

**Factors Associated with Quality of Life among Breast Cancer Patients
in Saudi Arabia**

**By
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Abstract

Background: Health-related quality of life (HRQOL) in Arab Female Breast Cancer Patients (AFBCPs) in Saudi Arabia can be influenced by multiple factors, such as spirituality, religiosity, social support, age and developmental stage, and the stigma associated with breast cancer. Understanding the role of these factors can raise awareness and help create policies to improve care for breast cancer patients. Yet, there is limited research addressing the impact of these factors on HRQOL in AFBCPs.

Purpose: The purpose of this study was to investigate factors influencing HRQOL in AFBCPs in Saudi Arabia.

Design: A cross-sectional descriptive design.

Setting: International Medical Center-Oncology department in Jeddah, Saudi Arabia.

Participants: Fifty-nine adult AFBCPs who were receiving active treatment, such as surgical, radiotherapy, chemotherapy, hormonal therapy, and biological agents participated in this study.

Methods: Convenience sampling was used. Participants completed an online survey or paper-based survey including questions on socio-demographics, HRQOL, social support, spirituality, religiosity, depressive symptoms, and breast cancer stigma scales. Standard descriptive statistics of means, standard deviations, frequencies, and percentages were used to describe sample demographics. Pearson correlation and multiple regression analysis were used to examine the unique influence of numerous factors on HRQOL in AFBCPs.

Results: The average age of participants was 49 ($SD \pm 8.31$). The mean HRQOL of HRQOL-sum score in this study was 71.39 ($SD \pm 18.57$). According to multiple linear regression analyses, cancer patients with high levels of spirituality, religiosity, and low levels of breast cancer stigma tended to have better HRQOL-sum scores. Spirituality and age explained 12% of the variances in the HRQOL-sum score followed by religiosity and age d (3%), and stigma and age (9%), respectively. Spirituality, religiosity, and breast cancer stigma were significant predictors of the HRQOL-sum score.

Keywords: quality of life, spirituality, religiosity, social support, and stigma.

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Chapter 1

Introduction

Breast cancer (BC) is the most frequent cancer found in women worldwide, affecting 2.1 million women annually (World Health Organization, 2018). In Saudi Arabia, 15,635 cancer cases were detected in 2013; the cancer rate was 53% for women and breast cancer had the highest ranking of reported cancer types among women in 2013 (Saudi Health Council Saudi Cancer Registry, 2016). With increasing numbers of BC patients, there is a need to optimize their quality of life (QOL). The Center for Disease Control and The Center for Disease Control and Prevention (2018) defined QOL as “physical and mental health perceptions (e.g., energy level, mood) and their correlates—including health risks and conditions, functional status, social support, and socioeconomic status” (paragraph 3). Improving QOL is important because poor QOL in cancer patients has been significantly associated with a desire to hasten death (Mystakidou, Parpa, Katsouda, Galanos, & Vlahos, 2004). Multiple factors can influence QOL, such as emotional status, social support, and physical status. Although spirituality was not included in the CDC QOL definition; there is evidence that spirituality has a significant impact on QOL in breast cancer patients (Al-Natour, Al Momani, & Qandil, 2017a). Many researchers believe that in order to develop a comprehensive understanding of QOL we need to examine the multidimensionality of this concept, especially associations with predictors that could improve QOL (Ferrans, 1990; Ferrell, Wisdom, & Wenzl, 1989).

Quality of Life among Breast Cancer Patients in Saudi Arabia

Multiple studies conducted in Arab countries in the Middle East have examined QOL in breast cancer patients. For instance, qualitative studies in the United Arab Emirates and Palestine found that having breast cancer provoked fear of abandonment and negatively affected patients' psychological health (Elobaid, Aw, Lim, Hamid, & Grivna, 2016a; Hammoudeh, Hogan, & Giacaman, 2016b). In the West, studies suggest that coping with cancer-related stress is influenced by multi-faceted predictors/factors associated with QOL, such as social predictors and spiritual predictors. Therefore, examining a single predictor to improve QOL in this population presents an incomplete picture (Wyatt & Friedman, 1996b). Although Western research and Western models have provided an important foundation for our understanding of QOL in breast cancer patients, there is a need for culturally sensitive models to examine QOL in Saudi Arabian cancer patients.

The modern Kingdom of Saudi Arabia occupies most of the Arabian Peninsula, covering an area of 907,500 square miles (Al-Subai, 2000). With a population of 32,276,000 (World Health Organization, 2019a), Saudi Arabia is considered the largest Gulf country, and it is developing quickly. The Saudi health care system consumes the most significant portion of the government's budget, and it is increasing by almost \$5 billion each year (Helping U.S. Companies Export, 2018). Despite this governmental spending, cancer research in Saudi Arabia is still developing, especially in the area of QOL. Research regarding QOL of cancer patients has been in existence in Western countries since the 1970s and has provided much important knowledge about the experience of cancer, but little is known about the cancer experience in Saudi Arabia.

One researcher in Saudi Arabia found that QOL in end-stage renal patients was also affected by multiple factors (psychological, social support, spiritual, and physical) in addition to vocational factors and healthcare services factors (Algarni, 2014). Even though end-stage renal disease is a different disease context and HRQOL is a slightly different (but related) concept to QOL, this work highlighted the need to examine multiple factors associated with QOL within the same Arab culture.

Most of the research in Saudi has focused on examining QOL among colorectal cancer patients (Alabbas et al., 2016; Almutairi, Alhelih, Al-Ajlan, & Vinluan, 2016; AlOtaibi et al., 2015), and the majority of this work has addressed QOL in relation to a single factor. For instance, some have examined the association between physiological status, such as pathological staging, with QOL in Arab Female Breast Cancer Patients (AFBCPs) (Ahmed, Alharbi, et al., 2017b). Others have examined the association between the psychological status of cancer patients and QOL (Sherif, Jehani, Saadani, & Andejani, 2001a). However, the impact/association of spirituality and social support on QOL, especially among AFBCPs, is missing in the Saudi research field. The dearth of research examining the impact of domains that improve QOL or HRQOL in breast cancer points to the need to examine QOL/HRQOL in AFBCPs. Additionally, there is a need to understand the role of multiple factors that potentially affect QOL/HRQOL in AFBCPs.

Spiritual Factor: Spirituality and Coping with Cancer in AFBCPs

Western researchers have found that different coping styles can improve poor outcomes related to depressive symptoms and poor QOL. For example, high levels of social support and dyadic coping have been associated with lower depressive symptoms in cancer patients (Donnelly et al., 2017; Falconier, Jackson, Hilpert, & Bodenmann,

2015; Manne et al., 2006). Others have found that positive thinking helps patients cope with cancer (Haase & Phillips, 2004; Wu, Chin, Haase, & Chen, 2009). On the other hand, many Arabs are highly dependent on their faith when coping with stressors, such as a cancer diagnosis (Bhui, King, Dein, & O'Connor, 2008). For instance, many studies of Arab cancer patients have described perceptions of cancer as a death sentence or fate, with concomitant acknowledgment that their relationship with God has helped them through their journey (Elobaid et al., 2016a; Hammoudeh et al., 2016b). There is strong evidence that AFBCPs commonly believe that having faith in God positively helps them cope with cancer (Al Omari, Wynaden, Al-Omari, & Khatatbeh, 2016; Goldblatt, Cohen, Azaiza, & Manassa, 2013; Obeidat, Lally, & Dickerson, 2012). For example, a recent study in Saudi Arabia examined the association between religiosity and depression in colon cancer patients. Al Ahwal, Al Zaben, Sehlo, Khalifa, and Koenig (2018b) found that depression symptoms and suicidal thoughts were less common in participants with higher levels of religiosity. Although these previous studies have highlighted the need for spiritual coping strategies among cancer patients, the impact of spiritual well-being and HRQOL/QOL remains understudied in AFBCPs. Also, there was a lack of research examining how different levels of spirituality affect HRQOL/QOL in AFBCPs in relation to other factors.

Social Factor: Perceived Social Support in AFBCPs

Arab female cancer patients can suffer from high levels of depression and poor QOL (Alaloul, Schreiber, Al Nusairat, & Andrykowski, 2016; Goldblatt et al., 2013; Obeidat et al., 2012). However, having a supportive social network can help alleviate these symptoms. For example, Arab female cancer patients in a qualitative study

acknowledged that having a supportive and understanding husband and family members helped lower their fear and depression levels. On the other hand, others said that harsh words from their family members poisoned their “body and being” (Alaloul et al., 2016; Hammoudeh et al., 2016b, p. 492). In a recent study in Saudi Arabia, breast cancer patients scored high on the emotional functioning section sub-scale of a QOL measure because of the presence of a supportive social system (Almutairi, Mansour, & Vinluan, 2016). Hence, previous studies have shown the beneficial effect of social support in improving depression and QOL in Arab female cancer patients. But in order to earn social support, individuals must protect family honor (Hassouneh, 2009). Additionally, individuals are raised to avoid acts that could detrimentally affect the family honor (Erickson & al-Timimi, 2001). Unfortunately, some diseases, such as mental illness and breast cancer, are stigmatized in the Middle East (Hassouneh, 2009). Many Middle Eastern qualitative studies have provided evidence of this problem (Elobaid et al., 2016a; Jassim & Whitford, 2013b). Still, much uncertainty remains about the impact of social support and stigma on AFBCPs’ QOL.

Age and Developmental Stage in Arab Female Breast Cancer Patients

Cancer studies in Western countries have identified poorer outcomes in younger patients in terms of depression and QOL compared to older patients based on their developmental stage (Berg & Upchurch, 2007a). Younger adult cancer patients have different concerns than older patients, such as fertility. Also, younger cancer patients may have higher depression rates than older patients because of the off-time nature of the illness. Most of these research findings are derived from Western models. According to Neugarten (1996) in *The Meanings of Age*, people’s perceptions change based on their

life cycle; the middle age period is associated mostly with the urge to have a job, to get married, and to improve health. Additionally, needs may change based on their life cycle. For instance, people may not expect to get sick early in life (middle age) because sickness is associated with older people. Another important context that influences patients' outcomes is culture. According to the Developmental Contextual Model, patients from different cultures react and cope differently with crisis (Berg & Upchurch, 2007a). Therefore, based on the previous information, the influence of age on cancer patients' QOL may vary by culture. In the Middle East, studies in Iran and Jordan have found that younger cancer patients, whose age ranged between 14–59, had worse QOL than older cancer patients, whose age was 60+ (Akhondi-Meybodi, Akhondi-Meybodi, Vakili, & Javaheri, 2016; Lazenby & Khatib, 2012b). Although these studies suggest that developmental stage may have similar effects on Middle Eastern breast cancer patients as have been found in Western samples, uncertainty about the impact of age on breast cancer patients in Saudi Arabia remains.

In Saudi Arabia, age is an important factor because breast cancer cases are detected at young ages, such as 20–29, although studies in Saudi have not explicitly reported on the role of age in predicting QOL in AFBCPs (Al Ahwal et al., 2018b; Almutairi, Mansour, et al., 2016; Shaheen Al Ahwal, Al Zaben, Khalifa, et al., 2015; Sherif, Jehani, Saadani, & Andejani, 2001b). Therefore, there is a need to examine the relationship between age and QOL outcome when studying the association between spirituality and social support predictors on QOL in AFBCPs.

Problem Statement and Significance

Reviewing the literature revealed that many factors can impact AFBCPs' QOL. Unfortunately, there has been a lack of research in Saudi Arabia addressing the impact of factors that assist patients to cope with cancer, such as spirituality, social support, stigma, and the role of age on QOL in AFBCPs.

Specific Aims and Hypotheses

This study identified the predictors that contribute to coping with different levels of QOL in AFBCPs. A cross-sectional design was used to achieve the following aims:

Aims:

1. Identify the association between spirituality and QOL in AFBCPs.
2. Identify the association between religiosity and QOL in AFBCPs.
3. Identify the association between social support and QOL in AFBCPs.
4. The exploratory aim was to explore the impact of breast cancer stigma on QOL in AFBCPs.

Hypotheses:

1. Patients with higher levels of spirituality will have higher levels of QOL after controlling for age.
2. Patients with higher levels of religiosity will have higher levels of QOL after controlling for age.
3. Patients with higher levels of social support will have higher levels of QOL after controlling for age.
4. Stigma will be inversely correlated with QOL.

5. Patients with high levels of stigma will have low levels of QOL after controlling for age.

Significance to Nursing

The number of breast cancer patients is increasing in Saudi Arabia; therefore, understanding the needs of AFBCPs has become essential for healthcare providers. The long-term goal of my work is to optimize the well-being of AFBCPs in Saudi Arabia and meet their needs. This study was an important initial step toward expanding our understanding of the relationship between factors that assist in coping and QOL and explaining how different levels of those predictive factors may affect the QOL in AFBCPs. In addition, it provided important insights to support future development of an individualized intervention based on the outcomes found in AFBCPs. Being familiar with AFBCPs' coping mechanisms will enable healthcare providers to become ready to identify AFBCPs' strengths and the challenges they face when dealing with cancer. As a healthcare professional, it is important to understand AFBCPs' coping with cancer before developing a care plan to help improve their QOL. Gaining knowledge about factors that predict QOL in AFBCPs after cancer will allow healthcare providers to identify patients vulnerable to negative outcomes.

This study addressed the gaps and limitations of previous work by examining multiple factors of QOL. Additionally, this study was innovative because it was the first to quantify the impact of stigma on HRQOL, as well as the impact of age on previous factors across AFBCPs in Saudi Arabia.

Chapter 2

Review of the Literature

To gain greater understanding of the literature relevant to Quality of Life and Health-Related Quality of Life (QOL/HRQOL) in Saudi Arabian breast cancer patients, this chapter considers the definition of QOL and HRQOL in Western and Middle Eastern contexts and reviews major conceptual frameworks relevant to the phenomenon. Next, this chapter provides an overview of the study's conceptual framework, followed by an exploration of the cultural context that influences Arab Female Breast Cancer Patients' (AFBCP) QOL/HRQOL. The remainder of this chapter critically reviews literature relevant to the religious and social domains of QOL/HRQOL in Middle Eastern countries and in Saudi Arabia particularly.

Cancer in Saudi Arabia

Saudi Arabia is located in the center of the Arabian Peninsula, with a total population of 32,276,000 (Figure 1; (World Health Organization, 2019a). The dominant religion in Saudi Arabia is Islam with Muslims comprising 93% of the population.



Figure 1. Map of Saudi Arabia.

There has been a rapid increase in the number of breast cancer cases in Saudi Arabia and other Gulf countries over the past 20 years. Cancer rates have increased in Saudi Arabia during this time for both genders, from 13,254 in 2009 to 15,653 in 2013 (Saudi Health Council Saudi Cancer Registry, 2016). The cancer rate was 53% for women compared to 47% in men, and breast cancer was the most common type of cancer affecting women in 2013 (Saudi Health Council Saudi Cancer Registry, 2016).

Breast cancer incidence in Saudi Arabian women has increased over time. For example, the breast cancer incidence rate was 13.5% in 2009; this rate increased to 16.2% in 2016 (Saudi Health Council Saudi Cancer Registry, 2016). Lack of awareness about breast cancer screening, and fear of cancer and its concomitant threats to family honor have contributed to delayed breast cancer detection in Saudi Arabia and in other Gulf countries (Elobaid et al., 2016a; Mahfouz et al.; Mahfouz et al., 2013). Late detection of breast cancer is significantly associated with high mortality rates and financial burden (Maruthappu et al., 2017; Tian, Wilson, & Zhan, 2011). According to recent statistics

from the Saudi Health Council in 2016, the median age of breast cancer diagnosis was 50 years old, with a range of 20–116 years. The three regions with the highest rate of breast cancer in Saudi Arabia were the Eastern Region with 41 cases per 100,000 population; Riyadh with 29.3 cases per 100,000 population; and Makkah, including Jeddah City, with 25.3 cases per 100,000 population (Saudi Health Council Saudi Cancer Registry, 2016). In response to this trend, the Saudi Ministry of Health has initiated breast cancer awareness campaigns with free access to oncology clinics and mammograms nationally (Ministry of Health Saudi Arabia, 2019).

Phillips and Currow (2010) recognized cancer as a chronic illness, an ongoing lifetime event. Additionally, living with cancer is associated with stress and fear and may require lifestyle modifications that can negatively impact QOL and HRQOL (Sowa et al., 2018). Hence, the continuous increase in the number of cancer patients in Saudi Arabia has switched the focus of healthcare providers from treating cancer and related symptoms to improving patients' QOL and HRQOL. However, QOL and HRQOL in breast cancer patients is still a developing area of research in the Middle East in general, and in Saudi Arabia particularly. For this reason, I began my review of QOL and HRQOL by examining Western conceptualizations.

Overlapping Definitions of Quality of Life and Health-Related Quality of Life in Western Cancer Research

The general concept of QOL was introduced in the United States in the early 1970s by psychologists and sociologists; decades later, QOL was introduced to the medical field. Some researchers identified psychological predictors such as happiness and satisfaction as salient to QOL (Haas, 1999). The World Health World Health

Organization (2019b) defined QOL as a multidimensional concept that is influenced by a person's psychological and physical health, personal beliefs, and social relationships, which in turn are affected by the surrounding environment and culture (WHO, 2018). Psychological predictors may include depression, stress, anxiety, and fear (Padilla & Grant, 1985). Physical predictors include disease type, treatment approach and side effects, and signs and symptoms (Wyatt & Friedman, 1996b). Social support is itself a multidimensional concept and includes financial and emotional assistance from friends and family members (Ferrans, 1990). Others have asserted that QOL also includes a spiritual domain (Wyatt & Friedman, 1996b). Spiritual predictors may be influenced by religious background (Wyatt & Friedman, 1996b).

Subsequent to the introduction of the concept of QOL, the concept of Health Related Quality of Life (HRQOL), which focuses on disease complications or associated signs and symptoms, was brought forward (Wilson & Cleary, 1995). An example of the use of this concept was the workshop addressing cancer and its treatment complications and challenges held by the Institute of Medicine in Washington, D.C., which focused on improving cancer patients' HRQOL (Balogh et al., 2011). Although HRQOL has developed into a large focal area in Western countries, such as Australia, Great Britain, and the United States (Darwish & Huber, 2003), it is still a developing area of research in the Middle East generally, and Saudi Arabia in particular.

Some have argued that the term *HRQOL* is not a valid construct because general domains, such as vocational status and the surrounding environment, are not specific to health (Guyatt, Feeny, & Patrick, 1993a, 1993b). Moreover, many QOL psychometric scales include sub-scales that examine signs and symptoms related to disease, such as

pain and hair loss (Awad, Denic, & El Taji, 2008a). Hence, there are inconsistencies in the definition and use of QOL and HRQOL found in the research literature with overlapping constructs and domains found in both. To ensure that this review includes all relevant literature, I have included research using both terms.

Definitions of HRQOL and QOL in Saudi Arabia

To my knowledge, use of the terms *QOL* and *HRQOL* in the Middle Eastern literature generally, and Saudi Arabia literature in particular, is based on Western definitions (Ferrans, 1990; Guyatt, 1993; Haas, 1999; Padilla & Grant, 1985). For example, the term QOL can be found in some peer-reviewed studies of Saudi Arabian cancer patients (Aboshaiqah et al., 2016b; Ahmed, Alharbi, et al., 2017a; Ahmed, Almuzaini, et al., 2017; Ahmed et al., 2014). The general term QOL was also introduced by the Ministry of Economy and Planning (2014) (MOEP) in Saudi Arabia in its Ninth Development Plan. The MOEP described QOL as the improvement of citizens' economic status and services that promote this status, suggesting that the Saudi Arabian government is interested in improving the standard of living of its citizens. The term HRQOL was introduced in the Saudi Arabian Handbook for Healthcare Guideline Development (SHHGD); the SHHGD defined HRQOL as an outcome of individual physical, social, and mental well-being in the presence or absence of disease (Ministry of Health, 2014). However, as far as I am aware, neither term has been used by the Ministry of Health in Saudi Arabia.

There has been inconsistency in defining and using the terms QOL and HRQOL in the Saudi cancer literature and Saudi governmental sectors. Additionally, the health care industry has not settled on a clear definition which has led to inconsistencies in the

definitions used in the empirical literature. In another disease context, Algarni (2014) introduced a novel HRQOL framework, derived inductively from Saudi End Stage Renal Failure. Algarni's definition of HRQOL offered a broader multidimensional conceptualization of HRQOL, which was "personal satisfaction with health, social, psychological and financial status, religious performance and the health care services provided" (Algarni, 2014, p. 132). Additionally, Algarni's conceptualization of HRQOL included a religious domain, which was overlooked by some other frameworks.

Consistent with what is found in the Western literature, there are inconsistent and overlapping definitions of QOL and HRQOL in the Saudi literature, which has hindered the development of distinct and coherent conceptual meanings for these concepts.

Definition of Quality of Life and Health-Related Quality of Life in Middle Eastern Countries in Cancer Patients

There is a dearth of literature about QOL or HRQOL in cancer patients in the Middle East, pointing to a need for research in this area. This work is essential to improving QOL and HRQOL in future cancer survivors. Additionally, the literature on QOL and HRQOL coming from Arab countries addresses multiple domains, including psychological, physical, social, spiritual, and financial. To my knowledge, only two studies conducted in Arabic Middle Eastern countries have addressed the impact of spirituality and social support on QOL or HRQOL. Therefore, the search was expanded to non-Arab Middle Eastern countries, such as Iran and Turkey, to cover all domains that influence QOL or HRQOL in cancer patients. The final search identified 33 articles that have examined quality of life in cancer patients in Middle Eastern countries using the search terms QOL and HRQOL.

Four articles provided a conceptual definition of HRQOL and eight articles used the general term QOL; some Middle Eastern studies have used the terms QOL and HQOL interchangeably (Alawadi & Ohaeri, 2009; Dreidi, Asmar, & Rjoub, 2017; Dreidi, Asmar, & Al-Rjoub, 2016; Melam, Buragadda, Alhusaini, & Arora, 2016). Although a conceptual definition of QOL and HRQOL in Middle Eastern countries is typically included in the introduction section of articles using these variables, an operational definition of these terms in the methods sections is missing, raising concerns about how these outcomes are measured in this body of work.

Several authors in the Middle East have used the general term QOL, describing it as “a multidimensional concept that has been developed and is commonly used as a measure of the patient’s physical, psychological, social, and spiritual dimensions or domains” (Aboshaiqah et al., 2016a, pp. 621-622; Jafari, Farajzadegan, et al., 2013, p. 1220; Thweib, 2011, p. S68). For unknown reasons, many authors have excluded the spiritual domain in their definition (Alacacioglu et al., 2010; Alawadi & Ohaeri, 2009; Almutairi, Alhelih, et al., 2016; AlOtaibi et al., 2015; Awad et al., 2008a; Dreidi et al., 2017; Dreidi et al., 2016; Mohebbifar, Pakpour, Nahvijou, & Sadeghi, 2015; Zamanian et al., 2015). This lack of attention to the spiritual domain is a concern given that Middle Easterners often heavily rely on religious practices to cope with stress (Obeidat et al., 2012).

QOL and HRQOL Framework Usage in Middle Eastern Cancer Literature

In Western societies, many authors have used either QOL or HRQOL frameworks to guide their research. For example, many Western studies have used the *City of Hope Model* and *QOL Models* to examine QOL in cancer patients (Ferrell et al., 1989; Wyatt &

Friedman, 1996a). Both frameworks have four domains that predict QOL as follows: physical, psychological, social, and spiritual. Neither framework addresses the financial domain, which can also affect QOL. The second model, *Cella's QOL Model* (Cella & Tulsky, 1993), includes the same domains minus the spiritual domain.

A well-known HRQOL framework was developed by Wilson and Cleary (1995), who classified different themes that may affect the final outcomes. The authors identified these themes as biological and physiological factors; symptoms; individual characteristics, and environmental characteristics, including socio-economic support, functioning, general health perception, and overall quality of life. Wilson and Cleary proposed that measuring HRQOL should not occur without understanding the underlying relationships between these aforementioned themes. Wilson and Cleary's framework relies on health-related underlying factors when addressing HRQOL. Additionally, this framework lacks a very important contextual factor extant in the Middle Eastern cultures that can affect HRQOL, namely spirituality. The significance of religion and spirituality in Arabic cultures is described in greater depth later in this chapter. This explanation highlights the inadequacy of Wilson and Cleary's framework for use in the Middle East. Also concerning is the fact that none of the QOL/HRQOL models have been developed or tested in Middle Eastern cultures. This is a major limitation because of the significant influence of culture on these constructs as described in the "Cultural Influences on Health-Related Quality of Life in Middle Eastern Countries" section of this chapter.

Many theoretical frameworks in Western studies have used QOL terminology. In contrast, a review of the Middle Eastern literature failed to identify theories or frameworks that assess QOL or HRQOL in Middle Eastern cancer patients generally, and

Saudi Arabian patients particularly. But other relevant literature is available.

Interestingly, Algarni's framework mentioned above has broader domains that affect HRQOL in Saudi Arabian patients with end-stage renal failure undergoing hemodialysis (Algarni, 2014). To my knowledge, Algarni was the first to use a HRQOL framework in Saudi Arabia. Strengths of the framework include its multidimensional conceptualization of HRQOL, which, unlike other models, includes a spiritual domain. The current pilot study used an adapted version of Algarni's framework, as well as HRQOL as the main outcome variable. A description of Algarni's framework is provided below followed by a description of the adapted framework.

Algarni's Original Theoretical Framework

Algarni's (2014) qualitative study identified internal and external domains that affect HRQOL. Internal domains were as follows: physical, social, psychological, religious, and vocational status; healthcare services comprised the external domain (Algarni, 2014). Algarni (2014) defined the conceptual terms in the framework as described below. The physical domain was defined as the physical ability to perform daily activities; co-morbidities influenced the physical domain and included the presence of another disease, illness treatment complications such as pain and discomfort, and problems with sexuality, sleep, weight and diet, and medications. The social domain was defined as socialization, such as social relationships, family support, or work relationships. The psychological domain was defined as patients' ability to enjoy life and the psychological status that results from trying to accept current stressors, such as depression, anxiety, fear, and body image. The religious domain was defined as the level of religiosity that assisted patients to accept and cope with stressors. Finally, the

vocational domain included employment status, financial security and employer support. Healthcare services were considered an external factor affecting the physical domain, and subsequently HRQOL.

Algarni's framework (2014) assumed that the physical domain had the greatest influence on HRQOL, followed by psychological, social, religious, and vocational domains. According to Algarni, the physical domain affects the social domain and psychological domains while, at the same time, the physical domain is influenced by the external factor of healthcare services. The psychological domain not only affects HRQOL but acts as a mediator between the physical domain and HRQOL; between the social domain and HRQOL; between the religious domain and HRQOL; and between the vocational domain and HRQOL. Examining the mediating relationships between dependent and independent variables helps identify the cause of outcomes (Bennett, 2000), and can contribute to our understanding of the influence of predictors on HRQOL. The social domains of Algarni's framework had a direct influence on HRQOL; also, it acted as a mediator between the physical domain and HRQOL. The religious domain had a direct influence on HRQOL. Finally, in Algarni's framework, the vocational domain did not have a direct effect on HRQOL. However, adding the psychological domain as mediator between the vocational domain and HRQOL makes the relationship between the vocational domain and HRQOL significant. Figure 2 displays these relationships.

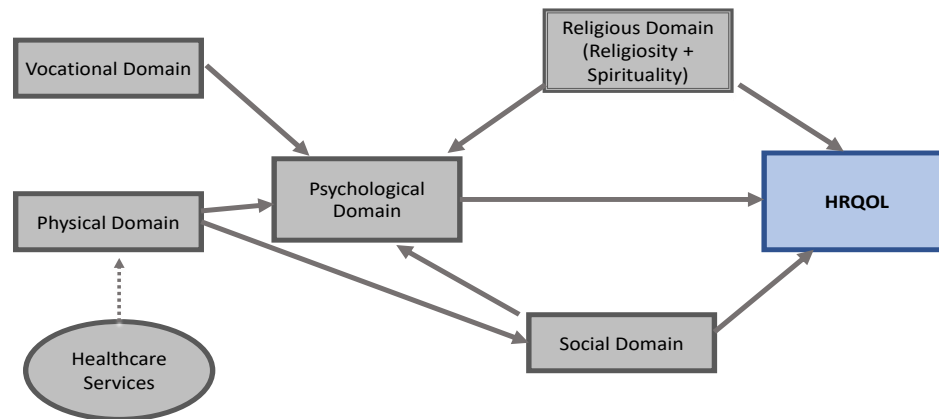


Figure 2. Algarni's HRQOL Theoretical Framework.

A limitation of Algarni's framework (2014) is the assumption that the physiological domain has the greatest influence on HRQOL because this assertion is incongruent with the findings presented in Algarni's paper. Participants quoted in the paper described the psychological domain as being at the center of the framework, contributing to all other domains. For example, a participant stated that having a high level of psychological well-being improved all aspects of life, such as social well-being, religious well-being, and financial well-being. Additionally, high levels of psychological well-being helped patients accept poor physical well-being (Algarni, 2014, p. 141). Algarni also focused on religious practice but did not address the importance of spirituality on HRQOL. Furthermore, Algarni failed to address the impact of health care services on psychological functioning.

Despite these limitations, Algarni (2014) shares a cultural background with the current study, which suggests that it can offer some guidance for understanding and examining HRQOL in Arab Female Breast Cancer Patients (AFBCPs). Algarni's

framework was inductively derived from a sample of Saudi Arabian patients, and as a result, the theoretical framework has greater cultural validity than untested Western formulations. Algarni's inclusion of a religious domain reflects this difference.

Adaptation of Algarni's Theoretical Framework for the Proposed Study

This study was limited in scope and focused on two factors of HRQOL that assist AFBCPs to cope with their disease, specifically, the religious and social domains.

Therefore, this study used a simplified version of Algarni's framework and adapted it to be applicable to AFBCPs. In addition, stigma, an important concept for Saudi women's health identified in the literature, was added to the model. Justification for adding stigma to the model was provided in the "Family Honor and Stigma" section of this chapter. The domains and relationships of the adapted model are displayed in Figure 3 inside the box.

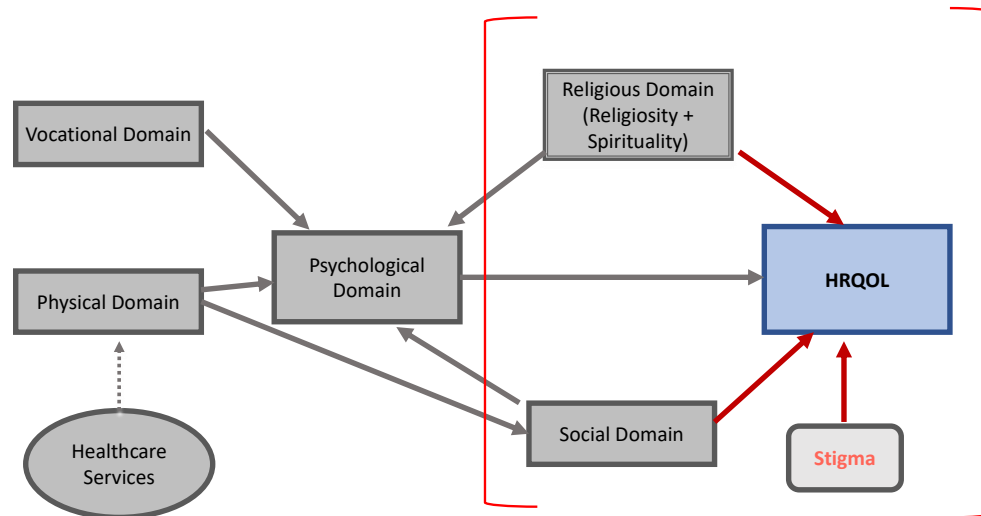


Figure 3. Adaptation of Algarni's Theoretical Framework for the study.

Cultural Influences on Health-Related Quality of Life in Middle Eastern Countries

The Middle Eastern countries span parts of South West Asia and the Northern part of Africa (Nobles & Sciarra, 2000). These large heterogeneous nations have diverse cultural, political, and historical influences. The majority of middle Eastern countries are Arabic speaking; the Arabic language emerged from the Arabian Peninsula, which is also the area where the Islamic religion arose (Nobles & Sciarra, 2000). Middle Eastern countries include Arabic and non-Arabic speaking countries. The non-Arabic speaking Middle Eastern countries are Turkey and Iran. The Quran (the Islamic holy book) is written in Arabic and hence, the Arabic language is widely associated with this faith.

Although nine out of ten people in the Middle East are Muslim (Pew Research Center, 2016), the region also includes a variety of other faith populations, including Christians, Jews, and Druze (Pew Research Center, 2016).

The Islamic faith incorporates many practices that influence health. For example, in a qualitative study conducted in Qatar, AlRawi et al. (2017) found that Muslims use Traditional Arabic & Islamic Medicine (TAIM) when dealing with disease. TAIM refers to practices and beliefs that involve spiritual therapies, herbal medicine, mind-body practice, and nutrition to treat or prevent diseases (Alrawi & Fetters, 2012). In Saudi Arabia, Abuelgasim et al. (2018) examined the use of complementary medicine (CAM) among cancer patients ($n = 156$). CAM had a religious nature, including the use of Holy Zamzam water, Quranic recitation, black seeds, and olive oil. The majority of participants (71%) used CAM during cancer treatment; 3.7% delayed cancer treatment using CAM first. Even though Abuelgasim et al. found that Saudi cancer patients are highly dependent on religious therapies and practices when treating cancer, there is lack of information about the impact of using CAM on HRQOL. In another disease context, Al Zaben et al. (2015) examined the association between religiosity and mental health in renal dialysis patients in Saudi Arabia and found that depressive symptoms were negatively associated with religious practice ($r = -0.05$), and positively associated with physical functioning ($r = 0.17$). The well-documented dependence of Saudis on religion and faith when managing disease highlights the importance of these variables in health care research conducted with this population.

Nydell (1987) described the family system as a person's first priority, which can exceed other obligations in Arab cultures. Family priorities can overcome those of

individual members, who can be forced to practice certain behaviors contrary to their wishes (Nydell, 1987). Therefore, the impact of family support is another important factor that can influence Arab patients' health.

Although little information is available about the relationship between family support and HRQOL in Arab cancer patients, research conducted in other Arab patient populations points to the significance of family support for health. Hyarat, Al-Gamal, and Dela Rama (2018) examined the association between social support and depression in Multiple Sclerosis (MS) Saudi patients. There was a negative correlation between depression and social support subscales as follows: family support ($r = -0.8$); significant person support ($r = -0.82$); and friends' support ($r = -0.63$) (Hyarat et al., 2018). These results suggest that higher social support was associated with lower levels of depressive symptoms in this population. Another study was conducted by Almutairi et al. (2017) that examined the effect of partner support on depression in post-partum Saudi women. Women who had low levels of partner support had high levels of post-partum depression ($\beta [t] = -0.238 [-2.038]$; (Almutairi et al., 2017). Social support was also an important factor in determining the level of depression and life satisfaction in Saudi caregivers of Alzheimer patients. Khusaifan and El Keshky (2017) found that social support was positively correlated with high levels of life satisfaction ($r = 0.483, p < 0.001$); and inversely correlated with depression ($r = -0.418, p < 0.001$) and life satisfaction ($r = -0.553, p \leq 0.001$) (Khusaifan & El Keshky, 2017).

Cultural Methods of Coping

Cultural influences shape coping strategies. Studies in the United States and Australia have found dyadic coping and social support assist in improving outcomes such

as depression and sexuality (Berg & Upchurch, 2007b; Berg et al., 2008; Gilbert, Ussher, & Perz, 2011). Others believe that positive thinking promotes coping with cancer (Haas, 1999; Haase & Phillips, 2004). Similar to Western cultures, there is evidence that Arabs in the Middle East commonly believe that social support improves their mental health and HRQOL (Abu-Saad Huijjer & Abboud, 2012; Hammoudeh et al., 2016b; Hammoudeh, Hogan, & Giacaman, 2016c; Hammoudeh, Hogan, & Giacaman, 2017). In addition, many qualitative studies in the Middle East have found that cancer patients are highly dependent on spirituality to cope with cancer. For example, a qualitative study in Iran found that Christian breast cancer patients fatalistically believed that cancer is caused by God and therefore must be accepted (Mehrabi, Hajian, Simbar, Hoshyari, & Zayeri, 2016). Additionally, Mehrabi et al.'s participants reported that praying helped them cope with cancer. Like Christian cancer patients in the Middle East, Muslims use spirituality to cope with cancer. For instance, many qualitative studies have found that spirituality plays an essential role in accepting cancer as destiny (Hammoudeh et al., 2016b; Jassim & Whitford, 2014a). Unexpectedly, even though many qualitative studies in the Middle East acknowledge the importance of spirituality in coping with cancer, few studies have examined the association between spirituality and QOL or HRQOL in cancer patients.

Six articles have examined the association between HRQOL or QOL and spirituality: in Jordan: one study used the term QOL (Al-Natour et al., 2017a) and another used HRQOL (Lazenby & Khatib, 2012b). In Iran, four studies used the term QOL in the body of work (Jafari, Farajzadegan, et al., 2013; Jafari, Zamani, et al., 2013b; Mohebbifar et al., 2015; Zamanian et al., 2015). Only Jafari, Zamani, et al.'s (2013a) study used an

experimental randomized controlled design, but the rest of the studies used cross-sectional descriptive designs. The sample sizes of these studies ranged between 60–244 cancer patients. The studies in Jordan and Iran used the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp12) questionnaire but different HRQOL scales. The Jordanian studies offer conflicting findings. Whereas one study found a negative correlation between FACIT-Sp12 and physical as well as emotional well-being in divorced women with advanced stage cancer (Lazenby & Khatib, 2012b), the other one found a positive correlation between FACIT-Sp12 and physical functioning and emotional well-being (Al-Natour et al., 2017a). Social well-being was positively correlated with FACIT-Sp12 for female cancer patients (Al-Natour et al., 2017a; Lazenby & Khatib, 2012b). Finally, functional well-being was positively correlated with FACIT-Sp12 in female cancer patients (Al-Natour et al., 2017a; Lazenby & Khatib, 2012b).

Four studies in Iran found a significant positive correlation between spiritual health, which includes “meaning” and “peace,” using the term QOL (Jafari, Farajzadegan, et al., 2013; Mohebbifar et al., 2015). The first and second studies found that spiritual well-being significantly predicted general QOL. Jafari, Farajzadegan, et al.’s study examined the effect of spirituality in Iranian women with breast cancer. Jafari, Farajzadegan, et al. found that spiritual well-being explained 61% of the variance in QOL. Zamanian et al. (2015) examined the association between positive and negative religious coping on QOL in Iranian breast cancer patients. Positive religious coping refers to solving problems by seeking help from God and negative religious coping refers to viewing problems as punitive action from God (Zamanian et al., 2015). Positive religious coping was positively correlated with QOL sub domains, including physical, social,

emotional, and functional well-being; on the other hand, negative religious coping was negatively correlated with the same domains. Additionally, negative religious coping was a significant predictor of poor QOL $p < 0.001$. In contrast, positive religious coping was a significant predictor of better QOL. Finally, the fourth Iranian study was a randomized controlled trial ($n = 68$) of a spiritual therapy intervention to improve QOL in breast cancer patients (Jafari, Zamani, et al., 2013b). The intervention consisted of six sessions. The main themes of those sessions were meditation, letting go of problems, identifying negative and positive feelings, positive relationships, and prayer therapy. Participants were encouraged to pray and talk to God to ask for help dealing with cancer. The participants filled out the QOL survey at baseline and immediately post-treatment. The intervention group had significant higher QOL scores than the control group $p < 0.01$. However, disease signs and symptoms, such as dyspnea and constipation, did not improve over time for the intervention or control group.

Literature analysis. Analysis of the literature on HRQOL or QOL in the Middle East reveals that most research studies conducted to date have used cross-sectional and descriptive designs. Future studies employing exploratory, longitudinal, and experimental approaches are needed to document the trajectory of HRQOL or QOL with cancer progression over time and support the development of targeted interventions. Although Jafari, Zamani, et al.'s (2013b) randomized trial of a spiritual intervention offered important evidence in support of developing such treatments, the study did not examine outcomes beyond six weeks, leaving questions about the long-term impact of such approaches unanswered.

Another limitation of this body of work is its lack of attention to the influence of developmental stage on spirituality levels, as well as HRQOL or QOL. Generalizing results from cancer patients at different developmental age stages may not be appropriate because younger adult cancer patients have different concerns than older patients, such as fertility. Also, younger cancer patients may suffer from higher levels of depressive symptoms than older patients because of the off-time nature of the illness. Stearns, Nadorff, Lantz, and McKay (2018) examined the moderating effect of age on adults' depression and religiosity. Stearns et al. (2018) found that religiosity was positively correlated with age, and older adults with high levels of religiosity had low depression rates. However, religiosity did not predict a high depression rate in younger adults aged 18–38 (Stearns et al., 2018). In Saudi Arabia, even though breast cancer cases are detected in young women age 20–29 (Saudi Health Council, 2016), studies conducted with this population have not explicitly reported the role of age in predicting QOL or HRQOL in AFBCPs. According to the Developmental-Contextual Model, coping behaviors are influenced by developmental age and stage (Berg & Upchurch, 2007b). There is evidence from two Western studies that younger cancer patients may have poorer outcomes, such as depression and low QOL or HRQOL compared to older patients; at the same time, there is evidence suggesting that spirituality offers an important coping strategy for young adults with cancer. A qualitative study ($n = 12$, participants' age 19–28 years) in which young adults comprised 66% of its sample believed that their spirituality was strengthened by the experience of having cancer (Ragsdale, Hegner, Mueller, & Davies, 2014). Similarly, a mixed method study ($n = 17$, participants' age 19–23 years) aimed to describe spirituality among teenage and young

adults; young adults comprised 35% of the sample. Findings indicated that this age group identified their spirituality as improving hope and giving meaning to their lives (Barton et al., 2018). Findings from the teen group in Barton et al.'s study were not included in the research report. Findings from the previous two Western studies are supported by a Jordanian study of youth with cancer. This Jordanian qualitative study of cancer and QOL found that spirituality played an important role in assisting Arab youth to cope with cancer and find hope (Al Omari et al., 2016). Moreover, spirituality level was correlated with HRQOL level in another Jordanian study. Lazenby and Khatib (2012b) examined the association between spirituality and HRQOL in Jordanian cancer patients. The study found that in cancer patients younger than 49 years old, high levels of spirituality were positively correlated with HRQOL subscales, including functional and social well-being, and negatively correlated with emotional and physical well-being (Lazenby & Khatib, 2012b). In the same study, patients who were age 50+ with high levels of spirituality were positively correlated with HRQOL subscales (functional, social, and emotional well-being) and negatively correlated with physical well-being (Lazenby & Khatib, 2012b).

In Saudi Arabia, only one study has examined the influence of religiosity and psychosocial outcomes in a sample of colon cancer patients and no studies have examined its relationship to HRQOL or QOL or age in breast cancer patients. Al Ahwal et al. (2018b) examined the relationship between religiosity and depressive symptoms in Saudi colon cancer patients and found an inverse correlation; they left the association between age and these variables unexamined and did not include QOL or HRQOL in their investigation (Al Ahwal et al., 2018b). The lack of information about the effect of

age on Saudi Arabian cancer patients' spirituality is indicative of the general lack of attention to QOL and HRQOL in the research literature. This gap is concerning because breast cancer cases in Saudi Arabia are on the rise and there is evidence that members of this population rely on Islamic faith and practices to cope with illness. This dearth of information points to the need for future research in these areas and provided a justification for focusing on the religious domain of HRQOL in the current study.

Factors Influencing QOL/HRQOL among Cancer Patients in the Middle East

Religious Domain

Spirituality Vs. Religiosity

Spirituality is commonly defined as “an individual’s belief in the sacred and transcendent nature of life, and the manifestation of these beliefs in a sense of connectedness with others (e.g., humans, spirits, and God), and in a quest for goodness;” (Mattis, 2002, p. 310). In contrast, Mattis defined religiosity as “the degree to which individuals adhere to the prescribed beliefs and practices of an organized religion” (p. 310). Although these concepts overlap, they are often distinct in Western societies. Nevertheless, it is common for researchers to use the terms interchangeably or use them as synonyms (Mattis, 2002). On the other hand, in Islam, spirituality and religiosity are commonly viewed as integrated phenomena. In fact, spirituality is viewed as something that exists within religiosity (Nasr, 1987). For instance, religiosity in Islam refers to the roadmap and activities that a person does to accomplish their purpose in life; but spirituality refers to the purpose that religion serves (Nasr, 1987). So, being spiritual but not religious could imply loss of the roadmap to reach God; in contrast, being religious but not spiritual could imply that the person is practicing religious activities without

having a purpose in life. Thus, the separation of spirituality and religiosity is inconsistent with common conceptions of Islam. Unfortunately, there is lack of agreement about combining or separating these two concepts in Middle Eastern studies. Some researchers don't distinguish between the concepts of spirituality and religiosity (Cruz et al., 2017) while others measure these two concepts separately (Jafari, Farajzadegan, et al., 2013; Shaheen Al Ahwal, Al Zaben, Sehlo, Khalifa, & Koenig, 2016b). In fact, many researchers in Saudi Arabia focus on measuring the concept of religiosity in their studies when assessing HRQOL or depression, although the scale used may be invalid for women (Al Ahwal, Al Zaben, Sehlo, Khalifa, & Koenig, 2018a; Shaheen Al Ahwal et al., 2016b). For example, Muslim men are mandated to pray at the Mosque on a daily basis, but women have the option to pray at the Mosque or elsewhere. A religiosity scale asks about the frequency of visiting the mosque and higher frequency indicates higher level of religiosity (Alakhdhair, Sheets, Geib, Alkhuwaildi, & Koenig, 2016; Shaheen Al Ahwal et al., 2016b).

To my knowledge there is a lack of validated instruments that examine Islamic spirituality in an integrated fashion. The reason for the absence of any Islamic scales is that Western instruments separate the concepts of spirituality and religiosity and have been translated and used uncritically in the Middle Eastern literature. This gap in research highlights the need for future researchers to construct an Islamic spirituality measure that can be used in health care research in multiple languages. Because of the absence of an integrated instrument for use with Muslims, the current pilot study used both religiosity and spirituality scales.

Social Domain

Algarni's (2014) framework highlighted the importance of understanding the impact of having social support for HRQOL. Hence, it is important to understand the contextual factors that can affect social support in Middle Eastern cultures, such as community structure, family honor, stigma, and gender role.

Community structure: individualism versus collectivism. In the Middle East, social support is affected by multiple factors, including community structure, family honor, and gender roles. Persons and groups may be oriented more or less toward individualism or collectivism in the spectrum of community structure. Darwish and Huber (2003) described individualism as the idea that people have an inalienable right to live their lives as they see fit, to act on their own judgment, to keep and use the products of their labor, and to live in accordance with their own values. In contrast, collectivism views a person's life as belonging not to the individual but to the group or society in which he or she belongs; each person must sacrifice their individual values and goals for the benefit of the greater group (Darwish & Huber, 2003).

It is not the individual, but Arabic society that is the unit of moral concern (Hofstede, 2000; Darwish & Huber, 2003). Many authors have posited that individualism and collectivism are more prevalent in Western and Eastern societies, respectively. Individualist values in Western societies are evident in constitutional law. Examples of collectivist values in Middle Eastern societies include maintaining family honor and keeping the family united (Whiteoak, Crawford, & Mapstone, 2005).

Family honor and stigma. As noted previously, in Arab societies the needs of the family may be prioritized over those of individual members (Hassouneh, 2009; Nobles &

Sciarra, 2000). Individuals in Arab societies often receive strong social support provided they support the family system (Hassouneh, & Kulwicki, 2009). Protecting family honor or reputation is the duty of each family member (Erickson & al-Timimi, 2001). Family honor can be attained through various means such as noble ancestry, wealth, and higher education (Zuhur, 2005). Individuals are socialized to avoid anything that might negatively affect or stigmatize the honor of their family (Erickson & al-Timimi, 2001). This has significance for breast cancer patients because many illnesses that are viewed as potentially having a genetic origin, such as psychiatric and cancer diagnoses, are stigmatized in Arab culture. Hassouneh & Kulwicki's study of Arab-American Muslim women's meanings of mental illness illustrated this concern. The authors found that families responded to social stigma and its concomitant threat to family well-being by maintaining strict secrecy about family members' mental illnesses to the extent possible (Hassouneh, & Kulwicki, 2009). This finding has been confirmed in other studies conducted in Arab societies; for persons with mental illness, fears of abandonment and divorce have been documented (Al-Darmaki, Thomas, & Yaaqeib, 2015), especially among women (Al-Krenawi, Graham, Al-Bedah, Kadri, & Sehwal, 2009). Although there is less information about cancer stigma relative to mental illness, similar evidence is available (Jassim & Whitford, 2014a). Having breast cancer can weaken family honor because of its perceived genetic origin (Al-Darmaki et al., 2015). Sadly, many qualitative studies in the Middle East have found that cancer patients, especially women, are stigmatized. For example, a qualitative study in Bahrain found some people avoided touching breast cancer patients because they thought the disease was contagious (Jassim & Whitford, 2014a). In the Emirates, women with breast cancer were afraid that they

would jeopardize the name of the family; they were concerned that having breast cancer in the family might prevent their daughters or sisters from getting married (Elobaid, Aw, Lim, Hamid, & Grivna, 2016b). These factors may lead some Middle Eastern women with breast cancer to hide their disease and suffer in silence, especially when they fear their illness will detract from family honor. This cultural context points to the need to explore the role of stigma on outcomes in Arab cancer patients.

Gender roles within the family. Arab culture is patriarchal, and women carry a disproportionate burden for maintaining the integrity of the family reputation; women may be punished or expelled from families if they behave in ways that are perceived as a threat to this reputation (Hassouneh, & Kulwicki, 2009). Honor crimes are extreme examples of this cultural pattern. In these situations, women are attacked and sometimes killed by their male relatives for perceived immorality such as premarital sex, adultery, or marrying someone unacceptable (Kulwicki, 2002). Although honor crimes usually occur behind closed doors and can be devastating stressors on women's health, there is no evidence suggesting that they are common. However, reports of honor crimes committed against Saudi Arabian women have been documented (e.g., The News, 2016). Such outcomes, although extreme, highlight the pressure women experience to maintain family honor. Because cancer carries a social stigma, it is reasonable to believe that the threat cancer poses to family honor is a potent stressor that negatively affects women's quality of life independent from the disease process itself.

Arab women with cancer in Middle Eastern countries report a moderate to low HRQOL but having supportive family members improves HRQOL in this group. A qualitative study of Palestinian breast cancer patients found that having social support

from relatives, friends, and husbands helped them deal with cancer (Hammoudeh et al., 2016b). Another qualitative study of the impact of breast cancer on Bahraini patients' lives had similar findings. Ghufran, Jassim & Whitford (2014) found that having a supportive husband helped alleviate women's sadness after receiving a cancer diagnosis. These findings were also supported by three studies conducted in Turkey. The three Turkish studies ($n = 202$, $n = 108$, $n = 187$) aimed to examine the association between social support and the general concept of QOL in breast and gynecologic cancer patients (Filazoglu & Griva, 2008a; Nazik, Ozdemir, & Soydan, 2014; Pinar, Okdem, Buyukgonenc, & Ayhan, 2012) and all found positive correlations between social support (i.e., family support, friends, and special person support) and the spiritual and social domains of HRQOL. Finally, similar results were found in a study conducted in Saudi Arabia. Ahmed, Almuzaini, et al. (2017) conducted a cross-sectional study ($n = 436$) examining predictors of HRQOL in cancer patients. The predictors were as follows: age, pain, metastasis, and social support. The HRQOL scale in this study had eight subscales including physical functioning, role limitations because of physical problems, social functioning, bodily pain, general mental health, role limitations because of emotional problems, vitality, and general health perceptions. Among those predictors, social support was positively correlated with high emotional functioning on the HRQOL sub scales.

Studies on the social domain of HRQOL reveal some methodological and statistical limitations. Most studies have used cross-sectional and descriptive designs, and few have employed more than descriptive and univariate analyses. Future research is needed to develop and test social support interventions to improve HRQOL in Middle Eastern cancer patients. The second limitation is the lack of attention to stigma in

quantitative studies and the absence of established measures of stigma for use with Middle Eastern cancer patients, which poses a major barrier to work in this important area.

Purpose of the Study

The literature review had revealed the significance of spirituality/religiosity and social support on coping with cancer in Middle Eastern breast cancer patients and identified gaps and limitations in existing knowledge addressing QOL and HRQOL in AFBCPs in Saudi Arabia. Only two studies have examined the impact of religiosity on Saudi cancer patients' HRQOL and these were both limited to colon cancer patients. There was a lack of information about the impact of religiosity/spirituality, social support, and stigma on breast cancer patients' HRQOL in Saudi Arabia. Hence, this pilot study began to address this gap in knowledge by examining religiosity, spirituality, social support, stigma, and age in AFBCPs.

Summary

This review of Middle Eastern QOL and HRQOL research in cancer patients suggests Middle Eastern cancer patients rely heavily on spirituality, religiosity, and social support to cope with stress. Unfortunately, to my knowledge there is a lack of research investigating these variables as they relate to QOL or HRQOL in breast cancer patients in Saudi Arabia and prior to the current study none had investigated the relationships among all of these variables simultaneously. To begin to address this gap in knowledge, this study focused on the influence of spirituality, religiosity, stigma, and social support on HRQOL in AFBCPs. This information will contribute to our understanding of the needs of this growing population while providing a foundation for future research in this area.

Despite the limited scope of this study, our findings could contribute to and benefit cancer research in Saudi Arabia by focusing on the importance of social support and stigma, as well as their impacts on HRQOL in breast cancer patients. Further, the conclusions of this study could trigger the need to revise current breast cancer interventions and help nurses in Saudi Arabia to provide holistic care to this population. Additionally, the current study may assist the breast cancer population by initiating a dialogue about the importance of the social and religious domains and promote identification of new methods to promote their well-being. Finally, this study shed light on the negative impact of stigma on breast cancer patients' mental health and HRQOL.

Chapter 3

Design and Method

This pilot study had three main aims and one exploratory aim: Aim 1) identify the association between spirituality and HRQOL in AFBCPs, controlling for age; Aim 2) identify the association between religiosity and HRQOL in AFBCPs, controlling for age; Aim 3) identify the association between social support and HRQOL in AFBCPs, controlling for age; and Aim 4) the exploratory aim was to analyze the impact of breast cancer stigma on HRQOL in AFBCPs, controlling for age. In this chapter, the design, method, and process for achieving these aims is described.

Research Design

The main purpose of this study was to examine the associations among spirituality, religiosity, social support, and HRQOL in AFBCPs. Therefore, a descriptive cross-sectional pilot study was used, and an estimated sample size of 91 participants was required to achieve a statistical power of 80%, p -value of 0.05, medium effect size (Cohen's $f_2 = 0.15$), with have five predictors and one covariate. Data collection took place over a period of three months and we were able to collect data from 59 participants.

Method

Setting

The study was conducted at the International Medical Center Hospital (IMC), Jeddah, Kingdom of Saudi Arabia. The data was collected from outpatient oncology clinics, in patient units, chemo infusion centers, and breast cancer organizations in Jeddah city (affiliated with IMC hospital).

Study Population

Women age 18 years and older with self-reported invasive breast cancer diagnosis of at least 2 months were included in this study. All stages and types of breast cancer were included in the sample to maximize generalizability. Participants had to be able to speak, read, and write Arabic. There were no other exclusion criteria to expand the enrollment.

Sample and Sampling Plan

Sampling was done by using a convenience homogenous sampling technique. We used multiple regression analysis; we had five predictors and one covariate. The four predictors were independent variables of primary interest and a covariate. The study was conducted over a three-month period. Participants were recruited by using two methods: a face-to-face paper-based survey and an online survey. The flyers contained my contact information and online URL. I (PI) approached participants from Breast Cancer Organizations to expand data collection beyond the IMC and re-sent/re-posted the URL link daily on the OHSU Facebook account. Ethical approval of this study was obtained from OHSU and the IMC IRBs.

Data Collection

Data collection had two parts: a face-to-face paper-based survey and an online survey. The face-to-face data collection was conducted at the IMC hospital oncology department (outpatient clinics, inpatient unit, and chemotherapy area). Patients who were interested in the study and were eligible signed the consent form, and then completed a set of questionnaires handed to them in person. I was available for questions and collected the questionnaires at the end of the meeting, which took approximately 30

minutes. Participants who missed meeting with me when I was on site and who were interested in the study contacted me via contact information listed on the flyers. In these instances, I explained the purpose of the study and screened participants for eligibility over the phone. If they were interested in the study, they were given the option of completing the paper-based survey in person at their next appointment or they could fill out the survey online. The distribution of the online survey used the Qualtrics program, which has an Arabic Language component. The online survey was distributed via an approved Oregon Health & Science University Facebook account. The online invitation had this heading in Arabic: “If you are an Arabic Muslim breast cancer patient and receive cancer treatment now, you are invited to participate in this online research study.”

Online participation was anonymous, and the survey had the same contents as the paper-based survey, such as questions about demographics, dependent and independent variables and covariates. The introductory page included a description of the study and a consent form including the following: the study purpose and objectives, data collection, risk and benefits, and confidentiality. The consent was part of the introductory page and included a mandatory question asking participants to read and consider the consent page and give permission to complete the survey (consent question). Participants who refused to participate exited the survey. After submission, a thank you phrase appeared on the screen.

Using an online survey had different advantages: it maintained the anonymity of the participants, which was especially important given the sensitive topics (Dayan & Ipsos, 2007). Additionally, Qualtrics offers an immediate data download. Finally, online surveys were user-friendly as long the participants had internet access (Fowler, 2014).

Online participation was anonymous and de-identified. The online survey included an introductory page and a mandatory consent form giving permission to participate in the study.

Potential Study Benefits

Participants were informed that it was unlikely that they would have direct benefit from participating in the proposed study. However, it was acknowledged that participants might appreciate knowing that their information could potentially contribute to the development of future strategies necessary for improving the current medical and nursing care practice.

Risks to Subjects

Participants can experience distress when participating in cancer research because of the sensitive nature of the questions. To minimize the risk of distress while completing surveys, I explained the nature of the study and the sensitivity of the questions during the recruitment phase (paper-based survey and online survey). Because of the nature of the culture, with the paper-based survey method, some participants wanted their male guardian to sign the consent sheet. In this case, when the woman agreed to participate, I explained the study to both of them at the same time. However, only the actual participant signed the form. In case the male guardian was in the room during the consent process, I asked him to leave the room when the patient answered the survey (if the patient wanted privacy when filling out the survey). For the online survey: the introductory page included a mandatory consent form which had to be completed before proceeding with the survey.

In both the paper-based and online surveys, participants were reminded that they did not have to answer any questions that they did not want to and that they could take a break or withdraw at any time during the interview. When participants experienced emotional distress in person, I assessed their condition and referred them to a primary health provider or local mental health resources.

Participants taking the online survey were reassured that experiencing emotional distress is a common experience. At the end of the survey participants were prompted to contact Mashael Dewan via email or telephone if they were experiencing (self-identified) significant emotional distress. If significant distress had occurred participants would have been, directed to resources. However, online participants did not reach out to me via email; thus, no referrals were needed.

Psychometric Measures of Spirituality and Religiosity in the Middle East

Spirituality. The FACIT-sp was used to examine spirituality in this study. The FACIT-G was originally designed to assess HRQOL in cancer patients; the FACIT-Sp was added later to examine spirituality. The FACIT-G has four subscales: physical well-being, social/family well-being, emotional well-being, and spiritual well-being (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002a). The FACIT-Sp version 4 has 12 items and uses a Likert response format. The Arabic FACIT-Sp was translated and validated with Arab Muslims with an acceptable alpha score = 0.7 (Lazenby, Khatib, Al-Khair, & Neamat, 2011). Additionally, the Arabic FACIT-Sp has previously been used to examine spirituality in Arab Middle Eastern cancer patients (Al-Natour et al., 2017a; Lazenby & Khatib, 2012b). The availability of the Arabic version of this scale and its

demonstrated reliability in Arab cancer patients made this scale a reasonable choice for this study.

The Spiritual Well-Being Scale (SWBS) was excluded because of its limitations. The literature review revealed that the SWBS was used in one Iranian study to examine the association between spiritual health and HRQOL in cancer patients. This scale consists of two subscales, which are religious well-being and existential well-being. Unfortunately, the SWBS scale has not been used to assess spirituality in cancer patients who speak Arabic. However, the scale was translated and validated in an Arab Jordanian Muslim, non-cancer population (Musa & Pevalin, 2012) and with Jordanian Christians (Musa & Pevalin, 2014) and has demonstrated good reliability ($\alpha = 0.83$). A limitation of this scale is its lack of distinction between spirituality and religiosity. Even though the SWBS was meant to assess spirituality, the authors stated that the scale contains religiosity as a subscale. The inconsistency of using two definitions raises concerns about the psychometric properties of this measure.

Religiosity. This study used the Arabic-Belief into Action Scale (BIAC) to examine religiosity level. The Arabic BIAC was translated and validated with Arab Muslims in Saudi Arabia with good reliability scores among all items (Alakhdhair et al., 2016). The mean age of participants of the Arabic BIAC was 31.9 ($SD \pm 10$). The Arabic BIAC scale has 10 items that aim to distinguish between religious and non-religious persons. The scale has a total score of 100 that ranges from 1–100. The items of this scale are designed for use with Muslims; for example, the authors ask about religious practice in the Masjid or Mosque. However, women may not choose to perform religious practice

at the Masjid. Unfortunately, there is lack a of Islamic religiosity scales that are gender neutral.

The following scales were not used in this study because of their limitations or applicability. The first scale was the Brief Religious Coping (RCOPE) and Muslim Religiosity Scale. This scale was originally designed and tested in an older U.S. population (Pargament, Smith, Koenig, & Perez, 1998). It has two subscales, positive and negative religious coping. Positive religious coping refers to solving problems with God's help, and negative religious coping refers to believing that God's actions are punitive. The RCOPE scale was translated into Arabic and validated in Iraq with acceptable Cronbach's alphas scores, ranging from 0.70–0.86 for the negative and positive subscales respectively (Al-Hadethe, Hunt, Thomas, & Al-Qaysi, 2016). However, because the Al-Hadethe et al. study recruited young participants between 16–19 years of age with post traumatic disease disorder, these psychometric properties may not be applicable to adult Saudi Arabian breast cancer patients.

The 13-item Muslim Religiosity Scale was used to examine religious practice in two studies of colon cancer patients in Saudi Arabia (Al Ahwal et al., 2018a; Shaheen Al Ahwal et al., 2016b), and in one study of dialysis patients in Saudi Arabia (Al Zaben et al., 2014). This scale has two subscales: the religious practice scale (10 items) and the intrinsic religious scale (3 items). The reliability of this measure is less than acceptable, with a Cronbach's alpha for the full-scale ranging between 0.64–0.68, making it a less desirable option than BIAC. Therefore, the optimum choice to measure religiosity for this study was the BIAC scale.

Psychometric Measures of Social Support in the Middle East

This study used the Multidimensional Scale of Perceived Social Support (MSPSS) to examine the association between social support with HRQOL. In the MSPSS, each item has a seven-point Likert scale, ranging from strongly agree (7 points) to strongly disagree (1 point). Higher scores indicate higher social support. Total scores range from 12–84. The MSPSS has three subscales or sources of support: family, friends, and special person, which refers to spouse, boyfriend/girlfriend, others (Zimet, Dahlem, Zimet, & Farley, 1988). A study in Lebanon used the MSPSS tool and was conducted at the community level (Kazarian & Merhi, 2012). Participants were mostly women, $n = 55.7%$; 34.9% were Christian, and the rest were Muslims. Finally, 41.4% of the participants were married in this version. Kazarian and Merhi did not change the “special person” term, although they asked about the relationship with the special person. To my knowledge, there is only one study that has validated the MSPSS in an Arab country. Thus, there was a need to expand the search and include the validation of MSPSS in other Arabic communities. However, these scales were not used in this study because of their limitations.

Aroian et al. (2010) validated the MSPSS scale among Arab Immigrant females (MSPSS-AW). The original scale used the term “special person” to describe one’s relationship with a significant other. However, Aroian and colleagues were concerned that using this term could lead to different interpretations. For instance, married women may refer to their husbands this way; divorced, separated, or widowed women may refer to their children this way; and single women may refer to close friends similarly. In Islamic communities, women are not expected to be in romantic relationships outside of

marriage. Therefore, the author in this version used the term “special person” in reference to a husband. Thus, unmarried women were not included in the study. Using MSPSS-AW in the current study would have eliminated unmarried breast cancer patients. Therefore, MSPSS was more suitable to use in this study. The MSPSS scale has a question to identify the source of support to the participants, for example, “Please explain the type of the relationship between the participant and special person such as a close friend.”

There was another study that validated the MSPSS in American adolescents; however, the participants’ ages ranged between 11–15 years old (Ramaswamy, Aroian, & Templin, 2009). The authors changed some items on the scale to make it age appropriate. Hence, the psychometric properties of this measure may not be applicable to this study population of adult Saudi Arabian women with breast cancer.

The concept of social support has also been examined in Middle Eastern countries using the Duke Social Support Index (DSSI). In Saudi Arabia, the DSSI has been used to examine the association between social support and depression in colorectal cancer patients (Al Ahwal et al., 2018a; Shaheen Al Ahwal et al.). Even though the translation process was not explained, the internal consistency of that sample was 0.89 (Shaheen Al Ahwal, Al Zaben, Sehlo, Khalifa, & Koenig, 2016a). Unfortunately, the DSSI has not been used in the breast cancer population in Saudi Arabia or in other Middle Eastern countries. There is still lack of knowledge about the reliability and validity of this measure for breast cancer patients. The dearth of research and information led to an expanded literature search that included other Middle Eastern countries including Arabic and non-Arabic countries.

Psychometric Measures of Breast Cancer Stigma in the Middle East

Even though there is a significant emphasis on stigma in women with breast cancer in the Middle Eastern qualitative literature, there are a lack of quantitative studies that assess the association between breast cancer stigma and HRQOL in the Middle East. The lack of studies could be because there was a lack of breast cancer Arabic stigma scales. On the other hand, Alacacioglu et al. (2010) in Turkey validated a stigma scale in cancer patients. The cancer stigma scale had two factors: impossibility of recovery and experience of social discrimination and stereotypes of cancer patients and demonstrated a Cronbach alpha > 0.88 (Alacacioglu et al., 2010). Unfortunately, the Turkish version has not been validated in the Arab population. The lack of Arabic stigma scale among breast cancer patients points to the need for future researchers to create a measure that can be used in healthcare research. Because of the absence of an integrated instrument for use with Arabs, the current pilot study explored stigma by using a self-developed 12-items questions, which was guided by Jones and Jones (1984) multidimensional stigma construct. Jones and Jones' concepts were used in developing these items because they have more subscales than Alacacioglu et al. that were applicable to the current study.

Jones and Jones (1984) believed that stigma is a multidimensional construct, which includes six dimensions of health-related stigma. The first component is related to perceived danger from the stigmatized person with the disease, which may lead to death. The second component is the deterioration of health over time. The third component is the belief that stigmatized people cause their illness. The fourth component is concealability, when stigmatized people hide their sickness from others. The fifth component, disruptiveness, refers to whether the stigmatized person can normally interact

with others. The last element is aesthetics, which considers whether illness detracts from the stigmatized person's physical appearance.

The second component of stigma, which is deterioration of health over time, was omitted from the stigma measure. The research team decided to eliminate the second concept because it may not be applicable to all breast cancer patients. On the other hand, shaming and devaluation of the patients or their families was added as a construct.

Study Variables and Data Collection Instruments

Demographics and covaries. A demographic form collected information about participants' marital status, age, level of education, nationality (i.e., Saudi vs. non-Saudi) with the option to write their nationality for non-Saudis, family income, employment, number of children, co-morbid conditions, and current treatment types (i.e., chemotherapy, radiotherapy, surgery, hormonal), type of surgery (mastectomy vs. lumpectomy), healthcare service type (private hospital vs. government hospital). Depressive symptoms as measured by the Center for Epidemiologic Studies Depression Scale (CES-D) was used as a covariate. Examining depressive symptoms in this population was important because it has been highly emphasized in other Middle Eastern research. A study in Saudi Arabia by Shaheen Al Ahwal et al. (2014) and a study in Turkey by Alacacioglu et al. (2009) found that patients with colon cancer had high levels of depression symptoms. Another study found that 69% of the Iranian breast cancer patients suffered from high levels of depressive symptoms. Thus, it was important to explore the depressive symptoms in our study (See Appendices K and L.).

Independent variables (IV). Measures of independent variables used in this study consisted of the following scales: Functional Assessment of Chronic Illness

Therapy — Spiritual Well-being (FACIT-Sp) version 4, Arabic-Belief into Action Scale (BIAC), and Multidimensional Scale of Perceived Social Support (MSPSS).

Additionally, the study included 12 items to explore the influence of stigma using a five-point Likert scale.

Independent Variables

FACIT-Sp, version 4. Scores range from 0–48 and higher score represents better well-being. (See Appendices D and E.) Items 4 and 8 were reversed coded because they were negatively worded. The Cronbach's alpha in an Arabic speaking and Muslim population was previously reported as 0.83 (Lazenby, Khatib, Al-Khair, & Neamat, 2013). In non-Arabic speaking populations the Cronbach alphas range from 0.75–0.95 (Bormann, Aschbacher, Wetherell, Roesch, & Redwine, 2009; Krupski et al., 2006; Peterman et al., 2002a).

BIAC. Scores range from 1–10 for each item with a total range from 10–100. Higher scores indicated a higher level of religiosity. Question 1 was recoded as follows: item 7 = 10 and all other answers in question 1 = 1. Scores were calculated by SUM of the recoded question one through question ten. (See Appendices F and G.)

MSPSS. The MSPSS uses a seven-point Likert scale, ranging from strongly agree (7 points) to strongly disagree (1 point). Higher scores indicate higher social support. (See Appendix H.) An additional two questions asked the patient to identify the relationship with the special person, for example siblings, friends, religious person, or someone else. Also, participants were asked to identify who is included in the does family, for instance grandparents, parents, children, grandchildren, siblings, relatives, or someone else. The total score was calculated by summing the 12 items, then dividing by

12. The “family” subscale score was calculated by summing items 3, 4, 8, and 11, then dividing by 4. The “significant other” subscale score was calculated by summing items 1, 2, 5, and 10, then dividing by 4. Finally, the “friends” subscale score was calculated by summing items 6, 7, 9, and 12, then dividing by 4.

Stigma. The breast cancer stigma scale was developed for this study. As previously noted, the concept of stigma was borrowed from Jones and Jones’s social stigma construct (Jones & Jones, 1984). The scale is multidimensional and has six constructs. (a) avoidance: perception of danger from the stigmatized person with the disease, which may lead to one’s own death; (b) personal responsibility: perception that people caused their illness; (c) concealment: when persons hide their illness from others; (d) functioning: disruptiveness, whether the stigmatized person can normally interact with others, or be productive; (e) wholeness: perception that the illness will make the stigmatized person less physically attractive; and (f) shaming: devaluing.

Response options used a five-point Likert scale: 1 (strongly agree), 2 (agree), 3 (neutral), 4 (disagree), 5 (strongly disagree). Lower scores indicated higher levels of stigma. (See Appendices I and J.) Each construct or sub-scale had two items. The items were written in Arabic and then translated to English. The items were rated by seven bilingual persons (Arabic/English) with an oncology background.

Outcome variables-Dependent Variables (DV). Study measures of the dependent variables consisted of the following scales: Arabic European Organization for Research and Treatment of Cancer (EORTC-QOL30 and the EORTC-QOL23 breast cancer specific model). Internal reliability in the Gulf and other countries range between 0.7–0.9 (Alawadhi & Ohaeri, 2010; Awad, Denic, & El Taji, 2008b; Huijjer, Sagherian, &

Tamim, 2013). However, the reliability and validity of these measures had not been examined in AFBCPs in Saudi Arabia prior to this study.

Health-related quality of life. EORTC-QOL-C30 is a 30-item instrument. It is composed of five functional subscales (physical, role, cognitive, emotional, and social), in addition to global health status and a HRQOL scale. It also includes five single items examining the most common cancer symptoms (dyspnea, insomnia, loss of appetite, constipation, and diarrhea). Scores range from 0–100, and higher scores indicate better functioning, except for the symptom scale where higher scores indicate more symptoms. According to Giesinger (2016), different strategies were used to calculate the summary score, such as summing all the items except financial difficulties (Nordin et al., 2001). On the other hand, a sum score of QOL-c30 could be calculated using the mean value of all 30 items, including financial difficulties and global health (Hinz et al., 2012). However, many have argued that financial difficulties and global health should not be included in the summary score because they are not related to health issues (Nordin et al., 2001; Guyatt, Feeny, & Patrick, 1993). Therefore, in this study the summary score of QOL-C30 scale was calculated by taking mean of all scores except for global health status and financial difficulties (PROscorer, 2019). (See Appendices M and N.)

The EORTC-QOL-C23 consists of two multi-items functional scales (body image and sexuality), and three symptoms scales (arm symptoms, breast symptoms, and systemic therapy side effects). It also has a single item that assesses sexual enjoyment. Each subscale in QOL-c23 was treated as dependent variable. (See Appendices O and P.)

Scales Reliability

Table 1

Scales Reliability

Concepts/Variables	Measures	Number of items	Cronbach's alpha
Health-related quality of life	EORTC-QOL30 and the EORTC-QOL23	EORTC-QOL30 is 30 items. EORTC-QOL23 is 23 items	0.7–0.9
Spirituality	FACIT-Sp	12 items	0.78–0.9
Religiosity	BIAC	10 items	0.8
Social Support	MSPSS	12 items	0.87
Stigma	Stigma	12 items	N/A

Exploratory data analysis. Data was examined for normality, homogeneity, skewness, and variance was assessed using standard descriptive statistics.

Descriptive statistics. Descriptive statistics of demographic variables including means, standard deviations, frequencies, and percentages were used to characterize religiosity, spirituality, social support, and HRQOL in breast cancer patients. Histograms were used to assess gaps and extreme values. Boxplots or scatterplots were used to identify outliers. In the case of outliers, after assessing the data and excluding data errors, I planned to transform or trimmed the data (Windsoring). Two-way Scatterplots were used to assess the relationship between two continuous measurements (Gauvreau & Pagano, 2000). Collinearity between predictors was assessed and post-hoc test “homoscedasticity” histograms were analyzed for normal distribution and regression residuals were examined for heteroscedasticity.

Neugarten (1996) emphasized that people's perceptions may change over time with the change in the life cycle, which can impact their expectations and outcomes. For instance, younger patients with chronic illness express a higher level of depression and worse level of HRQOL than older patients based on their needs in specific age group (Neugarten, 1996). A study in Saudi Arabia supported this statement. Ahmed et al. (2017) examined the impact of socioeconomic factors on breast cancer patients' QOL in Saudi Arabia. Age was divided into two groups: breast cancer patients older than 60 years old and younger than 60 years old. Ahmed et al. (2017) found that breast cancer patients younger than 60 years old had significantly better physical functioning and worse emotional functioning than older patients. Thus, it was essential to address the role of age on the outcome of the current study. To examine the impact of age variable, we controlled for age and used the coefficient to read the variability of age in each aim.

Minimizing missed data. To minimize having missed data, we did the following. With the paper-based survey, the answered survey was revised with the participants and examined to see if the participants missed any items (unless they purposefully decided not to answer a particular item). The online survey used an added forced response criterion for the main variables, such as HRQOL, spirituality, religiosity, social support, and age.

Plans for managing missed data. Missing data was assessed in the exploratory data analysis phase. Dealing with missing data was based on the type of missed data, which variable, and the pattern of missing data. When dealing with multi-items scales, such as EORTC-QOL30 and the EORTC-QOL23, if missing items are < 10% then we applied complete-case-analysis (CCA) (Eekhout et al., 2014). However, when more

than 25% of the data were missing, we planned to apply multiple imputation methods to the total score (Eekhout et al., 2014).

Data Analysis

The reliability and validity of the measures in the sample was assessed as follows.

Reliability. This was assessed by measuring the internal consistency Cronbach's alpha (DeVellis, 1991).

Validity. We planned to examine the validity of the breast cancer stigma scale by using the content validity (CVI), convergent validity, and exploratory factor analysis (EFA). Polit and Beck (2006) stated that computing content validity would require universal agreement among experts with a minimum number of six raters (if possible). Lynn (1986) suggested that when making a new scale, a CVI of five raters or fewer should be equal to 1.00, but when having six raters or more the CVI should not be less than 0.78. Convergent validity is a sub-type of construct validity and assists in examining if the measure is assessing the latent variable, which takes two measures and assesses if they are related (DeVellis, 1991). Results related to convergent validity and the CVI are provided in Chapter 4.

Finally, we planned to conduct EFA by using the known-group construct validity (DeVellis, 1991). Factor analysis can assist in determining how many latent factors underline set of items. Items in EFA are allowed to load on each factor or latent variable. In factor loading, items with a correlation of > 0.7 mean they have excellent loading. However, if items correlate 0.3 or less with a latent variable, then maybe it is better to remove it. Before eliminating any item, it is advisable to do the rotation technique either orthogonal or oblique as appropriate (DeVellis, 1991). Items rotation was planned to be

used to increase the interpretability between an item and latent variable. Additionally, it can increase the correlation for items with high correlation and reduce the correlation for items with low correlation (DeVellis, 1991). It is worth noting that performing EFA with a sample size less than 200 is not advisable (Guilford, 1954; Comrey, 1973). Because the sample size reached for this study was 59, we were unable to conduct EFA as originally planned.

Identifying Covariates

Bivariate testing. Bivariate associations were also run, between independent and dependent variables. This step can assist in identifying presence of multicollinearity between independent variables. Hence, we ran Pearson correlations for continuous independent variables.

Multivariate model. We used the Theoretical force fitting modeling and included the suggested variables in the framework into multiple linear regression (MLR). In MLR, we quantified the association between the DV and IVs while adjusting for age. We assessed the R-square and adjusted R-square in the results. There was a risk of having a strong linear association between spirituality and religiosity (independent variables). Therefore, prior to the analysis, we planned to examine the bivariate correlation matrix to identify the presence of any problematic correlations between independent variables; extreme multicollinearity (r of ± 0.8) between two independent variables would have been problematic.

Aim 1) Identify the association between spirituality and HRQOL in AFBCPs, controlling for age.

Hypothesis: Patients with higher levels of spirituality will have higher levels of HRQOL after controlling for age. To test this aim, MLR was used to examine the magnitude and significance of the association between spirituality and HRQOL with $p < 0.05$ for significant association.

Aim 2) Identify the association between religiosity with HRQOL in AFBCPs, controlling for age.

Hypothesis: Patients with higher levels of religiosity will have higher levels of HRQOL after controlling for age. To test this aim, MLR was used to examine the magnitude and significance of the association between religiosity and HRQOL with $p < 0.05$ for significant association.

Aim 3) Identify the association between social support with HRQOL in AFBCPs, controlling for age.

Hypothesis: Patients with higher levels of social support will have higher levels of HRQOL after controlling for age. To test this aim, MLR was used to examine the magnitude and significance of the association between social support and HRQOL with $p < 0.05$ for significant association.

Aim 4) The exploratory was to analyze the impact of between breast cancer stigma with HRQOL in AFBCPs, controlling for age.

Hypotheses: 1) Stigma will be inversely correlated with HRQOL and 2) patients with high levels of stigma will have low levels of HRQOL after controlling for age.

Pearson's or Spearman's correlation was used as appropriate to describe the relationship between stigma and HRQOL. To test this aim, MLR was used to examine the magnitude and significance of the association between stigma and HRQOL.

Anticipated Results

It was expected that higher levels of spirituality and religiosity would be associated with higher levels of HRQOL (QOL-sum score and QOL-c23 subscales); higher levels of social support would be associated with higher levels of HRQOL; and younger participants would have poorer HRQOL outcomes than older participants. Finally, it was expected that higher levels of stigma would negatively impact HRQOL.

Strengths and Limitations

This was the first study to assess the levels and the impact of stigma on HRQOL in breast cancer patients in Saudi Arabia. Findings from this study will provide a basis for future research. Testing factors affecting the HRQOL will help clinicians and researchers in Saudi Arabia.

This was a cross-sectional pilot study, and data collection happened at one time point. Therefore, the long-term effects of spirituality, religiosity, and social support, and stigma on the HRQOL were not measured. Additionally, the findings of the current proposal did not infer causation between the independent and dependent variables. A longitudinal design is necessary to address these limitations.

Potential Ethical Concerns

There was an ethical responsibility and concern to protect people who participated in this research from any potential harm or risks that might occur. Potential risks and discomforts related to becoming emotionally upset in response to questions that may seem personal or that deal with private or sensitive issues were clearly presented to the potential participants. With the face-to-face data collection, I recruited participants after obtaining verbal approval, and then participants were enrolled after signing a written

informed consent. Arabic informed consent was provided to all participants. Each element of the study was explained by me verbally and in the consent form, including purpose and objectives, data collection, risks and benefits, and confidentiality. My contact information was provided, and the right to withdraw was explained. If participants wrote any identifying information (e.g., name, date of birth, etc.) on the questionnaires, I de-identified the data and kept participants' names confidential in a spreadsheet (Master Sheet) which was kept in a locked file cabinet. The de-identified questionnaires were labelled with unique codes. Additionally, the consent forms that have participants' names were stored in a separate locked filing cabinet that did not contain raw data. The master data file (accessed only by me) and the electronic data were encrypted, and password protected. I had sole access to the master file which was located in a secured locked filing cabinet at the IMC.

Some participants refused to participate because of the sensitivity of this study. I assured them that their confidentiality would be protected. Participants might have experienced distress because of the nature of the study, as well as answering sensitive questions. I re-asked the participants about their preference for filling out the surveys. I was vigilant not to include any breast cancer patients before they fully understood the nature of the study. I also informed the participants that they have the right to withdraw from the study with no obligation or impact on their treatment at IMC.

Chapter 4

Results

This chapter presents the results of the dissertation. First, the preliminary analysis and sample descriptive are presented. Second, the internal consistency of each measure is presented. Third, initial validity and reliability of the newly developed stigma scale are presented. Finally, the results for each aim of the dissertation are presented.

Response Rate

Data collection for the current study started with a paper-based survey at the International Medical Center in Saudi Arabia. Thirty-four participants completed the paper-based survey. In order to increase the sample size, participants were provided two options to complete the survey: paper-based or online format. Twenty-eight participants completed the online survey with a total of 62 participants completing either the paper-based or online survey. Three participants from the online survey were excluded because they had chosen the “Refuse to Answer” option for the entire survey. Therefore, the final sample size for the dissertation was 59.

Sample Characteristics

Participants in this study were women with a diagnosis of breast cancer. The mean age was 49 ($SD = 8.311$), and the majority were married (86.4%). More than half of the participants had at least a college degree (58%). Just under half of the participants had metastasis to other organs (44%). The largest group of participants were non-Saudi (62.7%). The non-Saudi nationalities were: Egyptian (20.3%), Syrian (15.3%), Palestinian (6.8%), Jordanian (5.1%), Yemeni (6.8%), Hadramot (1.7%), Sudanese (3.4%), and Moroccan (1.7%). The majority of the participants were treated at a private

hospital (69.5%). Additionally, almost half of the participants were on hormonal therapy (46%). Other treatments being received included chemotherapy treatment (23.7%), biologic therapy (6.8%), and immunology and surgical treatments (5.1%). (See Table 2.) (For backgrounds and demographics, see Appendix C.)

Table 2

Sample Characteristics

	<i>N (%)</i>	<i>Mean (SD)</i>
Age	59	49 (8.3)
Marital Status		
Single	2 (3.4)	
Married	51 (86.4)	
Divorced/Separated	4 (6.8)	
Widowed	2 (3.4)	
Treatment		
Chemotherapy	14(23.7)	
Surgical	3(5.1)	
Hormonal	27(45.8)	
Immunology	3(5.1)	
Biology	4(6.8)	
Metastasis ^a		
No	30 (50.8)	
Yes	26 (44.1)	
Educational Level		
No College Degree	25 (42.4)	
College Degree and Above	34 (57.6)	
Saudi Nationality		
No	37(62.7)	
Yes	22(37.3)	
Hospital Type		
Government	17(28.8)	
Private	41(69.5)	

Note. A: metastasis to other organs.

Preliminary Analysis of Variables

Exploratory data analysis was conducted to examine missing data and the distribution of each predictor variable and covariates. Dependent variables included a summary score for the EORTC QLQ-C30 and the sub-scales of EORTC QLQ-C323 (as described in Chapter 3).

Missing Data

Missing data in predictors. After using list wise deletion method, the total number of predictor variables including age, stigma, social support, spirituality, and religiosity had 1.7% missed items.

Missing data in outcomes. Missing data on some parts of the EORTC QOL-C23-sub-scales' sample was largely because of the lack of certain symptoms experienced by participants in the study. For instance, arm symptoms, therapy side effects, body image, and future perspective had zero missed items ($N = 59$). On the other hand, sexual functioning had four missed data (missed is 6.78%) with a remaining sample size of 55 (93.22%). Two additional items from the EORTC QOL-C23 scale had a large amount of missed data: upset with hair loss and sexual enjoyment. Sexual enjoyment had 26 missed data (missed = 44.06%) and the remaining sample size was $N = 33$ (55.93%). The total number of answered items for "Upset with hair loss" was 35 participants (60%) with 24 missed data (40%) which was is classified as follows: (a) missed data zero; (b) not applicable (33.2%); and (c) refused to answer (6.8%). According to the EORTC QOL-C23 scoring guideline (Fayers, 2008), when patients answer the item "Do you have hair loss?" with "Not at all", the following item, "Are you upset with hair loss?" should be scored as not applicable. Fayers' guideline suggested that there is no distinction between

missed items and not applicable answers, and the analysis should only be performed on the remaining answered items. Scoring for the sexual enjoyment item was the same as “Upset with hair loss.” If participants answered, “Not at all” to the item “To what extent were you sexually active?” the following item, “To what extent was sex enjoyable for you?” was coded as not applicable. The total answered for the sexual enjoyment item was 33 (56%) participants which is equivalent to a total of 44% of missed data. Missed data were classified as follows: missed data (10.2%); 25% reported the item as not applicable and 9% refused to answer. According to Eekhout et al. (2014), complete-case analysis (CCA) is not recommended when missed data is > 10%. The missing data for both items “Sexual enjoyment” and “Upset with hair loss” was > 10%. Given the high amount of missingness on these two items, the decision was made not to do CCA on these two items and not to include them in the multiple regression analysis, but descriptive results for these items/symptoms are presented in this chapter.

Finally, the total number of participants with data for the sexual functioning item were 55 (93%) with 7% of participants having missed data. A complete-case-analysis of missed data on the sexual functioning item was performed. The sexual functioning item was recoded to a dichotomous variable with those with missingness coded as zero and those without missing data on the item coded as one. An independent *t*-test was performed to determine whether the two groups differed on age. No significant difference was found ($p = 0.90$), which indicates that data were missed at random. It was therefore decided that this item would be included in the regression analysis (see Tables section, Table 6).

EORTC QOL-30 QOL-sum score and EORTC QOL-C23 subscales. After

using list wise data deletion, the total number of participants with data on the EORTC QOL-30 QOL-sum score scale was 59 (100%). Similarly, in EORTC QOL-C23 subscales, breast symptoms, therapy side effects, arm symptoms, future perspectives, and body image all had complete data.

Distribution of dependent variables. The distribution of each dependent variable was examined for the range of skewness. The acceptable range of skewness is ± 2 (Gravetter, & Wallnau, 2014). The skewness level of HRQOL-Sum score was (-1.04), including arm symptoms (-0.87), breast symptoms (0.98), therapy side effects (-1.05), body image (-0.72), sexual function (-0.61), future perspective (-0.37). As they were all within the acceptable range, it was deemed appropriate to use the means as a measure of the central tendency (see Figures 4–10).

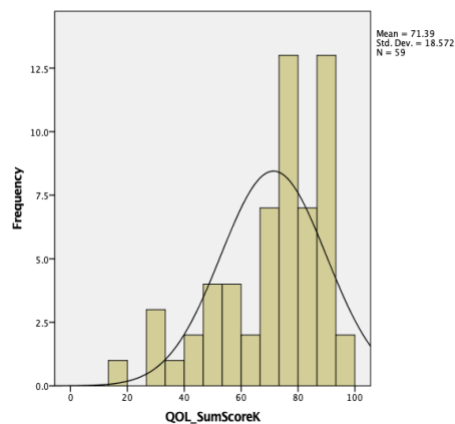


Figure 4. Distribution of HRQOL-sum score. Skewness (-1.04).

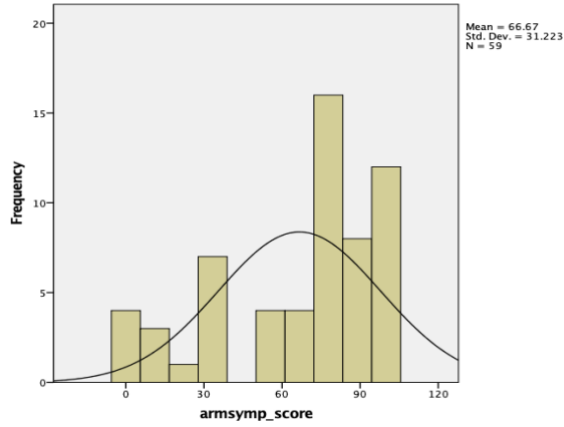


Figure 5. Distribution of arm symptoms. Skewness (-0.87).

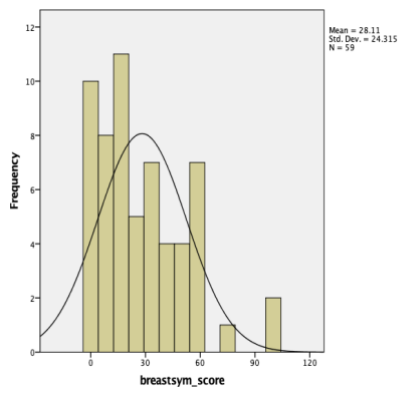


Figure 6. Distribution of breast symptoms. Skewness (0.98).

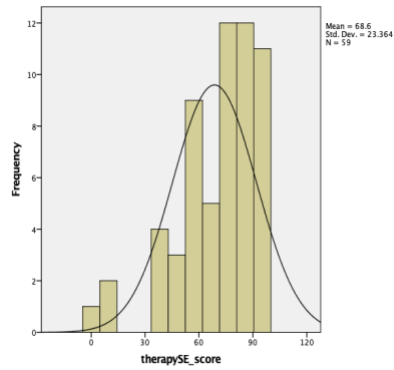


Figure 7. Distribution of therapy side effects. Skewness (-1.05).

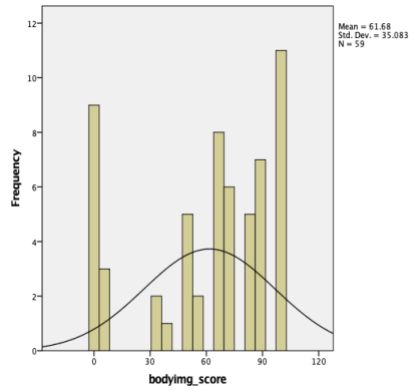


Figure 8. Distribution of body image. Skewness (-0.72).

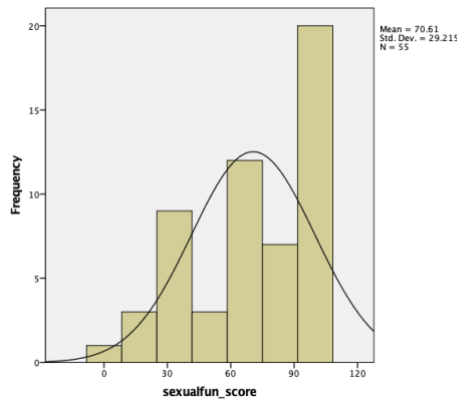


Figure 9. Distribution of sexual functioning. Skewness (-0.61).

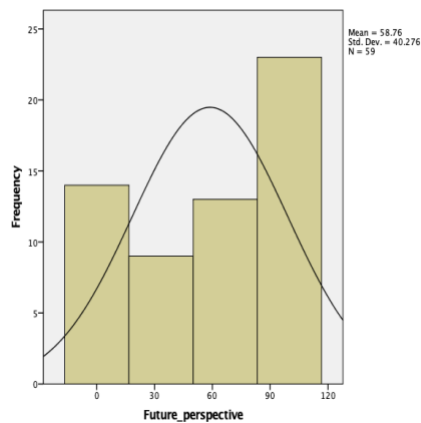


Figure 10. Distribution of future perspective. Skewness (-0.37).

Preliminary Analysis of Predictor Variables

Spirituality: FACIT-SP. Data were cleaned, and one missed item was reported.

The mean level of spirituality in our study was 39.67 ($SD = 8.0$), which represents moderate levels of spirituality in this population. Reliability of the measure was

examined for internal consistency using Cronbach's alpha and found to be within the acceptable range ($\alpha = 0.77$). (See Table 3.)

Religiosity-BIAC. Data were cleaned, and zero missed items were reported ($N = 59$; 100%). The mean score in our study was 50.93 ($SD = 13.41$), which indicates a moderate level of religiosity. Reliability of the measure (after recoding items) was examined for internal consistency using Cronbach's alpha and found to be within the adequate range ($\alpha = 0.67$). Cronbach's alpha of the BIAC scale in the original translated Arabic version was $\alpha = 0.80$ (Alakhdhair et al., 2016). (See Table 3.)

Social support-MSPSS. Data were cleaned, and the total number of entries of each item on the scale was 53 (89.8%) with six missed data (10.2%). However, after using list wise deletion the total number of entries in the whole scale was 55 with 1.8% missed data. The mean score of the total MSPSS scale was 6.20 ($SD = 1.19$), which indicates a high level of social support. Cronbach's alpha in our study was $\alpha = 0.81$ for the total score. Regarding the MSPSS subscales, the mean score of the "family" subscale was 6.10 ($SD = 0.155$) and the mean score of "significant others" was 6.18 ($SD = 0.180$), which indicates a high level of family and significant other support. Cronbach's alpha for "significant others" and "family subscales in the study was $\alpha = 0.81$ and $\alpha = 0.64$ respectively. The mean score of the "friends" subscales was 5.40 ($SD = 0.219$), which indicates an acceptable level of friends' support. Cronbach's alpha of the "friends" subscale in this study was $\alpha = 0.67$. (See Table 3.)

Participants defined their "significant other" in the MSPSS scale as follows: husband (55.3%), children (31.6%), parents (5.3%), niece (2.6%), siblings (2.6%), and none (2.6%). "Family support" was defined in this study as follows: children (28.1%),

husband (26.6%), siblings (25.8%), parents (11.7%), grandchildren (3.9%), grandparents (2.3%), and relatives (1.6%).

Depressive symptoms. Data were cleaned, and one missed item was reported. Cronbach's alpha, of the CES-D in our data was $\alpha = 0.88$. The mean value of the CES-D was 20.52 ($SD = 12.36$). In Western countries, a cut-off point of 16 is the suggested score for follow-up of depressive symptoms. For studies in the United Arab Emirates and Egypt, a cut-off point of 21 is recommended (Beshai, Dobson, & Adel, 2013; Ghubash, Daradkeh, Al Naseri, Al Bloushi, & Al Daher, 2000). Raising the cut-off points aims to minimize false-positive results (Husaini, Neff, Harrington, Hughes, & Stone, 1980) by addressing concerns about items that measure somatic symptoms (Beshai et al., 2013). (See Table 3.) In this study, almost half of the participants scored 21 or higher on the CES-D scale (46%). Although the mean in this study was barely below this cut-off, the standard deviation implies that we had women who were experiencing high levels of depressive symptoms.

Stigma. Data were cleaned, and one missed item was reported. The mean stigma score was 3.93 ($SD = 0.81$), which indicates a moderate level of stigma because of a breast cancer diagnosis. Cronbach's alpha for this study was $\alpha = 0.79$ and further examination of reliability and validity is reported below (see Table 3 and Table 4).

Table 3

Predictors Description

Predictor Variables	<i>N</i>	Mean \pm (<i>SD</i>)	Cronbach's alpha α
Stigma^a	58	3.93 (0.77)	0.79
MSPSS^b	55	6.20 (1.18)	0.81
Significant other support	58	6.18 (1.33)	0.81
Family support	58	6.10 (1.14)	0.64
Friends support	58	5.40 (1.62)	0.67
BIAC^c	58	50.93 (13.41)	0.67
FACIT^d	58	38.77 (7.69)	0.77
CES-D^e	58	20.52 (12.38)	0.88

Note. *a:* stigma scale. *b:* Multidimensional Scale of Perceived Social Support scale. *c:* Arabic-Belief into Action Scale. *d:* The Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale *e:* Center for Epidemiologic Studies Depression Scale. *N* = total number.

Initial Examination of the Reliability and Validity of the Stigma Measure

Reliability

As mentioned above and in Table 4 below, the reliability of the stigma measure was examined by computing a Cronbach's alpha for the measure and inspecting the inter-item correlation matrix (DeVellis, 1991). Cronbach's alpha was 0.79. Additionally, we examined the Cronbach's alpha of each item. After deleting each item individually, we noted that deleting item 8 increased the alpha to 0.80 ("I asked people closest to me to keep my breast cancer a secret"). Because of our small sample size, further psychometric testing is required in the future to confirm this finding before a recommendation to remove the item is made, especially as the alpha of 0.79 was within acceptable range and the item in question may have importance for the measure's validity. For example, 27.1%

of the participants answered this item as strongly agree and 8.5% of the participants answered it as “agree.” Having a sample size of 59 could explain why item-correlations ranged between -0.06–0.75. Ferketich (1991) asserted that an average of the item-correlations can range between 0.2–0.7 when sample sizes are 200 or less (see Table 4). No other concerns were observed.

Table 4

Cronbach Alpha Inter-Item Correlation

Items	(A) 1	(W) 1	(PR) 1	(F) 1	(F) 2	(W) 2	(PR) 2	(C) 1	(C) 2	(S) 1	(S) 2	(A) 2	Alpha if item deleted
Avoidance (A)1	1	-	-	-	-	-	-	-	-	-	-	-	0.77
Wholeness (W)2	0.34	1	-	-	-	-	-	-	-	-	-	-	0.76
Personal Responsibility (PR) 1	0.37	0.33	1	-	-	-	-	-	-	-	-	-	0.76
Functioning (F) 1	0.24	0.42	0.20	1	-	-	-	-	-	-	-	-	0.76
Functioning (F) 2	0.26	0.36	0.34	0.75	1	-	-	-	-	-	-	-	0.75
Wholeness (W) 2	0.27	0.52	0.26	0.57	0.58	1	-	-	-	-	-	-	0.74
Personal Responsibility (PR) 2	0.24	0.39	0.72	0.41	0.37	0.39	1	-	-	-	-	-	0.75
Concealment (C) 1	-	-	-	-	-	0.03	0.02	1	-	-	-	-	0.80
Concealment (C) 2	0.11	0.24	0.02	0.13	0.11	-	-	-	1	-	-	-	0.78
Shaming (S) 1	-	-	-	-	-	0.16	0.01	0.73	0.44	1	-	-	0.76
Shaming (S) 2	0.10	0.03	0.07	0.17	0.10	0.24	0.31	0.35	0.43	0.60	1	-	0.76
Avoidance (A)2	0.04	0.17	0.17	0.12	0.15	0.25	0.16	0.29	0.21	0.30	0.30	1	0.75

Note. N = 12.

Stigma Scale Validity

Content validity index (CVI). The validity of the stigma measure was examined by assessing the content validity index. Oncology experts who were bilingual in Arabic and English rated the stigma scale by rating the relevance of each item to the construct definition by using the following system: (1) not relevant to the construct, (2) somewhat

relevant to the construct, (3) quite relevant to the construct, and (4) highly relevant to the construct. According to seven experts in the field, the item-CVI was 0.85 and the total scale-CVI was 0.98 with Scale-CVI = 1 (see Table 5).

Table 5

Content Validity Index

Rater 1	Rater 2	Rater 3	Rater 4	Rater 5	Rater 6	Rater 7	Number of Items rated 3 or 4	I-CVI
4	4	4	4	4	4	3	7	1
4	4	4	4	4	4	1	6	0.85
4	4	4	4	4	4	3	7	1
4	4	4	4	4	3	3	7	1
4	4	4	4	4	4	4	7	1
4	4	4	4	4	4	4	7	1
4	4	4	4	4	4	4	7	1
4	4	4	4	4	4	3	7	1
4	4	4	4	3	4	3	7	1
4	4	4	4	3	4	4	7	1
4	4	4	4	3	4	2	6	0.85
4	4	4	4	4	4	3	7	1
Mean I-Content Validity Index								0.97
Scale-CVI								1

Convergent validity. Convergent validity was examined with a Pearson correlation between the stigma scale with the CES-D scale and between the stigma scale and social support (MSPSS). Low scores on the stigma scale (strongly agree), indicates high levels of stigma. High scores on the CES-D scale indicates high levels of depressive symptoms. Additionally, high scores on MSPSS suggest high levels of social support. The Pearson correlation between stigma and CES-D was $r = -0.31$ ($p < 0.01$), which indicates a low-moderate, negative correlation between stigma and depressive symptoms

in our sample as expected (Mukaka, 2012). Additionally, the Pearson correlation between stigma and MSPSS was $r = 0.17$ ($p < 0.20$), which indicates a low positive correlation. Although this association was in the expected direction for demonstrating convergent validity, the lack of significance and low strength of the association may be because of the small sample size (see Tables section, Table 7).

Identifying Predictors for Analysis of Aims

Based on the adapted theoretical model guiding this study, there were five proposed predictors: social support, spirituality, religiosity, stigma, and age. However, the HRQOL-sum score scale may be highly correlated with depressive symptoms because the scale contains items related to depression. Therefore, the final model did not include depressive symptoms to prevent this conceptual overlap. Including highly correlated predictors with the dependent variable might misinterpret the outcomes (Ray-Mukherjee et al., 2014). As proposed in Chapter 3, a separate multiple regression analysis was used for each independent variable to determine the association with each dependent variable (QOL-sum score or EORTC-C23 subscales) controlling for age. Thus, a preliminary correlational analysis of predictors with the main dependent variable (HRQOL summary score) was used to identify the predictors to be included in the regression analysis (see Tables section, Table 8).

Preliminary Analysis

The mean score of HRQOL-sum score in our study was 71.39 ($SD = 18.57$), which indicates that participants have moderate levels of HRQOL. Regarding the signs and symptoms associated with the breast cancer HRQOL scale, the mean scores were as follows: arm symptoms 66.67 ($SD = 31.22$), breast symptoms $M = 28.11$ ($SD = 24.31$),

upset with hair loss $M = 2.6$ ($SD = 1.19$), therapy side effects $M = 68.60$ ($SD = 23.36$), perception about body image $M = 61.68$ ($SD = 35.08$), sexual functioning $M = 70.61$ ($SD = 29.21$), hope about future perspective $M = 58.76$ ($SD = 40.27$), and sexual enjoyment $M = 2.45$ ($SD = 1.00$). In this study, Cronbach's alpha for the 28 items (HRQOL-sum score) was $\alpha = 0.93$ and the Cronbach's alpha for HRQOL-C23 breast cancer was $\alpha = 0.91$. Despite the missed scores described in the preliminary analysis, the results above indicate participants in our study had low to medium levels of HRQOL-sum score and QOL-c23 breast cancer subscales. Talking about sexuality is considered taboo in Middle Eastern culture, especially for unmarried women. Therefore, because the topic of sexuality is such a sensitive subject in general, and the majority of our participants were married (89%), the sexual functioning sub-scale did not represent the majority of women with breast cancer in Saudi Arabia. The EORTC-C23 contains two additional items that ask about sexual enjoyment and being upset with hair loss. These two items were not part of multiple regression analysis, but Chapter 4 presents the frequency of those two items.

Aim 1 Results

Aim 1) Identify the association between spirituality and HRQOL in AFBCPs.

Hypothesis: Patients with higher levels of spirituality will have higher levels of HRQOL (HRQOL-sum score and QOL-c23) after controlling for age.

We used multiple regression to identify the association between spirituality and HRQOL in AFBCPs. In this hypothesis, we controlled for age (see Tables section, Table 10 and Table 11).

HRQOL-sum score EORTC-QLQ-C30. After adjusting for age, spirituality was significantly associated with sum-score of quality of life ($\beta = 0.91 \pm 0.28$, $t = -3.19$, $p < 0.001$). The findings indicate that patients with higher levels of spirituality reported significantly better general quality of life than patients with lower levels of spirituality. The results of the regression indicated the two predictors explained 12% of the variance ($R^2 = 0.12$, $F(2,58) = 5.176$, $p < 0.009$) in the HRQOL-sum score in our model.

EORTC-QLQ-C23 subscales. After adjusting for age, spirituality was significantly associated with concerns about body image ($\beta = 1.8$, ± 0.53 , $t = 3.37$, $p < 0.001$). The results indicate that women with higher levels of spirituality were significantly more likely to have better perceptions about their body image. Age was not significantly related to body image (-0.25 ± 0.36) in the current sample (see Tables section, Table 7). Together, age and spirituality explained 14% of the variance ($R^2 = 0.14$, $F(2,58) = 5.86$, $p < 0.005$) in concerns about body image. Higher levels of spirituality were also significantly associated with better tolerance of therapy side effects ($\beta = 0.80$, ± 0.373 , $t = 2.14$, $p < 0.03$).

Also, age was not significantly related to therapy side effects ($p < 0.48$). Together age and spirituality explained 14% of the variance ($R^2 = 0.05$, $F(2,58) = 2.68$, $p < 0.07$) in tolerance for therapy side effects. Additionally, age did not have a significant relationship with body image ($p < 0.77$), which indicates that perceptions of body image were not affected by developmental stage (see Tables section, Table 11).

Spirituality also had a significant relationship with the “being hopeful about the future” perspective, after controlling for age ($\beta = -2.30$, ± 0.597 , $t = -3.86$, $p < 0.001$). This result suggests that patients with high levels of spirituality were less likely to worry

about the future. Age was not significantly related to “hope for the future” ($p = 0.35$), but when paired with spirituality, these two predictors explained 14% of the variance ($R^2 = 0.18$, $F(2,58) = 7.65$, $p < 0.001$) in participants’ “concerns for the future” in our model, a small effect size. Spirituality and age were not significantly associated with arm symptoms, sexual function, or breast symptoms (see Tables section, Table 11).

Aim 2 Results

Aim 2) Identify the association between religiosity and HRQOL in AFBCPs.

Hypothesis: Patients with higher levels of religiosity will have higher levels of HRQOL (QOL-sum score and QOL-c23) after controlling for age.

HRQOL-sum score EORTC-QLQ-C30. After adjusting for age, religiosity was significantly associated with sum-score of quality of life ($\beta = 0.36$, ± 0.17 , $t = 2.01$, $p < 0.05$), which indicates that patients with higher levels of religiosity reported better general quality of life than patients with lower levels of religiosity. Age was not significantly associated with the HRQOL sum score ($p < 0.75$). Together, the two predictors explained 3% of the variance ($R^2 = 0.03$, $F(2,58) = 2.09$, $p < 0.13$) for this aim (see Tables section, Table 12).

EORTC QLQ-C323 subscales. Neither age nor religiosity were significantly associated with concerns about body image ($p < 0.08$); or therapy side effects ($p < 0.13$). Similar to spirituality, religiosity was significantly associated with concerns about “future perspectives,” when controlling for age ($\beta = -1.25$, ± 0.36 , $t = -3.45$, $p < 0.001$). Patients with high levels of religiosity were less likely to “worry about the future.” Age was not significantly associated with “concerns about the future” ($p < 0.50$), which indicate that age and developmental stage did not affect patients’ “perspectives about the future.”

Together, the two predictors, religiosity and age, explained 15% of the variance about “the future” of HRQOL in our model ($R^2 = 0.15$, $F(2,58) = 6.16$, $p < 0.004$) (see Tables section, Table 13).

Religiosity was significantly associated with concerns about sexual function ($\beta = 0.56$, ± 0.28 , $t = 2.00$, $p < 0.050$); age was not ($p < 0.27$). Additionally, religiosity was significantly associated with having less breast symptoms ($\beta = -0.48$, ± 0.23 , $t = 2.08$, $p = 0.04$); age was not ($p = 0.53$). Patients with higher levels of religiosity reported better sexual functioning. Finally, religiosity ($p < 0.21$) and age ($p < 0.92$) were not significantly associated with arm symptoms. (See Tables section, Table 13.)

Aim 3 Results

Aim 3) To identify the association between social support with HRQOL in AFBCPs.

Hypothesis: Patients with higher levels of social support will have high levels of HRQOL (HRQOL-sum score and QOL-c23) after controlling for age.

HRQOL-sum score EORTC-QLQ-C30. After adjusting for age, social support was not significantly associated with HRQOL-sum score ($p < 0.59$). Age also did not have a significant relationship with HRQOL-sum score (-0.09 ± 0.29 , $p < 0.74$).

However, the coefficient score indicates each additional point in developmental age stage was significantly associated with worse quality of life in older compared to younger patients. (See Tables section, Table 14.)

EORTC QLQ-C323 subscales. After adjusting for age, social support was not significantly associated with any of the QOL-c23 subscales. (See Tables section, Table 15.)

Aim 4 Results

Aim 4) To identify the association between stigma with HRQOL in AFBCPs.

Hypothesis A: Stigma will be inversely correlated with HRQOL (high score in stigma indicates low levels of stigma).

The relationship between stigma and HRQOL (HRQOL-sum score and EORTC-C23 subscales) was tested by using a Pearson correlation. Findings indicated a significant relationship with HRQOL-sum score $r = 0.31, p < 0.02$; and some of the EORTC-C23 subscales: therapy side effects $r = 0.27, p < 0.03$; body image $r = 0.28, p < 0.03$; and future perspective $r = 0.34, p < 0.01$. Patients with high levels of stigma had worse HRQOL-sum score, tolerance of therapy side effects, body image perception, and lack of hope about the future. On the other hand, stigma had a nonsignificant relationship with the rest of EORTC-C23 subscales: arm symptoms $r = 0.18, p < 0.16$; breast symptoms $r = -0.23, p < 0.08$; and sexual functioning $r = -0.05, p < 0.69$.

Hypothesis B: Patients with high levels of stigma will have low levels of HRQOL (HRQOL-sum score and QOL-c23) after controlling for age.

HRQOL-sum score EORTC-QLQ-C30. After adjusting for age, stigma was significantly associated with the sum-score of quality of life ($\beta = 8.04, \pm 2.91, t = 2.75, p < 0.008$). Patients with lower levels of stigma reported better quality of life (high scores of stigma on the scale indicates low levels of stigma). On the other hand, age was not significantly associated with the sum-score of quality of life (-0.26 ± 0.28). Together, the two predictors accounted for 9% ($R^2 = 0.09, F(2,58) = 3.86, p < 0.027$) of the variance in sum-score of HRQOL in our model (see Tables section, Table 16).

EORTC QLQ-C323 subscales. After adjusting for age, stigma was significantly associated with concerns about body image ($\beta = 14.09 \pm 5.55$, $t = 2.53$, $p < 0.014$).

Patients with higher levels of stigma reported worse perceptions about body image. Age was not significantly associated with concerns about body image ($p < 0.29$). (See Tables section, Table 17.)

Stigma was also significantly associated with therapy side effects ($\beta = 9.25 \pm 3.69$, $t = 2.50$, $p < 0.015$). Patients with high levels of stigma were more likely to report worse tolerance of therapy side effect (low score in stigma indicates high levels of stigma). Stigma was also significantly associated with future perspectives ($\beta = -17.81 \pm 6.29$, $t = -2.82$, $p = 0.006$). Patients with lower levels of stigma were more likely to report better hope about the future. Additionally, patients with high levels of stigma reported worse perceptions of their body image ($\beta = -0.32 \pm 5.55$, $t = -2.53$, $p = 0.014$). However, stigma was not significantly associated with breast symptoms ($p = 0.15$); arm symptoms ($p = 0.13$) or sexual function ($p = 0.52$). The results indicate that stigma did not influence the breast symptoms and sexual function. Similar to stigma, age did not have a significant relationship with therapy side effects ($p = 0.17$). (See Tables section, Table 17.)

Multiple Regression Assumptions

Aim 1: After examining the results for Aim 1, we examined the Linear regression assumptions: linearity, normality, homoscedasticity, independence, and absence of multicollinearity. The histogram of residuals in EORTC QLQ-C30 (HRQOL-sum score) and EORTC QLQ-C323 were normally distributed (see Figures 11–16).

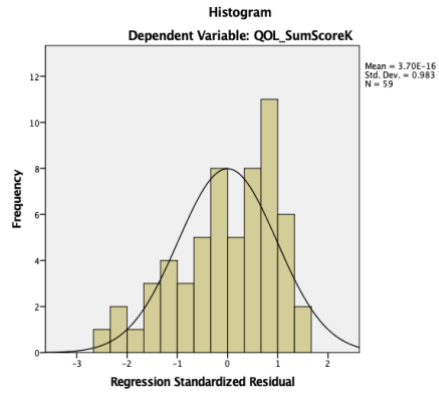


Figure 11. Aim 1 residuals distribution of HRQOL-sum score.

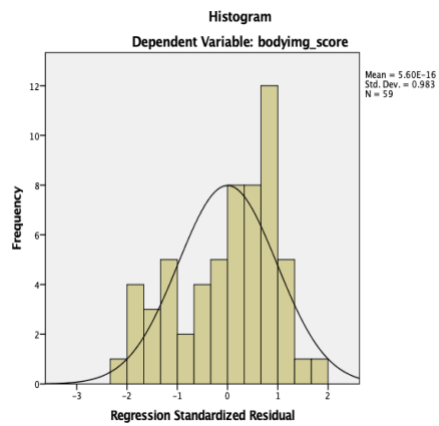


Figure 12. Aim 1 residuals distribution of body image.

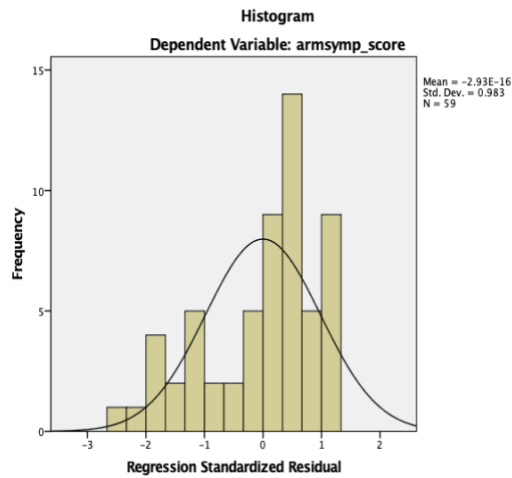


Figure 13. Aim 1 residuals distribution of arm symptoms.

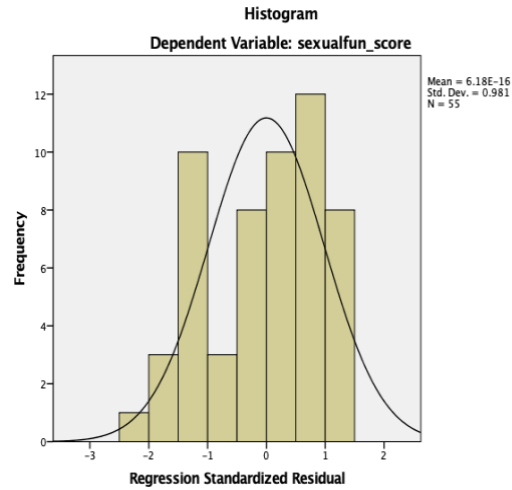


Figure 14. Aim 1 residuals distribution of sexual function.

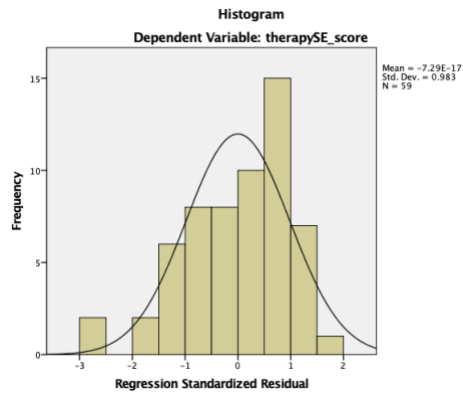


Figure 15. Aim 1 residuals distribution of therapy side effects.

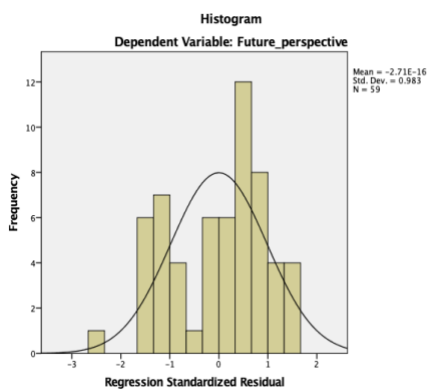


Figure 16. Aim 1 residuals distribution of future perspective.

In looking at the Variance Inflation Factor (VIF; the reciprocal of tolerance), there was no $VIF > 10$, so we were not concerned about multicollinearity according to the first output in Aim 1.

Aim 2: After examining the results for Aim 2, we examined the Linear regression assumptions: linearity, normality, homoscedasticity, independence, and absence of multicollinearity. The histogram of residuals in EORTC QLQ-C30 (HRQOL-sum score) and EORTC QLQ-C323 were normally distributed (see Figures 17–22).

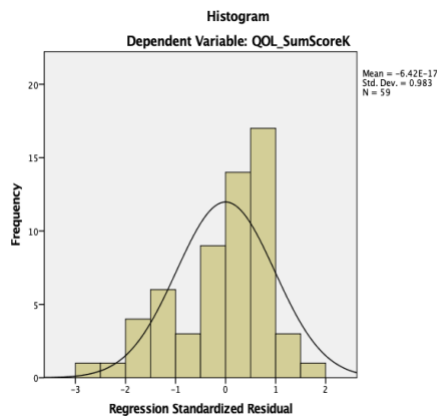


Figure 17. Aim 2 residuals distribution of HRQOL-sum score.

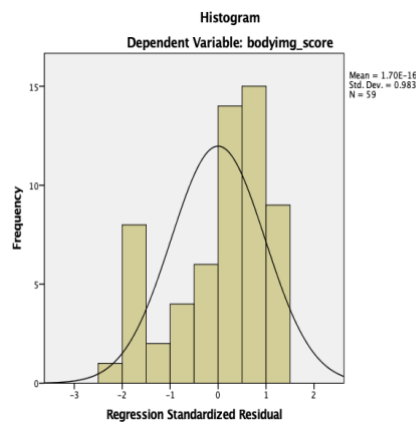


Figure 18. Aim 2 residuals distribution of body image.

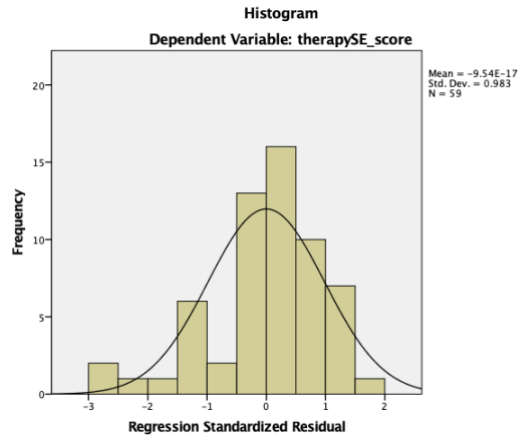


Figure 19. Aim 2 residuals distribution of therapy side effects.

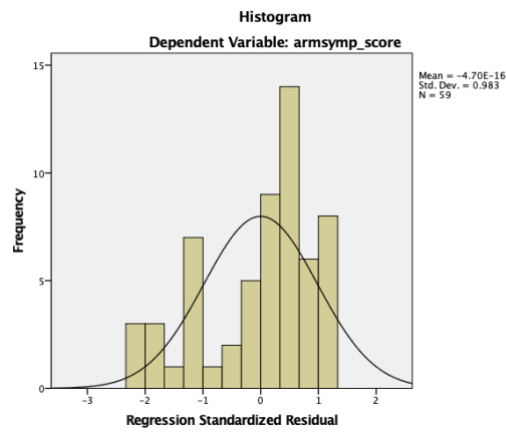


Figure 20. Aim 2 residuals distribution of arm symptoms.

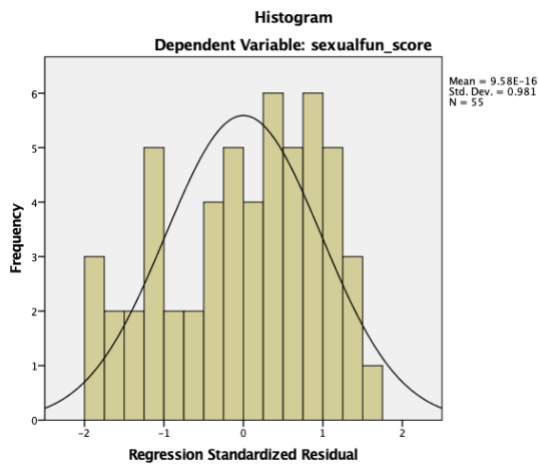


Figure 21. Aim 2 residuals distribution of sexual function.

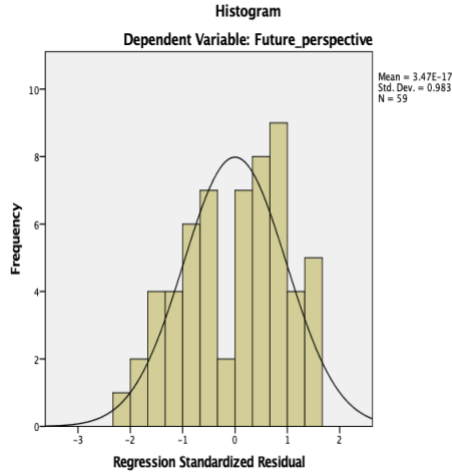


Figure 22. Aim 2 residuals distribution of future perspective.

In looking at the Variance Inflation Factor (VIF; the reciprocal of tolerance), there was no $VIF > 10$, so we were not concerned about multicollinearity in the first output for Aim 2.

Aim 3: After examining the results for Aim 3, we examined the Linear regression assumptions: linearity, normality, homoscedasticity, independence, and absence of multicollinearity. The histogram of residuals in EORTC QLQ-C30 (HRQOL-sum score) and EORTC QLQ-C323 were normally distributed (see Figures 23–29).

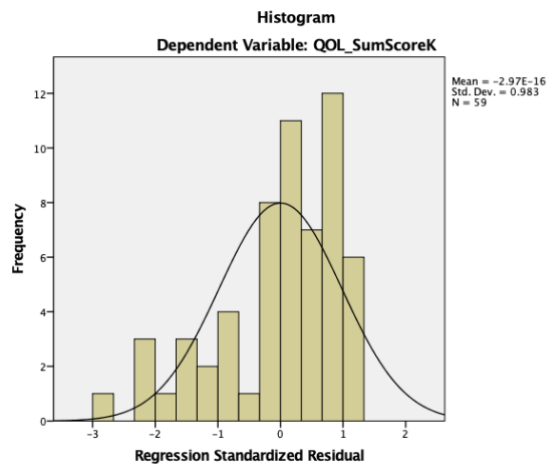


Figure 23. Aim 3 residuals distribution of HRQOL-sum score.

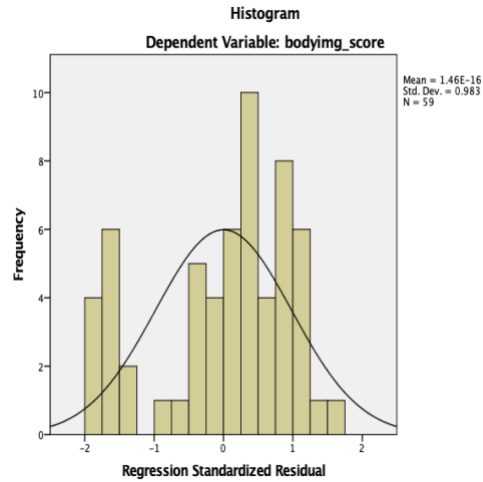


Figure 24. Aim 3 residuals distribution of body image.

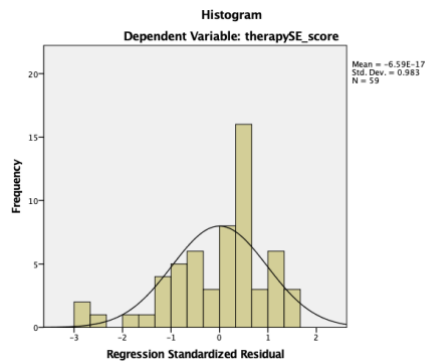


Figure 25. Aim 3 residuals distribution of therapy side effects.

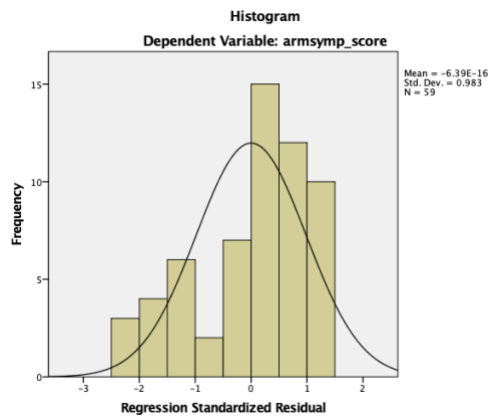


Figure 26. Aim 3 residuals distribution of arm symptoms.

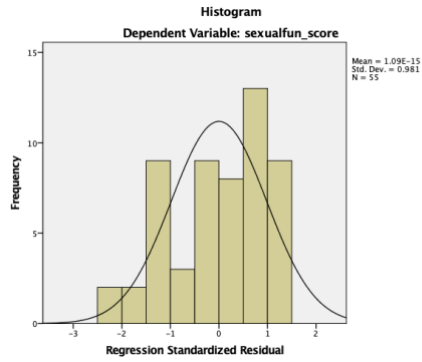


Figure 27. Aim 3 residuals distribution of sexual function.

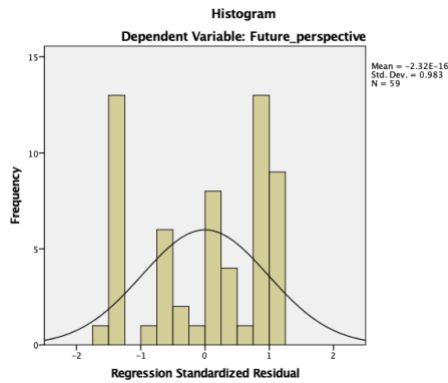


Figure 28. Aim 3 residuals distribution of future perspective.

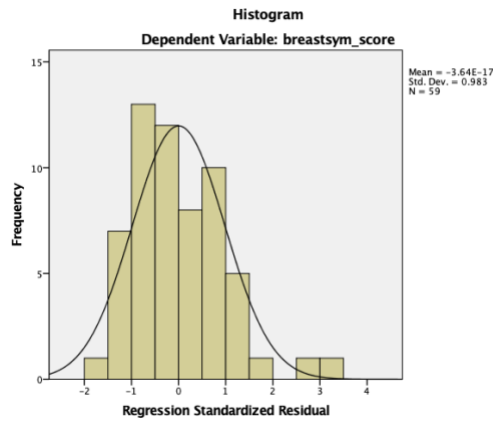


Figure 29. Aim 3 residuals distribution of breast symptoms.

In looking at the Variance Inflation Factor (VIF; the reciprocal of tolerance), there was no VIF >10, so we were not concerned about multicollinearity in the first output for Aim 3.

Aim 4: After examining the results of Aim 4, we examined the Linear regression assumptions: linearity, normality, homoscedasticity, independence, and absence of multicollinearity. The histogram of residuals in EORTC QLQ-C30 (HRQOL-sum score) and EORTC QLQ-C323 were normally distributed (see Figures 30–36).

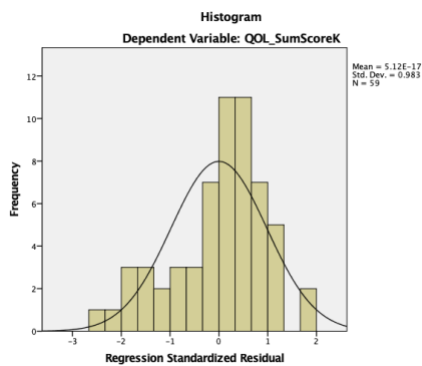


Figure 30. Aim 4 residuals distribution of HRQOL-sum score.

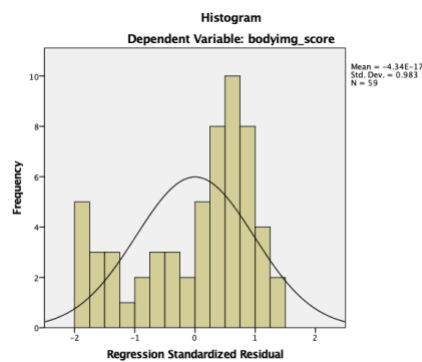


Figure 31. Aim 4 residuals distribution of body image.

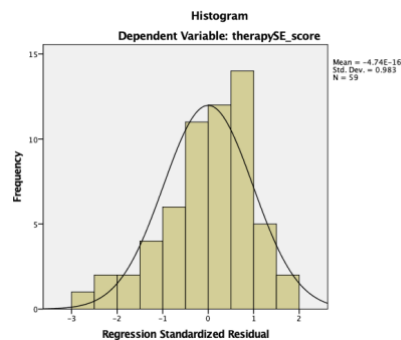


Figure 32. Aim 4 residuals distribution of therapy side effects.

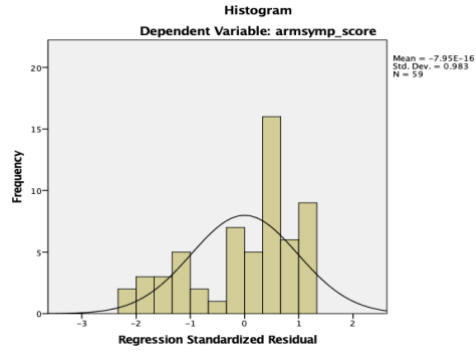


Figure 33. Aim 4 residuals distribution of arm symptoms.

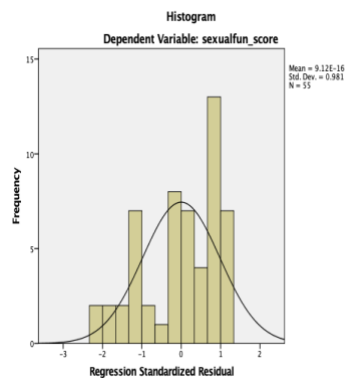


Figure 34. Aim 4 residuals distribution of sexual functioning.

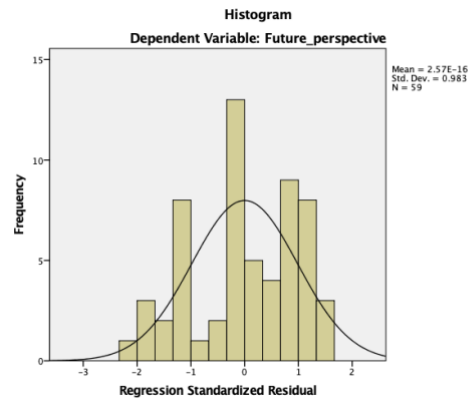


Figure 35. Aim 4 residuals distribution of future perspective.

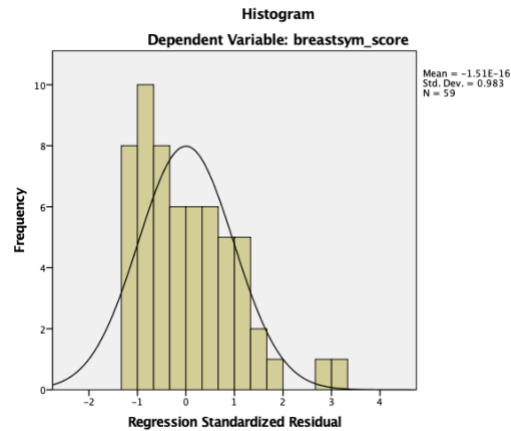


Figure 36. Aim 4 residuals distribution of breast symptoms.

In looking at the Variance Inflation Factor (VIF; the reciprocal of tolerance), there was no $VIF > 10$, so we were not concerned about multicollinearity in the first output for Aim 4.

Additional Exploratory Analysis

Online Survey Response Vs. Paper-Based Survey Response

Using an online survey has different advantages. Dayan and Ipsos (2007) believed that online surveys maintain the anonymity of the participants, especially when the survey includes sensitive topics. As we described in Chapter 2, depressive symptoms and stigma with breast cancer are highly sensitive topics in Middle Eastern cultures. There is also stigma associated with cancer and mental illness in these cultures. Therefore, some participants may have altered their responses to avoid being judged by others (Norman, Cairney, Streiner, & Streiner, 2015). In order to compare the differences between both versions of the survey, we compared the difference in means of depressive symptoms, religiosity, spirituality, and stigma scales between paper-based survey groups and the online survey group by using an independent *t*-test (see Tables section, Table 18 and Table 21).

Participants who filled out the paper-based form had significantly lower depressive symptoms ($M = 24.88$, $SD = 14.08$; $p < 0.014$); and higher religiosity scores ($M = 57.94$, $SD = 9.33$; $p < 0.00$). There was no significant difference between women in each group on levels of stigma (paper: $M = 3.98$, $SD = 0.711$; online: $M = 3.7$, $SD = 0.917$, $p < 0.238$); or women in each group on levels of spirituality (paper: $M = 40.42$, $SD = 6.78$; online: $M = 38.95$, $SD = 9.40$, $p < 0.49$).

Factors Influencing HRQOL in Breast Cancer Patients

Given the findings reported above for the proposed aims and the framework guiding this dissertation, an exploratory analysis including multiple predictors (spirituality, religiosity, social support, and stigma), controlling for age, was deemed appropriate with (HRQOL-sum score). Based on Algarni's (2014) HRQOL framework, depression can play a significant role in predicting HRQOL. On the other hand, depressive symptom and HRQOL scales were conceptually overlapped; the Pearson correlation between HRQOL-sum and depressive symptoms was $r = 0.65$, $p < 0.00$. Therefore, we examined the correlation matrix without depressive symptoms (see Tables section, Table 8).

Correlation. The relationship between HRQOL-sum score and other predictor variables was tested by using Pearson's correlation. The results indicate that stigma had a significant correlation with HRQOL-sum score, $r = 0.32$, $p < 0.05$. Spirituality and religiosity also had significant correlations with HRQOL-sum score, spirituality "SPS" $r = 0.39$, $p \leq 0.01$; religiosity "BIAC", $r = 0.26$, $p \leq 0.04$ (see Tables section, Table 9).

Conversely, social support and age did not have a significant relationship with HRQOL-sum score; social support "MSPSS", $r = 0.07$, $p \leq 0.58$; age, $r = -0.04$, $p < 0.73$

(see Tables section, Table 9). Even though age and social support were not significant, they were included in the final model because previous literatures quantify the influence of those predictors on HRQOL-sum score (Filazoglu & Griva, 2008a; Nazik et al., 2014; Pinar et al., 2012).

Regression HRQOL -sum score. With everything in the model, none of the predictors had a significant relationship with HRQOL-sum score, controlling for everything else; age ($p = 0.62$); stigma ($p = 0.15$); social support ($p = 0.84$); religiosity ($p = 0.55$); and spirituality ($p = 0.06$). Together, the set of variables accounted for 12% ($R^2 = 0.12$, $F(5,58) = 2.63$, $p < 0.03$) of the variance in sum-score of HRQOL in our model (see Tables section, Table 19).

Algarni's HRQOL Framework and Depression

According to Algarni's (2014) HRQOL framework, depressive symptoms can mediate the relationship between other predictors and HRQOL; or depressive symptoms may be treated as an outcome for other predictors (Figure 37).

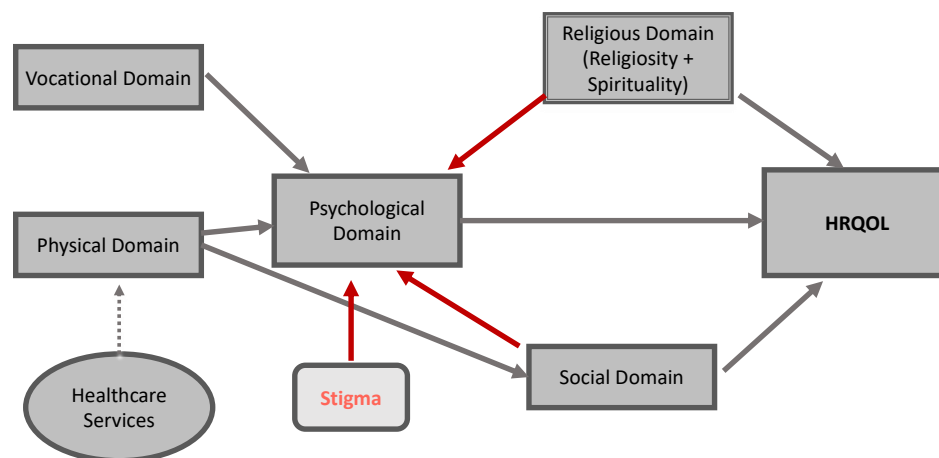


Figure 37. Algarni's Theoretical Framework.

In this exploratory model, we examined the influence of multiple predictors on predicting depressive symptom levels. Despite the emphasis on the depressive symptoms in breast cancer patients in Middle Eastern research (Dreidi et al., 2016; Shakeri et al., 2016; Yavas et al., 2012), to my knowledge, there are a lack of studies that have examined the effect of multiple factors on the depressive symptoms in breast cancer patients in Saudi Arabia. Thus, it was important to assess depressive symptoms in breast cancer patients in Saudi Arabia.

Although age and stigma were not part of Algarni's framework, these two factors play a significant role in influencing depressive symptoms. For instance, a Korean study found that cancer patients who experienced discrimination because of their illness were three times more likely to have depression compared to patients who did not ($p < 0.05$) (Cho et al., 2013).

Correlation. First, we ran a correlation matrix include the full predictors with depressive symptoms. The relationship between depressive symptoms scores and other predictor variables was tested by using Pearson's correlation. The results indicate that stigma had a significant correlation with depressive symptoms, $r = 0.30$, $p < 0.05$. Spirituality and religiosity also had significant correlations with depressive symptoms, spirituality "SPS" $r = -0.48$, $p \leq 0.01$; religiosity "BIAC", $r = -0.46^{**}$, $p \leq 0.05$ (see Tables section, Table 7).

Unlike HRQOL-sum score, social support had a significant relationship with depressive symptoms; social support "MSPSS", $r = -0.26^*$, $p = < 0.05$, but age did not, $r = 0.12$, $p \leq 0.34$ (see Tables section, Table 7). Even though age was not significant, they

were included in the final model because previous literature has quantified the influence of those predictors on depressive symptoms (Filazoglu & Griva, 2008a; Nazik et al., 2014; Pinar et al., 2012).

Regression and depressive symptoms. With everything in the model after controlling for everything else, only religiosity had a significant relationship with depressive symptoms, religiosity ($\beta = -0.26, \pm 0.11, t = -2.27, p = < 0.027$). Patients with lower levels of religiosity reported lower levels of depressive symptoms. On the other hand, the rest of the predictors were not significantly associated with depressive symptoms: age ($p = 0.31$); stigma ($p = 0.35$); social support ($p = 0.41$); and spirituality ($p = 0.052$). Together, the set of variables accounted for 27% ($R^2 = 0.27, F(5,57) = 5.41, p < 0.00$) of the variance in depressive symptoms in our model (see Tables section, Table 20).

Summary

In this chapter, we presented the analysis and results for 59 Arab female breast cancer patients in Saudi Arabia. Our findings indicate that spirituality, religiosity, and stigma influenced the HRQOL sub-scales scales significantly, but social support and age did not. Additionally, none of predictors had a significant relationship with HRQOL-sum score when running the full model. Participants who completed the online survey had higher levels of depressive symptoms compared to participants who completed the paper-based survey. Unlike depressive symptoms, there was no difference in stigma levels between participants who completed online or paper-based survey. Finally, only religiosity had a significant relationship with depressive symptoms when running the full model.

Chapter 5

Discussion

The main purpose of this study was to identify factors that affect HRQOL in Arab Female Breast Cancer Patients (AFBCPs) in Saudi Arabia. The study had four aims:

Aim 1) to identify the association between spirituality and HRQOL in AFBCPs, controlling for age; Aim 2) to identify the association between religiosity and HRQOL in AFBCPs, controlling for age; Aim 3) to identify the association between social support with HRQOL in AFBCPs, controlling for age; and Aim 4) to identify the association between stigma with HRQOL in AFBCPs, controlling for age. The hypotheses of our study were as follows: Aim 1 hypothesis: high levels of spirituality will be associated with high levels of HRQOL; Aim 2 hypothesis: high levels of religiosity will be associated with high levels of HRQOL; Aim 3 hypothesis: high levels of social support will be associated with high levels of HRQOL; and finally Aim 4-A hypothesis: stigma will be inversely correlated with HRQOL; hypothesis 4-B: high levels of stigma will be associated with low levels of HRQOL.

As guided by the adapted Health-Related Quality of Life theoretical framework (Algarni, 2014), the current study hypothesized that spirituality and religiosity acted as indicators of high levels of HRQOL. Our study also found that stigma was an important factor for predicting HRQOL in AFBCPs in Saudi Arabia. This is the first study to quantify the association between stigma and HRQOL in this population. This chapter interprets the findings of the study in the context of relevant literature, and discusses their implications, strengths and limitations, and provides insightful recommendations for future research (see Figure 3).

Major Findings

There were several important findings in this study regarding HRQOL. First, the hypothesis that high levels of religious factors including spirituality and religiosity will be associated with high levels of HRQOL was supported in this study. Religious factors were significant predictors of HRQOL-sum score and HRQOL-C23 sub-scales. Second, the third hypothesis, that high levels of social support will be associated with high levels of HRQOL was not supported. In this study, even though participants' levels of social support were moderate to high, social support did not predict high levels of HRQOL-sum score and HRQOL-C23 sub-scales. Third, the fourth hypotheses A and B, that stigma will be negatively correlated with HRQOL and that high levels of stigma will be associated with low levels of HRQOL respectively were supported. In this study, the newly developed breast cancer stigma scale was a predictor of poor sum-score and HRQOL-C23 sub-scales with Cronbach's alpha $\alpha = 0.79$. Finally, in our study, younger AFBCPs did not have lower levels of HRQOL than older AFBCPs. This indicates that developmental stage did not play a significant role in predicting HRQOL-sum score and HRQOL-C23 sub-scales.

The Role of Spirituality in Predicting HRQOL

This study used a cross-sectional design. In the study, AFBCPs had moderate levels of spirituality as measured by the FACIT-sp scale. Additionally, high levels of spirituality were associated with high HRQOL-sum scores and the HRQOL-C23 subscales body image, therapy side effects, and future perspective. Similar results were also reported by Al-Natour et al. (2017a) in Jordanian breast cancer patients; by Jafari, Farajzadegan, et al. (2013) in Iranian cancer patients; and by Lazenby and Khatib

(2012b) in Jordanian cancer patients. Al-Natour et al. (2017a) reported that breast cancer patients had moderate levels of spirituality and HRQOL, and that spirituality was positively correlated with HRQOL. In the same way, Lazenby and Khatib (2012b) found that spirituality was negatively correlated with the emotional subscale-HRQOL and that spirituality was positively correlated with the social subscale-HRQOL.

Jafari, Farajzadegan, et al. (2013) reported that spirituality was significantly associated with general HRQOL, body image, therapy side effects; breast and arm symptoms, while the current study found that spirituality was significantly associated with HRQOL-sum score and participants' perceptions of their body image. Our findings also supported those of previous qualitative studies conducted in Palestine and Bahrain that reported that spirituality assisted breast cancer patients to accept their disease (Hammoudeh, Hogan, & Giacaman, 2016a; Hammoudeh et al., 2016b; Jassim & Whitford, 2014a). The consistency of our findings with previous studies suggested that spirituality is an important protective factor for HRQOL in AFBCPs in Saudi Arabia.

In our study, there are several potential explanations for the lack of significant associations between spirituality and some of the HRQOL-C23 sub-scales, such as therapy side effects, future perspectives, arm symptoms, breast symptoms, and sexual functioning. Most of our patients were on hormonal treatment with fewer side effects compared to the patients in Jafari, Farajzadegan, et al.'s study (2013) who were on radiotherapy treatments with high rates of treatment side effects (Luutonen, Vahlberg, Eloranta, Hyvari, & Salminen, 2011). Another reason may be that 45% of participants in this study filled out the survey online in contrast to other authors who have exclusively used paper-based questionnaires in their work (Al-Natour et al., 2017a; Al-Natour, Al

Momani, & Qandil, 2017b; Lazenby & Khatib, 2012a; Lazenby & Khatib, 2012b). There is a possibility that patients may alter their responses on the paper-based compared to online surveys because they believe the former approach is less confidential (Norman et al., 2015).

The Role of Religiosity in Predicting HRQOL

Participants in our study had moderate levels of religiosity and similar to spirituality, religiosity was significantly associated with general HRQOL (sum-score) and some HRQOL-C23 sub-scales. Patients with high levels of religiosity worried less about the future, had better sexual functioning, and experienced fewer breast symptoms. Our results were consistent with Mohebbifar et al. (2015) who also examined the association between religiosity and HRQOL in Turkish cancer patients. It is interesting to note that in Mohebbifar et al.'s (2015) study, high levels of religiosity were associated with better cognitive function on the sub-domain but not the emotional functioning domain of HRQOL (Mohebbifar et al., 2015). Moreover, our results regarding participants' struggle with stigma and how religiosity improved their HRQOL supported the findings of a qualitative study conducted in Bahrain by Jassim and Whitford (2014a) which explored Bahraini women's the lived experience with breast cancer. Jassim and Whitford found that participants complained about peoples' reaction to their diagnosis. They also found reading the Quran and praying helped participants to overcome the stigma of the disease. Taken together, these findings suggested that religiosity is another important protective factor for improving the well-being of cancer patients. While it might be challenging to increase AFBCPs' levels of religiosity, we need to identify patients with low levels of religiosity because they may have greater risk for negative outcomes; these patients will

need more assistance. There are a few explanations for why enhancing the religiosity levels may be challenging. Levels of adherence to religious practices may vary in Arabic Muslim countries (Lazenby & Khatib, 2012b). Additionally, participants may have changed their answers about their religiosity levels because they were afraid of being judged if they stated that they were not adherent to the religious practices (Norman et al., 2015). Our findings supported this statement because participants who used the online survey scored lower on the religiosity scale than participants who used the paper-based survey. There is less evidence about how to modify religious values, but this is a promising avenue for future studies.

Spirituality and Religiosity

Western societies have studied spirituality and religiosity as separate concepts (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002b; Stearns et al., 2018). As a result of this conceptualization, researchers have created most well-known spirituality and religiosity scales separately (e.g., The Beliefs into Action: religiosity scale [BIAC]; (Koenig, Wang, Al Zaben, & Adi, 2015)) and the Functional Assessment of Chronic Illness-therapy Spiritual Well-beings (FACIT-sp; (Cella et al., 1993). On the other hand, in Islam, spirituality and religiosity are integrated concepts and should not be separated (Nasr, 1987). The Islamic definition suggests that these two concepts should be treated equally. Unfortunately, there is a lack of multidimensional scales that measure spirituality and religiosity based on an Islamic worldview. As a consequence, we assessed them separately in our study, with the expectation that spirituality and religiosity would have similar influences on HRQOL-sum score of HRQOL-c23 subscales. There was a

moderate correlation between FACIT-sp and BIAC scales as described in Chapter 4. Despite our small sample size, this expectation was confirmed by our results.

Of note, participants' moderate levels of religiosity were consistent with those reported (Alakhdhair et al., 2016) on the BIAC, the original Arabic religiosity scale used in Saudi Arabia. On the other hand, the Cronbach's alpha reported by Alakhdhair et al. (2016) was $\alpha = 0.80$, which was different from the Cronbach's alpha in our results ($\alpha = 0.67$). The difference in reliability scores may be because of gender differences in the samples. Whereas our study had 100% female patients, Alakhdhair et al. (2016) was 54% male. Additionally, the BIAC scale contains items asking about religious practice in the Masjid or Mosque. This item reflects a male gender bias since women are not required to attend Friday prayer at the masjid as men are. Our findings highlight the need for researchers to develop a multidimensional scale that integrates spirituality and religiosity grounded in the Islamic worldview.

The Role of Social Support in Predicting HRQOL

Participants in our study had higher levels of social support than the cancer patients described by Nazik et al. (2014) and by Filazoglu and Griva (2008b) in Turkey. These two studies found that social support was significantly associated with HRQOL. The findings of Turkish studies are consistent with those reported by the Middle Eastern qualitative researchers, namely that having supportive family members helps people to cope with the crisis of cancer (Hammoudeh et al., 2016b; Jassim & Whitford, 2014b). Interestingly, even though our study had high levels of social support, we did not find a significant association between social support and the HRQOL-sum score or HRQOL-c23 sub-scales scores. Our results are consistent with those reported by Ahmed,

Almuzaini, et al. (2017) who examined the role of social support on HRQOL in cancer patients in Saudi Arabia. They found that social support did not have a significant association with HRQOL in cancer patients. It should also be noted that our non-significant results may have been because of an insufficient sample size to detect an association between social support and HRQOL. Additionally, as noted above, there is a possibility that participants responses differ on paper-based versus online surveys (Norman et al., 2015).

Finally, it was hard to completely tease out the difference between “family” and “special person” in the MSPSS scale. In our study, AFBPCPs defined the “special person” mostly as husband or children and defined “family” also as husband and children. The lack of ability to distinguish between these two concepts may affect our findings. Despite the emphasis on social support assisting breast cancer patients found in the literature, it was not as important as spirituality or religiosity in influencing HRQOL in our sample.

Breast Cancer Stigma Scale for Arab-Patient Version

Creating a breast cancer stigma scale culturally appropriate for an Arab population was pivotal to our study. Most stigma scales were created for use either in Western or Asian cultures (Norman et al., 2015; Wong, Rindfleisch, & Burroughs, 2003). For instance, Mak and Cheung (2010) created a self-stigma scale (SSS) with a good reliability score, but this SSS did not cover patient or family-member shaming by others, which is significant in Arab Middle Eastern cultures. Jassim and Whitford (2014b) demonstrated this in their study of Bahraini breast cancer patients, who were fearful that public knowledge of their disease would result in dishonoring of family names and

negatively affect their daughters' marriage prospects. Given this cultural context, it was crucial to create a breast cancer stigma scale that was sensitive to the Middle Eastern culture for this study. We named this scale the Breast Cancer Stigma Scale — Arab-Patient version.

The Breast Cancer Stigma Scale — Arab-Patient version created for this study had an acceptable reliability with a Cronbach's alpha of 0.79 (DeVellis, 1991). Based on the inter-item correlation matrix the reliability would have increased, however, to 0.88 by eliminating the item "I asked people closest to me to keep my breast cancer a secret." Nevertheless, we decided to keep this item because 35% of our participants responded to it with "agree or strongly agree." The Breast Cancer Stigma Scale — Arab-Patient version had a significant negative correlation with depressive symptoms. This result was consistent with a study by Cho et al. (2013), which aimed to examine the association between cancer stigma and depression in Korean cancer survivors. The cancer stigma scale in the Korean study had three sub-scales: impossibility of recovery, stereotypes of cancer patients, and experience of social discrimination. According to Cho et al. (2013), stigmatized cancer patients were 2–3 times more likely to develop depression compared to non-stigmatized patients. On the other hand, our scale was not significantly correlated with social support as we expected. The lack of significance could be because patients were stigmatized by others and not by their family members. Although our sample size was small, our results yielded important findings that should be retested with a larger sample size in the future to further explore this phenomenon.

The Role of Stigma in Predicting HRQOL

Participants in this study had moderate levels of stigma and this variable was significantly associated with the HRQOL-sum score and some HRQOL-C23 sub-scales, such as body image, tolerance to therapy side effects, and future perspective. For instance, patients who had low levels of stigma had better perceptions of their body image, better tolerance of therapy side effects; and were less worried about the future. Similar results were reported by Wong et al. (2019) who examined HRQOL in Chinese American breast cancer survivors and found that stigma was negatively correlated with HRQOL.

Non-significant results for the association between stigma and the rest of HRQOL-C23 sub-scales, including body image, tolerance to therapy side effects, and future perspective may be due to the small sample size of this study. Also, talking about sexuality in Middle Eastern culture is not commonly acceptable and the participants may have been reluctant to answer these questions. Overall, our results highlighted the importance of stigma for breast cancer patients, which has heretofore been ignored by quantitative Arab Middle Eastern researchers. Future research is needed to address breast cancer stigma in Arab cancer patients and explore the ways in which this problem can be addressed in a culturally competent manner.

The Role of Age in Predicting HRQOL

According to Neugarten (1996), humans' needs may change based on developmental stage or because of the social expectations. For instance, young adults are expected to be healthy, have a job, and/or be in a stable intimate relationship. Western research has suggested that when people become sick at a young age, they are at higher

risk for poor outcomes relative to older adults. This finding may be because of a higher likelihood that young people expect to be healthy (Berg & Upchurch, 2007a). Those statements were supported by Jassim and Whitford (2013c), who examined the associated factors that affect the quality of life in Bahraini women with breast cancer. They found that patients younger than age 50 had higher levels of pain, worse sexual functioning, worse breast pain symptoms, and they worried more about the future compared to patients older than age 50. In contrast, research in Saudi Arabia by Ahmed, Alharbi, et al. (2017a) did not find this pattern in younger patients. According to Ahmed, Alharbi, et al. (2017a), women with breast cancer over age 65 reported worse physical functioning on the HRQOL sub-scale compared to patients younger than 65. Ahmed et al.'s finding may be because of higher rates of co-morbid illness found among older adults relative to younger persons. Additionally, older patients in Ahmed, Alharbi, et al. (2017a) may not have reported poor HRQOL in the remaining domains because younger generations are generally expected to care for older generations in Arab and Muslim cultures (Yount & Rashad, 2008).

Despite our a priori expectations to the contrary, we did not find a significant association between age on HRQOL-sum score or HRQOL-C23 sub-scale scores. Similar results were reported by Mohebbifar et al. (2015) when examining the association between spirituality and HRQOL in Iranian cancer patients; and by Filazoglu and Griva (2008b) when assessing the association between social support and HRQOL in Turkish breast cancer patients; neither study found significant differences by age. Having contradictory results in prior Middle Eastern studies and this study points to the need for future research in this area with larger samples of Arab Muslim breast cancer patients.

There are potential explanations for lack of the influence of age on HRQOL in our study. First, the mean age group in our sample was restricted, with a small standard deviation of $M = 49$, $SD = 8.31$. This lack of variability in the onset of the disease, combined with our small sample size, did not allow sufficient investigation of age as a variable.

Depressive Symptoms in Arab Female Breast Cancer Patients

In the exploratory additional analysis, we examined the correlation and association between depressive symptoms with other predictors. In our study, stigma levels were negatively correlated with depressive symptoms (a high score on stigma scale indicates low levels of stigma), which indicates that high levels of stigma were correlated with high levels of depressive symptoms. Our findings were supported by Cho et al. (2013), who examined the association between stigma and depression in cancer survivors and by Korea and by Ostroff et al. (2019), who examined the association between stigma with lung cancer and depression in the United States. Patients in the Korean study who had high levels of stigma were 2–3 times more likely to have depression compared to non-stigmatized patients. In the United States, the depressive symptoms in lung cancer patients were positively correlated with stigma subscales, such as internalized stigma, perceived stigma, and constrained disclosure.

Regarding religious factors, we found a significant negative correlation between spirituality and depressive symptoms, and between religiosity and depressive symptoms. These findings were supported by Shaheen Al Ahwal, Al Zaben, Sehlo, Khalifa, and Koenig (2015) who examined the association between religiosity and depression in colon cancer patients in Saudi Arabia; patients with high levels of religiosity were less likely to

have depressive symptoms (Shaheen Al Ahwal, Al Zaben, Sehlo, et al., 2015). Although research examining the association between spirituality and depression in cancer patients in Saudi Arabia is lacking, our findings were consistent with those reported previously by investigators who qualitatively examined the influence of spirituality on mental health in cancer patients in Jordan and Palestine. For instance, a study by Hammoudeh et al. (2016b) in Palestine reported that faith helped diminish the feeling of “becoming a burden” in women with breast cancer, while Alaloul et al. (2016) found that faith assisted Jordanian cancer patients to tolerate overwhelming treatments and find comfort.

Additionally, our study found a significant correlation between social support and depression. Similar results have been found in other Middle Eastern studies. Shaheen Al Ahwal et al. (2014) reported that social support acted as a protective factor against depressive disorders and depressive symptoms in colon cancer patients in Saudi Arabia, while Hammoudeh et al. (2016b) found that the availability of social support assisted breast cancer patients emotionally. On the other hand, breast cancer patients felt that they were a heavy burden when they lacked a social support system. Finally, age was not a predictor of depressive symptoms in the current study. This is consistent with findings reported by Shaheen Al Ahwal et al. (2014) who studied the prevalence of depressive symptoms in colon cancer patients in Saudi Arabia. Interestingly, in the current study, when running the full model that included the aforementioned predictors, only religiosity remained a significant predictor of depression in our study. Potential explanations for non-significant results in this study include the small sample size and restricted range of participants' ages. Second, previous research has documented that Saudi nationality is a risk factor for depressive symptoms compared to non-nationals residing in Saudi Arabia

(Shaheen Al Ahwal et al., 2014). Most of the patients in our study, however, were not Saudi nationals. A possible explanation for higher rates of depression levels in Saudis compared to non-Saudis is that Saudi nationals suffer from lack of community awareness about women's health rights, which in turn may impede help-seeking. Moreover, the majority of educated Saudi people still believe that Saudi women require a male guardian's approval to receive medical treatment, which is likely also a barrier to women seeking help. As an example, a recent cross-sectional study of Saudi Arabia medical students found 42.3% of the students believed women cannot seek medical or surgical treatment without male approval (Al-Amoudi et al., 2017). Lack of awareness about women's right to treatment in Saudi Arabia has resulted in unnecessary deaths. For example, some Saudi women presenting with uterine rupture have died because the medical team waited for spousal approval before operating (Al-Amoudi et al., 2017). Another reason for having higher rates of depression in Saudi nationals, especially among women, is the stigma associated with depression and mental illness generally. For this reason, people tend to hide their mental illness from others and suffer alone (Al-Darmaki et al., 2015; Hassouneh, 2009). All of these social influences combined likely have a negative impact on Saudi nationals' mental health. Public education about individual health rights and the right to treatment in Saudi Arabia is needed.

Finally, another possible explanation for the high levels of depression found in the current study could be because there was an option to complete the survey online. Participants who used the online version survey reported higher levels of depressive symptoms than those who used the paper-based survey. As previously noted, some patients may have altered their answers on the paper-based survey because they were

afraid of being judged, especially when answering sensitive questions about stigma and depression.

Implications

Implications for Theory

Our data fitted the adapted Algarni (2014) HRQOL framework we used to study the predictors of HRQOL in breast cancer patients in Saudi Arabia. The framework was comprehensive and allowed us to include multiple factors affecting HRQOL in our population. However, stigma associated with breast cancer resonated significantly with the nature of the disease in the context of Arab cultures and had to be added. Based on our findings, the predictors could be classified as level one (very important) and level two (less important). Regarding HRQOL as an outcome, religious factors (spirituality and religiosity) and stigma should be classified as a level one, while social support and age should be classified as level two. Future research should re-examine the influence of level two factors when developing a future theoretical framework. On the other hand, when examining depression as an outcome, religious factors (spirituality and religiosity), social support, and stigma should be classified as a level one, but age should be classified as level two. As we described in Chapter 4, there was a significant correlation between depressive symptoms and HRQOL-sum score. However, it was challenging to tease out if the reason for this significant result because of the theoretical overlap between the previous concepts and/or significant correlations. Thus, future studies should avoid using theoretically overlapping concepts between independent variables and dependent variables. Finally, these findings should be further examined in future studies with larger and more diverse samples. Due consideration should be given for use of the adapted

Algarni HRQOL framework to guide future cross-sectional studies. Given its limited application to date, the extent to which the adapted framework may also be appropriate for longitudinal designs is unclear.

Directions for Future Research

Breast cancer has been the focus of research in many Middle Eastern countries; but to our knowledge, no prior studies have used a theoretical framework to guide their research questions. Several questions for future research can be gleaned from our findings. First, there is a need to further develop a Middle Eastern breast cancer HRQOL theory using grounded theory designs, which is mostly used to establish a theoretical framework. Another recommendation for future research is to further develop and test the stigma scale created for this study and then, using this scale, conduct studies of stigma in Arab breast cancer patients. Further exploration of the conceptualization and experience of stigma in Arab breast cancer patients using mixed method and qualitative designs is needed. Identifying common perpetrators of stigma is another line of inquiry that could extend the current findings and provide a basis for risk assessment and intervention in the future.

Another concern noted in this study is the absence of a gender appropriate religiosity measure for use with Muslim women. Hence, future work should develop a religiosity scale that is appropriate for both men and women and rooted in an Islamic worldview. Another area of concern is the lack of culturally valid assessments for depressive symptoms in Arab populations. Cox (1982) and Kleinman, Good, Kleinman, and Good (1985) argued that people from different cultures may express depressive symptoms as somatic complaints, such as back pain or headache. Even though patients in

our study had high levels of depressive symptoms, future work exploring depressive symptom expression in Arab breast cancer patients is needed to provide information about the cultural relevance of commonly used measures of depression in this population. Rurality and socioeconomic status should also be considered in future investigations of depression in Arab breast cancer patients. Reid-Arndt and Cox's (2010) study of breast cancer patients found rural patients had poorer HRQOL compared to urban patients. Other studies have documented poorer HRQOL outcomes in patients of low socioeconomic status (Jassim & Whitford, 2013c; Shaheen Al Ahwal et al., 2014). The current study was conducted in Jeddah, one of the largest urban metropolitan cities in Saudi Arabia (Oxford Business Group, 2019). Hence, the sample lacked geographical diversity. Additionally, most participants were from high socioeconomic status backgrounds. Therefore, future research is needed to explore predictors of HRQOL in geographically and socioeconomically diverse samples. In our study, we found that participants reported higher levels of depressive symptoms on the online survey compared to the paper-based survey. Thus, future use of an online survey is suggested to improve disclosure. Additionally, future studies that involve caregivers are highly recommended to help capture the impact of breast cancer stigma on caregivers' depressive symptoms and HRQOL. A dyadic study found that caregivers of lung cancer patients developed high levels of depression (Lyons et al., 2014). Finally, further investigation to tease out the strength of the relationships between multiple predictors and HRQOL or depressive symptoms as outcomes is needed. This suggested future research is essential to building the knowledge base needed to better understand predictors of HRQOL and mental health in Arab breast cancer patients.

Clinical Implication

The current study found that even though HRQOL and depression levels were affected by multiple factors, spirituality, religiosity, and stigma were most influential. That is, some breast cancer patients reported low levels of HRQOL when they had low levels of spirituality, religiosity, and high levels of stigma. However, the source of stigma was not clear in our study. For instance, it was not clear if patients were being stigmatized by family members, friends, or by others. Our findings point to depression and stigma as important factors that alter the well-being of AFBCPs. Therefore, clinicians should assess for stigma and identify its source when working with Arab breast cancer patients. Identifying patients with higher depressive symptoms and lower levels of HRQOL may provide opportunities for anticipatory guidance and early intervention.

Our findings suggest identifying the factors affecting HRQOL and depressive symptoms in Arab breast cancer patients should be a priority for individual clinicians as well as the healthcare system at large. Along these lines, the Saudi Arabian Ministry of Health recently began a campaign to educate the community about breast cancer and the importance of early detection of breast cancer (Ministry of Health Saudi Arabia, 2019). However, to date, this campaign has failed to address the psychosocial aspects of breast cancer or the problem of social stigma experienced by breast cancer patients.

Previous Middle Eastern research has demonstrated important associations between factors affecting HRQOL and depression in breast cancer patients (Hammoudeh et al., 2016a; Hammoudeh et al., 2016b; Jassim & Whitford, 2014b; Shaheen Al Ahwal, Al Zaben, Khalifa, et al., 2015). A lack of preparedness, especially for dealing with stigma, may lead to negative outcomes in breast cancer patients. It was noted that

spirituality, religiosity, and stigma were more likely to alter the HRQOL and depression levels of our participants, unlike social support; however, having a small sample size limited our analysis. Additionally, as mentioned above, the source of stigma was not clear. A comprehensive assessment should be made when conducting appropriate interventions in the future.

Strengths and Limitations

Strengths

Our study had several strengths. First, this study was the first to be guided by a theoretical framework of HRQOL with breast cancer patients in the Middle East, unlike previous Middle Eastern cancer research, which has not been guided by a theoretical framework to help form their research question (Ahmed, Alharbi, et al., 2017a; Jassim & Whitford, 2013a; Shaheen Al Ahwal, Al Zaben, Khalifa, et al., 2015). Second, this study examined the influence of multiple factors affecting HRQOL or depressive symptoms in breast cancer patients. The majority of previous research in the Middle East has examined a single factor aside from demographics (Ahmed, Alharbi, et al., 2017a; Al Ahwal et al., 2018a; Al Ahwal et al., 2018b). Third, this study began development of a measure of stigma levels in Middle Eastern breast cancer patients. Most previous research in non-Arab cultures have used other cancer stigma measures that did not contain the important concept of stigma in Middle Eastern cultures, particularly family stigma (Cho et al., 2013; King et al., 2007). Fourth, this study established precedent for measuring stigma levels in Middle Eastern breast cancer patients. Previous studies of stigma in the Middle East have been limited to qualitative designs (Hammoudeh et al., 2016a; Jassim & Whitford, 2014b). Moreover, prior to this work, virtually no information was available

about the role of stigma in predicting HRQOL or depression in Arab breast cancer patients. The results of this study also helped identify the factors that may affect HRQOL or depression broadly, contributing to the knowledge base in these focal areas. Finally, this study used two forms of the survey, online and paper based. Although using different survey forms made it difficult for us to completely tease out the difference between patients' responses, it still provided participants with the autonomy to choose the version that might interest them.

Limitations

Even though this study had several strengths, it had some limitations that need to be addressed. Our study used a cross-sectional design; thus, it was not possible to identify the causal relationships between variables. Next, this study used the HRQOL-C23 breast cancer measure, which contains some single-items to assess the "sexual function" construct. According to Sarstedt and Wilczynski (2009), using a single-item tool is advantageous because it is practical, flexible, and increases the response rate because it is easy to fill out. However, it also has some disadvantages, including lower construct validity, difficulty replacing missed values, and lower reliability compared to a multi-items tools (Sarstedt & Wilczynski, 2009). Using multi-items tool to assess sexuality in breast cancer patients is thus recommended for the future work to better understand the broader dimensions of this phenomenon. Furthermore, the majority of the patients in this study were on hormonal treatments. Our study did not have a large number of younger women going through chemotherapy. Hence, generalizing the findings to patients undergoing other types of treatments, such as chemotherapy or radiotherapy is limited. Patients undergoing other types of treatments may have responded differently to the

survey. Further, the breast cancer patients in this study were not representative of the general population of AFBCPs because this study does not reflect the varying demography of Saudi society. For instance, patients were mostly married; thus, single patients may have demonstrated different outcomes. Additionally, our study did not have a large number of low-income participants because of the recruitment site, which limited generalizing our findings to low-income participants. The majority of our participants were non-Saudi nationals, which may restrict generalizing our findings to Saudi breast cancer patients.

One of the limitations of our study was having mixed-worded items in the spirituality scale. Wong et al. (2003) found that using negative-worded items in a scale was a confounder that altered the validity of the measure in cross-cultural populations. Finally, conceptual meanings may vary between Eastern and Western cultures because of translation errors, response biases, or cultural differences. Therefore, future researchers should establish a spirituality measure that is culturally appropriate and minimize the usage of negative-worded items. Despite the limitations of this study, our findings provide the first important step toward advancing the knowledge about AFBCPs.

Summary

This study targeted Arab female breast cancer patients in Saudi Arabia and identified the possible indicators of HRQOL guided by an adapted Algarni (2014) HRQOL framework. The study found that spirituality, religiosity, and stigma levels were the major contributors that affected participants' HRQOL and depressive symptoms. Social support and age did not play a significant role in influencing the outcomes of this study. Most Middle Eastern research on breast cancer has examined stigma using

qualitative designs. This study began to fill that gap by examining stigma using a psychometric measure adapted to the culture of the targeted population. Despite the limitations of this study, it has expanded our knowledge and shed light on important information related to breast cancer patients' HRQOL and depressive symptoms in Saudi Arabia. Examining the relationship between stigma, spirituality, and religiosity and their outcomes has provided a foundation for future research on this topic in the Middle East.

Tables

Table 6

Results of t-test of Complete Case Analysis of Sexual Function and Age

	<i>M</i>	<i>SD</i>	<i>N</i>	<i>P</i>	<i>CI</i>	<i>t</i>	<i>df</i>
Missed Data	49.50	7.23	4	0.90	[-8.15–9.22]	0.12	57
Not Missed Data	48.96	8.44	55	0.89	[-10.44–11.51]	0.14	3.62

Note. Independent *t*-test. *CI* = confidence interval. *Df* = degree of freedom. *N* = sample size.

Table 7

Depressive Symptoms Correlation Matrix with Predictors

Measures	1	2	3	4	5	6
1-Stigma	-					
2-MSPSS	0.09	-				
3-BIAC	0.30*	0.16	-			
4-SPS	0.40**	0.23	0.42**	-		
5-Age	0.20	-0.01	-0.01	-0.08	-	
6-Depressive Symptoms	-0.30*	-0.26*	-0.46**	-0.48**	0.12	-

Note. * $p < 0.05$ (2-tailed). ** $p < 0.01$ (2-tailed). $N = 58$.

Table 8

QOL Sum Score Correlation Matrix with All Predictors Including Depressive Symptoms

Measures	1	2	3	4	5	6	7
1-Stigma	-						
2-MSPSS	0.09	-					
3-BIAC	0.30*	0.16	-				
4-SPS	0.40**	0.23	0.42**	-			
5-Age	0.20	-0.01	-0.01	-0.08	-		
6-CES-D	-0.30*	-0.26*	0.46**	-.48**	0.12	-	
7-QOL- Sum score	0.32*	0.07	0.26*	0.39**	-0.04	-0.64**	-

Note. * $p < 0.05$ (2-tailed). ** $p < 0.01$ (2-tailed). $N = 58$.

Table 9

QOL Sum Score Correlation Matrix with Predictors

Measures	1	2	3	4	5	6
1-Stigma	-					
2-MSPSS	0.09	-				
3-BIAC	0.30*	0.16	-			
4-SPS	0.40**	0.23	0.42**	-		
5-Age	0.20	-0.01	-0.01	-0.08	-	
6-QOL- Sum score	0.32*	0.07	0.26*	0.39**	-0.04	-

Note. * $p < 0.05$ (2-tailed). ** $p < 0.01$ (2-tailed). $N = 58$.

Table 10

Predictors of HRQOL-sum Score QOL-c30

Variables	B	β	95% CI
(Constant)	36.61		[-0.31–73.53]
Spirituality	0.913*	0.394**	[0.341–1.48]
Age	-0.029	-0.013	[-0.58–0.52]

Note. Regression table. $N = 59$. CI = Confidence Interval. $p < 0.05$.

** $p < 0.01$. B = unstandardized coefficient. β = standardized coefficient.

Table 11

Predictors of HRQOLC-23 Subscales

Variables	Body image (N = 59)		
	B	β	95% CI
(Constant)	-2.47		[-71.50–66.56]
Spirituality	1.80*	0.53**	[0.73–2.87]
Age	-0.15	-0.03	[-1.18–0.88]
Therapy side effects (N = 59)			
	B	β	95% CI
(Constant)	49.18		[0.88–97.48]
Spirituality	0.80	0.37	[0.05–1.54]
Age	-0.25	-0.9	[-0.97–0.46]
Future perspective (N = 59)			
	B	β	95% CI
(Constant)	176.53		[99.29–253.76]
Spirituality	-2.30	-0.45	[-3.50–(-1.11)]
Age	-0.53	-0.11	[-1.68–0.61]
Arm symptoms (N = 59)			
	B	β	95% CI
(Constant)	43.02		[-23.96–110.02]
Spirituality	0.50	0.13	[-0.53–1.54]
Age	0.07	0.01	[-0.92–1.07]
Sexual function (N = 55)			
	B	β	95% CI
(Constant)	31.54		[-37.48–89.11]
Spirituality	0.50	0.98	[-0.51–1.50]
Age	0.47	0.14	[0.28–(-0.43)]
Breast symptoms (N = 59)			
	B	β	95% CI
(Constant)	65.22		[13.81–116.63]
Spirituality	-0.60	-0.20	[-1.40–0.18]
Age	-0.26	-0.09	[-1.03–0.50]

Note. Regression table. N = 59. CI = Confidence Interval. $p < 0.05$. ** $p < 0.01$. B = unstandardized coefficient. β = standardized coefficient.

Table 12

Predictors of HRQOL-sum Score QOL-c30

Variables	B	β	95% CI
(Constant)	57.42		[23.17–91.66]
Religiosity	0.36*	0.26	[0.00–0.71]
Age	-0.08	0.28	[-0.66–0.48]

Note. Regression table. $N = 59$. CI = Confidence Interval. $p < 0.05$.

** $p < 0.01$. B = unstandardized coefficient. β = standardized coefficient.

Table 13

Predictors of HRQOLC-23 Subscales

Variables	Body image (N = 59)		
	B	β	95% CI
(Constant)	44.71		[-20.42–109.85]
Religiosity	0.59	0.34	[-0.08–1.27]
Age	-0.27	0.34	[-1.37–0.82]
Therapy side effects (N = 59)			
	B	β	95% CI
(Constant)	66.09		[22.59–109.60]
Religiosity	0.34	0.37	[-0.11–0.79]
Age	-0.30	0.36	[-1.03–0.42]
Future perspective (N = 59)			
	B	β	95% CI
(Constant)	142.08		[72.39–211.76]
Religiosity	-1.25	0.36	[-1.98–(-0.52)]
Age	-0.39	0.58	[-1.56–0.78]
Arm symptoms (N = 59)			
	B	β	95% CI
(Constant)	44.99		[-13.87–103.85]
Religiosity	0.38	0.30	[-0.23–0.99]
Age	0.04	0.49	[-0.94–1.03]
Sexual function (N = 55)			
	B	β	95% CI
(Constant)	17.19		[-37.16–71.56]
Religiosity	0.56*	0.28	[0.00–1.12]
Age	0.51	0.14	[-0.40–1.42]
Breast symptoms (N = 59)			
	B	β	95% CI
(Constant)	64.18		[19.53–108.83]
Religiosity	-0.48*	-0.26	[-0.95–(-0.01)]
Age	-0.23	-0.07	[-0.98–0.52]

Note. Regression table. N = 59. CI = Confidence Interval. $p < 0.05$. ** $p < 0.01$. B = unstandardized coefficient. β = standardized coefficient.

Table 14

Predictors of HRQOL-sum Score QOL-c30

Variables	B	β	95% CI
(Constant)	69.28		[29.86–108.70]
Social support	1.11	2.07	[-3.04–5.27]
Age	-0.09	0.29	[-0.69–0.49]

Note. $N = 59$. CI = Confidence Interval. $p < 0.05$. $**p < 0.01$. B = unstandardized coefficient. β = standardized coefficient.

Table 15

Predictors of HRQOLC-23 Subscales

Variables	Body image (<i>N</i> = 59)		
	B	β	95% CI
(Constant)	49.99		[-23.80–123.80]
Social Support	4.13	0.14	[-3.64–11.92]
Age	-0.28	0.55	[-1.39–0.83]
Therapy side effects (<i>N</i> = 59)			
	B	β	95% CI
(Constant)	76.51		[27.15–125.87]
Social Support	1.19	0.06	[-4.01–6.39]
Age	-0.31	-0.11	[-1.05–0.43]
Future perspective (<i>N</i> = 59)			
	B	β	95% CI
(Constant)	99.33		[14.29–184.37]
Social Support	-3.68	-0.10	[-12.65–5.28]
Age	-0.36	-0.07	[-1.65–0.919]
Arm symptoms (<i>N</i> = 59)			
	B	β	95% CI
(Constant)	49.68		[-16.52–115.88]
Social Support	2.45	0.09	[-4.52–9.43]
Age	0.03	0.01	[-0.96–1.04]
Sexual function (<i>N</i> = 55)			
	B	β	95% CI
(Constant)	31.58		[-32.39–95.56]
Social Support	2.65	0.09	[-4.91–10.22]
Age	0.46	0.13	[-0.49–1.41]
Breast symptoms (<i>N</i> = 59)			
	B	β	95% CI
(Constant)	56.01		[4.84–107.18]
Social Support	-0.22	-0.13	[-8.14–2.64]
Age	-2.75	-0.07	[-0.99–0.54]

Note. Regression table. *N* = 59. CI = Confidence Interval. *p* < 0.05.

***p* < 0.01. B = unstandardized coefficient. β = standardized coefficient.

Table 16

Predictors of HRQOL-sum Score QOL-c30

Variables	B	β	95% CI
(Constant)	53.01		[20.42–85.60]
Age	-0.26	-0.11	[-0.83–0.31]
Stigma	8.04	0.35**	[2.19–13.88]

Note. Regression table. $N = 59$. CI = Confidence Interval. $p < 0.05$.

** $p < 0.01$. B = unstandardized coefficient. β = standardized coefficient.

Table 17

Predictors of HRQOLC-23 Subscales

Variables	Body image (N = 55)		
	B	β	95% CI
(Constant)	35.12		[-26.91–97.17]
Age	-0.57	-0.13	[-1.66–0.52]
Stigma	14.09	0.32*	[2.96–52.22]
	Therapy side effects (N = 59)		
	B	β	95% CI
(Constant)	57.23		[16.02–98.44]
Age	-0.49	-0.17	[-1.22–0.22]
Stigma	9.25	0.32*	[1.85–16.64]
	Future perspective (N = 59)		
	B	β	95% CI
(Constant)	127.79		[57.46–198.12]
Age	-0.01	-0.00	[-1.23–1.23]
Stigma	-17.81	-0.36**	[-30.42– -5.20]
	Arm Symptoms (N = 59)		
	B	β	95% CI
(Constant)	42.48		[-14.78–99.76]
Age	-0.12	-0.03	[-1.12–0.88]
Stigma	7.79	0.20	[-2.47–18.07]
	Sexual function (N = 55)		
	B	β	95% CI
(Constant)	55.57		[0.85–110.29]
Age	0.55	0.16	[-0.41–1.53]
Stigma	-3.19	-0.09	[-13.22–6.83]
	Breast symptoms (N=59)		
	B	β	95% CI
(Constant)	55.47		[10.91–100.04]
Age	-0.10	-0.03	[-0.88–0.68]
Stigma	-5.76	-0.19	[-13.75–2.22]

Note. Regression table. N = 59. CI = Confidence Interval. $p < 0.05$. ** $p < 0.01$. B = unstandardized coefficient. β = standardized coefficient.

Table 18

Results of t-test and Descriptive Statistics for Depressive Symptoms and Stigma by Survey Type

	Survey type						95% CI for mean difference	<i>t</i>	<i>df</i>
	Paper survey			Online survey					
	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>			
Depressive Symptoms CES-D	16.97	9.603	32	24.88	14.06	26	[-14.16, -1.66]	-2.53*	56
Stigma	3.98	0.711	32	3.73	0.91	27	[-0.172, 0.677]	1.192	57

Note: Independent *t*-test. CI = confidence interval. *Df* = degree of freedom. *N* = sample size.

Table 19

Predictors of HRQOLC-30 sum Score

Variables	HRQOLC-30 sum score		
	B	β	95% CI
(Constant)	31.36		[-11.02–73.74]
Age	-0.14	-0.06	[-0.71–0.43]
Stigma	4.70	0.20	[-1.76–11.16]
Social support	-0.39	-0.02	[-4.35–3.56]
Religiosity	0.11	0.08	[-0.27–0.49]
Spirituality	0.64	0.27	[-0.04–1.32]

Note. Regression table. *N* = 59. CI = Confidence Interval. $p < 0.05$. $**p < 0.01$. B = unstandardized coefficient. β = standardized coefficient.

Table 20

Predictors of Depressive Symptoms

Variables	Depressive symptoms		
	B	β	95% CI
(Constant)	55.82		[30.15–81.50]
Spirituality	-0.42	-0.27	[-0.84–0.00]
Age	0.17	0.11	[-0.17–0.52]
Religiosity	-0.26*	-0.28	[-0.49–(-0.03)]
Stigma	-1.80	-0.11	[-5.71–2.10]
Social support	-1.13	-0.09	[-3.87–1.61]

Note. Regression table. $N = 59$. CI = Confidence Interval. $p < 0.05$. ** $p < 0.01$. B = unstandardized coefficient. β = standardized coefficient.

Table 21

Results of t-test and Descriptive Statistics for Religiosity and Spirituality by Survey Type

	Survey type						95% CI for mean difference	<i>t</i>	<i>df</i>
	Paper survey			Online survey					
	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>			
<i>Religiosity BIAC</i>	57.94	9.33	31	44.19	12.16	27	[8.08, 19.41]	2.81	56
<i>Spirituality SPS</i>	40.42	6.78	31	38.95	9.40	27	[-2.80, 5.74]	2.13	57

Note: Independent *t*-test. CI = confidence interval. *Df* = degree of freedom. *N* = sample size.

Appendices

Appendix A

Letter of Invitation and Advertisement, English Flyer



Predictors of quality of life among breast cancer patients in Saudi Arabia

Share your story.

Study objective: The aim of the research is to determine the extent to which breast cancer affects the quality of life of breast cancer patients.

Is the search useful to me: This research will help healthcare providers to know your needs and provide a better health service to suit your needs.

What is my rule in this research: Your role is to fill out a questionnaire to share your experience with breast cancer and how it affects the quality of life.

If you want to participate in the research, please fill out the questionnaire in the oncology clinic in the first floor of the International Medical Center Hospital or you can fill the questionnaire online by asking about the researcher Mashael Dewan to get the questionnaire (paper-based or URL link to the online survey) or send an email.

URL: https://ohsu.ca1.qualtrics.com/jfe/form/SV_0iDyk3gFnbIb1e5

Sincerely,

Mashael Dewan
OHSU PhD Candidate
IRB# MOD00016916

Appendix B**Letter of Invitation and Advertisement, Arabic Flyer**

School of Nursing

عزيزتي مريضة الإستبيان التالي يناقش العوامل المؤثرة في حياة مرضى سرطان الثدي لغايات البحث العلمي لذلك نرجو منك أن تشاركينا رأيك:

غايات البحث العلمي: هذا البحث العلمي سوف يساعد الطاقم الطبي على معرفة متطلبات المرضى بشكل أفضل مما ينعكس إيجاباً على الخدمة المقدمة للمرضى وتقديم خدمة صحية أفضل بما يناسب إحتياجاتهم. **ما هو دور المريضة في هذا البحث:** دورك تتلخص في تعبئة إستبيان لمشاركة تجربتك مع سرطان الثدي وكيف أثر على جودة حياتك.

إذا أردتي المشاركة في البحث، الرجاء التفضل بتعبئة الإستبيان الموجود في عيادة الأورام الدولي وذلك عن طريق السؤال عن الباحثة مشاعل ديوان لأخذ الإستبيان، أو أون لاین. ملاحظة: نتعهد بالحفاظ على خصوصية معلومات المرضى و إستخدامها فقط من أجل أغراض تحسين جودة الخدمة الطبية.

طالبة الدكتوراه مشاعل ديوان

إيميل: dewama@ohsu.edu

هاتف: ٩٦٦٢٦٥٠٩٠٠٠, تحويلة ١٦٦٢/١٦٦١.

Appendix C

Study Questionnaires

English (19 items): This part examines your demographic and background variables.

Number	Demographic & Background Variables <i>Please complete the following inquiries</i>	
1	Marital status	1. Single 2. Married 3. Engaged 4. Divorced/ separated 5. Widowed 6. Decline to answer
2	If married, do you live with your husband?	1. Yes 2. No
3	With whom do you live	1. Alone 2. With children 3. With husband 4. With relatives 5. With others 6. Decline to answer
4	Are you Saudi	1. Yes 2. No If not Saudi, please write your nationality
5	Where do you live	1. Inside KSA 2. Outside KSA
6	Financially, do you say:	1. I have more than enough 2. I have just enough 3. I don't have enough 4. Decline to answer
7	Family annual income before tax in Saudi Riyals	1. Less than 1000 SAR 2. 1001-10,000 SAR

		<ol style="list-style-type: none"> 3. 10,001-20,000 SAR 4. 20,001-30,000 SAR 5. 30,001-40,000 SAR 6. More than 40,001 7. Decline to answer
8	Your highest educational level	<ol style="list-style-type: none"> 1. Elementary school 2. Intermediate school 3. High school 4. Undergraduate 5. Grad (master's degree) 6. Grad (PhD) 7. Something else, please specify.....
9	Age in years	
10	Are you employed?	<ol style="list-style-type: none"> 1. No, I do not work 2. No, I'm retired 3. Yes, part-time 4. Yes, full-time 5. Decline to answer
11	How many children do you have	
12	Please write if your children live with you, and write their age please	<p>Child 1 (yes, no), age #</p> <p>Child 2 (yes, no), age #</p> <p>Child 3 (yes, no), age #</p> <p>Child 4 (yes, no), age #</p> <p>Child 5 (yes, no), age #</p> <p>Child 6 (yes, no), age #</p> <p>Child 7 (yes, no), age #</p> <p>Child 8 (yes, no), age #</p> <p>Child 9 (yes, no), age #</p> <p>Child 10 (yes, no), age #</p>
13	Do you the following chronic illness?	<p>Heart disease (yes, no)</p> <p>Stroke (yes, no)</p> <p>Parkinson's disease (yes, no)</p> <p>Alzheimer's or memory loss (yes, no)</p>

		<p>Rheumatoid (yes, no)</p> <p>Diabetes (yes, no)</p> <p>Hypertension (yes, no)</p> <p>Other (yes, no), please specify</p>
14	When were you diagnosed with breast cancer?	Year..... month
15	Do you take any of the following treatment now related to breast cancer (chemotherapy, radiotherapy, surgical, hormonal, immunology, biology)?	<ol style="list-style-type: none"> 1. Yes 2. No
16	Please specify the treatment, choose all apply	<ol style="list-style-type: none"> 1. Chemotherapy 2. Radiotherapy 3. Surgical 4. Hormonal 5. Immunology 6. Biology
17	Did you have mastectomy?	<ol style="list-style-type: none"> 1. Yes, if yes which side (right, left, both) 2. No
18	Do you have metastasis to other organs?	<ol style="list-style-type: none"> 1. Yes, please write the organ 2. No
19	Where do you get the treatment now?	<ol style="list-style-type: none"> 1. Government hospital 2. Private hospital

Appendix D

FACIT-Sp, version 4: ENGLISH (12 items)

This part examines quality of the nursing practice environment through the Practice Environment Scale of the Nursing Work Index PES-NWI ©2002.

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	ADDITIONAL CONCERNS	Not at all	A little bit	Some-what	Quite a bit	Very much
1	I feel peaceful	0	1	2	3	4
2	I have a reason for living	0	1	2	3	4
3	My life has been productive	0	1	2	3	4
4	I have trouble feeling peace of mind	0	1	2	3	4
5	I feel a sense of purpose in my life	0	1	2	3	4
6	I am able to reach down deep into myself for comfort	0	1	2	3	4
7	I feel a sense of harmony within myself	0	1	2	3	4
8	My life lacks meaning and purpose	0	1	2	3	4
9	I find comfort in my faith or spiritual beliefs	0	1	2	3	4
10	I find strength in my faith or spiritual beliefs	0	1	2	3	4
11	My illness has strengthened my faith or spiritual beliefs	0	1	2	3	4
12	I know that whatever happens with my illness, things will be okay	0	1	2	3	4

Appendix E

FACIT-Sp, version 4: ARABIC

من فضلك ضع دائرة أو علامة على رقم واحد في كل سطر لبيان مدى انطباق إجابتك على حالتك في الأيام السبعة الأخيرة.

كثيراً جداً	غالباً	نوعاً ما	مرات قليلة	ليس على الإطلاق		
4	3	2	1	0	أشعر بالسلام	1
4	3	2	1	0	يوجد لدي سبب للعيش	2
4	3	2	1	0	حياتي ما تزال منتجة	3
4	3	2	1	0	أواجه مشاكل في الإحساس براحة البال	4
4	3	2	1	0	أشعر بشيء من الغاية في حياتي	5
4	3	2	1	0	أنا قادر على البحث عميقاً في نفسي للوصول إلى الراحة	6
4	3	2	1	0	أشعر بالانسجام مع نفسي	7
4	3	2	1	0	حياتي تفتقد للمعنى والهدف	8
4	3	2	1	0	أجد الراحة في إيماني أو في معتقداتي الدينية	9
4	3	2	1	0	أجد القوة في أيماني أو في معتقداتي الدينية	10
4	3	2	1	0	لقد عزز المرض من إيماني أو معتقداتي الدينية	11
4	3	2	1	0	أنا أعرف أنه مهما حصل مع مرضي، فإن الأمور ستكون على ما يرام	12

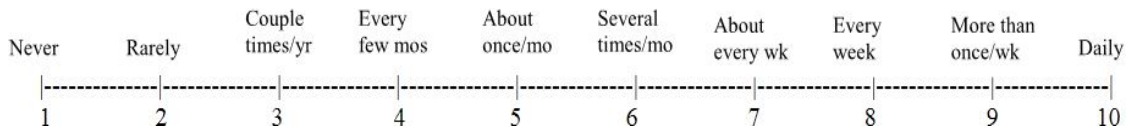
Appendix F

BIAC. Religiosity English

Please circle the highest priority in your life now? (most valued, prized)
[circle only one]

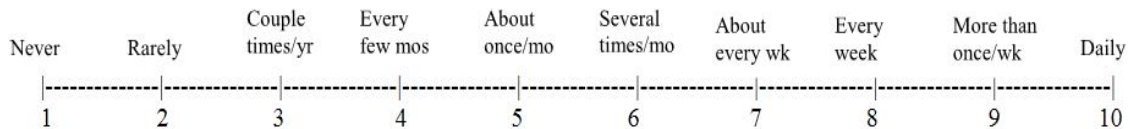
1. My health and independence
2. My family
3. My friendships
4. Job, career or business
5. My education
6. Financial security
7. Relationship with God
8. Ability to travel & see the world
9. Listening to music and partying
10. Freedom to live as I choose

2. How often do you attend religious services? (circle a number below)

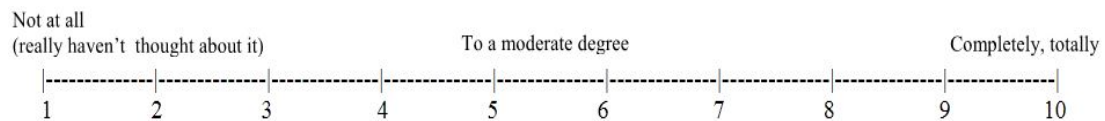


3. Other than religious services, how often do you get together with others for religious reasons

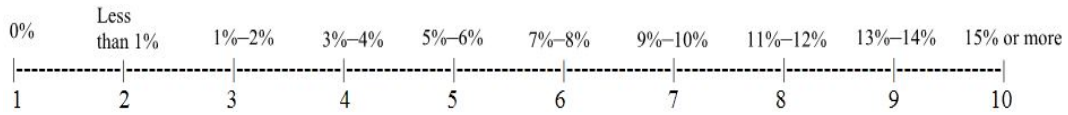
(prayer, religious discussions, volunteer work, etc.)?



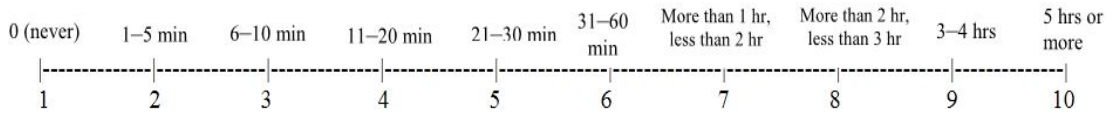
4. To what extent (on a 1 to 10 scale) have you decided to place your life under God's direction?



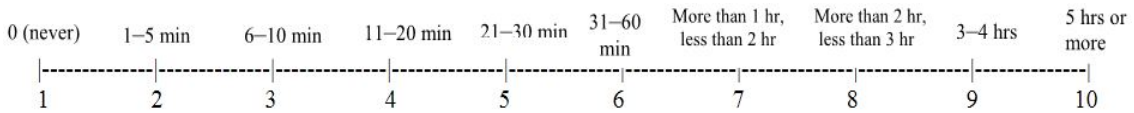
5. What percentage of your gross annual income do you give to your religious institution or to other religious causes each year?



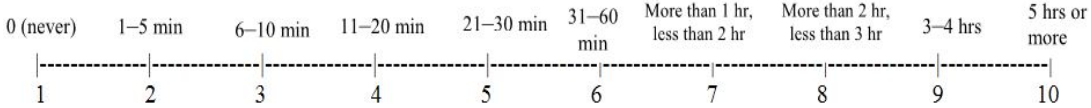
6. On average, how much time each day (in 24 hours) do you spend listening to religious music or radio, or watching religious TV?



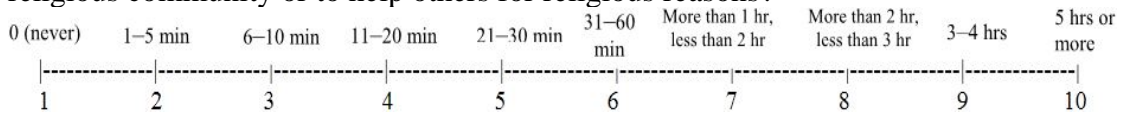
7. On average, how much time each day do you spend reading religious scriptures, books, or other religious literature?



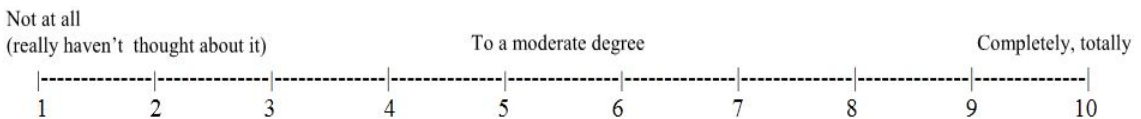
8. On average, how much time each day do you spend in private prayer or meditation?



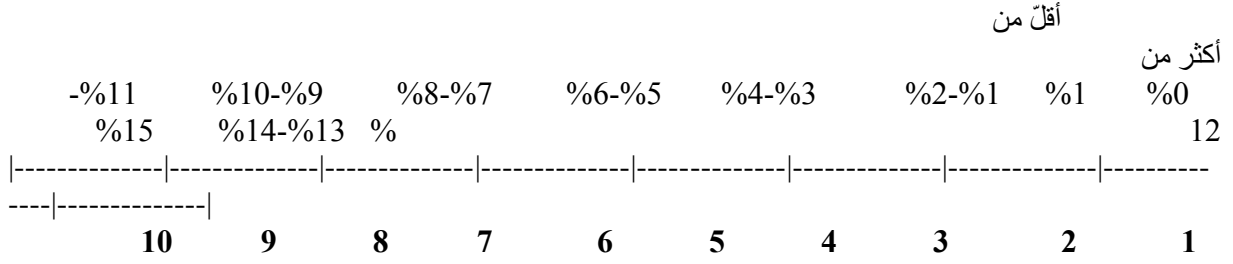
9. On average, how much time each day do you spend as a volunteer in your religious community or to help others for religious reasons?



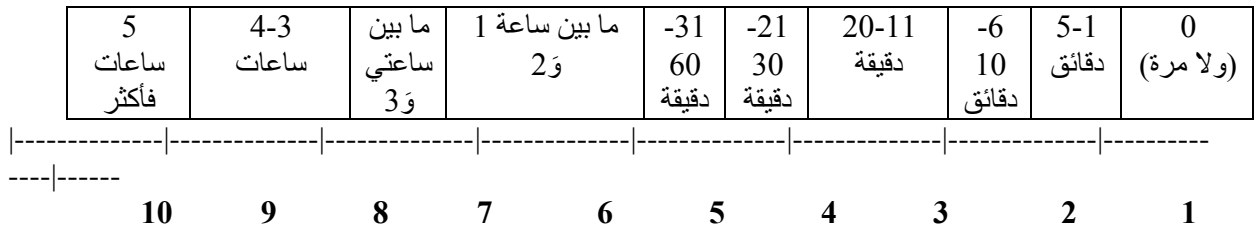
10. To what extent (on a 1 to 10 scale) have you decided to conform your life to the teachings of your religious faith?



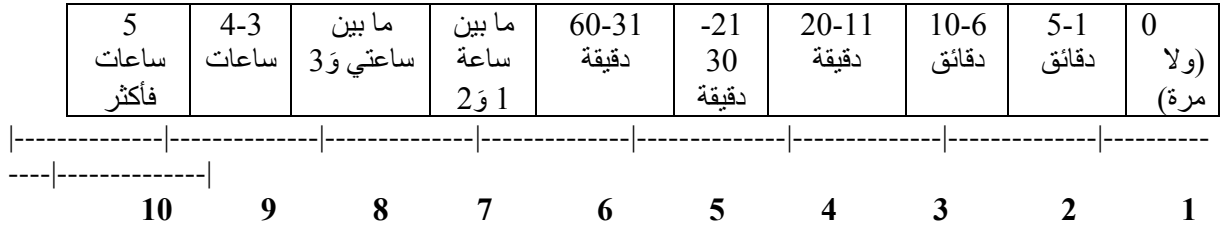
5- ما هي نسبة ما تنفقه من إجمالي دخلك السنوي لمؤسستك الدينية (كالمسجد) أو للأسباب الدينية الأخرى بشكل سنوي؟ (يشمل الزكاة، والعطايا المالية الأخرى غير الإجبارية)



6- في المتوسط ، ما المقدار الذي تقضيه من وقتك في اليوم الواحد (خلال 24 ساعة) في الاستماع للأنشيد الإسلامية ، أو تلاوة القرآن ، أو مشاهدة برنامج ديني ؟



7- في المتوسط ، ما المقدار الذي تقضيه من وقتك في اليوم الواحد في قراءة القرآن ، أو قراءة الكتب الدينية ، أو قراءة النصوص الدينية الأخرى ؟



8- في المتوسط ، ما المقدار الذي تقضيه من وقتك في اليوم الواحد في التأمل ، أو مختليا في صلاتك ؟



Appendix H

MSPSS. English/Arabic

This scale contains few questions about social support

1 very strongly disagree	2 strongly disagree	3 mildly disagree	4 neutral	5 mildly agree	6 strongly agree	7 very strongly agree
There is a special person who is around when I am in need	٦	٥	٤	٣	٢	١
There is a special person with whom I can share my joys and sorrows						هناك شخص مميز أستطيع ان أشارك افراحي واحزاني معه
My family really tries to help me						عائلتي تحاول مساعدتي
I get the emotional help and support I need from my family						انال مساعدة عاطفية ودعم من عائلتي
I have a special person who is real source of comfort to me						هناك شخص مميز هو/هي مصدر حقيقي للراحة لي
My friends really try to help me						أصدقائي يحاولون مساعدتي
I can count on my friends when things go wrong						بإمكاني الاعتماد على أصدقائي عندما تجري الامور بشكل سيئ
I can talk about my problems with my family						بإمكاني التحدث عن مشاكلي مع عائلتي
I have friends with whom I can share my joys and sorrows						عندي أصدقاء أستطيع ان أشارك افراحي وأحزاني معهم
There is a special person in my life who cares about my feelings						هناك شخص مميز في حياتي يهتم بمشاعري
My family is willing to help me make decisions						عائلتي ترغب في مساعدتي لاتخاذ القرارات
I can talk about my problems with friends						أستطيع ان اتحدث عن مشاكلي مع عائلتي

من هو الشخص المميز الذي اشرت إليه بالاستمارة؟ حددي علاقتك به وليس الاسم. مثلا أختي، زوجي

Who is the special person you meant in the scale above, please indicate the relationship not the name, example sister, a friend, husband, religious leader etc

In the scale above, how do define family:

1. Parents
2. Siblings
3. Husband
4. Grandparent
5. Children
6. Grandchildren
7. Relatives

في المقياس أعلاه ، كيف تحدد الأسرة

1. الوالدين
2. الأشقاء
3. الأجداد
4. الأبناء
5. الأحفاد
6. الأقارب

Appendix I

Breast Cancer Stigma Scale for Arab-Patient Version (English)

5-points Likert scale:

1. Strongly agree.	4. Disagree
2. Agree	5. Strongly Disagree
3. Neither agree nor disagree	

Items	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
Item1. Some people avoid me because they think breast cancer is a contagious disease.					
Item2: Some people avoid me because of my breast cancer reminds them of death.					
Item3: some people believe that I got breast cancer because God is punishing me					
Item4: some people believe that I got breast cancer because of my sins.					
Item5: I asked people close to me to keep my breast cancer a secret.					

Item6: I try to conceal my breast cancer.					
Item7: Some people think that I cannot be productive at work because of breast cancer.					
Item8 Some people think that I cannot take care of my family because of breast cancer.					
Item9: Some people think that my femininity has been diminished because of breast cancer.					
Item10: Some people think that I am is not a whole person because of breast cancer.					
Item11: I am worried that I will be socially stigmatized because I have “breast cancer.”					
Item12: I am worried that people will look down on my family because I have “breast cancer.”					

Appendix J

Breast Cancer Stigma Scale for Arab-Patient Version (Arabic)

قد يحتوي على أسئلة حساسة ولكنها مهمة. الرجاء الإجابة قدر الاستطاعة
الرجاء وضع دائرة على المكان المناسب

أعترض بشدة	أعترض	حيادي (لا أوافق أو أعترض)	أوافق	أوافق بشدة		
٥	٤	٣	٢	١	البعض قد يتجنبني لإعتقادهم ان سرطان الثدي مرض معدي	1
٥	٤	٣	٢	١	البعض يعتقد بأن أئوتتي قد نقصت بسبب إصابتي بمرض سرطان الثدي	2
٥	٤	٣	٢	١	يعتقد البعض أن سرطان الثدي هو عقاب من الله	3
٥	٤	٣	٢	١	البعض يعتقد أنه لا يمكنني أن أكون منتجة في عملي بسبب إصابتي بمرض سرطان الثدي	4
٥	٤	٣	٢	١	البعض يعتقد أنه لا يمكنني أن أعتني بأفراد أسرتي بسبب إصابتي بمرض سرطان الثدي	5
٥	٤	٣	٢	١	يعتقد البعض أن مريضة سرطان الثدي شخص غير كامل بسبب إصابتها بمرض سرطان الثدي	6
٥	٤	٣	٢	١	البعض يعتقد أني أصبت بمرض سرطان الثدي بسبب ذنوبي	7
٥	٤	٣	٢	١	طلبت من أقرائي أن يحافظوا على سرية إصابتي بمرض سرطان الثدي	8
٥	٤	٣	٢	١	انا احاول إخفاء إصابتي بمرض سرطان الثدي	9
٥	٤	٣	٢	١	أخشى أن أوصم بالعار عند معرفة الناس بإصابتي بمرض بسرطان الثدي	10
٥	٤	٣	٢	١	أخشى أن ينظر الناس لأهلي بنظرة دونية عند معرفتهم بإصابتي بسرطان الثدي	11
٥	٤	٣	٢	١	البعض قد يتجنبني لان مرض سرطان الثدي يذكرهم بالموت	12

Appendix K

Depressive Symptoms English

Center for Epidemiologic Studies Depression (CES-D)

Scale Description:

The following scale was developed by the Center for Epidemiologic Studies (Radlof, 1977). The scale has been found reliable (Alpha>.85) in previous research (Hann et. al., 1999). A Spanish version of this scale is also available.

Scale items:

Below is a list of some ways you may have felt or behaved. Please indicate how often you have felt this way during the last week by checking the appropriate space. Please only provide one answer to each question.

	During the past week:	<i>Rarely</i> or none of the time (less than 1 day)	<i>Some</i> or a <i>little</i> of the time (1-2 days)	<i>Occasionally</i> or a moderate amount of time (3-4 days)	<i>Most</i> or all of the time (5-7 days)
1	I was bothered by things that usually don't bother me.				
2	I did not feel like eating; my appetite was poor.				
3	I felt that I could not shake off the blues even with help from my family or friends.				
4	I felt I was just as good as other people.				
5	I had trouble keeping my mind on what I was doing.				
6	I felt depressed.				
7	I felt that everything I did was an effort.				
8	I felt hopeful about the future.				

9	I thought my life had been a failure.				
10	I felt fearful.				
11	My sleep was restless.				
12	I was happy.				
13	I talked less than usual.				
14	I felt lonely.				
15	People were unfriendly.				
16	I enjoyed life.				
17	I had crying spells.				
18	I felt sad.				
19	I felt that people disliked me.				
20	I could not get going.				

Appendix L

Depressive Symptoms Arabic — Center for Epidemiologic Studies Depression (CES-D)

الإرشادات: تلي لائحة بالمشاعر أو التصرفات التي قد تكون قمت بها. الرجاء تحديد عدد المرات التي شعرت أو تصرفت بها على هذا الشكل خلال الأسبوع الماضي وذلك بوضع دائرة حول الرقم المناسب من بين الأرقام التي تلي كل عبارة. استعن بالمقياس التالي:

خلال الأسبوع الماضي:

3	2	1	0
في معظم أو في كل الأوقات (5- 7 أيام)	أحياناً أو خلال مدة معتدلة من الوقت (3-4 أيام)	في بعض الأوقات أو قليلاً (يوم واحد أو يومين)	نادراً أو أبداً (أقل من يوم واحد)

3	2	1	0	1. أزعجتني أمور لا تزعجني عادةً.
3	2	1	0	2. لم أرغب في تناول الطعام. كانت شهيتي ضعيفة.
3	2	1	0	3. شعرت أنني لم أستطع أن أتخلص من كآبتي حتى بمساعدة عائلتي وأصدقائي.
3	2	1	0	4. شعرت أنني بمثابة الآخرين.
3	2	1	0	5. وجدت صعوبة في التركيز على ما أفعل.
3	2	1	0	6. شعرت بالكآبة.
3	2	1	0	7. شعرت أن القيام بأي عمل يجهدني.
3	2	1	0	8. كنت متفائلاً حول المستقبل.
3	2	1	0	9. شعرت أن حياتي كانت فاشلة.
3	2	1	0	10. شعرت بالخوف.
3	2	1	0	11. أصبت بالأرق.
3	2	1	0	12. كنت سعيداً.
3	2	1	0	13. تكلمت أقل من العادة.
3	2	1	0	14. شعرت بالوحدة.
3	2	1	0	15. لم يكن الناس ودودين.
3	2	1	0	16. تمتعت بالحياة.
3	2	1	0	17. أصبت بنوبات بكاء.
3	2	1	0	18. شعرت بالحزن.
3	2	1	0	19. شعرت أن الناس لا تحبني.
3	2	1	0	20. لم أستطع الاستمرار.

Appendix M

EORTC QLQ-C30 (Version 3) English

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.
 Your birthdate (Day, Month, Year):
 Today's date (Day, Month, Year):

		Not at all	A little	Quite a bit	Very much
1	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?				
2	Do you have any trouble taking a long walk?				
3	Do you have any trouble taking a short walk outside of the house?				
4	Do you need to stay in bed or a chair during the day?				
5	Do you need help with eating, dressing, washing yourself or using the toilet?				

During the past week:

		Not at all	A little	Quite a bit	Very much
6	Were you limited in doing either your work or other daily activities?				
7	Were you limited in pursuing your hobbies or other leisure time activities?				
8	Were you short of breath?				
9	Have you had pain?				
10	Did you need to rest?				
11	Have you had trouble sleeping?				
12	Have you felt weak?				
13	Have you lacked appetite?				
14	Have you felt nauseated?				
15	Have you vomited?				
16	Have you been constipated?				
17	Have you had diarrhea?				
18	Were you tired?				

19	Did pain interfere with your daily activities?				
20	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?				
21	Did you feel tense?				
22	Did you worry?				
23	Did you feel irritable?				
24	Did you feel depressed?				
25	Have you had difficulty remembering things?				
26	Has your physical condition or medical treatment interfered with your family life?				
27	Has your physical condition or medical treatment interfered with your social activities?				
28	Has your physical condition or medical treatment caused you financial difficulties?				

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7

1> Very poor

7>excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

1> Very poor

7>excellent

Appendix N

EORTC QLQ-C30 (Version 3) Arabic

European Organization for Research and Treatment of Cancer Quality of Life Questionnaire

نحن معنيون ببعض المعلومات عنك و عن صحتك لذا الرجاء الإجابة بنفسك عن كل من الأسئلة التالية و ذلك بوضع دائرة حول الإجابة الأكثر ملائمة لك علما بأنه لا يوجد جواب "صحيح" أو "خطأ" كما أن جميع المعلومات و البيانات التي سيتم جمعها هي لأغراض البحث العلمي فقط و ستعامل بسرية تامة.

الرجاء إملأ الحروف الأولى من اسمك

تاريخ ميلادك (اليوم، الشهر، السنة)

تاريخ اليوم (اليوم، الشهر، السنة)

الرقم	الفقرة	إطلاقاً	قليلاً	بما فيه الكفاية	كثيراً جداً
1.	هل لديك صعوبة في بذل جهد جسماني شاق مثل حمل كيس مشتريات ثقيل أو حقيبة؟	1	2	3	4
2.	هل لديك مشكلة بالسير لمسافة قصيرة خارج البيت؟	1	2	3	4
3.	هل لديك مشكلة بالسير لمسافة طويلة؟	1	2	3	4
4.	هل تحتاج للبقاء في السرير أو المقعد خلال اليوم؟	1	2	3	4
5.	هل تحتاج للمساعدة في الأكل أو ارتداء الملابس، الاغتسال، المراض؟	1	2	3	4
خلال الأسبوع الماضي تحديداً: -					
6.	هل كنت محدودة/ مقيدة بالقيام بعملك أو فعاليات يومية أخرى؟	1	2	3	4
7.	هل كنت محدودة/ مقيدة في ممارسة هواياتك او فعاليات في اوقات الفراغ؟	1	2	3	4
8.	هل ضاقت أنفاسك؟	1	2	3	4
9.	هل كان لديك ألم؟	1	2	3	4
10.	هل كنت بحاجة لان تستريح؟	1	2	3	4
11.	هل عانيت من مشاكل بالنوم (الأرق/ صعوبة بالنوم/تقطع النوم)؟	1	2	3	4
12.	هل شعرت بالوهن؟	1	2	3	4
13.	هل فقدت شهيتك؟	1	2	3	4
14.	هل شعرت بالغثيان؟	1	2	3	4
15.	هل تقيأت؟	1	2	3	4
16.	هل عانيت من إمساك؟	1	2	3	4
17.	هل كان لديك إسهال؟	1	2	3	4
18.	هل كنت متعبة؟	1	2	3	4
19.	هل الوجد شوش فعالياتك اليومية؟	1	2	3	4
20.	هل كان لديك صعوبة بالتركيز في الأمور مثل قراءة الجريدة أو مشاهدة التلفزيون؟	1	2	3	4
21.	هل شعرت بالتوتر؟	1	2	3	4
22.	هل شعرت بالقلق؟	1	2	3	4

الرقم	الفقرة	إطلاقاً	قليلاً	بما فيه الكفاية	كثيراً جداً
.23	هل شعرت بالهيجان (عصبية/ منزعجة)؟	1	2	3	4
.24	هل شعرت بالاكتئاب؟	1	2	3	4
.25	هل كانت لديك صعوبة بتذكر الأشياء؟	1	2	3	4
.26	هل حالتك الجسمانية أو علاجك الطبي تدخلت بحياتك العائلية؟	1	2	3	4
.27	هل حالتك الجسمانية أو علاجك الطبي تدخلت بحياتك الإجتماعية؟	1	2	3	4
.28	هل حالتك الجسمانية أو علاجك الطبي أديا إلى مشاكل اقتصادية؟	1	2	3	4

في الأسئلة التالية الرجاء الإشارة بدائرة حول الأرقام بين 1 - 7 الاكثر ملائمة

29. كيف تدرج / تدرجي صحتك عموماً خلال الأسبوع الماضي؟

1 2 3 4 5 6 7

سيء جداً ممتاز

30. كيف تدرج / تدرجي جودة حياتك عموماً/ مستوى حياتك عموماً خلال الأسبوع الماضي؟

1 2 3 4 5 6 7

سيء جداً ممتاز

Appendix O

EORTC QLQ-BR23 English

**European Organization for Research and Treatment of Cancer
Quality of Life Questionnaire (breast cancer)**

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week.

		Not at all	A little	Quite a bit	Very much
31	Did you have a dry mouth?				
32	Did food and drink taste different than usual?				
33	Were your eyes painful, irritated or watery?				
34	Have you lost any hair?				
35	Answer this question only if you had any hair loss: Were you upset by the loss of your hair?				
36	Did you feel ill or unwell?				
37	Did you have hot flushes?				
38	Did you have headaches?				
39	Have you felt physically less attractive as a result of your disease or treatment?				
40	Have you been feeling less feminine as a result of your disease or treatment?				
41	Did you find it difficult to look at yourself naked?				
42	Have you been dissatisfied with your body?				
43	Were you worried about your health in the future?				

During the past four weeks:

		Not at all	A little	Quite a bit	Very much
44	To what extent were you interested in sex?				
45	To what extent were you sexually active? (with or without intercourse)				
46	Answer this question only if you have been sexually active: To what extent was sex enjoyable for you?				

During the past week:

		Not at all	A little	Quite a bit	Very much
47	Did you have any pain in your arm or shoulder?				
48	Did you have a swollen arm or hand?				
49	Was it difficult to raise your arm or to move it sideways?				
50	Have you had any pain in the area of your affected breast?				
51	Was the area of your affected breast swollen?				
52	Was the area of your affected breast oversensitive?				
53	Have you had skin problems on or in the area of your affected breast (e.g., itchy, dry, flaky)?				

Appendix P

EORTC QLQ-BR23, Arabic

تبلغ المريضات بعض الأحيان بإصابتهم بالأعراض التالية، يرجى الإشارة إلى الدرجة التي عانيت فيها من مثل هذه الأعراض أو المشاكل خلال الأسبوع الماضي علما بأنه لا يوجد جواب "صحيح" أو "خطأ" كما أن جميع المعلومات و البيانات التي سيتم جمعها هي لأغراض البحث العلمي فقط و ستعامل بسرية تامة.

الرجاء إملأ الحروف الأولى من اسمك
تاريخ ميلادك (اليوم، الشهر، السنة)

تاريخ اليوم (اليوم، الشهر، السنة)

كثيرا جدا	بعض الشيء	قليلا	أبدا		
4	3	2	1	هل شعرت بجفاف في الفم؟	31.
4	3	2	1	هل اختلف مذاق الأكل أو الشرب عن الطعام الاعتيادي؟	32.
4	3	2	1	هل شعرت بالألم أو التهاب في العينين أو هل كانتا دامعتين؟	33.
4	3	2	1	هل تساقط شعرك؟	34.
4	3	2	1	اجب على هذا السؤال فقط إذا كنت تعاني من تساقط الشعر: هل كنت منزعج / منزعجة بسبب تساقط شعرك؟	35.
4	3	2	1	هل كنت مريضة أو متوعدة الصحة؟	36.
4	3	2	1	هل شعرت باحمرار أو تورد الوجه؟	37.
4	3	2	1	هل شعرت بالصداع؟	38.
4	3	2	1	هل شعرت انك اقل جاذبية (اقل مرغوبة) بسبب مرضك أو العلاج؟	39.
4	3	2	1	هل كنت تشعرين انك اقل أنوثة بسبب مرضك أو العلاج؟	40.
4	3	2	1	هل تجددين صعوبة عند النظر إلى نفسك و أنتي عارية؟	41.
4	3	2	1	هل كنت غير راضية عن جسدك؟	42.
4	3	2	1	هل كنت قلقة بخصوص صحتك في المستقبل؟	43.
خلال الأسابيع الأربعة الماضية: -					
4	3	2	1	إلى أي درجة كانت عندك رغبة بالجماع؟	44.
4	3	2	1	إلى أي درجة كنت نشيطة جنسيا (بجماع أو بدونه)؟	45.
4	3	2	1	أجيبني على هذا السؤال فقط إذا كنت نشيطة جنسيا: إلى أي درجة كان الجماع ممتعا بالنسبة لك؟	46.
خلال الأسبوع الماضي: -					
4	3	2	1	هل شعرت بأي ألم في الذراع أو في الكتف؟	47.
4	3	2	1	هل عانيت من تورم في اليد أو الذراع؟	48.
4	3	2	1	هل كان صعبا عليك رفع ذراعك أو تحريكه جانبيا؟	49.
4	3	2	1	هل كنت تشعرين بالألم في منطقة ثديك المصاب؟	50.
4	3	2	1	هل كانت منطقة ثديك المصاب متورمة؟	51.
4	3	2	1	هل كانت منطقة ثديك المصاب شديدة الحساسية؟	52.

4	3	2	1	هل عانيت من مشاكل البشرة حول منطقة صدرك المصاب أو حوله (مثلا الحكة، الجفاف، التقشر)؟	.53
كثيرا جدا	بعض الشيء	قليلا	أبدا	الفقرة	الرقم
4	3	2	1	هل شعرت بجفاف في الفم؟	.54
4	3	2	1	هل اختلف مذاق الأكل أو الشرب عن الطعم الاعتيادي؟	.55
4	3	2	1	هل شعرت بألم أو التهاب في العينين أو هل كانتا دامعتين؟	.56
4	3	2	1	هل تساقط شعرك؟	.57
4	3	2	1	اجب على هذا السؤال فقط إذا كنت تعاني من تساقط الشعر: هل كنت منزعج / منزعجة بسبب تساقط شعرك؟	.58
4	3	2	1	هل كنت مريضة أو متوعكة الصحة؟	.59
4	3	2	1	هل شعرت باحمرار أو تورد الوجه؟	.60
4	3	2	1	هل شعرت بالصداع؟	.61
4	3	2	1	هل شعرت انك اقل جاذبية (اقل مرغوبة) بسبب مرضك أو العلاج؟	.62
4	3	2	1	هل كنت تشعرين انك اقل أنوثة بسبب مرضك أو العلاج؟	.63
4	3	2	1	هل تجددين صعوبة عند النظر إلى نفسك و أنتي عارية؟	.64
4	3	2	1	هل كنت غير راضية عن جسديك؟	.65
4	3	2	1	هل كنت قلقة بخصوص صحتك في المستقبل؟	.66
خلال الأسابيع الأربعة الماضية: -					
4	3	2	1	إلى أي درجة كانت عندك رغبة بالجماع؟	.67
4	3	2	1	إلى أي درجة كنت نشيطة جنسيا (بجماع أو بدونه)؟	.68
4	3	2	1	أجيب على هذا السؤال فقط إذا كنت نشيطة جنسيا: إلى أي درجة كان الجماع ممتعا بالنسبة لك؟	.69
خلال الأسبوع الماضي: -					
4	3	2	1	هل شعرت بأي ألم في الذراع أو في الكتف؟	.70
4	3	2	1	هل عانيت من تورم في اليد أو الذراع؟	.71
4	3	2	1	هل كان صعبا عليك رفع ذراعك أو تحريكه جانبيا؟	.72
4	3	2	1	هل كنت تشعرين بألم في منطقة ثديك المصاب؟	.73
4	3	2	1	هل كانت منطقة ثديك المصاب متورمة؟	.74
4	3	2	1	هل كانت منطقة ثديك المصاب شديدة الحساسية؟	.75
4	3	2	1	هل عانيت من مشاكل البشرة حول منطقة صدرك المصاب أو حوله (مثلا الحكة، الجفاف، التقشر)؟	.76

Appendix Q

Functional Assessment of Chronic Illness Therapy (FACIT) Licensing Agreement



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Thank You

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