non-Denominational
- Jehovah's Witness
- Atheist
- Agnostic
- Nothing in particular
- Jewish
- Buddhist
- Mormon
- Hindu
- Muslim
- Sikh
- Other/specify: _____

To what extent do you consider yourself to be spiritual?

- Not at all spiritual
- Slightly spiritual
- Moderately spiritual
- Very spiritual
- Not sure

My treatment is working to treat my metastatic breast cancer.

- Strongly agree
- Somewhat agree
- Somewhat disagree
- Strongly disagree
- Not sure/do not know

I am able to manage/tolerate the side effects of my treatment.

- Strongly agree
- Somewhat agree
- Somewhat disagree
- Strongly disagree
- Not sure/do not know

The Religious Background and Behaviors Questionnaire Items

1. Which of the following best describes you at the present time? (Check one)

- ___ Atheist (I do not believe in God)
- ___ Agnostic (I believe we can't really know about God)
- ___ Unsure (I don't know what to believe about God)
- ___ Spiritual (I believe in God, but I'm not religious)
- ___ Religious (I believe in God and practice religion)
- ___ Agnostic (I believe we can't really know about God)

2. For the past year, how often have you done the following? (Circle one number for each line.)

	Never	Rarely	Once a month	Twice a month	Once a week	Twice a week	Almost daily	More than once a day
a. Thought about God	1	2	3	4	5	6	7	8
b. Prayed	1	2	3	4	5	6	7	8
c. Meditated	1	2	3	4	5	6	7	8
d. Attended worship service	1	2	3	4	5	6	7	8
e. Read-studied scriptures, holy writings	1	2	3	4	5	6	7	8
f. Had direct experiences of God	1	2	3	4	5	6	7	8

3. Have you ever in your life:

	Never	Yes, in the past but not now	Yes, and I still do
a. Believed in God?	1	2	3
b. Prayed?	1	2	3
c. Meditated?	1	2	3
d. Attended worship services regularly?	1	2	3
e. Read scriptures or holy writings regularly?	1	2	3
f. Had direct experiences of God?	1	2	3

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