Identifying the psychosocial needs of Emirati and expatriate breast cancer survivors in the U.A. E.: A mixed method investigation in a hospital setting

Thesis

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By

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DEDICATIONS

For my mother from whom I have inherited learning and education.

For my father, from whom I have inherited determination and sustainability to work hard and achieve goals.

For my sister, who inspired me to be kind.

For my husband, for his patience, his advice and his faith in me, because he always understood me.

For all cancer patients, who taught me how to be resilient in life.

DECLARATION

I declare that the work in this dissertation was carried out in accordance with the requirements of the University of Salford's Regulations and Code of Practice for PhD Degree Programmes and does not incorporate without acknowledgment any material previously submitted for any other academic award in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where indicated by specific references in the text. This thesis is the candidate's own work and any work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

Signed: Maria Aamir

Date: 15th September 2021

ABSTRACT

Cancer is considered as a chronic disease which requires high-quality, long-term, post-treatment care (Drayton, et. al., 2012; Phillips & Currow, 2010). However, long-term survivorship care has become a growing healthcare burden requiring numerous resources including psychosocial support, late and long-term side effects monitoring, follow-up care to screen cancer progression, recurrence or newly developed or secondary cancers (Howell, et. al., 2011; McCorkle, 2011; Morgan, 2009). Breast cancer is the most frequent cancer in the world and in the United Arab Emirates (UAE); yet there is little known about breast cancer survivors' psychosocial concerns in the UAE. Research shows that meeting the full range of psychosocial needs significantly contributes to survivor's wellbeing and potentially elevates the quality of the patient's life (Holland & Reznik, 2005; Institute of Medicine, 2008; Culbertson, et. al., 2020). Thus, it is important to understand and meet the needs of the country's diverse population to help cancer patients deal with the range of psychosocial issues they may experience. The aim of this study was to investigate the psychosocial concerns of breast cancer survivors in a hospital setting in the UAE and the association with cultural factors related to two groups: Emiratis and expatriates.

A two-phase mixed methods study was conducted involving a cross-sectional quantitative survey to examine survivors' concerns and semi-structured interviews to develop an in-depth understanding of their needs. Among 205 breast cancer survivors who completed Phase One, twenty six percent were Emiratis and eighty seven percent were expatriates with the mean age of 49 years (both groups). Sixty percent of participants were diagnosed in 2018 or after that period. Around seventy four percent of survivors had regional stage disease and thirty eight percent of survivors had multimodality treatment. Fifty nine percent were on treatment whereas forty one percent had their treatment complete or had no treatment. Seventy two percent coded their quality of life as "good". The severity scores of each psychosocial domain were calculated based on the participants' reported concerns using mean scores. Information concerns were the highest reported concerns with the mean score 4.3. Emotional needs were the second most concerning reported with a mean score of 3.4. Physical needs were reported by the survivors with some level of concerns, mainly pain and fatigue ($p=0.031$). Survivors had a significant level of social and financial concerns ($p<0.001$). Regression analysis t-test results indicated no significant differences in information and emotional needs between Emiratis and expatriates. However, a significant difference was found in physical and social & financial domains in two groups. There were no significant religious or spiritual concerns reported by survivors in both groups. A Chi-square test showed no association “between nationality and age” (Sig=0.287) and “between nationality and stage” (Sig=0.083) of the disease. Results also demonstrated significant positive association between physical concerns and received treatment whereas information concerns were significantly associated with age and type of the treatment received. The association between quality of life and psychosocial concerns was also explored using correlation analysis techniques. There was a negative correlation found between quality of life and the scores of psychosocial concerns including physical, social, emotional as well as spiritual concerns ($p< 0.01$) and a significant correlation was found between quality of life and information concern ($p<0.01$). Multiple regression results showed significant positive association between physical concerns and received treatment, whereas information concerns were significantly associated with age and type of the treatment received. Physical and emotional concerns were found to make the strongest contribution to explain quality of life (QOL) ($p<0.001$, and $p=0.001$ respectively). In phase two, thematic analysis revealed three broader themes including “living experience with breast cancer, survivors’ psychosocial concerns” and “survivors’ experience with healthcare providers which revealed in-depth concerns amongst cancer survivors about addressing their physical, informational, social, financial, emotional, and spiritual needs related to living with cancer.

Cancer survivors continue to face challenges and symptoms even after their treatment is completed (Tian, Cao & Feng; 2019; Rutten, 2005; Siemsen, 2001), however, culturally tailored psychosocial support would likely improve their survivorship experience. In order to do that, health providers need to facilitate the development of comprehensive and integrated cancer services to meet the ongoing psychosocial needs of cancer patients. The study has indicated several gaps and barriers in the provision of high-quality cancer care such as lack of routine assessment of survivors’ psychosocial concerns. It also highlights the need for further research in psychosocial needs and cancer survivorship care particularly in the region.

KEY WORDS: Breast cancer, psychosocial needs, expatriate in the United Arab Emirates, cultural dimensions of cancer care, cancer trajectory.

Chapter 1: INTRODUCTION

"All patients with cancer and their families should expect and receive cancer care that ensures the provision of appropriate psychosocial health services. It is not possible to deliver good-quality cancer care without addressing … psychosocial health needs (Institute of Medicine, 2008, pg. 1)".

1.1 RESEARCH QUESTION

What are the psychological needs of Emirati and Expatriates in the United Arab Emirates?

1.2 RESEARCH PROBLEM

Breast cancer survivors not only experience multiple long-term adverse effects of treatment (Lovelace, et. al., 2019; Haidinger & Bauerfeind; 2019; Ewertz & Jensen., 2011) but many face a challenge to address the pre-existing comorbidities of their therapies which often lead to multiple other issues (Bodai & Tuso., 2015, Senkus, 2011). Cancer survivors are at risk for recurrence, secondary cancers, comorbidities, functional decline, and poor quality of life (Kline, et. al., 2018). There is no standard psychological or emotional response to a cancer diagnosis, but many patients experience the emotional consequences to be the hardest to deal with (Towers, 2016). Women's experience of breast cancer is unique and a complex feature of survival which impacts individuals varyingly. For some, cancer may be experienced as a single event with a defined start and end point whereas for others, it could be a chronic spectrum of events from pre-diagnosis, through diagnosis, treatment and follow-up. Follow-up may encompass different outcomes and consequences from long-term survivorship, recurrence of cancer or death due to it. It is important to assess the prevalence and magnitude of difficulties and concerns that cancer survivors may experience throughout the cancer trajectory. To improve cancer survivorship experience and to help identify the services needed by the cancer survivors, it is crucial to identify and address their needs, concerns and benefit of having lived with, through and beyond a cancer diagnosis.

The needs of cancer survivors are wholly a unique interpretation for each individual which is heavily influenced by several psychosocial factors. Cultural norms and beliefs also play an important role. The disparities in cancer survivorship may occur due to the complex relationship of such factors. Thus, women of different cultural backgrounds may have different survival experiences from the disease and their needs could be distinct. Kagawa-Singer and colleagues, (2010) noted the impact of culture on cancer outcomes to be bidirectional in a way that one's culture influences the meaning assigned to the disease and their response to both disease and the healthcare system. Understanding sociocultural values has become the important aspect to detect potential determinants that could improve coordination of care and dynamics and meet culturally unique needs (IOM, 2013). In the absence of such understanding, cancer care strategies are less likely to be efficient to meet cancer patients' needs and to provide optimal cancer care. Additionally, large differences in cancer incidence and mortality have been consistently observed among social groups worldwide (Maskarinec, Sen & Koga, 2011; Ward, Cockkinides & Singh, 2004) yet, the underlying causes are not well understood (Ellis, et al., 2014). Studies have revealed that disease and illness are perceived individually in different cultures based on their beliefs and values (Morris, 2001; Resnicow, et. al., 1999). Moreover, the type and extent of the disease, the quality of care and psychological support services available to cancer survivors differ enormously across diverse settings (Andrykowski, et. al., 2008). Ethnic identification, religion, material realities, beliefs and behaviours lead to cultural diversity (Garrett-Rucks, 2016; Leavitt, 2002; Betancourt & Lopez, 1993).

Despite the high prevalence of cancer, there is a paucity of published data and limited understanding of the unmet needs of cancer patients in the Middle East (Nair, et. al., 2018). To date, relatively little is known about the psychosocial needs and its impact on cancer survivorship in the UAE. Majority of psychosocial issues and survivorship concerns have been studied in the Western world and awareness of these needs is relatively scarce in the Gulf region (Hulbert-Williams, et. al., 2019; Nair, et. al., 2019, 2018; Shapiro, 2018; Rowland & Bellizzi, 2008; Gilbert, et. al, 2008, Feuerstein, 2007, Ganz, 2003). Moreover, there is no structured survivorship program either at national or local level in the country. Psychosocial support services are generally provided upon request and referrals are made as needed. Knowledge of their specific psychosocial needs and if these needs are currently met, is also not known (Nair, et. al., 2018). In addition, there are only a few studies that have been conducted quite recently to assess cancer patients' needs in the diverse multicultural society (Nair, et. al., 2019; Nair. et. al., 2018, Assaf, et. al., 2017; Elbarazi, 2016). The findings showed that women in the UAE have significantly higher psychological unmet needs suggesting improvement in psychosocial care is an urgent priority.

1.3 AIMS AND OBJECTIVES

The aim of this study was to identify and investigate the psychosocial needs of Emirati and expatriate (UAE) residents who are not nationals, non-Emiratis) breast cancer survivors in the United Arab Emirates. Identification of cancer survivors' needs can indicate gaps in the service delivery and also identify utmost needs. The lack of literature for Emiratis breast cancer patients' needs provide the highest justification to pursue this study. This study is the first in the United Arab Emirates to address the breast cancer patients' needs. This research has identified concerns that breast cancer survivors deal with or fail to deal with. Thus, the study will aid in the development of culturally tailored cancer interventions that could improve survivorship care in the country and offers opportunities to redesign cancer services towards patient-centred care.

The study objectives were to:

- Identify the **physical, informational, social or financial, emotional and spiritual or religious needs** of cancer survivors residing in the UAE.
- Examine the **influence of nationality** on breast cancer survivors' needs.
    - ***Hypothesis 1:*** *There is no association between breast cancer survivors' nationality and age*
    - ***Hypothesis 2:*** *There is a significant association between nationality and stage of breast cancer.*
- Investigate **disparities in needs** of local Emiratis and expatriates utilising socio-demographics and clinical factors.
    - ***Hypothesis 3:*** *There is a significant relationship between demographic factors and psychosocial concerns of breast cancer survivors.*
- Identify factors to aid the development of culturally tailored **cancer survivorship programs.**
    - ***Hypothesis 4:*** *There is a significant relationship between psychosocial concerns of breast cancer survivors and their overall quality of life.*

1.4 SIGNIFICANCE OF THE STUDY

The widely accepted World Health Organisation (1948) definition of health encompasses physical, mental as well as social aspects of well-being which necessitates the use of multi-dimensional assessment of cancer patients' needs (Clinton-McHarg, et. al., 2010). The measurement of cancer patients' needs identifies their individual concerns and the extent of help likely to be required to address them (Rainbird, Perkins & Sanson-Fisher, 2005; Bonevski, et. al., 2000). By addressing the gaps in cancer patients' needs in accordance with different domains and in association with culture and sociodemographic factors, effective health interventions could be developed and tailored to meet the unique needs of each cancer survivor (Mukherjee, et. al., 2018; Setyowibowo, et. al., 2018; Douglas, et. al., 2016).

Understanding the full impact of unmet needs of the cancer survivors on their quality of life is crucial and clinically of prime importance throughout their continuum of survivorship to offer timely effective interventions. In addition, a robust body of knowledge to guide survivorship care is essential to optimally understand the healthcare needs of cancer survivors, identify evidence-based surveillance and follow-up strategies, identify and address unmet needs and determine ways to reduce occurrence and severity of treatment-related adverse effects among cancer survivors (Haylock & Curtiss, 2019). Several studies have found the direct association of greater supportive care with survival and its impact on better quality of life (Park & Hwang, 2012; Park & Hwang, 2012; Epplein, et. al., 2011; Uchida, et. al., 2011).

Improving the quality of life of breast cancer survivors requires addressing the unmet supportive care needs of the breast cancer patients (Lam, et. al., 2011). Investigating the needs of breast cancer patients offers a direct measure of the patients' support preference as well as gaps in the current services (Carlson, Waller & Mitchell, 2012). The identification of needs clarifies the areas where actions and resource allocation are needed in the cancer care setting to help cancer patients overcome their difficulties also result in reducing healthcare utilisation and cost by prioritising the urgent needs, and potentially enabling problems to be prevented or reduced through appropriate evidence-based early interventions (Akechi, et. al., 2011; Shim, et. al., 2006; Carlson & Bultz, 2004). Addressing breast cancer survivors' needs in the early stage of their survivorship provides guidance for new strategies in healthcare settings that could potentially reduce the burden of the disease and treatment in the long run thereby improving their quality of life (Edib, et. al., 2016). Research in this area is important to ensure the provision of culturally relevant and appropriate cancer care and to improve cancer outcomes for the cancer survivors residing in the UAE. It is paramount to gain a more comprehensive understanding of the psychosocial needs and concerns that cancer patients deal with to ensure their optimal management and care. Developing and evaluating culturally tailored psychosocial care interventions for UAE cancer survivors would likely ensure their optimal management and care.

This thesis is apparently the first to investigate breast cancer survivor's needs and survivorship concerns and to foster informed intervention strategies towards cancer survivorship programs and research in the region. Additionally, cultural myths associated with cancer are not directly addressed in many countries particularly in Middle Eastern countries (Daher, 2012), hence, it is the first to identify cultural disparities in the residing population to address their survivorship issues encompassing their psychosocial needs. The study guides the implementation of appropriate psychosocial services as part of routine standard cancer care which may likely have a positive impact on cancer survivors' wellbeing and their quality of life.

This study successfully bridges the research gaps in the context of culture and diversity in the United Arab Emirates. This study offers valuable direction for future research and evidence to inform the optimal cancer care and provision of psychosocial cancer care for all cancer survivors in the UAE.

1.5 ORGANISATION OF THESIS

This dissertation is organised into eight chapters that allows developing the material as specified by the School of Health and Society at University of Salford**.** Chapter one provides the introduction encompassing an overview of the research problem, aims and objectives, rationale of this research, personal experience of conducting this study, and overview of thesis organization. Chapter two provides a literature review which explores the scientific evidence on breast cancer survivors' needs. Chapter three explains the methodology that guided the achievement of the research's objectives. Chapter four presents the results and analyses from both quantitative and qualitative methods. Chapter five contains discussion and the conclusion of the research including dissemination strategies to address the problem to healthcare leaders.

Chapter six presents an overall conclusion extrapolated from the study. Chapter seven provides a list of references whereas Chapter eight contains appendices providing a list of materials, tools and resources used to conduct this research.

1.6 BACKGROUND

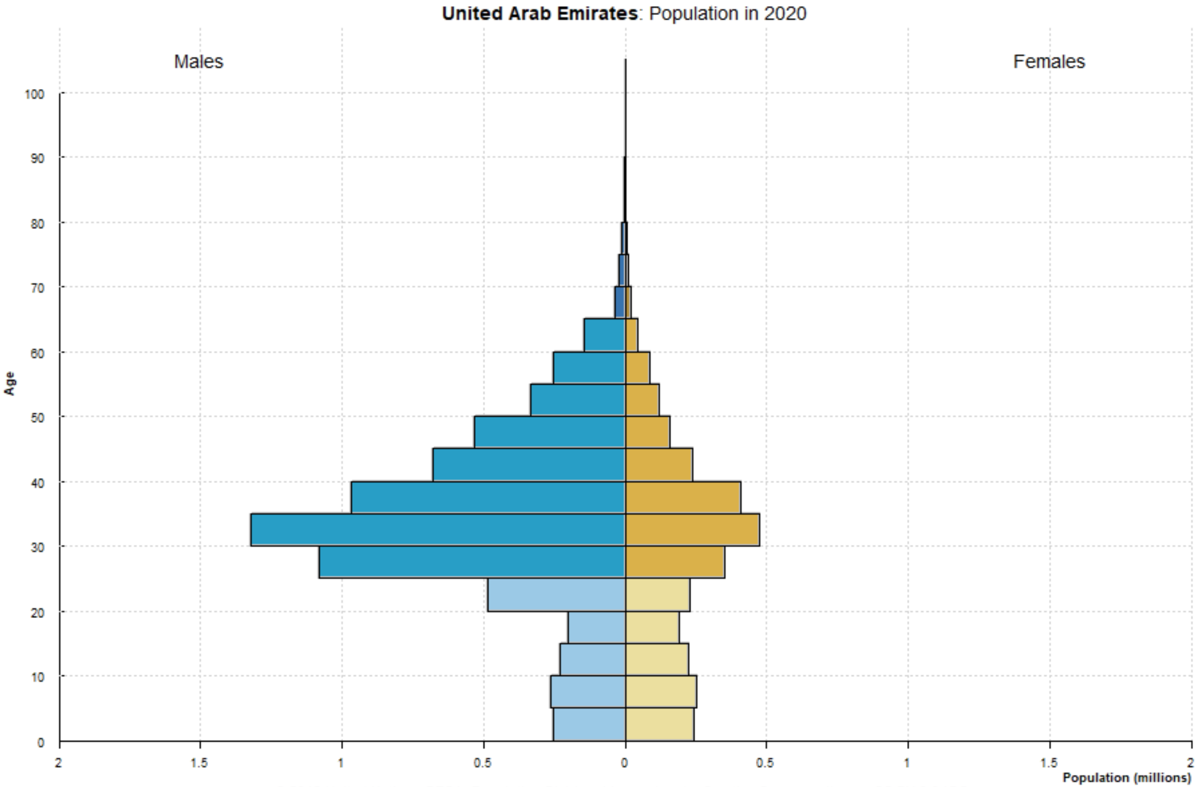
1.6.1 UNITED ARAB EMIRATES POPULATION

The UAE is a small country situated in the Middle East region of Asia between Saudi Arabia and Oman. It comprises seven emirates which include Abu Dhabi, Dubai, Sharjah, Ajman, Umm Al Quwain, Ras Al Khaimah, and Fujairah. The Emirate of Abu Dhabi is the capital and the largest, equivalent to 86.7% of the country's total areas excluding the islands (Kenneth & Miklos, 2017).

Figure 1: Map of United Arab Emirates

The UAE is considered as one of the richest countries in the world with GDP per capita $67,696 (World Economic Forum, 2017). It has the most diverse population in the Middle East due to a large number of expatriates. Over 75% of the UAE population is expatriate. The expatriates come from different nationalities and have different socioeconomic and cultural backgrounds than local Emiratis. About 50% of the UAE population is from South Asia mainly from India, Pakistan and Bangladesh. Those from other parts of Asia include Filipinos, Iranians and

Chinese contributing one million of the population. There are approximately 500,000 westerners from Europe or America in the country.



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United Nations, DESA, Population Division. *World Population Prospects 2019*. http://population.un.org/wpp/

Figure 2: United Arab Emirates Population Pyramid

The population has a skewed gender distribution consisting of twice as many males than females (United Nations, 2019). Eighty eight percent of the UAE population is urban and the illiteracy rate (1975-2019) among youth is over 90% (The World Bank, 2021). Islam is the largest and the official religion of the country among both expatriates and UAE nationals (UAE Government Portal, 2019; AlMazrouei & Pech, 2015). Although Life expectancy is 77.8% (UAE Government Portal, 2021), the population of the UAE is still relatively young, with 25.3% of the population under 15 years and 90.4% of the total population under 45 (Whitman & Aldinger, 2009). Healthcare insurance is mandatory for UAE residents and mainly provided by employers.

1.6.2 UAE HEALTHCARE SYSTEM

UAE is actively expanding its national healthcare system to meet the growing needs of its people and support economic diversification with leading medical centres, corporations and academic institutions playing vital roles in the process. All seven emirates provide healthcare services to their citizen and are rapidly building their healthcare infrastructure inclusive of hospitals and clinics.

The U.A.E. has a number of healthcare regulators at both the federal and emirate levels, each with their own geographic or functional purviews. U.A.E healthcare regulation has recently been shaped by two broad trends: (1) an expanding remit for the Ministry of Health and Prevention and (2) increasing coordination among regulatory authorities. At the federal level, the most important regulatory authority in the U.A.E healthcare sector is the Ministry of Health and Prevention (MOHAP) while others include the Insurance Authority and the UAE Nursing and Midwifery Council. While healthcare provision in some emirates (Northern emirates) is regulated entirely by MOHAP, certain emirates or free zones also have their own regulatory authorities, most notably The Department of Health – Abu `Dhabi (DOH) and Dubai Health Authority (DHA) which regulates the healthcare sector in Abu Dhabi and Dubai respectively. Whereas, Dubai Healthcare City Authority – Regulatory (DHCR), regulates Dubai’s healthcare free zone: Dubai Healthcare City and is responsible for the licensure of all healthcare professionals and healthcare operators in the free zone. On the other hand, Sharjah Health Authority Sharjah Health Authority (SHA), regulates Sharjah’s healthcare system in the emirate of Sharjah.

1.6.3 ABU DHABI HEALTHCARE SYSTEM

The Department of Health Abu Dhabi (DoH) is the regulatory body of the healthcare sector in the Emirate of Abu Dhabi that defines the strategy for the health system and monitors and analyses the status of population and performance of the healthcare system. The DoH has a comprehensive cancer control plan that includes prevention, early detection, diagnosis, treatment and palliative care. DoH has established the breast cancer management standards with the help of experts that include screening standards as well as genetic counselling. Yet, much work is needed towards raising awareness and implementing cancer survivorship strategies.

The Abu Dhabi Health Services Company (SEHA) is an independent public joint stock company that owns and operates all public hospitals and clinics across the Emirate of Abu Dhabi. SEHA claims to be is one of the largest healthcare networks in the U.A.E., consisting of 12 hospitals, 46 primary healthcare clinics, 10 disease prevention and screening centres, 3 mobile clinics, 1 school clinic, 2 blood banks, 4 dental centres, 2 employee healthcare centres, and 1 vaccination centre. SEHA's business entities are – in decreasing order of patients served – Tawam Hospital, Sheikh Khalifa Medical City, Al Ain Hospital, Al Gharbiya Hospitals, Al Mafraq Hospital, Al Rahba Hospital, Sheikh Shakhbout Medical City and Corniche Hospital (the U.A.E.'s largest maternity hospital). The Al Gharbia Hospitals business entity notably consists of six hospitals and four primary healthcare centres that serve more than 200,000 people living in the 60,000-square-kilometer area of Abu Dhabi known as the Western (Al Gharbia) Region.

In addition, Government-linked entities such as Mubadala Healthcare, a division of the prominent and diverse Abu Dhabi government investment vehicle Mubadala Investment Company, are supporting the development of a world-class, commercially sustainable private healthcare sector in the U.A.E. Mubadala Healthcare works with prominent international partners including Cleveland Clinic Abu Dhabi, Healthpoint, Imperial College London Diabetes Centre and Abu Dhabi Telemedicine Centre. Other Mubadala Healthcare assets include the Abu Dhabi Knee & Sports Medicine Centre, Capital Health Screening Centre, Tawam Molecular Imaging Centre, and the National Reference Laboratory.

Over the last decade, the U.A.E. has moved toward mandating health insurance for all citizens and residents. Healthcare insurance is mandatory for Abu Dhabi residents mainly provided by the employers whereas Abu Dhabi (now Department of Health) provides comprehensive health coverage to all U.A.E. nationals living in that emirate at no cost through the "Thiqa" program. However, despite breast screening being covered under health insurance, many women do not get checked. A recent study established that only 13.95% of females over the age of 40 in the UAE had a mammogram in a two-year period (So, et. al., 2019). A mammogram cost about

DHS 300 dirhams (£62); however, the major barriers to breast health seeking behaviour have been identified as cultural rather than economic.

1.6.4 CANCER DEFINITION AND BIOLOGY

Cancer can be defined as a disease in which a group of abnormal cells grow uncontrollably by disregarding the normal rules of cell division. Normal cells are constantly subject to signals that dictate whether the cell should divide, differentiate into another cell or die. Cancer cells develop a degree of autonomy from these signals, resulting in uncontrolled growth and proliferation. Abnormal cell growth (neoplasia) is the biological end point of the disease. If this proliferation is allowed to continue and spread, it can be fatal. Almost 90% of cancer related deaths are due to tumour spreading – a process called metastasis (Hejmadi, 2010). Initiation and progression of cancer depends on both external and internal factors within the cell such as (tobacco, chemicals, radiation and infectious organisms in the environment or inherited mutation, hormone or immune conditions or mutation that occur from metabolism within the cell). These factors can act together or in sequence, resulting in abnormal cell behaviour and excessive proliferation. As a result, cell masses grow and expand, affecting surrounding normal tissue and can also spread to other locations in the body which is called metastasis. Seyfried & Huysentruyt (2013) explained that tumour cell invasion of surrounding tissues and spread to distant organs is the primary cause of morbidity and mortality of cancer patients.

1.6.5 CANCER DIAGNOSIS

The diagnosis and development of cancer is a traumatic and life-changing event (Smith, et. al., 2016). It is a dreadful experience which disrupts a life of even the strongest individuals resulting in psychosocial consequences mainly, emotional distress, sadness, depression, anxiety and to the extent that families could break down too. Many women go through the intensive and challenging cascade of treatment with a diverse range of interventions. Cancer treatment often involves multiple options which can be toxic, exorbitant, intense and long-term. In addition, responses to cancer treatments could be quite variable thus predicting the potential risks and benefits of various treatment options for the individual cancer patients could be difficult. Because of the life-threatening nature of the disease and its emotional consequences along with limitations and complexity of treatment choices, it is often difficult for cancer survivors to make decisions about their care and to cope with the illness due to the fragmented nature of the cancer care system. The transition from the various stages during the cancer trajectory is generally challenging and adjustment to survivorship could be daunting (Chadder, et. al., 2018; Costanzo, et. al., 2011; Kantsiper, et. al., 2009; American Society of Clinical Oncology, 2007). Cancer diagnosis has deep effects not only on psychological state but also on the cognitive, emotional, spiritual and social features of the individual **(**Çürük, et. al., 2020; Gorman, 2018; Wei, et. al., 2016). Cancer survivorship remains a challenge because, in most cases, patients do not return to a precancerous state after the completion of treatment. Diagnosis and treatment of breast cancer are stressful events and may result in various psychosocial concerns which are more commonly experienced following treatment (Liao, et. al., 2014). Breast cancer survivors need not only medical treatment but also psychosocial support (Garlick, et. al., 2011) which results in delaying the frequency, duration and intensity of late and long-term effects of cancer treatment (Liao, et. al., 2010).

1.6.6 CANCER – A GLOBAL PROBLEM

Cancer has emerged as one of the most serious health issue globally threatening human health and lives both. Cancer incidence and mortality are rapidly growing worldwide. The reasons are complex and reflect both aging and increase in population (Bray, et. al., 2018). Cancer is the second leading cause of death globally responsible for an estimated 9.6 million deaths in 2018 (World Health Organisation, 2021, 2018a). Globally one in six deaths is due to cancer. Approximately 70% of deaths are reported from lower- and middle-income countries where late-stage presentation and inaccessible diagnosis and treatment are reported as main concerns. According to the World Health Organisation (2018b), around one third of deaths from cancer are due to behavioural and dietary risks. In addition, only one in five low- and middle-income countries have the necessary data to drive cancer policy. Data from GLOBOCAN (2018a) indicated that 43.8 million people diagnosed with cancer were alive within 5 years of a cancer diagnosis. Survivor population represents a diverse range of psychosocial issues emerging from cancer. Understanding cancer survivorship issues can help the public health community meet the needs of this expanding and heterogeneous population. Likewise, the burden of cancer in the United Arab Emirates is high which is ranked the second leading cause of non-communicable disease related mortality in the country (Ferlay, et. al., 2015; Loney, et. al., 2013). Radwan and colleagues (2018) reported that in the GLOBOCAN (2012) reports, cancer incidence and mortality rates in UAE reached 92.5 and 58 per 100,000 people, respectively.

1.6.7 BREAST CANCER EPIDEMIOLOGY

Globally, breast cancer is the second most common cancer and the most frequent cancer (11.6% of all cancers) among women with an estimated above 2.1 million new cancer cases diagnosed in 2018 (Globocan, 2018a). It ranks as the fifth leading cause of death (627,000 deaths, 6.6%) because the prognosis is relatively favourable, at least in more developed countries. According to the World Health Organisation (2015), it is also the leading cause of cancer death in women (15.0%). WHO's projected death rate from breast cancer is predicted to rise to 805,116 deaths per year by 2030, accounting for a 43% increase in the absolute number of deaths from the disease (World Health Organisation, 2017a). For breast cancer mortality, the UAE ranks 131 out of 172 countries (World Life Expectancy, 2017a).

Breast cancer in the UAE is the most common cancer affecting women regardless of nationality or gender (International agency for Research on Cancer, 2020). It constitutes almost 20% of all cancer cases annually (Ministry of Health & Prevention, 2017). In 2014, it accounted for 38% of all cancers in women (Kenneth & Miklos, 2017). According to the Ministry of Health, UAE (2014) latest cancer report, there were 819 new cases diagnosed with breast cancer in the UAE in 2014 of which 94% were malignant and 6% were in-situ tumours. Among malignant cases, 77% were expatriates and 23% UAE nationals, reflecting overall UAE population distribution. The age group 45-49 was the most prevalent with 18% of all cases, followed by 40-44 & 35-39 (14%) and 50-54 (14%). Reported by the Department of Health, Abu Dhabi, (2017), 12% of deaths occurred due to breast cancer in the Emirates. Approximately over thousand women are newly diagnosed with breast cancer (International agency for Research on Cancer, 2020). Women in the Gulf region are more likely to develop breast cancer at least a decade earlier than western countries (Najjar & Easson., 2010). As per 2010 report by the Centre of Arab Genomic studies, Arab women are most likely to develop breast cancer at an early age with the median age at diagnosis 10-15 years younger than North America and Europe (Friend of Cancer Patients, 2018). In the UAE, around 15% of breast cancers are metastatic (Globocan, 2015). This statistic is quite alarming as in younger women, breast cancer is generally more aggressive and less likely to have sustained response to treatment than in older women

(Bendardaf, et. al., 2020; Friend of Cancer Patients, 2018; Elobaid, et. al., 2016; Maarraoui, et. al., 2006).

Despite an increase in the number of women in the UAE taking up breast cancer screening and having access to the national screening programmes, only around 75% seek medical advice after experiencing signs and symptoms (Cardoso, et. al., 2018). A previous study in the UAE addressed that almost 49% of women never had a breast exam and 44% never had a mammography, expressing a lack of knowledge about the existing screening programs in the country (Elobaid, 2014). The study concluded that such healthcare choices are often considered as being associated with the complex religiously dominated culture of the UAE. Therefore, culture has a strong association with women's decision-making in the UAE society (Elobaid, et. al., 2016).

1.6.8 CANCER SURVIVOR AND CANCER SURVIVORSHIP

"What patients see through the glass is not a world outside cancer, but a world taken over by it—cancer reflected endlessly around them like a hall of mirrors." -- Siddhartha Mukherjee, The Emperor of All Maladies

A cancer patient is considered to be a survivor **from the time of diagnosis until the end of life** (National Cancer Institute, 2021a).

The concept of survivorship has been widely debatable and in the past few years a variety of other definitions of cancer survivorship have been outlined. The definition has been expanded to include family, friends, and caregivers (National Cancer Institute, 2021b; Bell & Ristovski-Slijepcevic, 2013)

American Society of Clinical Oncology (2017) defines cancer survivorship as the process of living with, through and beyond cancer. By this definition, cancer survivorship begins when a person is diagnosed (Doyle, 2008; Mullan, 1985).

Although the term survivor refers to an individual who is diagnosed with cancer from the time of initial diagnosis, cancer survivorship rather focuses on the health and life of a person with cancer **mainly post treatment until the end of life.** According to Bugos (2015), the conceptual difference between the phase of survivorship beginning at the time of diagnosis and survivorship following curative treatment creates conflict in defining the best time and ways to provide survivorship care, especially to people who are challenged by incurable cancers.

Survivorship covers the physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also part of the survivorship experience (National Cancer Institute, 2021). According to the Institute of Medicine (2006), survivorship begins at diagnosis, the moment the battle with cancer begins. Cancer survivorship describes the many experiences and emotions that are part of living life as a cancer survivor (Livestrong foundation, 2011; Lance Armstrong Foundation, 2004).

The definition of survivorship could differ around the scope of the population covered. Some refer to the term **"survivorship" to encapsulate individual experience through the cancer journey** whereas others apply the term to a distinct phase in the cancer trajectory between primary treatment and cancer recurrence or end of life (Rowland, et al., 2006; IOM & NRC, 2006). The later definition is widely accepted and commonly used to discuss cancer survivorship in general. **In this particular study, the survivorship concept has been applied considering the former definition** while broadening the scope of population**:** ***all cancer survivors from the time of initial diagnosis through the cancer trajectory***. The approach will avoid missing out the opportunity to capture the population which is generally considered as reserved and modest.

1.6.9 CANCER AND QUALITY OF LIFE (QOL)

Cancer can lead to severe distress as survivors face several complex issues through transition to survivorship (Melchior, et. al., 2013). Effects of cancer and its treatment and quality of life perception both are subjective perceptions and how cancer survivors perceive them in day-to-day life is quite an individual experience which is unique to each person. Although accepting the new norm, the majority of cancer survivors have difficulty adjusting to the trade-offs of survival whether it is long term or late effects or treatment. The ability of maintaining a sense of control greatly influences survivors' psychological wellbeing most commonly resulting in anxiety and depression (Gorman, 2018). Although breast cancer care today involves state-of-the-art biomedical treatment, it can fail to address the broader psychosocial issues associated with the transition to breast cancer survivorship (Culbertson, et. al., 2020). Physical symptoms, such as pain, infection, lymphedema and impaired arm mobility are known symptoms of breast cancer which adversely affect both physical functioning and psychological health, subsequently resulting in decreased QOL (Taghian, et. al., 2014; Fu, et. al., 2013). The QOL in the healthcare context is defined and measured by the perception of individuals where they stand in their lives geared by their culture and value system in which they live in relation to their goals, standards and concerns (WHO, 2012). Grant & Dean (2003) identified the domains of quality of life to include physical health, emotional state, level of independence, social relationships, environment, and spiritual state. In healthcare, physical, emotional, mental and spiritual elements of life are intricately woven together and interact to support a strong and healthy person (King, Smith & Gracey, 2009). Any change in one domain affects the other domain. For instance, fertility concerns affect the emotional, spiritual as well as social domains. Since breast cancer brings a multitude of problems in women, healthcare providers should take a holistic approach to identifying and addressing their psychosocial needs and adjustments of patients. Meeting cancer survivors' needs can lead to many positive patient outcomes, including better ability to cope with disease symptoms and treatment side-effects, improved physician–patient communication and better adherence to treatment regimens (Okediji, et. al., 2017; Brédart, et. al., 2012).

1.6.10 UNDERSTANDING CANCER AND CULTURE

"Experiences of cancer are culturally shaped and although it is impossible to know about all specific beliefs, we must recognise that differences exist. Cultural beliefs play an important role in whether people seek early diagnosis, how they understand their disease, the kind of support they are willing to accept, decisions about treatment and how they experience the process of getting well and dying (Cancer Forum, 1991).

Cancer is much more than a biological disease. The experience of illness cannot be separated from the cultural contexts in which it occurs. Cultural factors are involved at every stage in the journey through cancer from prevention to palliative care. Even the definition of what constitutes cancer varies according to the cultural context. For instance, in some cultures, only late-stage cancer is considered as real cancer that causes death and other non-fatal conditions are not perceived as cancer therefore screening is not widely used (Dein, 2007). The relationship between culture and cancer can be described as complex and multifaceted and might be expected to contribute to variability of the cancer burden across different cultural groups (Schmitz, et. al., 2013). In cancer patients, the perception of illness largely determines the quality of life and sense of well-being (Ma, et. al., 2018; Kus, et. al., 2017; Ashley, et. al., 2015). Levental's self-regulatory model provides a framework for understanding the impact that illness beliefs and emotions have on how an individual copes, adapts and responds to illness (Leventhal, et. al., 1984, 1980). According to this model, patients react to an illness based on a conceptual idea which is developed both cognitively and emotionally through a collection of personal experiences (Iskandarsyah, et. al., 2013; Kaptein, et. al., 2013). This model postulates that disease coping mechanisms depend on patients' perceptions about it which greatly influence their adherence to treatment, disease outcomes as well as sense of well-being (Ma, et. al., 2018; Kaptein, et. al., 2013; McCorry, et. al., 2013). Women of different ethnic backgrounds have different disease outcomes and survival (Tsai, et. al., 2011; Maskarinec, et. al., 2011). There is substantial evidence of the influence of ethnicity towards illness perception; for instance, people with darker skin colour perceive illness differently and have varied response to disease outcome compared to whites (Wang, et. al., 2013). Additionally, religion and spirituality have a positive influence on mind, body and soul which resulted in better health outcomes (Bowie, et al., 2003; Koenig, 2000; Tix & Frazier, 1998). The incongruence in cancer survivorship may also occur due to multifarious factors including socio-economic position, social and cultural injustice (Kingsley, 2010; Cancer Health Disparities, 2008). Thus, identifying the cultural determinants and cultural differences in cancer survivorship is critical for improving care (Lam, et. al., 2011).

Cultural issues have become an increasingly important consideration in cancer care. Culture plays a vital role in establishing perceptions of disease and health. Cultural determinants particularly beliefs about health and illness, societal values, family role, religious beliefs and disclosure of cancer information have been addressed for their association with cancer and cancer disparities (Gómez-de-Regil, 2014; Chaturvedi, et. al., 2014, Marshall, et. al., 2011). However, beliefs vary across different regions of the world which are largely shaped by religious values and are associated somehow to the essential elements of culture (Martsolf, 1997). It is often obscure whether those beliefs originated from religious affiliation or are associated with cultural background (Miller, 1995). People's beliefs about health and illness can clearly affect their behaviour (Gómez-de-Regil, 2014). Their perception of illness may influence the probability of seeking treatment (Kugbey, et. al., 2020; Agbokey, et. al., 2019; Fronda, 2017; Elobaid, et. al.,2016), treatment adherence (Nair, et. al., 2018; Lee, et. al., 2019), use of medical services (Qian-Xin, et. al., 2017; Meacham, et. al., 2016; Torres, et. al., 2016; Walijee, et. al., 2011) and quality of life (Lee, et. al., 2019; Hopman & Rijken, 2015). In some cultures, disease is considered God's punishment (Boyes, et. al., 2009, Wiggers, et. al., 1990) or one's 'karma' (fate) (Chaturvedi & Chandra, 1998). Illness and disease are considered to be weaknesses in Arab culture where families with ill individuals are perceived weak and vulnerable. In order to preserve Arab cultural values, disease is not discussed in societies and is considered a family issue which must be kept in their homes (Kane, et, al., 2020). Cancer is considered a bad word (Surbone, 2008) and individuals, particularly in Eastern cultures, have fatalistic views about living with passivity. Also, it is not uncommon that women's quality of life is partially shaped by gender hierarchies within some cultures particularly Arabs (Salem & Daher-Nashif, 2020) and is mainly described as the ability to fulfil their family roles as mothers and wives (Hwang, et. al., 2017; Hammoudeh, et. al., 2017; Elobaid, et. al., 2016; Jassim & Whitford, 2014; Taha, et. al., 2012). On the contrary, in Western cultures, most people involve themselves in fighting a battle against cancer and to win their health back (Chaturvedi, et. al., 2014).

How patients make healthcare decisions, may also be influenced by the cultural background. Some cultures place a strong value on the community while others encourage individual independence (Givler & Maani, 2020). Cultural geography influences an individual's needs, attitudes and response to cancer and can be targeted to improve comprehensive cancer care (Corner & Bailey 2008). Culture and dynamic belief, lifestyle and values systems pass through generations and shape people's definition of health and well-being (Kagawa-Singer & Kassim-Lakha, 2003; Angel & Thoits, 1987). Such influences are complex and may vary across different cultures (Fielding, et. al., 2013).

Multidimensional cultural factors such as language, environment, social structure, religion and economy influence health status, disease perception and medical care (Lopez-Class, et. al., 2011). There are strong social conventions which permit or prohibit the public expression of emotion. In some cultures, anger is a common response to cancer diagnosis whereas in others such as in Arabs, the expression of anger is seen as lack of faith in God. It is important for healthcare providers to understand the modes of emotional expression so that they are not labelled as unacceptable or pathological (Dein, 2007). Additionally, socio-cultural factors and family values are associated with receiving a late diagnosis and known to be constituted barriers to cancer screening, early diagnosis and treatment (Elobaid, at. Al., 2016; Australian Institute of Health and Welfare, 2014).

The possible reasons for a worse prognosis of some cancer in certain cultural groups have been addressed as late presentation, lack of treatment, treatment non-compliance, use of traditional healing and cultural insensitivity among health professionals (Salem & Daher-Nashif, 2020; Elobaid, at. al., 2016, Shahid, et. al., 2016; Kagawa-Singer, et. al., 2010; Dein, 2007; Brach & Fraser, 2000). Cancer has also been associated with the “Evil Eye” and believed to be resolved on its own or through home remedies such as rubbing the lump with olive oil (Salem & Daher-Nashif, 2020).

There are also variations in the way that a cancer diagnosis is conveyed to the patients. In non-Western cultures mainly in Arabs it is the family who are told about the diagnosis not the patient. This can cause major problems in Western healthcare setting where the ethos is towards open disclosures. Psychosocial issues may also vary between cultures because cultures view and value illness, treatment and caregiving differently (Shahid, et. al., 2011; Chen, et. al., 2011; Kumar, et. al., 2010). Similarly coping strategies can also be influenced by such view about illnesses and cultural beliefs (Arman, et. al., 2004; Arman & Rehensfeldt, 2003; Rodgers & Cowles, 1997). For instance, in Muslim societies, it is believed that the stronger their faith in Allah (God), the greater the chance of a cure (Al-Azri, 2013). Therefore, women in these societies tend to follow their religious beliefs and practices to cope up with the diagnosis including listing and reciting the Qur’an, praying and reciting religious verses (Green, et. al., 2018; Gleeson, et. al., 2016; Al-Azri, 2014).

It is crucial to understand the differences between societies in which their culture shapes individuals’ reaction to it. Cultural elements and traditions including gender hierarchies, family values, tribal mentality, cultural practices and perceptions may shape individual beliefs, social attitude, behaviours, perception, experience, needs as well as reaction and desired outcome of the disease and its treatment (Elobaid, et. al., 2016). The provision of high-quality cancer care to cancer survivors and their families require attention to their psychosocial needs and concerns which may be related to cultural aspects of survivors' experience. Cancer survivors' needs should be met on their own terms. The provision of holistic care necessitates understanding of cultural factors and its influence on survivors' cancer experience and needs play an important role in their comfort throughout the disease process and help them deal with the life-threatening illness (Wright, 2019).

1.6.11 CANCER SURVIVORSHIP CARE IN THE UAE

Although we have a greater knowledge about the ongoing challenges of cancer survivorship, fragmented cancer care in the country has hampered effective and coordinated delivery of needed psychosocial care to cancer survivors. Unfortunately, there is no institution or facility **in the UAE** which offers a **structured cancer survivorship programme** so far. Also, there is a lack of evidence-based, culturally relevant and supportive care programs for cancer survivors in the country. Although the number of cancer survivors are increasing worldwide (Kimberly, et. al., 2019; Bray, et. al., 2018; Parry, et. al., 2011), the lack of data on survival rates in the UAE further overshadows the predicted need of survivorship programmes that are uniquely designed to meet the needs of local communities. Furthermore, there is no evidence available in the UAE to quantify the association of sociodemographic and clinical factors with breast cancer patients' needs. The concept of cancer survivorship has received more attention in some developed countries, yet the survivorship issues are less recognised in developing countries including the UAE (Grunfeld, 2006; Hewitt, et. al., 2006). The UAE health authorities have recognised the chronic nature of cancer yet the existing healthcare policies for the cancer care continuum remain primarily focused on raising awareness, early detection and standardising cancer care. Attention to cancer survivorship and long-term care needs are unevaluated and lacking in this country. There is a gap in cancer services to provide systematic follow-up care for the growing number of survivors. Cancer survivorship issues in the UAE are more complexed since the key challenge is that the complete spectrum of care is not fully covered by insurance companies and the basic insurance scheme for unskilled and lower paid workers may not cover cancer treatment expenses, although they may be covered by charitable organizations (Global Health Delivery–Dubai, 2018). Thus, many cancer survivors do not pursue follow-up after completing their cancer treatment due to sporadically planned hospital-based follow-up care which could be a further challenge for expatriates as they need to pay out-of-their pockets.

Based on these findings, healthcare authorities in the UAE should establish and implement cancer services that include cancer survivorship programs to reflect the full range of psychosocial needs experienced by cancer patients from diagnosis to cure, or terminal care. Authorities need to ensure that health professionals understand the expectations of cancer patients and appreciate that psychosocial needs vary by patients' socio-demographics to help them deal with a range of their survivorship issues.

1.7 PERSONAL EXPERIENCE

Since I have been working in the Oncology field for the past 14 years, the desire to conduct this research initially emerged from my work experience. My role in the Oncology service line and cancer information services requires analysis of cancer data and reporting cancer information including patients' outcomes. In this role, I regularly review hundreds of cancer patients' records and read about their cancer experience through different healthcare facilities and with many different providers. I realise how cancer patients navigate through different systems and struggle to cope with the disease process and may get stressed during the transition from the various stages in the cancer trajectory. It is apparent that many cancer patients in this region keep the disease confidential and some do not even disclose it to their family members. Most patients wait to seek cancer care at their advanced stages probably due to cultural reasons as cancer has been considered as a social stigma in the UAE and in other Arab countries. I learned that most cancer patients seem to be less informed about the relationship and impact of continuity of care and their health outcomes. Furthermore, some cultural attributes such as the unobtrusive nature of the local population in the UAE are socially introverted in discussing cancer openly as well as in addressing their needs to health providers which may pose a challenge to provide patient-centred care. I empathize with the pain and suffering that cancer patients experience through their survivorship trajectory. The limited view of survivorship care and the lack of coordination in the currently fragmented healthcare system have led me to investigate the unexplored area of cancer patients' needs and concerns through cancer survivorship and the gaps in the current practices in this multicultural community. This research has provided me the opportunity to be the voice of cancer patients and I hope this study can make a positive difference in improving cancer services and cancer patients' lives in the UAE.

Chapter 2: LITERATURE REVIEW

This chapter begins with a presentation of the literature relevant to cancer survivors' needs and survivorship concerns including the identification of the gaps in the current knowledge. The process of conducting the search has been explained. The conceptual framework of survivorship needs has been described which forms the basis of the research question to highlight survivors' needs and experience of having cancer. The sub-sections explore the existing literature on distinct types of cancer survivors' needs in a detailed manner which includes concerns about physical, information or educational, social & financial, emotional, spiritual or religious concerns. **The cultural influence** has been studied in detail **to identify disparities** among different races and cultures to further understand how needs are influenced by certain socio-demographics. The last section provides a summary conclusion of the information gathered through the literature search.

2.1 LITERATURE SEARCH STRATEGY

An initial search was conducted on "cancer patient needs" through the Salford Library and EBSCO host search engines in English utilising all resources regardless of time frame. The initial query resulted in 167,247 resources which were further narrowed down to 833 with the availability of full text, resources type including articles, text resources and electronic books, selecting breast cancer only, and by selecting databases or resources including: Elsevier, MEDLINE, PubMed Central, Springer, Sage, BMJ, Wiley, JSTOR, BMJ, PMC, Ovid, Taylor & Francis online, ScienceDirect & EThOS. The Google search engine was also explored for the relevant search utilising combination of keywords: cancer, breast cancer, survivors, cancer survivorship, cancer patients, needs, perceived needs, needs assessment, supportive care needs, psychosocial needs, ethnicity, race, culture, expatriate, Emiratis, Arabs, United Arab Emirates, Middle East & Muslims. The term *cancer patient* was used as synonymous with cancer *survivors*. Additionally, "TRIP" database (Turning Research into Practice, 2018, 2017, 2005) which is a free access medical database was searched to maximise the outcome of the latest literature utilising the same search terms which resulted in 12,881 results that includes all resources. The latter search included all studies which assessed needs of cancer patients or described aspects of need with breast cancer and presented the results with cross-cultural disparities. All searches utilised the above-mentioned methodology. Excluded studies were those that resulted in other types of cancer or did not particularly specify breast cancer or provided abstracts only. Newspaper articles, websites & audio-visual resources were also excluded from the search. There was no time frame considered for the published literature. The abstracts were reviewed initially to examine the relevance of the literature to the research. The references were also used to identify additional searches if relevant to the similar subject discussed in the source materials. The relevant studies were reviewed to assess their research design, sampling methods and findings; hence both qualitative and quantitative studies were reviewed. The below section will discuss the theoretical framework used in this study.

2.2 THEORETICAL FRAMEWORK

2.2.1 BACKGROUND

The general objective of this research is to investigate the multidimensional needs of breast cancer survivors so opportunities for improvement in cancer care could be identified. Many studies have shown that breast cancer diagnosis and treatment have considerable negative effects on the physical, psychological, and social health of patients and can reduce their quality of life (Haidinger & Bauerfeind, 2019; Kline, et. al., 2018; Jacobs, et. al., 2017; Hofsø, et. al., 2012; Waljee, et. al., 2011; Byar, et. al., 2006). The psychosocial domain in cancer care focuses on cancer patients' unique responses and reactions to cancer diagnosis and its treatment; thus, quality cancer care strives to minimise the patients' cancer treatment-related effects and symptoms. Minimising these effects may reduce distress and suffering of cancer patients to enable them to understand and cope with the disease, its treatment and the consequences. Comprehensive and high-quality cancer care needs to be delivered in a context of mutually respectful patient-provider relationship and must incorporate physical, psychosocial, emotional and spiritual dimensions (Aghaei, et. al., 2021; World Health Organization, 2018c; IOM, 2013, Epstein & Richard, 2007). As per Holland (2002), cancer survivors seek a comforting philosophical, spiritual or religious belief system to help them give a meaning to the new world of illness since the diagnosis of cancer, with the fears and threat attached to it result in a complex set of issues including physical and psychological reactions to individuals and their family as well. It is critical that healthcare providers need to individualise cancer care by using knowledge of the patients' experiences, behaviours, feelings and perceptions (Radwin & Alster, 2002).

2.2.2 CONCEPT OF "NEED"

Breast cancer survivors' psychosocial concerns and needs are the main focus of the theoretical framework of this study. A 'need' can be defined as the requirement of some action or resource that is necessary, desirable or useful to attain optimal wellbeing in cancer patients (Koh, 2013).

Need is an idiosyncratic concept which compasses a subjective interpretation. Needs can also be viewed as a theoretical construct which consists of general principles of human existence (Holmes & Warelow, 1997). In literature, no consensus has been established about the meaning of "need" in health (Asadi-Lari, et. al., 2004). According to Robinson & Elkan (1996), need is a subjective concept that is both relative to time and place therefore it is important to understand the meaning of individual needs objectively. Murray (1938) and Carver & Scheier (2008) explain need as an internal state or condition, a lack of something that is necessary for well-being and motivates behaviour.

Bradshaw's (1972) taxonomy provides a useful way of considering different perspectives that may emerge while exploring the needs related to a particular issue or population group from different angles. According to Maslow (1943), human needs arrange themselves in "hierarchies of pre-potency" such that the appearance of one depends upon prior satisfaction of more pre-potent needs. The needs are composed of physiological, safety, love/belonging, esteem and finally self-actualisation. In his seminal model of the Hierarchy of Needs pyramid, Maslow organized human needs in five levels forming a pyramid with more basic needs (physiological needs) at the bottom of the hierarchy and the need for self-actualization at the apex of the pyramid. Individuals will usually be motivated to meet higher need levels when lower order needs are satisfied therefore, we all must satisfy our need for security if we hope to achieve our highest potential which is called self-actualisation. However, Maslow (1943) later clarified that satisfaction of a need is not an "all-or-none" phenomenon, admitting that his earlier statements may have given "the false impression that a need must be satisfied 100 percent before the next need emerges" (Maslow, 1987).

The quality of life and well-being of cancer patients is determined by how well their physical, social, psychological, emotional, and spiritual needs are being met. Ng., et. al., (2017) used Maslow's hierarchy of needs pyramid in the context of breast cancer with reference to Institute of Medicine (US) (2008), Schmid-Büchi, S. et, al., (2008), NCCS Breast Cancer Survivorship Programme (2016) (Figure, 3) and posited that the distinction between the hierarchy of needs may be difficult for cancer patients as their needs are often interlinked. Therefore, all aspects of cancer patients needs must be assessed and managed concurrently (Ng, et. al., 2017). Cancer survivors' psychosocial needs can be explained using Maslow's hierarchy of needs in the figure below in the context of breast cancer patients' psychosocial concerns.

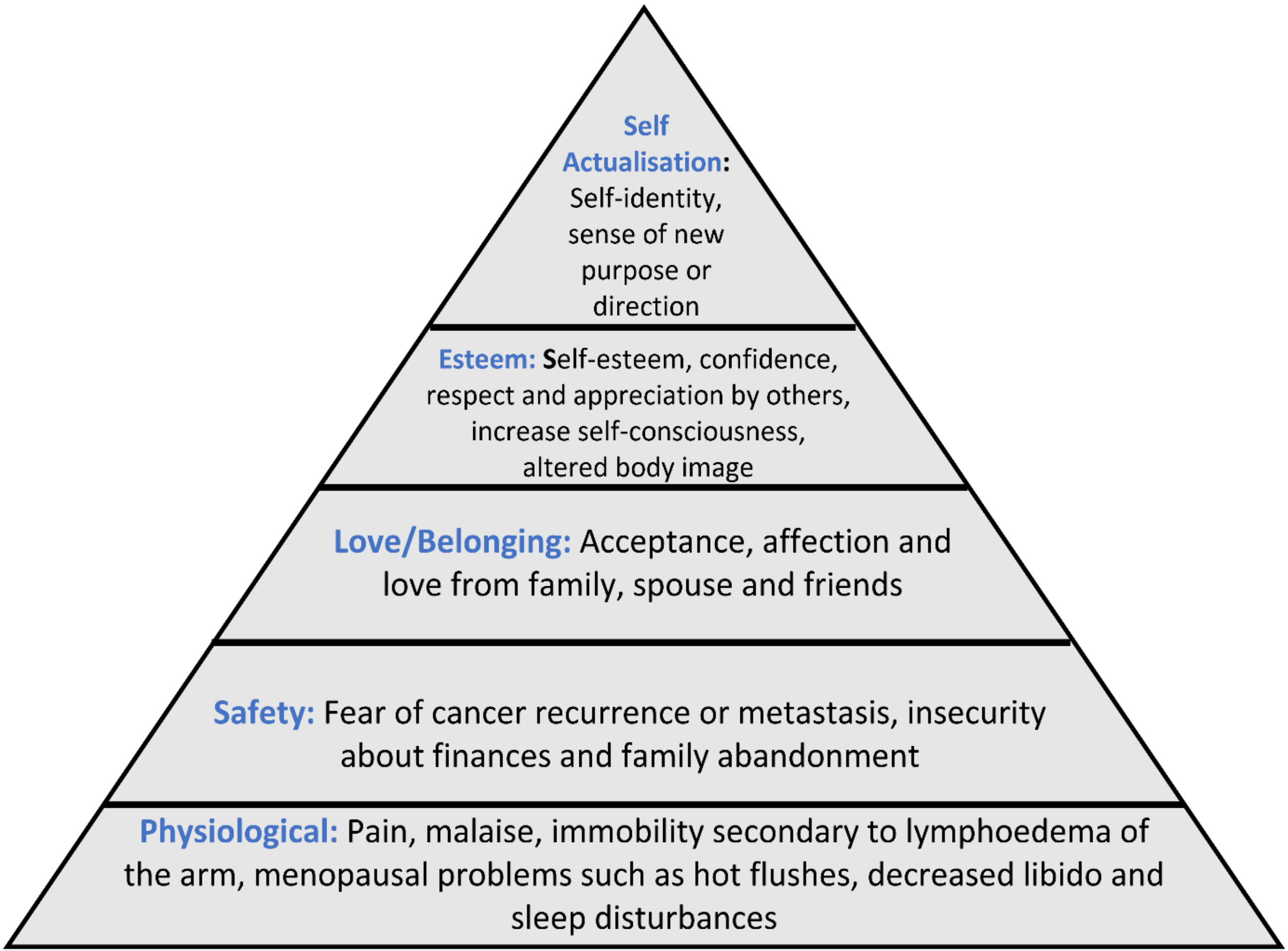


Figure 2: Maslow Hierarchy of Needs applied in the context of breast cancer, with reference from Institute of Medicine (US, 2008), Schmid-Buchi, S, et. al., 2008; NCCS Breast Cancer Survivorship Programme (2016)
Source: Ng, et. al., 2017

Figure 3: Maslow's hierarchy of needs in breast cancer context

Maslow's hierarchy of needs (1948) reflects on the key areas of everyday life and function that people with threatened health need such as cancer in order to continue their lives.

The first level which is the basic or physiological needs are of prime importance for the survival of the individual such as need for air, food, water and sleep; clothing and shelter and sexuality for the long-term survival of the human beings. If these needs are not met, the human body cannot function optimally. Maslow described the physiological needs as the most important since all the other needs become secondary until these needs are met. However, most humans effectively master physiological need-satisfying skills and then are freer to begin mastery of the skills required to satisfy the second level of needs that is “Safety needs”. Cancer may threaten fulfilment of even those basic needs. Physiological needs are the most pre-potent of Maslow’s needs pyramid and if these are not met as may be in the case of terminal cancer patients, other needs become meaningless and non-essentials. Cancer and cancer treatment may influence the patients’ basic biological and physiological needs and patients may have a need for help managing the effects of cancer and cancer treatment (Sanson-Fisher, et. al. 2000; Ferrell & Hassey, 1997)

At the next level, the needs for safety and security such as safe circumstances, stability and protection becomes important. People want to experience structure, order, predictability and control of their lives. These needs can be fulfilled by the family and society (e.g., police, schools, business and medical care). For example, emotional security, financial security (e.g., employment, social welfare), law and order, freedom from fear, social stability, property, health and wellbeing (e.g., safety against accidents and injury). While five-year survival is quite common with most of the cancer types (Allemani, 2015), still many people perceive cancer diagnosis as a death sentence. Cancer patients also feel loss of control over their life. Cancer raises fear, anxiety and insecurity that accompanies the diagnosis. It may cause emotional feelings of anxiety, distress and uncertainty, fear of loss of control, changes in daily routine and stability and fear of recurrence and it is important to feel free from such fears to satisfy the needs for safety and security and for one’s physiological health issues. Understanding these needs throughout their continuum of survivorship is crucial and clinically of high importance to offer survivors timely and effective interventions since challenges may exist beyond the initial diagnosis and treatment period as well (Stanton, et. al., 2015; Rowland & Bellizzi, 2014; Gilbert, et. al., 2008).

After physiological and safety needs have been fulfilled, the third level consists of '**belonging needs**'. Humans as social beings have a need for affectionate relationships and love, to belong to a group, to have friends, a family and a sense of community. Cancer has an impact on interpersonal relationships and sexuality which may lead to feelings of social isolation and loneliness or even depression (Adams, et. al., 2017).

Esteem needs constitute the fourth level which he classified into two categories: (a) **esteem** for oneself (dignity, achievement, mastery, independence) and (b) the desire for reputation or respect from others (e.g., status, prestige). The lower esteem is the need for respect from others, recognition, reputation, and status. The higher one is self-esteem. Humans have a need for self-respect. They want to feel good about themselves, valuable, competent, confident, independent and free. Maslow indicated that the need for respect or reputation is most important for children and adolescents and precedes real self-esteem or dignity. Many women experience a loss of confidence after having breast cancer and might avoid engaging socially due to low self-esteem due to changes and disfigurement in the body particularly after treatment such as surgery scars, changes in weight, skin, hair and the way one feels about her body. It is not uncommon for cancer patients to feel social rejection due to altered physical appearance for instance; after surgery (Arroyo & Lopez, 2011).

Maslow (1968) named the lower four levels of needs (physiological, security and safety, belongingness and esteem needs), deficiency needs or D-needs. Satisfying these needs is important in order to avoid unpleasant feelings or consequences

The fifth and highest level is **self-actualisation** which is based on a need to grow, to become what one is meant to be, and to develop one's potentials and capacities. These needs refer to the realization of a person's potential, self-fulfilment, seeking personal growth and peak experiences. Maslow (1943) describes this level as the desire to accomplish everything that one can, to become the most that one can be. As per Maslow (1968), growth is defined as the various processes which bring the person towards ultimate self-actualisation. Individuals may perceive or focus on this need very specifically. For instance, one individual may have a strong desire to become an ideal spouse, another may desire to be expressed economically, academically or athletically. For some, creatively, paintings, pictures or inventions are ways to express self-actualization. However, reversing the order of importance of needs is the exception rather than the rule. Although mastery of lower-level needs frees a person to invest more effort in satisfying the next high-level needs, if there is too much deprivation of the low-level needs, the person will become reinvested in the satisfaction of that lower-level needs. Cancer may pose existential questions about life and death for instance purpose of life or self-actualization with an opportunity for personal growth or self-reformulation (Mayan, et. al., 2006).

2.2.3 CANCER PATIENTS' NEEDS – AN OVERVIEW

Need in health care is caused by some form of "disturbance in health and well-being" (Donabedian, 1973). According to the World Health Organisation (1948), "Health is a state of complete physical, psychological, and social wellbeing and not simply the absence of disease or infirmity." This definition of health has not been amended since 1948. Cohen (1996) described healthcare as a basic human need. He further mentioned that if one does not receive this care, he or she will greatly suffer from it. Current medical literature accentuates the importance of health dimensions described by WHO from the perspective of patients to understand and assess their needs and improve their quality of life. Needs assessments are designed to identify needs, measure their importance, determine how well they are met and the factors that influence them (Lipscom, Gotay & Snyder; 2005). However, identifying the unique needs of the growing number of cancer survivors has been identified as a challenge (Alfano & Rowland, 2006). Cancer is a complex and devastating disease both physically and emotionally. Cancer experience depends on one's perspective and can be framed from various perspectives whether it is a patient, healthcare provider, researcher or a family member (Seyfried, 2012). Cancer survivors' needs can be influenced by a number of psychosocial issues for instance socioeconomic status, stage at the time of diagnosis or cultural norms and beliefs. Some of these factors have been reported as influencing the survival rate of breast cancer in some countries (World Health Organisation, 2015; Seedhom & Kamal, 2011).

Patients' needs differ individually throughout cancer trajectory and vary with the situation that cancer survivors experience and disease outcome. Folkman & Geer (2000) illustrated that the individual's response varies based on one's capacity to perceive how one thinks and judges the outcome of an event on his well-being. Assessment of cancer survivors' varying needs offers an opportunity to explore the individual preferences, identify areas of unmet needs and the gaps in cancer care services (Schouten, et. al., 2019; Cossich, Scholfield & McLanchlan, 2004). Such needs reflect coping demands of affected individuals throughout their cancer journey (Li, et. al., 2013) and ominously associated with psychological distress and poor outcome (Adler & Page, 2008). Hewitt, Herdman & Holland (2004) illustrated that the level of needs and distress varies individually and over the course of disease. Zimmermann (2015) further addressed the aspects of cancer survivorship that pertain to how psychological factors and the surrounding social environment influence the wellbeing of cancer survivors. Therefore, a thorough assessment of such factors is the key element to design an effective survivorship strategy.

A person's health status is widely considered to be closely associated with subjective well-being (Ngamaba, et. al., 2017). For many, health is viewed in biomedical terms as the absence of disease and disability and is determined primarily by physiological factors. A behavioural perspective, on the other hand, acknowledges the importance of this medical model but sees health as being influenced by the way in which people live their lives and therefore recognises behavioural as well as physiological determinants. An additional perspective on health is socio-economic approach which sees health as being primarily influenced by the social and economic environment within which people live and the constraints and opportunities such as structural factors create (Fines, Saunders & Forbes-Burford; 2013).

Most doctors will consider needs in terms of healthcare services that they can supply. Patients, however, may have a different view of what would make them healthier, for example, a job, a bus route to the hospital or health centre, or decent housing (Wright, Williams & Wilkinson; 1998). The government perspective of health needs is inherently political. It requires trade-offs and priority setting of health services while incorporating societal values and goals and compromising among stakeholders including the population since resources are scarce. Having said that, developing basic services and financial protection such as universal health coverage to all may results in major improvements in outcomes (American Cancer Society, 2021c). Since UAE is a high profile sustained country, prioritizing survivorship programming in a systematic way is imperative, given that, there are ongoing partnerships with some of the top ranked healthcare entities worldwide for instance, Johns Hopkins International, Cleveland Clinic and Mayo Clinic.

Cancer survivorship is the major aspect of cancer care that gives rise to multiple needs for cancer survivors (Walsh, et. al., 2011). Cancer is associated with substantial physical, emotional, social, and financial difficulties for affected individuals and their families (Niedzwiedz, et. al., 2019; Woźniak, & Iżycki, 2014; IOM, 2008). In the majority of cases, the diagnosis of cancer is either preceded by a period of gradual, nonspecific symptoms (NCI, 2004; Derogatis, et. al., 1983 or discovered by routine screening, and individuals are then thrust into a series of diagnostic testing, a range of procedures and treatments that are invasive and complicated with very little warning or opportunity to adjust their circumstances. Derogatis, et. al., (1983) reported that 68% of cancer patients have adjustment disorder during transition to cancer survivorship. According to the National Cancer Institute (2004), adjustment disorder is the most commonly diagnosed emotional disorder in cancer patients. Such adjustments of a person facing a life-threatening illness such as cancer are truly complex. Often, a multidisciplinary treatment approach is necessitated, leading patients to engage with multiple healthcare professionals from several different specialties and at several different locations. It is important that healthcare professionals facilitate patients' transition into care and navigate their cancer journey to minimize their distress and maximize their clinical outcomes (Giunti, 2013; Naylor, et. al., 2011, 2009, 2005; Naylor & Keating, 2008).

According to the Institute of Medicine & National Research Council (2006) and Aziz (2007), cancer survivors face unique short-term and long-term challenges to physical and mental health, family functioning and maintenance of a healthy lifestyle. For cancer patients, survivorship is a continuous struggle due to the consequences of complex treatment process and its multitude of long-term and late emerging side effects that have significant impact on physical, emotional, sexual, social and sometimes financial disturbances throughout the post-treatment phase (Tian, Cao & Feng; 2019; Rutten, 2005; Siemsen, 2001). Jacobs & Shulman (2017) have illustrated the potential long-term effects of treatment on cancer survivors in a circular diagram which illustrates the interplay between physical and emotional symptoms and how these are filtered by psychological factors, such as spiritual and existential needs in their impact upon the cancer survivor (Figure 4). These long-term and late effects of cancer treatment may arise during or after treatment and may persist throughout a patient's lifetime. Several studies have reported that cancer patients mostly suffer from physical, emotional, social, financial and psychological disturbances to a greater extent and unmet needs were highest in the post-treatment phase compared to the other phases of cancer continuum

(Thorsen, et. al., 2011; Wessels, et. al., 2010; Wong, Yee & Turner; 2008; Echlin & Rees; 2002). On the other hand, several studies mentioned the early stages of cancer survivorship had detrimental effects on the quality of cancer patients' lives (Wulff; 2012; Jenkinson, Coulter & Bruster; 2002).

Many cancer patients suffer unnecessary pain and distress and face major impediments to good end-of-life care (Silveira, et. al., 2000; Bretsher, et. al., 1999). In fact, *In Approaching Death*, the IOM (1997) identified key patient needs such as fears of abandonment and protracted death and called for reliable, respectful care that promotes "norms of decency". The IOM (1997) reports identified as a significant deficit the lack of data on patient needs and data on needs, especially the paucity of longitudinal data of diverse populations. Literature also identified inadequate understanding of needs among diverse populations as a major problem (Nair, et. al., 2018; Herschbach, et. al., 2008; Shane, et. al., 2004; IOM, 1997).

According to Minshull, et. al., (1986), unmet needs can lead to disorientation, instability and mental crisis. Cancer patients may need help to gain a sense of control, psychological stability, hope, confidence and a positive view for the future (Soothill, et. al., 2003; Bonevski, et. al., 2000; Ferrell & Hassey, 1997). Cancer patients may experience changes in interpersonal relationships, sexuality and everyday activities which may result in feelings of social isolation. If such belonging needs are not addressed, it may result in loneliness, rejection, friendlessness, rootlessness and alienation (Minshull, et. al., 1986). Moreover, cancer may result in changes in body appearance and body image thus an individual may develop concerns about attractiveness and fear of social rejection resulting in increased vulnerability and feelings of personal inadequacy (Hosseini & Padhy, 2020; Pawijit, et. al., 2017; Holland & Reznik, 2005). In order to integrate the cancer experience into life, cancer patients may develop the need to satisfy their esteem needs and to improve self-efficacy for their adjustment process (Morse & Carter,1996). However at least 50% of all cancer patients require emotional support and develop an ongoing psychiatric complication; 1 in 3 patients experience severe psychological distress at any one time (Ryan, et. al., 2011; Breitbart & Alici, 2009). These conditions are often not detected by health professionals. To combat psychiatric issues, distress screening in the clinical environment can be used to detect persons who may benefit from additional emotional support.

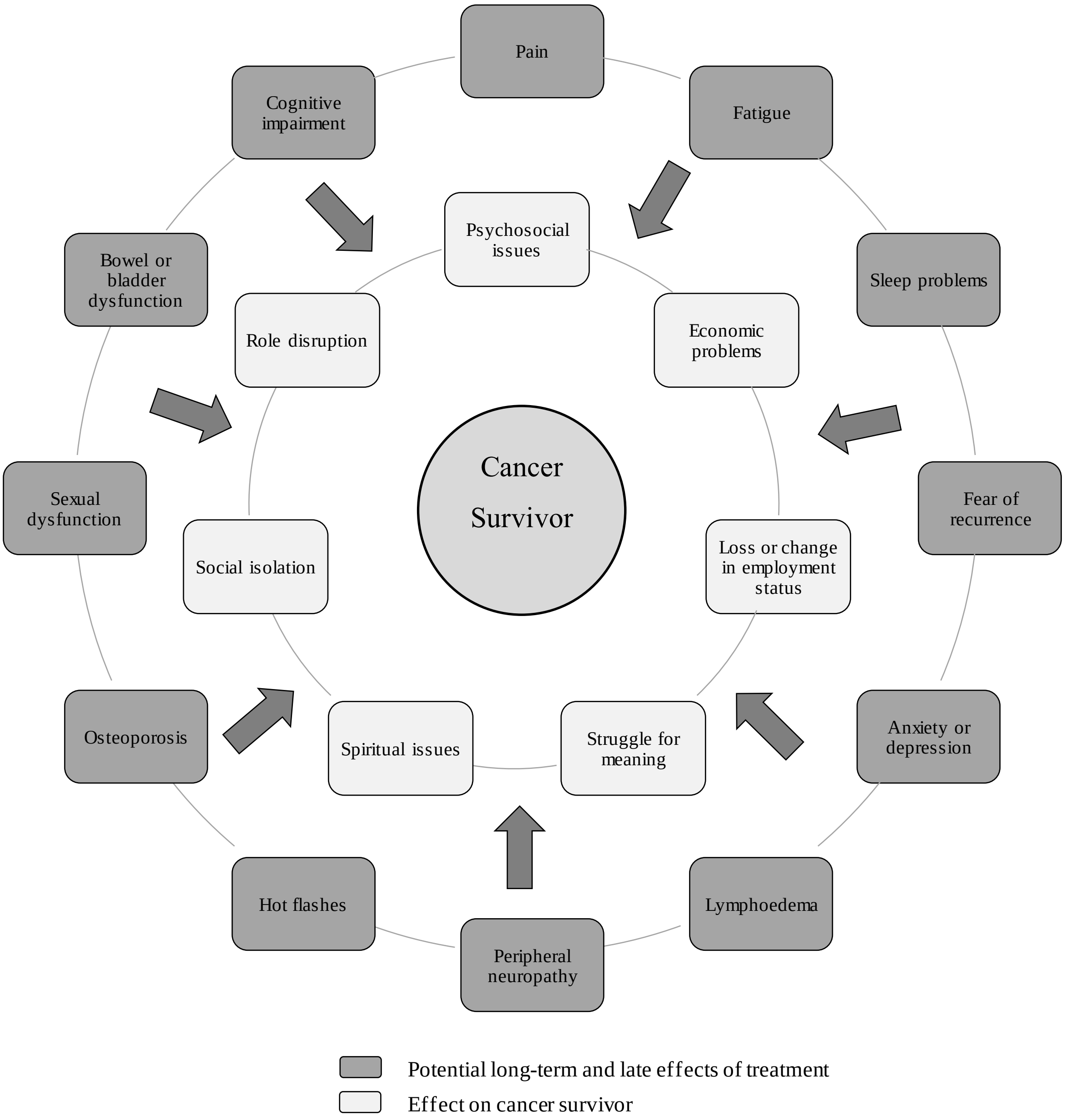


Figure 4: Potential long-term and late effects of treatment and how they affect cancer survivors. *Jacobs & Shulman., (2017)*

Challenges exist at almost each stage of the cancer trajectory. For instance, patients' ability to understand and retain information may vary (Butow, et. al., 1998) and upon being told of a diagnosis of cancer, patients as well as their carers will have many information needs but may not always be able to articulate adequately (Laxmi & Khan., 2013) or express their questions or retain the facts presented during the stress of receiving such devastating news (Balogh, et.

al., 2011; Bender, et. al., 2008; Okamura, et. al., 1998). Pitceathly & Maguire (2003) also found the association between lack of medical information and the development of anxiety and depression. In addition, patients' preferences and language needs when providing information, can affect the success of communicating information about cancer (Tay, Hegney & Ang; 2011). Many cancer patients do not discuss their needs with their health providers and when they do, they often omit important psychosocial concerns such as sexual concerns (Maguire; 1999; Suchman, et. al., 1997). Patients who seem unwilling to discuss their disease or feelings, showing a preference to seek support from family or friends, and those patients who give only subtle indications about their information needs (sometimes based on cultural norms and beliefs) also deter effective interchange (Hagerty, et. al., 2005). However, partners and family members of an individual diagnosed with cancer who provide crucial support, they also are at risk for serious psychosocial difficulties and psychiatric morbidity such as, lack of support network of their own, relationship difficulty with the patient, failure to reveal their own worries or reluctance to seek help (Woźniak, K., & Iżycki., 2014; Pitceathly & Maguire., 2003). Young siblings may struggle with feelings of concern for the sick sibling who is battling with lowered self-esteem, fear for their own health or feelings of being less valued (Houtzager, et. al., 1999). Therefore, generous attention and caring support should be offered to support them with the care process. Some patients do not share their needs because they believe that pain, grief and suffering are inevitable with cancer. On the other hand, some patients believe that clinicians do not want to address those needs in the absence of clinician inquiry or concerns required to develop a meaningful dialogue (Bober, et. al., 2016; IOM, 2008; Brédart, et. al., 2005; Gretchen, 2005; Wen & Gustafson, 2004; Schulz & Beach; 1999; Ford, et. al., 1996). The growing trend could be the outcome of pressure to increase productivity, contain cost or patient volume (Babbott, et. al., 2014; Fiscella & Epstein, 2008; Mechanic, 2003; Ross, Steward & Sinacore; 1993) or it could be a fundamental health system problem that do not truly understand the needs of patients (Lipscomb, Gotay & Snyder, 2005; Wen & Gustafson; 2004). There is substantial evidence of lack of information needs and support affecting patient care (Schulz & Beach; 1999; Vitaliano; 1997; Peters-Golden; 1982).

Cancer patients' needs change as their condition changes, for instance, as the patients return to their normal routine, some of the initial intense reactions tend to decrease, with intermittent periods of increased intensity (Gorman, 2018). A cancer patient is concerned about higher needs such as fear of the unknown or of newly diagnosed cancer as long as basic needs are met.

If the higher needs are met, one can seek esteem needs such as needs which are meaningful for an individual. Most individuals began examining and reviewing their lives soon after diagnosis while looking for meaning in what happened to them. This period of intense existential analysis can be difficult and painful for patients and their families. Everyone needs to view life as existentially meaningful; however, cancer undermines this effort (Northouse & Northouse, 1996).

Studies further indicated that cancer patients' needs depend on which phase they are in the cancer care trajectory (Kendall, et. al., 2006; Squiers, et. al., 2005; Rutten, et. al., 2005). Thorsen, et. al., (2011|) suggested that cancer patients' needs are also influenced by the type of treatment they receive and presence of other comorbidities. The coexistence of comorbidities has substantial implications for treatment decisions and treatment outcomes (IOM, 2013; Geraci, et. al., 2005; Extermann, 2000) Cancer patients' needs also vary according to demographic and clinical patient characteristics (Østerbye, et. al., 2010; Wessels, et. al., 2010).

The assessment of needs for cancer care is a critical step in providing high quality cancer care and achieving satisfaction of cancer patients and their families (Wen & Gustafon, 2004). Identifying and addressing their needs is crucial due to their significant association with both distress and the quality of life which results in increased medical utilisation and cost to both (Lam, et. al., 2011). It is critical to understand that cancer survivors' needs are not restricted to healthcare needs but include wider psychosocial and environmental determinants of health such as physical, information, social, financial, emotional and spiritual concerns. For instance, although forgiveness and reconciliation may facilitate peace of mind during end-of-life care in cancer patients (Renz, et. al., 2020). Some cancer patients may want pain relief, but others may not appreciate the importance of dealing with forgiveness before death. It is important to identify cancer patients who have the highest needs while not ignoring those who are doing their best to cope with their disease. Meeting their needs will help them regain emotional stability, social adjustment, cognitive function, body image, future perspective and physical strength (Draborg, et. al., 2009; Hove, et. al., 2006; Squiers, et. al., 2005).

In summary, there is an increase in the number of individuals who are being diagnosed and surviving with cancer (The Cancer atlas, 2021; Arnold, et. al., 2019; Allemani, et. al., 2018). According to the Cancer Atlas (2021), in 2018, there were approximately 43.8 million cancer survivors diagnosed within the previous 5 years. Due to advancement of technology and cancer research, treatments are becoming more complex, effective yet costly. Prolonged physical or mental fatigue, cognitive limitations, difficulty mobilizing support, difficulty managing stress and anxiety, difficulty coping with a new self-image are some crucial physical and mental health consequences of cancer and its treatments that impact cancer survivorship (Hardy, et. al., 2018; Weber, et. al., 2017; Yi & Syrjala., 2017; Fingeret, et. al., 2014), and therefore healthcare providers should address not only the patients' physical needs but also other psychosocial concerns including informational, emotional, social, financial or spiritual needs. By creating partnerships with patients to consider all their needs will result in a positive outcome. Routine assessment of psychosocial symptoms and functional impairments would allow for referrals to a multidisciplinary team of providers. For instance, referrals to exercise professionals and dieticians to promote health behaviour change in survivors have the potential to help decrease the risk of mortality from comorbid diseases, control ongoing symptoms such as fatigue and depression and improve physical functioning (Cheville, et. al., 2017; Mishra, et. al., 2012; Denmark, et. al., 2005), thus shifting care from point of care to point of need. Also, timely intervention and routine follow-up assessment to prevent cancer-related problems or to treat symptoms to avoid progression and disability will likely improve survivors' functioning and well-being (Alfano, et. al., 2019). This includes surveillance for recurrence, screening for new cancers, assessment and management of physical and emotional long-term and late effects, health promotion and care coordination, etc., (Alfano, et. al., 2019). Routine monitoring of chemotherapy-related symptoms will likely improve quality of life, reduce emergency department visits, drug adherence and improve survival. (Basch, et. al., 2017; 2016). Moreover, psychosocial interventions can also help survivors maintain employment contributing to better financial outcomes (Alfano, et. al., 2017).

2.2.4 CANCER NEED ASSESSMENT: THE PROCESS, ITS IMPORTANCE, BENEFITS & CHALLENGES

Understanding of health needs assessment of cancer patients requires a clear definition of need which particularly implies the capacity to benefit from an intervention. Need assessments are designed to identify needs, measure their importance and determine how well they are met. It is a systematic method of identifying the unmet health and healthcare needs of a population and making changes to meet these unmet needs. Needs assessment addresses a comprehensive appraisal of care needs of individuals including physical, emotional, information, social, financial, spiritual and health care needs and can help identify whether or not the individuals need support and provide insights into the extent of that need (Prue, Santin & Porter; 2015). Health needs assessment is used to improve health and other service planning as many patients do not communicate concerns to their clinicians (Frosch & Kaplan, 1999; Guadagnoli & Ward, 1998; Suchman, et. al., 1997), priority setting and policy development (Pencheon, et. al., 2006).

Need assessment can be approached in much the same way as doing a jigsaw puzzle, so that different pieces are put together to give a complete picture of local health. It is evident that improvements in healthcare are unlikely to occur without much better understanding of patients' needs and factors that influence them (Wen & Gustafson; 2004). Need assessments offer a number of advantages by enabling direct assessment of patients' perceived needs, thus allowing more specific identification of resources that are needed. Additionally, needs assessment can help to prioritise the allocation of services and resources to where there are most needed (Gustafson, et. al., 1993; Rose, 1990; Houts, et. al., 1988; Fletcher, et. al., 1983). UAE has free public healthcare for Emirati nationals; however, expatriates are covered for basic health needs only and pay significantly higher fees for treatment which are not covered, such as cancer. No country in the world including the UAE can provide health services to meet all the possible needs of the population. Multiple criteria play an important role in the process of priority setting of health needs for a population. The process of priority setting is often complex and requires interventions to be chosen mainly to maximize general population health, to reduce health inequalities or to deal with life-threatening situations considering both practical and budgetary constraints (Baltussen & Niessen., 2006). The disease control priorities (DCP3) and universal health coverage (UHC) are examples of person-centred approaches that aim to improve the global evidence and resources to achieve equity and to support best practices in priority setting and development of health benefit packages (Department of Global Health, UoW, 2018; Shelton, 2018). The UHC model for cancer survivors in the UAE could be designed to aim all individuals and communities receive the health services they need without suffering financial hardship by including the full spectrum of essential, quality health services from health promotion to prevention, treatment, rehabilitation, and palliative care. According to the Ministry of Health and Prevention, UAE (2021), UAE's strategic participation to the international community aims to achieve universal health coverage and sustainable development goals.

When it comes to studying cancer morbidity outcomes, three primary methodologies are applied: quality of life, patient satisfaction and need assessment (Brédart, et. al., 2013; Ware, Davies-Avery & Stewart, 1978). Quality of life evaluations assess the events of the disease for different aspects of patients' experience including patients' priorities as well as satisfaction (Haslam, et. al., 2020; Gustafson 1993; Gustafson, et. al., 1991) whereas the focus of patient satisfaction surveys is perceived quality of care issues (Al-Abri & Al-Balushi, 2014; Prakash, 2010; Ware, Davies-Avery & Stewart, 1978). Needs assessment encompasses both quality of life and quality of care concerns when the impact of disease on patients' needs is assessed (Bonevskie. et. al., 2000). Regardless of the content, the common goal is to acquire information about health outcomes pertinent to assisting in the improvement of the quality of patient care and the reduction of cancer-related morbidity (Bonevskie. et. al., 2000; IOM, 1999). Modern medicine has also slowly recognised the importance of the perspective of the patient in health care and has commended more investigations to understand the importance of the inter-relationships among health needs, satisfaction, and quality of life (Asadi-Lari, Tamburini, & Gray, 2004). The shift toward providing high value cancer care has placed an increasing importance on meeting patients' needs and preferences.

Literature has identified patients' supportive care needs at different phases pf cancer treatment and follow-up, for instance, at the start and end of palliative care, while receiving chemotherapy and radiation therapy and following cancer treatment (Ullrich, et. al., 2021; Sharma, et. al., 2019; Amatya, et. al., 2014). According to Sanson-Fisher, et al. (2000), time since diagnosis and the time since last admission for treatment correlated with some need in the physical and daily living domain. Nevertheless, working with patients at all stages to meet their current needs helps to optimize quality of life throughout the disease trajectory since concerns and needs continue to fluctuate based on the phase of the diagnosis and individualized patient and family priorities and needs (Payne & Murphy-Ende, 2019).

To address cancer survivors' needs, one should understand that cancer survivors are a heterogeneous group. No two human beings react in quite the same way – if we ask them what they have perceived they will give very diverse answers (Adler, 1954; 1927). As cancer differs from one another and person to person, similarly, the individual responses to the disease, cancer treatments and their adverse effects as well as their needs are unique and vary from person to person. Alder (1927) believed the individuality and uniqueness of people is explained in what they perceive and how they perceive it. Cancer patients strive to ensure their needs are fulfilled; however, when disease occurs, there may be times their daily needs are more likely to change as the course of the disease changes (Dudas & Carlson, 1988). This new situation creates new demands with anxiety and uncertainty of the future. Cancer survivors may need new information or new skills to meet their needs and to deal with the illness. If these needs remain unmet, an individual may continue to feel emotional distress and difficulties (Fitch, 2008).

Richardson, et. al., (2007) has argued that a rigorous and systematic needs assessment is the crucial first step in integrated and patient-centred cancer care. The assessment of needs for cancer care is a critical step in providing high quality care and achieving cancer patients' and families' satisfaction (Wen & Gustafson; 2004). Needs assessment in cancer patients is an ongoing process which is recommended to be carried out from pre-diagnosis to cure, progressing disease or death into bereavement (Richardson, et. al., 2007).

It is important that cancer survivors’ need assessment involve active, explicit and systematic identification of their unique needs rather than an ad-hoc implicit response to demand. The assessment of cancer patients’ needs can be made clearer by differentiating the issues into needs, demands and supply (Pencheon, et. al., 2006). While assessing cancer survivors’ unique needs, it is critical to make distinction between individual needs and the wider needs of the community. Hence, if individual needs are ignored then there is a danger of a top-down approach to providing health and other cancer services, reflecting what a few people perceive to be the needs of the population rather than what they are (Pencheon, et. al., 2006). It is also empirical to understand that cancer survivors’ needs are not static, and any health assessment only provides a snapshot of the needs of the local population. These needs are always changing (Wright, Williams & Wilkinson; 1998) and it is important to evaluate the impact of these assessments by reviewing and updating the process of these evaluations.

Benefits of Need Assessment related to Cancer

Accurate and effective needs assessment among cancer patients can assist in prioritizing care needs, allocating resources to the areas and individuals that need them most, developing more appropriate and cost-effective cancer care strategies to improve cancer survivorship experience and quality of cancer patients' lives (Bonevski, et. al., 2000). Sines, et. al., (2009) highlighted some of the key benefits of need assessment related to cancer as listed below:

- Better understanding of cancer care and cancer services issues faced by cancer survivors.
- Better understanding of cancer equalities within a community.
- Evidence based planning and development of interventions such as Cancer survivorship programs.
- Evidence-based prioritisation of cancer care issues.
- More effective and equitable allocation of cancer resources.
- Create shared understanding of needs and priorities between cancer survivors and cancer care providers.
- Cancer patients' involvement in decision making.
- Development of public skills of cancer professionals such as reflective skills, planning skills, project management, communication and research skills etc.

Challenges of Need Assessment

Healthcare need assessment is a complex process. Although there are clear benefits resulting from the improvement in healthcare by the need assessment, there exists a danger that the target- driven culture of health services with pre-determined priorities may limit the opportunities to implement relevant decisions associated with findings emerged from the need assessments. Commitment to provide these resources may not always be forthcoming and timescales may not match management priorities and deadlines (Macdowell, et. al., 2006; Cavanagh & Chadwick, 2005). There are other major obstacles associated with cancer patients' need assessments. For instance, many healthcare providers often overlook the needs of family members and do not include the full set of patients and family needs as they under-appreciate the role of family or care workers who help patients cope up with cancer. Moreover, many assessments do not document the changes in needs over time. Most need assessments identify how well needs have been met (typically some variant of a Likert scale) but few offer guidance on how to meet the needs. In addition, there is little understanding of how best to use needs assessment data to improve health care systems. Need assessment requires reflection and expects professionals to critically evaluate existing issues, perceptions, services, practices and norms. For conservative societies and cultures such as UAE, the process itself could be challenging and resultant findings arising from those assessments may require a fundamental shift and may be difficult to implement since cultures and norms can also act as a constraint to change (Row & Carey, 2004). Moreover, most cultural processes lead to the expectation that behaviour reinforces the mechanisms by which culture influences individual level psychological mechanisms such as needs, perceptions and belief (Kitayama, 1992).

2.2.5 NEED ASSESSMENT INSTRUMENT FOR CANCER

Unfortunately, very little information is available on how instrument developers went about identifying needs. Most instruments employ a self-reported format often sacrificing the richness of detail obtained, but on the other hand, they are relatively inexpensive and require much less time than interviews (Holland & Zittoun; 2012). The Likert-type scale is widely applied to measure importance and satisfaction of needs; however, it may produce "ceiling-effects," in which most needs are rated as very or somewhat important. This low variability among highly rated needs results in low separation of the needs and provides no guidance on where scarce resources should be concentrated (Wen & Gustafson; 2004). On the other hand, interviews or semi-structured interview approaches reduce missing data and might be employed in a clinical setting. Lipscomb, Gotay & Snyder (2005) cited the need to be more specific about the structure and process that is used in semi-structured interviews. Additionally, researchers should be aware of the importance of how they conduct interviews so that they facilitate the identification of needs by asking about specific areas rather than expecting participants to identify needs that they may not have reflected upon until asked.

Asking a cancer patient to think back to specific stages in their disease experience and to critical incidents is equally challenging. Retrospection may interfere with accurate assessment of their needs, given the challenges faced during the times of stress. For instance, a breast cancer patient was asked to think back to the time when she first felt the lump and was first told about the bad news however, she said that the surgeon talked to her for an hour, but she remembered nothing and all she wanted was to go home (Lipscomb, Gotay & Snyder; 2005). This experience might lead to the recommendation that patients have time to pull themselves together in a safe environment before taking the next steps. Attention to such techniques must be given while assessing cancer patients' needs.

Ideally cancer patients' need assessment must address the trade-offs between meeting different needs, variation in needs among different patients according to their demographics such as culture, ethnicity or age (Chaturvedi, et. al., 2014; Ashing-Giwa, et. al., 2004; Aziz & Rowland, 2002; IOM, 2008; Lehmann, et. al., 1978; Craig, Comstock & Geiser, 1974) and changes over time in patients' needs during progression of the disease and/or treatment (Chua, et. al., 2019; Shahidi, et. al., 2014; IOM., 2008; Mor, Guadagnoli & Wool, 1987; Lehmann, et. al., 1978).

Cancer patients' needs change as their condition deteriorates, for instance, a need for assistance with personal care with advanced cancer patients may increase during chemotherapy treatment. Factors other than events such as personal preferences can also influence when a need becomes important enough to seek help for it. For instance, some people tend to avoid conflict while others prefer to confront it (Lipscomb, et. al., 2005). Therefore, the implementation of interventions must be modified according to the individual. The author also argued that research to understand issues such as when and why needs become more or less important is also limited.

According to Wen & Gustafson (2004), few instruments have been designed to assess the needs of cancer patients during survivorship and bereavement stages; thus, more work should be undertaken for cancer survivorship needs assessments. In a review of instruments used to assess the needs of people with cancer and their families during palliative care, it was found that most instruments developed failed to address all aspects of palliative care and that these instruments were often for research purposes and not adapted to the clinical setting (Osse, et. al., 2007). Gough (2004) and Alkire (2005) state that needs and the way they are met are often determined by experts and not people who they are supposed to benefit. These instruments often do not include the beneficiaries for patients themselves and assess the needs that healthcare workers feel are important (Richardson, et. al., 2005). In a review of assessment instruments to assess cancer patients' needs, Richardson, et. al., (2007) argued that the process of their development and psychometric properties were reasonably well documented in the literature; however, data on how feasible they were to use in practice was scarce. He further stated that none were found to be complete for all dimensions of needs assessment and most were not sufficiently well tested for use in routine care.

Moreover, future research should determine how needs change overtime with consideration of key events across different stages of cancer across the disease continuum. More emphasis must be placed on how needs assessments have good test-retest reliability, are sensitive enough to detect differences and focus on a set of needs that are mutually exclusive and exhaustive. Research should be directed at defining needs and ways of meeting needs more operationally and move need assessment beyond simply rating “extent of need” to identifying evidence-based ways to meet needs (Lipscomb, Gotay & Snyder; 2005). To improve cancer care, health systems are required to meet cancer survivors’ needs and therefore health systems should identify these needs and find a way to prioritize these. Slade, et. al., (2004) emphasised on a wider approach to care with an assessment of the individual’s needs as an integral part of the care process. In order to provide adequate patient care, health systems need to assess the health needs of their populations, and this should include the social, financial or cultural factors that can be potential barriers (World Health Organization (WHO), 2007; Kay, Bengoa, & Assal, 2006; Bobadilla, 1996). There is a need to continue to develop and test instruments that could provide the holistic view of patients’ psychosocial needs and have the necessary attributes for effective operation of cancer care delivery and cancer research.

The above section discussed the concept of need in general, health needs with a focus on cancer survivors’ needs, health need assessment with benefits and challenges associated with the process. The next section provides an overview of gaps in the current literature regarding cancer care and cancer survivors’ needs.

2.3 GAPS IN THE CURRENT LITERATURE

Cancer remains a significant scientific, clinical and societal problem across the globe. With the advanced strategies to detect cancer early and treat it effectively along with the aging population, the number of individuals diagnosed with cancer are living longer and thus continuing to rise (Aziz, 2006; Aziz & Rowland, 2003; Aziz, 2002a). According to the

American Cancer Society (2021b), 68% of adults diagnosed with cancer can expect to be alive in 5 years in the absence of other competing causes of death. However, research reveals that the quality of survival is influenced by medical and sociocultural factors such as psychosocial and behavioural interventions, active screening behaviours and healthier lifestyles may also play an integral role in the overall survival (Demark-Wahnefried, et. al., 2005; Demark-Wahnefried, et. al., 2000). The goal of this research is to focus on cancer survivors' concerns and needs encapsulating their health and life experience beyond the acute diagnosis and treatment phase and throughout survivorship and to understand the factors that influence their survivorship experience.

The following section of the document discusses the issues relevant to cancer care focusing on survivors' concerns, needs and survivorship, while exploring the emerging research needs and gaps in different aspects of cancer care including evidence based-high quality cancer care, survivorship care, cancer patients' psychosocial needs, instruments to assess cancer survivors' needs, cultural association with needs and the current research gaps in the United Arab Emirates with regards to cancer survivors' needs and in the field of cancer survivorship which could be articulated into further knowledge and research.

2.3.1 EVIDENCE-BASED HIGH-QUALITY CANCER CARE

Literature provides considerable evidence of gaps between scientific evidence and clinical practice in many fields of healthcare (Cochrane, et. al., 2007; Buchan, 2004; McGlynn, et. al., 2003 & Grol, 2001). Grol (2001) quantified the percentage of patients as 40% who fail to receive treatments that are shown to be effective. McGlynn, at. al., (2003) further supported the fact that 20% to 25% receive unnecessary treatment which are not needed or those are potentially harmful. The IOM report (2008 & 2012) further recognised the lack of evidence-based decision making in cancer care stating that the increase in the complexity of cancer has impeded the ability of clinicians, patients and their families to formulate plans of care with the necessary speed, precision and quality. However, given increased acknowledgement of the need to address evidence-based practice gaps in cancer care, it is also expected that efforts to ensure effective translation of knowledge into clinical practice also have increased over time. However, Bensing (2000) & Groopman, (2007) suggested that evidence-based care focuses primarily on groups of patients rather than individuals and often fails to consider subgroup analyses, incorporation of patient values and preferences. It is critical to develop evidence-based standards of care and clinical practice guidelines to improve the quality of cancer survivorship. Research is also essential to design new cancer therapies that could result in low recurrence rate and reduce the treatment related adverse effects. However, the appropriate timing and frequency of screening for new cancers and complications of cancer treatments are still unclear (Haylock & Curtiss., 2019). It is important to design and conduct guidelines which are evidenced-based and have been evaluated for effectiveness and impact.

According to Haylock & Curtiss (2019), quality survivorship care is not clearly defined. In 1999, the IOM released the report ‘Ensuring Quality Cancer Care in which the US National Cancer Policy Board stated that ‘reasons for failure to deliver high-quality care have not been studied adequately’. The report made recommendations that clinical practice guidelines be developed and implemented to ensure optimal care is provided to patients and that the quality of care provided be measured and monitored. The report further stated that the lack of evidence-based practices impedes clinicians’ adoption and reporting of adherence to the standard guidelines.

Evidence-based practice is crucial to ensure accountability, quality of care and patient’s and improved survival, mainly quality of life. Reducing the gap between evidence based and clinical practice results in reduction in patient morbidity and mortality (Saslow, et. al., 2012; McCullough, et. al., 2011; Komajda, et. al., 2005) as well as lowering healthcare costs (Shapiro, et. al., 1993). However, clinical practice and guidelines can differ greatly in terms of quality and applicability. This is due to several reasons, for example, variation in methodology of development with different quality standards and massive delays in the development cycles which results in guidelines that are already outdated at the moment of publication (Classen & Mermel, 2015). Moreover, there is lack of evidence on specific topics or the focus on follow-up care and recurrence detection rather than on the whole care process for instance, breast cancer (Spronk, 2017). Spronk (2017) further suggested the need for development and adoption of high-quality evidence-based guidelines on site specific to support cancer survivorship care. Risk-based screening for cancer survivors helps ensure that those at high risk are followed more closely than others (Dood et. al., 2018). Yet, little research exists to understand the personal factors that affect an individual’s susceptibility to long-term and late effects (Nekhlyudov, et. al., 2017). Clinicians must weigh the risks of second cancers and complications from treatment to determine screening schedules and must use established evidence-based associations between therapeutic exposures and late effects to identify high-risk populations that benefit from frequent screening measures (Bhatia, Armenian, & Landier, 2017). This knowledge could identify preventive interventions and improve risk assessment strategies and outcomes (Linschoten, et. al., 2018; Myers, et. al., 2017).

The IOM (2013) recommends high-quality cancer care across the care continuum from diagnosis and treatment to maintaining the health of survivors and providing end-of-life care consistent with patients' needs, values, and preferences. According to Zapka, et. al., (2003), an opportunity to improve the quality of cancer care exists in all steps of care delivery, as well as in the transitions between the types of care. The provision of patient-centred care planning, palliative care; the prevention and management of long-term and late effects of cancer treatment; and family caregiver support should span the cancer care continuum from diagnosis through end-of-life care. The full cancer care continuum must also include the domains of prevention and risk reduction and screening of psychosocial concerns. However, despite acknowledging psychosocial assessment and management as important priorities for high-quality cancer services, unfortunately, in some areas of cancer care delivery such as palliative care, the dissemination of psychosocial care guidelines is lacking. Health providers are not mindful to conduct full psychosocial assessment and tend to only partially endorse spiritual and cultural assessment and management (Bickel, et. al., 2016).

According to the Institute of Medicine (IOM, 2011), there are several challenges associated with the provision of high-quality cancer care. For instance, the fragmented nature of cancer care delivery is generally not integrated across the continuum from diagnosis to end of life. In addition, continuing geographic, financial, and social barriers prevent patients from seeking and receiving multidisciplinary care planning and comprehensive cancer care. There are ongoing disparities, including late-stage diagnoses and poorer outcomes for racial and ethnic minorities with cancer. Many cancer patients are not informed about their treatment options and their preferences are not elicited. Many cancer patients have no understanding of their treatment goals. Moreover, quite often they do not know what treatments they have received or the consequences of their treatments for their future health. Furthermore, high-quality evidence is lacking for effectiveness in many applications of cancer care including personalised medicine (Ngai, Lucas & Jason, 2018).

The knowledge about cancer patients' preferences is critical to provide patient centred care (Laryionava, et. al., 2019) and the IOM (2001) have called for shared decision-making and accommodation of patient preferences to improve overall health care quality. Yet, the current literature does not provide an overview on cancer patients' preferences (Petersen, Knudsen & Vinter, 2015). Additionally, great variability in cancer patients' preferences has been reported regarding the content and format of communication from their physicians to assess patients' experience (Elkin, et. al., 2007; Helft, 2005 & Butow, et. al., 1997). Russo, et. al., (2019) argued that an overview of psychological dimensions and instruments used in patients' preferences and health-related decision studies is lacking and till date, most attention focused on how to elicit preferences with less attention to why patients prefer certain choices and decisions. Further challenges exist with the increase in cancer incidence and survival placing new demands on the cancer care delivery systems. According to the National Cancer Institute (2013; 2012; 2007), most people diagnosed with cancer, die from it and the majority of survivors are adults 65 year or older.

The IOM (2009) reported that the oncology workforce may soon be limited to care for the growing number of people diagnosed with cancer; this could threaten cancer care delivery and result in a major structural crisis. In addition, the escalating cost of cancer treatment makes cancer care less affordable for patients and their families resulting in disparities in access and the high-quality of cancer (IOM, 2013; Stump, et. al., 2013; Sullivan, et. al., 2011). Many cancer patients do not receive the supportive care to manage their cancer related symptoms and side effects. Most frequently this occurs because of the clinicians' lack of knowledge about how to provide this care or to make an appropriate referral based on patients' psychosocial needs.

The IOM (2013) noted that most healthcare providers do not identify psychosocial care management as an integral component of high-quality cancer care. However, despite these findings and their implications for clinical care, psychosocial problems in cancer are still minimised and underestimated (Grassi, et. al., 2017). Researchers and clinicians favour a multidimensional concept of health-related quality of life to be implemented for cancer survivors; however, the complexity of cancer treatments renders the adaptability of such models into clinical practice. Quality care improvement process and outcome metrics must be considered in oncology practice along with the capacity to build multidisciplinary partnerships of different healthcare providers to develop and implement interventions and supportive care services to promote cancer survivors' well-being and improve survivorship.

2.3.2 CANCER SURVIVORSHIP CARE

Although cancer specialists understand the obligation to offer long-term care for their patients, yet cancer patients feel abandoned as their treatment is over and face lack of resources to seek the care they need. Primary care physicians or General Practitioners lack confidence to deal with cancer related issues and feel they are not confident to provide specialised care as it is not their area of expertise. These healthcare system issues are universal for cancer care yet understudied. Due to fragmented nature of cancer care delivery, majority of the cancer care studies have focused on specific areas of cancer care mainly diagnosis and initial treatment leaving the gap to study cancer outcomes or survivors' needs after the completion of treatment (Hsieh, Chou, & Guo., 2018; Chua, Ten & Gandhi, 2018; Stanton, et. al., 2015; Fatima, et. al., 2013).

Due to the philosophical shift in treating cancer, the focus of cancer research stretches beyond treatment, representing the shift away from the medical deficit-dysfunction model toward a multidisciplinary approach (Aziz, 2007). However, cancer survivorship research studies should incorporate curing the disease and controlling the adverse and late effects of cancer as well as psychosocial domains in the conceptual models and research designs of cancer survivorship studies. Since cancer survivorship research today had added an incredible success in early detection and cancer treatment, resulting in an increased number of survivors (Aziz, 2006; Aziz & Rowland, 2003), there is a desire and a need to amalgamate the underlying mechanism, biology along with psychosocial factors influencing an individual's cancer experience.

It is important to understand the concept of survivorship to fully understand cancer survivors' needs during the different phases of cancer trajectory as it guides the development of comprehensive cancer survivorship programs. Yet, the need for research in all aspects of cancer survivorship is fertile, wide, and diverse (Haylock & Curtiss., 2019). There were 43.8 million cancer survivors diagnosed within the past 5 years across 185 countries (Bray, et. al., 2018). As the number of survivors are increasing worldwide propelled by advances in early detection and treatment and the aging population., it is placing a global challenge for survivors and their families, employers, healthcare systems and the governments. The rising number of cancer survivors highlight the public health magnitude of cancer survivorship as well as the importance of understanding and addressing the needs of cancer survivors. According to Canadian Partnership Against Cancer (2018), the hardest part of the cancer journey is after cancer treatment; however, most patients diagnosed with cancer experience delays in survivorship care in terms of lack of continuity, guidance and resources (Nekhlyudov, et. al., 2017). The lack of survivorship care can affect patients as they transition to a normal life following treatment (Bilodeau., Tremblay & Durand; 2019)

The science of cancer survivorship care is evolving yet in its infancy and little is known to guide best practices for studying groups of survivor populations, models of survivorship care outside of academic centres, health disparities or long-term biopsychosocial and spiritual consequences of cancer and cancer treatment (Haylock & Curtiss., 2019). In 1985, cancer survivor Fitzhugh Mullan, published an article about his own cancer experience called "Seasons of Survival: Reflections of a Physician with Cancer" in The New England Journal of Medicine which became the foundation for recognizing the stages of the cancer journey. Mullan identified the "seasons" of cancer survivorship as:

- Acute survivorship, which involves diagnosis and initial treatment.
- Extended survivorship, a time of watchful waiting with celebration, uncertainty, and transition.
- Permanent survivorship, the season of gradual confidence that there would be a future free of cancer.

According to Mullan (1985), the availability and widespread use of curative and effective treatments would lead to a low likelihood of recurrence and longer survival times; however, the potential impact of late and long-term adverse physiologic and psychosocial effects of treatment was not described. Consistent with the shift in new knowledge emerging from the scientific bodies and further advancement, it is necessary to incorporate the evolving paradigm of cancer survivorship research into Mullan's original description of the survivorship experience (Aziz, 2007).

Following the establishment of the US National Coalition for Cancer Survivorship in 1986, National Cancer Institute Office of Cancer Survivorship in 1996 and the formation of National Cancer Policy Board within the Institute of Medicine (IOM) of the National Academies the next year, many studies have been conducted with a significant upsurge on cancer survivorship (Urquhart, et. al., 2021; Fitch, 2019; Takahashi, 2016; Rowland, et. al., 2013; Harrop, et. al., 2011, Aziz, 2007, 2002). Besides the increase in the number of studies on survivorship, more research is needed primarily to address optimal survivorship care delivery. The American Society of Clinical Oncology (ASCO) established the Cancer Survivorship Committee in 2011 to provide leadership for its survivorship activities. In 2013, the committee recommended a comprehensive document with the statement Achieving High-Quality Cancer Survivorship Care outlining ASCO's survivorship agenda. The given statement proposed the creation of an inventory of existing research activities to guide strategic research planning (Jacobsen, et. al., 2016).

In 2016, a survey was conducted to identify the research studies conducted on cancer survivorship from American Society of Clinical Oncology and National Cancer Institute (Jacobsen, et. al., 2016). Out of 1,517 surveys, 699 responded and reported 714 studies of which 65% were observational and 35% were interventional. The most common age group was reported as 40-60 years in both observational and interventional studies and the time since diagnosis was less than 2 years. Although the findings may not be generalised but suggested several key gaps in the survivorship research. First, most studies on survivorship were conducted on breast cancer with a less attention to other common sites which were consistent with the findings of previously conducted studies (Jacobsen, et. al., 2016; Harrop, et. al., 2011).

Highly prevalent primary cancer sites such as colorectal, gynaecologic, head and neck, prostate and lung continue to be understudied with respect to medical outcomes (Aziz, 2007). Secondly, research on older cancer survivors, that is above 65 years has been limited. This gap is of concern because 60% of cancer survivors are reported to be 65 years of age or older (Jacobsen, et. al., 2016). In addition, most cancer survivors have reported a long-term survival rate (≥ 5 years) (DeSantis, et. al., 2014; de Moor, et al., 2013), yet research on long-term (≥ 5 years) cancer survivors does not seem to have been addressed (Richardson, et. al., 2011). Jacobsen, et. al., (2016) identified several key gaps.in cancer survivorship care research. Interventional studies on younger populations (age < 21 years) also seem to be lacking. Majority of the studies have focused on quality-of-life issues for instance emotional well-being both in observational and interventional research and there are many studies that have addressed physical concerns such as fertility and health behaviours for instance, exercise. On the other hand, only few studies have included biologic or genetic components which are related to recurrence and adverse effects yet are poorly understood.

Clinical trials for cancer survivors also present challenges since small groups of survivors and long latency of complications often prevent randomized controlled trials from determining what modality or timing would be superior in early detection of complications or reduction in morbidity and mortality (Bhatia, et. al., 2017). Jacobsen, et. al., (2016) also highlighted the need of research into practice and addressed identified problems with the delivery of high-quality cancer care in diverse settings. Moreover, substantial gaps exist regarding the process and outcomes of survivorship care planning. An integrative review of survivorship care plan studies revealed limited evidence of improved outcomes and only sporadic implementation of care planning (Mayer, et. al., 2015). Mayer also indicated massive variation in research on survivorship care plan content, implementation and dissemination processes, and outcomes. A systemic review by Jacobsen, et. al., (2018), reported the lack of evidence that survivorship care plans improve health outcomes and health delivery; however, the review found evidence of increased patient satisfaction with the amount of information received and delivery of care.

2.3.3 PSYCHOSOCIAL NEEDS OF CANCER SURVIVORS

Cancer care is a continuum process and survivor needs are also ongoing. Survivors' needs should be monitored and served at all phases along the cancer journey. However, many studies have mainly focused on the diagnosis and treatment phase only (Tamburini, et. al., 2003; Rutten, et. al., 2005). Wen & Gustafson (2004) highlighted many issues which exist to assess cancer survivors' needs including lack of clarity on best practices in initially identifying needs; determining possible levels of performance on each need; measuring the importance of needs and employing needs assessment data in design and improvement and evaluation efforts.

Researchers are also unable to identify the most critical period of the high levels of needs during the trajectory of illness (Pauwels, et. al., 2013; Adams, et. al., 2009; Schmid-Buchi, et. al., 2008; Hodgkinson et. al., 2007). Corner (2008) argued that the literature not only fails to highlight the content but also the timing of the highest needs. A study concluded that the highest but varied needs have been observed during the treatment, yet the majority of the cancer survivors have only been able to reveal their needs after the treatment (Harrison, et. al., 2009). Whereas Knobf, et. al., (2012, 2000), reported that the end of treatment is a vulnerable time as patients transition away from active treatment and have less contact and support from health providers. Whelan, et. al., (1997) recognized the need to provide more comprehensive services to all cancer patients at any stage of their illness. Moadel, et. al., (2007) stated that although cancer patient's needs have been identified by researchers, it is unclear whether these needs are applicable to the population as a whole. Additionally, little evidence is available on the influence of age on psychosocial needs beyond the acute phase of treatment (Thewes, et. al., 2004). Harrison, et. al., 2009 and den Bakker, et. al., 2018 reported similar levels of needs post-treatment.

Another research issue with regards to survivors' need in different phases of cancer survivorship is to understand the late versus long-term effects of cancer treatment since most of the cancer survivors today face persistent and the late effects of cancer therapies on their health, longevity and quality of life. Long-term effects refer to any side effects or complications of treatment for which a cancer patient must compensate; also known as persistent effects, they begin during treatment and continue beyond the end of treatment.

On the other hand, late effects, in contrast, appear months to years after the completion of treatment. Some researchers classify cognitive problems, fatigue, lymphedema and peripheral neuropathy as long-term effects while others classify them as late effects (Aziz, 2007). Despite the increase in the number of survivors and their longevity, we have limited knowledge about their health status and quality of life, particularly those who have been post-treatment for longer time periods. For instance, what are the most common late effects of the treatment? Who are the survivors at risk of developing recurrence or new malignancies and how to prevent it? In addition, it is important to consider what represents optimal surveillance and who are responsible to conduct the follow-up care? All these queries necessitate the need for continued research in the growing cancer survivors (Demark-Wahnefried, et. al., 2005; Aziz, 2002; Demark-Wahnefried, et. al., 2000; Mullan, 1985). Conclusions about effectiveness are also limited because of few randomised controlled trials thus more research using more rigorous research designs is needed including use of longer follow-up periods (Helgeson, 2005). For instance, to understand the outcome of psychotropic drugs to treat depression and other mental health conditions of patients with cancer. What needed is, more trials using larger populations that are studied over a longer period in order to accurately assess the drug efficacy. Studies are also needed to compare one drug with another and with the drug plus a psychosocial intervention.

Despite the known importance of need assessment, its potential appears not to have been met (Foot, 1996; Spiegel, 1994). Similarly, the above evidence, although supports the healthcare benefits of providing survivorship care effectively, yet there are still many unanswered questions. Key questions remain about how to address certain psychosocial health problems most effectively as well as how to deliver cancer services most efficiently to the various cancer survivors who need them. Several need assessments studies have been conducted on the development of different interventions to measure these needs however have not been adapted widely (Tian, et. al., 2019; Pauwels, et. al., 2013). A study conducted in the United State reported the availability of many support services for cancer survivors exist in Connecticut state however, those are often unknown or underutilized by the populations for which they are designed (Knobf, et. al., 2012). The author suggested that these findings could be utilized to target services and resources in the future, exchange of information and communication between patients and cancer care professionals.

According to the IOM (2008), the provision of psychosocial services to all who need them is hindered in part by limitations of the knowledge base. The challenge with the psychosocial research studies is that cancer is not a single disease; each cancer site's disease and pattern is different and even for a particular cancer site, individuals' specific psychosocial health care needs may vary (for instance; in early stage versus advanced disease). Since there are more than one hundred specific cancer types, it is therefore difficult to generalize about the benefits of a particular psychosocial intervention. Thus, evidence that an intervention works effectively for some populations does not necessarily mean that the same intervention is effective for or is generalizable to all people in all situations.

Another challenge with the psychosocial research is that most of these studies have focused on homogeneous samples of patients, making interpretation of outcomes more outstanding. Additionally, for some psychosocial problems, research has not resulted in any identified effective services to resolve them. Moreover, it is unclear that a given service which is effective does not exclude the possibility that another service is more effective for the same problem or equally effective at lower cost. All these issues have contributed to necessitate the need of psychosocial research towards a larger population covering all psychosocial domains. Questions about the effectiveness of many psychosocial services have evolved from addressing whether given services are effective to addressing whom and under what circumstances specific services are needed yet effective (Helgeson, et. al., 2005; Stanton, 2005; Cohen, 2004; Zebrack & Zeltzer, 2003).

It is also needed that understanding must be raised about the psychosocial issues of cancer survivors such as poor quality of life, fear of recurrence, poor self-esteem, anxiety and depression, relationship difficulties, body-image concerns, employment and financial hardships (Ganz, et. al., 2002; Schnoll, et. al., 2001; Gotay & Muraoka, 1998). However, there are great heterogeneity effects of cancer in individuals; older adults have been reported as having a greater need for psychosocial services (IOM, 2008). On the contrary, a Qatar study found no effect of age, educational level and other demographics on psychosocial support (Alagraa, et. al., 2015). Ganz, et. al., (1993) described the association of other socio-demographics factors such as marital and financial status in addition to age and ethnicity with survivors' needs however the extent to which the selected subgroups for example, age or stage of cancer may benefit from different types of psychosocial interventions remains unclear (Fors, et. al., 2011).

Most psychosociology studies tends to focus on a specific site mainly including breast (Ashing-Giwa, et. al., 2004; Thewes et al., 2004) limiting the scope of findings to the larger population. Moreover, most studies on psychosocial needs of breast cancer have focused on an older population (Scotté; et. al., 2018; Shahrokni; et. al., 2017; Posma; et. al., 2009; Velengtas & Dailing, 1994) therefore, findings could not relate to a younger population. Workplace discrimination and financial worries have also been reported in the same context (Fenn, et. al., 2014; Conti, 1995). However, the perceived experience of stress including more subjective measures and the extent to which cancer survivors may experience psychological stress is also unclear (Schoemaker; et. al; 2016; Andrykowski, et. al., 2008).

Additionally, couple-based psycho-social intervention to improve the quality of cancer survivors appears to be as efficacious for couple communication. However, it has not been adopted widely (Pauwels; et. al., 2012; Regan, et. al., 2012). In addition, studies on cancer patients' needs have predominantly conducted on Americans and Europeans as compared to

Asians which have reported different need patterns (White-Means & Osmani, 2017; Edib, et. al., 2016; Davey; et. al; 2016; Fielding, et. al., 2013; Wenzel; et. al., 2012; Im, E. O., 2006).

Another research gap is, cancer is recognised as having large impact on family members, they are rarely the subject of or included in research on psychosocial healthcare (Helgeson, 2005). More commonly, research guides towards the effectiveness of specific psychosocial services but offers limited evidence about whether a broad spectrum of patients including their family members benefit equally from those services in all situations (IOM, 2008). Helgeson (2005) stressed on studying the impact of variables that moderate treatment effects, for instance, many cancer survivors report manageable psychosocial distress that resolves over time without the need of formal care. On the other hand, other researchers have found that patients with higher levels of distress often show the greater reduction in symptoms when formal psychosocial care is provided (Andrykowski & Manne, 2006; Antoni, et. al., 2006).

Cohen (2004) found that the effectiveness of different types of psychosocial support in individuals with varying availability of social services can depend on the nature and extent of those supports. Due to such variability of the effectiveness of different psychosocial care, it is needed that a new generation of information must be developed with careful consideration of the nature of the sample used, type of interventions and resulting outcomes (Stanton, 2005). Another concern with measuring the effectiveness of psychosocial support is to develop a standard outcome measure by which the effectiveness of psychosocial services can be measured since ‘effectiveness’ is often measured using dimensions of quality of life, however there are various measures of quality of life, what one study finds effective may not be interpreted as effective by others. Research testing the effect of the receipt of psychosocial health services on physiological and clinical outcomes also could help build a conceptual framework underpinning required psychosocial support to guide, develop and offer new interventions to those who are most vulnerable (Patenaude & Kupst, 2015; Thacker, et. al., 2007). Such research should address links between different types of stress and immune system functioning and the effect of psychosocial support.

Information needs for cancer survivors have been described as high in several previous studies (Faller, et. al., 2016; Beckjord, et. al., 2008). There is also clear evidence showing the damaging effects of insufficiently addressing information and supportive care needs (Okuhara; et. al., 2018; Trenchard; et. al., 2016). Patients who are satisfied with the information provided are better prepared for the treatment (Husson, mols & de Poll-Franse, 2011). Although it is known that the treatment adherence may be affected due to anxiety and can leave a negative impact on coping strategies (Skarstein, et. al., 2000) yet, there is still a scarcity of prospective studies exploring the longitudinal relationship between satisfaction with information and levels of anxiety (Husson, mols & de Poll-Franse, 2011; Skarstein, et. al., 2000).

As both satisfaction with information and anxiety may have significant effects as such, it seems even more important to explore their interrelation (Goerling, et. al., 2020). Moreover, most of the longitudinal studies addressing the information needs have been conducted on breast cancer (Faller, et. al., 2017a; Halkett, et. al., 2012; Vogel, Bengel & Helmes, 2008) therefore further studies are needed capturing different aspects such as patients' specific concerns regarding both content and mode of information delivery, patients' information processing styles, influences of cultural background and communication strategies and various sources of information used by the patients (Goerling, et. al., 2020). The literature also suggests the need for information related to rehabilitation, disease recurrence, health promotion and available support services particularly with regards to the survivorship period (Lewis, et. al., 2009; Mayer et. al., 2007). With regards to mode of delivery and quality of information, (Cline & Haynes, 2001) estimated that more than seventy thousand websites disseminate health information to more than fifty million people seeking such information. The authors also highlighted growing concerns about people's ability to access good quality information online since most cancer patients use the internet for health information. However, variable quality of information on the web also can create greater confusion particularly when the internet is the only source used by cancer patients (Lorence & Greenberg, 2006).

Additionally, while the final consequences of cancer have received some acknowledgment there is no research on the impact of initiatives designed to deliver financial support (Moffatt, et. al., 2012). According to the American Cancer Society (2016), 28.7% of survivors reported at least one financial problem resulting from cancer diagnosis, treatment, or long-term side effects of treatment. A cancer diagnosis can be devastating for people who are experiencing financial hardship thereby influencing livelihood making it difficult for them to participate in cancer treatment (Callahan & Brintzenhofeszoc, 2015). Many cancer treatments are often costly and even well-insured patients can face high out-of-pocket costs putting both patients and families at risk of financial distress.

Research is needed to measure the extent of financial toxicity and to characterise financial distress in cancer patients and understand how it affects their quality of life (de Souza, & Wong, 2013). Research is also lacking on financial stresses and the consequences of this for the households, despite widespread reporting of financial strain (Hanratty, et. al., 2007). Moreover, the financial burden among cancer survivors is often overlooked in survivorship care planning. Pisu, et. al., (2014) suggested that addressing the survivors' perspectives on how to deal with this financial burden is a first crucial step to identifying the means to provide this supportive care; however, little data are available to address financial issues among them.

Several studies have suggested that financial disparities may lead to disparities in quality of life as well (Ell, et. al., 2008; Coons, et. al., 2007; IOM, 2005). Crawford (2018) reported the result of a survey which revealed that out of 1,054 study participants, approximately one-third were uninsured. Uninsured patients with metastatic cancer were more likely to identify as racial/ethnic minority, have lower income and work full-time compared to insured respondents which more often resulted in refusing or delaying treatment due to cost. Therefore, it is pivotal to gain further understanding of financial influence on cancer survivorship from different aspects such as different ethnic or cultural backgrounds

Likewise, financial concerns, spirituality and spiritual distress are also individual experiences, and both require an individual approach (Martins & Caldeira, 2018). Spirituality can help lower the effects of cancer and its treatment thus can improve quality of life. According to the National Comprehensive Cancer Network (2020), cancer patients who are spiritual, tend to be more compliant with treatment and live a healthier lifestyle. Deborah K. Davis, the director of field education at Princeton Theological Seminary, who was a chaplain at Princeton Medical Centre in New Jersey for many years stated that the spirituality is a chance to be reconnected to God, a religious tradition and a community that provides hope and strength for the cancer patient (National Comprehensive Cancer Network, 2020).

NCCN has also observed that cancer patients who are already religious often become more deeply religious being diagnosed with cancer, whereas others who were not religious sometimes seek spirituality and a connection to a power outside themselves after the diagnosis.

Cancer patients who rely on their faith or spirituality tend to experience increased hope and optimism, positive thoughts and attitudes, satisfaction and inner peace and meaning of life (Moosavi, et. al., 2019). On the other hand, spiritual distress is labelled in the existing literature as existential suffering, spiritual anguish, spiritual pain and spiritual struggle (Bates, 2016; Wilt, et. al., 2016; Exline, et. al., 2013; Delgado-Guay, et. al., 2013; Chaves, et. al., 2010). Several studies have supported the existence of spiritual distress in cancer patients during different phases of cancer survivorship (Caldeira, et. al., 2017; Gielen, et. al., 2016; Hui, et. al., 2011). Skalla & Fernell, (2015), reported that cancer patients seem more susceptible to spiritual distress when they are diagnosed during progression of the disease and at the end-of-life. Likewise, in other psychosocial domains, spirituality plays a major but ill-defined role in cancer survivorship, yet the subject has not been given ample consideration in the literature (Lee; 2019; Forouzi; et. al., 2017; Polit & Beck., 2014; Rasool, 2000).

Irrespective of studies providing scientific evidence on spiritual distress, a gap in implementing spiritual care also remains due to lack of training, overlooking or misunderstanding the spiritual aspect or meaning of spirituality and its role in cancer survivorship (Balboni, et. al., 2014; Rushton, 2014; Tiew, et. al., 2013 & Nascimento, et. al., 2010). Further research is pivotal to identify patients' spiritual needs to promote and provide holistic cancer care (Guerrero, et. al., (2011). Moreover, the literature consists of mostly qualitative studies to identify cancer patients' spiritual needs therefore the generalizability of those studies is limited. The question is whether the concept of spirituality can only be applied to religious cancer patients or those who have no religious background can also gain benefits with spirituality?

Further research with a larger population coverage and with different religions will help understand the influence of spirituality in a diverse population to target tailored interventions and to meet individual cancer patients' needs. Moreover, the expectations regarding spiritual needs in the context of cancer may vary by cultural background, this aspect of cancer patients' needs must be explored further with greater sensitivity (Astrow, et. al., 2016). While the psychosocial support including physical, psychological, informational and social support needs have been identified for cancer survivors, health care providers still lack the data necessary to help meet the needs of specific cancer survivor populations for instance; by age and ethnic background (Knobf, et. al., 2012). Therefore, additional data are needed to develop and appropriately target interventions as well as facilitate access to resources for cancer survivors to improve overall health and optimal quality of life. Nevertheless, questions remain as to how best to describe the experience of living with, through and beyond cancer, as well as how to provide the necessary supportive care to achieve optimal quality of life for given populations (McGrath & Holewa, 2012).

2.3.4 CANCER NEED ASSESSMENT INSTRUMENTS

It is also not very clear which screening instruments should be used to assess psychosocial health needs of cancer patients or whether there is a minimum set of domains that should be considered. What is the optimal or standardised care? Are there any existing instruments that could be improved to achieve greater utility? These questions could be answered if there is a valid psychosocial screening instrument that could be used to psychosocial health of cancer patients.

Wen & Gustafson (2004) conducted the systemic appraisal of needs assessment instruments for their reliability, validity, burden and psychometric properties and found several problems including wide variation in the needs addressed, inconsistency in domains within the instrument and in items included in similarly named domains, a lack of evidence of sensitivity to change over time, failure to address the period after initial treatment for cancer and failure to examine reading levels. The authors also expressed their concerns in whether one instrument could be developed to address all areas of interest and represents an ideal assessment tool. They also suggested developing a common set of domain terms to be adopted to form the core of need assessment and building a consensus on some items to be placed in the domains.

In an oncology setting, the ability of the survey to assess the magnitude of needs may be especially important in clinical oncology contexts (Bonevski, et. al., 2000). A 1996 review of the psychometric properties of needs assessment instruments used with oncology populations revealed that perhaps one of the reasons need assessment has not been commonly used is lack of quality instruments (Foot, 1996). The review of 71 articles found few needs assessment instruments met the criteria rated against 6 principles: 1) it measures the multidimensional impact of cancer on patients' needs; 2) it directly and comprehensively assesses subjective health-related needs for help; 3) it measures outcomes within a defined temporal context; 4) it demonstrates acceptable reliability and validity of assessment instruments and methods; 5) it is user-friendly; and 6) it is system-friendly. Another MEDLINE search of literature between

1996 and 1998 failed to reveal any advances in this area (Bonevski, et. al., 2000). Another literature review conducted in 2007, the researchers identified and appraised 15 instruments which were developed from 1984 to 2004 based on their validity, reliability, responsiveness and feasibility (Richardson, et. al., 2007). The findings showed that no instrument meet all the above criteria and were a good fit for the use in a clinical setting. Moreover, some instruments primarily focused on assessing other aspects of cancer care such as prevalence or severity of symptoms rather than assessing cancer patients' needs.

There have been recent advancement in developing new instruments such as Supportive Care Needs Survey-Short Form (SCNS-SF), Cancer Survivors' Unmet Needs Measure (CaSUN), Survivors Unmet Needs Survey (SUNS), and Needs Based Biopsychosocial Distress Instrument for Cancer Patients (CANDI) (Lowery, et. al., 2012; Campbell, et. al., 2010; Boyes, Girgis, Lecathelinais., 2009; Hodgkinson, et. al., 2007). Yet, their psychometric properties have not been systematically reviewed and compared (Tian, Cao & Feng., 2019). Lately, several cancer care need assessment instruments have been developed yet most are lacking the quality criteria of comprehensive and systematic appraisal of measurement properties of cancer-specific needs assessment instruments recommended by Terwee, et. al., (2007). This suggests the need for higher methodological quality studies on instrument development for cancer-specific care needs. While evaluating the psychometric properties of 20 instruments, a systemic review of identified 37 studies reported several inconsistencies and the need for future studies with the following recommendations (Tian, Cao & Feng., 2019):

- Development of site-specific modules for site specific tumours
- Clear identification of perceived symptoms and the needs of receiving care to remove the ambiguity about whether the individuals want assistance
- Need of higher methodological quality studies on instrument development for cancer-specific care needs assessment.
- In future studies, it is beneficial to incorporate measurement error as one of the measurement properties.
- Ability of instruments to detect clinically important change over time in the construct to be measured.
- Testing of criterion validity to assess an adequate gold standard for comparison in care needs among cancer patients.

- Test-retest reliability for the assessment of instrument stability with different time intervals.
- Development of multiple hypotheses regarding correlations or mean differences before data collection to improve the methodological quality of hypothesis testing.
- Cross-cultural adaptability and feasibility of the recruited tool and cross-cultural validation using a more appropriate factor analysis method (CFA) and inclusion of more samples.
- Further improvement of already existing and promising measurements.
- Selection of the most appropriate instrument for need assessment among cancer patients to early identify and effective cancer care management.

Needs-based assessment is a vital step in achieving optimal supportive care (Hall, et. al., 2014; Wen & Gustafson, 2004). Several cancer-specific needs assessment tools have been developed of which some of the most commonly used are **"Supportive Care Needs Survey-Short Form (SCNS-SF), Cancer Survivors' Unmet Needs Measure (CaSUN), Survivors Unmet Needs Survey (SUNS), Supportive Care Needs Survey (SCNS), Distress Thermometer (DT) with Problem List (PL),** ***Cancer Survivors Survey of Needs*** **and Needs Based Biopsychosocial Distress Instrument for Cancer Patients (CANDI)".** However, no previous multidimensional needs assessment instrument has been psychometrically evaluated for its utility in a different healthcare setting (Tian, et. al., 2019). Thus, further research is needed to address the obstacles for practicing the need assessments and to establish the relative importance and significance of identified needs. Below table (2.1) provides is a comparison of psychometric properties and the use of few available instruments that are most commonly used to assess cancer patients' needs (Al-Shaaobi, et. al., 2021; Tian, et. al., 2019; Jiao, et. al., 2015; Ehmke, et. al., 2016; Iskandarsyah, et. al.., 2013; Hughes, et. al., 2011; Schlairet, et. al., 2010).

TABLE 2.1: Comparison of Psychometric properties, design, strengths & weaknesses of commonly used instruments to assess cancer survivors' needs

PSYCHOMETRIC PROPERTIES OF COMMONLY USED INSTRUMENTS TO ASSESS CANCER SURVIVORS' NEEDS

0 = no results reported, − = no evidence in favour, + = limited evidence in favour, + + = some acceptable evidence in favour, but some aspects fail criteria or not reported, + + + = acceptable evidence in favour

Factors	**Survivor Unmet Needs Survey - (SUNS)**	**Short Form Survivor Unmet Needs Survey - (SF-SUNS)**	**Cancer Survivors Unmet Needs - (CaSUN)**	**Distress Thermometer (DT) with Problem List (PL)**	**Supportive Care Needs Survey (SCNS)**	**Cancer Survivors Survey of Needs**
Content validity	+++	+	+++	++	+++	+++
Construct	++	++	+	+	++	-
Internal Consistency	+++	+++	+++	++	+++	+
Cross-cultural	+	0	0	++	++	+
Hypothesis testing	+	+	++		+++	+
Responsiveness	_	_	0	0	0	0
Acceptability	_	+	++	++	++	++
INSTRUMENT DESIGN						
Design	First section 89 tick box questions covering 5 domains	A shortened version of the SUNS Contains 30 items derived	Contains 35 unmet need items, 6 positive change items	Patients rate their distress level from a range of 0 (none) to 10	Contains 59 items, while the recommended short form	Contains 50 questions covering five domains, including

	Second section closed questions	from the original 89 SUNS items	and an open-ended question	(extreme) in the past 7 days on the DT and tick off relevant problems on the PL	SCNS-SF-34 contains 34 items encompassing 5 domains: psychological, health system, physical & daily living, patient care & support, and sexuality	physical, emotional, social, spiritual, and other domain. It also contained open-ended questions about primary source of strength their primary concern regarding their healthcare needs. Overall QOL in the past 1 week prior to the survey in addition to demographics and clinical information about cancer are part of the survey.
KEY STRENTGHS						
Strengths	Used and validated in a large number of mixed and haematological cancer survivors. It appears to have high acceptability, internal consistency, content and construct validity.	Used and validated in mixed early cancer survivor patients. It appears to have good construct validity and internal consistency. Convenient tool that may have better acceptability in clinical care due to its shortened form.	Used and validated in cancer survivor. Appears to have good internal consistency evidence of face, content and construct validity	Used in cancer patients with the Problem List and is recommended by the NCCN for cancer patients at all stages of their disease including survivorship. Simple and fast to use and can easily be implemented in clinics. It has good sensitivity and specificity in cancer patients. An objective, structured and consistent way to screen for emotional	Used in cancer survivors. Convenient too to be utilised in clinical setting.	Used in cancer survivors. Convenient too to be utilised in clinical setting. Provide awareness and insight into the needs of cancer survivors. Provide leaders with valuable information needed to provide appropriate resources and plan

				distress and triage to supportive care services		supportive programs.
LIMITATIONS						
Limitations	It contains 89 items. It was validated in cancer survivors 1–5 years post-diagnosis. No questions on reproductive, sexual and spousal issues. Does not contain questions on physical symptoms. No studies on validation and implementation in clinical practice or patient outcome	Validated in cancer survivors 1–5 years post-diagnosis. Derived from SUNS but content validity of the short form tool was not completely reassessed. Does not contain questions on physical symptoms. No studies on validation and implementation in clinical practice or patient outcome	Developed and validated mainly in studies included females (81%) and had breast cancer (59.2%) or gynaecological cancer (16.9%). The average age was older (average 59.6 years) and had been diagnosed with cancer 2.3 years earlier (range 1–15 years). Limited test–retest reliability. No studies on validation and implementation in clinical practice or patient	May not reliably identify distress in cancer survivors. Does not measure level of unmet need. Items may need to be modified or added according to patient demographics. Usefulness and relevance of the tool is dependent on how it is used and communicated. Must be accompanied by clinical review	Developed and validated in cancer patients receiving treatment. Potentially missing needs relevant to cancer survivors. Limited questions on social & practical needs	Limited usage in research and clinical setting. It was validated by members of the cancer patient education network at Mayo Clinic.

There is limited research assessing the clinical use of the need assessment instruments. (Jiao, et. al., 2015). It is difficult to assess the validity of the needs assessment instruments as there is no gold standard tool for comparison. Thus, future research in the clinical setting is required to assess effectiveness in assessing needs. There is room for further refinement of the instrument that are currently used, **for instance, reduction of its length, continued testing with more diverse populations along with the translation into other languages and ability**. There is also a need to continue to develop and test the instruments that have necessary attributes for effective practice and research (Richardson, et. al., 2007). Healthcare providers should employ a needs assessment tool based on the relevance of the scale to their specific patient population and consider the psychometric rigour and practicality of the measure. Additionally, needs assessment instruments, especially checklists, may not identify all patient concerns (Taylor, et. al., 2011) thus healthcare providers should be aware of patient needs that may not be included in the needs assessment tool. Besides other highlighted issues, good listening and communication skills are required to establish a good relationship and trust with the patient to effectively identify needs including issues they may otherwise be reluctant to discuss. Patients should be included in the needs assessment process as active participants in their own care. Nevertheless, more research is required to evaluate the most effective and appropriate process before any firm recommendations are made based on the need assessments (Jiao, et. al., 2015). The author also emphasized that future research requirements of large longitudinal studies in the clinical setting to capture all cancer survivor groups, reassess validity and reliability and assess acceptability and feasibility. Structured and well-designed instruments can reduce Allgar, inequalities as they prompt discussion between patients and clinicians; however only few are designed for the use by clinicians while attention must be given to train them how to use it (Allgar, et. al., 2018). It is thus concluded that there is a need to develop and test instruments that have the attributes necessary for effective practice and research their outcome and effects to improve the quality of cancer care and patients' life (Richardson, et. al., 2007).

2.3.5 CANCER ASSOCIATION WITH CULTURE

Research shows that a number of studies have focused on addressing cancer patients' needs (Pauwels; et. al., 2012; Lam, et. al., 2011; Sanders, et. al., 2010; Harrison, et. al., 2009), however, disparities of diverse needs associated with different ethnicities or cultures are still poorly understood, inconsistently defined and ineffectively used in practice and research (Kagawa-Singer, et. al., 2010).

While cultural knowledge is recognized as key to reducing health disparities, yet the concept of culture and its relation to cancer remain poorly understood (Kagawa-Singer, et. al., 2010). Cancer related stigma and myths about cancer are critical survivorship issues that need to be addressed which are different from country to country (Daher, 2012). Likewise, contrary to the knowledge about long-term cancer survivorship, fewer studies have focused on the transitional journey from different stages from diagnosis to survivorship which is accompanied by impaired quality of life (Pauwels, et. al., 2013). This clearly indicates the variations in reported patterns of needs both geographically and culturally. Literature indicates that patients' needs differ according to socio-demographics characteristics of population (Coronado, et. al., 2017; Costa-Requena, et. al., 2015; Fife, Young, et. al., 2014; Skrzypczak, et. al.; 2012; Goldzweig, et. al., 2009, Lehto, et. al., 2005; Girgis, 2000; Kennedy & Robinson, 1994). Shea-Budgell, et. al., (2014) further emphasized on the need to understand the diverse information needs of this growing population of long-term survivors. Understanding of the individual's cultural needs came with experience, which helps to provide culturally respectful care (Huang, et. al., 2009).

To treat cancer holistically, it is critical to identify and develop culturally tailored interventions to meet cancer patients' unique psychosocial needs since such interventions have proven to be beneficial in improving the quality of life of cancer survivors (Ramírez-Perdomo, et. al. 2019; Kim, Chang, & Lee, 2018; Chee, et. al., 2017; Meyer & Mark, 1995; Devine & Westlake,1995). Edib, et. al., (2016) further reinforced rendering timely and appropriate psychological and physical rehabilitation programmes in healthcare settings. Author suggested that these interventions ought to be the highest priority to support cancer survivors in the long-term adjustment of survivorship and ensure a better quality of life.

Human behaviour can have a profound impact on how cancer is managed and may also affect disease-free or overall survival, we are not currently taking this information into consideration in the systematic delivery of care. There is a growing understanding of the role that socio-cultural and behavioural factors play in cancer care including perceptions about cancer, cancer outcomes, decision-making, adherence to treatment, post-treatment health maintenance behaviours and willingness to adopt appropriate surveillance (Aziz, 2007). However, there is little known about cancer outcomes among culturally diverse groups since this aspect of cancer care has been under-studied (Lwin, et. al., 2014; Palmer, et. al., 2013; Phillipson, et. al., 2012; Kagawa-Singer, et. al., 2010). In addition to recognition of psychosocial services needed for cancer survivors, it is important that the effectiveness of those services must also be evaluated in different populations. Effectiveness research on psychosocial health services has most often focused on women with breast cancer at the middle or upper idle socioeconomic levels without regards to the amount of psychosocial stress they experience (IOM, 2008). The IOM (2008) recommends that such interventions must be tested in patients from different cultural and socioeconomic backgrounds, in patients with cancer sites other than breast, across different stages of cancer and different levels of psychosocial needs. With regards to the effectiveness and impact of any psychosocial intervention, particular attention should be given to the socially disadvantaged population, examining the effect of socioeconomic status and ethnicity on the risk for psychosocial problems since the effectiveness of intervention is often considered to be linked with the quality of life. Nevertheless, to understand the influence of culture on cancer, it is first necessary to unravel the misperception of defining race, ethnicity and culture to carefully examine the impact of these on cancer patients' lives (Kagawa-Singer, et. al., 2010). The author also concluded that the health literature lacks clear, standardized definitions for culture, thus, further clarity of cultural factors will increase the scientific basis for the clinical practice and research among diverse groups of cancer survivors and will remove associated cultural health disparities.

Proficiency in cultural sensitivity is becoming increasingly important in cancer care as one comes from his or her own culture with the established set of norms, attitudes, beliefs and behaviours. It is important that health care providers not just become more culturally competent to understand one's culture but also their own, to understand how culture can impact survivors' as well as health care providers' reaction to cancer. It is important that prospective studies measure the association between cultural cancer-related behaviours and its impact on cancer survivorship. Studies must utilise rigorous research design that yields the magnitude of an intervention to better understand its effectiveness which attempt to address the unique psychosocial needs of cancer survivors while applying multicultural health principles of participation to recognise the needs of the particular culture.

There are significant gaps that bar the oncology care community in providing comprehensive cancer care including their need assessment and intervention for the whole person and for all persons. Moreover, the cancer patient and survivor population are increasingly diverse (Ashing, et. al., 2016). Therefore, it is needed that future studies include different models of care that include cancer survivors' distinctive needs incorporating their cultural beliefs, understandings and preferences for instances, addressing stigma and shame, religious beliefs, outcome expectancies, patient and providers' communication, rights of individuals to access to appropriate health information and quality health services that recognise their cultural needs.

2.3.6 PSYCHOSOCIAL NEEDS OF CANCER SURVIVORS IN THE UNITED ARAB EMIRATES

Despite the high prevalence of cancer in the United Arab Emirates, there is yet a limited number of studies and published data on cancer survivors' psychosocial needs and supportive care (Nair, et. al., 2019; Nair. et. al., 2018, Elbarazi, 2016). Nair, et. al., (2018) stated that there is a dearth of published data but also a limited understanding of unmet needs of cancer patients in the Middle East region, particularly in the Gulf Cooperation Council (GCC) countries, consisting of Kuwait, Qatar, Oman, Saudi Arabia, Bahrain and the United Arab Emirates (UAE). Nair, et. al., (2018) argued that the assessment of unmet needs of cancer patients in the UAE will improve the supportive care services and thereby positively impact the overall quality of life of cancer survivors in the country.

Keefe, et. al., (2016), emphasized on encouraging more physicians to specialise in supportive care along with specifying the crucial role of supportive care in medical education to improve the quality of life of cancer survivors and their satisfaction about treatment. The author also suggested medication associations to strengthen guidance and the integration of supportive care in oncology services highlighting them as the unique challenges of the Middle East region. In addition, it was also recommended that pharmaceutical industries and academia work together in research to develop fast-track drug discovery, evidence-based guidelines and commercialization. Despite cancer increasing in the UAE, the public health programs in the country have focused more on prevention and pharmaceutical responses, neglecting the psychosocial clinical aspect of cancer care (Silbermann, et. al., 2012, 2013). Researchers have more distinctly reported the scarcity of qualitative studies in cancer research in this region (Elbarazi, 2016; Nair, 2012; Aw, et. al., 2011; Tadmouri & Al-Sharhan,1985). Most research studies in the region have used a quantitative approach that lacks the exploratory aspect of cancer patients' needs (Elbarzazi, 2016). Author also reported the dearth of research in cancer patients' education as well as information needs in the UAE. Assaf, Holroyd & Lopez (2017), further confirmed that in the UAE, there are no extensive health-awareness programs due to diversity of nationalities and languages highlighting health education as a challenge due to the cultural fear of spreading bad news or reluctance of publicly discussing health issues in this sensitive culture.

2.4 CANCER DIAGNOSIS & SURVIVORSHIP

Cancer diagnosis is a life changing experience which restricts an individual's life psychologically, physically and socially (Azhar & Bruera; 2018; Usta, 2012; Stein, et al., 2008; IOM, 2008). Many people equate cancer as an early death (Straker, 2013; Röing, Hirsch & Holmstrom, 2006) however, if detected and treated earlier, cancer no longer serves a death sentence (Bush & Gorman; 2018; WHO, 2017; IOM, 2002). Receiving a cancer diagnosis is devastating news for an individual and for the family (Bumb, et. al., 2017; Woźniak & Iżycki; 2014). Prior to diagnosis, most patients do not perceive themselves to be at higher risk for the disease thus when patients or families are told that they have a diagnosis of breast cancer, their responses clearly vary; most of them experience fear, disbelief or existential crisis (Coronado, et. al., 2017; LeSeure, et. al., 2015; Wronski, 2015; Hewitt, 2004). A cancer diagnosis can influence many aspects of a person's life and disrupt one's physical and psychological state by inducing significant level of stress (Grassi, et. al., 2017; Wang, et. al., 2013). There is a complex relationship that exists between cancer and psychosocial factors that influence the survivorship experience and their quality of life (Coggin & Shaw-Perry, 2006; Carreira, et. al., 2018; Patsou, et. al., 2018; Usta, 2012;). Research shows that cancer survivors experience poor physical and mental health outcomes and poor quality of life (Carreira, et. al., 2018; Clough-Gorr, et. al., 2010; Foster, et. al., 2009; Fu, et. al., 2009).

An IOM (2006) report revealed that survivors' follow up needs are being unmet. The patients' experience with advanced cancer illustrates the implications of not designing the delivery system around a clear understanding of patients' needs (Wen & Gustafson, 2004). Patient-centred care is unlikely to occur without good understanding of patient needs and factors that influence them (Zucca, et. al., 2014).

According to the Office of Cancer Survivorship of the National Cancer Institute (2014), an individual becomes a **cancer survivor** from the time of diagnosis for the rest of her life (Riker, 2015; Denlinger, et. al., 2014). The psychosocial needs of each cancer survivor are unique and need to be identified and addressed during the different phases of care. The literature search in this study focuses on the needs and concerns of cancer patients through all phases of cancer survivorship (Figure 5). The pioneer model of survivorship was initially described by Mullan (1985) as seasons of survival with unique sets of concerns including *acute survivorship* (the experience of diagnosis and treatment), *extended survivorship* (a time for "watchful waiting"), and then *permanent survivorship* (long-term remission). This model was later elaborated by Hewitt, et. al., (2006) proposing a period of transition named transitional survivorship reflecting transition from active treatment to different forms of adaptation throughout as following:

- **Acute Survivorship:** The period that includes the diagnosis of cancer and its treatment. In this phase, patients typically experience a physically and emotionally difficult time.
- **Transitional Survivorship:** This begins at the completion of acute treatment. Cancer survivor experience transitioning back to previous responsibilities including work and family.
- **Extended Survivorship:** The period of remission after surgery, radiation or chemotherapy. This is a time of careful observation and surveillance.
- **Chronic Survivorship:** This entails people who are living with cancer as a chronic disease for instance women with metastatic breast cancer.
- **Permanent Survivorship:** This period recognises the heterogeneity in the permanent survivorship. This is a cancer free period, yet one might live cancer free for many years and develop late or long-term side effects or die from natural causes or die after a late recurrence or develop a second primary.

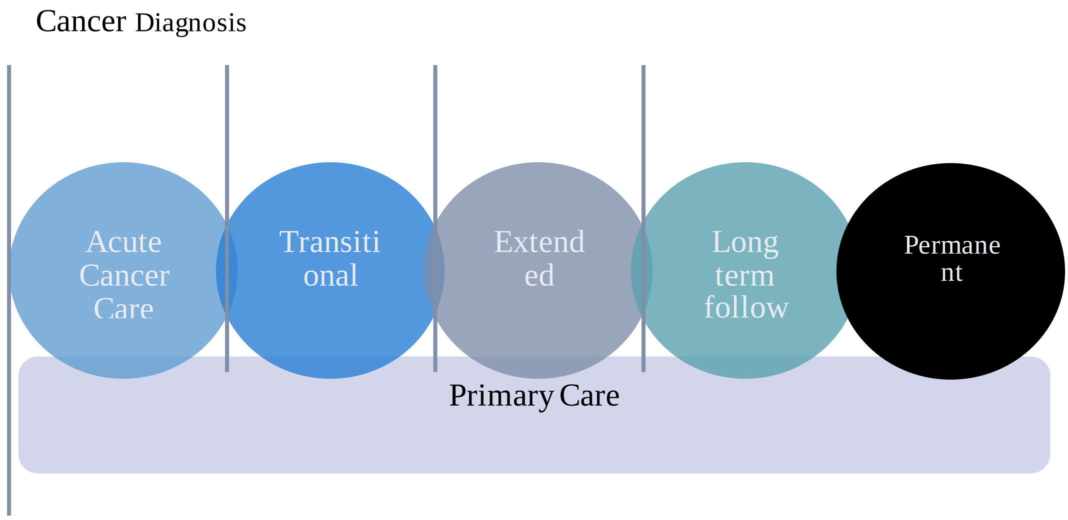


Figure 5: Phases of Cancer Survivorship

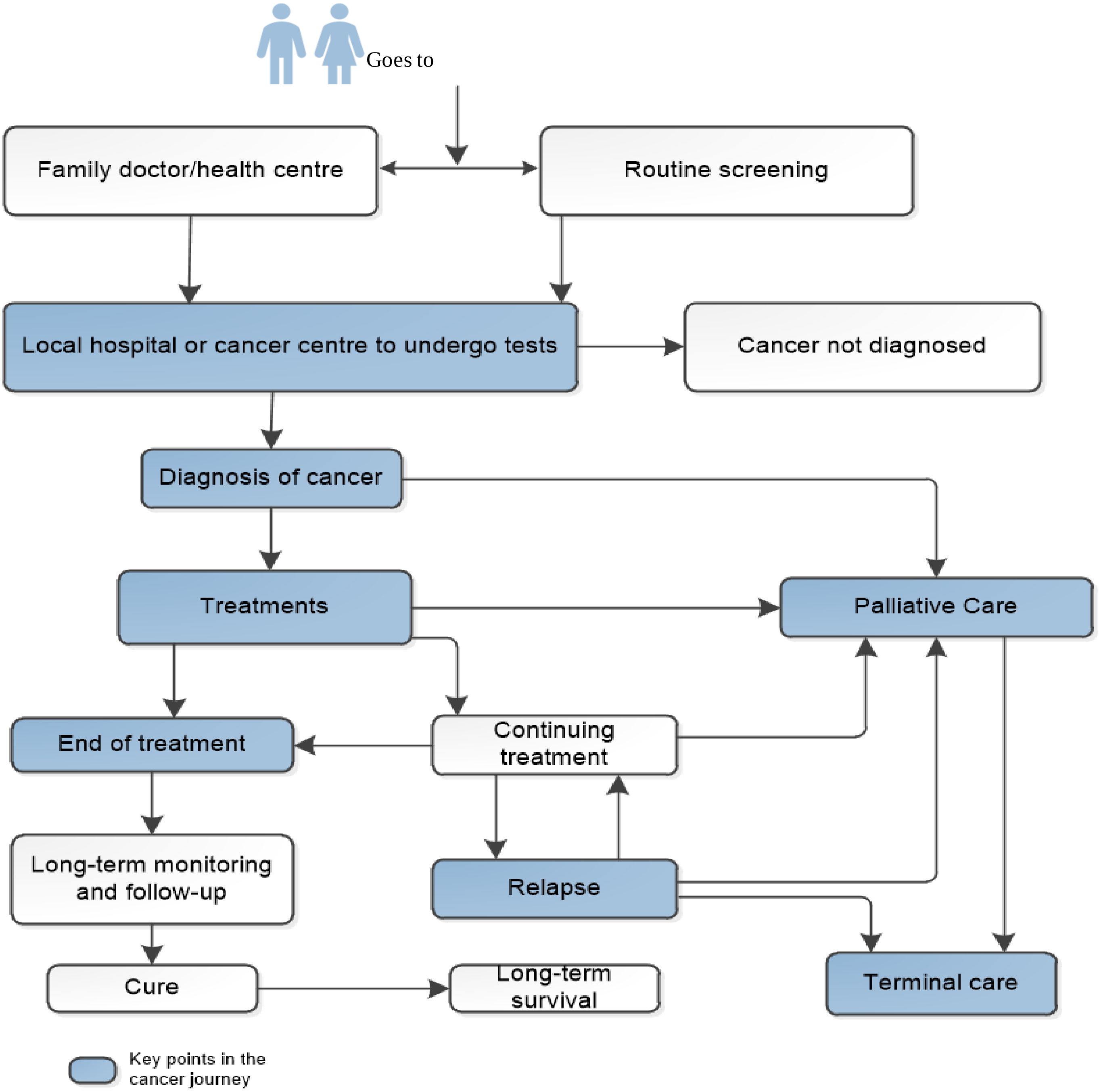
Adapted from Miller, K., 2012. Excellent Care for Cancer Survivors

2.5 BREAST CANCER SURVIVORSHIP

According to the American Cancer Society (2021), the average 5-year survival rate for people with breast cancer is 90%. Besides having better prognosis than other cancers, many breast cancer survivors suffer from long-term psychological distress because recurrence of cancer is mostly incurable (Chiriac, et. al., 2018; Tatsuo, et. al., 2015; Peled, et. al., 2008). Fear of recurrence, physical symptoms for instance, fatigue, pain, disruption of body image, stigma of disability, sexual dysfunction, treatment related issues & anxiety, family & relative's relationship issues have been reported as the major psychosocial needs in women with breast cancer (Sabiston, et. al., 2018; Zimmermann, 2015; Turnbull Macdonald, et. al., 2012). Additionally, advancements in breast cancer disease in terms of biology, diagnostic approaches, predicting prognostic factors and treatment decision making, have contributed to the complexity of the experience and influence of women's decision-making processes and psychological adjustment towards it (Holland, et. al., 2015; Pierce, 1988). An individual's emotional wellbeing and psychological adjustments towards disease can be positively or negatively influenced by factors such as personality attributes, preferences of information or choices of treatments, family or partner's relationship, sexuality concerns, religious or spiritual beliefs, patient-provider communication and degree of physical symptoms (Lamkin & Slavick, 2014; Paludi, 2014).

There is a variation in how women deal with cancer diagnosis and treatment and adapt to the uncertainty of life after it (Hajian, et. al., 2017; IOM & NCR, 2004; Ashing-Giwa, et. al., 2004). Fitch (2008) explained how a cancer patient may enter the cancer care system at various points and move through the variety of experiences at different paces and along different pathways (Figure 6). Some may just enter at the point of screening and may never proceed or at the point of diagnosis and move through different phases of treatment. Some become disease free and may have follow-up care without any symptoms while others may experience cancer recurrence. Some require palliative care, whereas some finally result in death as a cancer outcome. Each phase of the cancer journey is associated with unique needs for instance during the diagnosis phase, upon completion of treatment, survivorship phase when they re-enter their normal living, uncertainty of having recurrence of a disease or about the progression of cancer. Not everyone copes with these issues in a similar way (Fieldler & Koppelman, 2012). Tatsuo, et. al., (2015) suggested that different care for supporting breast cancer survivors after diagnosis should be in place. Literature shows that primary care providers often do not know how best to care for the specific concerns and needs of cancer survivors (Nekhlyudov, et. al., 2012). Thus, the IOM (2008) stressed that it is critical for healthcare providers to be aware and supportive towards the range of psychosocial needs at each stage of the continuum of care (Denlinger, et. al., 2014; Ogce, et. al., 2007). Moreover, at each stage survivors' concerns and the needs must be understood in the context of other related issues, for instance, cultural or financial issues which may influence patients' quality of life and wellbeing (Ng, et. al., 2017; Costa-Requena, et. al., 2015).

Figure 6: Understanding Cancer



Fitch, M. I., (2008). Supportive care framework

2.6 BREAST CANCER SURVIVORS' CONCERNS

2.6.1 SURVIVORSHIP CONCERNS AT DIAGNOSIS

Payne (2014) described cancer as a universally stressful experience. Receiving a cancer diagnosis is associated with immense negative feelings and distress for many (Nail, 2001). Although distress is highly prevalent and diverse at all stages of cancer (Holland & Alici; 2010) yet anxiety, uncertainty and psychological distress are universal elements reported during the diagnosis phase particularly before and after the mammography and after the pathological findings (Ghaemi, et. al., 2019; Ramírez-Perdomo, et. al., 2018; Jennifer & Yingling., 2018; Geyikci, et. al; 2018; Carreira, et. al., 2018; Holland, et. al., 2015). Ganz & Stanton (2015) argued that the most common psychological denominator of cancer regardless of any stage of the disease is the experience of life threat and uncertainty. Cancer diagnosis can disrupt one's life by threatening a person's sense of security (Bush & Gorman; 2018) and can create negative consequences on physical and psychological well-being (Epplein, et. al., 2011). Most women acutely experience fear and disbelief after being diagnosed with breast cancer (Tsaras, et. al., 2018; Coronado, et. al., 2017; Wronski, 2015; IOM & NRC, 2004). Apart from accepting the diagnosis, breast cancer survivors also grapple with self-esteem issues (Türk, et. al., 2018; Landry, et. al; 2018; Ng, et. al., 2017). According to Holland (2002), no disease has sustained as strong as a negative stigma as cancer.

Spittler, et. al., (2012) found that after being diagnosed with breast cancer, women were exposed to numerous healthcare professionals to discuss the disease process, prognosis and treatment options. For many women this process to acquire new information could be overwhelming resulting in making hasty decisions about choice of treatment as well as treatment centres (Bush & Gorman; 2018). The decision about choice of treatment can be quite challenging (Levit, et. al., 2013). In addition, where to have these treatments builds up further anxiety as one must deal with the little knowledge or information about the disease (Behboudifar, et. al., 2018; Hauffman, et. al., 2017; Katz, 2015; Canil, et. al., 2012). The ongoing uncertainty about the future affects how the individual views the future (de Vries & Stiefel, 2014).

Delivering bad news is one of the most challenging tasks oncology professionals must undertake (Buckman, 2005). Good communication is the key aspect of patient care thus, physicians should be sensitive toward disclosing the diagnosis considering the patient's emotional state by hoping for the best and preparing for the worst (Prip, et. al., 2018; Sarafis, et. al., 2013; Dias, et. Al., 2003). Considering the importance of communication, many medical schools have implemented training programs delivering news to the patients in their curricula (Bousquet, et. al., 2015; Reed et al., 2015). Nevertheless, how compassionate or skilled the health professionals are in delivering bad news, patients may experience intense emotional reactions (Shell & Kirsch, 2001). Healthcare professionals, including oncology nurses, need to develop skills in accurately and empathetically presenting information (Azadi, et. al., 2018). In doing so, they can maintain hope regardless of the patient's prognosis.

When cancer occurs in an individual's life, it also enters the lives of family members (Bush & Gorman; 2018). According to Zaider & Kissane (2015), cancer diagnosis marks a major transition in the family's life. Nevertheless, family member's support plays an integral part in cancer patients' psychological and mental wellbeing (Laryionava, et. al., 2018; Segrin, et. al., 2005) and play a key role in the support system for most patients (Bush & Gorman; 2018).

2.6.2 SURVIVORSHIP CONCERNS DURING TREATMENT

Once diagnosed with breast cancer, the initial decision-making lies with the choice of therapy for most patients, either to choose local tumour removal with radiotherapy or mastectomy with or without reconstruction (Manning & Sacchini, 2016). Prophylactic contralateral mastectomy which is defined as the removal of a healthy breast in a patient undergoing mastectomy for ipsilateral cancer is often considered as part of the initial plan of treatment (Boughey, et. al., 2016).

For early-stage breast cancer (0 to IIIA), radiation therapy for six weeks is the standard approach (American Cancer Society, 2019b; Holland, et. al., 2015). Fatigue is the most common side effect associated with radiotherapy in addition to skin and sensation reaction as well as swelling of breast (Nicholas, 2016). Black women have been reported with more frequent and severe skin changes associated with pain and psychological distress resulting in disruption of daily functions (Schnur, et. al., 2011; Ryan, et. al., 2007). In younger women, incision related asymmetry, long term hypopigmentation and fibrosis resulting from implanted brachytherapy have been reported influencing women's psychological state (Walijee, et. al., 2008).

Axillary Lymph node dissection (ALND) has been a standard procedure for staging to measure the extent of disease which often results in surgical morbidity including sensory changes, infection risk and other serious adverse effects including pain, functional limitations particularly lymphedema which demand lifetime adjustments to avoid infection in addition to psychological distress, body image concerns and alteration of clothing which significantly impacts all domains of quality of life (Hulett & Armer, 2016; Paskett, et al., 2012).

Women who consider mastectomy as a treatment choice are often offered reconstruction, of which implant reconstruction is the most common (30%) reconstructive choice globally (Dellacroce & Wolfe, 2012). Reconstruction may require use of tissue expander for better aesthetic outcome; however, the late effects of expander usage may result in discomfort or pain with a need of re-surgery for the placement of permanent implant (Adkinson, et. al., 2015). Moreover, the implant reconstruction may fail and could lead to extrusion or capsular extraction (Holland, et. al., 2015). However, these events are uncommon with 40% risks reported in a review of published literature (Rabey, et. al., 2013). Higher acceptance rate of reconstructions has been reported in white, younger and higher socioeconomic status; is further supported by educational level, financial issues and the decision-making process (Nelson, et. al., 2012).

Standard adjuvant chemotherapy commonly takes about four to six months and is associated with symptoms including nausea, fatigue, peripheral neuropathy, alopecia, menopause, weight gain, joint pain, skin changes and insomnia and others (American Cancer Society, 2019c; Nicholas, 2016; Holland, et. al., 2015). Endocrine therapy is prescribed for pre-and post-menopausal women having estrogenic dependent tumours which later results in increasing endometrial cancer and thromboembolic risks (Schiavon & Smith, 2014). Aromatase inhibitors (AI) are recommended for postmenopausal women. Both these drugs have adverse symptoms such as hot flushes, night sweats, sleep alterations, vaginal discharge or dryness and dyspareunia (Warren, et. al., 2000). Sometimes patients need to discontinue AI therapy as it may result in moderate to severe musculoskeletal symptoms (Henry, et. al., 2012). Approximately up to 30% of patients receiving Herceptin for having Her-2/neu overexpression of tumours. In the UAE, younger women are more likely to have breast cancer at an earlier age with a higher incidence of HER2 positive and ER/PR negative tumours, which are known to be associated with worse disease outcome (Bashir, et. al., 2012). Although there have been significant improved survival rates noted with adjuvant Herceptin, cardiac toxicity is the major concern associated with it (Dang, et. al., 2016; Onitilo, et. al., 2014).

Health challenges such as pain, fatigue, functional disability, sexual dysfunction, cognitive changes, fear of relapse, depression, anxiety or lack of social support can be a result of or exacerbate cancer treatment (Wei, et. al., 2016). It is important to address concerns to avoid patients and their families experiencing negative effects and to improve the delivery of healthcare. Psychological distress along with physical symptoms have been rated as moderate to severe in women more commonly resulting in difficulty in coping in those who did not feel prepared or had inadequate information (Knobf, 2008). Social isolation or mental illness must also be treated to avoid additional emotional distress and to improve patients' ability to adhere to their treatment (Grassi, et. al., 2017; Weinstein, et. al., 2016). Healthcare systems and providers need to consider how to integrate psychosocial factors within the management of care (Mukherjee, et. al., 2018; Grassi, et. al., 2017; Recklitis, et. al., 2017). Psychosocial health services can enable patients with cancer, their families and healthcare providers to manage the disease more effectively resulting in improved quality of life (Advisory Board., 2018; Wei, et. al., 2016; Paraskevi, 2012; Galway, et. al., 2012).

2.6.3 SURVIVORSHIP CONCERNS AFTER TREATMENT

Literature suggests that the majority of breast cancer survivors cope well with the disease (Rah, et. al., 2019; Committee on Appropriations, U. S, 2002). However, negative consequences of breast cancer may persist for many years even after the acute phase (Bodai & Tuso, 2015). The end of treatment and the beginning of survivorship are often observed with diminished support from providers and health systems (Tompkins, et. al., 2016; Knobf, 2013; Cappiello, et. al., 2007). This phase continues with emotional highs and lows and vulnerability of being "new" normal or back to normal (Holland, et. al., 2015). How a woman adjusts into survivorship phase depends on the degree of symptoms she experiences, the adequate level of information she acquires to manage disease and late effects, psychological therapy focused on empowerment and increased self-care and coping skills (van Londen, et. al., 2013).

Fear of recurrence, uncertainly of reintegration into normal life or fear of mortality with other physical symptoms negatively affects patient's wellbeing (van de Wal, et. al., 2018; IOM, 2008). Younger age limited social support, poor communication with the providers and pre-existing psychosocial problems have been identified factors that could challenge women's recovery (Holland, et. al., 2015; Fillon, 2013; Zhou, et. al., 2010). On the other hand, Andersen, et. al., (1989) and Ganz, et. al., (2002) argued that several studies have reported few differences in long-term physical and emotional wellbeing when compared breast cancer survivors to healthy, age matched populations. A study of long-term adjustment of women 20 years after treatment reported 18% women with post-traumatic stress, 27% with lymphedema and 20% with numbness as persistent problems (Kornblith, et. al., 2003).

Continuous support from healthcare providers is essential to help cancer survivors cope with the cancer transitions that occur during the course of illness (IOM, 2006; Maguire, 1999). As cancer treatment ends, many survivors face abandonment from the care providers and experience the need to adjust to temporary or permanent physical and emotional changes (IOM, 2006). Cancer survivors need ongoing support throughout their lives to ensure they have appropriate medical care, including screening for new primaries and recurrences, access to services they need particularly emotional concerns and opportunities to engage them as active participants in cancer decision making (Philip & Merluzzi, 2016; Ganz, 2007).

For many survivors, coordination of their care is often observed as sub-optimal (Miller, 2012). There is a clear need for health systems to ensure a seamless patient experience throughout the cancer journey (Chadder, et. al., 2018). Treatment and summary care plans (Appendix 9) should be provided by healthcare providers to ensure appropriate coordination among the members of the extended care team and to support effective communication of a survivor's health status and long-term care needs. Survivorship programs can help them navigate the complexities of care and to bridge the care coordination as for the survivors, coordination of their care is often observed as sub-optimal (Miller, 2012).

Unfortunately, there is no survivorship program in the UAE cancer care system which can help cancer survivors navigate the complexities of care and to bridge the care coordination. Moreover, lack of evidence and literature on cancer survivorship in the UAE pose a great challenge to understand the issues associated with the local community.

2.7 KEY DOMAINS OF BREAST CANCER SURVIVORS' CONCERNS

Needs of human beings are not limited to physical aspects as there are various domains of needs, for instance, emotional, psychological, social and spiritual. Human beings take actions throughout the day to ensure these needs are met (Maslow, 1998). Dudas & Carlson (1998) argued that the usual way of meeting daily needs becomes ineffective as life events change; thus, a person's needs cannot be met in the same manner applying the routine approaches. The new situation may require new demands with the feeling of vulnerability leading to anxiety, uncertainty and a sense of loss of control over the situation. The individual may require learning new skills, new information or seek additional help to fulfil his needs. These circumstances could be challenging and add an additional burden during the time of distress (Ganz & Stanton, 2015; Vivar, Whyte, & McQueen, 2010; Taylor, 1983). A person may continue to feel vulnerable and feel emotional distress if these needs remain unmet (Fitch, 2008).

Cancer diagnosis is a universally stressful experience (Payne, 2014) which is influenced by a variety of factors; thus, needs emerge and change accordingly and overtime. The diagnosis and treatment of cancer can be conceptualized as an unexpected life event or series of events across a spectrum of experience with a disease (Fitch, 2008)

Throughout the illness, practical changes impact patient's needs which do vary from person to person (Fitch, 2000). Cancer and its treatment have an impact on individuals that can be felt in many ways. In addition to physical changes, cancer may evoke emotional, social, financial, information and spiritual changes (Figure 7). Following are the five main domains in which the key concerns of breast cancer survivors are discussed in greater detail:

1. **Physical Concerns**
2. **Information or Educational Concerns**
3. **Social or Financial Concerns**
4. **Emotional Concerns**
5. **Spiritual or Religious Concerns**

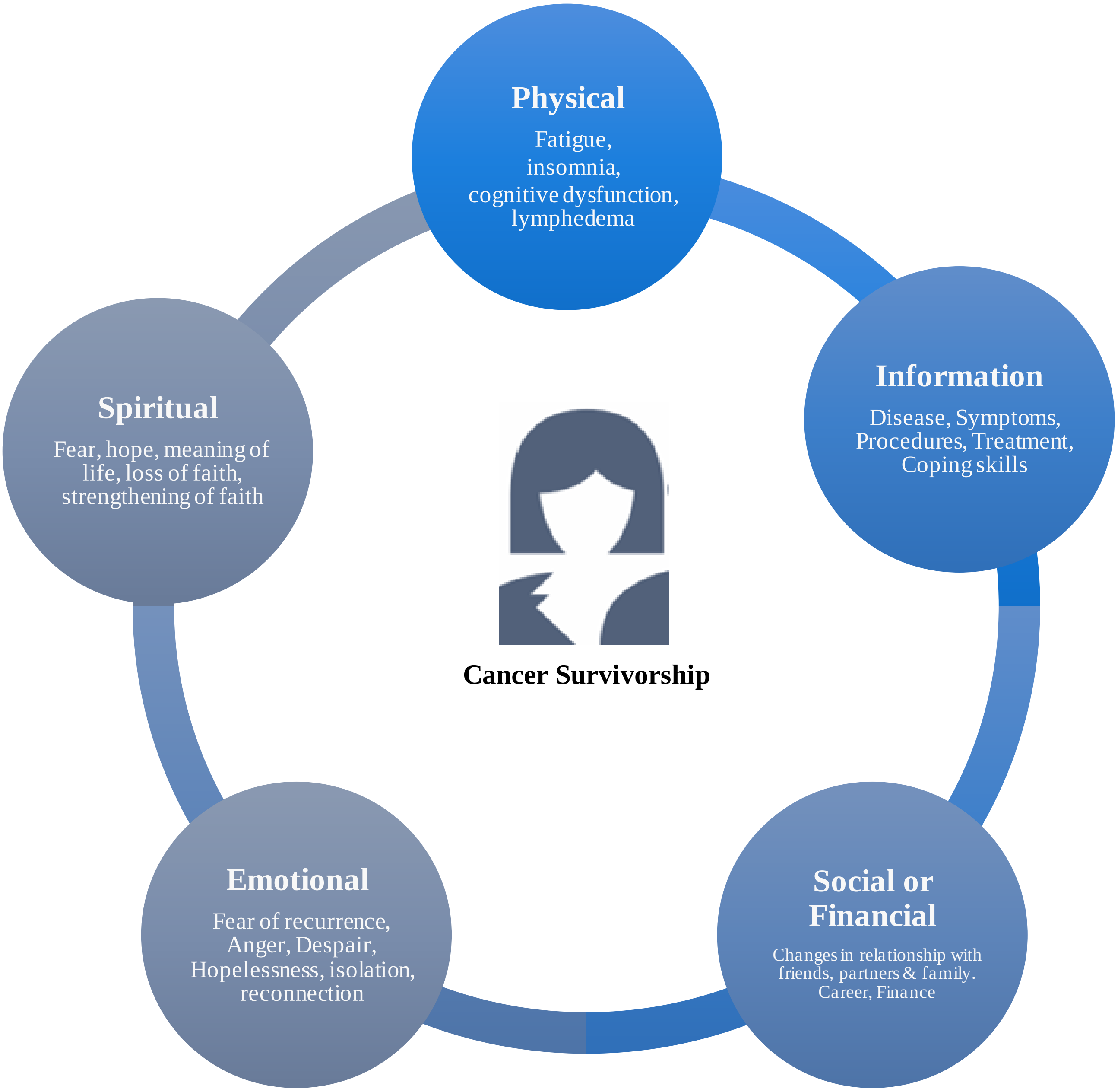


Figure 7: Key domains of Breast Cancer Survivorship

2.7.1 PHYSICAL CONCERNS OF BREAST CANCER SURVIVORS

Breast cancer diagnosis is critical in its physical implications and may turn into a crisis for the patient at an emotional level (Kirby, et. al., 2017; Ray & Baum, 1985). Physical needs encompass but are not limited to needs for physical discomfort and freedom from pain, optimum nutrition, ability to carry out one’s usual day to day functions and activities of daily living (Fitch, 2008; Hewitt, et. al., 2003). Physical discomfort or disability may impede an individual’s capability to fulfil his or her needs (Zabora, et. al, 1997). Physical impairment such as fatigue, pain, post-surgical and persistent upper-quadrant issues, chemotherapy-induced peripheral neuropathy, lymphedema, cardiotoxic effects of chemotherapy and radiotherapy, weight gain, bone health challenges, and arthralgias are the most common concerns that survivors experience during or after the course of treatment which leads to limitation of one’s daily activities (Schmitz, et al., 2012).

The IOM (2008) reported that people with cancer or with a history of cancer more frequently have poor health (30%), other chronic medical conditions (42%), one or more limitations in the ability to perform activities of daily living (11%) and other functional disabilities (58%). The National Health Interview Survey (NHIS) data from 1998, 1999 and 2000 indicated that a medical history of cancer at least doubles an individual’s likelihood of poor health and disability. Hewitt, et. al., (2003) reported that the individuals with a history of cancer have significantly higher rates of other chronic illnesses resulting in 5 to 10% higher disability rate than expected.

Fatigue is the most frequently reported symptom of breast cancer (Bower, 2014; Narayanan & Koshy, 2009; Bardwell, et. al., 2008). which has been reported as major obstacle in maintaining their routine daily activities and has serious impact on quality of life (Rao & Cohen, 2004; Portenoy, & Itri, 1999). Cancer fatigue is generally not alleviated by sleep or rest, is typically of greater duration and severity, is often associated with high levels of distress, and is disproportionate to the level of exertion (Bower, 2014; Bardwell & Ancoli-Israel, 2008). In the literature, the proportion of patients experiencing cancer-related fatigue varies widely between 40% and 100% of the overall number of patients with cancer either due to lack of diagnostic criteria and assessment instruments and the effect of disease stage and status on fatigue (Savina & Zaydiner, 2019). A 2002 review by the Agency for Healthcare Research and Quality (AHRQ) found that mechanisms of cancer-related fatigue have been poorly explored, and current treatment options for fatigue are also limited (Carr, et. al., 2002). Ness, et. al., (2013) reported that the highest mean scores overall (rating 0–5) within the physical domain were fatigue, sleep disturbance, memory and concentration, and loss of strength. However, when excluding those who rated a score of zero, and only reporting on items rated 1–5, the most prevalent items were sexual issues, peripheral neuropathy (numbness and tingling), hair and skin care, and fertility.

Pain resulting from the cancer and its treatment is experienced by one third to one-half of the patients (66%) and is often moderate to severe intensity in multiple sites (Caraceni & Shkodra, 2019; IOM, 2008). There is substantial evidence that the management of cancer pain is still often suboptimal (IOM, 2008; Kwon, 2014; Greco, et. al., 2014) and often undertreated, thus, remains despite the administration of analgesics and other therapies and continues to be a concern even in the absence of signs of cancer (IOM, 2008).

Disability, fatigue and pain can result even when there are no longer any signs of the disease which results in added emotional distress and leads to social problems such as inability to work (IOM, 2008).

Cognitive impairment has also been reported in some cancer survivors who were treated with chemotherapy for instance, subtle decline in cognitive functioning mainly language skills, short-term memory and spatial abilities (Lange & Joly, 2017; Adler & Page, 2008). There is a likelihood of infertility in younger women in addition to acute toxicities or radiation and chemotherapy treatments. The symptomatic burden of premature menopause can also result in mood disorders and complaints of cognitive impairment (Warga, 2000).

Anxiety and depression may be triggered by the events of cancer while at the same time lumpectomy or mastectomy and/or other treatment could lead to additional stress (Elobaid, 2014; O’Connor, et. al., 2011; Golden-Kreutz & Andersen, 2004). One study reported that 42% of women found the most stressful part of the cancer experience was the period immediately after finding the lump (Ray & Baum, 1985).

Parizadeh & Abbadi, (2012) defined Body Image as the attitudes and perceptions of individuals towards their appearances and the belief with respect to their body. Among Arab women, great cultural value is placed on body image; thus, anxiety about cancer detection and fear of breast loss consequently led them to resist seeking help. Yam (2013) and Anstett (2016) noted that body image is highly associated with cultural perceptions. Many Arab women tend not to have a mastectomy and would wish to keep their breast as they fear that being diagnosed with the disease and breast removed will result in negative consequences with family relationships

(Donnelly, et. al., 2017). Rezaei, et. al., (2016) and Boing, et. al., (2019) found that women with a low level of education suffer more from discomfort over their body image.

Sexual issues due to treatment could have destructive effects on women's relationship with their spouses or partners (Henson, 2012). Removal of the breast or other treatments could lead to sexual problems, for instance, dryness of vagina which could result in sexual dysfunction and adverse effects on women's sexuality leading to additional psychological trauma (Bakht & Najafi, 2010). After mastectomy, femininity of women may be considered lessened after losing an important sexual organ (Cordero, et al., 2015). Since the breast is a symbol of femininity and sexuality, any damage to it could lead to distress and could harm a women's whole life (Rezaei, et al., 2016). These physical changes triggered psychological trauma resulting in physical and emotional stress eventually undermine one's self-confidence (Almeida, et. al., 2012; Cohen, et. al., 2012). Yeung (2009) and Mckee & Schover (2001) concluded that most patients receive little or no assistance in dealing with the effects of cancer treatment may have on sexual intimacy. After cancer treatment, many patients continue to have unmet needs for information about restoring sexual function (Schover, et. al., 2014). Sexual dysfunction is not something that is generally identified by the health **providers,** and neither is sexual counselling routinely provided (Medndoza, et. al., 2017; Shankar, et. al., 2017 Vaziri, & Lotfi, 2012). Health systems should define and standardise the screening procedures to identify individual perceived needs. For instance, questions about sexual difficulties and intimacy have been recommended as part of the initial evaluation of patients with cancer (Avasthi & Sathyanarayana, 2017; IOM, 2008; McKee & Schover, 2001). In addition, sexual counselling has been recommended both early and continuing through treatment and recovery for those who need it (Barbera, et. al., 2017; Higano, et. al., 2016; Dizon, et. al., 2014).

Hospitalisation and surgery could be petrifying events for a breast cancer patient. Gruendemann (1965) has described surgery as a planned physical assault on the body. This observation was further supported by (Everly, 1989; Clarke, 1984; Masterson, 1979) stating that surgery, regardless of the specific nature of the operation, is purported to be a stressful experience**.** Cancer treatments including surgery can have direct physical effects on the patient and often lead to substantial permanent impairment of several organ systems with resultant disability (Aziz & Rowland, 2003). A Tunisian study showed a significant deterioration in physical, cognitive and social functioning among patients who underwent treatment, while an

Egyptian study reported marked change in physical and social functioning both pre-and post-treatment (Haddou, et. al., 2016).

Physical recovery after breast cancer surgery may be impaired in women with greater comorbidity (Lash and Silliman, 2000), which may contribute to greater psychological distress. Arab women are known to experience a greater impact of treatment type on their quality of life, particularly if treatment had a multimodality approach (El-Sharkawi, et al., 1997). The fragmented approach of treatment delivery for instance surgery, radiation, chemotherapy and attending survivorship clinics in different entities or different healthcare providers can lead to patients getting "lost" in the system, thereby failing to access appropriate services and adding additional barriers to a coherent approach to cancer care (Walsh, et. al., 2010; IOM and National Research Council, 2006).

A tailored treatment that meets cancer patients' medical and psychosocial needs may result in improved pain management and functional ability (Fischer, et, al., 2010). Physical activity for cancer survivors appears to be associated with an improved quality of life (Acton, 2011). This finding was strengthened by another study which concluded that regular physical activity shows promise as an aid to alleviating poor sleep and an increase in fatigue which can be consequences of having cancer (Humpel & Iverson, 2010). In order to alleviate physical symptoms, survivors must seek expert advice provided by the cancer care team. Pikler & Winterowd (2003) described cognitive coping strategies, social support and adaptations as the most effective interventions to reduce the impact of disease-related issues with women's body image.

It is imperative for health providers to work with patients to develop a personalised follow-up care plan (Daudt, et. al., 2014). The establishment of a survivorship program as part of cancer programs is considered a mandatory requirement by the Commission on Cancer, standard 3.3 (Stricker & O'Brien, 2014). Additionally, targeted exercise programmes for breast cancer survivors aid to prevent stiffness of body parts and reduce the chances of developing lymphedema (American Cancer Society, 2020). On the other hand, non-targeted exercises enhance patients' psychological and physical wellbeing; for example, yoga or weightlifting etc. which have been found to be effective in reducing anxiety, depression and fatigue in cancer survivors (Ng, 2017).

2.7.2 INFORMATION OR EDUCATIONAL CONCERNS OF BREAST CANCER SURVIVORS

Information needs have consistently been addressed as the top unmet need of cancer survivors in the literature (Wang, et. al., 2018; Chiesi, et. al., 2017; Fong & Cheah, 2016; Fiszer, et. al., 2014; Campbell, et. al., 2009; Harrison, et al., 2009). The benefits of information provision to cancer patients include but are not limited to an improved coping ability, reduction in anxiety and patient readiness to cope up with future events of illness. Several studies have explored the information and educational needs of breast cancer patients and modes to deliver such information (Findik, 2017; Shea–Budgell, et. al., 2014; Li, et. al., 2011; Wallberg, et. al., 2000).

Literature suggests that breast cancer patient's information needs are higher and directly associated with longer survival and well-being (Kimiafar, et. al., 2016; Tsuchiya & Horn, 2009). Treatment related information such as available treatments options have been the most frequent type of information reported in the literature followed by information seeking about the cancer type (Okuhara, et. al., 2018; Chua, et. al., 2018; Rechis, et. al., 2014; Squiers, et. al., 2005; Rutten, et. al., 2005; Bader & Theofanos, 2003).

In Eastern cultures, families act as bearers of bad news and strongly demand a "do not tell" approach (Zakri & Karim, 2015; Salem & Salem, 2013). Patients reported feeling upset after hearing the devastating news of cancer diagnosis and such anxiety may result in making it more difficult to provide further information (Konstantis & Exiara, 2015; Stoll, 1986). The delivery of bad news continues to be stressful for health providers and a traumatic experience for cancer patients and their families (Günüşen, et. al., 2018; Stiefel, 2006; Fallowfield & Jenkins, 2004).

Although no communication intervention can eliminate the impact of cancer diagnosis, yet the effective delivery of bad news can at least help patients become better informed, to increase patients' trust, to improve the quality of communication and to be able to better navigate the healthcare system (Sobczak, et. al., 2018, Mostafavian & Shaye; 2018; Back, et. al., 2005). Bellamy (2004) argued that patient education must be a core component of medical school curriculum. A large body of literature has recommended courses for students and residents for delivering such sensitive news, yet clinicians often deliver diagnostic information without proper training or support (Azadi, et. al., 2018; Kissane, et. al., 2017; Dresser, 2012; Eggly, et al., 1997). It is even more complex task for physicians working in Muslim countries who need to require culture-specific training in order to break bad news; they are convinced of wholeheartedly and truthfully informing their patients about a bad diagnosis or a disastrous morbidity (Salem & Salem, 2013).

A cross-sectional study in Qatar, reported that a majority of physicians would disclose a cancer diagnosis, yet 66% would make exceptions in rare cases (Arnott-Smith & Keselman, 2015). Only Arab or Muslim physicians, who are studied in the region, reported that their usual policy is not to tell however it is also believed that their practice might change with the result of empirical research (Rodriguez, et. al., 2012). It is not uncommon in other parts of the world to deal with the disclosure of cancer news with patients as the most difficult scenario in a clinical setting as some patients may show denial and may experience great fear of death and disabilities while others may experience various levels of anxiety that leads to depression (Coulter, et. al., 2008; Eapen & Revesz, 2003). Many physicians too have reported having felt overwhelmed and traumatised by their early experience at delivering the bad news (Mostafavian & Shaye; 2018; Sobczak, et. al., 2018; Salem & Salem, 2013; Orlander, et. al., 2002).

Effective communication skills are the key to good cancer care (IOM, 2013; Stiefel, 2006). Inadequate communication may cause much distress for patients and their families, who often require considerably more information that is usually provided (Bush, et. al., 2018; Silistraru, 2018; Fallowfield & Jenkins, 1999). Not surprisingly, many cancer patients have been reported dissatisfied with much of the communication that takes place within hospitals (Avestan, et. al; 2019; Tu, et. al., 2019; Mahapatra, et. al., 2016; Zamanzadeh, et. al., 2014; Epstein & Street, 2007). Moreover, satisfaction rates associated with the information provided by healthcare providers have also been reported as relatively low in South Asian countries including UAE (Elbarazi, 2015; Au, et. al., 2013; Liao, et. al., 2012) which necessitates the access to accurate and timely information as well as educational needs.

Effective patient-clinician communication and shared decision making are key components of patient-centred care (Delaney, 2018; Newell & Jordan, 2015; IOM, 2013, King & Hoppe, 2013). In patient-centred care, the patient, clinician and healthcare system dynamically interact to influence patient centred care which leads to improved communication and health outcomes (Jardien-Babooa, et. al., 2016; IOM, 2013). Literature suggested that patient-centred communication should be sensitive to patients’ vulnerability, degree of education and ability to understand medical terms, concepts, risks, and benefits, possible reluctance to assert preferences and ask questions, preferences related to treatment and cultural and spiritual outlook (IOM, 2011). Oskay-Ozcelik, et. al., (2007), Kash, et. al., (2005) and Shilling, et. al., (2003) suggested that the patient centredness of cancer care can be improved in several ways, such as more supportive care, better communication, better information supply and better cooperation amongst physicians. Institute of medicine (2008) illustrated a model of psychosocial care delivery emphasizing on effective communication between patients and providers with shared decision making as below:

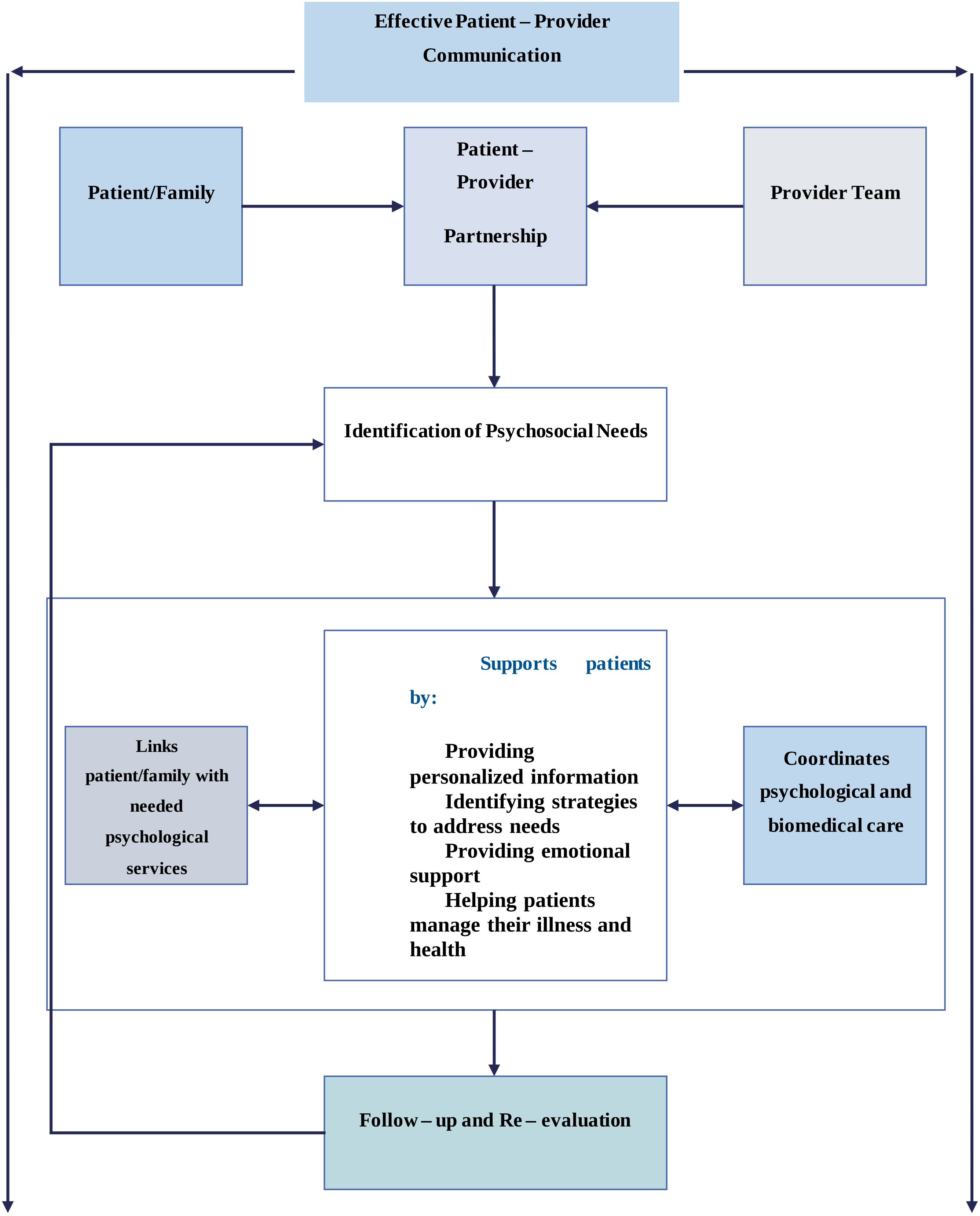


Figure 8: Effective patient – provider communication & shared decision making

IOM, (2011). Patient centred cancer treatment planning: Improving the quality of oncology care, Pg 20

Patient centred care includes good communication between patient and healthcare providers, delivering the evidence-based information to inform patients and practicing shared decision making (Nekhlyudov, et. al., 2014). The main dimensions of patient centred care are to recognize each patient as a unique person, to respect the patient's values and beliefs, and to respond to the patient's individual needs and preferences (Delaney, 2018; Entwistle & Watt, 2013; Pelzang, 2010; IOM, 2001). When it comes to treatment goals, shared decision-making and patient's preferences are particularly important, such as opting for less aggressive treatment options to maintain high quality of life (Glatzer, et. al., 2018; IOM 2013; Fraenkel, 2013; Berman, 2012; IOM, 2011)

Noguera, et. al., (2014) observed that most patients preferred a shared or active decision making and wanted accurate information about their diagnosis and preferences. On the contrary, a Greek study reported 71 percent of women's preference to play a passive role in the treatment decision making (Almyroudi, et. al., 2011). Another study has also shown that supporting patients to be active participants in their health journey from diagnosis to long-term survival can offer patients an increased level of autonomy in their health and may enhance overall quality of life (Jordan, et. al., 2008; Arora, et. al., 2002; Luker, et. al., 1995).

Post, et. al., (2001) argued that ethnic differences play a huge part in the communication process between patients and health providers. Not all patients are eager to learn what health providers want and some are not able to understand the complex teaching (Freda, 2004). A Saudi study reported various socio-cultural factors that play a role in deciding how much information should be given to cancer patients. For instance, families are key participants in medical related decision-making (Al-Amri, 2009). Obeidat & Khrais (2015) emphasized healthcare providers to assess patients' preferences about individuals' particular needs and disclosure of cancer diagnosis and related information. Elbarazi (2015) reported the higher needs to improve patient-physician communication taking into consideration the cultural and language barriers.

It is equally important to understand that information needs of cancer patients do not remain constant and may change over the course of illness (Hsieh, et. al., 2018; Al-Qadire, 2014; Ankem, 2005; Hewitt, et. al., 2004). It is important to understand what type, amount and quality of information delivery is necessary to achieve better health outcomes (Rood, et. al., 2018;

Degner, 1997). Rutten, et. al; (2005) suggested that the stage of cancer determines the information needs of the patients.

A study found the needs of information declined from initial consultation to follow-up nevertheless remained high whereas increased or remained stable by the time of follow-up (Douma, et. al., 2012). Information needs related to rehabilitation, recurrence and access to available support services have been reported higher during the follow-up phases of cancer care (Lewis, et. al., 2009; Squiers, et. al., 2005). Van Mossel, et. al (2014, 2012) and Matsuyama, et. al. (2013) affirm the need to identify the information needs at each stage of the cancer in order to accommodate specific unmet needs at each phase of cancer journey.

Additionally, patients may perceive information differently from one another as an individual's personality influences their perception of the information (Cowan & Hoskins, 2007). As information needs vary based on severity of disease and type of treatment (Shea–Budgell, et al., 2014; Meredith, et. al., 1996), researchers have also identified differences in information needs based on patient demographics and ethnicity (Al-Amri, 2013; Matsuyama, et. al., 2011 & Rutten, et al 2005). Ankem (2006) reported factors such as age, gender and education level influencing the information needs. The study found that younger patients had more needs than older patients and preferred a more active role in decision making. Wallberg, et al., (2000) and Papadakos, et. al., (2014) also found higher information needs in younger patients and in those with a higher education background.

A Jordanian study also reported that younger and higher education patients are more likely to prefer the truthful disclosure of breast cancer diagnosis (Obeidat & Khrasi, 2015). On the other hand, Recio-Saucedo, et. al., (2016) found the process of decision making in younger women quite challenging thus recommended the efforts to provide information regarding sexuality, body image, reconstruction, fertility and likelihood of familial predisposition. Meredith, et. al., (1996) noted that affluent patients required more information than those from deprived areas. Other demographics for instance, gender and religion were also found to be associated with the need for information.

Cultural and religious beliefs might be such factors impeding the information seeking behaviour mainly in Arabs (El-Obaid, et. al., 2014; Ortashi, et. al., 2012; Hatefnia, et. al., 2010; Al-Amri, 2009; Bener, et. al., 2002). Donnelly, et. al., (2013) found that women in Qatar, who believed that cancer is God’s punishment or bad luck, were significantly less likely to practice any kind of breast cancer program compared to participants who wanted to know if they have cancer.

Information and educational needs have become the most important part of cancer care to inform patients about their treatment plans and effectively cope up with the disease (Chua, et. al., 2018; IOM, 2011). Berger, et. al., (2018) addressed that well informed patients are more satisfied with care, have a better sense of control of their total situation, and report a better quality of life. Frenkel & Cohen, (2014) further illustrated that effective communication is the key to improved health outcomes. What information and when patients need to know and from whom has become the pivotal to ensure the delivery of patient-centred care (NIH, 2017; Rutten, et. al., 2005).

Most patient educational programs in the UAE are unstructured and fragmented (El Obaid, 2014; Aw, et al., 2011;). Availability to health educators is rare and the majority of the health education is delivered within the community (Sharif & Blair, 2011). Educational programmes should start with proper needs assessment and goal setting to meet those unique needs of the targeted population (Johnson, 2014; Ratzan, 2009). Fallowfield & Jenkins (1999) explained that multidisciplinary and comprehensive education programs are part of the process of patient empowerment (Chen, et. al., 2016). Less education or lack of literacy would delay seeking medical support in the presence of symptoms, thus, likely to be delayed for screening, resulting in progress or advanced stage at the time of diagnosis. (Al-Naggar, et. al., 2012). Several studies have reported a significant association of poor quality of life with lower levels of education and awareness and lower socio-economic status (Musarezaie, et. al., 2012; Sprague, et. al., 2011; Salonen, et al., 2009; Esbensen, et al., 2004). Thus, raising awareness and empowering women with knowledge and information could heighten their ability to avoid associated risk, understand the nature of the disease and to comply with the treatment regime that is most suitable for her.

Cancer patients should receive accurate information throughout their cancer journey to alleviate their fears and to cope with illness (Lawler, et. al., 2016; Rutten, et. al., 2005; Girgis, et. al., 2000; Leydon, et. al., 2000). Tailoring information as per patients’ needs result in empowering patients to be part of decision-making and can ensure that the appropriate type and amount of information is received (Shea-Budgell, et. al., 2014). It could also guide healthcare providers to deliver the most appropriate care through which patients could greatly benefit. According to Garza, et. al., (2005) and Fitzpatrick (2016), culturally designed interventions result in increased information access, reduce barriers, improve screening and survivorship.

Viewed optimistically, increased partnership and diminished power differentials between patients and their providers have resulted in optimal outcomes, enhanced patient autonomy and meeting unique patient's needs more than ever before (Chen, et. al., 2016). Empowered and informed patients have transformed the face of the current healthcare system (Lenert, 2010). Patients must be encouraged to develop a bond with their health providers. Cancer patients should be provided information about the available support services, helpline, books, trusted websites, secure patient information portals or material. Healthcare providers should enable their patients to work towards shared goals through optimal education processes (Paterick, et. al., 2017), such as by improvising their engagement in the decision-making process, by encouraging those to take ownership of their disease and by providing information that helps them integrate the illness into daily life and to navigate through the healthcare system.

Kissane, et. al., (2017) argued that it is imperative to make patients feel less tense and every attempt should be made to reduce their fear while providing the information they seek or need. Physicians should disclose cancer diagnosis in a personal setting and discuss the diagnosis and treatment options as well as adverse effects of each treatment with patients in a sensitive manner considering cultural variations among cancer patients (Figg, et. al., 2010). Additionally, appropriate training programs for health professionals involved in cancer management will help them to deliver adequate information to patients through professional-patient communication.

2.7.3 SOCIAL AND FINANCIAL CONCERNS OF BREAST CANCER SURVIVORS

The concept of social support in the literature is multidimensional and provides several definitions which also are vague and circular (Hardan-Khalil & Mayo; 2015; Rodriguez & Cohen, 1998). Marmot (2005) argued that social support is influenced by social structural constraints and mainly addressed the individual links of networks in terms of social cohesion. In the literature, the term is generally referred to as the mechanisms by which interpersonal relationships support and protect people from the negative consequences of stress (Pietromonaco & Collins, 2017; Bertero, 2000). Soylar & Genc (2016) defined social support as the help provided for the individual who is under stress or in a difficult situation by people around the individual. Taylor (2011) defines social support as the experience that one is part of a mutually supportive social network which has beneficial effects on mental and physical health. Despite the various interpretations of social support, it has been claimed to be associated with improved survival and have positive outcomes on physical and mental wellbeing (Gallant, 2013; Whitford, et. al., 2008; Astrow, et. al., 2007; Wortman, 1984). There is a large body of evidence indicating that social support affects physical and emotional health positively by meeting fundamental social needs such as love, compassion and belonging to a group, and is a significant help for the person in coping with difficulties in life (Pietromonaco & Collins; 2017; Soylar & Genc, 2016; Cohen & Wills, 1985).

The transition from the various stages in the cancer trajectory is a challenge to women with breast cancer. As needs of survivors shift from disease management to recovery, the adjustment is often not seamless and can be overwhelming, with many challenges including psychological and social well-being (Alexander, et. al., 2019; Chadder, et. al., 2018). Rosedale (2009) observed that isolation and loneliness are common among women who have experienced breast cancer. Wei, et. al., (2016) remarked that breast cancer and its treatment alter social roles and limit the social or daily activities of patients. According to IOM (2008), the physical and psychological problems that emerge from cancer can be exacerbated by or produce significant new social problems.

Social support has long been recognized as an important component of physical and mental health (Snyder & Pearse, 2010). Older women are more likely to face loss of a spouse or reduction in economic status (Carr & Bodnar-Deren, 2009). Many women with breast cancer managed to deal with their illnesses and treatments based largely on social support they received; however, patients are often unaware of resources available to help them overcome psychosocial problems (Bayliss, et. al., 2003). And even if they are informed of available resources, problems with mobility, fatigue, poor understanding of disease, depression, lack of support, negative emotions or financial problems etc. prevent them from taking advantage of these resources (Jerant, et al., 2005). These problems are more apparent in particularly vulnerable and disadvantaged populations such as those with lower socioeconomic background or lower levels of literacy. When these resources are not available, the ability to manage cancer and its outcome is also decreased (IOM, 2008).

The importance of support from support groups and various other sources is well recognised (Adorna, et. al., 2015; Morris, et. al., 2014; Matthews, et. al., 2004; Leadbeater, 2004; Till, 2003). The social support system could be evolved at three levels: the primary level which includes close family and friends, the secondary level which includes other friends, relatives, neighbours and work colleagues and the third level which comprises groups and organisation (Peltonen, 1996; seeFigure 9). Peltonen explained that the primary level is most suitable for giving emotional and practical support when needed as lack of support or support which is not timely could lead to negative consequences. Dedeli, et. al., (2008) also stated that a large part of social support consisted of the patient’s own family support. Peltonen (1996) associated the second and third levels of support to cultural, political and religious ideologies and other social values.

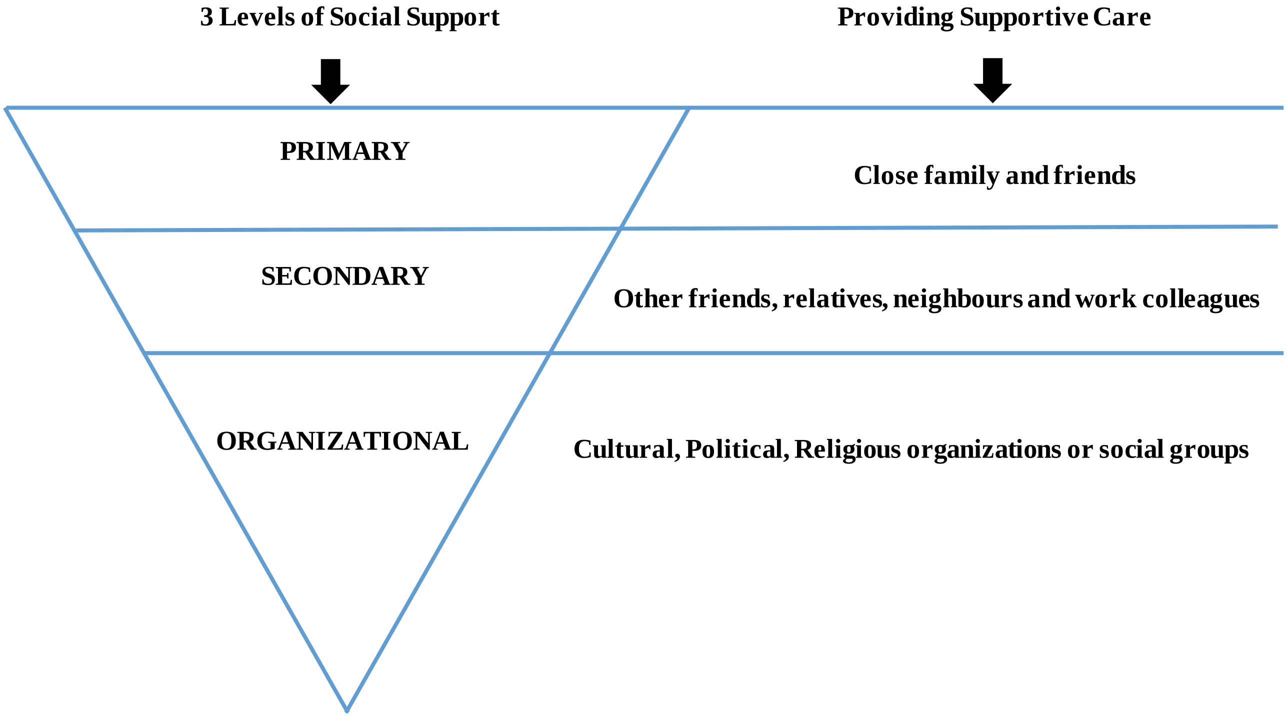


Figure 9: Three levels of social support system (Peltonen, 1996)

Family has the highest impact compared with significant other support with social support resources (Vrontaras, 2018; Snyder & Pearse, 2010; Bertero, 2000). The person receives support from their family or significant people in their life when they feel their abilities are inadequate; however, when such support is lacking, the psychosocial symptoms and issues are aggravated. On the other hand, social networks and expanding social networks post diagnosis are critically helpful resources for any cancer survivors since cancer experience sometimes may become an ordeal and could pose a challenging situation when family and friends are unavailable or unsupportive (Ginter & Braun, 2017; Eakin & Strycker, 2001). Social support becomes vitally important for patients who are lacking informal support that one desires from the closed circle or relationships.

It has been observed that Arab women with breast cancer suffer in silence over many things; for instance, due to stigma and prejudice, women with breast cancer often prefer to stay home as they do not want their families to suffer with guilt and shame just because one has breast cancer (Islam, et. al., 2017; Elobaid, et. al., 2016; Baider & Goldzweig, 2016; Hwang, et. al., 2015; Surbone, et. al., 2013). Women are hugely under pressure and do not ruin their family image by disclosing that breast cancer runs in the family. Often, they are worried if their husband would still want to produce offspring with women with breast cancer or whether they are still able to produce children. Cancer is not something that one can openly talk about in Arab culture and is a topic surrounded by shame and silence (Elobaid, 2014). Moreover, in the Arab world, the role of women is often defined by marriage and children and fulfils multiple responsibilities for their families and society. Breast cancer diagnosis exposes women to disfigure this image and role that fulfils multiple responsibilities for their families and society. Women do not go and seek any social or medical help unless they are in extreme pain (Elobaid, 2014).

Isolation from society is another cultural myth linked with breast cancer as people do not want to visit a woman with breast cancer as they are afraid of the evil eye or bad luck which is an Arabic interpretation of envy and jealousy from a sick person towards a healthy one (Elobaid, at. al., 2016; Donnelly, et. al., 2013; Soskolne, 2007). In Arabs, women with breast cancer are commonly being labelled as guilty of having cancer due to the mistakes and sins that she carried out during her life. The lack of knowledge about the disease keeps them unaware of disease consequences and seeks any support when they have relevant signs and symptoms of breast cancer. Religious and cultural restriction of seeking medical help from male physicians to examine or treat her adds additional obstacle to health seeking behaviour for Muslim women (Donnelly, et. al., 2017; Elobaid, 2014). Shirazi, et al. (2013) argued that many Muslim women are socially or linguistically isolated thus support groups from their own culture or society may be best resource to accommodate their specific needs. The concepts of evil eye and cancer linked with sins may be a cultural dimension and not necessarily an Islamic dimension. According to Islam, a person should not lose hope and make every effort to seek possible treatment yet being thankful to Allah. The Islamic perspective of the disease has been discussed in detail in section 2.7.5 on Spiritual concerns.

In addition to social support needs, e**conomic burden** has also been found to have a significant impact on breast cancer survivorship (Landier, et. al., 2020; Lorgelly & Neri, 2018; Hrishikesh, et. al., 2016; Meneses, et. al., 2011). Financial stability is an integral part of good quality cancer care. Financial stress from low income, the cost of healthcare or lack of health insurance or reduced employment or income can result in substantial stress and can hinder receiving the appropriate care. The adverse effects of no or inadequate health insurance are well documented and include poor health prior to receipt of care, delayed or no treatment, failure to get needed prescribed medications and worse outcomes of medical treatment (IOM & NRC, 2006). A study found that financial needs were most likely to be unmet and that for some of those experiencing financial hardship, 'this aspect of living with cancer was almost worse than the disease itself' (Soothill, et. al., 2001).

Over 75% of the population in the UAE are expatriates and their insurance is covered generally by their employers. Problems with health insurance are affected by problems with employment. If an individual loses their job, they also run the risk of losing health insurance coverage and income. Not having insurance is a catastrophe for an expatriate who is diagnosed with cancer in the UAE as the treatment is quite expensive. Cancer as a chronic disease is not usually covered by the basic insurance which is provided by the employers. The struggle for cancer patients is not just financial but once they are ready to return to work, they face two challenges — landing a job and coping with the chronic symptoms of the disease and some simply lose their jobs or resign from work. Bradley, et. al., (2002) observed that breast cancer may impose an economic hardship because it affects women's ability to work.

Expatriates who do not have the financial means to support their treatment in the UAE also do not have the financial means to receive it in their own country. Most of them do not even disclose to their families that they're sick. It becomes both a financial and psychological struggle. Furthermore, the prohibitive costs of cancer treatment demonstrate that many people do not end up seeking treatment and may terminate the care halfway. There are no current health policies in the UAE that consider coverage of cancer for expatriates thus cancer patients need to make a hard choice either to leave the country or suffer the illness if they remain in the country. Nevertheless, there are authorised charities, non-profit organisations and support groups in the country that may help cancer patients to provide financial assistance for instance, Pink Caravan, Breast Cancer Arabia, Friends of Cancer Patients, Emirates Cancer Foundation, Al Jalila Foundation and Rahma and UAE Government mandates. The majority of these groups provide psychosocial counselling, informational and emotional support and minimum financial help to all UAE residents regardless of their nationality.

As part of patient-centred care, it is critical for health professionals to screen cancer patients for social and financial difficulties. For instance, for some patients, transportation has been observed as a paramount concern by cancer care teams (Matthews, et. al., 2004). Policies must be in place to enhance systematic healthcare reform that promotes patient-centred cancer treatment and to have quality metrics and incentives to ensure that patient-centred care is delivered. In addition to promoting patient centred cancer care policies, there is a clear need for health policies to balance out disparities in cancer care in the UAE by sustainable and affordable health insurance coverage for all residents. There is also a need for employment related policies with regards to cancer to ensure job security and to eliminate any discrimination at work due to cancer.

2.7.4 EMOTIONAL CONCERNS OF BREAST CANCER SURVIVORS

Distress is a common concern across the cancer trajectory, beginning at diagnosis and extending to the post-treatment phase of cancer and long term (Howell & Oslen, 2011). Distress is defined as a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment (Ng, et. al., 2017). According to the IOM and National Research Council (2006), cancer patients may experience a generalised feeling of worry, sadness, fear of future, indecisiveness, uncertainty, higher sense of vulnerability, social isolation, fear of reproductive ability and sexual functions and changes in the individual's role or relationship. The emotional stress of cancer, for instance, long term treatment, fear of recurrence or new cancer, anxiety, mood disturbance, concerns about body, distress due to daily physical concerns can lead to or exacerbate pre-existing distress for cancer survivors and their families (IOM, 2008). Studies have found higher levels of depression among cancer patients (Hegel, et. al., 2006; Spiegel & Giese-Davis, 2003). According to the Agency for Healthcare Research and Quality (AHRQ, 2002), the prevalence rate of having major depressive disorders among cancer patients is four times higher than in the general population.

A study of 215 cancer patients among whom half of the patients had breast cancer revealed that 47% had psychiatric disorders with symptoms of reactive anxiety, depression or mix of both (Derogatis et al., 1983). Although there is some evidence that distress is greater in cancers with poor prognosis, yet it is not fully known whether women with breast cancer have higher rates of distress than others (Zabora, et. al., 2001). Emotional distress and psychiatric syndromes have been consistently reported by the breast cancer population at large (Izci, et. al., 2016; Uchida, et. al., 2011; Hegel, et al., 2006); however, the literature reveals that sensitivity to patients' emotional needs seems to be deficient in current practice (Bramley & Matiti, 2014; Oguchi et. al., 2011; Sheldon, et. al., 2009; Adler & Page, 2008).

Younger breast cancer survivors seem to have higher emotional needs (Knox, et. al., 2017; Fiszer, et. al., 2014; Vivar & McQueen, 2005; Epping-Jordan, et. al., 1999) showed that young adults with advanced cancer became socially isolated because they felt misunderstood and alienated from the rest of the world. The experience could be even more stressful as some may be thinking about planning a family or having more children. Young patients with breast cancer treated with chemotherapy can experience ovarian failure, which can lead to chemotherapy-induced menopause impacting the quality of life (Passildas, et. al., 2019). For some women, chemotherapy can cause early menopause which can be very distressing itself. Such factors contribute to greater psychological distress in younger women (Bloom & Kessler, 1994). Warga (2000) mentioned that amenorrhea and premature menopause due to hormonal changes which are associated with breast cancer can be linked to mood disorders and cognitive impairment in younger women. In addition, women with no husbands or intimate partners are more likely to suffer from emotional distress and dysphoria and have concerns about her femininity, attractiveness, reproduction and future relationship or partner (Bloom and Kessler, 1994).

On the other hand, older women may face a new illness in addition to other pre-existing problems such as being the eldest caregiver of the family. Any pre-existing condition could add additional distress and influence on women's psychosocial health. For instance, several studies have indicated that women with comorbid conditions or impaired performance status report higher levels of psychological distress after a breast cancer diagnosis (Sun, et. al., 2019; Ganz, et. al., 1993; Lansky, et. al., 1985). Greenfield, et al., (1987) suggested that there is a likelihood of greater comorbidity at diagnosis with an increase in age. Moreover, physical recovery after breast cancer surgery can be impaired in women with comorbidities (Lash & Silliman, 2000).

Although emotional response to treatment has been extensively studied, most patients receive little or no assistance in dealing with the effects of cancer treatment on sexual intimacy (Eun-young & Hyunjin, 2018; Mckee & Schover, 2001). Young women diagnosed with breast cancer need more emotional support at and after diagnosis, along with more informational support on fertility and cancer-related sexual dysfunction (Lewis, et. al., 2012). Sexual function changes after breast cancer in most women. A study reported that ninety percent of women suffer from some type of sexual dysfunction (Cobo-Cuenca, et. al., 2018).

Silence or 'quite' acceptance about breast cancer coping is much pronounced in Muslim women (El-Obaid, 2014; Al-Amoudi, et. al., 2013; Singh-Carlson, et al., 2013; Sheppard, et. al., 2010; Banning, et. al., 2009). For many Muslims, the secrecy of illness and coping mechanisms is very personalised and involves a spiritual experience. For instance, one study conducted in Muslim women found out that spirituality is the primary source of psychological and emotional support among participants (Harandy, et al., 2008). Another study among Muslim women described similar findings of cultural influence on women's emotional attitude, *"initially I did not tell anyone, and I hide it from my family, I went for spiritual treatment, and I felt better"* (Banning, et al., 2009). It is important that future researchers focus on the inter-relationship of survivors' emotional needs from different socio-demographic backgrounds to explore social or cultural determinants. Cultural sensitivity conferred with breast cancer requires further research which could help in developing effective culturally sensitive health interventions.

There is no right or wrong way to manage emotional distress but only what is right and workable for the individual. It is natural to be anxious since women are coping with a life-threatening illness. To manage stress and anxiety, strategies such as distraction which involves diverting focus on learning new things of interest or using a hobby, relaxation or meditation to reduce tension in mind and body, regular physical activity such as brisk walk, yoga and adapting healthy living can help them cope at a difficult time and navigate through the cancer experience by levelling down the stress and anxiety. In addition, counselling could identify feelings such as anger, anxiety, grief or other sources of emotional disturbance that could be related to cancer diagnosis. Cognitive behaviour therapy can also help changing patterns and thinking and behaviour to improve patients' current mindset (Cully & Teten, 2008). Healthcare professionals may recommend anti-depressant however the anticipated result could take longer to achieve full benefits (Machado-Vieira, et. al., 2010; IQWiG., 2006). Family, friends and neighbours are more likely to provide the most needed emotional support; however, speaking to local health providers may benefit particularly for an appropriate referral (Recklitis & Syrjala., 2017).

There is no standardised psychological response to cancer diagnosis, but many patients experience the emotional consequences to be the hardest to deal with. (Towers, 2016). Breast cancer patients can experience depression at any level of the disease from diagnosis to the end of the treatment or even post-treatment. It is also important to recognise depression at the earliest possible time. Patients must seek support either through their close circle of family or friends or professional counselling (Gordon, et. al., 2010). The available local support groups could provide confidential and non-judgemental emotional assistance that is most relevant to the patient (Matthews, et. al., 2004; Eakin & Strycker, 2001). Most cancer patients were found to receive inadequate emotional and social support from their health providers (Wang, et. al., 2018; Cox, et. al., 2016; McKee & Schover, 2001; Schover, 1999). A study observed that only 22% of oncologists provided an empathetic response to their patients (Pollak, et. al., 2007). Cancer may be a lifelong process and require adjustment over time (Naus, et al., 2009) thus interventions to address emotional needs must meet the needs of newly diagnosed breast cancer patients as well as long term survivors to adjust the ongoing survivorship issues.

2.7.5 SPIRITUAL CONCERNS OF BREAST CANCER SURVIVORS

Spirituality is an inherent component of being human and is subjective, intangible, and multidimensional (Tanyi, 2002). According to Wright (1999), spirituality is the summation of our values which determines the process of how we interact with the world. It is worth noting that not everyone has faith in God; this means that some people explore spirituality through other means for instance; significant relationships, self-chosen values and goals (Tanyi, 2002).

Religion and spirituality were reported to have a positive influence on mind, body and soul which resulted in better health outcomes (Bowie, et al., 2003; Koenig, 2000; Johnson, et. al, 1999; Tix & Frazier, 1998). Studies have found a well-connected link between religious coping with spiritual growth which resulted in better mental health and positive outcomes following stressful life events (Ano & Vasconcelles, 2015; Pargament, 1997). Crouch & Meurier (2005) argued that meaningful care includes care that meets the spiritual needs of patients. The heightened distress experienced by the cancer survivors may have a spiritual dimension which significantly influences patients' self-esteem and personal relationships (Hatamipour, et. al., 2015; Maxwell & Aldredge-Clanton, 1994).

Cancer patients, being ready to help others increases the meaning and hope in their life and yet brings hope to others (Samson & Zerter, 2003). Stephenson, et. al. (2003) explored the experience of spirituality in the lives of hospice patients and illustrated that 93% of sampled patients with cancer expressed that spirituality helped them to sustain their hopes. Rahnama, et. al., (2012) further stated that spiritual and religious resources can lead to an overall sense of hope and optimism toward life. In a small study, Moch (1998) reported that breast cancer women found the meaning and purpose in their lives through their connectivity with the environment, self and others. Hulett, et. al., (2017) studied a group of breast cancer survivors and found that positive spiritual beliefs were associated with neuroendocrine-mediated peak cortisol awakening response activity. Another study by Yanez, et al. (2009), examined the relationship between spiritual well-being and psychological adjustment in 418 breast cancer patients and found a decline in depressive symptoms and increase in vitality within a 12-month period.

A study on Muslims' beliefs on breast cancer reported that *"It is God who determines who develops breast cancer (and other diseases) and who is cured"* (Johnson, et. al., 1999. Khayat

(1997) also noted that Muslims believe that disease and calamities are sent to people to shed their sins and are tested for their patience and faith. On the contrary, seeking treatment for illness is not regarded as a sign of conflict with reliance on Allah for a cure. According to Prophet Mohammad's (Peace Be Upon Him), *"There is no disease that Allah has created, except that He also has created its treatment".* The holy book Qur'an contains guidance for Muslims that every disease has a remedy for instance; *"Say: It is for those who believe, a guide and a healing" [Fussilat 41:44]*". *"And We send down of the Quran that which is a healing and a mercy to those who believe" [al-Israa' 17:82].* "Muslims' views towards health and illness incorporate the notion of receiving illness and death with patience, meditation and prayers (Rasool, 2000). The belief is that a Muslim person should accept his afflictions with patience and should pray Allah to reduce his suffering. Another study on Arab women emphasized the importance of spirituality and religion to cope with the disease (Haddou, et. al., 2016).

It is critical to understand the link between religious values and beliefs which shape patients' notion of health and illness. In Islam, health is considered as a form of blessings from God (Allah) and illness or suffering is viewed as a test from Him (Lovering, 2012; Rasool, 2000). Muslims view God as the sole controller of health and illness (DeShaw, 2006; Ypinazar & Margolis, 2006). For Muslims, it involves connectedness with Allah through remembering and surrendering oneself to the Will of Allah (Ahmad, et. al., 2010). At the same time, Muslims are obligated to make every effort to seek the best possible treatment as well for an illness.

Spirituality is an essential element of personalised care. Spirituality as a whole provides a purpose of life as many cancer patients often reach a point of uncertainty and loss of hope which affects not just the body but the soul too (Villagomeza, 2005). In addition to other physical and psychosocial concerns, the treatment plan must also include spiritual needs to gain optimism and positive feelings toward health and life and strengthen one's relationship with Allah (God). Survivorship guidelines from the American Society of Clinical Oncology (ASCO) also acknowledge the effects of primary cancer therapy of spiritual nature. Two of the four survivorship guidelines (National Comprehensive Cancer Network & American Society of Clinical Oncology) recommend management suggestions including consideration of chaplaincy or spiritual interventions. In addition, the National Comprehensive Cancer Network Distress Guideline recommends chaplaincy care for distress management, including spiritual assessment and counselling (Swenson, 2016). Integrating spirituality as part of the care process will alleviate the physical and psychological symptoms and will result in better health outcomes. Nevertheless, further research is required to design standardised measures on spiritually based interventions and to understand how to best implement these interventions into a patient's treatment.

The next section will discuss the disparities in cancer survivors' needs and survivorship focusing on Arabs Muslim community in the cultural and ethnicity framework.

2.8 DISPARITIES IN BREAST CANCER SURVIVORSHIP

ARAB MUSLIMS CULTURE & ETHNICITY

Psycho-oncologist Holland, J. C., (2010) said that culture plays a big role in how cancer is discussed particularly regarding the truth about a diagnosis, how the illness and its treatment is perceived and how patients and families can cope up with it (Mendoza-Dreisbach, & Dreisbach, 2018; Benowiltz, 1999). Culture is defined as a set of shared and socially transmitted ideas about the world that are passed down from generation to generation (Daher, 2012), whereas ethnicity is a social construct which is defined by individuals themselves (Dewis & Gribbin, 2009). It represents shared cultural values, beliefs and behaviours (Morre & Spiegel, 2004). In US literature, 'ethnicity' has often been considered a proxy for socio-economic status (Meer, 2014; Brawley, 2002). The association of ethnicity and socioeconomic position on cancer survival has also been acknowledged (Shen, et. al., 2007; Merkin, et. al., 2002). Schmitz, et. al., (2013) also described ethnicity as an independent predictor of disease-free survival in breast cancer patients.

Ethnic differences have been observed in cancer biomarker levels. For instance, a study showed that the Ki-67 labelling index, a biomarker of invasiveness in breast cancer, was higher in Arab/Moroccan patients compared with European individuals (Preat, et. al., 2014). Researchers have also reported ethnic variations in lifestyle factors such as diet and body, tumour biology as well as in tolerability and treatment response among breast cancer patients (Bhoo-Pathy, et al., 2012; Tellj, et al., 2011; Wallace, et. al., 2011; Ma, et. al., 2010). Survivors' needs differ according to demographics and clinical characteristics (Søndergaard, et. al., 2013). Ethnic and cultural disparities in mortality and survivorship among breast cancer patients have also been addressed with significant differences found in almost all domains of needs (Im, et. al., 2008). However, little attention has been directed towards identifying needs associated with ethnicity or underserved populations (Moadel, Morgan & Dutcher, 2007).

Culture and ethnicity both influence an individual's needs, attitudes and response to cancer and can be targeted to improve comprehensive cancer care and to enhance health equity among cancer survivors (Surbone & Halpern, 2016; Kagawa-Singer, et. al., 2010; Corner & Bailey 2008). Such influences are complex and may vary across different cultures (Fielding, et. al., 2013). For instance, in western culture, patients like to discuss and demand more knowledge about different treatment options as well as western medical literature tends to prioritize patient autonomy and corresponding truth telling (Rosenberg, 2017; Benowiltz, 1999). In faith-based communities, prayer is often used to cope with disease (Aschenbrenner & Veneable, 2009). Wang, et. al., (2013) observed substantial evidence of influence of ethnicity towards cancer for instance, people with darker skin colour have found to perceive illness in different ways and have varied response to disease outcome compared to whites. Alden, et. al., (2018) further suggested that health providers should avoid East–West cultural stereotypes.

Apparently, there is a lack of evidence on how cultural backgrounds interact with cancer care delivery and supportive needs of breast cancer survivors. Particularly, the literature on Arab cancer survivors’ needs in the UAE and Gulf region is limited. Nevertheless, the physical and information needs are more commonly addressed in most of the cultures (Tariman, et. al., 2014; Binkley, et. al., 2012; Bilodeau & Degner, 1996; Luker, et. Al., 1995). The concept of dependency has been uniquely reported in Egyptian Arabs (Ali, et. al., 1993). The language, communication, information and the need to get relief from dependency (being dependent or being a burden on the family) are the most frequently reported unmet needs among Arabs (Alananzeh, et. al., 2016; Shaw, et. al., 2013). An Australian study found that access to an interpreter did not eradicate the relevant need of information and support for migrant Arab patients (Butow, et al., 2011). Arabs in the western world have reported higher needs of additional “high quality” information to be available in their native language (Alananzeh, et. al., 2016). Shaw, et. al., (2015) suggested that information needs appear to be pivotal for the Arab community; however, little is known about the extent of information they have been provided and how it has been utilised. Strong association of information needs were also linked to Asian cancer patients as reported by Levesque, et. al., (2015). Another study found that 26% of Arab patients did not answer items related to sexual needs while conducting functional assessment of cancer therapy and 18% skipped these items suggesting that sexual needs are not commonly disclosed among Arab culture and thus could be under-reported (Bell, et al., 2013).

In the Arab world, cancer is often deemed as a social stigma (Mellon, et. al., 2013; Bou Khalil, 2013; Donnelly, et. al., 2013; Daher, 2012). There are several myths in the Arab community regarding cancer (Habib, et. al., 2010) for instance, it is contagious and if removed, it can spread. It is often perceived as a death sentence or God’s will or punishment (Padela, et. al., 2014; Daher, 2012; Walaa, et. al.,2012). The complex cultural beliefs and health behaviours in

Arabs have a huge influence on how cancer is discussed and perceived (Walaa, et. al., 2012). Arab women, in general, tend to keep the disease confidential and seek medical facilities only when they feel ill or symptoms appear (Amin, et. al., 2009). Lack of knowledge about breast cancer has also been reported with the majority of them having been found to have false beliefs regarding treatment as well as prevention (Al-Sharbatti, et. al., 2014). These beliefs may serve as a key barrier to healthcare access in many Asian and Middle Eastern populations (Meiser, et. al., 2001).

In many Arab countries including the UAE, cancer is generally referred to as a “sign of shame” for a woman as well as for her family (Elobaid, et. al., 2016; Kawar,2013). Amongst Arabs, shame and honour are highly emphasized within the context of kinship as personal ill health not only dishonours the individual but also the entire family. Breast cancer represents a cultural stigma to be dealt with in utmost secrecy; thus, women prefer to be silent sufferers who tolerate considerable distress and seek help at advanced stages (Ravichandran, et. al., 2011; Abdel, 2000).

Breast cancer and mental illness both are viewed as a matter of shame and kept hidden as community will view the condition as hereditary defect which might affect one’s social standing and eligibility of marriage among their tribes or families as most Arabs marriages are inter-family or inter-community (Hamamy, 2012; Dhami & Sheikh, 2000). Arab marriages are often arranged to secure the wealth with a family thus the consanguinity concept is socially acceptable in the Arab world (Bromfield, 2014). The age of marriage for women is also very low compared to other countries; most women marry in their teens.

Cultural barriers could be viewed with regards to women’s relatively early age at the diagnosis and later stages at presentation in Arab countries (Elobaid, 2014; Mehdi, et. al., 2014; Zidan, et. al., 2012). Many Muslim women bear more household duties which limits their time to take care for themselves for instance raising children is considered to be main duties of Arabian women (Ezenkwele & Roodsari, 2013). Many Arab women keep their own cancer diagnoses secret from their children in order to protect them (Elobaid, 2014; Mellon, 2013). Although studies have addressed women’s difficulty in communicating with children due to fear of causing them emotional harm and informing them of their possibly hereditary risk of cancer, no research has been conducted so far on how Arab women communicate about their cancer illness with their children (Mellon, et. al., 2013).

Family is the foundation of Arab culture. The Arab's notion of family goes beyond the immediate relatives and extends to all members of a tribe. Muslim women's health priorities are particularly aligned with the patriarchal family structures and Islamic religious values, for instance, perception of cancer as punishment and death, sterility from cancer leading to rejection and divorce, genetic family illness causing dishonour and stigma or no physical exposure to physicians (Baider & Goldzwig, 2016; Anstett, 2016). An Arab American study suggested that the low use of genetic testing is likely due to structural and cultural barriers that reduce access to preventive healthcare (Mellon, et. al., 2013). Moreover, obtaining an accurate family history could be another challenge to effectively operate screening services in the community which eventually result in underestimation of hereditary cancer risk.

Religious beliefs and cultural differences have also been identified influencing Muslim women's choices in healthcare utilisation (Fitzpatrick, 2016). Arab women tend to refuse further diagnostic workup after being diagnosed as having suspicious malignancy (Elobaid, 2014). The refusal is based on Arab women's belief that if others come to know about it then her daughter would lose the eligibility of marriage and would be considered as undesirable to other families. She may pursue further workup with a reassurance from health providers to keep the information completely confidential. Participation in any healthcare activity would lead to a possible early diagnosis which could conflict with Muslim traditional duties (Remennick, 2006). Moreover, patriarchal family structures, family interference, male approval and women's role and commitment are such factors which have been observed conflicting with the health seeking behaviours. For instance, Arab men may not allow their wives to consult male physicians as exposure of the female body misperceived as forbidden by Islamic religion as well as parents may not allow their daughters to consult physicians about breast cancer concerns (Kawar, 2013).

The families in Arab culture often dictate the care including the extent of the care. Families are viewed as the principal decision-makers. Physicians frequently discuss major ethical decisions with the family without the patient's involvement (Young, 2014). Kawar (2013) also reported that there are cultural consequences when a woman gets breast cancer as the man will be advised by his family to leave her and to marry another woman. Thus, most women are likely to keep the illness a secret and avoid seeking medical support. Halligan (2006) reported that family involvement is a significant contributor to the emotional, social, and psychological well-being of the patient. Mataoui & Sheldon (2016) also emphasized on understanding the gender role in Muslim communities to consider when planning care and sharing information.

Moreover, cancer could result in sexual discomfort or dissatisfaction; however, these concerns are not revealed or discussed with care providers due to conservative cultural views (Elobaid, at. al., 2016). Marital breakdown is not more frequent among breast cancer survivors in Arabs, yet sexual dissatisfaction could be recognised as fairgrounds for divorce both religiously and by law (Ashrof, 2005). The belief that husbands abandon wives who have breast cancer is not uncommon in this community which could aggravate stress and deteriorate emotional wellbeing of women particularly in younger women (Elobaid, et. al., 2016).

Increased awareness and sensitivity of cultural diversity is critical to understand cancer patients' concerns and needs and is a prerequisite to design effective need assessments (Kagawa-Singer, et al., 2010; Andrulis & Brach, 2007). Kai (2003) points out, effective cross-cultural communication means being sensitive to an individual's culture in its broadest dynamic sense including ethnicity, socio-economic background, education and religion.

Healthcare systems should be designed to serve an ethnically diverse patient population, providers need to consider various patient perspectives, values, and behaviours about their health. Failure to do so will result in healthcare inequalities and poor health outcomes (Agency for Healthcare Research and Quality, 2015). However, to design culturally tailored effective cancer care interventions, a set of congruent practices and policies are crucial in addition to awareness of the health beliefs and effective communication with patients (Truong, et. al., 2014). Baty, et. al., (2003) further stated that information instruments tailored to patients' culture have been successfully implemented in other ethnic minorities in health improvement programs. Such methods could be effective and result in improvement of Arab women's knowledge and understanding of cancer disease and treatments.

Identifying the determinants for ethnic disparities is critical for improving care (Lam, et. al., 2011), yet little is known about the influence of culture and beliefs about breast cancer, and its implications on preventive health behaviour among the UAE population. It is critical to consider a multidimensional contextual framework and the role of the culture while understanding breast cancer patients' needs in this region so appropriate and effective interventions could be developed with cultural knowledge and sensitivity.

The above literature review provided a richer understanding of what are the concerns of breast cancer survivors, the contexts in which they are generated and how the patients and providers respond to those needs.

Tower (2016) described cancer diagnosis as a dreadful experience which disrupts the life of even the strongest individuals resulting in psychosocial consequences mainly, emotional distress, sadness, depression, anxiety and to the extent that families could break down too. Cancer diagnosis is not necessarily a life-threatening condition; however, it often results in physical and psychological burdens. In most cases, cancer survivors may not return to "normal life" after treatment. Cancer and its treatment impact an individual's life from the day of diagnosis through the long-term survival; therefore, the term 'survivor' which has been used in this study recognises the cancer patient as cancer survivor right from the identification of diagnosis through the various stages of cancer journey.

Many women go through the intensive and challenging cascade of treatment with a diverse range of interventions. Many experience long-term side effects and other challenges for years afterwards. Others with incurable cancer may remain on treatment for the rest of their lives. Short- and long-term effects of cancer treatment can affect every aspect of daily life. Transition at the end of the treatment is generally challenging and adjustment to survivorship could be daunting. Physical issues include but are not limited to fatigue, sleep disturbance, bowel problems, weight changes and incontinence. Emotional and psychological effects include shock, fear of recurrence, distress, depression and low self-esteem whereas common social issues include lack of support, altered relationships, loss of identity and fear of being a burden on family. However, what constitutes a psychosocial need is wholly a unique interpretation of each survivor.

The primary goal of this research was to explore and understand the unique needs of breast cancer survivors through the cancer trajectory to improve our understanding and management of the physical and psychological sequelae associated with the cancer diagnosis and treatment also known as survivorship care. The IOM (2008) emphasised that the continual assessment of cancer survivors' needs is critical to improve their health outcomes and to maximise the quality of their lives.

Although recent advances in the treatment of breast cancer have reduced the morbidity rates (American Cancer Society, 2019a) yet cancer can be a threat to a person's life (Gorman, 2018). Healthcare systems are still lacking to provide the holistic care planning and approach encompassing patient's psychosocial needs to help cancer survivors to cope through the illness (Cadet, et. al., 2016). Likewise, there is no structured cancer survivorship program in the UAE at any cancer centre. Cancer services in the UAE need establishment and implementation of cancer survivorship programs integrating multidisciplinary teams to reflect the full range of needs experienced by cancer patients from the diagnosis to cure or terminal care. UAE health authorities need to ensure that health professionals understand the expectations of their cancer patients and appreciate that psychosocial needs vary by patients' socio-demographics and ethnicity and cultural background. UAE healthcare facilities need to meet the needs of its diverse population to help patients deal with a range of psychosocial issues and if unavailable, appropriate referrals should be made through their network to address patients' specific needs.

To understand breast cancer survivors' concerns and to establish the appropriate survivorship program, local need assessment is the prerequisite. Meeting the full range of psychosocial needs will significantly contribute to survivor's wellbeing and eventually will elevate the quality of patients' life. Cancer survivors are often left in a gap between fragmented cancer care delivery which leads to poor health outcomes due to the lack of survivorship care. Survivors are exposed to the risk of experiencing diverse physical and psychosocial symptoms and seek to enhance daily functioning and quality of life through different interventions. Survivorship care programs are necessary to enhance patients' health, improve survival and to prevent further illness (recurrence) and side effects.

Cancer patients are often uncertain about how to address their needs, and little is known about their specific needs in the cultural context and interventions necessary to meet them. Many people living with cancer have reported their healthcare needs are not well addressed in their care process and showed dissatisfaction at the most fundamental level throughout the cancer journey including diagnosis, treatment and post-treatment. Cancer patients must not only live with such challenges and risks posed to their psychosocial health but also should overcome the obstacles that can interfere with their healthcare and diminish their health and function. Unfortunately, the current healthcare system often fails to adequately recognise and integrate psychosocial needs and resources or offer appropriate referrals.

Understanding and addressing cancer patients' needs must be an integral part of the cancer programs or cancer care however a significant number of patients do not receive the assessment of their needs even though the IOM (2008) has described it as prerequisite for ensuring optimal cancer care and achieving cancer patients' and their families' satisfaction. The post-treatment phase of cancer is largely neglected although better coordination of care among health providers and communication with patients could improve the situation with the provision of critical clinical information flow between health care providers with the use of treatment summary and survivorship care plan as recommended by the Institute of Medicine (Shulman, et. al., 2015). According to the IOM (2008), all components of the healthcare system that are involved in cancer care should explicitly incorporate attention to psychosocial needs into their policies, practices and standards addressing clinical health care and to provide such services to all patients who need them. The IOM (2006) report on survivor care suggests recognising the impact of unaddressed psychosocial problems and recommends more attention to these factors in the design and delivery of health care considering psychosocial needs assessment as an integral part of cancer care.

At large, the needs of people who survive cancer have not been prioritised (Cardoso, et. al., 2013; Ganz, et. al., 2013). This is because the focus of healthcare providers has been on survival, rather than the quality of lives of those who have survived. There is a call for both addressing the specific needs throughout the cancer journey and further ensuring those needs are met. The specific aim of survivorship care is to optimise the patients' physical, psychological and social functioning while minimising the limitations resulting from the side effects of cancer treatment. Limited research has been conducted on the complexities of cancer survivorship needs in the context of culture and ethnicity.

The purpose of conducting this research is not only to identify and address breast cancer survivors' needs but also to identify deficiencies and to recognise resources that may already be available and those which are necessary but are not in place to meet survivors' unique needs. Formalised and systematic assessment of survivors' needs is prerequisite for ensuring sufficient support through their cancer trajectory. Thus, the exploration of the unique needs of breast cancer survivors will help determine which model of care delivery is most feasible for the UAE's diverse population. This is thought to be the first study to investigate and describe the needs and concerns of breast cancer survivors and provides plans as informed by patients at different stages of cancer including the time of diagnosis, during and after the treatment. Furthermore, the study explored the differences in unique needs of survivors by their demographics and clinical factors in order to understand the systems of care that would best meet their specific needs. Since there is no formal survivorship program for cancer patients in the UAE, the healthcare system has no obligation to identify cancer patients' needs as part of their care. The situation underpins an urgent need for a systemic survivorship program encompassing four essential components of survivorship including prevention, surveillance, intervention and coordination based on needs assessment of cancer survivors. Coordination among different healthcare providers will be needed to establish such an intervention ensuring the high-quality cancer care and support that every cancer patient deserves.

The next chapter describes the methodological approach and justification of the specific chosen methods citing relevant literature.

Chapter 3: METHODOLOGY

This chapter starts with describing how a sequential mixed methods study design is considered to achieve the aim and objectives of this study. The chapter starts with the brief description and justification of the selected design, followed by a description of the study design including participants and setting. An integration of the findings from two phases is discussed, which forms the key component of a mixed methods study. Following that, detailed descriptions of the methodology of the study's quantitative and qualitative components is presented. This chapter also describes the status of ethical approval and permission to conduct the study following IRB approval. The below section provides the philosophical overview of research design and describes details about a mixed methods design which was adapted to conduct this research.

3.1 PHILOSOPHICAL ORIENTATION OF RESEARCH DESIGN

The philosophy of science can be divided into two major areas: (a) Ontology, or the science of being, poses questions about *'what is'* and (b) Epistemology, the science of knowledge, is concerned with '*how we know'*. Ben Letaifa (2006) argued that epistemological questions correspond, necessarily, to our ontological assumptions about the reality under investigation. In other words, questions of how we know intersect with questions concerning what sorts of things there are to know about (Masadeh, 2012). In the context of healthcare, it is critical to understand how certain research methods and certain approaches to data collection have emerged from vastly different traditions, and more importantly, how they produce different understandings of the social world. In the healthcare research context, a researcher's paradigmatic positioning relates to their understanding of reality (their *ontological standpoint*) and the nature of knowledge (*their epistemological standpoint*).

According to Guba & Lincoln (1994), paradigms are superior to methods of enquiry in research. Quantitative research predominantly assumes a positivist world view (Henn, et. al., 2006) which are called paradigms and tied to research techniques firmly (Hughes, 1990). Quantitative research paradigm emphasizes the importance of generalizability and reliability (Henn, et. al., 2006). However, positivism imposes certain constraints on results and may neglect important findings while capturing complex phenomena in a single (or a few) controlled quantifiable variable(s) which can be misleading (Weber, 2004). Sociologists argued that people's experiences are complex, subjective and embedded in specific social and historical context (Silverman, 2001).

Positivist approach does not provide sufficient attention to a person's lived experience (Rubin & Rubin 2005; Bryman, 2001) and lacks a detailed explanation of causes and processes of a research phenomenon and fails to acknowledge that the world is fragmented with disorganised units which must be observed distinctly through interactions (Balarabe Kura, 2021). Hammersley (2013) further argued strongly that it could be impossible to measure phenomena related to intention, attitudes, and thoughts of a human because these profound concepts may not explicitly be observed or measured with sense experience or without evidence. To overcome such limitations with positivism, social scientists need to endeavour the integration of supplementary descriptive methods along with the positivist approach such as the interpretivist methodology (Barbara Kura., 2012; Guba & Lincoln., 1994).

Interpretive methodology focuses on investigating interaction among individuals as well as the historical and cultural contexts which people inhabit (Creswell, 2009). In interpretivist paradigm, the fundamental endeavour is to understand the subjective world of human experience (Guba & Lincoln, 1989). The key principle of the interpretivist paradigm is that reality is socially constructed (Bogdan & Biklen, 1998). Interpretivism uses research methods to understand details of interaction in humans' context with the belief that social reality is based on subjective interpretation of actions. Interpretivists adopt a relativist ontology in which a single phenomenon may have multiple interpretations; therefore, researchers tend to gain a deeper understanding of the phenomenon and its complexity in its unique context rather than generalising the understanding to a larger population (Creswell, 2007).

Reflecting on the value of interpretive paradigm, there are shortcomings of the approach that although the interpretive paradigm is sensitive to individual meanings that can be neglected within broader generalizations (Cohen, et. al., 2011; Samdahl, 1999). Mack (2010) criticized that the ontological view of interpretivism tends to be subjective rather than objective. Knowledge produced by this paradigm has limited transferability as it is usually fragmented and not unified into a coherent body (Otoo, 2020, Scotland, 2012). Hence, it raises a question about verifying validity and usefulness of research outcomes with using scientific procedures

(Hesse-Biber, & Johnson, 2015; Scotland, 2012. However, there is no real consensus was noted among qualitative researchers on appropriate methods of data collection and analysis (Bryman, 2001). The author claimed that qualitative researchers often adopt convenience sampling which results in samples that could be seen biased through the researchers' assumptions and respondent self-selection strategies.

Mixed methods that combine both quantitative and qualitative approach in a single study, correspond to another paradigm called **"Pragmatism".** Pragmatism is based on the belief that theories can be both contextual and generalizable by analysing them for ''transferability'' to another situation thus maintaining both subjectivity and objectivity in the research process (Shannon-Baker, 2015). According to Creswell & Clark (2011), pragmatism assumes that there can be single or multiple realities that are open to empirical inquiry.

A major underpinning of pragmatist philosophy is that knowledge and reality are based on beliefs and habits that are socially constructed (Yefimov, 2004) but some versions of those social constructions match individuals' experiences more than others (Morgan, 2014). Pragmatism is typically associated with abductive reasoning that moves back and forth between deduction and induction thus select the research design and the methodology that are most appropriate to address the research question (Kaushik & Walsh, 2019). In this approach, researchers emphasize on the research problem and use all approaches available to understand the problem rather than focusing on methods (Rossman & Wilson, 1985). The pragmatist researchers look to the 'what' and 'how' to research based on the intended consequences— where they want to go with it.

Truth is what works at the time. It is not based on a duality between reality independent of the mind or within the mind. Thus, in mixed methods research, researchers use both quantitative and qualitative data because they work to provide the best understanding of a research problem.

3.2 OVERVIEW OF MIXED METHODS

Choosing the right methodology for a given research project can be a challenge. Creswell, (1994) and Newman & Benz, (1998) highlighted that the selection of appropriate research tools requires meticulous understanding of the type of research question or phenomenon under study or investigation. In addition, careful consideration of the process at each stage must be paramount to select the right tool and must consider factors that may influence the study and thus must be tailored. According to Burrell & Morgan (1979), subscribing to a given research paradigm can be somehow seen as an act of faith. In some scenarios, the question under study may call upon for a combination of different methodologies (Yin, 1993); Newman & Benz, (1998); Tashakkori & Teddlie, 1998), all of which is dictated by the larger research paradigm to some extent which in turn can be influenced by the research process itself. It is important that the research question must be designed in a way that lends itself to a mixed methods design, ideally one in which using a method alone (qualitative or qualitative) would be insufficient.

The term “mixed methods” refers to an emergent methodology of research that advances the systematic integration, or “mixing,” of quantitative and qualitative data within a single investigation (Wisdom & Creswell; 2013). The use of mixed methods allows for a deeper understanding of a phenomenon of interest than the use of either a quantitative or qualitative approach alone, especially when the phenomenon is complex (Fawcett, 2015; Doorenbos, 2014). Positive power and synergy of using mixed methods complements one’s research findings.

Mixed-method research is currently being accepted as a ‘new research paradigm’ with an intention not only to re-establish the prevailing paradigms but to mitigate the weaknesses of individual research approaches (Creswell, 2013). This method can be particularly useful in healthcare research as only a broader range of perspectives can do justice to the complexity of the phenomena studied (Foss & Ellefsen, 2002; Steckler, et. al.,1992; Clarke & Yaros, 1988).

Kroll & Neri, (2009) characterised mixed methods research as one which involves integration of the qualitative and quantitative findings at some stage of the research process, either during data collection, analysis or at the interpretative stage of the research. Mixed methods research includes both quantitative and qualitative approaches. Quantitative methods are based on numbers to claim objectivity, whereas qualitative methods generate theories relying on subjectivity (Kaur, 2016). The approach draws on potential strengths of both quantitative and qualitative methods allowing researchers to explore diverse perspectives and uncover relationships that exist between intricate layers of multifaceted research questions (Shorten & Smith, 2017).

Mixed methods researchers use and often make explicit diverse philosophical positions. These positions often are referred to as dialectal stances that bridge postpositivist and social constructivist worldviews, pragmatic perspectives, and transformative perspectives (de Salazar & Villar, 2018). For example, researchers who hold different philosophical positions may find mixed methods research to be challenging because of the tensions created by their different beliefs (Greene, 2007). Yet, it presents an opportunity to transform these tensions into new knowledge through a dialectical discovery.

Johnson & Onquegbuzie, (2004), clarified that mixed methods research can be viewed as an approach which draws upon the strengths and perspectives of each method recognising the existence and importance of the physical natural world as well as the importance of reality and influence of human experience. It allows combining macro and micro levels of a study by enriching the understanding of the measures and causal processes, constituting an interactive process, both in design and analysis and interpretation of data (Creswell, 2013). Onwuegbuzie & Leech (2004) described the advantages of using mixed methods as combining quantitative and qualitative research enables evaluation researchers to be more flexible and holistic in their investigative techniques, as they endeavour to address a range of complex research questions that arise. Moreover, it allows researchers to develop a framework to validate quantitative results by linking the information extracted from the qualitative phase of the study and to construct indices from qualitative data that can be utilized to analyse quantitative data (Madey, 1982). There is a general consensus that the quality of mixed methods study can be enhanced when the limitations of using a single approach can be counterbalanced (Cheng, 2012). It provides researchers, across research disciplines, with a rigorous approach to answering research questions (Aramo-Immonen, 2013).

The strengths and weaknesses of this mixed-methods design have been widely discussed in the literature (Creswell, 2003, 2005; Moghaddam, Walker & Harre, 2003; Green & Caracelli 1997; Creswell, Goodchild, & Turner, 1996). The key strengths of mixed methods research are words, pictures, and narrative that are used to add meaning to numbers. This methodology is particularly beneficial and appropriate when results arising from a quantitative study are unexpected (Morse, 1991). The main limitations of this design are lengthy time and feasibility of resources to collect and analyse both types of data. Since the research utilises both quantitative and qualitative methods, it can answer a more broad and complete range of research questions since it is not confined to a single method. Thus, use the strengths of an additional method to overcome the weaknesses in another method in a single study. It can provide stronger evidence for a conclusion through convergence and corroboration of findings and add insights and deeper understanding that might be missed when a single method is used.

The method can be used to increase the generalizability of the results and to assess the validity of quantitative finding by using the qualitative data. Therefore, mixed methods approach guarantees greater validity of the research results (Ben Letaifa, 2006; Sale, et. al., 2002; Threlfall, 1999; Tashakkori & Teddlie, 1998). Quantitative data can also be used to help generate the qualitative sample or explain findings from the qualitative data. Moreover, the qualitative inquiry can inform the development or refinement of quantitative instruments or interventions or generate hypotheses in the qualitative component for testing in the quantitative component (O'Cathain, Murphy & Nicholl, 2010). Succinctly, mixed methods produce additional knowledge necessary to inform theory into practice. Its advantages include straightforwardness and opportunities for the exploration of the quantitative results in more detail. As claimed by Tashakkori & Teddlie (2003), mixed methods research eventually has become the standard methodological approach in both social and behavioural sciences.

Nevertheless, there are weaknesses of mixed methods research as the design can be a challenge for a single researcher especially if two or more approaches are expected to be used concurrently thus it may require a research team. It places high demands on researchers who may require additional skills and learning about utilising multiple methods and approaches to understand how to integrate them into a single study appropriately. Although there are many potential gains from data integration in mixed methodology, the extent to which mixed methods studies implement integration remains limited (Lewin, Glenton & Oxman 2009; Bryman 2006). Bazeley (2009) also highlighted the most concerning issue, is the guidance on the analysis and the integration of qualitative and the quantitative data in the mixed methods research. Pragmatic guidance is needed since the current literature is lacking such understanding (Östlunda, et. al., 2011; Creswell & Clark., 2011; Curry, Nembhard, & Bradley., 2009).

The lengthy nature of mixed methods research generally makes them unsuitable for publication in journals (Creswell, 1994). It is relatively more expensive and more time consuming and labour intensive. Although, it is easy to implement and enables the focus of the research to be maintained, as a result of one set of data building upon the other yet the challenge lies in the selection of participants in order that pertinent information is available (Almalki, 2016), hence, the recruitment for the qualitative phase could be problematic as the participants may no longer be available due to a longer timeframe required to undertake the study. The other challenge of this design is the fact that it is generally an emergent design where the second phase cannot be fully developed until the first phase is completed. This may result in a second ethics or institutional review board (IRB) approval for the qualitative phase (Creswell & Clark, 2011).

Additionally, as the need and the use of mixed methods research is rapidly growing, it is also becoming increasingly important to consider the issue of quality (O'Cathain, et. al., 2008, 2007). The author also observed that the reporting of mixed methods studies is quite challenging in terms of clarity and transparency. Erzberger & Kelle, (2003) suggested that using triangulation as methodological metaphor and by explicitly showing the types of data used as the basis of interpretation, the lack of quality issue in reporting the result of mixed methods research could be tackled. Some research studies may require some details of mixed methods research to be worked out fully by a research methodologist for instance the problems of paradigm mixing such as how to qualitatively analyse the quantitative data and how to interpret conflicting results.

It is essential that mixed methodologist meet two primary goals which were developed by the American Educational Research Association (2006): Mixed methods researchers should (1) conduct and report research that is warranted or defensible in terms of documenting evidence, substantiating results, and validating conclusions; and (2) ensure that the conduct of research is transparent in terms of clarifying the logic underpinning the inquiry (Wisdom, et. al., 2012). It has been concluded that researchers' devotion, persistence and a lot of rigor is required in order to apply mixed methods for valid and reliable findings.

Several frameworks have been published to guide the rigorous conduct and evaluation of mixed methods research (Creswell & Clark, 2011; Tashakkori & Teddlie, 2010; Curry, Nembhard, & Bradley, 2009; Collins, Onwuegbuzie, & Sutton 2006). The frameworks recommend explicit rationales for all decisions regarding study design including the justification of employing both qualitative and quantitative methods. It is advised that study procedures should be reported transparently, including sufficient detail to allow the reader to make inferences about study quality (Curry, Nembhard, & Bradley 2009; Leech, et. al. 2009; Teddlie & Tashakkori, 2009; Armstrong, et. al. 2008; Creswell, 2008). Further advising that each component of both methods should be conducted rigorously in accordance with established principles in its field while keeping the methodological reporting utterly transparent. For instance, sampling design must be specified (Onwuegbuzie & Collins, 2007), the level of mixing methods whether fully or partially, time orientation whether sequential or concurrent components of research and emphasis of an approach (if any whether equal importance or one more dominant) should be described (Leech & Onwuegbuzie, 2009).

3.3 JUSTIFICATION OF SELECTED METHOD

To conduct this study, mixed methods design was considered as the more appropriate method to address the research questions. Since mixed methods research holds greater potential to address these complex questions by acknowledging the dynamic interconnections that traditional research methods have not adequately addressed (Hesse-Biber & Crofts, 2008; Hesse-Biber & Leavy, 2006), mixing both qualitative and quantitative data was considered as neither quantitative nor qualitative methods were deemed sufficient to capture the details of survivors' needs. By combining qualitative and quantitative findings, the overall findings were verified, which was not possible by using a singular approach (Bryman, 2007). When used in combination, quantitative and qualitative methods complemented each other and allowed for a more robust analysis, taking advantage of the strengths of each (Tashakkori & Teddlie, 1998; Green & Caracelli, 1997; Miles & Huberman, 1994; Green, Caracelli & Graham, 1989).

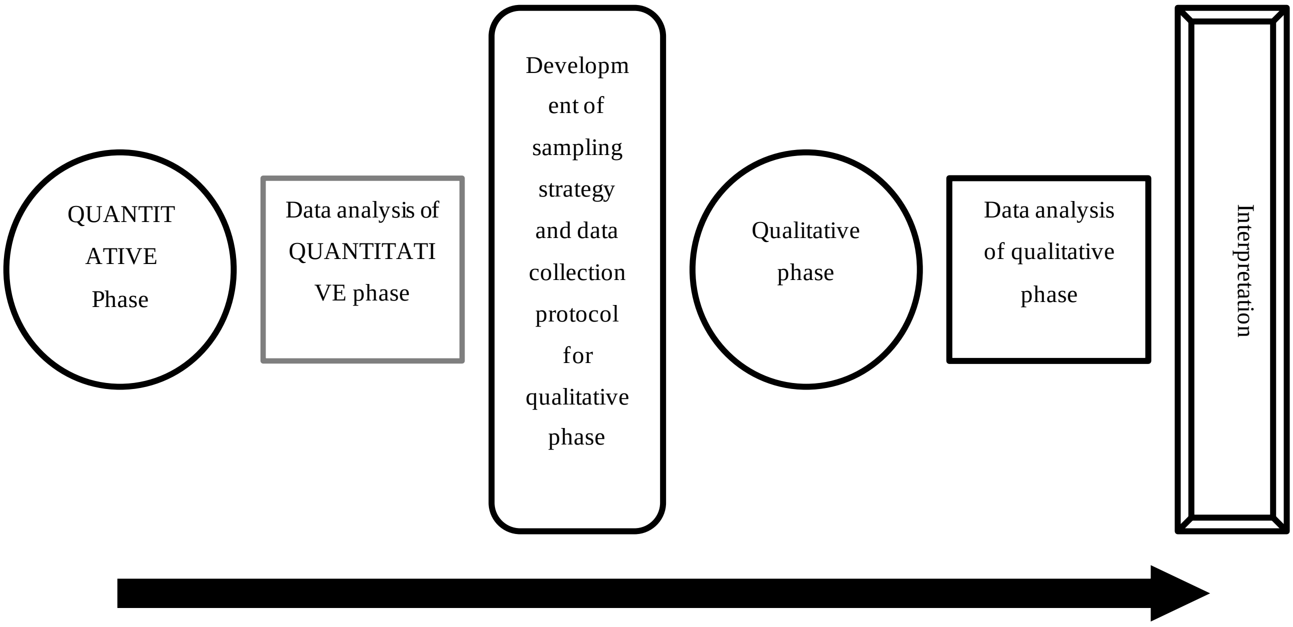


Figure 10: Explanatory Design

Source: Adapted from Figure 3.2(b): Creswell and Plano Clark (2011: 69)

To conduct this mixed methods research, "Explanatory sequential design" was chosen which is two-phase mixed method design that starts with the collection and analysis of quantitative data followed by the subsequent collection and analysis of qualitative data which follows from (or connects to) the results of the first quantitative phase (Creswell & Clark., 2006). Sequential design with the quantitative component first and the qualitative second, added a "value-added" understanding of the results from both methods (Hesse-Biber, 2010). The combination of mixed methods was chosen to explore some cultural meanings that might be challenging to identify merely through quantitative data, minimising errors that may arise from a single technique and maximising the meaning from the results of data interpretation (Tashakkori & Teddlie 2003; Patton, 2002). The flowchart of the procedures for the chosen design is presented in the figure 11 below.

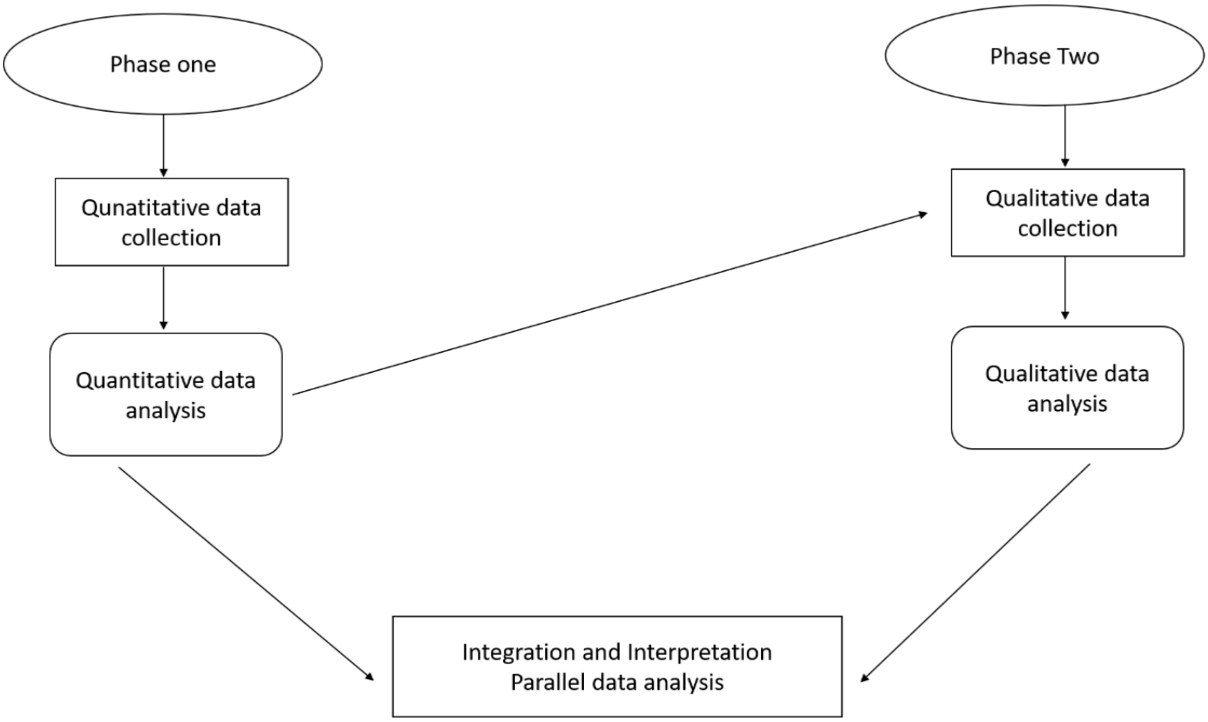


Figure 11: Flowchart of Sequential Explanatory mixed method design

Adapted from the figure (7.4a) Creswell, Clark, Gutmann, and Hanson (2003, p. 180)

In this design, the data collection and analysis occurred sequentially. The investigation begins by a quantitative analysis followed by qualitative exploration of breast cancer survivors' needs. The quantitative results (what, who, where and when) were integrated with qualitative findings to explain the in-depth understanding (why and how). Based on findings from the survey, survivors' needs were assessed in UAE cultural context along with sociodemographic and clinical indicators including stage of the illness and treatment received. The results of the quantitative phase guided the "development" of the qualitative phase and assisted in the development of the second phase by creating a synergic effect whereby the result from quantitative data helped develop and inform the qualitative phase (Greene, et. al., 1989).

Phase one findings from statistical data were used to contribute to the methodology of phase Two guiding the purposive sampling and developing a semi structured interview in phase Two where participants were selected as sub-sample from the quantitative phase who showed willingness to be interviewed and scored high, intermediate, or low on the survey for in-depth understanding of the differences in their utmost needs.

Another rationale to use mixed methods design in this research was **"complementarity"** - seeking elaboration, enhancement, illustration and clarification of the results from one method with the results from another' (Greene et al., 1989).

In-depth, semi-structured interviews with participants allowed clarifying and further exploring the different aspects of breast cancer survivors' multidimensional needs that could not be obtained by quantitative methods alone. It was achieved by utilising both quantitative and qualitative data and not just the numerical or narrative explanation alone to understand the social phenomenon as a whole. It was further used as a tool for the cross-validation to produce comparable data (Yauch & Steudel, 2003). Thus, it allowed gaining a fuller understanding and clarifying the findings.

Triangulation was another reason for using this design to add credibility to this study as it used different sources of data and different approaches to analyse the data thus it allowed convergence, corroboration and correspondence of results from different methods (O'Cathain, et. al., 2010; Greene, et. al., 1989) in order to seek corroboration between quantitative methods which provided an overview of the breast cancer survivor's need and qualitative methods to further explore the highest needs during cancer survivorship. Such integration of findings in both methods provided convergent results with in-depth and comprehensive understanding of the research phenomenon which could not be achieved employing a single method.

Rovai, et. al., (2014) suggested that while employing the mixed method research there must be a purposeful and carefully implemented sequence to the study which must be conscientiously documented and evaluated. To establish the **priority and sequence** of the study, whether quantitative or qualitative (or both) to implement first, all the nuances of the study design were

visually represented for conceptual purposes as well as to provide its better comprehension. In solving the issues of priority, the decision-making process was guided by the purpose of the study and its research questions, as well as by the methodological discussions in the literature (Creswell, et. al., 2003; Morgan, 1998; Tashakkori and Teddlie 1998; Morse, 1991).

As this is a preliminary study on an unexplored topic, for the first phase, it was considered that the quantitative data would inform the choice of interview questions and reveal what areas of survivors' concerns are required to explore in a more in-depth approach. Moreover, quantitative initial data collection was deemed easy to administer in the conservative UAE culture since talking about cancer is a sensitive and confidential subject in this society (Younis, et. al., 2016; Elobaid, at. al., 2016, 2014). In the second phase, qualitative semi-structured interviews were conducted to probe deeper understanding of unique needs of breast cancer survivors as perceived by them. Qualitative data illuminated quantitative findings by putting 'meat on the bones' of dry quantitative data (Bryman, 2006). Thus, it helped by featuring the similarities and differences between particular aspects of a survivors' unique needs utilising both methods (Bernardi, et. al., 2007) allowing individuals' subjective experiences to be taken into account.

It involved the collection and analysis of both quantitative and qualitative data in a single study in which the data were collected sequentially and integrated at later stages in the process of research (Hanson, et. al., 2005; Creswell, et. al., 2003) for the purpose of gaining a better understanding of the research problem (Creswell, 2005; Tashakkori & Teddlie 2003) and to increase the breadth and depth of understanding of survivors' needs (Johnson, Onwuegbuzie & Turner, 2007). This approach was considered as the more appropriate method to address the research question since quantitative data and their subsequent analysis provided a general understanding of the research problem and qualitative data and their analysis refined and explained those statistical results by exploring participants' views in more depth (Creswell, 2003; Tashakkori & Teddlie 1998; Rossman & Wilson1985).

The overall purpose of this design is that qualitative data helps explain or build upon initial quantitative results (Creswell et. al., 2003). Morse (1991) explained that this design is well suited to a study in which qualitative data was used to explain significant (or nonsignificant) results or surprising results. Finally, the quantitative and qualitative findings of the study were integrated by comparing and contrasting quantitative and qualitative data in the interpretation phase to further complement study conclusions. Thus, combining qualitative and quantitative methods yielded more useful and valid results, offering different perspectives on the survivors' needs offering greater overall understanding of the research.

3.4 DATA INTEGRATION

Integration refers to the stage or stages in the research process where the mixing or integration of the quantitative and qualitative methods occurs (Creswell, et. al., 2003; Tashakkori & Teddlie 1998). The integration of qualitative and quantitative approaches in any study is a considerably more complex undertaking and continues to be one of much debate (Bryman, 2004; Morgan, 2007; Onwuegbuzie & Leech, 2005). There are relatively few guidelines about 'how, when and why different research methods might be combined (Bryman, 1988). In particular, the different epistemological and ontological assumptions and paradigms associated with qualitative and quantitative research have had a major influence on discussions on whether the integration of the two is feasible, let alone desirable (Morgan, 2007; Sale, et. al., 2002).

Data integration is the fundamental concept of mixed methods research. Without integration, findings cannot be correlated and will remain independent leading to incomplete understanding of survivors' needs. Data integration can be performed at different stages starting from data collection to data interpretation. Teddlie & Tashakkori (2003), mentioned the possibility of mixing of quantitative and qualitative methods at the initial stages of the study while formulating the purpose of the study and the research questions as opposed to Teddlie & Tashakkori (2003), who suggested the integration to occur at the interpretation stage of the study. On the other hand, Hanson, et. al., (2005), informed that in the mixed methods sequential designs, the quantitative and qualitative are connected in the intermediate stage when the result of quantitative data analysis informs the qualitative data collection. Creswell, et. al., (2003), argued that in the sequential explanatory design, the two phases are typically connected in a way that quantitative results from the first phase guide the selection of participants for the qualitative follow-up analysis. Another strategy might be the development of qualitative data collection protocols, grounded in the results from the first (quantitative) phase, to investigate and analyse those results in more depth.

In this study, integration occurred at the methods level by connecting the sample frame (Fetters, et. al., 2013) with cancer survivors who completed the survey also participated in the interviews to enhance the quantitative findings. The quantitative and qualitative phases were connected during the research process while selecting the participants for the qualitative study from those who responded to the survey in the quantitative phase based on their numeric scores. Later, the data from two phases were analysed separately and integrated at the interpretative stage to explain the study phenomenon, which is to explore the survivors' needs. This technique was chosen so the two data types could be compared, contrasted and later combined in a way that integrity of data remain preserved while exerting more focus on the potential to attain deeper understanding from the combination of findings of both datasets.

The use of integration leads to three consequences: divergence, convergence, and complementarity (Tashakkori & Teddlie, 2003). If the mixed methods applied in the study lead to divergent results (i.e., the qualitative and quantitative results contradict each other), two possible explanations exist: either the divergence is the result of methodological mistakes or inaccurate initial theoretical assumptions (Erzberger & Kelle, 2003). Thus, one could have an opportunity to revise theoretical assumptions as a consequence of divergent findings carefully so newly developed hypotheses must increase the empirical content of the initial theoretical assumptions without diminishing their consistency. Divergence occurs in cases where qualitative and quantitative results are inconsistent; thus, re-examination of the designs of the two approaches is needed.

If the inconsistency is due to methodological design, then it should be addressed under study limitations. If the quantitative and qualitative methods lead to convergent results (i.e., the qualitative and quantitative methods lead to the same results), then the integration may provide good arguments for the quality of the inferences and strengthen the initial theoretical assumptions (Erzberger & Kelle, 2003; Teddlie & Tashakkori, 2003). As in this research, if a mixed methods approach leads to **complementary results** (i.e., the qualitative and quantitative results relate to different objects or phenomena but may complement each other), then the integration provides a more complete picture of the empirical domain under study (Erzberger & Kelle, 2003).

The quantitative and qualitative approaches were integrated while interpreting the main outcomes of the study. The qualitative data provided additional complementarity support for the quantitative evidence, hence, further validating the acquired assumptions (Teddlie & Tashakkori, 2003). This mutual verification process enhanced the validity of the findings, which is the primary objective of the mixed methods design. In this study, the consistent and compatible results generated from the two approaches were examined carefully and were reconciled to achieve a coherent interpretation and explanation of the breast cancer survivors' needs. During the interpretation and reporting, integration was applied while explaining the results where the qualitative and quantitative findings were presented separately and discussed in a single section in "Results" Chapter.

Nevertheless, the challenges associated with integration techniques have been well established. Proponents of mixed methods research suggest that the purist view, that quantitative and qualitative approaches cannot be merged, poses a threat to the advancement of science (Onwuegbuzie & Leech, 2005) and that while epistemological and ontological commitments may be associated with certain research methods, the connections are not necessarily deterministic (Bryman, 2004). Maxwell (1990) suggested that the theoretical debate about combining methods has prevented us from seeing the different ways in which researchers are actually combining methods. Researchers may encounter short-term inconvenience while integrating the results, in many cases the reappraisal and reanalysis required can reap long-term analytical rewards: alerting the researcher to the possibility that issues are more multifaceted than they may have initially supposed and offering the opportunity to develop more convincing and robust social explanations of the social processes being investigated (Deacon, et. al., 1998).

3.5 PHASE ONE: QUANTITATIVE METHODOLOGY

3.5.1 ETHICAL APPROVAL

Institution Review Board approval was obtained from the local IRB to conduct both phases (Appendices 1 & 2) and from the University of Salford Health Research Ethics Panel.

Ethical issues were given careful consideration, particularly patient safety and wellbeing, through the study with the availability of support groups and appropriate referrals as needed and to anyone who experienced distress. During the entire study, no patient experienced distress or asked for further support. The survey was conducted in a very safe manner within the centre in a n allocated room with a safe environment. All participants were informed about the purpose, procedure of the study and their voluntary participation by providing the "Patient Information Sheet" (Appendix 4). Participants were fully informed about their right to withdraw at any time in case they felt any anxiety or stressful event. Participants were fully informed of the purpose of the research. For phase one, all participants signed a written consent form (Appendix 3) prior to the survey. Data confidentiality protocols were maintained considerably during the research. To protect confidentiality, each participant used an allocated numerical code instead of their names. The coding list was kept in a locked cabinet, which was accessible only to the researcher.

Following the local IRB approval (Appendix 1), participants were identified and contacted through the cancer registry by telephone in phase one. Patients previously signed the general hospital consent which specifies usage of patients' health data for research purposes (Appendix 1) as customary practice within the hospital. Patients were contacted by the researcher and asked if they were interested in the study by providing a brief overview and aim of the study over the telephone. Agreed participants were given a copy of the participant information sheet (Appendix 4) and the consent form (Appendix 3) upon their due follow-up visit which they were attending at the hospital not particularly for the specific research session only. Those who were interested and had no further questions were given the opportunity to sign the written consent form to participate in the study by completing the survey (Appendix 5).

Prior to each patient's visit, patients' medical records were reviewed to perform pre-screening to collect demographics and specific clinical details including type of cancer, stage of the disease and treatment information with the purpose to gather accurate information during the survey. During the survey, health professionals were available to provide emotional support at no cost to the patients who might have found the survey to be an emotionally stressful experience, yet no referral was made. A research assistant trained in confidentiality and data protection issues was also available for participants who had difficulty with communicating in

English. Additionally, the researcher was also present throughout the survey to answer their questions if participants had any concern about any aspect of this study.

The survey was conducted at the follow-up clinics at Tawam Breast Cancer Centre where an area was allocated for the participants. The expected time of completion lasted for approximately 30 minutes and refreshments were available in appreciation for their time. Confidentiality was maintained by coding the surveys with a subject identification number. The survey was translated into Arabic and verified by the two physician members of the Oncology team at Tawam Hospital who were competent in both English and Arabic languages. The surveys were provided in both English and Arabic languages and were completed by the participants using pen and paper. A hospital translator was present to translate answers for any participants who preferred to complete the surveys in their native language; these translators were trained by the Cancer Centre to consider the sensitive nature of the survey and were committed to following data confidentiality protocols throughout the survey process. The survey was used in accordance with the UAE context by modifying the information that reflects the particular setting, for instance Nationality was recorded as the representative of the passport held by an individual.

3.5.2 PARTICIPANTS & SETTING

The proposed study was conducted in Tawam Breast Care Centre in Al Ain city. The justification for conducting the study at Tawam Hospital is, the hospital is considered as a national referral centre and the centre of excellence in Oncology providing cancer care services to the local community across the region and neighbouring gulf countries. Participants were recruited from Tawam Hospital who were identified initially by the Cancer Registry which is located within the Hospital. At patients’ registration, all patients served by the hospital are required to provide an initial consent to allow the usage of their health data for research (Appendix 1) as part of hospital routine policy. The research was conducted after obtaining the ethical approval through the Hospital Research Office (Appendices 2 & 3). Participants were informed that the participation in the survey was not compulsory, and they could withdraw from the study at any time without any consequences. They were also assured that their responses would not affect their care process at the hospital. The survey could be completed during their follow-up visit either in the waiting area or in clinic rooms available in the Breast Cancer Centre at Tawam Hospital.

Target Population

This study population consisted of all women in the UAE who were diagnosed with breast cancer in the year 2018. Tawam Hospital as national referral centre serves most of the cancer patients in the country and the accessible patients from the hospital could assume to be generalised as target population for the study.

Accessible Population

A total of 368 patients who were diagnosed or treated with breast cancer in the year 2018 were selected for the study

Inclusion Criteria

Women with all ages who were diagnosed with breast cancer and who were currently residing in the UAE. There were almost 368 new cancer cases diagnosed in the year 2018 at Tawam as reported by the hospital Cancer Registry. Based on the previously mentioned criteria, a total of 218 (59.2%) patients were included in this study which provides a good sample size based on the number of new breast cancer cases diagnosed each year.

Exclusion Criteria

Patients were excluded from the study based on the below mentioned criteria:

- Three (0.8%) male breast cancer survivors diagnosed in 2018
- Thirty-nine (10.5%) women with multiple primary cancers who have two or more different types of cancer)
- Thirty-eight women (10.3%) who lost to follow-up or deceased
- Seventy (19%) patients had their stage data missing or unknown whose essential data was missing

A total of 150, (40.7%) were excluded, thus, **218** (59.2%) patients were included in this study which provides a good sample size based on the number of new breast cancer cases diagnosed each year.

The quantitative study aimed to relate the findings to be applied to the general population of breast cancer patients; thus, careful consideration was given to the selection of a sample representative of the population (Delice, 2010). The optimal sample size was determined based on yearly new cases registered in the cancer registry which was between 300 -350. In this study, census sampling was used which often an actual national population (Lavrakas, 2008). The census sampling is defined as the subset of the population selected to represent the entire group, in all its characteristics. The objective of the census sampling is to collect data in relation to every member of the population under study to truly represent the whole population (McLennan, 1999). Since Tawam Hospital serves as national referral centre, the source provided access to all possible members of the population within a reasonable time with almost full enumeration of the target population.

The main disadvantage of a census sampling is access to the population within a reasonable time however in this study, all women were approached during their follow-up visits with no difficulty to reach them. This sampling technique was both cost as well as time efficient. The relevance of bias and sampling error using census sampling was predicted as not being high as all new breast cancer patients were identified through the registry and approached thus, the census sampling method was found more appropriate for the setting. After applying inclusion criteria, a total of **218** patients were recruited to be part of the study.

3.5.3 RESPONSE RATE OF THE SURVEY

The survey response rate was 94% considering the refusal of 13 (3.5%) patients out of a total of 218 patients who participated in the survey.

3.5.4 INSTRUMENT

Despite several needs assessments instruments available to assess the needs of cancer survivors, **Cancer Survivors Survey of Needs** from the Pearlman Mayo Clinic (Appendix 5) was selected to conduct the quantitative phase of the study. The main reason for using this survey was it was convenient to conduct in the specific patient population. The survey was considered well formulated, relevant to the purpose of the study encompassing all psychosocial domains in addition to areas that might be of potential learning interest for cancer survivors. It was less time consuming compared to other commonly used surveys and was pilot tested on both Emiratis and expatriates in the current setting, thus, considered to be the most effective and appropriate need assessment instrument for this study. Official permission was obtained through email confirmation to utilise the survey in Tawam Hospital setting from the Cancer Education Program, Mayo Clinic Cancer Centre in Rochester, Minnesota, US prior to the conduct phase one (Appendix 13). The Mayo Clinic Cancer Centre developed this survey with the help of an interdisciplinary team of clinicians, administrators and investigators with support from the Mayo Survey Research Centre (consultation and feedback on instrument development, pilot sampling, and data analysis). Additional review of the survey tool was provided by medical, educational, and behavioural researchers. Survey questions were chosen based on current literature recommendations (IOM, 2006; Vachon, 2006; Baker, et. al., 2005) as well as from the developers' experience which was reviewed by members of the cancer patient education network. Data collected from this tool is intended to direct appropriate resources and plan supportive programs for cancer survivors (Jiao, et. al., 2015). The **content validity** of this survey was established by the author through the review by members of the Cancer Patient Education Network. Single-item linear analogue scales, including Likert scales, have been validated as general measures of global QOL dimensional constructs in several settings (Locke, et. al., 2007; Grunberg, et. al.,1996; Gudex, et. al., 1996; Hyland & Sodergren, 1996; Wewers & Lowe, 1990; Sriwatanakul, et. al., 1983). Reliability was assessed with the Cronbach alpha coefficient of 0.96 calculated across all subscales.

3.5.5 DATA COLLECTION

The data was collected on 69 items out of which 52 items used to rate psychosocial needs on a six-point Likert scale, with 0 indicating no concerns and 5 indicating extreme concerns. It had six domains: physical effects, information issues, social issues, emotional aspects, spiritual issues and other issues. The survey contained additional questions on educational needs, preferred learning on topics and what specific topics the patient is interested in learning about. Overall, the survey contained eleven sections aimed to provide awareness and insight into the needs of cancer survivors so those could be evaluated to guide the development of a survivorship program model to address these needs.

1. Demographics (7 items)
2. Quality of Life Assessment (1 item)
3. Physical concerns (20 items).
4. Information/Educational Concerns (7 items)
5. Social & Financial Concerns (6 items)
6. Emotional Concerns (14 items),
7. Spiritual Concerns (4 items)
8. Other concerns (1 items)
9. Mode of delivery assessment (4 items)
10. Identification of specific areas of survivor's interest (4 items)
11. Assessment of patient's drive through cancer experience (1 item)

Socio-demographic and clinical characteristics

The **first two sections** were based on patient demographics followed by the assessment of survivor's quality of life range from **0 to 10 (scoring from bad to good).** The demographics and cancer information including diagnosis and treatment were also extracted from the Tawam Cancer Registry to further validate survivor's responses. Demographic and clinical variables included age at diagnosis, nationality, year of cancer diagnosis, type of cancer, stage of cancer, type of treatment received and whether currently on treatment or not. In case of any conflicts, responses were verified by reviewing the clinical notes and by further verifying the patients' demographic as well as clinical data which was usually registered by the front desk staff at the hospital and was more prone to errors. **The second section** contains one question which was designed and studied to measure overall quality of life (QOL) using an 11-point Likert scale from 0 (as bad as it can be) to 10 (as good as it can be). This item reflected their quality of life in the past one week prior to the survey.

In **sections 3-7**, *patients rated their concerns* as of today from **0 to 5 (No concerns to extreme concerns)** *to indicate the level of need* using a Likert-type scale which allowed quantifying the needs in each section. This section of the questionnaire assessed the critical need domains as perceived by the survivors.

The last 2 sections of the survey contained three open-ended questions to identify the source of strength during the cancer experience, their topmost concern and any additional comments that survivors may have.

To complete the survey, survivors were asked to indicate whether they were experiencing a need or concern and to rate the level of it. The total summed score (Item 3-7) was used to indicate a greater level of needs and perceptions of greater concerns whereas the lower score represented lower needs and thus represented less concerns. The applied threshold value for excluding incomplete surveys was set at 3 missing sections from the total of 11 items.

3.5.6 QUANTITATIVE DATA ANALYSIS

Quantitative data analysis was conducted using SPSS software. The statistical analysis includes **descriptive statistics** of socio-demographics and clinical characteristics (extracted from the Cancer Registry) and survivor's needs. To compare the socio-demographics and clinical characteristics of two groups (Emiratis and expatriates), **a Chi-square test for categorical variables** was used for statistical significance and **Student *t*-test for continuous variables** (Byrne, 2007). Differences between the Emiratis and expatriates were analysed to see if they are significant, and a significant mean difference was investigated between these two groups. **Multivariate multiple regression was applied to compare the differences in each psychosocial need domain** in order to adjust for possible confounding effects by sample differences by adjusting the effect of demographic and clinical characteristics since higher needs may be associated with the extension of disease or tumour characteristics).

Following the quantitative analysis, these results were used to inform the development of semi-structured interviews in the qualitative phase of the study, particularly those which needed deeper understanding or could lead to multiple interpretations by the patient.

3.6 PHASE TWO: QUALITATIVE METHODOLOGY

3.6.1 ETHICAL APPROVAL

Phase two qualitative part was initiated with the **pre-obtained ethical approval** taken from the local IRB (Appendices 1 & 2) to conduct the mixed methods study.

This study considered all core areas of ethical concerns as described by Willig (2008) and the British Psychological Society Code of Human Research Ethics (2014). It includes informed **consent concerns, confidentiality and consequences of the research** with regards to possible risks as well as expected benefits of participating in the study.

A written consent was obtained from patients who met study inclusion criteria and agreed to take part in the qualitative study. During phase two of the study, all participants were asked to sign the **informed consent** which indicated information about the purpose and the procedure of the study (i.e., 'The interviews will be audio-recorded') and were explained to the participants what was required of them. They were also assured of confidentiality and privacy of their information. They were also informed to have access to the final results of the study. All participants were informed about their **rights to withdraw** from the study, that they could decide to terminate the interviews any time without any ramifications or judgement, and they have the right to choose what information they want to disclose to avoid discomfort. Participants were also assured that there will be no right or wrong statements because the researcher would only be interested in hearing their perspectives and concerns about the cancer experience. **Debriefing sessions** were pre-arranged, and participants were informed prior to commencing the interviews that some aspects of interviews may potentially result in psychological discomfort for which participants would be offered a debriefing session or if needed, would be referred to the required psychosocial support services.

To ensure the **confidentiality** of the interview data in phase two, the audio-interview files were stored on the secure university One Drive where only the researcher had access to the data. The identity of all participants was protected through the study using pseudonyms for instance, all names and personal data were removed and any information that had a potential to compromise the participant's anonymity was altered appropriately to avoid disclosure of the patients' identification. Participants were informed that their interviews would be audio recorded and transcribed after that and would be erased and other data records would be destroyed three years after the final thesis would be submitted to the university. Moreover, it was also declared that all interviews, transcriptions, records and accompanying material would be securely protected using password encrypted electronics on a secure university drive and no printed material would hold any identifiable information about the participants.

3.6.2 PARTICIPANTS & SETTING

All participants in the first phase of the study (quantitative) were asked about their interest to take part in phase two (qualitative). Once potential participants who met the criteria for the phase two were identified and who agreed to participate were contacted over the phone and asked for the convenient time to attend the interviews during their follow-up visit at Tawam Hospital Breast Care Centre. According to Creswell (2012), in any qualitative study, it is important to select people or sites that can best help understand the central phenomenon, thus, the interviews were held at Tawam Hospital Breast Cancer Centre which is known as a national cancer referral centre. Participants were interviewed in the nursing consultation room of the centre as it provided a quiet and safe environment. On the interview day, participants were briefed about the study and were given the oral and written explanations about the purpose of the study. After that their informed consent was obtained.

Sampling in qualitative research is contingent on many considerations since it is not a matter of representative opinions, but a matter of information richness (Guetterman, 2015). Participants for phase two were purposively selected from the sample in phase one. The appropriateness of sampling was achieved through the **purposive sub-sampling** of participants because the purposively selected participants could provide rich in-depth information on their multidimensional needs. Portney & Watkins (2009) described the purposive sampling as a method of non-probability sampling where the investigator selects the study participants based on specific criteria and excludes those who do not fit the criteria. Coyne (1997) & Patton (2001) suggested that this type of sampling usually aims to capture a wide range of the participants' perspectives on the complex phenomenon being studied and mainly to enhance data validity. Smith, et. al. (2009) stated that "samples which are selected purposely (rather than through probability methods), can offer a research project insight into a particular experience".

There is no straightforward answer to the question of 'how many' and that sample size is contingent on a number of factors relating to epistemological, methodological and practical issues (Baker & Edwards, 2012). Morse & Field (1996) suggested that sampling in the qualitative study was guided by two principles: **appropriateness (relevance) and adequacy**. Appropriateness of sampling addresses the quality of data obtained from identifying and utilizing participants who best represent or have knowledge of the research topic whereas adequacy of sampling refers to the sufficiency of the data gathered to provide a full and rich description of the research phenomenon (Cheng, 2012).

A total of ten participants (five expatriates and five Emirati nationals) were chosen based on their scores on the survey to represent high, intermediate or low scores that allowed maximum variation in their perceptions of the needs which justified the appropriateness of the sample (Coyne, 1997)**.** During the interview process, the participants were encouraged to talk about their most worrisome concerns about cancer survivorship which were handled in a respectful and purely non-judgmental manner by the researcher. The sample size was determined based on informational needs and study requirement which was guided with the principle of adequacy to attain sufficient data collection to reach the data saturation, that is, sampling to the point at which no new information is obtained and redundancy is achieved (Polit & Beck, 2014).

Creswell (1998) and Morse (1994) have recommended some guidelines to develop the sample size ranging from 20 to 50. Polkinghorne (1989), recommended interviewing 5 to 10 participants for phenomenological research who have all experienced similar events (phenomenon) so the commonality of their experiences can be captured and interpreted. Wertz (2005) indicated that the number of participants is dependent on the research problem. The selection of these participants should reflect and represent the homogeneity that exists among the participants' sample pool as it provides a better gauge and a 'better understanding' of the overall perceptions among the participants' 'lived experiences' (Alase, 2017). Stebbins (2001) described the conventional approach for determining sample size, theoretical saturation, as the point at which no new information is produced from additional cases. In qualitative research, the data is collected until data saturation has occurred.

Glaser, et. al. (1968), also suggested the concept of saturation for accomplishing an appropriate sample size in qualitative studies. Guest, et. al., (2006) proposed the use of the grounded theory concept of the theoretical situation. Saturation, although, is commonly considered as the "gold standard" for determining sample size yet it might not be the optimal indication of an adequate sample. There are no definitive criteria or rules for the sample size needed to reach data saturation. Additionally, saturation is varyingly defined or is sometimes undefined. There are various views on how many cases must be considered to achieve data saturation. The number of respondents for data saturation depends on how homogeneous the sample is and on the qualitative design. The more homogeneous the sample, the fewer cases needed for data saturation. The more heterogeneous the sample, the more cases needed for data saturation.

These different views, thus, raise a number of problematic conceptual and methodological concerns (O’Reilly & Parker, 2013; Dey, 1999; Bowen, 2008). O'Reilly & Parker., (2013) argued the relevance of theoretical or thematic saturation beyond grounded theory methodology and claimed for more transparency in achieving saturation. Although Safman & Sobal (2004) quantified the need of less than 30 participants using in-depth interviews to obtain data saturation, yet the recommendation was challenged by the researchers who suggested that such recommendations reflect the researcher’s personal experience and that data saturation is actually determined by a number of factors such as the quality of data collected, methods of data collection, study design and the nature of the enquiry (Ritchie, et. al., 2003; Sandelowski, 1995).

3.6.3 INTERVIEW GUIDE

The following were the key topics and questions in the interview guide and semi-structured interviews:

Part 1: Introduction

The following were described to the participants as part of the introduction of the study:

- Aim and objectives
- Personal (researcher’s) interest in the study
- Contribution to the public or community

Part 2: Semi-structured Interview

1. **Breast cancer occurrence:**
    a. Can you tell me what has happened since the moment you were diagnosed with breast cancer?

   b. What were your thoughts and feelings when you were told you had breast cancer?

2. **Breast cancer experience/Living with Cancer:**
   a. What are your experiences with having breast cancer, its treatment, side effects and care that you received at the hospital?
   b. Tell me about the treatment choices and life changes you made after the treatment; how breast cancer impacted your life.

3. **Utmost Needs or Concerns during the survivorship:**
   a. Can you tell me what your main concerns or biggest challenges were; (prompt: focusing physical, information, social, emotional, spiritual or any other)
   b. How those have influenced your breast cancer experience? (Prompt: health, family, work, relationships).
   c. How did you manage to deal with them or from where you received the support?

Expectations about care and service delivery:

   d. What do you think and what elements of the service delivery and care at the hospital you were satisfied or not satisfied with?
   e. What change or improvement you would expect if possible or what kind of support you need? (Prompt: what comes to your mind, what do you want in terms of support that can make you feel better or to improve your experience).

3.6.4 DATA COLLECTION

Semi-structured face-to-face interviews

According to Smith, et. al., (2009) “A qualitative research interview is often described as ‘a conversation with a purpose’ which must be implicitly informed by the research question. The selected method of data collection was face to face semi-structured interviews because it facilitated the building of rapport, and the interviews allowed the opportunity to gather rich information in greater depth than the quantitative survey already used in this research. One-to-one interviews provide a powerful way to acquire insight into issues via gaining understanding of the experiences of people and makes the participant feel that their story is important

(Seidman, 1991). Denzin & Linclon (1998) affirmed that information gathered via a one-to-one interview avenue of inquiry is one of the most powerful ways to understand individual experiences. In addition, face to face semi-structured interviews involve numerous pre-determined topics to be discussed with each participant thus maintaining consistency. Moreover, the semi-structured interviews provide freedom to the participants to freely expand upon their answers. It is also worth mentioning the decision to choose individual interviews for the methodology rather than focus groups for the purpose to attain as much information from individuals without participants being influenced by ideas or perceptions of what other people hold or say.

In this phase, semi-structured interviews were considered as the more appropriate means of interviewing compared to unstructured interviews as it allows individuals to express their experiences, thoughts and attitudes related to a sensitive topic without group influence (Erdogan, 2014). It provides freedom to elicit new responses while maintaining the data consistency as it involves several predetermined topics to be discussed with each participant (Berg, 2009). Moreover, it allows 'gaining information on the perspectives, understanding, and meanings constructed by people regarding the events and experiences of their lives' (Grbich, 1999). The interview questions were based on the results from the quantitative study as well as the theoretical framework to explore cancer survivors' needs.

Interview Schedule

Each interview lasted for 30 to 45 minutes. Semi-structured interviews were recorded using a voice recorder and transcribed manually for analysis within a few days after the interview. At the beginning of each interview session, participants were welcomed and valued by expressing gratitude towards their participation. Some rapport was established with each participant to make them feel relaxed and comfortable. Following introductions, participants were told the purpose of the study. Efforts were made to establish trust and ease in order to obtain rich information from them about their concerns related to breast cancer. They were informed about the expected length of the interview and how the interviews would be recorded. Participants were reassured that they could repeat or clarify questions if needed and that there were no right or wrong answers. They were informed that they could take a break or stop at any time if needed. They were encouraged to ask any preliminary questions they might have before the start of the interview. The aims and objectives were clarified with a provision of brief description of the research, and it was explained why their involvement is needed and how their insights would add significance that could lead to improved healthcare services. Privacy was assured throughout the interviews to enable participants to talk freely about their concerns without any disruption (Berg, 2009).

Data Collection Procedures

A total of ten interviews were conducted and were audio-recorded. Each interview was assigned a unique code, for example "Participant 1, 6th May 2020". If more than one interview took place on the same date, the interviews were identified by an assigned number that represents a unique participant for instance, "Participant 2, 18th May 2020".

Prior to each interview, written consent was obtained from each participant. Each interview began with a general, open question for instance, "Can you tell me what has happened since the moment you were diagnosed with breast cancer?" which was followed by specific questions to elicit particular concerns about breast cancer such as, "What are your experiences with having breast cancer, its treatment, side effects and care that you received at the hospital?" General questions were used to allow the participants to give as much detail as they would like about their unique experiences without restricting their responses by using questions that would be too specific or limiting. Follow-up probes such as "in what ways? or "why do you feel that way? - could you tell me more about this?" were used to encourage them to elaborate more on their responses. Such probing prompts deeper responses from the participants and adds richness to the data.

A semi-structured **interview topic guide** was used as a layout to probe further on issues with regard to the objectives of the study in order to help direct the conversation toward the topics and issues highlighted in the phase one and were relevant to the research questions. **The interview guide was constructed on the bases of the items in the questionnaire which are considered less deeply explored in the scientific literature or could lead to multiple interpretations by the patients, thus requiring further understanding.** To ensure that the topic areas would be reflective of the participants' experience as well as being appropriate and understandable, the questions were pre-tested with two breast cancer patients and two oncologists**.** Pre-testing allowed refinement of the interview questions based on their current practice as well as permitted direct comparisons between participants' answers providing them the freedom to speak openly about significant aspects of particular questions. A few changes were made according to the feedback received from both oncologists and the patients, mainly to modify the language or tone of the questions as well as to consider probing questions if needed. For example, based on oncologist' suggestions and to broaden up the survivors' view to allow survivors to speak more broadly about their perceptions instead of asking "can you tell me what is happening to you due to your illness", the question was modified as "can you tell me what has happened since the moment you were diagnosed with breast cancer". Another example is, the question which was originally worded "What are your experiences with having breast cancer" was modified based on patients' suggestions to cover all aspects and to highlight treatment as being the most challenging and life changing aspect of having cancer to: "What are your experiences with having breast cancer, its treatment, side effects and care that you received at the hospital? "Tell me about the treatment choices and life changes you made after the treatment; how breast cancer impacted your life".

Participants had the freedom to express their views in their own words, and to raise any issues of concern. However, patients were also allowed to raise any issues of concern. Use of this interview guide allowed direct comparisons between participants' answers while simultaneously permitting their' freedom of response and giving them the ability to speak to personally significant aspects of particular questions (Rose, 1994).

The interview process was engaging for both researcher and participants in that the researcher was actively listening to what the participants were saying and asked follow-up questions, including for clarification of any points where needed. All questions in the semi-structured interviews were organised systematically; however, not necessarily were asked in the same sequence during the interview. The questioning sequence of each interview was adjusted based on the participant's responses. Also, not all the questions from the interview guide were asked. The number of questions and duration of interviews varied among each participant as there was an interchange of views between two persons about a theme of mutual interest. In addition, initial questions were also modified in the light of participants' responses to enquire about any related relevant experiences.

The questions were open-ended, encouraging participants to fully describe their experiences according to their own perceptions and in their own words, and follow-up questions used to ensure there was no risk of loss of meaning because of imposing a standard way of asking questions. Greater latitude was allowed as some interviews moved away from the planned questions and entered an area that was not predicted or unprompted to provide maximum autonomy to the participants to express their concerns. However, the researcher was careful not to let the conversation stray too much for the interview questions so as not to include irrelevant material. Questions were asked one at a time, and minimal probes were used. Most patients talked about these topics without needing much probing, but probing was used based on careful listening to what the participants presented in order to help participants to open up about their utmost needs. If participants appeared uncomfortable with a particular line of questioning, another attempt was made to ask the questions more gently or to back off this line of questioning altogether. The questions were "directed to participants' experience, feelings, concerns or needs and beliefs about the theme in question (Welman & Kruger, 1999).

The interviews were conducted until the data reached saturation, where there was no new information contributed during the interview based on the questions and domains mentioned in the interview guide (Guest, et. al., 2006). In order to minimize the participants' vulnerability, the researcher avoided confirmatory gestures or judgmental expressions.

3.7 QUALITATIVE DATA ANALYSIS METHODS – AN OVERVIEW

Grbich (2007) argued that there is diversity on how to process the preliminary data analysis and that it is an individual process based on the research and the researcher. In this study, **thematic analysis** was employed which is described as **a "method for identifying, analysing and reporting patterns (themes) within data"** (Braun & Clarke, 2006). Thematic analysis has been widely used in qualitative research (Braun & Clarke, 2006), although there is no clear consensus about what thematic analysis is and how you go about it (Tuckett, 2005; Attride-Stirling, 2001). Braun & Clarke (2006) argued that thematic analysis should be a foundational method for qualitative analysis and should be considered as a standalone method (Braun & Clarke, 2006; King, 2004; Thorne, 2000). Since it provides core skills to conduct many other forms of qualitative analysis and is used by many qualitative methods thus many authors argued that it should not be considered as a separate method and should be used to assist researchers in analysis (Holloway & Todres, 2003; Ryan & Bernard, 2000; Boyatzis, 1998).

Content analysis is another method that can be used to identify patterns across the qualitative data; however, it tends to focus more at micro level and often provides (frequency) counts (Wilkinson, 2000) and allows for quantitative analyses of initially qualitative data (Ryan & Bernard, 2000). Boyatzis (1998) suggested that thematic analysis can be used to transform qualitative data into quantitative form and be subjected to statistical analyses. However, in thematic analysis themes tend not to be quantified, (Braun & Clarke, 2006).

Both **interpretative phenomenological analysis (IPA) and grounded theory** seek patterns in the data but are theoretically bounded. IPA's theoretical underpinnings stem from the phenomenology which originated with Husserl's (1931) attempts to construct a philosophical science of consciousness, with hermeneutics (Biggerstaff & Thompson, 2008) which allows deeper insight of people's everyday experience of reality to gain an understanding of the phenomenon in question (McLeod, 2001). Likewise, the goal of a grounded theory analysis is to generate a theory of the phenomenon which is grounded in the data (McLeod, 2001). On the contrary, in thematic analysis, there are no theoretical commitments of grounded theory to be subscribed by the researcher if they do not intend to produce grounded theory analysis (Braun & Clarke, 2006).

On the other hand, the term, **thematic discourse analysis,** is used to refer to a wide-range of pattern-type analysis of data encompassing thematic analysis within social constructionist epistemology to form analysis similar to the interpretative repertoire form of discourse analysis (Clarke, 2005). Whereas **thematic decomposition analysis** is a form of thematic discourse analysis which identifies patterns within data and theorises language as constitutive of meaning as social (Braun & Clarke, 2006).

This research was conducted using **realist** research paradigm in a subjective manner to examine the experiences, needs, meanings and the reality of breast cancer survivors since there is a direct relationship between experiences and meanings and language. (Potter & Wetherell, 1987; Widdicombe & Wooffitt, 1995).

3.7.1 RATIONALE FOR USING THEMATIC ANALYSIS

Given the scarcity of research conducted in the UAE on cancer survivors' psychosocial needs and lack of evidence based psychosocial interventions in this region, Braun & Clarke's (2006) thematic analysis seemed to be most appropriate method for this qualitative research since this approach allows for a deeper understanding of participants' lives and provides the flexibility allowing for complex analysis without dependence on theory that is required given the exploratory nature of this study. Additionally, by gathering 'deep' information and perceptions through the inductive method, the approach valued the phenomenological viewpoint of how participants perceived and expressed their needs.

The rationale of using an inductive thematic analysis of latent information was, it was open to participant's experiences, rather than seeking views on themes informed by the literature. This helped in avoiding assumptions and biases in the literature being perpetuated (Braun & Clarkes, 2006). It also limited personal influence and pre-existing belief as a researcher that added true knowledge about the individuals to this study. However, this does not imply that one can completely get rid of his/her theoretical "epistemological responsibilities". It is for this reason that inductive thematic analysis was believed to be an appropriate method of analysis.

This data driven approach was also beneficial as it allowed identification of unexpected themes in the data rather than themes that were developed based on prior theories or preconceptions. Additionally, literature shows that several studies have employed the Braun and Clarke's (2006) method of thematic analysis to explore cancer survivors' needs in other settings (Naidoo, et. al.., 2020; Wan-Tzu, Patsy & Raymond., 2018; Dsouza, et. al., 2018; Mazanec, et. al., 2017; Ness, et. al., 2013; Maura, Heddon & Griffis., 2010).

Another reason to use thematic analysis, was its breadth of scope since it can be broader and include social and cultural phenomenon as well. Additionally, it allows greater flexibility with regard to theoretical framework and with the use of analytical tools.

Succinctly, thematic analysis was deemed appropriate, as the purpose of the analysis was to examine the ideas, issues and thoughts regarding psychosocial needs mentioned by the participants.

3.7.2 THEMATIC ANALYSIS – PROCESS OVERVIEW

Thematic analysis is defined broadly as **“a way of seeing”** and **“making sense out of seemingly unrelated material”** (Boyatzis, 1998). Braun, Clarke & Terry (2015), described the procedure as a personal and even emotional experience. In this research, the process of applied thematic analysis was organic and reflexive that involved researcher’s engagement and intuition to be part of the analysis. It helped researchers establish what cancer survivors consider important, how they perceived their needs and cancer experience and categorized them, and how various categories are associated with each other (Herzog, Handke & Hitters, 2019).

According to Braun & Clarke (2006), thematic analysis provides a highly flexible approach due to its theoretical freedom and can be modified as needed, providing rich and detailed yet complex data. It is a useful method to examine the participants’ perspectives, highlighting similarities and differences to generate deeper understanding and insight. Whereas interpretative phenomenological analysis or discourse analysis provides a more accessible form of analysis (Braun & Clarke, 2006) and makes it easier for researchers to employ the procedure with easy grasped understanding and learning.

Thematic analysis can be conducted within several other research paradigms yet the focus to conduct the analysis would be different for different paradigms. Thematic analysis can also use a **constructionist** paradigm that assumes that meaning and experiences are socially developed and not due to an individual perspective (Burr, 1995). Therefore, the thematic analysis with the constructionist framework leans more towards the socio-cultural phenomena and structural context rather than subjective factors that arise from the individual data (Majumdar, 2019). Thematic analysis can also be a **contextualist** method characterised by theories such as critical realism (Willig, 1999), which acknowledge the ways individuals make meaning of their experiences and the ways the society impinges on those meanings while maintaining focus on the material and the other limits of “reality” (Braun & Clarke, 2006). It is important to make clear the theoretical position of a thematic analysis.

For the analysis purpose, the recorded texts were assumed as the data and codes were developed by closely examining the texts as salient themes that were generated inductively from the texts.

The essence-capturing codes consisted of words as well as short phrases (Saldaña, 2016) which were modified as needed flexibly throughout the analysis (King, 2004).

The process of thematic analysis involved searching across a dataset a repeated pattern of meaning. Thematic analysis proceeded by first identifying codes then themes and eventually patterns in qualitative data. Themes captured something important related to the research topic and represented a sort of patterned response within the dataset. What was important to understand was the judgment about the theme as some were given considerable space in some data items and little or none in others or some appeared relatively little of the dataset. Thus, the flexibility of thematic analysis allowed determining themes in a number of ways. Considerable attention was given to the prevalence of themes so a rich thematic description of the entire dataset could be attained in order to derive the important themes which accurately reflect the entire dataset. Coding and theme development were driven by the goal of retaining considerable details in the data items in a way to interpret credible meanings from the complex data.

Themes within the data were identified through an **inductive (bottom up)** approach (Braun & Clarke, 2006) which were associated with the data itself and were not driven by the researcher's theoretical interest. An **inductive approach** is a process of coding of the data without trying to fit it into a pre-existing preconception; thus, this form of thematic analysis is data-driven. However, it must be noted that researchers cannot detach themselves of their theoretical or epistemological commitments and data are not coded in an epistemological vacuum (Braun & Clarke, 2006). Herzog, Handke & Hitters, (2019) supported the same notion that in thematic analysis, verbal expressions are analysed without relying on any pre-existing theoretical concepts and instead the interpretations reflect the judgment of the researcher in each individual case. The analysis identified latent (interpretative) themes which provide more detailed and nuanced analysis across the whole data set, moving beyond the semantic (surface) level of analysis to identify the implicit meaning of what the survivors expressed and underlying beliefs.

The latent inductive analysis was conducted where the identified themes reflected the surface of the meanings of the data. This includes describing the data, summarising it followed by interpreting the data in relation to the broader meanings and implications (Patton, 1990).

Boyatzis (1998) explained that all research aims at developing theory; thus, a phenomenon can be learned by drawing knowledge from the previous studies to establish something new. Boyatzis (1998), pointed out that ‘you do not have to reinvent the wheel every time you want to get somewhere.

Phases to conduct Thematic Analysis – Process Demonstration

To conduct the process of thematic analysis, Braun & Clarke’s (2006) six-phased linear method is demonstrated below (Figure, 12) although there were steps which were iterative and reflexive that developed over time (Ely, et. al., 1997). The whole process involved a constant moving back and forth as needed, throughout the phases (Nowell, et. al., 2017).

Phase 1: Creating transcripts from audio recordings

The data was collected by interactive semi-structured face to face interviews through audio recordings. Data was analysed with some knowledge which was gained from quantitative results and some analytic interests of interview questions (Tuckett, 2005).

Analysis of the data began after all interviews were transcribed manually with the aim to enhance the quality of the information gathered in each interview. Since transcription is a representational process immersed in the subjective interpretation of the researcher (Bucholtz, 2000), each transcript was printed and reviewed and reread several times for the actual representation of interviews, their accuracy and understanding of the correct wording and to get familiar with the data and expressions of the participants about their concerns with regards to breast cancer.

Audio recordings were carefully heard and thoroughly understood to attain deeper familiarity with the depth and breadth of the content of data as well as to creating thick descriptions from them. Afterwards, the entire dataset was read repeatedly to search meanings, patterns and other key words or phrases, to draw ideas and identification of possible patterns (Brain & Clarke, 2006). Repeated reading of thick descriptions was time consuming but was performed to build the foundation for the rest of the analysis.

During this phase, the entire dataset was broken down to read through to be actively engaged with it by searching for the patterns of meaning. Parallelly, data analysis was also started while searching for patterns of meanings by linking and making notes of statements of cancer survivors' interviews. Since thematic analysis is applied in relation to a dataset in a written form, the transcripts were created during this phase. The verbal texts from interviews were transformed into written texts in a manner that retains the true nature of key information from the verbal account (Braun & Clarke, 2006). Transcribing the verbal texts was quite a time-consuming activity, however meticulously performed as it informed the early stages of analysis and continuous further understanding of data by checking back against the original audio recording for accuracy (Braun & Clarke, 2006). Moreover, all ideas for coding or searching patterns were documented to revisit in subsequent phases if needed to develop a more formal coding process which continued throughout the entire analysis (Braun & Clarke, 2012; 2006).

Since language is the fundamental tool for creating and validating knowledge in qualitative research (Taylor & Francis; 2013), all interviews were translated into English in case conducted in Arabic. Most of the patients were from Arabic speaking backgrounds regardless of different nationalities and most of them were good at speaking in English; non-Arabic people like Filipinos were interviewed in English for most of the communication. The interviews of Arabic speaking participants were translated by the Arabic speaking physicians who helped to maintain the original meaning of the text as described by the participants to check the accuracy of translated statements. The translators were further involved in the data analysis as well to reduce the chance of translational and conceptual assumptions, improve the clarity of meaning and understand how the breast cancer survivors described their concerns. Significant time was allocated during the data analysis process to identify the meanings of words in Arabic and also to understand the meaning of the data collected. All efforts were made to quote the participants during the transcription process to avoid any bias yet at some stages, participants' view was interpreted for the better understanding; for instance, some unfamiliar words were rephrased to gain complete sense of the statements which were rechecked by participants themselves to maintain the accuracy.

Participants were contacted as needed to fill the missing gaps found during the process of data analysis as well as to ensure the accuracy of information (Stuckey, 2014) provided during the interviews. This allowed co-construction of the knowledge by providing participants with the opportunity to engage with and add to interview and interpret the data (Birt, et. al., 2016). All efforts were made to conduct the process of transcriptions not necessarily with neutrality but responsibility (Bucholtz, 2000). The key challenges associated with only a few transcriptions include the volume and the length of the interview recordings, the strong Arabic accent, incomplete sentences or omissions (Bailey, 2008; McLellan, et. al., 2003) which were dealt meticulously by member checking as described above.

Phase 2: Generation of initial codes

Savage (2000) explained qualitative coding as a process of reflection and a way of interacting with and thinking about data. The second phase involved the production of initial codes after reading and being familiarised with the data, having an initial list of ideas of what is in the data and what is interesting about them.

The entire dataset was organised into meaningful groups and codes were manually assigned to the data segments that provided the information from the raw data in a meaningful way (Kelle, 2004; Seale, 2000; Boyatzis, 1998). First, each transcript was read thoroughly several times and notes were taken if needed to familiarise with the data. During reading and re-reading, aspects of the data which were found interesting were noted down. This was performed manually on the transcripts. Line by line analysis of data was conducted and identified statements were highlighted and initial data-derived codes were generated at latent level to present participants' experience in a more detailed way. The latent codes provided the opportunity to bring new identified data-driven codes. Although quite time consuming, this ensured that nothing was missed out while performing the coding process. During this phase, A template was created to justify the inclusion of each code to assist in interpretation and clear evidence to add credibility to the research (King, 2004) and to enable the reader to judge whether the final outcome is rooted in the data generated (Ryan, et. al., 2007). Data was coded based on notes that were written and highlighted to indicate potential themes.

Following coding, the entire data was collated together within each code that formed the basis of themes (Braun & Clarke, 2006). Themes were created from the data itself without having any presumption in mind.

Phase 3: Searching for themes

A theme is an abstract entity that brings meanings and identity to a recurrent experience and its variant manifestations (DeSantis & Ugarriza, 2000). A theme captures something important in relation to the overall research question (Braun & Clarke, 2006), and unifies the nature or basis of experience into a meaningful whole (Nowell, et. al., 2017). Phase 3 begins after coding and collation of data with a creation of a list of different identified codes across the data.

This process involved bringing together ideas or experiences which may seem meaningless if viewed alone (Aronson, 1994). Upon producing the list of the codes, they were sorted out into initial themes. Themes were identified as salient by participants' responses based on something important to them as well as perceived frequent if the number of participants raised the similar theme not on the basis of frequency of statements made. This phase involved sorting and collating all potentially relevant coded data extracts into themes (Braun & Clarke, 2006). During this phase, codes were first analysed by organising and visualising them to conceptualise patterns and relationships within the data (Attride-Stirling, 2001).

Each code was written with a description and mind-maps were created to form an overarching theme. Mapping helped to develop an understanding of the significance of the themes (Herzog, Handke & Hitters, 2019). Some initial codes formed main themes whereas some were assigned as sub-themes, and some were discarded. Themes were generated inductively from the raw data (Boyatzis, 1998) thus were strongly linked to the data themselves (Nowell, et. al., 2017). Data coding was performed without trying to fit it into pre-existing ideas or preconceptions (Braun & Clarke, 2006).

Themes were created with a good number of predefined codes to help guide analysis. Most relevant themes were identified in relation with the research questions (King, 2004). Detailed notes were taken about the development and theme creation that helped establish confirmability in the audit trail (Halpren, 1983). The phase ended up with the collection of relevant themes and sub-themes and coding of all data extracts without leaving any area of data neglected.

Phase 4: Reviewing of themes

The fourth phase began after devising a set of themes to refine them more (Braun & Clarke, 2006). This phase involves two levels: reviewing and refining themes by developing candidate themes into final themes. During this phase, the entire data was re-read to assure whether the themes and sub-themes are coherent with the dataset and accurately represent that data. Also, to code any additional data within themes that might have been missed during the initial coding since recoding was considered ongoing (Braun & Clarke, 2006).

At level one, coded data extracts were reviewed for each theme to consider the coherent pattern. Some themes didn't have enough data to support them, some candidate themes were not really themes, some collapsed into each other, and some were broken down into separate themes (Braun & Clarke, 2006).

After achieving the coherent patterns, the second level involved refining of identified themes that are relevant to the data extract. The potential themes were aggregated to achieve a more manageable set of significant themes. (Attride-Stirling, 2001). Data within themes were cohered together in a way that clear and identifiable distinctions could be made between themes keeping internal homogeneity and external homogeneity (Patton, 1990). In the second level of analysis, the validity of individual themes was assessed to determine whether the themes accurately reflect the accurate representation of the dataset as whole (Braun & Clarke, 2006). In this phase, inadequacies in the initial coding and themes were identified and amendments were made accordingly (King, 2004).

After rereading, recoding, possibilities of identifying new themes were explored to generate any possible themes till the refinements added nothing substantial, the process was halted. At the end of the process, all transcripts were compared separately to identify significant statements that represent similar findings. Likewise, differences were collated across each interview to draw further conclusions based on that. Referential adequacy was tested by trailing back to the raw data and comparing it to the developed themes to make sure all conclusions were firmly grounded in the data (Lincoln & Guba, 1985).

Phase 5: Defining and Naming Themes

In this phase, a thematic map was developed. At this point themes were defined and redefined by identifying the essence of what they are about and analysed to determine which aspect of the data is captured by each theme (Braun & Clarke, 2006). Themes were reviewed, refined and defined with a concise name and theme were considered in relationship with each other in a 'thematic map' (Fig, 17). The analysis appeared to reach thematic saturation at a point when no additional themes were found from the reviewing of successive data regarding each investigated category (Guest, Bunce, & Johnson, 2006, Glaser & Strauss, 1967).

A detailed analysis for each individual theme was conducted to identify the story that each theme tells in relation to the research question(s). Part of the refinement was to identify sub-themes which are essentially themes within themes which are useful to structure large and complex data and to demonstrate the hierarchy of meaning within the data. Themes were not finalised until all the texts were included which were relevant to the research questions, added to that, investing sufficient time to develop the themes increases the probability of developing credible findings.

At the end of this phase, themes were clearly identified. All themes were given concise names to the identified themes to provide a quick sense about what the theme is all about.

All stages of the analysis were peer reviewed and participants' statements were subject to rechecking by a reviewer as well as with the relevant participant as suggested by Robson (2002). The rechecking with the participant was carried out either by phone or voice notes as preferred by the participant. Finally, the original interview transcripts were re-read several times to ensure the final themes were supported by the original data. Although the stages used in the analysis of the data seemed sequential, they were iterative and built on the previous stage, making the analysis typically a recursive process with a back-and-forth movement between different phases (Braun & Clarke, 2006).

Phase 6: Producing the Report

The final phase was dedicated to the writing up of the analysis. It began after the establishment of a set of fully worked-out themes for final analysis and write-up of the report (Braun &

Clarke, 2006). Findings were developed in a way that is accessible to a reader in a way that claims made in relation to the dataset are rendered credible and believable. All methodological notes were taken to the audit trail to add trustworthiness and credibility (Halpren, 1983).

A reflexive journal was maintained throughout the research to ensure findings and conclusions were interpreted in a trustworthy manner and whether the literature is in line with the conclusion or not (Polit & Beck, 2008; Halpren, 1983). The aim was to articulate the meanings and implications of each theme as well as the assumptions that underpin it (Braun & Clarke, 2006). Also, to build a valid argument for themes selection and to add credibility to the discussion by including all relevant whether unanticipated outcomes that did not correspond to the research (Côté & Turgeon, 2005). The final results were aimed to be shared with the participants for their feedback to allow linking between respondents' views and representations (Tobin & Begley, 2004; Lincoln & Guba, 1985). The entire process of thematic analysis was recursive during which the writing up and analysis were executed parallelly in a way where assumptions were applied congruently with conceptualization of the research questions (Reicher & Taylor, 2005).

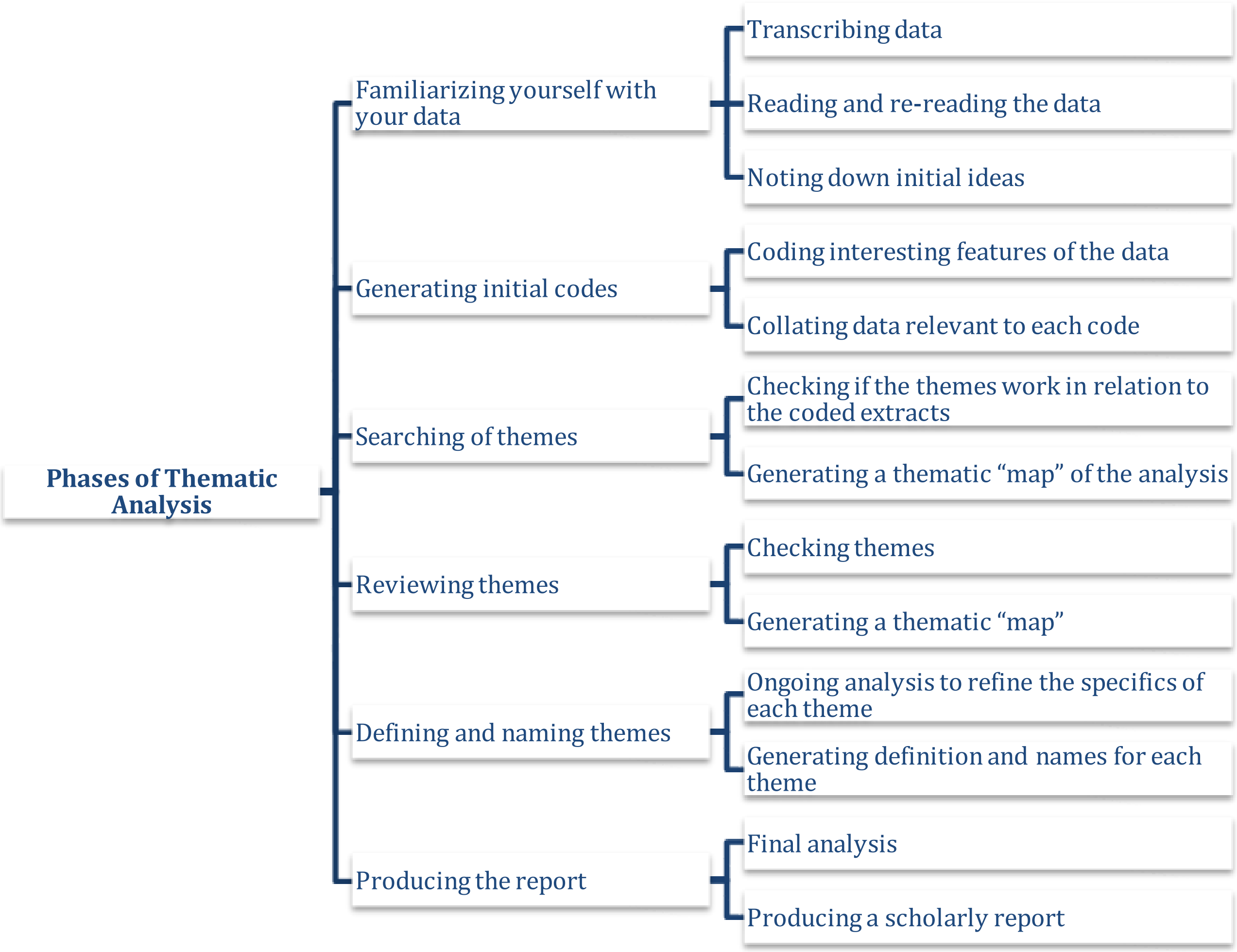


Figure 12: Phases of thematic analysis (adapted from Braun & Clark’s 2006)

https://www.researchgate.net/figure/Phases-of-Thematic-Analysis-Adapted-from-Braun-Clarke-2006-p-87_fig1_275952540

3.7.3 TRUSTWORTHINESS AND REFLEXIVITY

Conducting a naturalistic inquiry is not a straightforward task. Qualitative studies are complex in many ways compared to quantitative research which follows a structured and rigid design. Apparently, it seems like there are many similarities among various qualitative methods and the nature of qualitative enquiry is subjective (Creswell, 2013; Polit & Beck, 2012; Ryan, et. al., 2007). Qualitative research has tried to address methodological concerns by offering guidelines for trustworthiness and reflexivity in order to assure that the method is rigorous (Cypress, 2017). Rigor was addressed for the first time by Lincoln and Guba (1985) in their model of trustworthiness of qualitative research.

Trustworthiness is used as the central concept in their framework to appraise the rigor of a qualitative study. Trustworthiness has been applied to quality, authenticity and truthfulness of findings and can be described as the degree of trust described in many different ways by the researchers. It relates to the degree of trust or confidence that readers have in results (Schmidt & Brown, 2015). Trustworthiness is used as a criterion to evaluate the quality of a research design (Yin, 1994) and addresses methods that ensure that the research process has been carried out correctly (Guba & Lincoln, 1989). Trustworthiness is based on the concepts of reliability and validity and objectivity (Manning, 1997; Seale, 1999). Lincoln & Guba (1985) clearly established four criteria as benchmarks for quality based on the identification of four aspects of trustworthiness that are relevant to both quantitative and qualitative studies, which are ***truth value, applicability, consistency*** and ***neutrality.*** In this study, the concept of trustworthy in terms of **credibility, transferability, dependability and confirmability** was used to determine the validity and reliability of study findings (Lincoln & Guba's, 1985).

Credibility refers to the "fit" between participants' views and the researcher's representation of them (Tobin & Begley, 2004). It is defined as the truth of the study findings including the structural description of the phenomenon being studied (Anney, 2014; Ryan, et. al., 2007). Credibility was achieved by spending enough time and prolonged engagement with participants to gain deeper understanding of participants' responses, establishing rapport and trust with them. Also interviewing participants until data saturation was reached (Anney, 2014; Polit & Beck, 2012; Baxter & Eyles, 1997). Other ways to achieve credibility included **data triangulation** which was achieved by cross-checking the data and interpretations of each area described by the participants, by two other researchers who were experts in qualitative research methods. Moreover, **purposive sampling** for the qualitative part of the study (different age, stage, survival and treatment), peer review for an **external check** on the research process as well as **referential adequacy** to check preliminary findings against the raw data were added strategies to add credibility to the current study. This was carried out during the dissertation while writing up the findings and final analysis (Baxter & Eyles, 1997).

“Memoing” is an important data source in qualitative research that was considered while conducting interviews (Miles & Huberman, 1984). According to Lofland & Lofland, (1999) field notes (memoing) which are the secondary data storage method in qualitative research, are crucial to retain data gathered as the human mind tends to forget quickly. In this study, field notes were taken upon hearing, seeing, experiencing or thinking in the course of collecting and reflecting on the process as it is crucial to be aware of descriptive notes and reflective notes such as presentiments, impressions, expressions or feelings etc. Morgan (1997) suggested that since field notes involve interpretation thus, they are part of data analysis rather than the data collection or a step toward data analysis. **Field notes** were taken to trail back to the raw data. Findings were also shared with the participants to check the accuracy of interpretations to add further credibility to the study (Baxter & Eyles, 1997; Lincoln & Guba, 1985). It was ensured that personal bias did not interfere with the study at any stage thus notes taking was considered during data collection and data analysis to examine and avoid personal engagement. Field notes were made to capture non-verbal expressions and behaviours observed during interviews. This was an essential step that contributed to the richness of data and to interpret verbal information (Berg, 2009).

After making sense of the data, all efforts were made to identify and illuminate emerging themes and descriptions. Credibility was finally sought by coordinating best the **methodological and analytical materials utilised** in the entire research.

Transferability refers to the generalisability of inquiry. In qualitative research, this concerns only case-to-case transfer (Tobin & Begley, 2004). In this research, transferability was achieved by the **purposive sampling** recruiting participants from different emirates and with different nationalities (Anney, 2014; Creswell, 2013; Polit & Beck, 2012) and **data saturation** to obtain rich with a wide possible range of information and thick description of the phenomenon who had experienced it (Creswell, 2013; Polit & Beck, 2012). Data was collected from a single source and thus could result in lack of transferability; however, this was overcome by obtaining detailed descriptions of the participants’ experience of the phenomenon in an attempt to know (Baxter & Eyles, 1997). Special consideration was given to the process of data collection, data identification and data analysis throughout the course of the study. The audio records were carefully transcribed after numerous rereading for future scrutiny and all attempts were made to document all aspects of analysis in a way to make sense of the data and to write the final draft as accurately as possible (Merriam, 1995).

Dependability is the degree to which the study findings could be stabilised over time. It was established by an audit trail and data triangulation which involve recording of all the original data, reviewing and re-reading all transcripts, field notes, audio recordings and keeping notes, feedbacks and comments from the assessors to ensure the research process is logical, traceable and clearly documented (Anney, 2014; Tobin & Begley, 2004; Baxter & Eyles, 1997). According to Lincoln & Guba (1985), readers are better able to judge the dependability of the research if they can examine the research process. In this study dependability was established by an **audit trail** (Koch, 1994) as well as **data triangulation** which includes documenting and reviewing the original data, maintaining and reviewing all transcripts, field notes and audio recordings, refining the work upon feedbacks and comments from the supervisors and assessors who were expert in thematic analysis (Anney, 2014). All ten interviews were transcribed and then reviewed and correctly translated to **ensure accuracy** of documentation. Transcripts were repeatedly reviewed and reread to determine the meaning units (themes and subthemes) to understand the deeper meanings. Finally, the findings of thematic analysis were reviewed and assessed by two qualitative researchers experienced in thematic analysis from the UAE University Tawam Campus in the audit trail confirming that all possible codes and themes were identified, ensuring **accuracy of the interpretations** (Mays & Pope, 1995). Further discussions were carried out to discuss the datasets and to resolve discrepancies such as whether to consider treatment effects such as hair loss, skin or weight changes under “physical concerns” or “emotional concerns”. Finally, full alignment was obtained by ironing out the discrepancies to achieve unified understanding. Findings were also **shared with the participants to validate the results** over the telephone (member checking) in order to check whether the findings were reported true or not (Ziebland & McPherson, 2006).

Confirmability is the degree to which the study findings can be confirmed by the other researchers (Baxter & Eyles, 1997). It is concerned with establishing that the researchers’ interpretations are clearly derived from the data. According to Guba & Lincoln (1989), confirmability is established when credibility, transferability and dependability are all achieved. In this study, **conclusions and interpretations** were clearly demonstrated to establish confirmability (Tobin & Begley, 2004). In addition, the reasons for theoretical**,**

methodological and analytical choices were highlighted throughout the study with the aim to build understanding to other readers about how and why decisions were made (Nowell, et. al., 2017).

Reflexivity is central to the audit trail; (Nowell, et. al., 2017). Tobin & Begley (2004) suggested that researchers should keep a self-critical account of the research process, including internal and external dialogues. This can be used to document the methodological decision, rationales and to record researcher's **personal reflections** of their values, interest and insight information about self (Lincoln & Guba, 1985).

In this study, all internal and external communication was maintained to self-evaluate the research process (Tobin & Begley, 2004). A **reflexive journal** was used to record the **daily documentation** of the research, methodological decisions and reasons to record personal reflections, interests and insights information about self (Lincoln & Guba, 1985). In addition, the research process and the particular epistemological stance was examined to figure out if it might have influenced any aspect of data analysis (Willig, 2008). For instance, having a certain stance on UAE culture and women's status, it was presumed that women might not be able to talk openly about cancer and share their views about cancer experience yet, all women encouraged the researcher that their voices were heard for the first time. It was also discovered during qualitative interviews that UAE men were supportive toward their families who suffered from cancer. Most Emirati women showed gratitude towards their spouse and families for the continuous support and mentioned religion as the highest source of strength and coping with illness which falsified the set notion and pre-conceived ideas about the UAE culture, women's modesty and the dominant role of Muslim men in decision making that might be considered hindering in seeking treatment for breast cancer or resulting in fears as presented in the existing literature (ElObaid, 2016, 2014; Donnnelly, et. al., 2013; Bou Khalil., 2013; Daher, 2012; Bener, et. al., 2001; Milaat., 2000).

Eventually, the findings of the qualitative study were integrated with the quantitative study in order to address the research objectives. This chapter has provided an overview of the used methodology and methods pursued and applied to process and analyse the data. The next chapter provides the results and findings of both quantitative and qualitative phases of the study.

Summary

The methodology of the study was presented in this chapter. A sequential, explanatory mixed-methods (quantitative phase followed by qualitative phase) approach was used in the current study to identify the psychosocial needs of breast cancer survivors in the UAE. A cross-sectional design was used in the quantitative phase, followed by a semi-structured interview in the qualitative phase. The procedures for recruitment of a sample, data collection methods and data analysis approaches were described in details.

In quantitative phase one, **Cancer Survivors Survey of Needs** was used to identify the psychosocial needs of breast cancer survivors. Census sampling was used with the aim to reflect the entire population under study. The data was collected on 205 patients utilising quantitative survey with 94% response rate. Data analysis approaches was described to mention the use of SPSS software to provide descriptive statistic of survivors' demographics and clinical characteristics, the significant mean differences between two groups (Emiratis and expatriates) using chi-square test and t-test and multivariate multiple regression to compare the differences in each domain of psychosocial needs of survivors.

In qualitative second phase, ten semi-structured interviews were conducted to gain in-depth understanding of the needs of breast cancer survivors who were selected through purposive subsampling from phase one. Data collection procedures were described including the creation of an interview guide which was constructed on the basis of items in the questionnaire to gain further understanding. The procedure of data analysis was explained which utilised Braun and Clarke's (2006) inductive thematic analysis methodology demonstrating its six phases. The chapter ended with the provision reflexivity in this research and the methods used to achieve trustworthiness which included transferability, dependability and confirmability, dependability and confirmability.

Chapter 4: RESULTS

Chapter four presents the result and overall finding of the study. This chapter is organised by presentation of the demographics of the sample along with the findings of phase one of the study followed by the demonstrating phase two findings that includes describing process and techniques used for coding, creation of categories and the development of themes. Further explanations of findings revealed from both phases and results were integrated with the aim to understand comprehensively the needs and concerns of breast cancer survivors which were obtained by analysis and integrating findings from both methods. The summary has also been provided at the end of each section to present a succinct view of both quantitative and qualitative findings.

This chapter consists of two major sections, that is section 4.1 and 4.2. The first section (4.1) presents the quantitative results of the study. The statistical analyses were performed using version 17.0 of SPSS. **Quantitative results have been organised as follows:**

- **Descriptive data analysis**
- **Application of Chi-square test** for independence to compare the socio-demographics and clinical characteristics of two groups (Emiratis and expatriates) for statistical significance.
- **Significant mean differences** were investigated between two groups.
- **Application of t-test** to explore any significant differences between nationality (Expats and Emiratis) and psychosocial concerns.
- **Pearson Correlation Coefficient** was used to measure the correlation between psychosocial needs and demographics factors (age & QOL) and
- **Multiple regression** testing to determine the significance of the effect of the independent variables on the dependent variables.

Section 4.2 provides qualitative results which were later integrated in order to obtain a complete and synergistic utilisation of the data than results that were achieved separately from quantitative and qualitative data collection and analysis.

4.1 DESCRIPTIVE DATA ANALYSIS

The section below includes a descriptive statistics analysis including **frequency distribution, means, standard deviation (SD), medians, and proportions** which were calculated for all socio-demographic variables.

Demographic and clinical variables included **age at diagnosis, nationality, year of cancer diagnosis, type of cancer, stage of cancer, type of treatment received and whether currently on treatment or not,** were also analysed.

With regards to **psychosocial concerns** of cancer survivors, **physical concerns, information or educational concerns, social & financial concerns, emotional concerns and spiritual concerns were rated by the patients from 0 to 5 (No concerns to extreme concerns)** which indicates the level of need using a Likert-type scale. This allowed quantifying the concerns in each domain of psychosocial needs. These factors assessed the critical need domains as perceived by the survivors.

Data was cleaned and manipulated in order to create the scores for each psychosocial domain for instance physical concern (20 items) describing the mean, minimum, maximum and the standard deviation.

4.1.1 DEMOGRAPHIC CHARACTERSTICS OF BREAST CANCER SURVIVORS

Nationality distribution of cancer survivors

A total of 205 women, 54 (26.3%) cancer survivors were UAE nationals and 151 **(73.7%) were Expatriates**. This is also in line with the current population as expatriates contribute to approximately 75% of the UAE population.

Age group of cancer survivors

The **mean age of the women was 49 years** (SD = 11.864, range = 22–86 years). The median age of breast cancer survivors was 44-54 years. There were 12 (6 %) women who developed breast cancer at an earlier age ranging from 22-32. The majority of the women (124 = **60 %**) diagnosed with breast cancer were **between** the **33-54** age category. Alternatively, it could be concluded that 23.4 % of survivors were between 25-39 years, **64.9 % of them between 40-64 years**. Only 20 (10 %) women were diagnosed with breast cancer who were above the 65 years age group.

Year of initial diagnosis of cancer survivors

Out of a total of 205 participants, 80 (39%) of the breast cancer survivor patients were initially diagnosed with cancer between 2012 to 2017. Whereas the highest number of breast cancer survivors (122, **59.5%), were diagnosed either in or after 2018**. Only 3 breast cancer survivors were diagnosed in 2011 or earlier as shown in Table 1.

Stage at diagnosis of cancer survivors

The highest number of survivors (n=105, 51.2%) diagnosed with breast cancer stage II, regional without lymph node involvement followed by stage III, regional with lymph node involvement (n=48, 23.4%)**.** It is evident that the majority of breast cancer survivors are diagnosed with **regional stage** cancer at the time of diagnosis. There were no survivors who presented with advanced disease at the time of diagnosis. Only 13 (6.3%) survivors were diagnosed with the **in-situ stage**, which denoted the lowest level of disease when there's no cancer, only abnormal cells with the potential to become cancer. No woman out of 205 women presented with late advanced **stage IV** in the study sample.

Type of treatment received by cancer survivors

Majority of the expatriate women with breast cancer **(n=78, 38%) received multimodality treatment with combination of surgery, radiation, chemotherapy, hormonal and other treatment** whereas 26 women (12.7%) were treated with the combination of surgery, radiation and hormone therapy. Only 1 (0.5%) cancer survivor received chemotherapy followed by surgery. 6 women (2.9%) were given chemotherapy along with other treatment.

Type of treatment received by Nationality

Majority of the expatriate women with breast cancer **(n=55, 36.4%) received multimodality treatment with combination of surgery, radiation, chemotherapy, hormonal and other treatment** whereas the highest number of Emirati women **(n=12, 22.2%) went for the combination of surgery, radiation and chemotherapy**. Only 1 (1.9 %) expatriate cancer survivors received chemotherapy followed by surgery, likewise only 1 (1.9%) Emirati woman had chemotherapy along with other treatment.

Overall quality of life rated by cancer survivors

Out of 205 participants 149 (72.2%) of breast cancer survivors described their quality of life during the past week of the study as good. The mean score for overall quality of life for both group Emirati and Expatriates was 9.40 (SD = 1.262) which represents a good quality of life. Over 86% of patients rated their quality of life as 9/10 on a scale of 1 to 10.

The table 1. below provides the summary results of breast cancer survivors' demographics and their clinical characteristics of breast cancer survivors.

Table 1: Summary results of demographic analysis & clinical characteristics of breast cancer survivors

Breast Cancer Survivors Demographic Factors (n=205)		
DEMOGRAPHICS	**n**	**%**
NATIONALITY		
Emirati	54	26.3
Expatriate	151	73.7
AGE		
Mean= 48.84; SD=11.864; Min=22; Max=86		
22-32	12	5.9
33-43	64	31.2
44-54	64	31.2
55- 65	45	22.0
Above 65	20	9.8
CLINICAL CHARACTERSTICS		
Year of diagnosis		
2000-2005	2	1.0
2006-2011	1	0.5
2012-2017	80	39.0
>=2018	122	59.5
Type of cancer		
Breast	205	100
Stage of cancer		
I	39	19.0
II	105	51.2
III	48	23.4
In-situ	13	6.3
Currently receiving treatment (Treatment Received)		
No	84	41.0
Yes	121	59.0
Overall QOL	Mean=9.40, SD=1.262	

4.1.2 BREAST CANCER SURVIVORS' (a) PREFERRED LEARNING SOURCES, (b) TOPICS OF INTEREST & (c) PRIMARY SOURCE OF STRENGTH (SECTION 9-11)

4.1.2.1a CANCER SURVIVORS' PREFERRED LEARNING SOURCES

Breast cancer survivors were asked to indicate their **preferred source of learning** about the **psychosocial concerns including:**

1. **Physical**
2. **Social**
3. **Emotional**
4. **Spiritual**.

The options included writt**en materials, class, video, healthcare specialist, other cancer survivors or internet.**

BREAST CANCER SURVIVORS' PREFERRED LEARNING SOURCES ABOUT PHYSICAL CONCERNS

The table 2. below presents breast cancer survivors' preferred learning sources about physical concerns. It shows that out of a total of 205 breast cancer survivors, almost **59%** breast cancer survivors opted to consult "only' the **healthcare specialist** for physical issues. **8%** of cancer survivors preferred learning through **videos and health specialists**, **7%** wished to learn through **video**, **3%** showed their interest to learn physical issues through other **cancer survivors** and another **3%** preferred learning through **written materials, class, video as well as through healthcare specialists**. Whereas, only 0.5% of survivors preferred the internet as a learning resource about their physical concerns.

Thus, it was concluded that the majority of the breast cancer survivors preferred to consult with and learn from the health specialist for their physical concerns whereas internet resources were the least favourable choice of cancer survivors.

Table 2: Breast cancer survivors' preferred learning sources about physical concerns

Learning sources about physical concerns	Frequency	Percent
Cancer Survivor	6	2.9
Cancer Survivor, Written Materials, Class, Video, Healthcare Specialist	1	.5
Class	1	.5
Class, Healthcare Specialist	1	.5
Class, Healthcare Specialist, Cancer Survivor	1	.5
Class, Video	2	1.0
Class, Video Specialist	4	2.0
Healthcare Specialist	120	58.5
Healthcare Specialist, Cancer Survivor	3	1.5
Healthcare Specialist, Class	2	1.0
Healthcare Specialist, Video	8	3.9
Healthcare Specialist, Video Survivor	1	.5
Healthcare Specialist, Video Materials	1	.5
Healthcare Specialist, Written Materials	1	.5
Healthcare Specialist, Written Materials, Video	1	.5
Video	14	6.8
Video, Healthcare Specialist	16	7.8
Video, Healthcare Video, Healthcare Materials	1	.5
Video, Internet	1	.5
Written Materials	2	1.0
Written Materials, Class	1	.5
Written Materials, Class Specialist	1	.5
Written Materials, Class Specialist, Video	1	.5
Written Specialist, Video	1	.5
Written Materials, Class, Video, Healthcare Specialist	6	2.9
Written Materials, Class, Video, Healthcare Specialist, Cancer Survivor	3	1.5
Written Materials, Healthcare Specialist	4	2.0
Written Materials, Healthcare Specialist, Cancer Survivor	1	.5
Total	**205**	**100.0**

BREAST CANCER SURVIVORS' PREFERRED LEARNING SOURCES ABOUT EMOTIONAL CONCERNS

The table 3. below presents breast cancer survivors' preferred learning sources about social concerns. It shows that out of a total of 205 breast cancer survivors, almost **68%** breast cancer survivors opted to consult the **healthcare specialist only** whereas 7% preferred learning through **videos only** for their social issues whereas **7%** of cancer survivors preferred learning through video and healthcare specialist both. 3% preferred to learn from other cancer survivors. Only 2% wished to learn through **healthcare specialists and other cancer survivors** and another 2% preferred learning about their social concerns through **healthcare specialists and video.**

Thus, it was concluded that the majority of the breast cancer survivors preferred to consult with and learn from the health specialist as well as from videos for their social concerns whereas using the internet to learn emotional concerns was the least favourable choice among those patients.

Table 3: Breast cancer survivors' preferred learning source about social concerns

Learning sources about social concerns	Frequency	Percent
Cancer Survivor	6	2.9
Cancer Survivor, Written Materials, Class, Video, Healthcare Specialist	1	.5
Class	1	.5
Class, Cancer Survivor	1	.5
Class, Healthcare Specialist, Cancer Survivor	1	.5
Class, Video	1	.5
Class, Video Specialist	2	1.0
Healthcare Specialist	139	67.8
Healthcare Specialist, Cancer Survivor	4	2.0
Healthcare Specialist, Cancer	1	.5
Healthcare Specialist, Video	4	2.0
Healthcare Specialist, Video	1	.5
Healthcare Specialist, Video Materials, Cancer Survivor	1	.5
Healthcare Specialist, Written Specialist, Written Survivor	1	.5
Healthcare Specialist, Written Materials, Video	1	.5
Internet, Video	1	.5
Video	14	6.8
Video, Healthcare Specialist	14	6.8

Video, Internet	1	.5
Written Materials	1	.5
Written Materials, Class	2	1.0
Written Materials, Class, Video, Healthcare Specialist	3	1.5
Written Materials, Class, Video, Healthcare Specialist, Cancer Survivor	1	.5
Written Materials, Healthcare Specialist	3	1.4
Total	**205**	**100.0**

BREAST CANCER SURVIVORS' PREFERRED LEARNING SOURCES ABOUT EMOTIONAL CONCERNS

The table 4. below presents breast cancer survivors' preferred learning sources about emotional concerns. It shows out of a total of 205 breast cancer survivors, almost **69%** breast cancer survivors opted to consult the **healthcare specialist only** whereas **8%** preferred learning through the **video** for their emotional issues. **6%** of cancer survivors preferred learning through **video and healthcare professionals. 3%** wished to learn through **other cancer survivors** and another **3%** showed learning from **healthcare specialists and other cancer survivors** about their emotional concerns. Only **1.5%** of survivors preferred **class** as a source of learning about emotional concerns.

Thus, it was concluded that the majority of breast cancer survivors preferred to consult with and learn from the health specialist as well as from video for their emotional concerns whereas the internet was the least favourable choice among cancer survivors.

Table 4: Breast cancer survivors' preferred learning source about emotional concerns

Learning sources about emotional concerns	Frequency	Percent
Cancer Survivor	7	3.4
Cancer Survivor, Healthcare Specialist	1	.5
Cancer Survivor, Healthcare Specialist, Video Materials	1	.5
Class	3	1.5
Class, Cancer Survivor	1	.5
Class, Healthcare Specialist, Cancer Survivor	1	.5
Class, Video	1	.5
Class, Video Specialist	1	.5
Healthcare Specialist	142	69.3
Healthcare Specialist, Cancer Survivor	6	2.9
Healthcare Specialist, Video	2	1.0
Healthcare Specialist, Video	2	1.0
Video	16	7.8
Video, Class	1	.5
Video, Healthcare Specialist	13	6.3
Video, Internet	1	.5
Written Materials	1	.5
Written Materials, Class	1	.5
Written Specialist, Video	1	.5

Written Materials, Class, Video, Healthcare Specialist, Cancer Survivor	1	.5
Written Materials, Healthcare Specialist	2	.9
Total	204	100.0

BREAST CANCER SURVIVORS' PREFERRED LEARNING SOURCES ABOUT SPRITUAL/RELIGIOUS CONCERNS

The table 5. below presents breast cancer survivors' preferred learning sources about spiritual or religious concerns. It shows that out of a total of 204 breast cancer survivors (excluding blank, n=1), almost **41%** breast cancer survivors opted to consult the **healthcare specialist only** whereas **24%** preferred learning through **classes only** for their spiritual or religious needs. **6%** of cancer survivors preferred learning through **video only.** Only **4%** wished to learn through **video and healthcare specialists** about the spiritual or religious concerns.

Thus, it was concluded that the majority of the breast cancer survivors preferred to consult with and learn from the health specialist as well as classes for their spiritual or religious concerns whereas Internet and written material were observed as the least favourable choices among cancer survivors.

Table 5: Breast cancer survivors' preferred learning source about spiritual or religious concerns

Learning sources about emotional concerns	Frequency	Percent
Cancer Survivor	7	3.4
Cancer Survivor, Class	3	1.5
Cancer Survivor, Healthcare Specialist, Cancer	1	0.5
Class, Healthcare Specialist	5	2.5
Class, Healthcare Specialist, Cancer Survivor	1	0.5
Class, Video	6	2.9
Class, Video Specialist	3	1.5
Class, Video Specialist, Class	1	0.5
Class, Video Survivor, Internet	1	0.5
Class	49	24.0
Healthcare Specialist	84	41.2
Healthcare Specialist, Cancer Survivor	3	1.5
Healthcare Specialist, Class	5	2.5
Healthcare Specialist, Class Survivor	1	0.5
Internet	1	0.5
Internet, Video	1	0.5
Survivor, Internet	1	0.5
Video	12	5.9
Video, Class	9	4.4
Video, Healthcare Specialist	9	4.4
Video, Internet	1	0.5

Cancer Survivor	7	3.4
Cancer Survivor, Class	3	1.5
Cancer Survivor, Healthcare Specialist, Cancer	1	0.5
Class, Healthcare Specialist	5	2.5
Class, Healthcare Specialist, Cancer Survivor	1	0.5
Class, Video	6	2.9
Class, Video, Healthcare Specialist	3	1.5
Total	204	100.0

4.1.2.1b BREAST CANCER SURVIVORS' PREFERRED TOPIC OF LEARNING INTEREST

Breast cancer survivors were asked to indicate their **preferred choices** about four **areas including Healthy living choices, Financial Concerns, Enhancing communication and Health Screening.** The options included for each area are mentioned below:

(A) Healthy living choices including nutrition, safe exercise and smoking cessation.

(B) Financial Concerns including living wills and disability**.**

(C) Enhancing communication including enhancing communication with either doctors or with a spouse or a partner whereas

(D) Health Screening including enhancing communication Health screening included cancer and heart screening.

BREAST CANCER SURVIVORS' PREFERRED TOPIC OF LEARNING INTEREST ABOUT HEALTHY LIVING

The table 6. below provides breast cancer survivors' preferred topic of learning interest about healthy living. It shows that out of a total of 196 breast cancer survivors (excluding blank, n=9), **46%** of breast cancer survivors mentioned that they were interested in learning more about **nutrition and safe exercise** with regards to **healthy living choices.** Whereas **40%** showed their interest in learning about **nutrition only. 12%** of survivors preferred learning about **safe exercise**. Whereas only 0.5% of cancer survivors showed their interest in **smoking cessation and nutrition** both to achieve healthy living choices.

Thus, it was concluded that the majority of breast cancer survivors preferred to learn about nutrition and safe exercise to achieve a healthy lifestyle. Smoking cessation was the least interesting topic for learning and only 1% of the survivors opted for this option.

Table 6: Breast cancer survivors' preferred topic of learning interest about healthy living

Learning interest about healthy living	Frequency	Percent
Nutrition	79	40.3
Nutrition, Safe exercise	91	46.4
Nutrition, Smoking cessation	1	0.5
Safe exercise	24	12.2
Smoking cessation, Nutrition	1	0.5
Total	196	100.0

BREAST CANCER SURVIVORS' LEARNING INTEREST ABOUT FINANCIAL CONCERNS

The table 7. below shows breast cancer survivors' preferred topic of learning interest about financial concerns. With regards to **financial concerns**, **79% (n=162)** of survivors did not provide an answer about their interest to learn more about financial concerns. Majority of the cancer survivors (67%) mentioned that they were interested in **living will,** which is a written document in which a person specifies the type of medical treatment they would like if they became so ill that they are certain to die and are unable to communicate their wishes about their treatment. Only 7% survivors showed their interest in learning more about **disability** and equally 7% mentioned **living will and disability both**.

Thus, it was concluded that the majority of breast cancer survivors preferred not to answer about financial concerns which could be their inability to manage their finances. However, some survivors showed their interest in learning more about living wills and very few were interested in knowing more about disabilities.

Table 7: Breast cancer survivors' preferred topic of learning interest about financial concerns

Learning interest about financial concerns	Frequency	Percent
Disability	7	16.2
Living wills	29	67.4
Living wills, Disability	7	16.2
Total	43	100.0

BREAST CANCER SURVIVORS' LEARNING INTEREST ABOUT ENHANCING COMMUNICATION

The table 8. below shows breast cancer survivors' preferred topic of learning interest about enhancing communication. With regards to **enhancing communication**, **55%** (n=113) of survivors did not provide an answer about their interest in enhancing communication with either of the options given. Whereas, 18% showed their interest in doctors or spouse communication enhancement. **73%** survivors mentioned their interest in enhancing communication **with doctors** and only 4% mentioned their interest in improving communication only with their **spouse or significant other.**

Thus, it was concluded that the majority of the breast cancer survivors preferred not to answer about interest in enhancing communication. However, those who answered, showed more interest in approaching their doctors only for enhancing communication compared to their spouse or significant other which were only few.

Table 8: Breast cancer survivors' preferred topic of learning interest about enhancing communication

Learning interest about enhancing communication	Frequency	Percent
With your doctors	67	72.8
With your doctors, With your spouse or significant other	17	18.4
With your spouse or significant other	8	8.6
Total	92	100.0

BREAST CANCER SURVIVORS' LEARNING INTEREST ABOUT HEALTH SCREENING

The table 9. below shows breast cancer survivors' preferred topic of learning interest about health screening. With regards to **Health Screenings**, approximately **8% (n=16) of patients** did not answer for their interest to learn about health screenings. However, **64% of survivors** mentioned that they are interested to learn about **cancer screening** whereas 36% showed their interest in **health screening**s **including both cancer and heart**.

Thus, it was concluded that the majority of the breast cancer survivors were interested in learning more about health screening particularly in cancer screening in addition to some interest in knowing more about health screening in order to attain health living.

Table 9: Breast cancer survivors' preferred topic of learning interest about health screening

Learning interest about health screening	Frequency	Percent
Cancer	121	64.0
Cancer, Heart	68	35.9
Total	189	100.0

4.1.2.1c BREAST CANCER SURVIVORS' PRIMARY SOURCE OF STRENGTH

The breast cancer survivors' primary source of strength was explored during their cancer experience including God, God & Family and Family & friend.

The table 10. below presents breast cancer survivors' primary source of strength during the course of disease. Out of a total of 193 breast cancer survivors (excluding blank, n=12), **79%** specified **God** as the only primary source of strength during their cancer experience. **12 % of patients** considered **God and family** both as the sources of strength. Approximately, **9%** mentioned **family and friends** as their primary sources of strength during the cancer journey and 6% of patients decided not to answer and left this question blank in the survey.

Table 10: Breast cancer survivors' primary source of strength

Primary source of strength	frequency	Percent
Family & Friends	17	8.8
God	153	79.2
God & Family	23	11.9
Total	193	100.0

4.1.3 MOST PREVELANT PSYCHOSCOIAL CONCERNS OF BREAST CANCER SURVIVORS'

Breast cancer survivors concerns were explored by their severity level within six psychosocial domains, as mentioned below. (See Appendix 5A, Section 3):

1. **Physical concerns** (Pain; fatigue; sleep disturbance; memory and concentration; nausea and vomiting; poor appetite; trouble swallowing; dental or mouth problems; weight changes; balance, walking, and mobility; loss of strength; peripheral neuropathy; lymphedema; osteoporosis and bone health; hair and skin care issues; body changes; bowel or bladder changes; hot flashes; sexual issues; and fertility issues.
2. **Information/Educational** Concerns (Being fully informed about their cancer and treatment, potential side effects and long-term adverse effects of the treatment, any familial risk associated with the disease, any symptom appear (recurrence/new primary), who to contact if any symptom appear (recurrence/new primary), next follow-up date, place and physician, the Psychosocial support and resources to other support services).
3. **Social & Financial Concerns** (Managing household activities, caring for family members, talking about cancer with family and friends, returning to work, health insurance, financial concerns, and debt from medical bills).
4. **Emotional Concerns** (Defining a new sense of normal; managing difficult emotions such as anger, fear, sadness, depression, guilt, and anxiety; coping with grief and loss; living with uncertainty; fear of recurrence; managing stress; isolation and feeling alone; intimacy issues; looking for the bright side with gratitude, forgiveness, love, happiness, and contentment; having a sense of well-being; changing relationships with spouse, family, and others; finding support resources; connecting to counselling services; and genetic counselling which includes concerns and fear about your children getting cancer).
5. **Spiritual Concerns** (Religious or spiritual support, religious or spiritual distress, loss of faith and end-of-life concerns).
6. **Other concerns** (Staying connected with the medical system, knowing who to call for medical problems, keeping your primary care physician informed of your cancer

treatment and risk of recurrence, use of complementary and alternative therapies, and concern about long-term effects of treatment).

Mean severity concern scores were calculated based on the entire sample. In addition, the data was analysed to explore survivors' major concerns using the sample of 205 patients as a whole as well as by time elapsed since diagnosis.

The individual severity scores of all concern items were categorised into three groups including: low concerns (score: 0 to 1), moderate concerns (score: 2 to 3) and extreme concerns (score: 4 to 5).

Correlational and regression analysis to evaluate the relationship between independent participants' characteristics and severity of concerns (dependent variables) was planned and undertaken.

The independent variables used in the modelling process for regression were gender, age, nationality, treatment of treatment and time since diagnosis. On the other hand, the dependent variable was set as an extreme concern with a rating of 4 to 5. Multivariate linear models were created, and the relationship was also evaluated between overall quality of life scored and having an extreme level of concern (score: 4-5).

Table 11 below provides the overall summary of descriptive statistics of breast cancer survivors' most prevalent concerns.

- The breast cancer survivors had, on average, **low or some concerns about their physical needs** (mean = 6.14, SD= 12.27).
- The breast cancer survivors had, on average, more **extreme concerns about their information needs** (mean = 27.9, SD= 11.0).
- The mean score of **social and financial concern** is approximately 7. This indicates that the breast cancer survivors had, on average, **some social and financial concern** (mean = 7.13, SD= 6.32).
- The mean score for **emotional concern** is apparently one which indicates that the breast cancer survivors had, on average, **some level of emotional concerns** (mean = 15.05, SD= 10.89).

- The mean score of **spiritual concerns** is less than one which denotes, on average, **no or very low concerns either regarding their spiritual or religious needs** (mean = 0.20, SD= 0.915).

Therefore, it is concluded that the informational needs were, on average, the highest worry for the majority of breast cancer survivors than any other domain of psychosocial concerns.

It should also be noted that the data on the total scores for the different psychosocial concerns and overall quality of life is significantly skewed (see Appendix 10) and therefore that the results involving these variables, including the multiple regression analysis, should be interpreted with caution.

Table 11: Summary Results of most prevalent psychosocial concerns of breast cancer

Score of Psychosocial needs	Mean	S. D
Physical Concerns	6.14	12.273
Information Concerns	27.99	11.020
Social & Financial Concerns	7.13	6.323
Emotional Concerns	15.05	10.896
Spiritual/Religious Concerns	.20	0.915

4.1.4 MOST PREVALENT PSYCHOSOCIAL CONCERNS OF BREAST CANCER SURVIVORS BY YEAR OF DIAGNOSIS

The data about breast cancer survivors' concerns was divided into three timeframes based on the time elapsed since initial diagnosis which are 0 to 1 year, 2 to 5 years and 6 and earlier years since initial diagnosis in order to identify the most prevalent extreme concerns described by the participants within certain timeframes.

Within the first year after breast cancer diagnosis (2018 and onwards), respondents reported extreme concerns regarding **information with the highest mean score** (32) and then emotional concern with a mean score of 13.89.

Between 2- 5 years after breast cancer diagnosis (2012-2017), respondents reported the same concerns as they reported after a year of initial diagnosis which were **information concerns** with a mean score approximately 30 and emotional concern with a mean score of 17.

Above 6 years and earlier after breast cancer diagnosis (2011 and earlier), **information concerns** remained the most prevalent as reported by the participants in other two timeframes with mean score of 32; however, social and financial concerns were reported high from six years since the initial diagnosis with mean score of 10. Table 12 below provides the breast cancer survivors' most prevalent concerns during three different time frames.

Table 12: Breast cancer survivors' most prevalent concerns by year of diagnosis

Most Prevalent Concerns by Year of diagnosis	n	mean	SD
0–1 year since diagnosis, >=2018 (n =122)			
Physical	122	7	13.3
Information	122	26.6	11.5
Social and financial	122	6.30	6.2
Emotional	122	13.89	10.6
Spiritual and religious	122	6.23	1.02
2–5 years since diagnosis, 2012-2017 (n = 80)			
Physical	80	4.31	8.7
Information	80	29.9	10
Social and financial	80	8.3	6.4
Emotional	80	17	11.3
Spiritual and religious	80	0.16	0.75
6 and earlier since diagnosis (n = 3)			

Physical	3	4.31	33.2
Information	3	32	5.2
Social and financial	3	10	7.2
Emotional	3	9.3	4.04
Spiritual and religious	3	0	0

4.1.5 SEVERITY OF BREAST CANCER SURVIVORS' PSYCHOSOCIAL CONCERNS

The severity of breast cancer survivors' concerns' scores within each psychosocial domain was calculated as below. The most extreme concern reported by the breast cancer survivors among all psychosocial domains was **"being fully informed about potential Psychosocial needs and long-term adverse effects"** with a mean of **4.34**. That indicated that **information was one of the most severe concerns** reported from the majority of the participants.

SEVERITY OF BREAST CANCER SURVIVORS' PHYSICAL CONCERNS

Within the physical domain, the highest mean scores overall (rating 0-5) were **fatigue, pain, hair and skin concerns and sleep disturbance** however, when excluding those who rated a score of 0 (No concern) and only reporting on items rated 1 to 5 (as a concern), the most prevalent concerns reported were hot flashes, hair and skin care, weight changes, and fertility concerns. Utilising the entire sample, the result indicates that the mean score is less than one indicating that the **breast cancer survivors had no major physical concern** about their health. Table 13. below presents the severity of breast cancer survivors' physical concerns.

Table 13: Severity of breast cancer survivors' Physical concerns

PHYSICAL CONCERNS *a Range = 0–5* *b Excludes participants who selected 0 responses (range = 1–5)*		SCORE 0-5		SCORE 1-5	
		Severity *a*		**Severity *b***	
		Mean	**SD**	**Mean**	**SD**
PHYC1	Pain	.64	1.274	2.40	1.355
PHYC2	**Fatigue**	**.69**	**1.283**	**2.24**	**1.376**
PHYC3	Sleep disturbance	.38	1.044	2.44	1.413
PHYC4	Memory and concentration	.25	.757	1.93	1.072
PHYC5	Nausea / Vomiting	.25	.757	1.93	1.072
PHYC6	Poor appetite	.22	.803	2.30	1.380
PHYC7	Trouble swallowing	.25	.757	1.93	1.072
PHYC8	Dental or mouth problems	.14	.622	2.07	1.328
PHYC9	Weight changes	.35	.992	2.57	1.230
PHYC10	Balance / Walking / Mobility	.29	.908	2.46	1.318
PHYC11	Loss of strength	.28	.889	2.38	1.345

PHYC12	Tingling or numbness in feet & hands (neuropathy)	.19	.630	1.73	1.032
PHYC13	Swelling in legs or arms (lymphedema)	.15	.587	1.72	1.127
PHYC14	Osteoporosis / Bone health	.27	.899	2.33	1.465
PHYC15	Hair and skin care concerns	.46	1.161	2.64	1.397
PHYC16	Body changes	.36	.983	2.35	1.305
PHYC17	Bowel or bladder changes	.33	.963	2.31	1.417
PHYC18	Hot flashes	.32	1.068	3.00	1.633
PHYC19	Sexual concerns	.09	.404	1.58	0.669
PHYC20	Fertility concerns	.21	.786	2.53	1.281

SEVERITY OF BREAST CANCER SURVIVORS' INFORMATION CONCERNS

In the information domain, the most prevalent concern with a highest means score (4.34) was" **being fully informed about potential psychosocial needs and long-term adverse effects"** (n=205) followed by concerns related to "**being fully informed about any symptom appear (recurrence/new primary)"** (n=202) and "**being fully informed about any familial risk"** (n=201), with more than half (above 50%) of the participants reporting concerns in all but one of these areas. When excluding those who rated a score of 0 (No concern) and only reporting on items rated 1 to 5 (as a concern), the most prevalent concerns reported were being fully informed about potential psychosocial needs and long-term adverse, being fully informed about the Psychosocial support and resources to other support services and being fully informed about who to contact if any symptom appears (recurrence/new primary). The overall results indicate that the mean score is approximately between 3 and 4 (approximately 4) which denotes that the **breast cancer survivors apparently had more concern about the information needs**. Table 14. below presents the severity of breast cancer survivors' information concerns.

Table 14: Severity of breast cancer survivors' information concerns

INFORMATION CONCERNS *a Range = 0–5* *b Excludes participants who selected 0 responses (range = 1–5)*		**SCORE 0-5**		**SCORE 1-5**	
		Severity *a*		**Severity *b***	
		Mean	**SD**	**Mean**	**SD**
INF_1	Being fully informed about my cancer and treatment	3.89	1.829	4.5028	1.04514
INF_2	**Being fully informed about potential Psychosocial needs and long-term adverse effects**	**4.346**	**1.4810**	4.7143	0.79417
INF_3	Being fully informed about any familial risk	3.96	1.765	4.5111	1.02749
INF_4	Being fully informed about any symptom appear (recurrence/new primary)	4.00	1.749	4.5556	0.97007
INF_5	Being fully informed about who to contact if any symptom appears (recurrence/new primary)	3.93	1.812	4.5739	0.92285
INF_6	Being fully informed about next follow-up date, place and physician	3.94	1.793	4.5337	0.99234
INF_7	Being fully informed about the Psychosocial support and resources to other support services	3.93	1.808	4.5795	0.90990

SEVERITY OF BREAST CANCER SURVIVORS' SOCIAL AND FINANCIAL CONCERNS

In the social and financial domain, the two most prevalent concerns with the highest mean score for each 1.96 were **health Insurance and financial issues**. The result indicates that the mean score is approximately one. This represents that breast cancer survivors **had less concern about the social and financial needs**. When excluding those who rated a score of 0 (No concern) and only reporting on items rated 1 to 5 (as a concern), the most prevalent concerns reported were also with 0 concern and the mean score was 3.0455. Table 15. below presents the severity of breast cancer survivors' social & financial concerns.

Table 15: Severity of breast cancer survivors' social & financial concerns

SOCIAL & FINANCIAL CONCERNS *a Range = 0–5* *b Excludes participants who selected 0 responses (range = 1–5)*		**SCORE 0-5**		**SCORE 1-5**	
		Severity *a*		**Severity *b***	
		Mean	**SD**	**Mean**	**SD**
SFC1	Managing household activities	.85	1.204	1.8229	1.15161
SFC2	Caring for family members	.86	1.168	1.7917	1.08499

SFC3	Talking about cancer with family and friends	.61	1.052	1.7391	1.09346
SFC4	Returning to work	.94	1.420	2.3457	1.31492
SFC5	Health insurance	1.96	1.860	3.0455	1.43492
SFC6	Financial concerns	1.96	1.860	3.0455	1.43492

SEVERITY OF BREAST CANCER SURVIVORS' EMOTIONAL CONCERNS

In the emotional domain, "**fear of recurrence**" (n=205) **and "genetic counselling"** (worries about children getting cancer (n=203) were the most prevalent concerns with a highest mean score of 3.4 for each item. When excluding those who rated a score of 0 (No concern) and only reporting on items rated 1 to 5 (as a concern), the most prevalent concerns reported were also as with 0 concern and the mean score was around 4.33. The overall result in this domain represents that the mean score is approximately one, indicating that the breast cancer survivors had **some concerns about the emotional needs except factors including fear of recurrence and genetic counselling.** This explains that they had concerns about cancer reappearing and worries about their offspring getting cancer inherently. Table 16. below presents the severity of breast cancer survivors' emotional concerns.

Table 16: Severity of breast cancer survivors' emotional concerns

EMOTIONAL CONCERNS ***a Range = 0–5*** ***b Excludes participants who selected 0 responses (range = 1–5)***		**SCORE 0-5**		**SCORE 1-5**	
		Severity *a*		**Severity *b***	
		Mean	**SD**	**Mean**	**SD**
EC1	Defining a new sense of normal	1.04	1.380	2.1616	1.23476
EC2	Managing difficult emotions: anger, fear, sadness, depression, guilt, anxiety)	.78	1.200	1.9390	1.15841
EC3	Coping with grief and loss	.40	.905	1.8409	1.07710
EC4	Living with uncertainty	1.41	1.828	3.0421	1.49407
EC5	**Fear of recurrence**	**3.44**	**1.966**	**4.3049**	**1.05306**
EC6	Managing stress	.97	1.246	1.9604	1.09472
EC7	Isolation / Feeling alone	.40	.911	1.8444	1.06506
EC8	Intimacy issues	.26	.718	1.7097	0.97275

EC9	Looking for the bright side: gratitude, forgiveness, love, happiness, contentment	.59	1.079	2.0167	1.04948
EC10	Having a sense of well being	1.04	1.537	2.6962	1.28457
EC11	Changing relationships with spouse, family, and others	.28	.797	1.9333	1.08066
EC12	Finding support resources	.45	1.095	2.3846	1.31019
EC13	Connecting to counselling services	.54	1.140	2.2653	1.23787
EC14	**Genetic counselling (worry about your children getting cancer)**	**3.44**	**1.988**	**4.3313**	**1.05442**

SEVERITY OF BREAST CANCER SURVIVORS' RELIGIOUS/SPIRITUAL CONCERNS

Religious or spiritual concerns were neither prevalent nor significant and did not score high as compared to other psychosocial domains. However, for those who did rate some level of concern (rating 1 to 5), end of life concerns was reported by 13 participants (6%) with a mean of 0.16, whereas the majority of the patients above 95% showed no spiritual or religious concerns in any of the item apart from end-of-life care. The domain results show that the **spiritual or religious needs were less concerning** as the mean score was less than one. In the other domain, no participant reported any concerns. Table 17. below presents the severity of breast cancer survivors' religious or spiritual concerns.

Table 17: Severity of breast cancer survivors' religious/spiritual concerns

RELIGIOUS/SPRITITUAL CONCERNS *a Range = 0–5* *b Excludes participants who selected 0 responses (range = 1–5)*		**SCORE 0-5**		**SCORE 1-5**	
		Severity *a*		**Severity *b***	
		Mean	**SD**	**Mean**	**SD**
SRC1	Religious or spiritual support	.02	.279	4.0000	
SRC2	Religious or spiritual distress	.02	.279	4.0000	
SRC3	Loss of faith	.00	.000		
SRC4	End of life concerns	.16	.738	2.5385	1.61325

4.1.6 ASSOCIATION BETWEEN BREAST CANCER SURVIVORS' (A) NATIONALITY & AGE (B) NATIONALITY & STAGE OF CANCER

Literature shows that the breast cancer occurrence in Emirati women is at earlier ages unlike other world population or nationalities (Al-Shamsi & Alrawi, 2018; FOCP, 2018; Najjar & Easson; 2010; Elobaid, 2010; Tadmouri, & Al-Sharhan, 1985). Additionally, there is a late presentation with an advanced stage of cancer in Emiratis than other nationalities (Younis, et. al., 2016; Elobaid, 2010). Thus, an association between nationality and stage of breast cancer was explored using Chi-Square test as follows:

4.1.6a ASSOCIATION BETWEEN BREAST CANCER SURVIVORS' NATIONALITY & AGE

HYPOTHESIS 1:

H0: There is no association between age and nationality

H1: There is an association between age and nationality

It is observed that the breast cancer occurrence in Emirati women is at earlier ages unlike other world population or nationalities thus an association between nationality and age was explored as below:

Breast cancer survivors' age group by nationality

Table 18a presents the percentage of breast cancer survivors by age groups in both Emiratis and expatriates:

- 91.7% of survivors aged [22-32] were expatriate, while 8.3 % were Emirati.
- 68.9 % of survivors aged [33-43] were expatriate, while 31.3 % % were Emirati.
- 21.9% of survivors aged [44-54] were Emirati, while 78.1 % were expatriates.
- 33.4% of survivors aged [55-65] were Emirati, while 66.7 % were expatriates.
- 20.0% of survivors aged above 65 were Emirati, while 80.0 % were expatriate

Table 18a: Breast cancer survivors' age by nationality

Age group * Nationality Crosstabulation

Each subscript letter denotes a subset of Nationality categories whose column proportions do not differ significantly from each other at .05 level.

			Nationality		**Total**
			Emirati	**Expatriate**	
Age group	**22-32**	Count	1a	11a	12
		Expected Count	3.2	8.8	12.0
	33-43	Count	20a	44a	64
		Expected Count	16.9	47.1	64.0
	44-54	Count	14a	50a	64
		Expected Count	16.9a	47.1a	64.0
	55-65	Count	15	30	45
		Expected Count	11.9	33.1	45.0
	>65	Count	4a	16a	20
		Expected Count	5.3	14.7	20.0
Total		**Count**	**54**	**151**	205
		Expected Count	**54.0**	**151.0**	205.0

Hypothesis 1 – There is no association between breast cancer survivors' nationality and age

Table 18b provides the result of Chi-square test conducted for hypothesis one showing that the proportion of breast cancer survivors' ages, those who were Emirati was not significantly different from the proportion of survivor's ages, who were expatriates. Therefore, it can be concluded that **there was no significant association between age and nationality** (X2 = 5.007, p=0.287).

Table 18b: Hypothesis 1 – Chi-Square Tests

Chi-Square Tests			
	Value	**Df**	**Asymptotic Significance (2-sided)**
Pearson Chi-Square	5.007[a]	4	.287
Likelihood Ratio	5.479	4	.242
Linear-by-Linear Association	.069	1	.792
N of Valid Cases	205		
a. 1 cells (10.0%) have expected count less than 5. The minimum expected count is 3.16.			

There are a number of effect size statistics available in the crosstabs procedure. For 2 by 2 tables, the most commonly used one is the **phi coefficient**, which is a correlation coefficient and can range from 0 to 1. The higher value indicates a stronger association between the two variables. Table 18c provides the Phi value in the symmetric measures which was calculated as **0.156**. This considers a **very minimal effect** using Cohen's (1988).

Table 18c: Hypothesis 1 – phi Coefficient

		Value	**Approximate Significance**
Nominal by Nominal	**Phi**	.0156	.287
	Cramer's V	.056	.287
N of Valid Cases		205	

Conclusion: "A Chi-Square test for independence indicated no significant association between age and nationality, Pearson chi Square (df=4, n=205) =5.007, Sig=0.287, phi=0.156 from what would be expected by chance".

4.1.6b ASSOCIATION BETWEEN BREAST CANCER SURVIVORS' STAGE OF CANCER & NATIONALITY

HYPOTHESIS 2:

H0: There is no association between nationality and stage of breast cancer survivors

H1: There is an association between nationality and stage of breast cancer survivors

It is observed that there is a late presentation with an advanced stage of cancer

Breast cancer survivors' stage of cancer by nationality

Table 19a presents the percentage of breast cancer survivors by stage groups in both Emiratis and expatriates:

- **In-situ stage:** In total of 13 patients with In-situ stage, 61% of survivors were expatriate and 39 % were Emirati.
- **Stage I:** In total of 39 patients with stage I, 69% of survivors were expatriate and 31 % were Emirati.
- **Stage II:** In total of 105 patients with stage II, 70% of survivors were expatriate and 30 % were Emirati.
- **Stage III:** In total of 48 patients with stage III, 88% of survivors were expatriate and 12 % were Emirati.

Table 19a: Breast cancer survivors stage by nationality

Breast cancer Stage by Nationality Crosstabulation

			Nationality		**Total**
			Emirati	**Expatriate**	
Breast Cancer Stage	**In-Situ**	Count	5_{a}	8_{a}	13
		% Within Stage	38.5%	61.5%	100.0%
	Stage I	Count	12_{a}	27_{a}	39
		% Within Stage	30.8%	69.2%	100.0%
	Stage II	Count	31_{a}	74_{a}	105
		% Within Stage	29.5%	70.5%	100.0%
	Stage III	Count	6_{a}	42_{b}	48
		% Within Stage	12.5%	87.5%	100.0%
Total		Count	54	151	205
		% Within Stage	26.3%	73.7%	100.0%

Each subscript letter denotes a subset of Nationality categories whose column proportions do not differ significantly from each other at the .05 level.

Hypothesis 2 – There is no association between stage of breast cancer and nationality

The below tables 19b and 19c, Chi square Z test show that there is no association in most part between nationality and cancer stage however the Z test shows a significant association for stage 3 with significantly higher numbers for expatriates and lower numbers for Emirati than would be expected by chance.

Chi square Z test shows that there is no association in most part between nationality and modified stage however the Z test shows a significant association for stage 3 with significantly higher numbers for expatriates and lower numbers for Emirati than would be expected by chance. Because we have not violated the assumption of Chi-Square concerning the minimum expected value frequency, which should be 5 or greater (or at least 80 per cent of the total value. The value 12.5 % has an expected count less than 5, thus considered Asymptotic sig. (2-sided), Sig=0.083 showing that **our result is not significant.** This me**ans that the proportion of breast cancer survivors from different stages was not significantly different** from what would be expected by chance with the exception of stage 3 as noted above from the Z tests.

Table 19b: Hypothesis 2 – Z TEST

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	6.666[a]	3	.083
Likelihood Ratio	7.344	3	.062
Linear-by-Linear Association	4.949	1	.026
N of Valid Cases	205		

a. 1 cells (12.5%) have expected count less than 5. The minimum expected count is 3.42.

Since the cross table above is larger than 2 by 2, the value to report is Cramer's V, which takes into account the degrees of freedom. The Cramer's V in the symmetric measures is 0.180, which is considered as a weal effect using Cohen's (1988). Thus, the result of this hypothesis can be presented as: ***"A Chi-Square test for independence indicated a non-significant association between stage of cancer and nationality, Pearson chi Square (df=3, n=205) =13.661, Sig=0.083, Cramer'V=0.256".***

Table 19c: Hypothesis 2 – phi Coefficient

Symmetric Measures			
		Value	**Approximate Significance**
Nominal by Nominal	**Phi**	.180	.083
	Cramer's V	.180	.083
N of Valid Cases		205	

4.1.7 INFLUENCE OF NATIONALITY ON PSYCHOSOCIAL NEEDS SCORES OF BREAST CANCER SURVIVORS

An independent Sample t-test (Welch's test) was conducted to test if nationality has an influence on scoring rated by breast cancer survivors on each domain of psychosocial concerns.

From the below table 20a., the following conclusion can be made:

- A **significant difference was found between Emirati and expatriate** breast cancer survivors in **physical domain** (t= -2.180, p< 0.05) as well as **social & financial domain** (t=-4.997, p<0.05)
- There were no significant differences between Emirati and expatriates in other domains of psychosocial concerns including information, emotional and spiritual or religious concerns.

Table 20a: Summary of differences in psychosocial concerns scores between Emiratis and expatriates breast cancer survivors

Score	T-test	p-value	Decision
Physical Concerns	**-2.180**	**0.031**	**S**
Information Concerns	-0.986	0.326	N/S
Social & Financial Concerns	**-4.997**	**0.000**	**S**
Emotional Concerns	1.676	0.097	N/S
Spiritual/Religious Concerns	0.727	0.468	N/S

S*= Significant,* ***N/S****= Not Significant*

Welch's t test was used because of unequal variances between the groups arising from unequal sample sizes.

Influence of nationality on physical concerns of breast cancer survivors

T-tests were performed to explore the differences in **Physical Concerns** between two groups, Emiratis and Expatriates.

Result: There was a statistically significant difference in Physical Concerns between Emiratis and Expatriates (3.48). Physical Concerns were higher in Expatriates (7.05) than Emiratis (3.57). **t=-2.153, p-value=0.033.**

Table 20b: Difference in physical concerns between emiratis and expatriates breast cancer survivors

	Nationality	N	Mean	SD	Std. Err/Mean	t-value	p-value
Physical Concerns	**Emirati**	54	3.57	8.878	1.208	-2.153	0.033
	Expatriate	151	7.05	13.183	1.073		

Influence of nationality on information concerns of breast cancer survivors

T-tests were performed to explore the differences in **Information Concerns** between two groups Emiratis and Expatriates.

Result: There were no differences in information needs between Emiratis and Expatriates. **t=-1.020, p-value=0.311.**

Table 20c: Difference in information concerns between Emiratis and expatriates breast cancer survivors

	Nationality	N	Mean	SD	Std. Err/ Mean	t-value	p-value
Information Concerns	**Emirati**	**54**	**26.41**	**14.395**	**1.959**	**-1.020**	**0.311**
	Expatriate	151	28.56	9.524	0.775		

Influence of nationality on social/financial concerns of breast cancer survivors

T-tests were performed to explore the differences in **Social & Financial Concerns** between two groups Emiratis and Expatriates.

Result: There were higher differences in Social & Financial Concerns between Emiratis and Expatriates (4.8). Social and financial Concerns were higher in Expatriates (8.39) than Emiratis (3.59). **t=-5.067, p<0.001.**

Table 20d: Difference in social/financial concerns between Emiratis and expatriates breast cancer survivors

	Nationality	N	Mean	SD	Std. Err/Mean	t-value	p-value
Social Concerns	**Emirati**	54	3.59	3.839	0.522	-5.067	<0.001
	Expatriate	151	8.39	6.561	0.534		

Influence of nationality on emotional concerns of breast cancer survivors

T-tests were performed to explore the differences in **Emotional Concerns** between two groups Emiratis and Expatriates.

Result: There were no differences in emotional needs between Emiratis and Expatriates. **t=1.671, p-value=0.096.**

Table 20e: Difference in emotional concerns between emiratis and expatriates breast cancer survivors

	Nationality	N	Mean	SD	Std. Err/Mean	t-value	p-value
Emotional Concerns	**Emirati**	54	17.17	10.056	1.368	1.671	0.096
	Expatriate	151	14.29	11.116	0.905		

Influence of nationality on religious spiritual concerns of breast cancer survivors

T-tests were performed to explore the differences in spiritual/**religious concerns** between two groups Emiratis and Expatriates.

Result: There were no differences in spiritual/religious concerns between Emiratis and Expatriates. **t=0.727, p-value=0.468.**

Table 20f: Difference in spiritual/religious concerns between emiratis and expatriates

	Nationality	N	Mean	SD	Std. Err/Mean	t-value	p-value
Religious/Spiritual Concerns	**Emirati**	54	0.28	0.960	0.131	0.727	0.468
	Expatriate	151	0.17	0.900	0.073		

4.1.8 CORRELATION BETWEEN QUALITY OF LIFE & PSYCHOSOCIAL CONCERNS OF BREAST CANCER SURVIVORS

Correlation **between quality of life and psychosocial concerns** was also explored to find out whether there is any positive or negative correlation between the two factors.

There was a significant **negative correlation found between quality of life and the scores of psychosocial concerns including physical, social, emotional as well as spiritual concerns** ($p < 0.01$). The results indicated that the higher the psychosocial concerns (including physical, social, emotional as well as spiritual or religious concerns), the lower the quality of life (one increases the other decreases) as in line with the literature (DiSipio, et. al., 2009; Avis & Crawford, 2005; Edib, et. al., 2016).

A **positive correlation was found between quality of life and information concern** ($p < 0.01$). In other words, it could be concluded that if quality of life scores increase, the information concerns also increase along with it. Therefore, an assumption can be made that those cancer survivors who scored higher in the information domain also reflected higher scores in quality-of-life assessment which is quite consistent with the previous studies (Park & Hwang, 2012; Carey, et. al., 2012; Uchida, et. al., 2011).

Table 21: Correlation between quality of life and psychosocial concerns scoring breast cancer survivors

Relationship	Correlation (R-value)	Significance level (P-value)
Overall QL and physical concerns	-0.481	<0.001
Overall QL and information concerns	0.208	0.003
Overall QL and social concerns	-0.271	<0.001
Overall QL and emotional concerns	-0.366	<0.001
Overall QL and spiritual concerns	-0.166	0.017

4.1.9 RELATIONSHIP BETWEEN (a) DEMOGRAPHIC FACTORS & PSYCHOSOCIAL CONCERNS, (b) PSYCHOSOCIAL CONCERNS & QUALITY OF LIFE OF BREAST CANCER SURVIVORS

Multiple regression was used to measure the **degree of variance between demographic factors and psychosocial concerns** (physical concerns, information concerns, social and financial concerns, emotional concerns, and spiritual or religious concerns) **and between psychosocial concerns and overall quality of life.**

Multiple regression is a technique used **to explore the relationship between the dependant continuous variable such as physical concerns score and a number of independent variables** or predictors (continuous or categorical variables) for instance, age, stage of cancer, or currently receiving treatment to identify the coefficient of variation of the independent variables in the dependent variable. Also, to observe the coefficients, whether these are significant or not. Although multiple regression is based on correlation, it allows a more sophisticated exploration of the interrelationship among a set of variables and predictor variables can be categorical as well as continuous with categories predicting greater or less proportions of variance in scores the dependent measure. This makes it ideal for the investigation of more complex real-life, rather than laboratory-based, research questions.

Multiple regression is used to address a variety of research questions. It can inform how well a set of variables is able to predict a particular outcome. Multiple regression provides information about the model as a whole and the relative contribution of each of the variables that make up the model. The stepwise multiple regression was utilised in the analysis. This type of regression uses the highest independent variable that is correlated with the dependent variable and puts it into an equation. The process was continued until a model was reached to obtain all significant factors and excluded all non-significant factors.

4.1.9a RELATIONSHIP BETWEEN DEMOGRAPHIC FACTORS & PSYCHOSOCIAL CONCERNS OF BREAST CANCER SURVIVORS

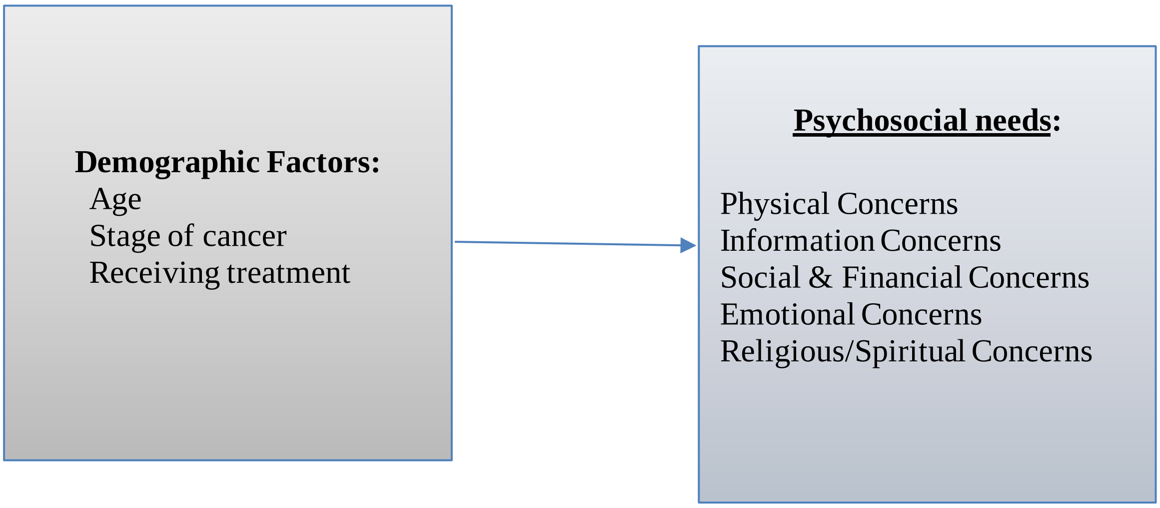


Figure 13: Relationship between demographic factors & psychosocial concerns of breast cancer survivors

The relationship has been explored between the scores of different domains of psychosocial concerns and the independent variables including age, stage of cancer and currently receiving treatment. The figure above shows the conceptual model for testing the following hypothesis.

HYPOTHESIS 3:

There is a significant relationship between demographic factors and psychosocial concerns of breast cancer survivors.

RELATIONSHIP BETWEEN DEMOGRAPHIC FACTORS & PHYSICAL CONCERNS OF BREAST CANCER SURVIVORS

The below table 22a. shows that correlation between **each of the demographic variables and physical concern was not significant**, so multiple regression was not conducted since demographic factors were not significantly related to the physical concerns (for SPSS output see Appendix 10, table 34).

Table 22a: Relationship between demographic factors and physical concerns of breast cancer survivors

Relationship	Correlation (R-value)	Significance level (P-value)
Age & physical concerns	-0.114	0.104
Stage & physical concerns	-0.041	0.562
Receiving treatment & physical concerns	0.117	0.095

RELATIONSHIP BETWEEN DEMOGRAPHIC FACTORS & INFORMATION CONCERNS OF BREAST CANCER SURVIVORS

The below table 22b. shows that there was a significant positive correlation between age and information concern, r=0.182, p=.009 and a significant positive correlation between information concern and receiving treatment, r=0.179, p=.010. The relationship between stage of cancer and information concerns was not significant, r=.044, p=.528 and therefore stage of cancer was not included in the multiple regression below.

Multiple linear regression (using the stepwise method with p<.05 for entry and p>.10 for removal) was conducted to assess if the two significant correlates with information concerns are also significant predictors (for SPSS output see Appendix 10, table 35).

In the first model, with age as the sole predictor, R=.182, R-square = .033 and adjusted R square = .028, F (df=1, 203) =6.956, p=.009, which shows that age is a significant predictor of information concerns (confirming the significant correlation reported above) accounting for 3.3% of the variance of information concern.

In the second model by adding a second predictor of currently receiving treatment, R=.252, R -square=.063, and adjusted R-square = .054, F (df=2, 202) =6.832, p=.001, which shows that age and currently receiving treatment together are significant predictors of information concerns and account for 6.3 % of the variance of information concern. It is furthermore the case that in the second model that R-square change=.03, F-change (df=1, 202) =6.591, p=.011, which shows that when currently receiving treatment is added to the equation that explains a significant extra amount of the variance of information concern (with a similar F and level of significance as for when age was entered as the sole predictor variable).

Table 22b: Relationship between demographic factor and information concerns of breast cancer survivors

Relationship	Correlation (R-value)	Significance level (p-value)
Age and information concerns	0.182	0.009
Stage of cancer and information concerns	0.044	0.528
Receiving treatment and information concerns	0.179	0.010

The below table confirms that Age is a significant predictor of information concerns when it is the sole predictor in model 1, Beta=.182, t=2.637, p=.009. In model 2, when currently receiving treatment is also entered into the equation, then Age remains a significant predictor of information concerns, Beta=.177, t=2.602, p=.010 and currently receiving treatment is also a significant predictor of information concerns, Beta=.174, t=2.553, p=.011. Both predictors appear to be of similar size and significance, as also shown by the similar F and F-change results reported above for model 1 and model 2.

Model Summary

				Significance level (p-value)
Model 1	Age	.182	2.637	.009
Model 2	Age	.177	2.602	.010
	Currently receiving treatment	.174	2.553	.011

RELATIONSHIP BETWEEN DEMOGRAPHIC FACTORS AND SOCIAL & FINANCIAL CONCERNS OF BREAST CANCER SURVIVORS

In the correlation table 22c., there was a positive significant correlation between stage of cancer and social financial concern, r=0.157, p=.025 and also a significant positive correlation between receiving treatment and social financial concern, r=0.246, p<.001. There was a non-significant relationship between age and social financial concerns, r=-0.060, p=.394 and therefore age factor will not be included in the multiple regression below.

Multiple linear regression (using the stepwise method with p<.05 for entry and p>.10 for removal) was conducted to assess if the two significant correlates with social financial concerns are also significant predictors (for SPSS output see Appendix 10, table 36).

In the first model, with currently receiving treatment as the sole predictor R=.246, R-square = .061 and adjusted R square = .056, F (df=1, 203) = 13.118, p=.000 which shows that currently receiving treatment is a significant predictor of social and financial concerns (confirming the significant correlation reported above) accounting for 5.6% of the variance of social and financial concerns.

In the second model by adding a second predictor of cancer stage, R=.286, R -square=.082, and adjusted R-square = .073, F (df=2, 202) =6.832, p=.001, which shows that currently receiving treatment and cancer stage together are significant predictors of social and financial concerns and account for 7.3 % of the variance of social and financial concern. It is furthermore the case that in the second model that R-square change=.03, F-change (df=1, 202) =4.625, p=.011, which shows that when cancer stage is added to the equation that explains a significant extra amount of the variance of social and financial concerns (with a similar F and level of significance as for when currently receiving treatment was entered as the sole predictor variable).

Table 22c: Relationship between demographic factors and social & financial concerns of breast cancer survivors

Relationship	Correlation (R-value)	Significance level (P-value)
Age and Social financial concerns	-0.060	0.394
Stage of cancer and Social financial concerns	0.157	0.025
Receiving treatment and Social financial concerns	0.246	<0.001

The below table confirms that currently receiving treatment is a significant predictor of social and financial concerns when it is the sole predictor in model 1, Beta=.246, t=3.622, p=.000. In model 2, when cancer stage is also entered into the equation, then currently receiving treatment remains a significant predictor of social and financial concerns, Beta=.239, t=3.545, p=.000 and cancer stage is also a significant predictor of social and financial concerns, Beta=.145, t=2.151, p=.033. Both predictors appear to be of similar size and significance, as also shown by the similar F and F-change results reported above for model 1 and model 2.

Model Summary

Model	Predictor variable	Standardised regression coefficient beta	t-value	Significance level (p-value)
Model 1	Receiving treatment	0.246	3.622	0.000
Model 2	Receiving treatment	0.239	3.545	0.000
	Stage of cancer	0.145	2.151	0.033

RELATIONSHIP BETWEEN DEMOGRAPHIC FACTORS & EMOTIONAL CONCERNS OF BREAST CANCER SURVIVORS

In the correlation table 22d., there was only a significant positive correlation between receiving treatment and emotional concerns, r=0.240, p=.001. There was also a non-significant relationship between age and emotional concerns, r=0.133, p=.058, although this approaching statistical significance and stage of cancer and emotional concerns, r=0.037, p=.602 and therefore age factor and stage of cancer will not be included in the regression below.

Linear regression (using the stepwise method with p<.05 for entry and p>.10 for removal) was conducted (for SPSS output see Appendix 10, table 37) with currently receiving treatment as the sole predictor R=.240, R-square = .058 and adjusted R square = .053, F (df=1, 203) = 12.417, p=.001 which shows that currently receiving treatment is a significant predictor of emotional concerns (confirming the significant correlation reported above) accounting for 5.3% of the variance of emotional concerns.

Table 22d: Relationship between demographic factors and emotional concerns of breast cancer survivors

Relationship	Correlation (R-value)	Significance level (p-value)
Age and emotional concerns	0.133	0.058
Stage of cancer and emotional concerns	0.037	0.602
Receiving treatment and emotional concerns	0.240	0.001

The below table confirms that currently receiving treatment is a significant predictor of emotional concerns when it is the sole predictor with Beta=.240, t=3.524, p=.001.

Model Summary

Model	Predictor variable	Standardised regression coefficient beta	t-value	Significance level (p-value)
Model	Receiving treatment	0.240	3.524	0.001

RELATIONSHIP BETWEEN DEMOGRAPHIC FACTORS & RELIGIOUS OR SPIRITUAL CONCERNS OF BREAST CANCER SURVIVORS

In the correlation table 22e. there was no positive significant correlation between spiritual or religious concerns and all the demographics factors. Thus, multiple regression was not calculated since demographic factors were not significantly related to associated with spiritual or religious concerns. .

Table 22e: Relationship between demographic factors and religious or spiritual concerns of breast cancer survivors

Relationship	Correlation (R-value)	Significance level (p-value)
Age and religious or spiritual concerns	0.045	0.523
Stage of cancer and religious or spiritual concerns	-0.069	0.325
Receiving treatment and religious concerns	-0.024	0.734

4.1.9b RELATIONSHIP BETWEEN PSYCHOSOCIAL CONCERNS & OVERALL QUALITY OF LIFE OF BREAST CANCER SURVIVORS

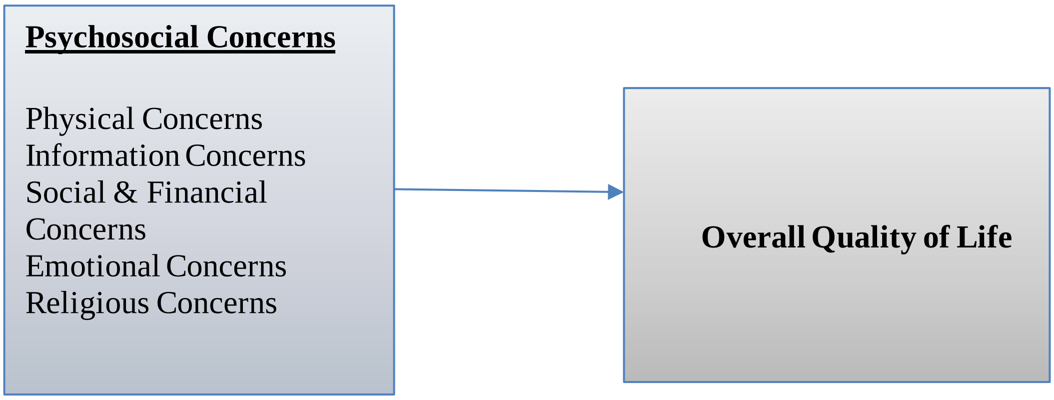


Figure 14: Relationship between psychosocial concerns & overall QOL of breast cancer survivors

The relationship was explored between the scores of different domains of psychosocial concerns and the overall quality of life. The figure above shows the conceptual model for testing the following hypothesis.

HYPOTHESIS 4:

Psychosocial concerns of breast cancer survivors are significantly related to their ‘Overall Quality of Life’.

RELATIONSHIP BETWEEN PSYCHOSOCIAL CONCERNS AND OVERALL QUALITY OF LIFE OF BREAST CANCER SURVIVORS

The below table 23a. shows that there was a significant negative correlation between quality of life and psychosocial concerns including physical concerns r=-0.481, p<.001, social and financial concerns, r=-0.271, p<.001emotional concerns, r=-0.366, p<.001 and spiritual or religious concerns, r=-0.166, p<.001. whereas information concerns were significantly positively correlated with quality of life, r=0.208, p<.003.

Table 23a: Relationship between psychosocial concerns and overall quality of life of breast cancer survivors

Relationship	Correlation (R-value)	Significance level (P-value)
Quality of life & physical concern	-0.481	<0.0001
Quality of life & information concern	0.208	0.003
Quality of life & social financial concern	-0.271	<0.0001
Quality of life & emotional concern	-0.366	<0.0001
Quality of life & spiritual concern	-0.166	<0.0001

Multiple linear regression (using the stepwise method with p<.05 for entry and p>.10 for removal) was conducted to assess if the two significant correlates with information concerns are also significant predictors (for SPSS output see Appendix 10, table 39).

In the first model, with physical concerns as the sole predictor, R=.483, R-square = .234 and adjusted R square = .230, F (df=1, 203) =61.848, p<0.001, which shows that physical concerns is a significant predictor of quality of life (confirming the significant correlation reported above) accounting for 23% of the variance of quality of life.

In the second model by adding a second predictor of emotional concerns, R=.521, R - square=.271, and adjusted R-square = .264, F (df=2, 202) =37.582, p<0.001, which shows that physical concerns and emotional concerns together are significant predictors of quality of life and account for 26.4 % of the variance of quality of life. It is furthermore the case that in the second model that R-square change=0.038, F-change (df=1, 202) =10.440, p=.001, which shows that when emotional concerns is added to the equation that explains a significant extra amount of the variance of quality of life.

In the third model by adding a third predictor of information concerns, R=.540, R -square=.292, and adjusted R-square = .281, F (df=3,201) =27.625, p<0.0001, which shows that physical concerns, emotional and information concerns together are significant predictors of quality of life and account for 28.1 % of the variance of quality of life It is furthermore the case that in the second model R-square change=0.021, F-change (df=1, 201) =5.892, p=.016) which shows that when information concerns is added to the equation that it explains a significant extra amount of the variance of quality of life.

Model Summary

Model	**Predictor variable**	**Standardized regression coefficient (Beta)**	**t value**	**p (Significance level)**
Model 1	**Physical Concerns**	-0.483	-7.864	<0.001
Model 2	**Physical Concerns**	-0.405	-6.259	<0.001
	Emotional Concerns	-0.209	-3.231	<0.001
Model 3	**Physical Concerns**	-0.337	-.4817	<0.001
	Emotional Concerns	-0.261	-3.868	<0.001
	Information Concerns	0.160	2.427	0.016

4.2 QUALITATIVE DATA ANALYSIS

“We are not ourselves when nature, being oppressed, commands the mind to suffer with the body — William Shakespeare”

4.2.1 INTRODUCTION

This section presents the findings of the qualitative component of the current study to gain deeper insight and rich understanding of the survivors’ needs that might not be identified through a single procedure. Ten semi-structured interviews were conducted to thoroughly examine the psychosocial needs of breast cancer survivors. The 10 participants who agreed to conduct interviews were selected from the 205 participants who completed the questionnaire in phase one of the study based on their responses. Ten consenting participants were purposely selected who had scored as low, intermediate and high; five Emiratis and five expatriates. To maintain confidentiality, all women were assigned unidentifiable numbers (Table 24).

This phase entails contextualizing the quantitative findings to better understand breast cancer survivors’ needs and concerns during the survivorship. At the start of each interview, participants received a summary of the significant quantitative findings from Phase One. They were asked to review the findings and provide their comment on that. No cancer survivor was surprised by the findings, confirming that the results were consistent with what they experienced.

The below table 24. presents ten breast cancer survivors who were interviewed and their demographics (age, nationality) and their clinical characteristics (histology and stage group). Out of a total of ten women, three were between 31-39 age group, three from 41-46 age group and four women had their age between 50 to 62 age group. Within the 31-39 age group, 2 women were expatriates, and one was Emirati. Among the 41-46 age group, one woman survivor was an expatriate and two were Emiratis and in the most aged group which was 50-62 years, there were two participants in each group, meaning two Emiratis and 2 expatriates.

With regards to participants' nationality, ten out of five participants were Emirati nationals and five were expatriates from different countries including Egypt, South Africa, Russia, Philippines and Iraq. Nine participants' religion was Islam and only one participant was Christian.

To describe clinical characteristics (Histology and Stage) of the breast cancer survivors, seven out of ten had infiltrating duct carcinoma which is the most common histology of breast cancer and three had infiltrating lobular carcinoma which occurs only in 5-10% of population yet both ductal and lobular types are aggressive in nature. Four out of five expatriates had infiltrating duct carcinoma and one had infiltrating lobular type whereas three Emirati women had infiltrating duct carcinoma and two had infiltrating lobular type.

Seven out of ten breast cancer survivors presented with stage II cancer which denotes regional spread means cancer spreads into lymph nodes, under the arm on the same side as breast cancer; three of them were expatriates and four women were Emiratis. Two survivors including one Emirati and one expatriate, diagnosed with localised stage I showing cancer spreading beyond its original location and into the surrounding breast tissue with no lymph node involvement or any other body areas. Only one participant who was an expatriate, had stage III cancer at diagnosis. Stage III is a locally advanced stage showing cancer spreading to adjacent lymph nodes, organs or tissues and in some cases, it spreads beyond its organ of origin. In breast cancer patients, stage III denotes cancer extending to the chest wall and or the skin of the breast and cancer cells may be found in nearby lymph nodes but not to the distant organs. There was no participant presented with stage IV cancer which represents distant metastasis for instance lung, bone, liver or brain

Table 24: Breast Cancer Survivors' demographics in Qualitative Phase

Participant	Age	Nationality	Religion	Histology	Stage
CS034 – Participant 1	**46**	**Philippines**	**Muslim**	**Infiltrating duct carcinoma, NOS**	**2B**
CS040 – Participant 2	**31**	**Egypt**	**Muslim**	**Infiltrating duct carcinoma, NOS**	**3A**

CS048 – Participant 3	**36**	**Russia**	**Christian**	**Infiltrating duct carcinoma, NOS**	**2A**
CS070 – Participant 4	**50**	**South Africa**	**Muslim**	**Infiltrating lobular carcinoma, NOS**	**2A**
CS109 – Participant 5	**62**	**Iraq**	**Muslim**	**Infiltrating duct carcinoma, NOS**	**1A**
CS1333 – Participant 6	**41**	**UAE**	**Muslim**	**Infiltrating lobular carcinoma, NOS**	**2B**
CS141 – Participant 7	**39**	**UAE**	**Muslim**	**Infiltrating duct carcinoma, NOS**	**1A**
CS159 – Participant 8	**44**	**UAE**	**Muslim**	**Infiltrating duct carcinoma, NOS**	**2A**
CS009 – Participant 9	**50**	**UAE**	**Muslim**	**Infiltrating duct carcinoma, NOS**	**2A**
CS016 – Participant 10	**54**	**UAE**	**Muslim**	**Infiltrating lobular carcinoma, NOS**	**2B**

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4.2.2 THEMATIC ANALYSIS

There were three broad areas used to categorise and understand the utmost concerns of breast cancer survivors aiming to achieve the research objectives. The categories were **survivors' living experience with breast cancer**, **psychosocial concerns** including *physical, information, social & financial, emotional and spiritual or religious concerns* and the third was **survivors' expectations of healthcare delivery or support needed**. The emerging themes were identified for each category. Category 1 was living experience with breasts: diagnosis, acceptance, fear, anger. Category 2 included **psychosocial** concerns with sub themes as **"Physical:** complications of treatment and impact on daily life; **Information:** access, type, sources; **Social & Financial**: insurance coverage, financial coverage, charity sources, access to support groups; **Emotional:** relationships support, fear, anger, hope, acceptance, isolation; **Spiritual or Religious:** 'faith value, reliance on Allah or God".

4.2.2.1 Theme 1: Living experience with Breast Cancer

4.2.2.1a Sub-theme 1: Diagnosis of Cancer
4.2.2.1b Sub-theme 2: Living with cancer/difficulties
4.2.2.1ac Sub-theme 3: Difficulty in access to health care
4.2.2.1d Sub-theme 4: Health decision-making

4.2.2.2 Theme 2: Breast Cancer Survivors' Concerns

4.2.2.2a Sub-theme 1: Physical concerns
4.2.2.2b Sub-theme 2: Information concerns
4.2.2.2c Sub-theme 3: Social & Financial concerns
4.2.2.2d Sub-theme 4: Emotional concerns
4.2.2.2e Sub-theme 5: Spiritual/Religious concerns

4.2.2.3 Theme 3: Patient experience with healthcare providers

4.2.2.3a Sub-theme 1: Patient Satisfaction
4.2.2.3b Sub-theme 2: Patient Expectations

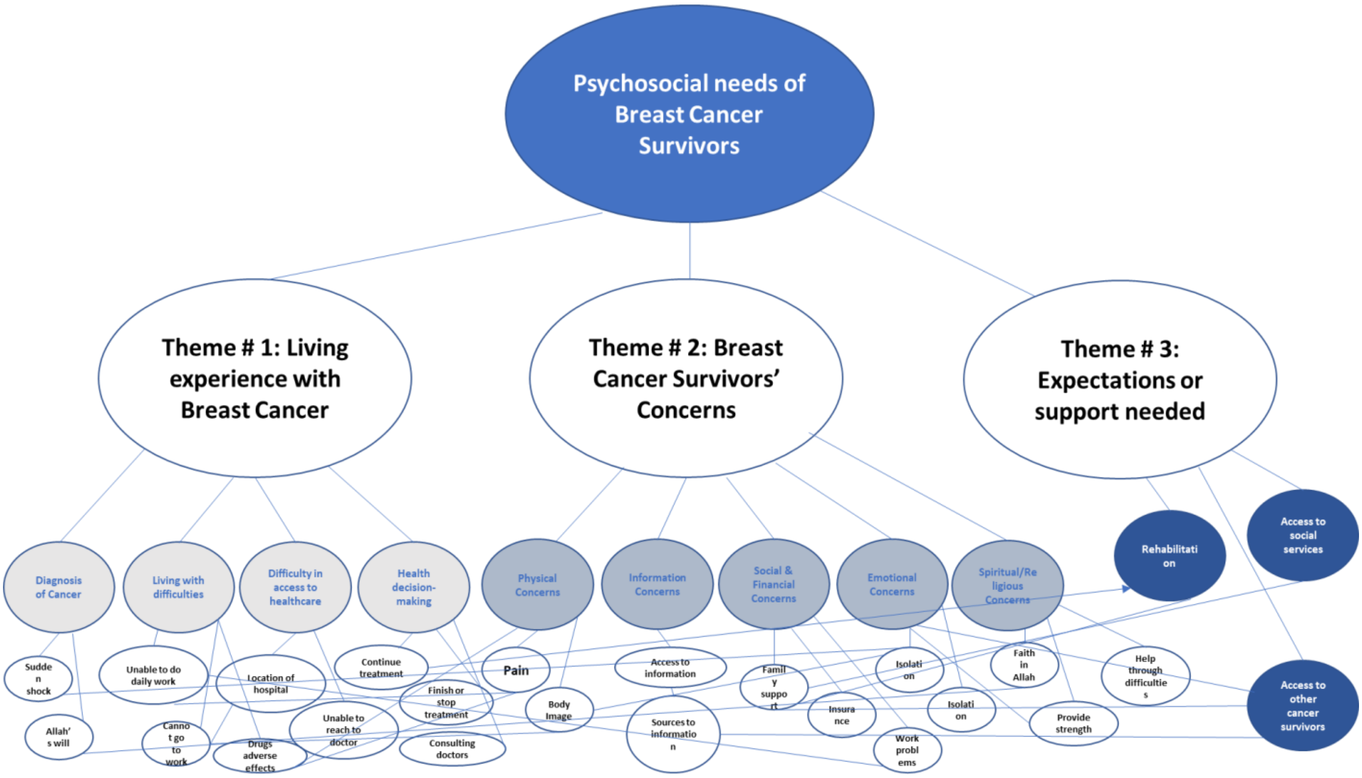

Figure 15: Thematic Map: Psychosocial needs of Breast Cancer Survivors

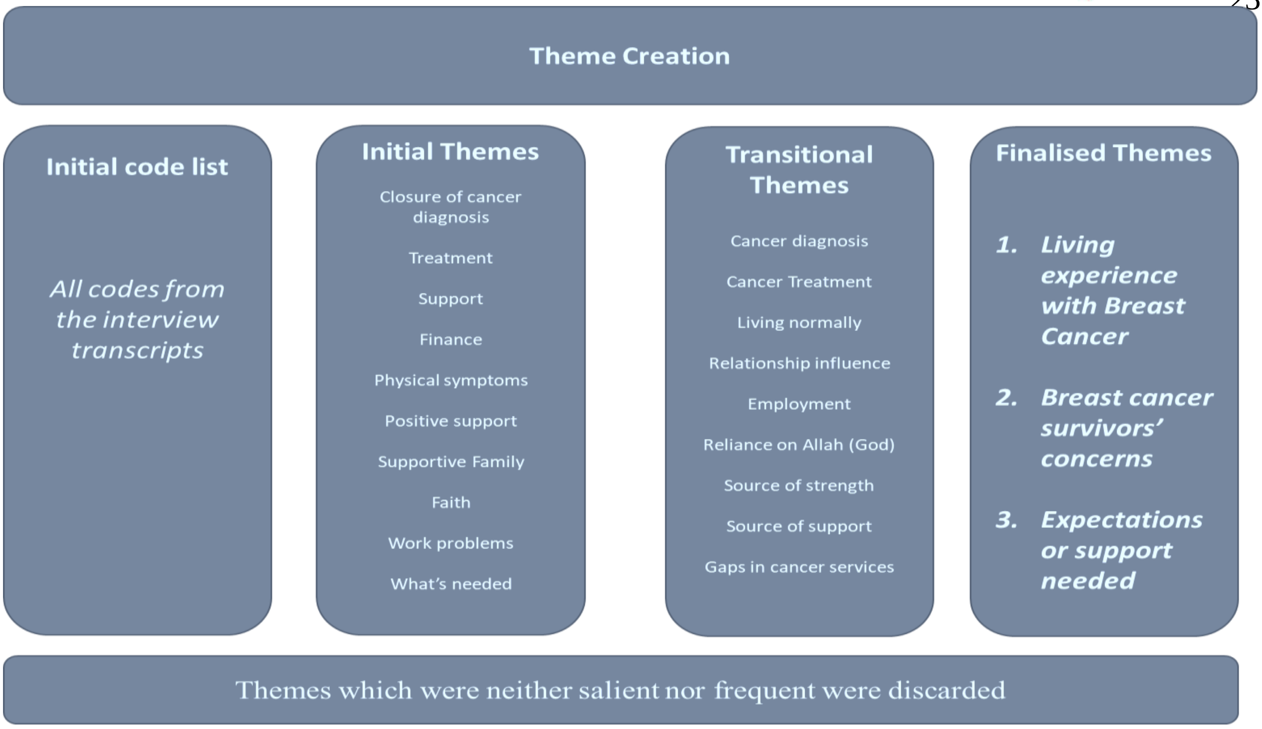

Figure 16: Creation of Themes

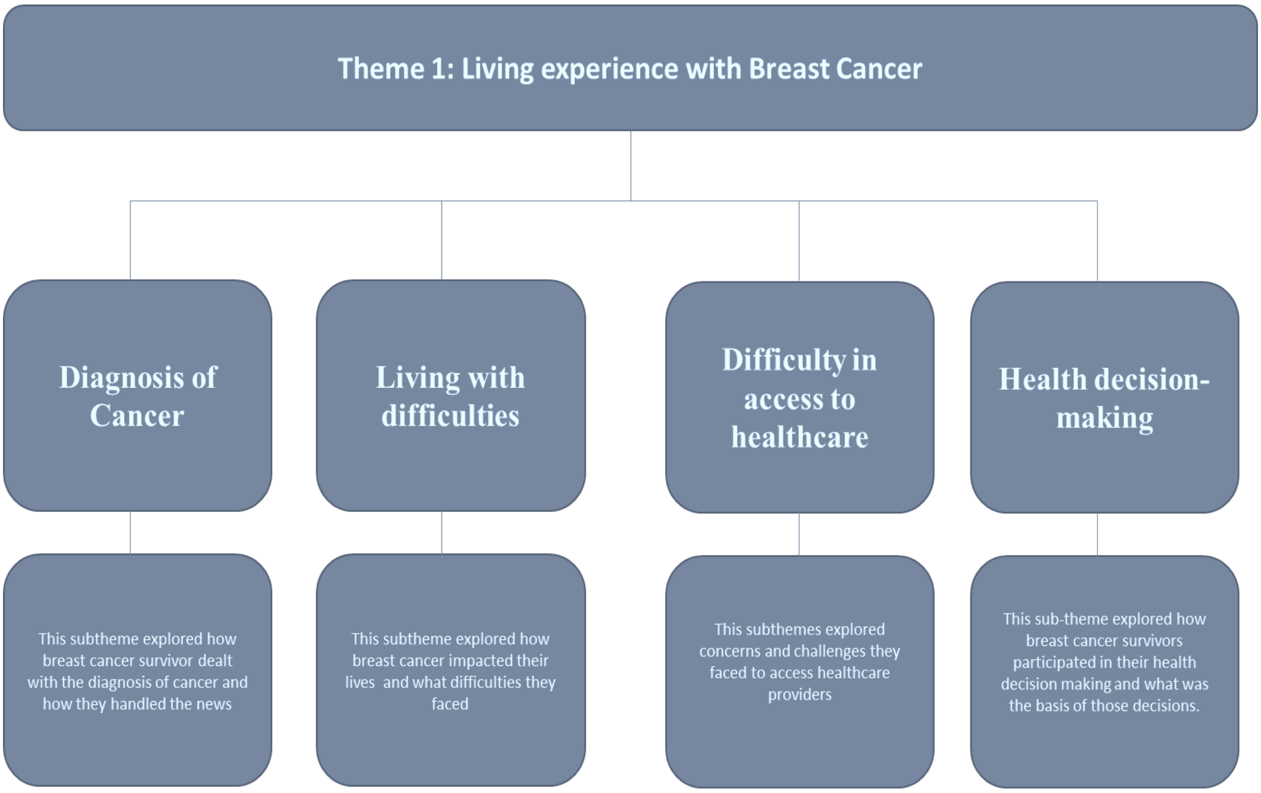

Figure 17: Theme One: Living experience

4.2.2.1 THEME 1: LIVING EXPERIENCE WITH BREAST CANCER

This theme encapsulates breast cancer survivors' living experience with breast cancer whose lives were affected by the cancer. The main theme was categorised into four sub-themes and identified how survivors dealt with the cancer diagnosis and how cancer shaped their living experience with and beyond cancer, difficulties in accessing healthcare and their decision making towards disease identification and disease management.

4.2.2.1a Sub-theme 1: Diagnosis of Cancer

The word cancer can create extreme disruption in the life of almost any individual and can be a threat to one's sense of security that none is ever prepared for such an event. Although the majority of cancers are treatable, for most survivors, the word cancer is a truly unanticipated event that is experienced as a shock, which represents pain, suffering and fear of death that no individual anticipates. Even though one foresees the diagnosis, most individuals' initial response is shock and disbelief (Gorman, 2018).

> ***Participant 1:*** *"It was by sudden"*
>
> ***Participant 2:*** *"Something different I feel it"*
>
> ***Participant 3:*** *"When I was told I had cancer; I was sort of shocked, like I paused. It was not what I was expecting, or I thought I would ever face, but of course I later accepted it as part of the reality. I was not angry or sad but shocked you can say as it hit me from nowhere, something unexpected that you never thought of it"*
>
> ***Participant 6:*** *"I was shocked and devastated to hear that I have cancer"*
>
> ***Participant 7:*** *"It was a complete surprise for me that such a thing happened to me"*
>
> ***Participant 10:*** *"I was shocked, I was shocked really. The doctor told me that I needed to remove my breast; I had no other choice. There was a shock in the beginning when the doctor told me to remove my breast completely"*

Some individuals initially respond with denial, which is a protective response against the threat. It is a common reaction which decreases over time. Although some individuals are able to deal with the situation as they research about the disease and treatment options, an emotional reaction can become evident at any time.

> **Participant 5:** *"It was a sense of denial; I never thought myself being in that situation"*

In Muslims' culture, it is not uncommon that cancer survivors consider the disease as a will from Allah and accepted as their destiny. The spiritual connection with God does help believers in dealing with the diagnosis of cancer with hope and positivity while providing a strong coping mechanism through faith.

> **Participant 4:** *"I was surprised but it was my destiny, it's from Allah and it took it easy"*

> **Participant 8:** *"When I heard the first time, I was shocked, sure it was a shock for me but later I said it's ok Alhamdulillah, I will pray"*

It is not unlikely that some cancer survivors not just react but also feel normal and get on with their life as normal as they were used to in the past. For instance,

> **Participant 9:** *"In Oct 2018, I diagnosed with breast cancer with stage II cancer. When I heard the news, I didn't feel bad, I was positive, and I felt normal"*

4.2.2.1b Sub-theme 2: Living with cancer/difficulties

The sub-theme 2 describes the impact of cancer on survivors' daily life and provides insight into one's perception about continuing life and carrying on a new normal. It also entails the experience of living with cancer and difficulties an individual faces during daily living. Normally after treatment most cancer survivors return to normal life the way they used to have or ready to do a fresh start at something new yet at the same time feeling sad and worried is something one cannot eradicate so quickly, and it can take time to recover. Many are uncertain about how to come to new terms with the new normal. Adjusting to new circumstances and making changes accordingly can be both physically as well as emotionally challenging.

For some cancer survivors, **one of the hardest things is dealing with the difficulties during survivorship**. For some, it is a drastic change hence, the most difficult to deal with however, the majority of them find a way out to deal with cancer issues with different coping strategies in order to adapt to the new normal.

> ***Participant 1:*** *"It was difficult; it was challenging to deal with the problems; there were some difficulties especially throughout the mechanical treatment; there were difficulties, but I managed all hamdullila"*
>
> ***Participant 8:*** *"After the treatment, everything changed for me; everything changed for me hair, body, everything"*
>
> ***Participant 4****: "I had difficulties, but I was able to manage my daily life and tasks as normal"*
>
> ***Participant 3:*** *"I just accepted that it happened, what else I could do; it was sure not easy and sometimes pain and other disturbances were too much for me to handle but I managed somehow"*

Cancer patients may see themselves and life in a different way or find that others think of them differently after cancer. Most survivors find that this transition period after being diagnosed with cancer is about finding out what is meaningful for them now. Some become more considerate about their family and loved ones and seek a new purpose of life. It could be a change of perspective about themselves, about others, about values and priorities or about their own life. Material and little things may be less important for them than concerns about family and loved ones.

> **Participant 7:** *"If you compare me one and half year back and now it is different; when I had the treatment, I understood it's my life now"*

> **Participant 3:** *"I felt my life changed to slow and I became more thoughtful and considerate towards my family than myself"*

> **Participant 6:** *"I had no idea, it is gonna be that tough; my life has changed including me, my appearance, my feelings, my priorities. Everything has changed to the extent that it is all just new. It has changed my life completely. My quality of life was just, I just lived for the weekend so I could just stay in bed. I just did the most essential groceries in my house and put them like noodles, easy things for my daughter to make for herself. Your life just will not be the same again"*

> **Participant 6:** *"It's such a big thing, it's like a paradigm shift, it's never the same. Like before, I would like, oh look at this line, you know that was the main concern, health wise. It was so shallow; you got other things now. I couldn't be bothered anymore"*

Breast cancer treatment can have an impact on one's body, psyche as well as self-confidence. Depending on the type of treatment, one's body can change drastically in a short period of time. It is not unlikely that a survivor may discover that nothing in the closet fits right and finding new clothes that make one feel confident becomes a difficult task.

> **Participant 6:** *"At this point of my life, as you can see, even the small things will affect your life. You know what I mean. It affects how you dress. Like inside my apartment, I would go without my Sheila (scarf) but even in the balcony, I am gonna cover myself because I just don't want everybody to see"*

> **Participant 5:** *"Until now, you know I cannot wear a bra. It's very hard for me to wear the bra because when I wear the bra, my pain increases. For example, until now when my nieces and nephews come and hug me, my breast is like somebody hit me or something like this slightly and I feel pain"*

Expressing sexuality remains important to all of us including people with cancer. Cancer affects how a woman perceives her sexual identity, for instance, an altered body image. Along with that cancer impacts intimate relationships and it is an issue that many people find it difficult to address. Body changes can occur immediately after treatment or over a long period of time. It can affect the way one thinks and feels about her body image and self-confidence to the extent that one could worry that people will treat a person with cancer differently because of the change to the body image (Fitch, 2020; Rosenberg, 2020; Diaz-Montes, 2010). These concerns about the body could be challenging to deal with (Bolton, et. al., 2010) and can occur at any time (Rosenberg, 2020).

> ***Participant 6:*** *"I have become more comfortable not having breasts but it's difficult. Every aspect of your life changes drastically. Because it's like I would have a conversation with my gardener; I can't do this anymore. This is too difficult. Because my view of myself changed and it was going to change immensely after and coming to terms with my new body, I can tell you at this point that I do not have a partner in my life, but this is gonna impact me having one again"*

In many cases, cancer affects a person's work life. Whether a person is able to work during or after treatment depends on several things, for instance, the type and stage of cancer, the type of treatment one has and its side effects, how one feels during treatment and the kind of work a person does. Many people return to "normal life" including work after treatment ends, yet cancer can change this plan for many reasons. Sometimes cancer treatments cause massive fatigue and physical disability or memory problems that make a person unable to work. The decision of how much time off a person needs depends on the support and flexibility of both health providers as well as employers. Most people who want to keep working during treatment are able to do so in some capacity either by adjusting their work hours or working part time whereas some take a break (Lawless, 2009., National Institutes of health. U. S.,1993). Each person's situation is different as not everyone with the same type of cancer can make the same decision about their work. **Continuing work could be very stressful and challenging** for some people as cancer experience is unique for each individual and could be quite challenging. It is best to consider what one feels right for herself and what one feels normal. It is important that health providers must discuss and support employment and work issues with regards to a person's health since being able to take time off work does not appear to be a legitimate option equally available to all cancer survivors.

> **Participant 5:** *"Still I am suffering that I have to go to work, and I still don't have a reason that could stop me to go the work; they just gave me sick leave for just six months and then they let me go and said I am fit but I was not fit; They said, you are fine, and this is normal. What's normal? Normal is when people can do and practice daily life. They can go and come as they wish. This is not normal!*
>
> *I told my doctor this and she said, you are just saying…of course I am saying, I am not doing something from my mind that I am sick or something. Doctors have to believe what patients are saying. I am not creating these things. How could you know that I am having this, or I don't have one? You won't see inside me!"*

Many people after being diagnosed with cancer begin a new chapter in their lives. **For most people, getting back to a new normal does not mean going back to life exactly as it was**; in some areas of life, the new normal is very different (Katz, 2011; National Cancer Institute, 2019). Having said that, there are some for whom things go back to exactly what they used to be.

> **Participant 9:** *"I would say none was challenging for me, my life didn't change much; I have no problems as such in daily tasks of daily living, it's normal".*
>
> **Participant 10:** *"I would say it didn't change for me even one percent, I went to my work the same after the surgery. I am doing my life activity as before, nothing changed for me at all; everything was like the past. I can't believe it has been one year and half years since I did it, it was so easy Alhamdullila"*
>
> **Participant 2:** *"I have been alright during and after the treatments hamdullila"*

4.2.2.1c Sub-theme 3: Difficulty in access to health care

The sub-theme 3 describes the issues and challenges that most cancer patients face, particularly newly diagnosed. The link between poor access to care and poor health outcomes is well acknowledged however, the reasons for inadequate access are not well understood. Accessing appropriate cancer care is the most common barrier to cancer patients. Access, as defined by the Institute of Medicine (1994, pg. 4), is the timely use of personal health services to achieve the best possible health outcomes. This definition of access encapsulates both the use of health services as well as the quality of such services. This sub-theme mainly focuses on difficulties faced by cancer survivors in accessing cancer care as well as concerns about care coordination with healthcare providers. This includes attributes of the healthcare delivery system such as geographic distribution of cancer care facilities as well as attributes of healthcare providers, for instance, lack of knowledge about cancer care or treatment. Identification of such barriers is critical in order to address and implement strategies that could help on both individual as well organisational level.

Some patients travel from a far distance to attend scheduled appointments for the consultation with their doctors or to receive treatment; this adds additional stress and burden as fatigue and pain are the most common concerns among cancer survivors. The remoteness and the lack of availability of specialised services could be the major obstacle in accessing the appropriate cancer care which either result in delayed diagnosis or could add both physical and emotional toll on particularly vulnerable cancer patients.

Participant 1: *"I am very far from the hospital (Al Ain); Sometimes I cannot reach the doctor".*

> **Participant 8:** *"You know, I am driving from Abu Dhabi to Al Ain and it's considerably very far for a patient".*

According to the literature, physicians' treatment recommendations could be influenced by a number of factors including physician age, gender, specialty and his or her belief in efficacy of care (Mosadeghrad, 2014; 2013; Cooper-Patrick, et. al., 1999; Levy, 1985). The content of physician communication also varies according to patient characteristics including age, income, education, race or ethnicity and expected prognosis. Variation in offering different type of treatments can be explained by physician specialty, training and experience while delaying in adoption or lack of compliance with practice guidelines can limit access to recommended cancer care. Accessing appropriate cancer care requires establishment of trust between doctors and patients as well as clear communication. The quality of doctor-patient relationship is critical and can affect clinical outcomes, adjustment to cancer, patients' quality of life and satisfaction with care thus communication gap can result in lack of trust and could be highly worrisome to some patients.

> **Participant 2:** *"They did a wrong operation on me, wallah. They didn't remove the lymph node under my arm. "They took like half from my breast and the doctor said, khalas, you are ok." "My doctor, Dr. XYZ was so much angry because it's wrong operation and they should have removed everything."*
>
> *"They took too much flesh from my left side"*
>
> **Participant 5:** *"All doctors are like take it…take it…how can I take it? Even I asked them, did you have a patient like me?" This happened, and they said let's try. What's let's try?"*

4.2.2.1d Sub-theme 4: Health decision-making

Sub-theme 4 describes the decision-making process by cancer patients about their treatment choices. Decision-making is one of the most complex skills required in oncology associated with decision making by both doctors and patients (Glatzer, 2020). Literature suggests that there are many psychological factors involved when patients consider treatment options, including prior experience, quality of life during or after treatment, life expectancy, opinion of their care provider and preference of the patient's family (Glatzer, 2020; Jin, et. al., 2008; Adachi, et. al., 2007). Each patient brings her own personal values and beliefs to the decision-making process. One big concern for patients diagnosed with cancer is whether there is time to research about choosing an oncologist and treatment facility or getting a second opinion before starting the treatment. Similarly, sometimes patients prefer to participate in deciding whether to undergo different treatment for instance, which chemotherapy protocol is likely to benefit the patient. Some patients go to private facilities to do additional tests or to get a second opinion and pay to get an assurance that the choice of treatment is right.

> **Participant 1:** *"I went to Al-Zahra hospital in Sharjah (Private facility) before coming to Tawam"; "I decided to go to Tawam Hospital to complete my treatment". "But now I stopped chemo". "I finished chemotherapy, I finished surgery, I finished the radiation and now I am on hormonal treatment"*
>
> **Participant 2:** *"I had an operation and radiation"; "I didn't take chemotherapy, only radiation".*
>
> **Participant 4:** *"I had chemotherapy"; "I had surgery"; "I took radiation for a month"*
>
> **Participant 5:** *"I did the radiation; I had the surgery; I was taking this hormone therapy; "we need to do the hormone therapy which I didn't complete"; "I had a radiation; surgery and I started this hormone therapy then I stopped it"*
>
> **Participant 10:** *"If I didn't remove it, it may have gone to another place and I didn't know what would happen, so I am really happy that it was removed. I don't regret anything"*

Most cancers are symptomatic. Patient pathways to presentation of those symptoms to healthcare professionals and its initial management are key determinants of outcomes in cancer (World Health Organisation, 2017b). It is possible to improve the prognosis and reduce the need for extensive and aggressive treatment of cancer patients who seek timely care and detect the symptoms at early stages (World Health Organisation, 2017c). There could be a number of psychological or socio-cultural factors that influence patient decision making about seeking or delaying timely care (Tetteh & Faulkner, 2016; Elobaid, 2014). In addition, sometimes, family situations could have an effect on an individual's health priorities. Understanding these factors are important to address and illustrate the underlying problems in patient delay (Saeed, et. al., 2021).

> ***Participant 2:*** *"Then I said, it happened but it will go; But it took time and there was my sister's wedding and then I said not now till my sister's wedding is over. You know then after that I went to see the doctor here in Sharjah"*

It could also be socio-cultural context or a behavioural delay that some patients just do not take the symptoms seriously until it becomes distinctive or aggressive.

> ***Participant 2:*** *"When I went there to see the doctor without an appointment and thought they would see me, and they will say nothing, and I will return"*
>
> ***Participant 3:*** *When I was taking care of him, I knew I had a lump but when he passed away after that I decided to go and see the doctor; "Before that I was ignoring my condition"*

People facing serious illnesses such as cancer have a great stake in the decision-making process. Patients' trust in their physicians is the major concern when it comes to decision-making. It is considered essential for high quality and effective cancer care, and it is well acknowledged that trusting patients are more satisfied and more involved in the diction-making process (Paduca, et. al., 2021; Ruhnke, et. al., 2020; Mahlich, et. al., 2019; Xu & Wong., 2017; Krist, et. al., 2017). Informed decision making is central to patient-centred care where the physician provides the information to the patient and then the patient makes the decision. Patient preferences and values must be considered and respected by the healthcare providers with regard to the outcomes of options.

> **Participant 2:** *"I went to Tawam to see Dr. XYZ and she did the surgery for me". "She (Doctor) said it's better to remove all and the second one; even if you don't have cancer in that, remove it". "I said remove both (breasts). She said you don't have cancer in the other one and I said, it's better for me to do it both"*
>
> **Participant 10:** *"I didn't take any chemo; I just had my surgery done". "The best thing that I did it Alhamdullila because if I didn't do it, I would be suffering from it." "You know, if I had to choose chemotherapy, I would take the tablet (hormone therapy) not chemotherapy, so it was good for me. I didn't take chemo or radiation, so it was just fine with me. It was just the best that I didn't do these two treatments. I am satisfied that I am on tablets/hormonal treatment, it is easier."*
>
> **Participant 8:** *"I took my treatment, it was concentrated chemo; I changed my treatment and when I changed my treatment, I took radiation and my treatment together. I had surgery, I removed my breast and it's difficult for me, but I accepted so I agree for everything."*
>
> *"I told you about the medicine, the hormonal treatment, I didn't feel anything. It's difficult for me."*

It is not uncommon that many patients feel that they are not active participants in developing their cancer treatment plans (Institute of Medicine, 2011, pg. 7). Few people realise that they can ask questions from the health providers and even fewer know what questions to be asked during patient-doctor consultations. Some consider support groups and seek support through forums where they can find other cancer survivors to share their experience. Most cancer patients need extensive and detailed information to recognise and appreciate the effect treatment has on their lives. Thus, it is important that healthcare providers understand patients' priorities and perceptions of their treatment which may change over time and include them in discussions during decision-making.

> **Participant 6:** *"So, if there is a forum, if there are people who have gone through the same things, they can relate. There should be a safe place to speak about it"*

Technological advancement has provided cancer patients an interactive platform to change experiences of living with breast cancer. There are growing numbers of cancer survivors who want to connect with other people sharing similar experiences and support each other. Forums and community support groups are created to provide a safer place for cancer patients to discuss their concerns so survivors could connect with one another and support each other.

> ***Participant 6:*** *I put myself into the forum mainly because of the effects chemotherapy has had on me". "I associated myself with the forum."*

Being diagnosed with breast cancer can be both confusing and daunting particularly at earlier stages when less is known about the disease. And at that stage peer to peer information sharing becomes very meaningful (Allicock, et. al., 2017). People may feel more comfortable questioning their peers within the informal environment than health professionals within time constrained consultations in a hospital setting. Doctors' time is also limited thus not all concerns could be addressed by the patients and many could be left unanswered. Limited time and resources also tend to shift the care of patients to alternate health professionals, or they could be left unattended.

> ***Participant 6:*** *"When you are first diagnosed, if you speak to a doctor in her office, her time is gonna be limited because there will be more patients waiting outside her room"*
>
> *"There was a lady, and she was on her first session when I was on my 3rd or 4th session. She came from Fujairah to Tawam. She asked me how it feels now where you are and what you need to look for and I told her, listen, look for this and this and this and then after a couple of sessions down the line, we landed up together in the same room and she said the same thing to her. She said she did on Wednesday. She said from Sunday to Thursday she couldn't do anything so what I had told her so basically prepared her for that, so we need that"*

In these forums people share information on issues that most health professionals have no direct experience of such as how it feels when one undergoes a treatment and what it feels like to live with a change in body image after surgery or chemotherapy treatment. This first-hand knowledge of experience of breast cancer is the key to empower cancer survivors, support decision-making and help them to regain some control.

Participant 6: *"When those people who have cancer, if they can come around together and tell, listen, this is what you need to look for and this is how you're gonna feel"*

4.2.2.2 THEME 2: BREAST CANCER SURVIVORS' CONCERNS

Theme 2 encapsulates psychosocial issues as described by the breast cancer survivors. This theme was sub-categorised into five domains including survivors' concerns about physical, information, social & financial, emotional and spiritual or religious domains.

4.2.2.2a Sub-theme 1: Physical concerns

The sub-theme 2 summed up physical concerns associated with the disease and its treatment described by breast cancer survivors. Women with breast cancer face many physical challenges associated with disease and mainly treatment such as changes in weight and in body compositions, menopausal symptoms, persistent fatigue as well as psychological symptoms associated with the alteration in body image resulting from either surgery, adjuvant therapy or side effects of chemotherapy or hormonal therapy. The majority of the women experienced higher physical needs and had more concerns, the most challenging to deal with particularly pain after surgery and fatigue (Bardwell & Ancoli-Israel, 2008; Amiel, et. al., 2016).

> **Participant 1:** *"My major concern was physical appearance like, no hair, skin change".*
>
> **Participant 5:** *"Pain, physical concerns for sure. Pain was the most difficult."*
>
> *"This was the biggest challenge because the pain, pain on the chest cannot let you sleep."*
>
> *"They told me that pain will go away after one year. It has been more than one year, and I am having that pain, seriously unbearable pain."*
>
> **Participant 6:** *"Physical concerns and emotional concerns were the most important issues I had to deal with cancer".*
>
> **Participant 8:** *"Physical concerns were the highest".*
>
> **Participant 10:** *"Maybe the physical concerns were more challenging in terms of like surgery made something happen to me, it was dangerous to my life, I thought like this".*

Participant 2: *"The difficult part was after the operation. I had pain and sometimes I was about to vomit. I suffered from this part so mainly physical".*

Participant 3: *"As I said, I did not have much difficulty but of course after surgery I suffered pain. Pain was the main problem".*

Participant 4: *"I got pain in my bones and body; I had pain in the area where I had surgery, but it wasn't that much". "Pain in terms of I do not take the tablet, the yellow tablet, I do not take one". "The intensity of pain and cramps; having all your periods and childbirth is just nothing like that swear to God.". "Other was fatigue, I couldn't leave my pillow…that was the level of fatigue"*

For some women, their ability to carry out activities of daily living such as driving or daily jobs becomes very challenging because of the effects of the medication they take to manage their disease. They feel weaker to walk or drive after chemotherapy sessions. For some women employment or particular type of job becomes a struggle.

Participant 8: *"After I had a session, I drove back to Abu Dhabi to Al Ain. OK, I felt so much pain and tiredness, but I did manage". "I have too much pain and you know I work in sales, and I should stand for hours but hamdullila. I try to manage not that I can manage but I try to manage every day."*

Cancer affects each one differently and every one-person's experience is unique. Although pain was the most commonly reported concern among breast cancer survivors, yet the level of intensity was described differently by few. Some women suffered with mild pain only and their physical concerns disappeared with time or were not extreme.

Participant 7: *"Mainly fatigue was the biggest challenge. I didn't have any other problems from any treatment. I was very lucky"*

Participant 9: *"I have had mild pain in my knee, not too much".*

Participant 10: "*There was pain but after surgery two to three weeks, everything was fine. It was so easy, no difficulty like I didn't do anything." "Like two months, there*

> *was little difficulty in activities, say for walking, sitting, you know but after that it was ok, nothing changed".*

Some women described unique physical concerns other than pain such as problems with eyesight, or issues with the immune system which affected their daily lives to the extent, for instance.

> **Participant 4:** *"My eyesight dropped, and I couldn't see particularly at night. Mainly the left eye. At night I had all blurry vision"*

> **Participant 5:** *"I am having the flu frequently. Most days I have this flu. There is no day when I don't have congested nose. My immune system became down, and I told them, and they said everything is fine. How? I wasn't like this!"*

Sleep disturbance, poor sleep or insomnia are common concerns of breast cancer patients associated with psychological and medical consequences. In breast cancer patients, the phenomenology of sleep is that the challenges faced by cancer patients may contribute to or result in sleep disturbances or could increase a risk of insomnia. **Pain has been well acknowledged as one of the eye's most frequent negative symptoms experienced by cancer** yet other comorbid conditions could largely result in difficulty in sleeping in breast cancer survivors.

> **Participant 3:** *"I was having a sleep disturbance"*

> **Participant 5:** *"Whole night I couldn't sleep because of my congested nose, how could I do daily work? Also, I am having asthma, so it affects my chest so until now I am suffering from this"*

Participant 6: *"Inability of sleep, I was just awake. I would sleep one hour and then awake"*

Most breast cancer survivors experience body image dissatisfaction. After diagnosis and surgery most of them experience changes in their appearance and become dissatisfied with their bodies for many reasons, for instance altered body image could affect women's sexuality and could be quite traumatic psychologically. Hair fall, skin and weight changes, all these are the most common symptoms experienced by breast cancer survivors. Such symptoms could have a significant emotional impact on the survivors' quality of life. Beauty is often based on the outer appearance and when it is altered, it can have a negative impact on one's life. Losing hair could be losing self-worth. For some women loss of hair and skin changes are bigger concerns as it affects their self-confidence and could be quite devastating to deal with (Iddrisu, et. al., 2020; Rezaei, et. al., 2016; Preston, 2010).

> ***Participant 6:*** *"It affects your sexuality"*
>
> ***Participant 4:*** *"My hair fell"*
>
> ***Participant 8:*** *"Everything changed for me, hair, body, everything".*
>
> ***Participant 1: "****The main problem I faced was the outlook and changes in my face and my skin. My eyebrows started falling during the treatment. There were no eyebrows, no hair"*
>
> *"All the side effects that I faced were in the chemo. The main problems I faced with Chemo treatment were mainly physical and outlook change"*
>
> *"The side effects were on my skin…darkness on my face, on my arms, on my neck"*
>
> ***Participant 6:*** *My hair fell off. I was just showing my nephew the picture of my pillow after my second chemo. And my pillow, it was just full of hair, that was the amount of hair I lost. I just went to the bathroom, I didn't have the shaver, I just put the Veet all over my head"*

Weight changes after breast cancer diagnosis may have a negative impact on quality of life (Chen, et. al., 2011). Weight changes, either weight loss or weight gain are common during cancer treatment (American Cancer Society., 2021a). Weight loss is typically due to poor appetite or nauseas which could be the side effects of chemotherapy. Some weight loss could be quite drastic yet most women with breast cancer gain weight during treatment due to change in hormone levels or menopause which could result from chemotherapy.

> **Participant 1:** *"My appetite was very bad, I couldn't eat, I lost weight, I lost around five kilos"*
>
> **Participant 4:** *"I lost weight".*
>
> **Participant 6:** *"Because of the side effects of chemo I lost 7 kilos".*
>
> **Participant 9:** *I have become fatty. Before I was sixty-five kilos and now, I am seventy-two.*

Many survivors have to deal with the effects of cancer treatment. Some adverse effects last a short time and have little influence on survivors' quality of life, yet others can cause long-term complications and add to increased suffering. Some women described their health as "very bad" whereas others mentioned the problems and suffering of daily living due to adverse effects of cancer treatment. Nausea, vomiting and headache are some symptoms that result in treatment being needed immediately.

> **Participant 5:** *"I had this period for a long time", "I was having my periods more than twenty days, so my health became very bad"*
>
> **Participant 6: "***The side effects of the chemo, to use a bad word…just terrible it is. Side effects are long, it's like, one time I found myself crawling to the bathroom like I have diarrhoea". "That was so like today I am going to the bathroom and after that I couldn't go back to it and it escalated so much the first time, I was just floating. My whole face showed it. I was just in my bed; I couldn't do anything, just couldn't do anything"*
>
> *"I did start my chemo on Wednesday, and it was only on Sunday when I woke up, I started vomiting and diarrhoea and my stomach was so tortured"*
>
> *"And taste in mouth, anything I eat, it tastes off, I couldn't eat anything and whole six months of chemo because of that"*
>
> **Participant 8***: "I also had lots of difficulty with my stomach, my hand, my mouth but after sessions I went to work". "My hand got too much black and my colleague told me*

(participant name) why your hand is like this, you want to wash your hand and I told them No, it's from the treatment"

"In the first session, I was tired for sure. After three days, I was a little bit OK but because I had so much problem with my stomach, I was vomiting, also my mouth, for sure my hair fell"

"Sometimes I went to emergency, three times because I had too much headache and vomiting"

"I had some days, I couldn't stand because I had too much vomiting, I took water, I vomited, I had too much headache and I went to emergency maybe three times"

Participant 9: *"I had lots of side effects mainly vomiting but I managed"*

4.2.2.2b Sub-theme 2: Information concerns

Cancer patients have better health outcomes when they are more informed about their disease and more involved in their treatment choices. Information provided to cancer patients relieve anxiety and help them make informed treatment decisions. The amount and the type of information cancer patients want depends on their unique information needs which vary according to stage, age, culture or beliefs. In addition, information satisfaction is a prediction of quality of life. Breast cancer survivors were asked whether they had any concerns, or they faced any difficulties in obtaining information. The sub-theme 2 presents those concerns described by the breast cancer survivors during their interview process.

There was a mixed response when participants were asked about their information concerns; most women were fully satisfied with the information provided to them and mentioned that there was no difficulty in obtaining information, yet few showed their concerns about information delivery from healthcare providers.

> ***Participant 6:*** *"Yes, I was fully informed". "I was fully informed about the side effects of chemo; I remember my doctor told me all"*
>
> *"I was fully informed about all the symptoms and side effects"*
>
> *"I was also informed of all the services available if needed"*
>
> ***Participant 7:*** *"I was fully informed, even more I needed to know".*
>
> ***Participant 9:*** *"I was given all sorts of information and I had no issues with that".*
>
> ***Participant 10:*** *"The doctor told me everything, every single detail about the treatment, everything to do. All the information I got and the details also"*

One of the participants appreciated today's world where all sorts of information is easily accessible over the internet. From disease to treatment and their side effects could be researched using Google or YouTube. However, some information is specific to an individual for which they need expert's help.

> **Participant 1:** *“There is no difficulty if you want to know anything. Just google and YouTube and you will know everything. The Internet helps me”*
>
> *“What should we eat and what we shouldn’t eat? That is what I needed most”*
>
> **Participant 7:** *We are living in the world of information. We can open Google and check on whatever we want.*

Some women informed their close interaction with the healthcare providers and showed their doctors’ involvement to keep them up-to-date and maintain regular follow-up with them. Most women mentioned they were fully informed by their doctors. They found the information clear and had no difficulty in obtaining the information. They showed their satisfaction by appraising the healthcare providers.

> **Participant 2:** *“Dr. XYZ, she explained everything to me and also Dr. XYZ a ". “I had no problems with obtaining information at all”*
>
> **Participant 3:** *“I was fully informed multiple times about the side effects of medications”. “I was fully informed of the symptoms I had”*
>
> *“The Healthcare department was calling me regularly and asking me how I am doing, how I am progressing”*
>
> **Participant 4:** *“They were clear, and I had no difficulty in obtaining information. I was told everything”*

Not just the type of information, it is also equally important for some women from whom the information is provided. Some only consider the information from the doctors as authentic. It is important that healthcare providers must provide detailed, accurate and satisfactory information to their patients as they rely on them more than anyone.

> **Participant 7:** *“I didn’t know anything and you even offered me all the information which is enough for me but it all must be for my doctor”.*

> *"If I know something, it will change my life but no, it will not change my life. If my doctor doesn't know some information, it will affect me but if I don't know some information, I don't think it will change my life"*

On the other side, not all were happy with the information provided. Some did mention their concerns either about lack of information or information they received was not sufficient to fulfil their knowledge or needs.

> **Participant 8:** *"In the session, they gave me some medication and I slept. I was not informed"*

One participant had a different opinion than the rest where she showed her disappointments towards her doctor that although they provided information, their answers were not sufficient for her. The doctor was not able to answer all her queries and consequently her health deteriorated. She complained further that the doctor only informed what they learned but their knowledge was not broad enough to satisfy her queries. In summary, some cancer patients seek specific information, for instance whether the condition is unique to the patient or others may have the similar consequences of the disease. This information may help an individual to prepare in advance to adjust to the outcomes of cancer whereas a lack of information may negatively impact their quality of life.

> **Participant 5:** *"They think I don't have anything, so their answers were not convenient to me at all".*
>
> *"Lack of information from the doctors, this effect"*
>
> *"Some words were related to me but others, not especially my health was going down and they didn't answer me"*
>
> *"I am asking them to give me information. Did it happen before, is it something naturally happening? Do you have other cases or not? So, in that situation, they just want to do what they learned"*

Cancer diagnosis brings with it many challenges, anxiety and uncertainty which adversely affects a person's emotional and psychological well-being. Unfortunately, it is not uncommon that while cancer patients are generally well treated medically for their disease, their healthcare providers fail to address cancer related psychosocial or emotional aspects in a helpful manner or worse they are not screened routinely for this aspect of cancer.

> **Participant 6:** *"They go very efficient in everything but the psychological and emotional side, nobody said you are gonna be depressed afterwards"*
>
> *"If you are gonna see the mirror for the first time, you are gonna break down in tears. Nobody prepared you for that"*

Some women do individual research and build their own knowledge through various channels, yet they are not fully prepared to face unforeseen circumstances. Some are given information in bits and pieces thus while encountering an adverse effect, they have no idea what to do since they were not fully informed or fully prepared for that.

> **Participant 6:** *"Nothing prepared me for that. Yes, I prepared myself for that but not to that level that will float me"*
>
> *"I had read, I had researched but I did not know that it was such a fine balance that you had to run between diarrhoea and normal bathroom needs that need to be there.... that was not there"*

Some cancer survivors may have very unique queries particularly when they are fully informed about their circumstance for instance about the course of the disease however, there are unanticipated situations where a person is not prepared.

> **Participant 6:** *"Having my double mastectomy, when do I stop it? Yes, I was told, and I remember everything that the doctor said at that time but there was a time when I was like what do I do now?*
>
> *"Once I had to come to the ER on Friday evening. After 9, I had to call my friend, I had a fever. I just showed that, so I went to him. But it wasn't covered where to go or whom to speak to if I have any social needs"*

> **Participant 7:** *"I don't remember but I don't think I was told if I face such and such issues, I can go to this person or that person, but I think this is something you need".*

It is also important that healthcare providers provide clear and detailed information regarding all aspects of disease in order to prepare patients for expected as well as for unexpected events during the course of the disease. One woman appreciated the information that was shared by her doctor about the disease and possible side effects of treatment, yet she was not prepared to what extent she had to deal with side effects. She also emphasized that she wanted to know more about what could go wrong instead of what will go right. She stressed that she needed clarity on such issues from her doctor as a survivor could have more queries which cannot be answered in a limited consultation with doctors considering their time constraints.

> **Participant 6:** *"My doctor, my oncologist, she explained to me what's going to happen but as I said I didn't own it. I didn't realise that's gonna be you that's gonna happen to you like other people". "Side effects, yes gonna be there but to what level……I cannot say questions answered but addressed"*
>
> *"Tell me these things, I don't want to hear that you are gonna be OK cause you are not going to be OK. So, be clear like my doctor said chemo will not but the side effects throw you"*
>
> *"You know all my questions were answered, I have to say that but like I have had time to think about it and I have more questions so who's gonna follow that, it cannot be the doctor because she has other patients to see"*

Being an expatriate, itself could be a challenge for a cancer patient as they are not quite familiar with the resources available in that country. Healthcare providers must ensure that all cancer patients are fully informed about the available resources including groups and charities that could help expatriates. One woman talked about this important aspect and shared her concern of being an expatriate.

> **Participant 6:** *"Because I am not from here, I do not know, I can go there or go there".*

4.2.2.2c Sub-theme 3: Social & Financial concerns

Cancer not only takes a physical and emotional toll, but it also has a huge social impact on many aspects of life such as personal relationships, social interactions, finances or employment etc (Banegas, et. al., 2019). The physical and psychological problems can be exacerbated by or result in serious social problems. The cost of health care, lack of insurance, low income or employment issues all could contribute to major financial stress. However, social and financial issues are beyond the capabilities of healthcare providers yet addressing these issues are an integral part of a good quality healthcare system (Golics, et. al., 2013; Goldman. 2010). The sub-theme 3 describes the impact of social and financial difficulties or concerns on women with breast cancer.

Financial worries were mentioned mostly by expatriates since all Emirati women were covered by national insurance called “Thiqa”. The UAE government provides Emiratis full health coverage; thus, no financial worries or concerns were found among Emirati cancer survivors.

> ***Participant 1:* “**I had no financial problems”. “It is covered”

> ***Participant 2:*** *“No, I had no financial or social issues; is covered by insurance alhamdullilah”.*

> ***Participant 3:*** *“No financial problem; my healthcare was covered by insurance”*

> ***Participant 4:*** *“No, I had no issues with finance, it is covered, and they did everything”*

> ***Participant 5:*** *“No, I didn’t have any financial problem because this is all from the government”*

There were two women who did not mention any financial concerns with regards to insurance or health coverage as their insurance provided them full health coverage.

> ***Participant 9:*** *“I had no problems financially because my treatment is covered by Daman (insurance)”.*

> ***Participant 10:*** *“I had my insurance, and it was totally fine. I had no problems anything alhamdulilla”*

According to UAE law, providing health coverage is the employer's responsibility which could either be basic coverage or enhanced coverage to cover chronic health conditions with or without co-existing issues. It also reflects the employment status of an individual; most highly paid jobs provide enhanced health coverage. Average employment does not cover entire health issues thus an expatriate could face serious health problems especially when one has extensive disease or other comorbidities (Dubai Health Authority, 2020; Jones, 2000).

> **Participant 6:** *"Dr. XYZ will tell you the issues I had with NEXtCare which is my provider from the Ministry of Education".*
>
> *"They said that I have to pay ten thousand and I said I can't do that…I can't afford it"*

Some patient's health coverage was not covered by the insurance thus they were supported by a mandate issued by the UAE government to support cancer patients (mainly expatriates) by providing financial support to those who could not afford and have limited financial resources.

Participant 6 also mentioned her difficulties in delaying her treatment session because of delays in the approval process from the insurance which sometimes resulted in her missing sessions until approval was granted. She mentioned her difficulties and frustration in chasing up and following healthcare providers for approvals so she can get the treatment.

> **Participant 6:** *"Sometimes I would come, and the approval will not go through entirely so a couple of sessions I had to miss. When I had started my chemotherapy, the first session had to be postponed because they didn't approve it. Lot of the time, initially the first few weeks of my chemo, I didn't do it. After that it had to be postponed to next Wednesday because it wasn't approved. I have had a lot of issues in the beginning".*
>
> *"Every time I come for chemo; I have learned that the day before I had to call them to ask them if it was approved. The ladies here, they are putting the request and then tell me that I put it in ten days ago and say they are still working on it. It is ridiculous! They said go to the social worker and speak to the social worker and they asked if I had insurance and I said yes, I have insurance and they said then you cannot have it, go to the principal"*

> **Participant 8:** *"My insurance is very bad, now I took treatment under mandate because my insurance doesn't cover anything"*
>
> *"For my surgery I had money problems and I couldn't manage the money for surgery"*

Another participant mentioned that having a mandate helps cancer patients and provide financial support, yet it only covers the existing condition. She had another cancer and the mandate only covered one condition thus it was somehow helped but not fully and she had to bear expenses to cover other health problems besides breast cancer which added to her financial burden. She also mentioned the ease of being treated by one physician at a single facility"

Participant 7: *"I have a SEHA mandate. It is really hard for me for example in my case"*

> **"***Because I do not have a mandate approved from Abu Dhabi for gynaecological cancer. They said, "If you have breast cancer, we can help you with that, but we cannot cover this gynaecological cancer care"*
>
> *"It is most comfortable; if I get the gynaecologist here, I cannot pay two thousand dirhams for a gynaecologist. I did this once here, but this is, in my job, it is quite expensive. So, this is the challenge I faced here, because I would like to be here, but I cannot afford this amount"*

Having financial support is a big relief for expatriates, particularly those who have average employment status. Even some of the support made a difference in their lives. Women with breast cancer expressed their gratitude towards the UAE government for such support and appreciated the consideration as it saved their lives. Some healthcare facilities also helped getting cancer patients their health coverage by making the patients eligible to receive the required care for instance, admitting them as in-patients as out-patients are not eligible for some of the essential treatment and coverage is only reserved for outpatients.

> **Participant 7:** *"My gynaecology is not covered here*
>
> *"It's not going to affect me as such. I actually really appreciate all that has happened to me, the chemo, the doctors, all covered, it's really big help and it saved my life"*

> ***Participant 6:*** *"They (insurance) did not cover because that insurance wanted to block patients so they kind of wangle it so it would be inpatient so they (hospital) can give it to me in the hospital and I didn't have to pay for it. So, the hospital was very accommodating"*
>
> ***"****But to be honest, I would be at home, and it would have been coming out of my pocket, I am extremely grateful that I am here in the UAE"*

Fortunately, most women manage their psychosocial distress quite well provided they have an available support system, including spouse, family or friends. In addition, professional support from healthcare providers with intensive professional guidance and referral to appropriate resources or support groups are critical to avoid psychosocial distress that unfortunately comes along with breast cancer. Most women anticipate positive relationships with their loved ones to gain strength and to maintain their psychological well-being.

Family support plays a critical part to deal with cancer. Most people manage the circumstances and find a way to deal with cancer because of the strength they receive from their families. Talking to family members openly reduces cancer distress, fear and anxiety caused by cancer (Vrontaras, 2018; National Cancer Institute, 2021)

> ***Participant 1:*** *"I talked to my husband; That was from my husband, I was strong"*
>
> *"I have found so much support from my family, from my relatives that's why they gave us strength hamdullila"*
>
> *"I found a way to deal with it through my faith and my family support"*
>
> *"I managed all with my family and my doctor"*
>
> ***Participant 2:*** ***"****My two sons and daughter, they are with me. They told me, do like this, don't eat like this, put me in a good way you know for my food, my exercise. They were with me, and I managed"*

“Mainly from my children, my family and my sisters. I had lots of support from my family. I managed well with their support”

Participant 3: ***“****My sister-in-law had cancer, so I was comfortable talking to her and get the support I needed”*

“*I spoke to my family, and they were all with me to support me”*

“My husband was very supportive though, and I had no issue talking to him about it”

Participant 3 described she was affected positively by the sister-in-law and was comfortable talking about it which gave her support.

Participant 4: *“Everything and everyone was good and supportive. I had no emotional or social concerns hamdullila”*

Participant 5: *“I had all the support from my sisters”*

Apart from family, having a good social circle and having good friends do not just ease emotional distress but some really understand the pain and difficulties in performing daily tasks and provide as much support as possible.

Participant 6: ***“****I had lots of friends assisting me”*

“*Everybody was most helpful”*

“*I am not lying, I swear to God, every day I had lunch, I had dinner. It would be left at my door. Every day she sent somebody from the cleaning company, every day my apartment got cleaned because I cannot, I must not do anything. Alhamdulilla, she took me like her sister, and she did it for the whole of my period when I was recovering till I did it and I said Amina, I can do it and only then did she stop”*

Participant 9: *“I am happy with my family, and I managed all”.*

“My family has been very supportive, and they supported me all”

Participant 10: *“You know my family; they were there for me”.*

> *"My daughter and my son, really. Maybe they encouraged me so much to do. They were more scared about it; I was like I will do it anyways, but they were scared about it. My husband passed away seven years ago, but I got all the support from my family"*

Employment concerns are equally challenging as cancer impacts one's physical ability thus maintaining a job could be quite challenging. Support from employers is crucial. Employment concerns were only mentioned by two women but positively. Their supervisors or managers were empathetic and went a long way to support them, so their job was not negatively affected by their cancer (Sun, et. al., 2016., de Rijk, et. al., 2020).

> **Participant 4:** *"My work was OK and flexible, and they knew my condition and allowed me to leave at twelve because I couldn't stay more as I got tired. They told me; you can leave early"*

> **Participant 6:** *"My principle was assisting me. I am a teacher, so she took away some of my classes, so it won't drain me out. She put another teacher with me in the class so if I can't do anymore, she takes over. I am blessed with a very good principal alhamdulilla and she has been immensely supportive".*

> **Participant 7:** *"My director in the school, he knows what happened to me. Actually, he gave me one month off when I started my chemo so I can continue my job"*

> **Participant 8: "***Because my manager told me, you can sit no problem; your salary is OK but for me I said, No, I should go to work".*

> **Participant 5:** *"I didn't have any support except the people at my work who helped me".*

Participant 5 appreciated her only support from her workplace yet mentioned her disappointment to receive appropriate support from healthcare providers.

> *"The doctors didn't support me in this"*

Yet, every person's experience with healthcare providers is different and some receive quite a good support from healthcare providers.

> **Participant 7:** *"I do remember, the first chemo, there was a Syrian nurse, she did my first chemo. I cried; I don't know how to explain. I felt there was something in my body, I don't know, I felt like I wouldn't wake up. She was standing right next to me and said why are you crying, are you missing someone. Everything will be OK"*
>
> *"All the doctors, nurses, they have become more concerned than my friends"*

Most of the women mentioned immense support from their family and friends yet every person's life experience is different. There were some participants who did not receive any support from their family or friends. They expressed their disappointments and difficulties due to lack of support from their very close people. Unfortunately, they mentioned adverse reactions from them.

> **Participant 7:** *"You know through this sickness, almost all my people changed, people whom I was with and thought they are close, and I thought they are my relatives"*
>
> **Participant 8:** *"I have so my sister brought my mother. This gave me strength. My husband …NO, he is X (showed the cross sign). he didn't stand up with me. From my husband, No…. there was no support. My family gave me this, not my husband. I have two kids and my husband, but he didn't support me emotionally, he didn't support me financially. It is difficult for me, my husband has money, he could have given me money for my surgery, but he didn't give me. He let me go to Hilal Ahmar (Charity) like this to manage my surgery. It was difficult for me"*

4.2.2.2d Sub-theme 4: Emotional concerns

Breast cancer experience requires a person to consider an array of psychosocial and emotional demands, mainly emotional. The experience of breast cancer diagnosis and treatment may result in considerable emotional distress that brings fear and challenges about a woman's identity, self-esteem, body image as well as relationships. Although most women adjust well to these commonly felt difficulties particularly in the absence of advanced symptoms and if they do not experience recurrence, the negative impact of breast cancer can be significant. Family, relationships and other support groups are protective factors to avoid emotional distress. Understanding and addressing emotional concerns is crucial among these vulnerable populations as the risk of distress can seriously impact their quality of life (Karunanithi, et. al., 2018). The sub-theme 4 describes emotional concerns among women with breast cancer and their intrusive thoughts about their breast cancer experience and how it had an impact on their well-being.

Although breast cancer diagnosis affects a person from many different psychosocial aspects, emotional concerns are the highest and the most challenging among this population (Conley, et. al., 2016).

> ***Participant 7:*** *"Dealing with emotions, maybe, was the biggest challenge for me because you need lots of strength and it is very important for you to have supportive people"*
>
> ***Participant 6:*** *"Emotional concerns were the most important issues I had to deal with".*
>
> ***Participant 8:*** *I would say physical and emotional.*

Being hit with news of having breast cancer can be completely overwhelming. A diagnosis of cancer itself can be traumatic and can trigger a variety of emotions. It can affect the emotional health of patients and their families. At first, it may be hard to accept the news and to believe it that some may not feel real or feel blank or stunned while others feel frightened, angry, sad, worried or express mixed emotions. Dealing with emotions may not be easy at first. It is difficult to identify and accept. For some it is hard to accept the reality and some just accept it right from the time they got the news.

> **Participant 1:** **"***I was not happy because there were some worries and things to be worried about but you"*
>
> **Participant 2:** *"I was thinking all the time if they would tell me something bad, what I will do"*
>
> **Participant 3:** *"I was a little depressed of course it's not good news but later I accepted the reality"*
>
> **Participant 4:** *"I was worried and of course unhappy"*
>
> **Participant 6:** **"***It also had a psychological effect; I became very depressed". It was like I was devastated"*
>
> *"I just sit on my muslaah (prayer mat) and cry… cry in the middle of the night"*
>
> **Participant 7:** *First, I remember, I was sitting down and crying". "Of course, it was angry, like sadness, fear, it was like no emotions at all. So, all, emotions or mixed emotions"*
>
> *"Before I prayed, and I didn't cry but this time I pray, and I cry so that I can say it's different"*
>
> **Participant 8:** *"It's difficult to accept"*

Some women feel alone or isolated after cancer diagnosis and treatment. Sometimes people do not know how to deal with cancer and the emotions it brings up. Feeling of being isolated could be for many reasons such as one tries to avoid people to pretend everything is fine and to carry on normal life while one could feel pressure to be positive, making it hard for one to discuss how one feels after cancer. One may think she is experiencing something that others haven't been through. Yet, loneliness can be worse if one finds it difficult to talk about her feelings as this can help patients find ways to support them.

Participant 3: **"***I do not have many friends. I wasn't going out much and I was a bit down, so I was always with my family"*

***Participant 6:* "*I didn't feel like I wanted to go to my friends and colleagues to tell them like I feel this, like they have enough of them. "I feel like I cannot go to them all the time, I feel like I cannot vent out my story"*

Some may have family history or members who had cancer and they are prepared in advance. This could be a learning experience. Although cancer can impact one's life negatively, yet most women deal with the situation and build strength to think and live positively in order to fight the cancer battle.

> ***Participant 4:* "*I didn't experience any psychological or emotional issues with family or with my friend or colleagues. I had no emotional or social concerns hamdullila. In our family, there are lots of people who have cancer. My sister also has breast cancer, so it wasn't that much"*
>
> ***Participant 2:*** *"How you think, it's very important. Think in a good way"*
>
> ***Participant 6:* "*I tried to get myself as positive as I could".*
>
> ***Participant 8:*** *"My colleague told me why you told her about it, and I said no problem, it's time and InshAllah it will pass. I didn't think too much about depression and I told myself, ``now I am taking treatment, let's live now"*

Most women share the news of their diagnosis with their closest family members, others may hide the news from their family members for various reasons.

> ***Participant 10:*** *"I didn't tell anyone about it because you know, they would be worried about me. I didn't want that, so I kept it to myself. And you know when people hear about it, they will be shocked; oh, how would you do it, it is dangerous. I didn't want that negativity"*

Breasts are important for female beauty, identity and sexuality. It creates women's' body image and can affect relationships between couples. It is not always about appearance but sometimes loss of sensation or sexuality. Dealing with body image concerns after breast cancer diagnosis and treatment is a process rather than an event. For few women, physical changes after treatment make some of them less comfortable with their bodies. While discussing her concerns about breast cancer, one of the women said that the look after surgery is affecting her psychologically and she is quite unhappy about it (Jayarajah, U., & Samarasekera., 2017; Sarwer & Spitzer., 2012).

> ***Participant 5:*** *"The look of the surgery is very bad. It is affecting me psychologically"*

Other women mentioned that looking at herself in the mirror was an emotional experience.

> ***Participant 10:*** *"But there was difficulty like when I saw myself in the mirror, it was a bit psychological or say emotional"*

> ***Participant 6:*** **"**The *psychological and emotional impact it had on me; I didn't know how this would affect my life like…"*

> *"I don't wanna share as I said I have a daughter, I didn't want her to let her see because first I had to own it for myself, I had to look at it and I didn't after the operation. I would just not look into the mirror. And I had a mirror, the one full body mirror which I put in my room and now I have just a small round one and I needed to speak to someone"*

She talked about her feelings towards having no breast after surgery and mentioned that the decision to remove both breasts was itself an emotional experience and she wanted to talk to somebody about it.

> *"The decision to remove both of my breasts, it was such an immense step; I needed someone to speak to"*

On the Contrary, for some women, physical appearance was the least priority since they have other important priority such as family and children, etc.

> ***Participant 2:*** *"I had no issues with my physical appearance……I don't care…. this is the last thing I care about.*

Fear is the predominant emotion in cancer patients (Singer, et. al., 2015) and it could be both physiological and subjective experience resulting from the presence of a threat (Mazzocco, et. al., 2019). Some women described fear as an affectively charged emotional response towards cancer including fear of recurrence, fear of the unknown or fear of losing a job because of cancer consequences. Fear of cancer relapse is associated with a poor quality of life and contributes to more distress. Fear of cancer returning or fear of getting a new cancer was commonly described as emotional concern in breast cancer survivors.

Participant 9: *"I was scared"*

Participant 6: *"The fear of recurrence that it will come back"*

Participant 3: *"I had a fear of recurrence; I was always having this fear that I might get another cancer"*

Participant 7: *"What I have to do. And of course, when you don't know what chemo is, how does it affect you? This scares you because you don't know anything"*

Participant 6: "*That is always at the back of my mind, tomorrow I can lose my job and then what do I do?"*

4.2.2.2e Sub-theme 5: Spiritual/Religious concerns

Spirituality has been recognised as an essential part of health and a person's well-being (Puchalski., 2001) whereas religion is an aspect of a person's faith that is used to cope with major stressor such as breast cancer (Hebert, et. al., 2009). The sub-theme 5 describes how breast cancer women used their religion as the major resource to overcome fears, finding hope and meaning in their lives. A person's strong faith that God knows and cares about them helped breast cancer survivors to accept their circumstances and provided them invisible support and strength to fight with cancer.

> ***Participant 1:*** *"Muslim always has faith, so I said alhamdulilla". "It worked for me so I should say alhamdulilla as I have faith"*
>
> *"When we have faith, it helps us pass through all the difficulties hamdullila" "Islam is a gift; it is really a gift. It helps us to pass everything. I found a way to deal with it through my faith"*
>
> *"Most importantly with my faith in Allah, there were difficulties, but I managed all hamdullila"*
>
> ***Participant 2: "****When he told me, I felt that God gave me something like power".*
>
> *"If this is what, God wants it". "Allah loves me"*
>
> ***Participant 3:*** *"I managed it all with my faith in Allah". "Allah made it easy for me"*
>
> *"I found more peace and courage with my strong faith in Allah and in my religion"*

Most women mentioned their relationship with Allah (God) has flourished and they found themselves even closer to God than ever before. After being diagnosed with cancer, their faith in God became even more stronger.

> ***Participant 4: "****When I was diagnosed with cancer, since then I got much closer to Allah"*

> *"During my disease and while I was receiving my treatment, I found myself closer to Allah".*
>
> **Participant 5:** *"This disease made my faith into God stronger".*
>
> *"Because the way God stands with me, nobody can be with me. In this situation, you will feel how God is closest to you"*
>
> **Participant 6:** *"I have gone closer to my God"*
>
> **Participant 7:** *"I think I got more closer to the God"*
>
> *"You know I think God is with me cause the treatment did not affect me that I had to stop the work."*
>
> **Participant 8:** *"I told my god I agree with everything. Alhamdullila, I got more closer to Allah. From the beginning, I accepted, I prayed, and I told my Allah, I agree with all I have"*
>
> **Participant 10: "***It made me closer to God"*

While sharing the importance of having or following religion, participant 7 appreciated the fact of being Muslim as it provided strength to her. She emphasized that without religion, one has no direction. She found herself being a more committed Muslim after being diagnosed with cancer. Another woman shared that positive aspect of the religion as it removed negativity and fears.

> **Participant 6:** *We need religion like something to hold onto. I have always been a Muslim but now I am gonna be a strong Muslim. I made a lot of Tahajjud (night prayer) and salah during the Ramadan. I have done more sunna prayers. Because if you don't have religion, you are lost.*
>
> **Participant 7:** *"You know when you pray, it releases your fears". "Through prayers, the words you read in a particular way, it already gives your brain a different world and of course the feelings, when you are in this situation, and you really are going to think about this.*

Participant 7 also expressed her thoughts about God and her relationship as whichever emotional state you are in, you find yourself as close to God. She also showed gratitude that she was blessed that she suffered no side effects from cancer treatment.

> *"When you are happy, you are close to God, if you are sad, you are close to God"*
>
> *"Really this is a miracle that I really didn't get any bad effects from the treatment, and I think it is from God"*

Most women showed their reliance on God as well as the future in God's hand as they have faith that God loves them and there is always a reason in God's plan. They acknowledged that the support from God gave them the strength to deal with the life-threatening disease.

> **Participant 8:** *"I will put tomorrow up to God. Because I accepted all from the beginning"*
>
> *"I got the main support from my God. Hamdullila, it is from my God"*
>
> **Participant 9:** *"My God and my family really supported me. My religious belief really helped me through the disease and to cope up"*
>
> **Participant 10:** *"I believe if anything happens to anyone, it is for a reason so Allah… He knows what is better for you, so it was totally fine"*

4.2.2.3 THEME 3: PATIENT EXPERIENCE WITH HEALTHCARE PROVIDERS

A woman with breast cancer tries to balance her role as a patient, daughter, sister, mother, friend or as a colleague. Each of these role changes after cancer which alters her needs, expectations as well as her relationships in various different positions. Theme 3 describes breast cancer survivor's expectations and kinds of support they need to balance her position and role after breast cancer diagnosis.

To cope with breast cancer requires different kinds of support at different times. Getting support and being satisfied with the care they receive is important for breast cancer survivors' wellbeing and adjustment to the new normal. Almost all women showed a good level of satisfaction with the care they received from their health providers. They mentioned that they were treated in a polite way and found the hospital staff quite helpful yet there were some expectations from them towards healthcare providers to improve their services in certain areas.

4.2.2.3a Sub-theme 1: Patient Satisfaction

Patient satisfaction is an important indicator of quality of life (Jackson, et. al., 2001). The delivery of cancer services needs to aim to improve survivors' well-being and their quality of life (Elder, et. al., 2005). Unidentified and met psychosocial needs of cancer survivors may lead to predicted subsequent poor patient satisfaction (Lam, et. al., 2018). High patient satisfaction is associated with better practice guideline adherence and lower inpatient mortality rates (Glickman, et. al., 2010). It is imperative to acknowledge and reinforce the importance of patient satisfaction and patient-centred care models in cancer care delivery.

Faith, religious concerns and beliefs of cancer patients should be considered in providing more holistic cancer care, particularly in ethnically diverse cancer patients which may differ by cultural background since religiosity significantly relates to general satisfaction with life and feelings of hopelessness (Ringdal, 1966). Qualitative results in this study revealed that religious beliefs and faith that emerged from the cultural roots represent the practical relevance of an individual life. Results showed that women who expressed their belief found to be satisfied and seemed more content and positive.

> ***Participant 1:*** *"Muslim always has faith, so I said alhamdullila"*

“It worked for me so I should say alhamdullila as I have faith”

Moreover, the psychological mechanisms arising from the spiritual beliefs may be assumed to be closely linked with many perceived positive life outcomes to regain and maintain balance, health, well-being and quality of life (Sharma, et. al., 2020). High levels of spiritual needs are known to be associated with lower levels of satisfaction and diminished perception of quality of care (Astrow, et. al., 2017).

Participant 8: *“After I came here, hamdullila from my God, I feel I am comfortable”.*

Breast cancer carries many psychosocial consequences. It is important to analyse the relationship between patients’ satisfaction, meaning in life, optimism, body image and depression. Meaning in life and optimism are positively correlated with life satisfaction where higher depression and body image disturbance appeared to be associated with lower life satisfaction (Fonseca, et. al., 2014). The study result showed that most patients treated were satisfied with the care and hence had minimum concerns with healthcare delivery.

Participant 1: *“I was satisfied, and I am still satisfied especially with my doctor”.*

Participant 2: *“Yes, I am satisfied with the care I received”. “They (health providers) treated me a good way. All the people were good even when I had radiation, they were helpful people hamdullilah”*

Participant 3: *“I don’t think there is anything missing from the healthcare department. I received all the updates I needed from my doctors and nurses and the doctor was calling me to check on me how I am doing so I got sufficient support from the healthcare department”*

“I was fully satisfied with the care I received. Everything was good and the doctor kept on checking about everything”

Participant 4: *“I was satisfied with the care I received. I didn’t have any issues really”*

Participant 5: *“You have very good treatment so you cannot say that you didn’t have good care”.*

Participant 6: *"I was satisfied with the care"*

Participant 7: *"I am so happy about the nurses and researchers. I can say that they are with us in this. It's their job and people can do their job in different ways, see here it's really helpful"*

Participant 9: **"***I was fully satisfied with the care I received. For me it's all good, the service Tawam Hospital provided. Today I am a survivor because of all the doctors and staff at Tawam Hospital Oncology department"*

Participant 9: **"***But it is all good and I think they are doing all fine"*

Participant 10: *"The care I received was perfect. I was satisfied with everything. I got the care that I need and even more really"*

4.2.2.3b Sub-theme 2: Patient Expectations

The gap between patients' and physicians' expectations has been a difficult problem in cancer care (Takeuchi, et. al., 2016). Adequate cancer care and treatment outcomes are crucial for every cancer patient yet could be challenging for health providers to meet their expectations. Once the diagnosis of cancer has been established, treatment choices and decisions take the central place in cancer patients' lives (Warning, 2000). All cancer patients' clearly express their expectations regarding these choices which may differ by age, gender and education level (Hoofman, et. al., 2004). Knowing that patient satisfaction is subjective and may not be determined from the satisfaction of the healthcare providers (Leser, et. al., 2021), careful consideration needs to be given to understand and meet cancer patients' expectations and to relate their experience to enhance their quality of life.

The qualitative result showed that there were some unique concerns or expectations shared to improve the current services such as adding *Nutritionist in treatment planning, improved pharmacy services, enhanced or expanded mandate to cover comorbidities, improvement in information delivery, emotional and physical support provision by doctors.*

Some patients expressed their concerns that services needed to be improved and be more efficient; for example, one participant wanted to have sessions with a nutritionist while another was concerned about the slow delivery of pharmaceutical services.

> **Participant 1:** *"I really needed a Nutritionist. You just need someone to advise you on how one can deal with appetite. What should we eat and what we shouldn't eat? That is what I needed most"*
>
> **Participant 2:** *"Tawam pharmacy services are very slow; I think that should be improved for faster services and better delivery"*

Furthermore, some participants felt that healthcare professionals needed to provide more information and another person pointed out that they should provide emotional support as well.

> **Participant 5:** *"Lack of information from the doctors, this affects"*
>
> **Participant 6:** *"There should be an improvement in information delivery"*
>
> **Participant 8:** *"Maybe if doctors can provide emotional support. I prefer if I receive more support from health providers about the physical issues I have. Maybe doctors can also provide emotional support"*

To foster an open patient-provider communication, it is imperative to understand the factors that influence patient's expectations regarding care delivery and health system. Policies need to be appropriately framed to emphasise the goal to meet patients' expectations to enhance the quality of care rather than reducing the cost. Health insurance coverage is critical to increase patients' access to cancer care (Goss, et. al., 2009; C-Change, 2008). Although health insurance is covered for all UAE residents (mostly by employers), expatriate cancer patients continue to experience problems accessing the care they need. Insurance coverage expansion and enhancement of current mandates have been the most visible concerns expressed by the expatriates in this study.

> **Participant 9: "***If hospitals can provide enhanced coverage for those who cannot afford the treatment, this would be very helpful"*

Participant 7: **“***Because see I have two ways of my surgery, so plastic doesn’t come under mandate approved treatment but, in my case, better to go for this operation. So, for some patients, like in my case like something to do with the increase or enhanced coverage. Expand the mandate, this will help me of course but will help my doctor as well”*

“I really appreciate SEHA or whoever created this program for expatriates to get this treatment”

4.2.3 SUMMARY OF QUANTITATIVE & QUALITATIVE RESULTS

Chapter 4 was divided into two parts; the first part included the quantitative result followed by qualitative findings answering the research questions in relation to explore the psychosocial concerns of breast cancer survivors. The quantitative results showed that the most prevalent and most rated concerns by breast cancer survivors were **"information concerns"** followed by **"emotional concerns".** There was some level of needs mentioned by the survivors with regards to social and financial concerns. Survivors showed much lower **"Physical concerns"** compared to other concerns such as information or emotional concerns which were rated as extreme concerns in the survey, whereas no major concerns were reported in the "**spiritual or religious"** domain.

The overall results in this study demonstrated that women with breast cancer regardless of their nationalities experienced a range of survivorship concerns related to breast cancer experience. After exploring the concerns mentioned by breast cancer survivors in the quantitative phase, further understanding was developed with face-to-face interviews to explore those concerns in greater detail and to gain further understanding about **survivors' living experience** with breast cancer encompassing their typical living challenges and consequences of the breast cancer diagnosis on their lives. Almost all women experienced difficulties in transitioning their lives as their priorities as well as perspective of life shifted through cancer survivorship. Psychosocial concerns of cancer survivors covering five domains were explored n quantitative results and further understood individually as five sub-themes including physical concerns, information concerns, social & financial concerns, emotional concerns and spiritual or religious concerns.

For most women the first reaction to **breast cancer diagnosis** was shock while they gradually came to terms with the diagnosis. For some it was denial and trouble believing or accepting the fact that they have cancer. Denial may be helpful as it gives time to adjust to the diagnosis and most women, they work through it. With regards to **access to care**, some women experienced difficulties in accessing healthcare and mentioned their concerns about **trusting their healthcare** providers. Seeking care and getting the right treatment was another concern as cancer treatment is complex and involves multiple modalities which could relate to sociocultural contexts as well as doctor-patient relationship and trust in healthcare providers. Although breast cancer survivors showed no major concerns with regards to **physical needs** in the quantitative analysis, the interviews gave survivors the opportunity to explain in more depth how their lives were impacted and transformed due to physical difficulties that survivors encountered due to cancer and its treatment effects, mainly fatigue, pain, sleep disturbance and body changes etc. The quantitative results significantly highlighted the differences in physical concerns between Emiratis and expatriates where expatriates showed higher concerns than Emiratis. Some differences in the severity of concerns were noted, for instance, physical concerns were the lowest rated in the survey whereas the qualitative evaluation of the data showed that almost all women complained about their **higher physical concerns.** This could be explained with an understanding that cancer is a complex human phenomenon which is interpreted uniquely by all individuals. While qualitative data should not be generalised, it is nevertheless very important in helping to gain deeper understandings about the women's experiences, specifically the 'how' and 'why' rather than the 'what'. Regardless of differences in severity found in both quantitative and qualitative data, the results yielded rich information about each psychosocial domain as complementary, where results were used to supplement each other. Additionally, a qualitative sample of a very small group cannot be representative of the overall sample or the larger population.

Information concerns were the most prevalent concern in phase one. **Being fully informed about potential Psychosocial needs and long-term adverse effects, recurrence, familial risk, cancer and its treatment, follow-up and support services were the significantly raised concerns about the information needs.** However, the qualitative data showed that almost all women were quite satisfied with the information delivery from their healthcare providers yet concerns about being more specific in terms of adverse effects and unique queries about their specific conditions were raised. The same rationale could be applied to understand the difference in outcomes in two forms of data collection as in the later phase the severity was further explained where data was not meant for generalisation but to acquire in-depth understanding. Both quantitative and qualitative results were integrated to facilitate an improved understanding of their needs, survivorship experience and to reflect survivors' point of view to ensure the study findings are grounded in survivors' experience which provided a more complete story than either method would alone.

It was also revealed by reviewing the qualitative data that patients must be fully informed at all levels through the cancer survivorship as needs and circumstances change along the course of the disease. Few survivors were not given any information about what could happen next and what they could face which added to their distress. They were not informed about their specific queries as everyone could have different questions which must be answered in advance so they can cope appropriately upon facing the situation. It was also evident that most doctors do not address the psychosocial aspect of cancer and focus on treatment to get rid of cancer from the body. Expatriate women could have more information needs, particularly about available resources and support groups. It was clear that breast cancer survivors prefer information from their health providers than from any other source yet they acknowledged the need to search for the best information about treatment as it was lacking by their health providers.

Considering the UAE's financial status and healthcare system coverage for nationals, it was expected that there would be no major **financial concerns** among Emirati women as they had full health coverage through national insurance. Also, expatriate women were covered either by their insurance or they had a mandate from the government which covered their cancer treatment. Nevertheless, a few women who mentioned financial difficulties were expatriates. Social and financial concerns were reported higher in expatriates than Emiratis. They mentioned their challenges faced with their insurance providers, mainly approval of procedures as they sometimes had to postpone their treatment. With regards to **social concerns,** almost all patients showed their appreciation towards their family as they received the appropriate support from their family members. No women raised concerns about their work performance and instead, some of them mentioned the support from their colleagues and employers to carry out their jobs and set appropriate work adjustments.

In the quantitative phase, **emotional concerns** were the second most commonly rated concerns by the survivors following information concerns. Dealing with the news of having a breast cancer diagnosis itself was an emotional issue for almost all the women. Most women were unhappy, depressed, worried, angry or having mixed emotions at the time they were diagnosed with the cancer. For some it was difficult to accept the reality which made them very emotional. Feeling isolated and not sharing their feelings about breast cancer affected few survivors quite seriously yet some showed positive attributes and tried to stay positive. Qualitative data further explained that concerns about body image especially after surgery were both psychologically and emotionally challenging experience for the women and for some it was loss of identity and sexuality. Fear of recurrence, future worries mainly about family and children and living with uncertainty were the utmost emotional concerns revealed during both phases. Fear of recurrence and uncertainty such as losing the job were some of the factors that were expressed by survivors as most concerning. The qualitative results revealed a rich understanding about how breast cancer survivors feel and deal with their utmost concerns. They expressed several concerns about their body image, appearance, hair fall, sleep disturbance, weight, appetite and other health issues mainly from the side effects of cancer treatment which affected them psychologically as well as emotionally**.**

None of the women had any **religious or spiritual concerns** rather almost all found it a way of strengthening themselves to fight cancer. During the survivorship, getting close to God immensely helped cancer survivors in building their faith and positivity. Some had their utter belief that it happened by Allah’s (God) will and Allah will take care of that. God was the primary source of strength for almost all cancer survivors regardless of their nationality.

There were no differences in information, emotion, spiritual or religious domains in Emiratis and expatriates. With regards to breast cancer survivors’ **experience with healthcare providers**, most women were satisfied with the care they received yet few provided suggestions to improve current services based on their unique needs such as adding nutritionists to advise, enhanced mandate’s coverage and improvement in delivery of information by the doctors to their patients.

The data from both phases were integrated to strengthen the rigor, enrich the analysis and findings and acquire deeper and more meaningful understanding of cancer survivors’ experiences, concerns and challenges.

The next chapter presents the detailed discussion on both sets of findings in the light of available literature in line with the conceptual framework of the breast cancer survivors’ concerns.

Chapter 5: DISCUSSION

The aim of this chapter is to discuss the findings and identify the concerns of breast cancer exhibited by the women and to address the research question in relation to findings from the study and available literature. This chapter discusses the findings of the study to address the four objectives including: identifying the psychosocial needs of breast cancer survivors, examining the influence of nationality on survivors' needs, investigate disparities in Emiratis and expatriates utilising the sociodemographic and clinical characteristics of the participants and to identify the factors to aid the development of culturally tailored cancer survivorship program.

Breast cancer is the most frequently diagnosed cancer in the world and the most frequent cause of death among women (Ferlay, et. al., 2019; World Health Organization, 2018). Similarly, in Arab countries, breast cancer is the most common cancer in females (Abulkhair, et. al., 2010) representing an estimated 17.7% to 19% of all new cancers in 2018 (Global Cancer Observatory, 2018; Globocan, 2018b). With a growing number of women surviving breast cancer each year and despite the high prevalence of cancer in the country, the literature on the needs of cancer survivors is rudimentary. There is limited research conducted to report the needs of breast cancer survivors in the United Arab Emirates. To the best of my knowledge, this is the first study that explores and addresses the psychosocial needs of breast cancer survivors in the UAE and highlights the existent gaps in the literature that is the lack of studies on exploration of psychosocial needs of breast cancer survivors in this region. In general, the concerns and needs expressed by the breast cancer survivors in this study were consistent with survivorship issues that have been addressed in the literature (Connell, et. al., 2006; Vos, et. al., 2004; National Breast Cancer Centre, 2003; Marlow, et. al., 2003; National Health and Medical Research Council, 2000). However, this study provides some unique and rich findings with new discoveries which are discussed in detail in the chapter below.

5.1 DEMOGRAPHICS AND CLINICAL CHARACTERISTICS OF BREAST CANCER SURVIVORS

With regards to participants' demographics and clinical characteristics, 205 women with breast cancer were surveyed to explore their psychosocial needs among whom 26% were Emiratis and 74% were expatriates in line with the country's population structure. The mean age of the participants was 49 years. More than half of the participants were between 35 to54 years of age. Over half of the survivors who were surveyed, diagnosed either in or after 2018 whereas 37% had their diagnosis established between 2012 and 2017. Majority of the surveyed women (74%) had regional disease whereas 25% presented with an early or localised stage at the time of diagnosis. The survey result showed that the majority (72%) of the women with breast cancer in the UAE perceived they had a good quality of life (Table 1, section 4.1.1).

To explore the **relationship between nationality and patients' demographics and clinical factors,** the two associations were explored based on the current observations and literature findings: "nationality and participants' age" and "nationality and patients' stage of the disease" (Section 4.1.6). The results showed **no significant association between survivors' nationality and their age or stage of cancer at the time of diagnosis**. The result has added valuable evidence to the existing literature where Arab physicians' impression about women has been noted as having it at an earlier age and at a more advanced stage than in western world (Hashim, et. al., 2018; Aldosari, 2017; Elobaid, 2014; Chouchane, et. al., 2013; Najjar & Easson, 2010; El Saghir, et. al., 2007; AbdelHadi, 2006). The result has confirmed that such an observation is not scientifically valid, and results could differ among different Arab populations. The result also showed that there are **significant differences in domains of physical needs and social and financial needs between Emiratis and expatriates (Table. 20a)**. As UAE had a larger number of expatriates compared to nationals reflective of the sample of the study. The sample of the study was unequal leading to unequal variance of groups. Therefore, the differences were signified by using Welch's test instead of t-tests.

5.2 DIAGNOSIS AND CANCER EXPERIENCE

The diagnosis and treatment of cancer can provoke serious psychosocial disruption in a manner that anxiety and depression can elevate significantly in comparison to normal individuals (Jacobsen & Andrykowski, 2015). Diagnosis of cancer is disruptive news for an individual and for the family. When people have cancer, life can change for them and for the people who care about them which can be difficult to handle. Cancer diagnosis is an emotional experience and can bring a number of different emotions and sometimes confusing emotions may appear. Literature shows that the moment of receiving a breast cancer diagnosis resulted in much fear and anxiety for Arab women (Hammoudeh, et. al., 2017; Obeidat, et. al., 2013a; Montazeri, 2008).

The finding in this study shows that for most patients, diagnosis of cancer is a shock for which they are unprepared; uncertainty and fear are common reactions (Participant 1, 3, 6, 7, 10, section, 4.2.2.1a). One may feel shocked, angry or depressed; such feelings may vary from hope to despair or from courage to fear. These are normal reactions for cancer patients which is a disturbing change in their lives. Although openness about the diagnosis enables patients to think more realistically yet healthcare providers need to create a balance between providing information without alienating the patients which can be difficult (Carroll-Johnson, et. al., 2006). Most individuals are able to adjust to the diagnosis over time, religious beliefs help too; however, concerns about the future, medical tests, hospital stays and medical bills are common. Patients usually are better able to adjust their emotions and cope up with the circumstances if they can talk openly about their illness and their feelings with their families (Hagag, 1999). Healthcare providers can facilitate cancer patients and their families in adapting to the changes due to cancer by providing helpful information considering cultural context as sometimes the patients may not be the first to know the diagnosis.

To better understand the breast cancer concerns, during the interviews, women were asked to share their **living experiences of cancer**. Each cancer patient responds differently to cancer and its treatment. The outcome of cancer differs as well so their experience, concerns and needs as well. Some may find it difficult to accept that they have the disease (Participant 3, 8, section 4.2.2.1a) some may find it easy to have conversation about it whereas others may shun the discussion when the topic arises (Participant 6, 10, section 4.2.2.2d). Some may become anxious and depressed and for some the impact of cancer is not as high and they can get on with their life as normal as it was before the diagnosis. Each cancer survivor interprets cancer differently from their own individual perspective. The findings illustrated that cancer did impact the lives of breast cancer survivors in various ways that included changes in their perspective, behaviour and lifestyle.

Cancer threatens a persons' well-being which cannot be overemphasized (World Health Organisation, 2014; Eilertsen et al., 2012). In addition to the array of emotions, coping with cancer can be physically demanding and can lead to physical and mental health impairment which together can lead to major social problems (IOM, 2008). Findings show that diagnosis of breast cancer and its treatment is associated with the range of symptoms that impact an individual's physical, emotional as well as financial situation (Lehto, et. al., 2005). Changes in the body could affect a woman's self-esteem and cognitive functioning which can have profound impact on her well-being and quality of life which indicates which facets of an individual's life are most affected by disease and treatment (World Health Organisation, 2012).

Literature also reports an association between compromised quality of life and clinical outcome including survival (WislØff, et. al., 1997). Consistent with other studies, results of this study suggest that cancer changes every part of an individual life (Participant 2, 3, 6, 7, section 4.2.2.1b**)**. Study found that psychosocial and emotional impact of cancer is so profound that patients had adjustment and stress issues mainly related to treatment (Participant 2, 6, 10, section 4.2.2.2a; participant 6, section 4.2.2.2d) as mentioned in studies carried out earlier (Von Essen, et. al., 2000; Hudson, et. al., 2003; Li, et. al., 2013). The physical changes influence not just a person's way of living but also the priorities and meaning of life resulting in a complete paradigm shift. Surviving cancer becomes a way of life so one adapts to live the rest of the life with changes that cancer brings during the survivorship. Finding shows (Participant 6, section 4.2.2.1b; Participant 1, 4, 5, 6, 8, section 4.2.2.2a; Participant 2, 4, 6, 8, section 4.2.2.2d) that participants experienced serious psychosocial symptoms emphasizing emotional and physical side effects such as body changes, pain, fatigue, hair loss, weight changes that impact their ability to carry out the daily living, roles and responsibilities (Jassim & Whitford, 2014).

In this region, responsibilities to fulfil the needs of families take priority over individual needs compared to western regions (Jassim & Whitford, 2014; Surbone, 2008). Participants

(Participant 4, 5, 6, 7, section 4.2.2.1b) endured the adverse effects of cancer treatment in order to carry out their role as a mother, continued employment and housework for their family similar to the findings earlier reported among Arab women in the literature (Al-Azri et al., 2014; Jassim & Whitford, 2014). Most Muslim women believed that the health and disease come from Allah thus accepted the reality and became more appreciative towards life and gain a new perspective to seek new normality and relied on God for their future and health (Table 10; Participant 1, 2, 3, 8, 10, section 4.2.2.2e). Previous research has shown that religious practices and faith are means of coping with the illness which shows their trust in God (Hammoudeh. et. al., 2017; Assaf, et. al., 2017; Al-Azri et al., 2014). On the other hand, in this study, there were participants who expressed no impact on their lives (Participant 2, 10 section 4.2.2.1b; Participant 10, section 4.2.2.2.a; Participant 9, section 4.2.2.1a), and they simply returned to normal living following treatment suggesting that cancer is a unique experience of each individual that determines the level of impact that breast cancer can have on each person's life.

5.3 ACCESS TO CARE

To prevent new or recurring cancer and its late- and long-term psychosocial consequences, cancer survivors require ongoing timely access to care to ensure early intervention and coordination between healthcare providers (National Research Council, 2006). Unfortunately, there are numerous barriers to timely and equitable access to cancer care that exist across the cancer continuum which negatively impact cancer outcomes. To improve access to care and reduce disparities in cancer outcomes requires identifying, understanding and addressing those barriers which differ by location and population. These barriers could be structural, geographical, sociocultural, personal or financial.

This study demonstrates that structural barriers including geographical location, need of transport, insufficient diagnostic or treatment services or insufficient trained workforce in the place of residence were some of the barriers to access quality cancer care for some survivors (Participant 1, 8, section 4.2.2.1c). Personal barriers such as mistrust of the health system, poor delivery of care or lack of trust in healthcare providers result in greater psychosocial effects on cancer survivors and impact their lives negatively. Hence, identification of target population and such barriers can also help identification of the best intervention for improving access to care for instance, programs to improve structural barriers emphasize on multidisciplinary approaches, guidelines and standards for referrals and quality metrics to track down timely access from presentation with breast cancer concerns to diagnosis and time from diagnosis to treatment (Pan American Health Organisation, 2016; IOM, 2002a).

Programs to reduce structural and personal barriers ideally involve community groups as well as breast cancer survivors in educational or supportive services. Improving access and utilisation of healthcare services can impact breast cancer incidence and survival both. Thus, strategies for improving equitable access to care must be customised to meet the needs of the targeted population (Anderson, et. al., 2017). Literature also suggests that patients who require more complex interventions must have access to trained professionals within routine cancer services (Hackett, et. al., 2018; Grassi & Watson, 2012). A document published by Ministry of Health, New Zealand (2010) on guidance to improve supportive care for adults with cancer suggested that the best-practice service approaches must ensure that adults with cancer and their families must have access to the supportive care needed throughout the stages of cancer, from diagnosis onwards (Ministry of Health, New Zealand, 2010).

With regards to **access to care**, most women understood the significance of their symptoms straightaway yet **delayed consulting a doctor** about their breast symptoms (Participant 2, 3 4.2.2.1d; Fallowfield & Clark, 1991). Previous studies in the region also confirmed the similar findings that despite advancement in breast cancer treatment, treatment coverage and well-established screening services, there is a considerable lack of awareness about breast health mainly due to sociodemographic behavioural and cultural factors (Elobaid, et. al., 2021, 2016, 2014; Arafa, et. al., 2020; Younis, et. al., 2016). Findings from this study, also revealed a lack of trust on the part of healthcare providers which led to **second opinions** or visits to other providers or abroad in order to seek expert help (participant 2, section, 4.2.2.1c; participant 1, 2, section, 4.2.2.1d). Patients need to trust that their healthcare providers will be able to care for them appropriately, being experts in the field of Oncology.

The IOM (2013) reported that there is a need for converse acceptance of responsibility emphasizing the importance of building trust with patients and maintaining therapeutic relationship with them over the entire extent of their treatment is crucial. Interestingly, neither the first opinion nor second opinion is an absolute truth (Payne, et. al., 2014; Axon, et. al.,

2008) Second opinion may benefit patients as they bring more certainty; however, if the second opinion differs from the first, it could result in increased uncertainty which may lead to further opinions at higher cost (Hillen, et. al., 2017). Preliminary evidence suggests that patients' motivations to second opinion are more often based on impairment of physician patient relationship rather than on patients' doubts about their physicians' medical competence (van Dalen, et. al., 2001; Payne, et. al., 2014). Literature suggests that the main reasons to seek second opinion are either patients feel the need of confirmation, lack of trust or dissatisfactory communication with the health providers or a need for more personalised information (Hillen, et. al., 2017). Therefore, if patients desire a need for more certainty or express the need to gain more information, the healthcare providers need to either refer them to the available resources which could offer such treatment or offer an extra time to provide more information as some patients are hesitant to admit the lack of trust or dissatisfaction, in that case, health providers can explore patients' need or difficulties (Back, et al., 2005). Oncologists may refer the patient to a colleague within the same facility rather than seeking for a second opinion in case the patient's relationship is damaged due to poor or undesired outcomes (Hillen, et. al., 2017).

5.4 HEALTH DECISION-MAKING

Many women with breast cancer face psychosocial challenges at the time of cancer diagnosis and treatment. **Health decision-making** has a critical importance in cancer care particularly since the introduction of the patient-centred approach which emphasises the relationship between patients and doctors to promote a shared decision-making model (Mazzocco, et. al., 2019). Cancer treatment decision-making is often complex and based on a multidisciplinary team's opinion to opt for the best available evidence-based treatment choices (Institute of Medicine (2013), this approach falls on physicians' decision and is less likely to involve patients and consider patients' desires. As a result, these women can often be lost in transition and may experience distress or other psychological symptoms at a critical juncture during the cancer care pathway.

In contrast to the existing literature which informs that women often perceive themselves as peripheral to any treatment decisions and sometimes undergo treatment against their wishes (Obeidat & Lally., 2014; Jassim & Whitford, 2014; Obeidat, et. al., 2013b; Doumit, et. al., 2010), this study results show that despite being informed about the appropriate treatment, it was often the women who made decisions and choices about the treatment recommended by their doctors (Participant 1, 5, section, 4.2.2.1d). Thus, it was observed that women in this region regardless of their nationalities, are not passive recipients nowadays as stated in the literature, they rather actively take part in the treatment decision-making. They also showed their desire to be more aware and increase their knowledge about treatment and their side effects (Table 14, section 4.1.5; participant 7, section, 4.2.2.2b).

Nevertheless, their decision-making could be affected by various cultural factors such as knowledge and awareness of possible side effects, fear of recurrence, trust in their own judgement, family responsibilities or priorities etc., (Participant 2, section 4.2.2.1d). It was also noted that surgical decision-making was driven by fear of recurrence (Participant 10, section 4.2.2.1d; Fernandes-Taylor, et. al., 2015). **Shared decision-making** allows patients and their providers to make better decisions, taking into account patients' values and preferences with the best scientific evidence available. It was also noted that the majority of the patients preferred to share decision-making and improved communication with their physicians (Table 8; Nies, et. al., 2017). **With regards to autonomy in the decision-making process, the study results show that women who were certain and did take part in their treatment choices at their comfort level demonstrated confidence and greater treatment satisfaction** (Participant 2, 5, 8, 10, section, 4.2.2.1d). Katz, et. al., (2014) reported similar results in his study in the US population suggesting that more informed and engaged patients are more satisfied and have better outcomes.

Women may experience severe psychosocial symptoms at the time of diagnosis (section 4.2.2.1a) and treatment decision-making as anxiety and depression are more commonly experienced around that time (Fiszer, et. al., 2014). Some women took up the primary role in treatment decision-making instead of letting their physicians decide. They benefited themselves with this active approach as they outweighed and managed the emotional burden of breast cancer while deciding among treatment choices taking the benefits of it against adverse effects (Participant 6, 4.2.2.2d; Fernandes-Taylor, et. al., 2015). Numerous studies have shown that some of the psychosocial factors can predominantly affect the breast cancer patients' therapeutic decision-making. For instance, support from healthcare providers, family and colleagues (Halford, et. al., 2001; Makabe, 1999; Stanton, et. al., 1998), degree of patients' involvement, their expectations, values and satisfaction with the treatment (Sato, 2005;

Petersen, et. al., 2001; Stanton, et. al., 1998; Morris & Ingham, 1988). It has been found that for some women who chose treatment voluntarily, it was a more important factor than treatment itself, for psychological adjustment afterwards (Participant 10, section, 4.2.2.1d; Stanton, et. al., 1998; Morris & Ingham, 1988). Hence, it is important that offered treatment meets the patients' expectation to ensure her psychological well-being and adjustment (Asadi-Lari, et. al., 2004; Lateef, 2011). Therefore, offering flexibility instead of rigid discipline by healthcare providers may help in building trust and confidence in patients advocating partnering not paternalism (Dawson-Rose, et. al., 2016; Saha, et. al., 2008).

5.5 THE ROLE OF SUPPORT FORUMS

A 'Support forum' is a formal environment which offers its members an opportunity to reduce stress and isolation and share information and experiences among other cancer survivors. In such a place, patients can share their fears and concerns with other people with similar experiences who understand what one is going through since they have been in such a situation. The results of this study show that some women expressed their deep desire to gain some personalised information about their disease by associating with support forums, in which information can be sought anonymously which would aid those patients who are reluctant to ask due to concerns about physician time being limited to due to personal shyness about talking directly about their health concerns.

Support forums may enhance the communication, understanding and knowledge about breast cancer and its treatment, diet and nutrition, health behaviours, coping and adjustment and available resources to cancer survivors to provide social and psychological support (Hillen, et. al., 2017). However, the quality of information and readability are important factors to consider while gaining information from online communities and forums. A study found that although breast cancer websites have good readability, they may still not be understood by the average patient as, to be understood by 75% of the population, readability should be at a sixth-grade level (Arif, & Ghezzi, 2018). Nevertheless, the available information on online forums have been evaluated with 90% accuracy (Bender, et. al., 2013).

5.6 PSYCHOSOCIAL CONCERNS OF BREAST CANCER SURVIVORS

In this study, psychosocial concerns of breast cancer survivors were explored to identify their needs in five domains including physical, information, social and financial, emotional, religious or spiritual. It has been shown that cancer survivors experience various difficulties in their daily lives including physical, emotional, social or economic difficulties (Amir, et. al., 2012; Boyes, et. al., 2012). These concerns include but are not limited to adjusting to new normality (Participant 5, 8, section 4.2.2.1b), adjustment with stress and other psychological issues, managing expectations, dealing with emotions and several other concerns (Participant 3, 4, 6, section 4.2.2.1b).

The results of this study strengthened the finding from the previous study conducted by Nair and colleagues (2018) on cancer survivors' needs in the UAE and demonstrated that breast cancer patients require a wide range of psychosocial care in the UAE. The result of the study showed that breast cancer survivors had their concerns and needs which were prevalent in both groups including UAE nationals and Emiratis (Table 20a).

Information and emotional needs were highly rated concerns in the survey (Table 20a) whereas physical needs were mostly specified during the qualitative interviews (4.2.2.1b; 4.2.2.2a). Patients showed their desire to have more information to manage treatment side effects and to deal with cancer that had an impact on their daily functioning consistent with the needs described in the literature (Participant 6, section 4.2.2.2b; Participant 5, 6, section 4.2.2.3b). The needs of information and being well-informed commence first before any other needs. Secondly, breast cancer survivors showed that the need to have emotional support and to speak to someone who can empathise is critical to manage the disease during the survivorship, consistent with previous studies (Participant 6, section 4.2.2.2d; Connel, et. al., 2006; Thewes, et. al., 2004; Marlow, et. al., 2003; Gray, et. al., 1998). Broader literature also suggests that Arab women with breast cancer who remain symptomatic with limited access to reliable information may struggle to transition to a new normal even several years after the treatment (Fearon, et. al., 2019). These factors could be cultural, thus culturally-based intervention must be considered for the targeted population.

5.6.1 PHYSICAL CONCERNS OF BREAST CANCER SURVIVORS

Despite the awareness of **physical impairments** that can occur after breast cancer treatments, there is little known how best to manage those (Harris, et. al., 2012). Participants described how they adapted to living with pain and other physical difficulties resulting from disease and mainly treatment (Participant 1, 6, 8, section 4.2.2.1b). Physical concerns were much more highlighted as major concerns by the survivors during the qualitative interviews (section 4.2.2.2a). The integrated result (Table 13; section, 4.2.2.2a**)** revealed that **pain and fatigue** were the most concerning aspects of physical concerns described by the participants in both groups consistent with previous studies (Jensen, et. al., 2010; Bardwell & Ancoli-Israel., 2008). Jensen, et. al., (2010) also noted that although pain is a common problem among women with breast cancer, its impact and predictors have not been studied at large.

Pain has been more commonly reported in breast cancer survivors than any other survivors' group such as those with a history of cancer of other sites for instance colorectal or prostate (Jiang, et. al., 2019; Boland & Ahmedzai, 2017; Glare, et. al., 2014; Brown, et. al., 2014; Deimling, et. Al., 2007). The potential impact of pain on patient functioning and quality of life has also been reported in previous studies; researchers found that survivors who reported pain also reported several functional difficulties required to carry out daily activities compared to those who did not report any pain (Peuckmann, et al., 2009; Deimling, et. al., 2007; Gulluoglu, et al., 2006).

In this study, the participants described the intensity of the pain to variable degree, some described it as manageable, others found it difficult to manage with work responsibilities due to their pain which affected their living too (Participant 2, 3, 4, 5, section 4.2.2.2a). The intensity of pain described by the breast cancer survivors in the literature as mild where moderate to severe pain was very rare (Jensen, et. al., 2010) which is consistent with the findings in this study (Participant 9, 10, section 4.2.2.2a). Finding showed that pain was a great contributor (mean=.64, SD=1.274) that impacted survivors' daily living, but the adverse effects of the treatment affected psychologically as well as negatively (Participant 1, section 4.2.2.2a; participant 6, section 4.2.2.2d). Significant associations have been found between both the presence and severity of pain and psychological functioning and physical functioning both (Jensen, et al., 2010).

Fatigue was another common symptom reported by most women in this study (mean=.69, SD=1.283). Fatigue has been recognised as a distressing, persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning (National Comprehensive Cancer Network, 2010). Fatigue is a multidimensional concept that affects patients differently. This cause of fatigue can be disease itself, treatments, nutritional issues, pain, drugs, sleeping problems or other psychosocial problems such as anxiety or depression. Therefore, the management of fatigue in cancer patients is generally theoretical and medical approaches focus on treatments rather than focus on the symptoms of fatigue (Aydiner, et. al., 2019). Cancer related fatigue and sleep disturbances are reported to have common aetiology and are related to pain, depression, concentration and cognitive functional loss (Roussi, et. al., 2007).

Apart from pain and fatigue, several other physical concerns were expressed by the survivors for instance, body image, appearance, hair fall, sleep disturbance, weight, appetite and other health issues mainly due to the side effects of cancer treatment which affected them both psychologically as well as emotionally (Participant 1, 3, 4, 6, 8, section 4.2.2.2a; Jassim & Whitford, 2014; Nizamli et al., 2011; IOM, 2008). The results of this study demonstrate that loss of breasts or breast tissue to minimise the risk of having breast cancer or to treat cancer, resulted in body image concerns in most of the women which affected the survivor's psychological health (Participant 8, section 4.2.2.2a; participant 5, 6, 7, section 4.2.2.2d). Finding confirmed that altered body image and concerns about femininity and sexuality can remain silent issues in cancer care particularly in Arab women due to reserve culture (Participant 6, 10, section 4.2.2.1b**)**. However, these issues can remain either silent or arise long-after treatment that many people may feel they don't know where to turn for information and support.

Asymmetry in appearance after removal of breast tissue resulted in great difficulties both physically and psychologically. Survivors explained that their living changed and lifestyle too; for instance, lack of choices in finding clothes that could fit them was another concern. Owning the new body shape was a psychologically difficult process as reported by the survivors. For some women, change in physical appearance was least concerning since other priorities were more important for them. On the contrary, for some, **the body or self-image** was related to their self-confidence (Participant 6, section 4.2.2.1b**)**.

Body image after surgery had a great impact on women's lives and their self-confidence as other researchers found the negative correlation between body image and self-esteem (Morales-Sánchez, et. al., 2021; Prates, et. al., 2017; Bolton, et. al., 2010; Sertöz, et. al., 2004; Al-Ghazal, et. al., 2000). Literature shows that the only factor differed significantly between groups of women who had different type of surgeries for breast cancer was the body image (Cohen, et al., 2000). In this study, other than pain, fatigue and body image, survivors also discussed **sleep disturbance and insomnia** which became worse with other conditions for instance, chest pain or other comorbidities. A study reported that women who experience neuropathic pain which is sometimes severe, increases with the movement and interferes with sleep as found in more than 50% of cancer survivors (Aydiner, et. al., 2019).

In this study, qualitative findings further discussed that **adverse effects of chemotherapy** were the worst aspect of the physical concerns due to its unpleasant and unexpected side effects (Participant 6, section 4.2.2.1d). Total or partial **hair loss** caused by chemotherapy and hair regrowth issues were commonly described by women who had chemotherapy (Participant, 1, 4, 6, 8, section 4.2.2.2a; Choudhury, et. al., 2018; IOM 2008). **Skin changes, mainly** discoloration, was also noted by some women (Participant, 1, section 4.2.2.2a). Weight gain and weight loss both after treatment were also reported in some women, particularly weight gain in women who had hormone therapy (Participant, 1, 4, 9, section 4.2.2.2a). These findings were commonly reported in the literature earlier and show that women may continue to experience these physical concerns throughout cancer survivorship (IOM, 2008; Cappiello, et. al., 2007).

By losing such feminine physical characteristics, some women developed social stigma which induced stress and a physical burden of the disease in them (Participant, 1, section 4.2.2.2a; participant 5, 10, section 4.2.2.2d). This can further reduce the opportunities in life and increase isolation and social rejection which greatly impact them with poor health outcomes (Kagawa-Singer, et. al., 2010; Freeman, 2004). These physical issues may limit the ability of breast cancer women to carry out their roles and responsibilities which may result in the loss of confidence and control leading to decreased autonomy and thus become dependent on others

(Luoma, et. al., 2004). Yet, most women showed that they were able to adapt and continued their roles to look after their children or families as their common traditional role, mainly Muslims or Arab women, even after transitioning from caretaker to care receiver (Kawar, 2013; Taha, et. al., 2012). It is crucial to understand that some breast cancer survivors' outcomes depend not only on their prognosis but also on other factors such as cancer treatment and its adverse effects of cancer treatment (Du, et. al., 2021; Odle, 2014). Therefore, breast cancer survivors must be monitored and then treated when any physical symptoms are indicated (Bardia, et. al., 2012).

Participants also noted that their **physicians did not try to understand the patients' difficulties** in terms of physical issues thus left unattended or unaddressed appropriately which may lead to maladaptive behaviours, poor prognosis and low quality of life (Participant 2, 5, section 4.2.2.1c; Participant 5, section 4.2.2.1b; participant 5, section 4.2.2.2c**;** Reyes-Gibby, 2012). Healthcare providers must consider that breast cancer patients may lose the physical traits they face weakness and emaciation thus, they may not be able to take care of themselves and do personal care routines as prior to disease. As a result, they may not be recognised as the same person by others. This can make a person feel less loveable. Maintaining cancer survivor's dignity, respecting modesty and supporting personal care all are important supportive care measures that must be considered while assisting with breast cancer survivors' physical concerns (Gorman, 2018).

This study also assessed cancer survivors' preferences about learning sources and topics. Fifty nine percent participants showed their **preferred learning source** with regards to physical concerns was only healthcare specialists (59%) (Table 2). For **preferred learning topics**, 46% of participants showed they had interest in learning more about nutrition and safe exercises whereas 40% wanted to know about nutrition only suggesting that participants understand that nutrition plays an important role towards adapting to healthy living (Table 6). Over half of the women (64%) wanted to know more about cancer screening and 36% showed their interest in health screening (Table 9). 73% showed their interest in learning about enhancing communication with their doctors, 18% mentioned both doctors and their spouses, suggesting satisfied communication patterns with their healthcare providers (Table 8).

5.6.2 INFORMATION CONCERNS OF BREAST CANCER SURVIVORS

In this study, results showed that breast cancer survivors had ***extreme concerns*** **about the "information needs"** which scored highest in rating (mean=27.99, SD=1.020). **Information needs were the major worry for most breast cancer survivors than any other psychosocial domain.** Information concerns have been reported as of highest need than any other psychosocial concerns in numerous studies that were conducted earlier to identify cancer survivors' needs (Legese, et. al., 2021; Kuruppu, et. al., 2020; Fong & Cheah, 2016; Shea–Budgell, et. al., 2014).

Participants showed their strong desire to gain more knowledge about breast cancer issues; they felt they had insufficient information about breast cancer and its management (Participant 5, 6, section 4.2.2.3b). From their physicians, they received only the basic information such as adverse effects of chemotherapy; however, what else could go wrong and what else could be anticipated apart from side effects were important aspects that were missing from the information delivery (Participant 6, section 4.2.2.2b). Elbarazi (2016) argued that multicultural communities pose challenges to healthcare providers in providing the appropriate information to meet their unique needs appropriate with the cultural values. It is a critical aspect of cancer care, yet, little is known about the information needs of breast cancer survivors in the UAE. One possible reason for this lack could be the practicing model of physician centred care rather than patient-centred care which is rare in this region (Elbarazi, 2016). Another obvious reason which is also consistent with previous studies is, physicians mainly focus on biological or physical symptoms or medical strategies and usually do not address or provide information about the psychosocial impact of breast cancer (Eaton, et. al., 2020; Smith, et. al., 2011; Henkel, 2005; IOM & NRC, 2004).

Survivors opted to be linked with online forums, searching the internet for the specific information (Mancini, et. al., 2006; Jenkins, et. al., 2001) or talked to other survivors to educate themselves since some survivors found physicians' limitations with the information delivery which were either time constraints (Obeidat & Khrais, 2015), lack of accurate information or communication issues mainly trust (Dean, et. al., 2017; Kaiser, et. al., 2011). Qualitative findings further strengthen the quantitative findings and explained that information concerns remain exist throughout cancer survivorship and must be addressed at all levels of cancer trajectory as circumstances and needs change overtime or vary at different points in the disease process (Participant 5, 6, section 4.2.2.2b; Participant 5, 6, section 4.2.2.3b; Lu, et al., 2020; Parker, et. al., 2007). Also, the level of need can differ by socio-demographics or cancer characteristics (Playdon, et al., 2016).

Communication is the core requirement for setting healthcare goals. Although the majority of the patients in qualitative interviews showed satisfaction with obtaining the information from their healthcare providers (Participant 1, 2, 3, 7, 9, 10, section 4.2.2.2b) yet some were not confined with the amount as well as the content of information by their physician and perceived that there was no professional or healthcare setting available for patients to get the specific information about their specific issues (Participant 5, 6, section 4.2.2.2b). Majority of the participants showed the **preferred source** to provide cancer information must be their doctors (Table 2, 3, 4, 5, section 4.1.2; participant 7, section 4.2.2.b; Maloney, et. al., 2015). **Findings confirmed that the major issue with the information needs was not the delivery or how information was delivered but what was delivered** as most women had access but were not confined with the amount of information provided or to gain personalised information to meet their specific information needs (Participant 5, 6, section 4.2.2.b).

Participants also showed their desire for **communication with peers** and need to be prepared for upcoming treatments by talking to other survivors and sharing experiences as they had been through the same and could educate and inform other patients in advance (Participant 6, section 4.2.2.1d; Allicock, et. al., 2014). It was concluded that information concerns were the greatest need expressed by both Emiratis and expatriates and there were no differences found in information needs between these two groups (Table 20a) suggesting that **information needs are the key concern of cancer survivors regardless of nationality.** ***Being fully informed about potential psychosocial needs and long-term adverse effects were the most alarming*** information concerns reported by the survivors (mean=4.346). Consistent with this study results, Mills & Sullivan (1999) also expressed that information about treatment and side effects, the extent of the disease, prognosis and self-care were the most relevant for cancer survivors (Table 14). Other information concerns include, *being fully informed about any symptom appearing (recurrence/new primary), being fully informed about any familial risk,* *next follow-up date, place and physician, who to contact for new symptoms, about psychosocial support as well as about cancer and its treatment* (Table 14). This suggests that breast cancer survivors' biggest worries and uncertainties are associated with the treatments' adverse effects, fear of recurrence, support needed to manage the disease, risk to family, follow-up on disease. Survivors' information needs are continuous throughout the cancer trajectory. Unavailability of psychosocial resources, structured cancer survivorship programs, lack of support groups and rehabilitation programs are serious considerations and a call for actions to improve cancer care and survivors experience and their quality of life.

Additionally, cancer survivors' most prevalent concerns were identified and assessed for three different timeframes that are 0-1 year since diagnosis (2018 or above), 2-5 years of diagnosis (2012-2017) and 6 years of initial diagnosis or earlier. The results indicated that **information concerns were the most extreme concerns reported in all three timeframes suggesting the constant need of information among cancer survivors** throughout the survivorship (Table 12). Furthermore, a significant positive correlation was found between quality of life and information concern ($p < 0.01$) means, with the increase in information needs, quality of life scores will also increase suggesting those who scored higher in the information domain also had higher scores in quality-of-life evaluation (Table 21).

Previous studies have identified that cancer patients' information needs differ with gender, age, stage and type of cancer (Davison & Breckon, 2012; Bernstein, et. al., 2011; Rolnick, et. al., 2007; Jenkins, et. al., 2001). Chua and colleagues (2018) argued that there is, however, little understanding on the type and amount of information that patients require. This study results show that cancer patients desire to attain the most authentic information (Participant 7, section 4.2.2.2b). Accurate and reliable information can empower cancer survivors, relieve anxiety and depression, hence, can improve quality of life (Chua, et. al., 2018). Having said that, many studies have not addressed the different dimensions of the information needs such as patients' satisfaction or mode of delivery of information which is also part of the worry of some survivors reported in this study.

Providing information to all cancer survivors helps them with treatment choices, decision-making and cope with disease or treatment side effects, reduce anxiety, fears, depression thus leads to patient satisfaction, improves communication and quality of life (Miyashita, et. al., 2015; Davison & Breckon., 2012). There is a clear need to conduct research on cancer patients' information needs in the UAE (Elbarazi, 2016). Meeting cancer survivors' information needs is a fundamental aspect of patient-centred care (Davis, et. al., 2005) and patient satisfaction with the information provision is a key indicator of quality cancer care.

5.6.3 SOCIAL AND FINANCIAL CONCERNS OF BREAST CANCER SURVIVORS

In this study, social and financial concerns were expressed and rated as the highest (mean=1.96) mainly in expatriates which indicated 'some' level of needs. **Health insurance and financial concerns** were the main worry for expatriates as Emirati women had full national coverage by the government ($p<0.05$, table 20a,). UAE mandates compulsory health insurance for all UAE citizens. The UAE government provides full medical coverage to all nationals whereas for expatriates, the insurance is provided by the employers for which the extent of coverage is determined by their salary, designation etc. Studies show that financial stress is associated with poor quality of life (Salem & Daher-Nashif, 2020; Carroll-Johnson, et. al., 2006).

In this study, few expatriates expressed their challenges with the insurance approval process as they had to either wait and postponed their planned treatment (Participant 6, section 4.2.2.2c), yet no patients declared major financial or insurance issues as those who had no or lack of insurance coverage, they utilised government mandate which issued from the local government to facilitate patients who cannot afford the treatment (Participant 7, section 4.2.2.2c). Financial concerns were not reported very high in this study (Table 15); thus, it can be concluded that unlike many other countries, in UAE, the financial concerns of breast cancer survivors were not the most distressing concerns affecting their quality of life (Delgado-Guay, et. al., 2015; Zafar & Abernethy, 2013; Sharp & Carsin; 2013; Klimmek, et. al., 2010). Additionally, employers and colleagues were equally supportive which helped them sustain their jobs. Qualitative results showed that most of the patients managed their employment with the support of colleagues and employers yet, some mentioned problems such as having needs for time off from work due to treatment (Lim, et. al., 2017).

Healthcare providers can assist cancer patients through directing them to any available financial support programs to cover the cost of cancer treatment for those who can't afford it.

Literature (Fenn, et. al., 2014) indicates that increased financial burden due to cancer treatment cost is the strongest independent predictor of poor quality of life which affect it negatively and lead to other psychological symptoms for instance, anxiety, depression and distress among cancer survivors (Fenn, et. al., 2014; Sharp, et. al., 2013). Therefore, early identification of financial concerns, appropriate referrals, support services and other early interventions such as problem-solving, cognitive behavioural therapy and family group support may help lessens these concerns and could be effective ways to reduce the depression and anxiety induced by financial burden for those who are at risk (Semin, et. al., 2020; Azzani, et. al., 2015; Zabora, 2015; Cagle & Loscalzo, 2015; Damaskos & Parry, 2015).

This study also assessed social concerns of cancer survivors and findings showed that almost all participants had received a good level of support from their husbands and other family members which helped them cope up with their disease (Participant, 1, 2, 3, 4, 5, 9, 10, section 4.2.2.2c). For most women, family was an important source of strength to manage the disease, showing the importance of the role of family in both diagnosis and treatment stages. Although the current literature presents gender domination in Arab and Muslim culture where men are considered dominant and quite conservatives about their women to the extent that they object their partners and their families to be seen by clinicians and expose their body to other than husband (Salem & Daher-Nashif, 2020; Ziadeh, et. al., 2018, Doumit, et. al., 2010; Almegewly, et. al., 2018; Donnelly, et. al., 2017; Hwang, et. al., 2017; Saca-Hazboun, 2017; Elobaid, et. al., 2016; Haddou, et. al., 2016).

Breast cancer survivors were affected by the presence or absence of family support (Snyder & Pearse, 2010). Family and husband both were the source of support for the women throughout the course of the disease, differing the existing literature which demonstrates men dominance over women in Arabs in terms of health decision making. Women were open to talk about their disease and for some women, these were their husbands who encouraged them to go and see doctors (Participant 1, 2, section, 4.2.2.2c). This could be due to increased availability of information on the internet, increased awareness about breast cancer and screening by health authorities or social media information in the region. Although the findings of this study show no major social concerns yet; it is important for healthcare providers to understand that cancer survivors, when they are diagnosed or even when they are cured, often continue to experience psychosocial difficulties associated with the disease, such as cancer stigma and changes in relationships with their acquaintances, which are medically difficult to solve (Knapp, et. al., 2014; Lebel & Devins, 2008; Burg, et. al., 2015) therefore preventive interventions including couple-based interventions (Zimmermann, 2015) or psycho-oncology interventions (Faller, et. al., 2013) could be more effective to benefit patients and their spouses to gain advantage of it as they both adjust to cancer together.

5.6.4 EMOTIONAL CONCERNS OF BREAST CANCER SURVIVORS

Breast cancer has been acknowledged as a possible traumatic stressor, researchers have documented that dealing with breast cancer could result in poor psychological outcomes for instance, post-traumatic stress disorder or enhanced appreciation of life known as post-traumatic growth (Aydiner, et. al., 2019). These psychological issues can remain a concern for many survivors and these patients have an increased risk of major depression (Ewertz & Jenson, 2011). Many women report the need for emotional support for recovery (Thewes, et. al., 2004) and for well-being (Bloom, et. al., 2004).

In addition to information concerns, **the second most prevalent extreme concerns for breast cancer survivors were emotional concerns** (mean=15.05). Findings show that emotional needs which ranged from concerns associated with the cancer diagnosis itself, dealing with emotions and mixed emotions, fear of recurrence, genetic counselling, worrying about future and family particularly children, fear of losing job and loneliness were contributing factors which affected those women emotionally (Participant 2, 3, 4, 6, 7, 8, 9, section 4.2.2.2d). Fear of recurrence and *genetic counselling* were the most prevalent emotional concerns with a mean of 3.4 for each factor in quantitative results (Table 16). Also, there were **no significant differences** (**p>0.05)** in emotional needs between Emiratis and expatriates (Table 20). However, the multiple regression model explained the increase in emotional concerns with the increase in receiving treatment suggesting multiple treatment will add more to women's emotional burden (Table 22d).

Diagnosis of cancer is itself an emotional experience which brings other fears along with it. These fears relate to treatment, recurrence of cancer, getting through the process, being exposed to others or fear that other members of the family will also get the cancer. The results of this study reveal that most participants became sad and cried when they were told they had cancer (Participant 1, 3, 4, 6, 7, 8, section 4.2.2.2d). Women showed denial and worry at the time of initial diagnosis wondering whether their symptoms were serious or whether they really had cancer; most were not expecting the disease and were shocked and in a state of denial initially (Participant 8, section, 4.2.2.2d; Participant, 1, 3, 4, 5, 6, 7, 8, 10, section 4.2.2.1a; Price, 2019; Baio, 2017; Aydiner, et. al., 2019). They found it hard to accept that they had cancer (Participant 8, section 4.2.2.2d). Fear of recurrence continues after diagnosis in most survivors (Participant 3, 6, section 4.2.2.2d; Vickberg, 2001; Ferrell, et al., 1998). It was a distressing problem in most of survivors (Participant 3, 6, 7, section, 4.2.2.2d; Ziner, et. al., 2012). Fear of recurrence was also found a contributing factor to anxiety (Participant 3, section 4.2.2.2d; Aydiner, et. al., 2019).

Secondary problems such as pain and discomfort due to changes in the body were commonly reported after surgery which led to depressive symptoms (Participant 8, section 4.2.2.1b; Participant 4, 10, section 4.2.2.2a; Cordero, et. al., 2015; Bower, 2008). Surprisingly, some women had no issues at all with the physical appearance as physical appearance was the last thing that mattered to them, and they were rather worried about their family and children and describing their feelings that they must be strong as they have families and responsibilities towards them (Participant 2, section 4.2.2.2d; Castillo, et. al., 2019; Carroll-Johnson, 20006). It is more concerning to Arab women whose main role in the society and family is to be a care provider and protector of their children, husband and families as mothers, wives and daughters (Fearon, et. al., 2020).

Feelings of permanent and temporary loss were commonly depicted as concerns by the survivors associated with depression, anxiety and feelings of grief as women perceive their breast as something that makes them complete thus feel demoralised when they lose their breast (Alhusban, 2019; Mermer, et. al., 2016). Results showed that surgery not only creates an intensified sense of loss for some women, but it has the potential to unleash psychological reactions since it damages the symbolic connection of the breast to femininity and sexuality (Participant 6, 4.2.2.2a). The results of this study demonstrate that breast cancer impacted women’ functions, body image, perception, psychological state and relations with those around them (Participant 5, 6, 10, section 4.2.2.2d). Furthermore, it provoked various concerns and fear including fear of recurrence and passing it to family, difficulties for family mainly children, sexuality and loss of self-esteem etc.

One of the biggest worries found was fear of disease recurrence (Participant 3, 6, 9, section 4.2.2.2d). Although women in the UAE do not talk about sexuality or issues with sexual relationships which could be due to reserved culture however, they expressed their embarrassment of exposing the body, discomfort seeing and showing the scars or overall body changes (Fingeret, et. al., 2014; Collins, et. al., 2011). The first study on psychological reactions associated with surgery was conducted in 1952 by Renneker & Cutler which drew attention to the existence of grief defined by depression, anxiety, insomnia, guilt and defined the relationship between this state and organ loss. After that mastectomy practice has become a significant area of research to understand the relationship between cancer, organ loss and psychopathology (Özkan, et. al., 2010; Özkan, et. al., 2003).

Social isolation or changes in social interaction occurred with some of the survivors as they felt isolated and lost their interest in maintaining relationships with colleagues and friends (Participant 3, 6, section 4.2.2.2d). This either could be due to grief of cancer, lack of self-confidence, concerns that change of appearance may reveal a breast cancer diagnosis to others or to avoid the conversation on this topic. It is also worth considering that in Arab communities, family members tend to hide illness and disease from the community since cultural values require them to keep family issues within the home (Kane, et. al., 2020).

Ferrel, et. al., (1998) explained that breast cancer survivors continue to experience fatigue, pain, fear of breast cancer recurrence, fear of breast cancer in female relatives, and the stress of living with uncertainty and maintaining hope. Findings show that accepting that one has cancer was not easily digestible on any scale, it was overpowering and scary but most Muslims women with breast cancer eventually arrived at the stage of acceptance believing it is from Allah (God) (Participant 3, 4, 8 section 4.2.2.1a; Participant 3, 8, section 4.2.2.1d). Acknowledging one has a disease is half the battle. Accepting that one has a disease really allows a person to get in the fight towards beating cancer (Baio, 2017). Findings showed that most survivors did hope for a positive future while focusing on the present, possibly due to their stronger faith in almighty Allah (Participant 1, 3, 10, section 4.2.2.2e).

Some patients showed their concerns about the absence of not having psychologist and emotional support services available during their care process to receive appropriate psychological or emotional care (Participant 6, 7, section, 4.2.2.2b; Participant section, 6, 4.2.2.1d). However, this is usually the case in advanced countries where patients can request for a clinical psychologist (Giesler, et. al., 2019). These services are however, not usually part of the routine cancer care. Breast cancer survivors require holistic care from healthcare providers (Iddrisu, et. al., 2020). It is important that at every stage along the cancer continuum, the care delivered must address physical aspects of the illness in addition to the mental health and coping strengths of the patient and family (Carroll-Johnson, et. al., 2006).

5.6.5 SPIRITUAL OR RELIGIOUS CONCERNS OF BREAST CANCER SURVIVORS

Spiritual or religious concerns can be identified as concerns about a relationship with a higher-being, concerns about personal religious practices and concerns about meaning or purpose of life (Holland, et. al., 2015). Although spiritual or religious concerns are individuals' essential needs in all places and time (Yousefi & Abedi., 2011) but for cancer patients, spiritual or religious concerns are likely to reflect on existential issues due to uncertainty of their future (Nixon, et. al., 2013). Spiritual or religious concerns are highly correlated with depression, anxiety and a measure of overall distress (Wells-Di Gregorio, et. al., 2013).

In this study, participants shared their perceptions about their breast cancer experience and how their psychosocial needs had an impact on their lives. They described how they face daily life challenges due to cancer so life could be managed, how they learned to adapt to a new normal and manage their living with physical, emotional, social issues and how their faith helped them through the difficulties (Section 4.2.2.1) and ease their struggles and religion became the source of strength during cancer survivorship (Table 10, section 4.1.4). Thus, no spiritual or religious concerns found in this study (mean = 0.20, SD= 0.915), rather survivors' faith and belief in Allah (God) helped them accept the disease and suffering of cancer (Section, 4.2.2.2e).

The findings of this study are consistent with the research conducted earlier while presenting some new discoveries related to the unique UAE population (Assaf, 2017; Elobaid, at. al., 2016). The study findings confirmed that religion was a fundamental aspect of women living with breast cancer in this region (Jassim & Whitford, 2014; Lazenby & Khatib, 2012; Ahmad, et. al., 2011). It was also evident that religion was the source of strength for almost all survivors regardless of their nationality (Table, 10). Religion also was the central aspect for almost all survivors as they relied on their faith and religion more than any other source to get through the course of the disease and to attain hope.

Participants believed that religion is the way of life for all issues of Muslim's life (Nabolsi & Carso, 2011) and everything including disease, cure, life and death is in Allah's hand and it is Allah's decision too. In general, Muslims believe that Allah predetermines everything that happens to them in their lives including diseases (Khater & Alkwiese, 2013; Obeidat et al., 2013a; Alqaissi & Dickerson, 2010). The holy book "Quran" states that Allah is the disposer of affairs (Surat Al-Zumar 39:62); "And when I am ill, it is He who cures me" (Surat ash-Shu`ara` 26:80). Therefore, Muslims believe that Allah is the ultimate healer. Muslim breast cancer survivors believed that cancer is a test from Allah for their patience and tolerance thus they seek help through their faith as it is believed that disease expatiate their sins in this life (Khater &Alkwiese, 2013; Taha, 2012).

All participants believed that cancer has strengthened and has added more of their faith (tawakkal) in Allah (God) (Jassim & Whitford, 2014; Nizamli, et. al., 2011). They also described that their faith and religion was the source of strength, comfort and hope in line with the holy verse in Quran. "It is (the Qur'ãn) for those who believe, a guide and a healing" (Surat Fussilat 41:44). Their trust in Allah eased their experience and gave them the ability to cope up and deal with their worries and difficulties, suffering, pain and uncertainties and more importantly to accept their disease (Jassim & Whitford, 2014). Participants mentioned that they have become closer to Allah than ever before and have increased their prayer practice by investing their time more toward recalling and reminding Allah and reading the Quran - It is also mentioned in Surat AlBaqarah 2:155, "We will test you with something of fear, hunger and loss of wealth, and lives and vegetation. And give glad tidings to those who have patience".

These beliefs helped the Muslims to surrender to Allah and make them contend with whatever difficulties cancer brings to their lives (Jassim & Whitford, 2014; Doumit, et. al., 2009). Literature suggests that cancer survivors who practiced religious activity more frequently daily had better health behaviours for instance, greater likelihood to follow their physicians' advice, an association that was mediated by self-assurance. In contrast, higher reports of religious struggle for instance, feeling abandoned or punished by God were associated with poor health behaviour, an association that was mediated by guilt (Park, et. al.,2009). Thus, it is important to screen cancer patients for their religious or spiritual distress and possibly for their beliefs that may influence cancer related health behaviour negatively such as beliefs that may compromise the adherence to guidelines and treatment. The quantitative finding also showed that **end of life** concerns were the most prevalent in the spiritual domain and there were no significant differences in spiritual or religious concerns in both groups, that is Emiratis and expatriates.

Spiritual or religious needs related to patients' disease can affect their mental health and failure to meet these needs may impact their quality of life (Arrey, et. al., 2016), which is an important concept of cancer care. Musick, et. al., (1998) observed that the use of spiritual or religious coping may be more commonly observed in black race since they face more discrimination and prejudice in general. Earlier studies also have reported association between religious or spiritual practices and well-being by race with higher levels of spiritual well-being in blacks than whites, yet the question remains if these differences in religious or spiritual practices are associated with differences in higher quality of life or to health disparities (Canada, et. al., 2013). Ell & Nishimoto (1989) found some notable differences in coping between Non-Hispanic, White and Hispanic cancer patients where Hispanics tend to have more difficulty accepting cancer than other groups and were more likely to rely on religion than Whites.

Nevertheless, further research is needed on whether religious or spiritual practices or cultural practices remain constant or changes across cancer trajectory. It is also important to be aware of cultural and religious differences when looking at patterns of adjustment to cancer. A knowledge of the role that religion and spirituality play in the patients’ life may enable healthcare professionals to understand how religious or spiritual beliefs affect patients’ response to cancer diagnosis and decisions about treatment. This study explains how survivors’ faith in Allah (God) permeates all aspects of cancer survivorship, believing cancer is Allah’s will and almighty is the healer. Their strong faith in Allah strengthened and guided them to live through the life-threatening disease. Therefore, while assessing cancer patients’ spiritual or religious needs, healthcare providers must understand that western cultures use different coping strategies than individuals from non-western cultures (Barg & Gullatee, 2001).

5.6.6 QUALITY OF LIFE OF BREAST CANCER SURVIVORS

In this study, all participants expressed their satisfaction with the care received at the cancer facility stating they were fully satisfied with the treatment received and the staff. Yet, they made suggestions to improve cancer services stating that the presence of nutritionist and psychosocial services while receiving definitive cancer treatment would improve the current cancer care. Additionally, information delivery was one of the aspects of care that was highlighted for improvement. Other services such as efficient pharmacy services and enhanced coverage for mandate to include other comorbid conditions for those who cannot afford cancer care were few expectations from the cancer survivors who were interviewed that were suggestive of enhancing their cancer experience.

The World Health Organization (2021) defined quality of life as individuals' perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, standards, and concerns. The results of this study show that the majority of cancer survivors deemed their quality of life as good, representing the majority of women who possessed a good quality of life (Mean=9.40). There was a **negative correlation between quality of life and the scores of psychosocial concerns including physical, social, emotional as well as spiritual concerns** ($p < 0.01$). The results indicated that the higher the psychosocial concerns (including physical, social, emotional as well as spiritual or religious concerns), the lowest the quality of life as in line with the literature (Edib, et. al., 2016; DiSipio, et al., 2009; Avis & Crawford, 2005). However, there was a **positive correlation between quality of life and information concern** ($p < 0.01$, table 21), suggesting if quality of life scores increases, the information concerns also increase along with it suggesting those cancer survivors who scored higher in the information domain also reflected higher scores in quality-of-life assessment which is quite consistent with the previous studies (Park & Hwang, 2012; Carey, et. al., 2012; Uchida, et. al., 2011).

5.7 REFLECTIONS

***"For the story of my life is always embedded in the story of those communities from which I derive my identity….the self has to find its moral identity in and through its membership in communities such as those of the family, the neighbourhood, the city, and the tribe….without those moral particularities to begin from there would never be anywhere to begin; but it is in moving forward from such particularity that the search for the good, for the universal consist** – Alasdair Macintyre, 1984 - 221"*

As I reflect on my journey writing this dissertation, I think about how much I have learned and experienced personally and professionally over the last few years. The experience of being a researcher pushed me to explore my own strengths and weaknesses in a unique way both personally as well as academically which I have learnt how to overcome diligently. I feel proud of the work I have done and became the voice of vulnerable people with cancer who may have spoken for the first time since in my opinion, this was the first mixed method study on psychosocial needs exploration of cancer survivors in the United Arab Emirates.

I began my PhD because of my sheer passion in Oncology which I developed during my employment and dealing with cancer patients records and reading their stories and gathering information for healthcare providers so they could do the needful to provide the best possible care. While working in the biggest Oncology centre in the country, I have seen how breast cancer patients suffer from depression besides the consequences of illness and its treatment. I was concerned about the care survivors receive which is quite fragmented. I have raised this concern in several Oncology task force meetings during my employment. This triggered my compassion and curiosity both towards cancer patients who often are treated for their disease not as a whole.

These concerns renewed numerous times even while conducting the research when I was speaking to the cancer survivors about their concerns. My passion guided me to bridge the observed gaps between oncology practice and survivorship and I am extremely grateful for the opportunity to share my knowledge that I gathered through this research with others to make a positive impact in cancer survivors' lives. I remember, survivors overwhelmingly showed the highest gratitude and thanked me for addressing their unidentified needs and acknowledging the existence of their ongoing and unidentified problems. I feel very proud and fortunate to take this opportunity and become the voice of the cancer survivors. As a principal investigator my study allowed me to critically explore the challenges associated with breast cancer in the cultural context. The current oncology practice in the UAE focuses mainly on treating the disease not a person. As a result, most patients either go unnoticed or accept the disease as it is, do not question local medical practices and some seek treatment abroad if they can afford to which is most likely the case. However, cancer is not a static disease and it can continue throughout a person's life. Those who return to the country need to seek or continue treatment locally. I believe very strongly that it is time to reflect and improve current local practices and incorporate survivorship care as part of the standard oncology practice so individuals could be screened for psychosocial needs associated with cancer rather than just receiving the treatment. While working in Tawam Hospital and having my workplace in the middle of the oncology ward made me even more determined to conduct this research and I felt great compassion when I used to see patients in waiting room waiting for their chemotherapy sessions. Most of them used to look fatigued and struggling with their disease. Most patients used to come for treatment sessions only. Physicians' time was also a challenge as it was mainly to allocate the right protocol as per defined cancer staged not by their psychosocial needs. I was very much aware of most of the common issues and challenges that are faced by breast cancer survivors in the UAE in terms of disease as well as healthcare practices which became the main driving force for me to conduct this research and wanting to make a difference. During the research, I personally was very touched by cancer patients and built a real connection with them as I came to understand their emotional needs. The appreciation I received from the participants motivated me to pursue my research and attempt to guide policy makers and leaders to uncover the reality that is usually not investigated by clinicians. I realised that it is important to gain patients' trust to understand and treat them well and with due consideration of the whole person. I was surprised on many occasions to know how others perceive women's stance in the UAE, without an appreciation of how very knowledgeable women are and fully able to address their concerns and guide health providers about their choices if they are given an opportunity to express themselves. I also agree that health providers need to build a partnership with their patients with shared autonomy of decision-making process and meeting their unique needs.

With regards to methodological reflections, verification of face validity of the survey and to ensure that the survey items were well formulated, it was pilot tested on five Emiratis and five expatriate cancer survivors during their waiting time in the Radiotherapy unit at Tawam Hospital assisted by the Oncologist. The pilot testing assured the consciousness of cultural sensitivity, prior adjustments and the mutual interest of cancer survivors to take part in the research. Additionally, the opinion from the oncology physician regarding usage of appropriate wording in the survey poised the survey readiness. The survey results were further verified by reviewing their health records in the registry to resolve any discrepancies in the responses whether demographics or clinical. The comparison showed that responses were accurately recorded without any conflicts. The selection of interview questions was a meticulous process which covered all psychosocial aspects of survivors' needs. Field notes were taken for each interview to relate findings with conscious observations of speech, pauses and gestures as well as my own perspectives. Distinctions were made between data and field notes to eliminate preconceptions through self-reflection.

Analytical reflections include peer and participants' review of all analytical stages and rechecking results and interpretations. Peer reviews include residents and physicians working in the Oncology unit at Tawam Hospital Breast Care Centre who were involved in the patient care, thus adding more authenticity of findings. Moreover, two qualitative research experts were contacted to provide suggestions, review the applied thematic analysis and to verify results from the Faculty of Medicine, UAE University which is located adjacent to Tawam Hospital. There were few suggestions on refinement and addition of sub-themes which were added at a later stage of writing. Results were also shared with participants over the phone to ensure that interviewed were interpreted and reported accurately and to gain true perspectives of cancer survivors on their needs.

Since the lack of awareness of survivorship care both at patients and healthcare setting level, the findings may fall short given that cultural norms and different backgrounds and regional settings may have masked the identification of survivors' needs. Thus, caution must be taken in applying these findings to other contexts while indicating the need of further research on cancer survivors' needs addressing psychosocial forces and cultural disparities and expectations to improve their cancer experiences and survivorship. The research also suggests opportunities for innovation in the public health practices to design cancer control framework encompassing survivorship as a recognised part of cancer care continuum, develop guidelines of survivorship care as part of routine practices and encourage and develop strategies and interventions that engage survivors in their care processes promoting shared care and patient physicians partnership models that could aim to meet their needs and improve their quality of life.

5.8 STRENGTHS AND LIMITATIONS

This study possesses some unique values and strengths. With the best of the knowledge this is the first ever study in the United Ara Emirates as well as in the region that addresses the needs and concerns of breast cancer survivors (UAE's top most common cancer) utilising mixed methods approach and adds some great value by confirming the existing and producing some new knowledge towards cancer survivorship literature. The study demonstrates the strengths and advantages of combining both qualitative and quantitative approaches in a mixed-method study. The quantitative survey gathered the information from cancer survivors identifying their needs at different points of cancer trajectory. The rich and descriptive data obtained from the qualitative interviews offer evidence-based information on breast cancer survivors' concerns which will help provide valuable insight to guide policy makers and healthcare providers establishing evidence-based survivorship programs to meet their unique needs and to improve cancer care. It also addresses the key concerns to consider for prevention and remediation efforts. Since the study is apparently the first of its kind to examine the psychosocial concerns of people living with breast cancer, it makes a significant contribution in highlighting an important area for further study in the United Arab Emirates, and furthermore benefits from using mixed methods to give more comprehensive and meaningful results in this area.

Although this study provides insight into breast cancer survivors' concerns representing the larger cancer population in the UAE, it is not without limitations. A number of factors hampered the research process among which ethics approval from both Tawam Hospital and University of Salford was predominant as it took longer than anticipated timeframe which delayed the process of data collection. Delayed approval altered the timeframe resulting in the loss of some participants as they left the country for the preferred treatment. Bear in mind that Emiratis (local) patients are supported by the government to be treated outside the UAE on its expenses, thus most Emiratis prefer to be treated at world-class facilities in countries such as Singapore, Thailand, Korea, US or UK.

An additional view that was not considered in this study was whether or not the participants received all the care at another facility whether outside the country or at another clinical setting and attended Tawam Hospital for just follow-up as there is a possibility that their concerns with the current health providers either could have been missed if the current care was given at the optimal grounds and they were all satisfied and revealed only the current needs. Switching healthcare providers or treatment facilities might have implied some degree of bias in the evaluation of survivors' needs and this factor was not considered in the current study. Moreover, it is not uncommon that some of the cancer patients prefer to seek treatment at other private facilities either due distance to their residence or to some extent due to an inaccessibility to afford treatment which could be due to lack of insurance coverage and never visited Tawam Hospital.

Also, it is important to consider that the concerns of breast cancer survivors were assessed for a recent timeframe of the past one week which gave critical insight into women's breast cancer needs and concerns at a potentially reflective point. The approach allowed identification of concerns at that particular phase which undoubtedly overlooked acute psychosocial concerns or needs that they might have confronted earlier. However, if these were asked about the concerns, they had years prior, this would introduce a recall bias. The data obtained at one point of the study from the selective group of cancer survivors might not be able to capture the changes in breast cancer survivors' concerns over time and changes over the trajectory of cancer survivorship. Although most women were able to speak English, it still needs to be taken into consideration that for those who did not, some material and nuance will inevitably have been lost in translation from Arabic to English.

According to Doyle (2008), cancer survivorship is a dynamic and evolving journey that begins with a diagnosis and continues through the remainder of a person's life however this cross-sectional study design does not favour the assessment of psychosocial constructs over time that is; pre-diagnosis, during treatment and post-treatment to examine and explore the changes in patterns of psychosocial functioning and health behaviour across the continuum of the cancer experience. A longitudinal study of cancer survivors' needs, and their concerns is therefore required to best understand the critical and gain complete insights on ever changing unique concerns of breast cancer survivors such as assessment of needs after the diagnosis phases, during the treatment and after the treatment for instance after five years of treatment.

Other limitations including methodological as well as organisational limitations inherited in the study that might affect the generalization of the results must be acknowledged before drawing implications from the study findings. Limitations of the qualitative phases included the potential for bias in the selection of participants through purposive sampling. The participants were selected based on their availability and willingness to be part of the study, so it is possible that interviews with other participants would have yielded different results. The qualitative results were intended to add depth and breadth to understanding the lived experienced of cancer survivors, and should not be generalised to the general population. Although Tawam Hospital is a national referral centre for cancer patients yet; the selected sample size was not fully representative of the entire cancer population in the United Arab Emirates as some patients might have not visited to Tawam for the treatment and received treatment at other facilities or abroad.

Another inconvenience was the inaccessibility recruitment site, Tawam Hospital is considerably far for the majority of the cancer patients who mostly resides in other emirates which are considered distant, thus, arranging an interview during the follow-up visit was quite a challenge as patients were required to stay even longer during their farthest visit.

Participants were largely expatriate and among most of them had health coverage whereas Emiratis were just fully covered by national health insurance and were also entitled to get treatment abroad utilising the government funds thus financial concerns were hard to assess and were not fully representative of entire population and if assessed among a different sample, would have most likely yielded different study results.

Perhaps the biggest limitation was scarcity of research into psychosocial aspects of breast cancer in this region which might not allow comparison or integration of the study findings with other populations or groups. This is the first study to explore breast cancer survivors' concerns in the UAE.

5.9 IMPLICATIONS

The psychosocial impact that cancer causes is devastating, severe and enduring and affects individuals, their families and their loved ones. While delivering cancer care, it is essential to address not only the physical but mental health also to be taken into by routine screening for any psychological or emotional distress or other related symptoms. Additionally, patients and their family must also be educated for coping mechanisms to deal with the life-threatening illness.

This study indicates that psychosocial concerns and needs of cancer patients in the UAE are continuous throughout the cancer trajectory which should be met to improve cancer survivorship. The study addresses that a considerable portion of the women desire prolonged psychosocial intervention throughout the cancer trajectory. Data also indicates that cancer survivors in the UAE have different dimensions of needs where information, emotional and physical concerns are the highest that require serious attention.

The findings provide several opportunities to improve a number of key aspects of cancer care and toward meeting the psychosocial needs of cancer survivors that are usually missed during the routine cancer care as most physicians' treat cancer patients for the biological aspect of the disease missing out psychosocial concerns. Most important is to break the silence and hear the concerns of the patients. A key barrier to addressing psychosocial well-being of cancer survivors is that providers do not ask about it, and this is compounded by their reluctance to discuss their personal concerns. It is vital that providers include the routine screening and assessment of cancer survivors' psychosocial needs including anxiety and depression as a part of care across the cancer care trajectory. Future policies could support the proactive identification of at-risk survivors within the medical setting as a standard of practice. The findings inform that a holistic oncology model is needed that includes psychosocial and survivorship care as a distinctive part of it. The higher prevalence of information and emotional concerns among breast cancer survivors living in the UAE supports the need for both active screening and the use of a range of culturally tailored interventions to address and meet those needs timely and efficiently.

Identifying and recognizing that each cancer patient has unique cancer experience, and their needs are unique too, is an important element to remember while establishing and providing cancer services. Cancer care facilities should consider establishing a structured survivorship program which should include psychosocial services including all psychosocial domains to meet the needs of all cancer patients which are unique, specific and ongoing. A comprehensive and carefully considered approach to meet the challenges and barriers in survivorship care should be used in the delivery of cancer follow-up. Survivorship care plans, including written treatment summaries and plans for follow-up care, have been suggested as a means for providing adequate information and improving survivor outcomes. Thorough examination of survivors' needs, development and testing of survivorship care models, assessment of provider knowledge as well as future research is needed to establish understanding of the barriers and possible solutions necessary to deliver high-quality cancer care.

Cancer survivorship has ascended as an important aspect of cancer care and has been recognised as a crucial component of cancer care. Standard setting organizations for cancer care, such as American Society of Clinical Oncology (ASCO) and National Cancer Institute (NCI) advocate strongly to address the needs of cancer survivors by establishing and promoting standards for oncology and cancer care and to consider psychosocial and survivorship care as part of cancer program and routine services. The National Cancer Institute (US) has established the Office of Cancer Survivorship to create more awareness of survivorship issues experienced by cancer survivors, particularly post-treatment. Health organizations in the UAE are required to raise awareness of cancer survivors’ needs and recognise cancer survivorship as a distinct phase of the cancer continuum that needs to be incorporated in the standard cancer care. Risk assessment and intervention should be considered both at diagnosis and follow-up so that healthcare providers can better understand how cancer treatment may affect a patient’s life as a survivor and tailor treatment accordingly. Giving the right therapy to the right person at the right time should be the goal. High risk individuals need to be identified and addressed for second malignant neoplasms by primary prevention. Additionally, appropriate and personalised treatment will help in reducing morbidity, and to minimize late effects and optimize healthcare resources.

Also, there is an urgent need to integrate evidence-based psychosocial services into current cancer care delivery from the time of diagnosis and in follow-up focusing on prevention of late and long-term effects. This requires collection of outcomes data on survivors and continuous follow-up care.

New care delivery models will require the development and implementation of quality measures focused on survivorship care. Hence, an adequately educated and trained workforce will be needed to identify, address and manage survivorship issues to meet cancer survivors' psychological needs. Healthcare providers need to develop the core knowledge about the impact of cancer diagnosis and treatment on cancer patients' lives. Likewise, cancer survivors need to be educated and given accurate and timely information about what to expect after the diagnosis, treatment and after the completion of treatment. Clinicians might not have the expertise that they need to address many possible issues reported by survivors therefore guidance may require to address and manage survivor's physical and emotional health, health behaviours and other psychosocial concerns since these remain throughout the cancer survivorship and if unmet can negatively affect quality of life. Survivors need to be fully informed about the psychological changes that may occur, the long-term physical effects of treatment, the impact of the financial or social issues on disease and the effect of the disease on an individual and their family.

Cancer survivors should be prepared for the anxiety that is associated with follow-up medical appointments, symptoms monitoring, self-care, the end of treatment, reactions when returning to work and disease related emotions to provide them support and reassurance. They must be encouraged to seek medical assistance for all aspects of their disease and must continue medical follow-up. They should be provided full information of resources and support groups available. Moreover, family members and their caregivers also need to be prepared and educated about the process of survivorship.

This study indicates that women in the UAE express a need for an immediate intervention right after diagnosis in order to get prepared for what may occur in future. Having said that, it is important to understand and accept that healthcare systems are increasingly depending on each individual for follow-up as breast care is rapidly changing. Resources to provide psychosocial care are no exception in the UAE as they continue to be a challenge to constantly push to meet cancer patients' needs and the need of psychosocial support is dire. Thus, healthcare professionals may need to alter their understanding about how to best provide psychosocial support women with breast cancer to enhance their experience using cost-effective techniques that help survivors to help themselves.

This could be possible by providing them with an early emotional foundation on which they can stand more firmly throughout the disease trajectory. In order to achieve this, healthcare providers need to find ways to work smarter in a system where the level of psychosocial support provision becomes a routine, and this may be accomplished by focusing on better preparing cancer survivors for what lies ahead when they are diagnosed and when they complete their treatment. It is critical to assess the quality of psychosocial services once implemented to ensure their needs are met. Structured survivorship programs will ensure that all cancer patients receive appropriate survivorship care (IOM, 2008, 2006) to provide quality cancer care encompassing all aspects of psychosocial needs of cancer survivors. Results from this study can support and guide survivorship care services focusing on information, physical and emotional needs and setting up resources to help manage these concerns for instance, fear of recurrence, genetic counselling, pain, fatigue, emotional support etc. Since “no formal survivorship program” exists either locally or at national level, thus, this study can be the foundation to address the need for a structured survivorship program and guide facilities and authorities.

Cancer survivorship has been a neglected area with little awareness both among physicians and cancer survivors. Study findings call for further research since the subject has not been given much attention and studied despite having a high incidence of cancer and having the best and modern healthcare system and facilities in the UAE. Future psychosocial research needs to be the priority to find ways to support breast cancer survivors and provide immediate effective support. Longitudinal studies are imperative to understand changes in survivor’s needs and concerns overtime. Also, more knowledge about symptom management will result in improving the survivor's well-being.

Approaches to develop measurement instruments to measure these needs to allow direct comparison of patients’ needs should also be considered for future research. Additionally, more research is needed using different research designs including qualitative methods and mixed methods in this area as there are only few studies that have been conducted which mostly have utilised quantitative methodology. Using qualitative and mixed methods, psychosocial concerns could be explored, and in-depth understanding can be gained. Although this study has identified key concerns of cancer survivors, yet further research is required to explore how these needs could be met. Finally, an establishment of a psychosocial registry should be considered to make predictions and prioritizations of psychosocial services and its allocation in the future.

SUMMARY

There are thousands of cancer survivors in the United Arab Emirates who are getting older and are receiving treatment across healthcare settings. Although, UAE health systems have made a remarkable progress lately, it is important to focus on improving the quality of comprehensive survivorship care. The study findings provides a comprehensive survivorship care road map to address and systematically improve the quality of psychosocial care for cancer patients that may be used across the cancer population in the United Arab Emirates. This study proposes several strategies for healthcare systems, policy, research and cancer survivors aiming to address gaps in knowledge and policy and to implement effective and evidence-based clinical survivorship care that meets the need of cancer patients in the UAE.

Implications for Healthcare Systems

- Psychosocial distress screening & survivorship care to be part of routine care
- Develop survivorship care guidelines for clinical and psychosocial needs
- Provision of ‘Treatment/survivorship care plan’ to each survivor
- Coordinated, unfragmented, comprehensive and culturally sensitive patient-centred cancer care
- Enhance physician patient partnership & patient empowerment
- Transition from medical paternalism to patient autonomy
- Develop evidence-based interventions
- Education & training of health care professionals

Implications for Policy

- Reimbursement for essential post-treatment survivorship care
- Enhance cancer mandate coverage
- Develop professional guidelines and training on cancer survivorship care
- Measures to address shared decision making and patients satisfaction in health promotion and disease management
- Develop evidence-based, culturally appropriate information and resources to meet the needs of survivors

Implications for Research

- Funding for survivorship research to increase evidence base
- Further research on cancer psychosocial care and survivorship care
- Education of policy makers to increase awareness of survivorship issues

Implications for Cancer Survivors

- Awareness about psychosocial concerns & survivorship care in general public
- Develop models for cancer survivorship to help empower survivors to manage their survivorship care

The final chapter of this dissertation presents conclusions that were drawn from this research and summarizes the viewpoints that were extrapolated from the study findings.

Chapter 6: CONCLUSIONS

"Becoming human is becoming individual, and we become individual under the guidance of cultural patterns, historically created systems of meaning in terms of which we give form, order, point, and direction to our lives (Geertz, 1973, pg. 13)".

There are thousands of adults and children in the UAE who are cancer survivors. Most of them are often relieved by the end of the treatment yet the transition to a new normal could be quite challenging which may impact them not just physically but also mentally and emotionally. It may require adjustment to a new world, new emotions, new concerns, new ways of support as their perspective to the world changes after being diagnosed with cancer.

Comprehensive cancer care delivery requires coordinated care and the provision of services that meets the unique needs of cancer survivors. Physicians-led care can be suboptimal; hence healthcare professionals need to work in partnership with cancer survivors to offer a holistic approach that addresses and meet cancer survivors needs throughout the cancer continuum by developing new models of shared care. This research emphasises on the critical and often neglected role of healthcare providers in addressing cancer survivors needs which may differ among the diverse UAE population. Additionally, it also underscores the increasingly important role of the breast cancer survivors

Cancer survivorship awareness and the rise of cancer survivors in the UAE has enabled the need of more coherent research in this region to acquire evidence-based knowledge about this unexplored area. Standard cancer care practices in the UAE need to implement standard guidelines for survivors' clinical and psychosocial needs which are often lacking in routine care. Each cancer survivor needs to be provided with a survivorship care plan while transitioning to post-treatment period as part of a standard oncology practice. for each survivor. There is a need to identify gaps in cancer survivorship research in the UAE including survivors' psychosocial needs, need of coordinated care, management of long-term and late psychosocial effects, need to understand ethno-cultural disparities among cancer survivors which may lead to the development an efficient healthcare system and delivery of more comprehensive, coordinated and evidence-based quality care to the UAE residents. Moreover, such applied research can guide and form the basis of development of evidence-based guidelines for the provision of culturally sensitive and quality cancer care.

Nonetheless, without integrative care models, advocacy, proper reimbursement and placement of incentives for healthcare professionals to administer survivorship care provided limited resources and time constraints could be challenging. Thus, appropriate policies and advocacy efforts will be needed to ensure the implementation of person-centred compassionate quality cancer care in the UAE.

This research fills the existing knowledge gap regarding the breast cancer survivors' psychosocial needs in the United Arab Emirates. The mixed method design adds to the literature that breast cancer survivors experience a variety of psychosocial health effects resulting from cancer and its treatment which impact their lives in numerous ways. To navigate with these changes and adapting to a new normal is a dynamic process of adjustment to life changes. Survivors' needs could differ by age, gender, ethnicity and clinical presentation of the cancer; thus, it is important to design and implement culturally relevant intervention to meet their unique needs. Although this research was limited to breast cancer survivors only in one geographic region of the country, this study provides a conceptual model to develop an integrated care model to enhance physician patient partnership. Nevertheless, further understanding is needed to refine this model to address the dynamics and multifaceted aspects of breast cancer survivors needs by conducting further research which can serve as a framework to guide future oncology practice in the UAE.

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Chapter 8: APPENDICES

Following are the list of documents provided in this section:

Appendix 1: General Consent Form Tawam Hospital

- Appendix 1a: General Hospital Consent Form - Original
- Appendix 1b: General Hospital Consent Form - Highlighted
- Appendix 1c: Email confirmation

Appendix 2: IRB Approvals

- Appendix 2a: IRB approval Tawam Hospital
- Appendix 2b: IRB approval Tawam Hospital - Extension
- Appendix 2c: IRB approval Salford University

Appendix 3: Written Consent Form

- Appendix 3a: Written Consent Form - English
- Appendix 3b: Written Consent Form - Arabic

Appendix 4: Patient Information Sheet

- Appendix 4a: Patient Information Sheet - English
- Appendix 4b: Patient Information Sheet - Arabic

Appendix 5: Cancer Patients' Need Survey

- Appendix 5a: Cancer Patients' Need Survey - English
- Appendix 5b: Cancer Patients' Need Survey - Arabic

Appendix 6: Data Collection Form Cancer Registry

Appendix 7: Risk Assessment Form

Appendix 8: Data Confidentiality Form

Appendix 9: Survivorship Care Plan (SCP)

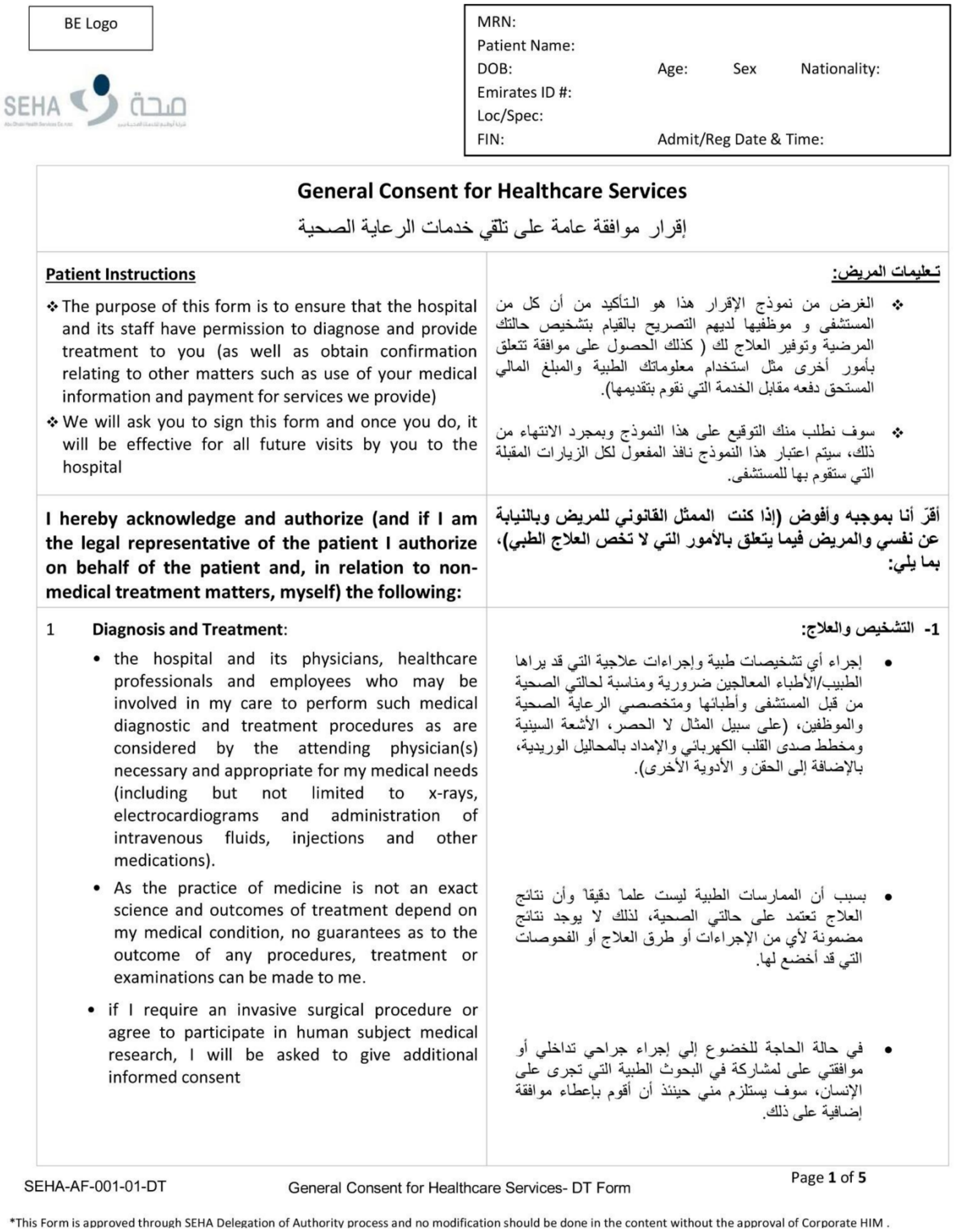
Appendix 10: Quantitative Data Extraction File

Appendix 11: Qualitative Interviews

Appendix 12: Glossary of terms used (Abbreviations)

Appendix 13: Approved Permission Mayo Clinic Survey

APPENDIX 1a: GENERAL CONSENT FOR HEALTHCARE SERVICES - ORIGINAL



BE Logo

MRN:
Patient Name:
DOB: Age: Sex Nationality:
Emirates ID #:
Loc/Spec:
FIN: Admit/Reg Date & Time:

General Consent for Healthcare Services

إقرار موافقة عامة على تلقي خدمات الرعاية الصحية

Patient Instructions ❖ The purpose of this form is to ensure that the hospital and its staff have permission to diagnose and provide treatment to you (as well as obtain confirmation relating to other matters such as use of your medical information and payment for services we provide) ❖ We will ask you to sign this form and once you do, it will be effective for all future visits by you to the hospital	**تـعليمات المريض:** ❖ الغرض من نموذج الإقرار هذا هو الـتأكيد من أن كل من المستشفى و موظفيها لديهم التصريح بالقيام بتشخيص حالتك المرضية وتوفير العلاج لك (كذلك الحصول على موافقة تتعلق بأمور أخرى مثل استخدام معلوماتك الطبية والمبلغ المالي المستحق دفعه مقابل الخدمة التي نقوم بتقديمها). ❖ سوف نطلب منك التوقيع على هذا النموذج وبمجرد الانتهاء من ذلك، سيتم اعتبار هذا النموذج نافذ المفعول لكل الزيارات المقبلة التي ستقوم بها للمستشفى.
I hereby acknowledge and authorize (and if I am the legal representative of the patient I authorize on behalf of the patient and, in relation to non-medical treatment matters, myself) the following:	**أقرّ أنا بموجبه وأفوض (إذا كنت الممثل القانوني للمريض وبالنيابة عن نفسي والمريض فيما يتعلق بالأمور التي لا تخص العلاج الطبي)، بما يلي:**
1 **Diagnosis and Treatment**: • the hospital and its physicians, healthcare professionals and employees who may be involved in my care to perform such medical diagnostic and treatment procedures as are considered by the attending physician(s) necessary and appropriate for my medical needs (including but not limited to x-rays, electrocardiograms and administration of intravenous fluids, injections and other medications). • As the practice of medicine is not an exact science and outcomes of treatment depend on my medical condition, no guarantees as to the outcome of any procedures, treatment or examinations can be made to me. • if I require an invasive surgical procedure or agree to participate in human subject medical research, I will be asked to give additional informed consent	**1- التشخيص والعلاج:** • إجراء أي تشخيصات طبية وإجراءات علاجية التي قد يراها الطبيب/الأطباء المعالجين ضرورية ومناسبة لحالتي الصحية من قبل المستشفى وأطبائها ومتخصصي الرعاية الصحية والموظفين، (على سبيل المثال لا الحصر، الأشعة السينية ومخطط صدى القلب الكهربائي والإمداد بالمحاليل الوريدية، بالإضافة إلى الحقن و الأدوية الأخرى). • بسبب أن الممارسات الطبية ليست علماً دقيقاً وأن نتائج العلاج تعتمد على حالتي الصحية، لذلك لا يوجد نتائج مضمونة لأي من الإجراءات أو طرق العلاج أو الفحوصات التي قد أخضع لها. • في حالة الحاجة للخضوع إلي إجراء جراحي تداخلي أو موافقتي على لمشاركة في البحوث الطبية التي تجرى على الإنسان، سوف يستلزم مني حينئذ أن أقوم بإعطاء موافقة إضافية على ذلك.

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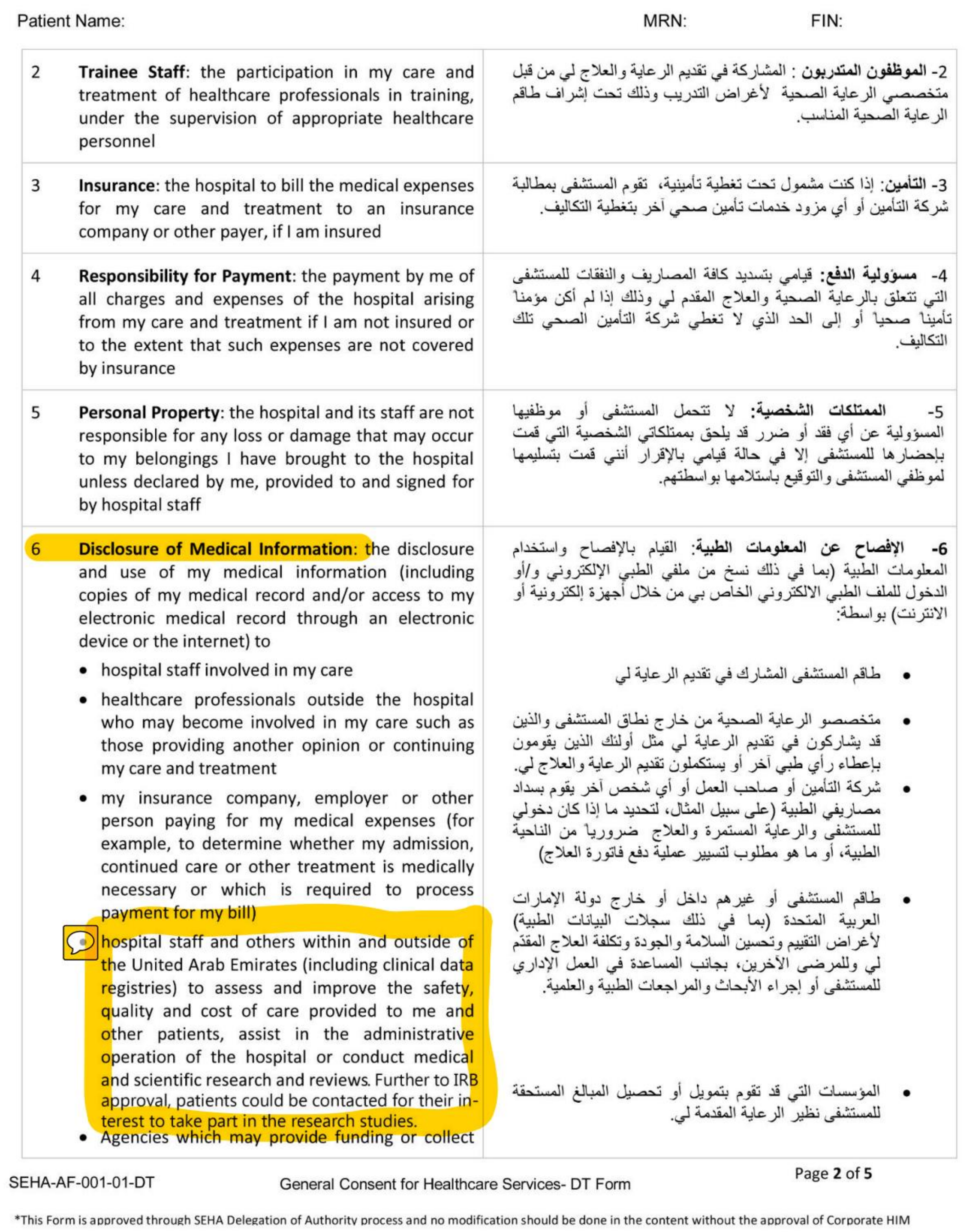
*This Form is approved through SEHA Delegation of Authority process and no modification should be done in the content without the approval of Corporate HIM .



Patient Name: MRN: FIN:

2	**Trainee Staff**: the participation in my care and treatment of healthcare professionals in training, under the supervision of appropriate healthcare personnel	2- **الموظفون المتدربون** : المشاركة في تقديم الرعاية والعلاج لي من قبل متخصصي الرعاية الصحية لأغراض التدريب وذلك تحت إشراف طاقم الرعاية الصحية المناسب.
3	**Insurance**: the hospital to bill the medical expenses for my care and treatment to an insurance company or other payer, if I am insured	3- **التأمين**: إذا كنت مشمول تحت تغطية تأمينية، تقوم المستشفى بمطالبة شركة التأمين أو أي مزود خدمات تأمين صحي آخر بتغطية التكاليف.
4	**Responsibility for Payment**: the payment by me of all charges and expenses of the hospital arising from my care and treatment if I am not insured or to the extent that such expenses are not covered by insurance	4- **مسؤولية الدفع:** قيامي بتسديد كافة المصاريف والنفقات للمستشفى التي تتعلق بالرعاية الصحية والعلاج المقدم لي وذلك إذا لم أكن مؤمناً تأميناً صحياً أو إلى الحد الذي لا تغطي شركة التأمين الصحي تلك التكاليف.
5	**Personal Property**: the hospital and its staff are not responsible for any loss or damage that may occur to my belongings I have brought to the hospital unless declared by me, provided to and signed for by hospital staff	5- **الممتلكات الشخصية:** لا تتحمل المستشفى أو موظفيها المسؤولية عن أي فقد أو ضرر قد يلحق بممتلكاتي الشخصية التي قمت بإحضارها للمستشفى إلا في حالة قيامي بالإقرار أنني قمت بتسليمها لموظفي المستشفى والتوقيع باستلامها بواسطتهم.
6	**Disclosure of Medical Information**: the disclosure and use of my medical information (including copies of my medical record and/or access to my electronic medical record through an electronic device or the internet) to • hospital staff involved in my care • healthcare professionals outside the hospital who may become involved in my care such as those providing another opinion or continuing my care and treatment • my insurance company, employer or other person paying for my medical expenses (for example, to determine whether my admission, continued care or other treatment is medically necessary or which is required to process payment for my bill) • hospital staff and others within and outside of the United Arab Emirates (including clinical data registries) to assess and improve the safety, quality and cost of care provided to me and other patients, assist in the administrative operation of the hospital or conduct medical and scientific research and reviews. Further to IRB approval, patients could be contacted for their interest to take part in the research studies. • Agencies which may provide funding or collect	6- **الإفصاح عن المعلومات الطبية:** القيام بالإفصاح واستخدام المعلومات الطبية (بما في ذلك نسخ من ملفي الطبي الإلكتروني و/أو الدخول للملف الطبي الالكتروني الخاص بي من خلال أجهزة إلكترونية أو الانترنت) بواسطة: • طاقم المستشفى المشارك في تقديم الرعاية لي • متخصصو الرعاية الصحية من خارج نطاق المستشفى والذين قد يشاركون في تقديم الرعاية لي مثل أولئك الذين يقومون بإعطاء رأي طبي آخر أو يستكملون تقديم الرعاية والعلاج لي. • شركة التأمين أو صاحب العمل أو أي شخص آخر يقوم بسداد مصاريفي الطبية (على سبيل المثال، لتحديد ما إذا كان دخولي للمستشفى والرعاية المستمرة والعلاج ضرورياً من الناحية الطبية، أو ما هو مطلوب لتسيير عملية دفع فاتورة العلاج) • طاقم المستشفى أو غيرهم داخل أو خارج دولة الإمارات العربية المتحدة (بما في ذلك سجلات البيانات الطبية) لأغراض التقييم وتحسين السلامة والجودة وتكلفة العلاج المقدّم لي وللمرضى الآخرين، بجانب المساعدة في العمل الإداري للمستشفى أو إجراء الأبحاث والمراجعات الطبية والعلمية. • المؤسسات التي قد تقوم بتمويل أو تحصيل المبالغ المستحقة للمستشفى نظير الرعاية المقدمة لي.

Patient Name: MRN: FIN:

	payments owed to the hospital for my care - Regulatory, judicial and other governmental authorities where authorized or required by laws and regulations (including in relation to suspected illegal activities).	- الهيئات الحكومية التنظيمية والقضائية وغيرها كما هو مُصرح لها، أو الذي تستلزمه القوانين واللوائح (بما في ذلك يما يتعلق بأنشطة غير مشروعة مشتبه بها).
7	**Request from Prior Healthcare Providers**: the hospital and its staff to contact other healthcare providers whose names I have provided in order to obtain information related to the care and treatment provided to me by such providers.	**7- تقديم طلب لمقدمي الرعاية الصحية السابقين:** أن يقوم المستشفى وموظفيه بمخاطبة مقدمي الرعاية الصحية الآخرين الذين قمت بذكر أسماءهم من أجل الحصول على معلومات متعلقة بالرعاية الصحية والعلاج الذي تم تقديمه لي من قبلهم.
8	**Blood withdrawal and Receipt**: the drawing from my body of blood for diagnosis and testing and, in emergencies where I am unable to provide a separate consent, administration or transfusion of blood, blood plasma or other blood products deemed necessary by the healthcare professional staff.	**8- سحب الدم واستلامه:** إجراء سحب الدم بهدف التشخيص والفحص، وفي الحالات الطارئة التي لا أتمكن فيها من إعطاء موافقة منفصلة، القيام بتزويدي بالدم وبلازما الدم أو أي من مشتقاته الأخرى التي يعتبرها طاقم الرعاية الصحية المختص ضرورية .
9	**Tissues and Specimens**: the hospital to examine, use, store and dispose of any tissue, fluids or specimens obtained from my body during my care and treatment.	9- **الأنسجة والعينات:** أن تقوم المستشفى بفحص واستخدام وتخزين والتخلص من أي نسيج أو السوائل أو العينات التي تم سحبها من جسمي خلال فترة الرعاية الصحية والعلاج المقدم لي.
10	**Hospital Rules**: the hospital to take appropriate actions for the safety and welfare of myself and other patients if I do not follow the rules of the hospital explained to me by hospital staff.	10- **قوانين المستشفى:** أن تتخذ المستشفى الإجراءات المناسبة لتحقيق السلامة والصحة لي وللمرضى الآخرين وذلك في حالة لم أقم باتباع قوانين المستشفى التي سبق وأن شرحت لي من قبل طاقم المستشفى.
11	**Obstetrics/Gynecology Patients**: if I am an obstetric patient, this General Consent for Healthcare Services also applies to any children born to me during my or their hospitalization.	11- مرضى أمراض النساء والولادة: : إذا أنا كنت من مرضى النساء الحوامل، سينطبق أيضاً إقرار موافقة عامة على تلقّي خدمات الرعاية الصحية هذا على أي أطفال يولدون أثناء مدة إقامتي أو إقامتهم في المستشفى.
12	**Duration of Consent**: the hospital and its staff to rely upon the above mentioned General Consent until I revoke them in writing (which I may do at any time by indicating my revocation on a copy of this or a new form and providing it to the registration staff of the hospital).	12- **مدة الموافقة:** إعتماد المستشفى وموظفيها إقرار الموافقة العامة الموضح أعلاه حتى أقوم أنا بإلغائه كتابيّاً في أي وقت موضحاً قيامي بالإلغاء على هذه النسخة أو على نموذج جديد وتقديمه لموظف التسجيل بالمستشفى).

Patient Name: MRN: FIN:

13 **Additional Disclosure**: release of my medical information (including copies of my medical record) to the following persons (in addition to any others entitled under applicable law): 1. First Name : ____________ Last Name : ____________ Relationship: ____________ *ID (Type): ____________ *ID (No.): ____________ 2. First Name : ____________ Last Name : ____________ Relationship: ____________ *ID (Type): ____________ *ID (No.): ____________ * if known ☐ Release only to me	13- **إقرار إضافي**: يجوز إعطاء المعلومات الطبية الخاصة بي (بما في ذلك نُسخ من ملفي الطبي للأشخاص التالية أسماؤهم (بالإضافة إلى أي أشخاص آخرين مخولين بموجب القانون المعمول به): 1. الاسم الأول: ____________ اسم العائلة: ____________ الصلة: ____________ ** الهوية الشخصية (النوع):____________ ** الهوية الشخصية (الرقم):____________ 2. الاسم الأول: ____________ اسم العائلة: ____________ الصلة:____________ ** الهوية الشخصية (النوع):____________ ** الهوية الشخصية (الرقم):____________ ** إذا ما كان معلوماً ☐إعطاء المعلومات الطبية لي فقط
14 **Patient Rights Materials**: I have received the following printed materials: • Patient Rights and Responsibilities	14- وثائق حقوق المريض: لقد استلمت الوثائق التالية: • حقوق ومسؤوليات المريض
PATIENT SIGNATURE:	**تـوقيع المريض**
I have read and understand the information provided to me on this form	لقد قمت بقراءة وفهم المعلومات التي يحتوي عليه هذا النموذج
Patient Name:	اسم المريض:
Patient Signature :	توقيع المريض:
Date and Time:	التاريخ والوقت:
LEGAL REPRESENTATIVE SIGNATURE: (if patient is unable to or does not have legal capacity to sign form e.g. patient is under 18)	**توقيع الممثل القانوني:** (في حالة كان المريض غير قادر أو ليس لديه الأهلية القانونية تخوله لتوقيع هذا النموذج ، على سبيل المثال: تحت 18 من العمر).
I am the legal representative of the patient and I have read and understand the information provided to me on this form.	أنا، بصفتي الممثل القانوني للمريض، لقد قمت بقراءة وفهم المعلومات المقدمة لي في هذا النموذج.
Reason Patient Unable to Sign:	سبب عدم قدرة المريض على التوقيع:
Legal Representative Name (If applicable):	اسم الممثل القانوني (إن وجد):
Relationship to Patient:	العلاقة مع المريض:
Legal Representative Signature:	توقيع الممثل القانوني:

SEHA-AF-001-01-DT General Consent for Healthcare Services- DT Form Page **4** of **5**

*This Form is approved through SEHA Delegation of Authority process and no modification should be done in the content without the approval of Corporate HIM

Patient Name: MRN: FIN:

Date and Time:	التاريخ والوقت:
SEHA STAFF SIGNATURE:	**توقيع موظف شركة صحة**
I have explained to the patient (or legal representative) the purpose of this form, provided sufficient opportunity for questions and have answered any questions to his/her satisfaction.	لقد قمت أنا، بتقديم شرح للمريض (أو الممثل القانوني) عن الغرض من هذا النموذج ، بالإضافة إلى توفير مساحة كافية لتلقي أي استفسارات وعليه فقد قمت بالإجابة عن أي أسئلة أو استفسارات على النحو الذي يرضيه.
Staff Name:	اسم الموظف:
Electronically Signed By:	التوقيع الإلكتروني:
Date and Time:	التاريخ والوقت:
☐ **AFFIRMATION BY STAFF (IF THE PATIENT IS UNCONSCIOUS OR UNABLE TO SIGN)**	☐ إقرار من قبل الموظف (في حالة كان المريض غير واعي أو غير قادر على التوقيع)
I confirm that medical staff has informed me that the patient is unable to sign this form on his/her own behalf due to a medical emergency (including unconsciousness)	أقر أنا، بأن الطاقم الطبي قد قام بإبلاغي بأن المريض غير قادر على القيام بالتوقيع على هذا النموذج بصفته الشخصية بسبب حالته الطبية الطارئة (بما في ذلك فقدان الوعي).
Reason Patient Unable to Sign:	سبب عدم قدرة المريض على التوقيع:
Staff Name:	اسم الموظف:
Electronically Signed By:	التوقيع الإلكتروني:
Name of Authorizing Medical Staff:	اسم موظف الرعاية الطبية المخول:
Date and Time:	التاريخ والوقت:
TRANSLATOR SIGNATURE (if any):	**توقيع المترجم (إن وجد):**
Translator Name:	اسم المترجم :
Translator Signature:	توقيع المترجم:
Date and Time:	التاريخ والوقت:

APPENDIX 1b: GENERAL CONSENT FOR HEALTHCARE SERVICES - HIGHLIGHTED

*(including consent to be contacted for research purposes in box 6)

Version 1, dated 03.10.18

Please see separate attachment for the complete document.

Box 6 (our highlighting) states:

Disclosure of Medical Information: the disclosure and use of my medical information (including copies of my medical record and/or access to my electronic medical record through an electronic device or the internet) to …

hospital staff and others within and outside of the United Arab Emirates (including clinical data registries) to assess and improve the safety, quality and cost of care provided to me and other patients, assist in the administrative operation of the hospital or conduct medical and scientific research and reviews. Further to IRB approval, patients could be contacted for their interest to take part in the research studies.

APPENDIX 1c: EMAIL CONFIRMING AUTHORIZATION TO CONTACT PATIENTS THROUGH THE REGISTRY BY TELEPHONE

Version 1, dated 03.10.18

Dear x,

Further to the IRB approval for the study No: 546, the central office would like to confirm that you have been authorized to contact patients through the registry identification process for the recruitment. We further confirm that the practice to call patients for their interest in participation of your study is legitimate and in line of ethics protocol for which you also have been granted the ethics approval.

Hope the email satisfies the ethics committee at your university.

Best wishes,

Central office of Cancer Registry

NCR

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Tawam Hospital مستشفى توام

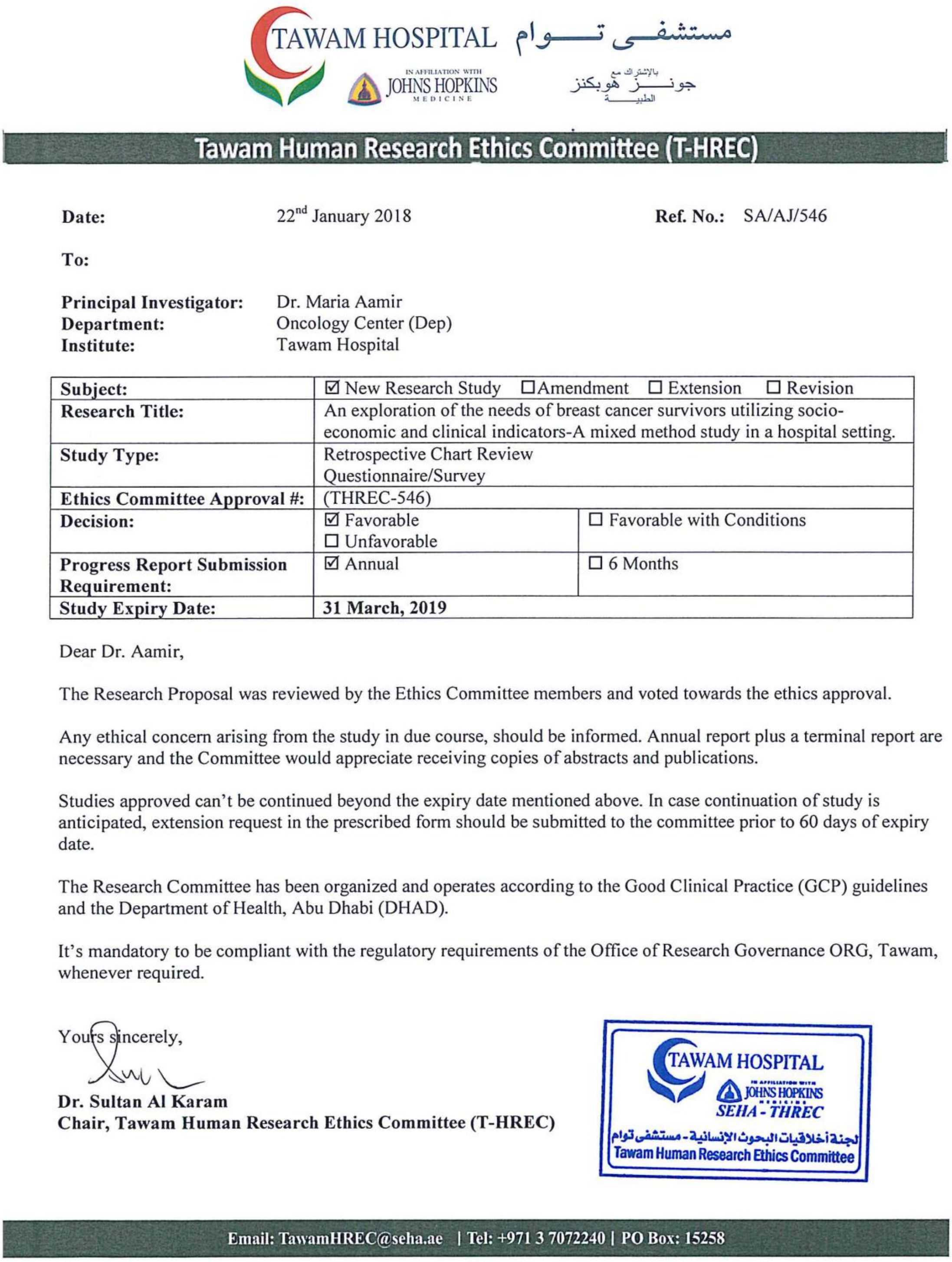
☎ +971 37677444 PO Box.15258, Al Ain, UAE @ ncr@seha.ae www.seha.ae

SEHA صحة
شركة أبوظبي للخدمات الصحية ش.م.ع
Abu Dhabi Health Services Co.P.J.S.C

رسالتنا: تطوير نظام صحي متميز للإرتقاء بالخدمات الصحية المقدمة إلى أعلى المستويات العالمية في الجودة الطبية وخدمة المتعاملين

Our Mission: Transform our healthcare system services to the highest medical quality and customer care international standards.

APPENDIX 2a: IRB APPROVAL – TAWAM HOSPITAL



TAWAM HOSPITAL مستشفى توام
IN AFFILIATION WITH JOHNS HOPKINS MEDICINE
بالاشتراك مع جونز هوبكنز الطبية

Tawam Human Research Ethics Committee (T-HREC)

Date: 22nd January 2018 **Ref. No.:** SA/AJ/546

To:

Principal Investigator: Dr. Maria Aamir
Department: Oncology Center (Dep)
Institute: Tawam Hospital

Subject:	☑ New Research Study ☐Amendment ☐ Extension ☐ Revision	
Research Title:	An exploration of the needs of breast cancer survivors utilizing socio-economic and clinical indicators-A mixed method study in a hospital setting.	
Study Type:	Retrospective Chart Review Questionnaire/Survey	
Ethics Committee Approval #:	(THREC-546)	
Decision:	☑ Favorable ☐ Unfavorable	☐ Favorable with Conditions
Progress Report Submission Requirement:	☑ Annual	☐ 6 Months
Study Expiry Date:	**31 March, 2019**	

Dear Dr. Aamir,

The Research Proposal was reviewed by the Ethics Committee members and voted towards the ethics approval.

Any ethical concern arising from the study in due course, should be informed. Annual report plus a terminal report are necessary and the Committee would appreciate receiving copies of abstracts and publications.

Studies approved can't be continued beyond the expiry date mentioned above. In case continuation of study is anticipated, extension request in the prescribed form should be submitted to the committee prior to 60 days of expiry date.

The Research Committee has been organized and operates according to the Good Clinical Practice (GCP) guidelines and the Department of Health, Abu Dhabi (DHAD).

It's mandatory to be compliant with the regulatory requirements of the Office of Research Governance ORG, Tawam, whenever required.

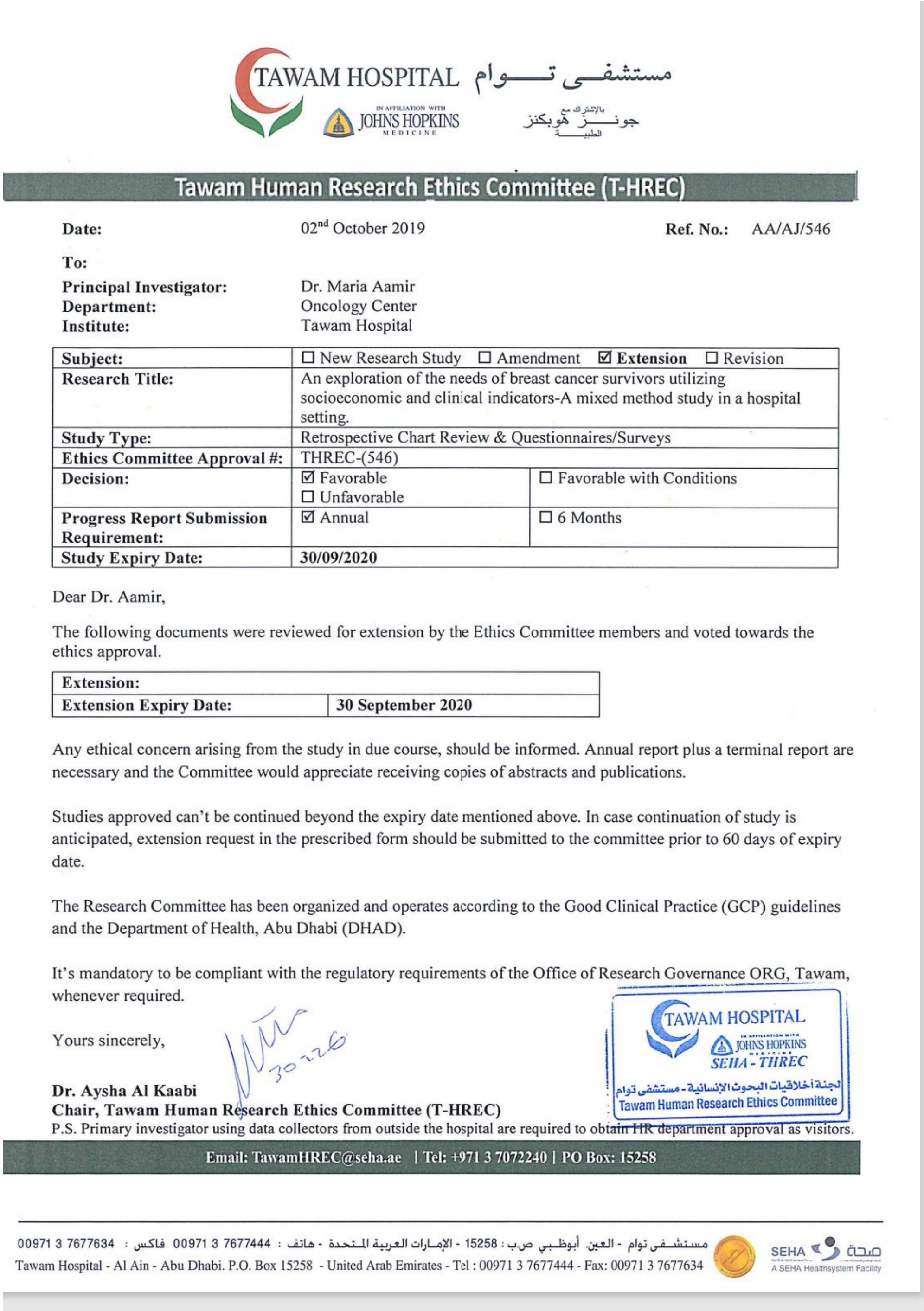
Yours sincerely,

Dr. Sultan Al Karam
Chair, Tawam Human Research Ethics Committee (T-HREC)

TAWAM HOSPITAL
IN AFFILIATION WITH JOHNS HOPKINS MEDICINE
SEHA - THREC
لجنة أخلاقيات البحوث الإنسانية - مستشفى توام
Tawam Human Research Ethics Committee

Email: TawamHREC@seha.ae | Tel: +971 3 7072240 | PO Box: 15258

APPENDIX 2b: IRB APPROVAL – TAWAM HOSPITAL



TAWAM HOSPITAL مستشفى تـــوام
IN AFFILIATION WITH JOHNS HOPKINS MEDICINE
بالاشتراك مع جونـــز هوبكنز الطبيـــة

Tawam Human Research Ethics Committee (T-HREC)

Date: 02nd October 2019 **Ref. No.:** AA/AJ/546

To:
Principal Investigator: Dr. Maria Aamir
Department: Oncology Center
Institute: Tawam Hospital

Subject:	☐ New Research Study ☐ Amendment ☑ **Extension** ☐ Revision	
Research Title:	An exploration of the needs of breast cancer survivors utilizing socioeconomic and clinical indicators-A mixed method study in a hospital setting.	
Study Type:	Retrospective Chart Review & Questionnaires/Surveys	
Ethics Committee Approval #:	THREC-(546)	
Decision:	☑ Favorable ☐ Unfavorable	☐ Favorable with Conditions
Progress Report Submission Requirement:	☑ Annual	☐ 6 Months
Study Expiry Date:	**30/09/2020**	

Dear Dr. Aamir,

The following documents were reviewed for extension by the Ethics Committee members and voted towards the ethics approval.

Extension:	
Extension Expiry Date:	**30 September 2020**

Any ethical concern arising from the study in due course, should be informed. Annual report plus a terminal report are necessary and the Committee would appreciate receiving copies of abstracts and publications.

Studies approved can't be continued beyond the expiry date mentioned above. In case continuation of study is anticipated, extension request in the prescribed form should be submitted to the committee prior to 60 days of expiry date.

The Research Committee has been organized and operates according to the Good Clinical Practice (GCP) guidelines and the Department of Health, Abu Dhabi (DHAD).

It's mandatory to be compliant with the regulatory requirements of the Office of Research Governance ORG, Tawam, whenever required.

Yours sincerely,

30226

Dr. Aysha Al Kaabi
Chair, Tawam Human Research Ethics Committee (T-HREC)

TAWAM HOSPITAL
IN AFFILIATION WITH JOHNS HOPKINS MEDICINE
SEHA - THREC
لجنة أخلاقيات البحوث الإنسانية - مستشفى توام
Tawam Human Research Ethics Committee

P.S. Primary investigator using data collectors from outside the hospital are required to obtain HR department approval as visitors.

Email: TawamHREC@seha.ae | Tel: +971 3 7072240 | PO Box: 15258

مستشفى توام - العين. أبوظبي ص.ب : 15258 - الإمارات العربية المتحدة - هاتف : 00971 3 7677444 فاكس : 00971 3 7677634
Tawam Hospital - Al Ain - Abu Dhabi. P.O. Box 15258 - United Arab Emirates - Tel : 00971 3 7677444 - Fax: 00971 3 7677634
SEHA صحة
A SEHA Healthsystem Facility

APPENDIX 2c: IRB APPROVAL – UNIVERSITY OF SALFORD

Research, Enterprise and Engagement
Ethical Approval Panel

Doctoral & Research Support
Research and Knowledge Exchange,
Room 827, Maxwell Building,
University of Salford,
Manchester
M5 4WT

T +44(0)161 295 2280

www.salford.ac.uk

22 February 2019

Dear Maria,

RE: ETHICS APPLICATION–HSR1819-016 – 'An exploration of the psychosocial needs of breast cancer survivors and its association with cultural differences and clinical indicators – A mixed method study in a hospital setting.'

Based on the information that you have provided, I am pleased to inform you that ethics application HSR1819-016 has been approved.

If there are any changes to the project and/or its methodology, then please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

Professor Sue McAndrew
Chair of the Research Ethics Panel

APPENDIX 3a & 3b: CONSENT FORM (ENGLISH)

Version 2b, dated 04/02/19

Title of study: Identifying the psychological needs of Emirati and expatriate breast cancer survivors in the U.A. E.: A mixed method investigation in a hospital setting.

Name of Researcher: Maria Aamir

Please complete and sign this form **after** you have read and understood the study information sheet. Read the following statements, and select ‘Yes’ or ‘No’ in the box on the right hand side.

1. I confirm that I have read and understand the study information sheet Version 2b, dated 22.01.19, for the above study. Yes/No

   I have had the opportunity to consider the information and to ask questions which have been answered satisfactorily. Yes/No

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my rights being affected.

3. If I do decide to withdraw I understand for my data to be removed from the study, I must inform the researcher of my decision within 30 days of my participation. Yes/No

4. I agree to participate by being interviewed and to having my interview audio-recorded. Yes/No

5. I understand that my personal details will be kept confidential and will not be revealed to people outside the research team. Yes/No

6. I understand that my anonymised data will be used in the researcher’s thesis, research reports, other academic publications, conferences/presentations, reports to Tawam Hopsital, Ministry of Health, and further research. Yes/No

7. If I choose to participate in my native language rather than English, I agree to having a translator present. Yes/No

8. I agree to take part in the study. Yes/No

Name of participant	**Date**	**Signature**
Name of person taking consent	**Date**	**Signature**

APPENDIX 3b: CONSENT FORM - ARABIC

نموذج الموافقة

المشارك يرجى ملء النموذج بأكمله

نحن ندعوك للمشاركة في الدراسة البحثية التي أعدّها مجموعة من المهنين العاملين في مجال الصحة داخل مستشفى توام بغرض البحث والكشف عن احتياجات الناجيات من سرطان الثدي ومن أجل تقديم أفضل وأعلى مستوى للرعاية لمرضى السرطان في المستشفى .

قبل موافقتك على المشاركة في الدراسة ، نطلب منك قراءة ورقة معلومات المشترك ودائرة نعم/لا حسب الاقتضاء. إذا كانت لديك أي أسئلة أو استفسارات قبل التوقيع على نموذج الموافقة ، فيرجى التحدث إلى المحقق ماريا عامر.

أؤكد أنني قد قرأت ورقة المعلومات وأدركت تمامًا ما هو متوقع مني في هذه الدراسة. [**نعم / لا**]

أؤكد أنه أتيحت لي الفرصة لطرح أي أسئلة وللرد عليها. **[نعم / لا]**

أدرك أنه سيتم جمع إجاباتي بشكل مجهول. **[نعم / لا]**

أدرك أن إجاباتي والمعلومات التي سأقدمها سيتم الاحتفاظ بها حتى يتم فحص مشروع البحث. **[نعم / لا]**

أدرك أن مشاركتي طوعية وأنني حر في الانسحاب في أي وقت دون إبداء أي سبب ، دون أن تتأثر رعايتي الطبية أو حقوقي القانونية. **[نعم / لا]**

أدرك أنه بمجرد أن يتم الكشف عن بياناتي مجهولة الهوية والنتائج التي توصلت إليها ، قد لا يكون من الممكن سحبها، على الرغم من أنه سيتم بذل كل محاولة لاستخراج بياناتي ، حتى نقطة النشر. **[نعم / لا]**

أدرك أن المعلومات الواردة في الاستطلاع سيتم تجميعها مع ردود المشاركين الآخرين ، وسيتم الكشف عن هويتهم وقد يتم نشرها. **[نعم / لا]**

أوافق على المعلومات الواردة من ردود المسح التي تستخدمها في التقارير والمؤتمرات والفعاليات التدريبية.

[نعم / لا]

أدرك أن أي معلومات سأقدمها ستبقى سرية ومجهولة تمامًا ما لم يكن هناك اعتقاد بوجود خطر على نفسي أو للآخرين ، وفي هذه الحالة سيحتاج الباحث الرئيسي إلى مشاركة هذه المعلومات مع مشرف أبحاثها. **[نعم / لا]**

أوافق على مستشفى توام الذي يحتفظ بمعلوماتي لمدة ____ سنة بعد انتهاء الدراسة. **[نعم / لا]**

أوافق بموجبه على المشاركة في هذه الدراسة

اسم المشارك ____________ _ **التوقيع** ______________ **التاريخ** __________

اسم الباحث ______________ **التوقيع** ____________________ **التاريخ** __________

APPENDIX 4a: PATIENT INFORMATION SHEET - ENGLISH

Version 2, dated 04.02.19

Study Title

Identifying the psychological needs of Emirati and expatriate breast cancer survivors in the U.A. E.: A mixed method investigation in a hospital setting.

Invitation paragraph

I would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or you would like more information. Take time to decide whether or not to take part.

Please take time to read the following information carefully and contact us for any questions if some part of the information is not clear to you or if you would like more information. You may decide to be in the study or not take part at all. If you do decide to take part in this study, you may stop at any time. However, before you decide, it is important that you understand why this research is being done and what it will involve. Your decision will not lead to any penalty or affect your regular medical care or any benefit to which you are otherwise entitled.

What is the purpose of the study?

The purpose of this study is to find out from patients what your supportive care needs are and have been during your illness. We want to know what kind of support might make your situation better and help you cope with the illness.

Why have I been invited?

You have been invited as you have been registered and treated at Tawam Hospital for the breast cancer and during the registration you signed to give consent to participate in health research which could benefit the community. The study is conducted by a PhD student Maria Aamir who is undertaking the research at the ~~Salford~~ University of Salford, UK to understand and explore the psychosocial needs of breast cancer survivors who have been treated at Tawam Hospital.

Do I have to take part?

'It is up to you to decide. We will describe the study and go through this information sheet which we will give to you. We will then ask you to sign a consent form to show that you have agreed to take part. You are free to withdraw at any time, without giving a reason and this will not affect the standard of care you receive.

If you decide to withdraw from the study after the completion of survey, and then simply inform the researcher within thirty days, your responses will be deleted and all related information will be destroyed; none of your information will be used in the study.

What will happen to me if I take part?

If you decide to participate in this study, you will be given a consent form to sign to indicate that you are agreeing to take part in this study voluntarily. Along with this, you will need to fill out a questionnaire which will take about 30 minutes to complete. Your responses will help us understand what has been important for you that could ease your life. The information to be asked about will include:

- *Your needs including information, financial, medical, relationship, emotional and any other need that you think important for you.*

- *Personal details such as your age, gender, type of cancer, type of cancer treatment and when you commenced treatment will have been collected as well.*

Some of you will be invited to a further interview after the questionnaire results are analysed. The choice of interview participants will be made to reflect a range of responses on the questionnaires and the purpose of the interview will be to explore in more depth and detail aspects of your personal experiences. The length of the interview will be 45-90 minutes depending on how detailed your responses are, and the interviews will be audio recorded and then transcribed. The interviews will take place in a private room in the hospital. Whether or not you are asked to participate in an interview and whether or not you choose to do so, you will continue with your cancer care follow up plan as per normal department follow up.

For both the questionnaires and the interviews, a hospital translator trained in confidentiality and data protection issues will be available if you have difficulty communicating in English and would prefer to use your native language. These translators have been trained to consider the sensitive nature of the survey and interview questions.

Expenses and payments?

As compensation, there are no expenses or payments to take part in the study however refreshments will be available free during the course of study which is during the survey and interview process.

What are the possible disadvantages and risks of taking part?

We will try to be very cautious with the questions asked but this is a sensitive topic for many and at occasion, some may find it as an emotional or stressful experience. In those circumstances, if you need to be referred to a health professional for emotional support, the researcher will ensure this occurs as soon as possible. This support will be offered at no cost to you.

What are the possible benefits of taking part?

There may be no direct benefit to participation in this study but you may find it a positive experience to participate in this research because your participation can benefit you and others who have similar symptoms and experiencing the same challenges through their illness. Also, the study will offer an opportunity to improve cancer services and patient care by understanding what are the different type of needs you have in order to improve the way care is delivered and to prepare individuals more appropriately in the future.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher (Maria Aamir, contact: 037072686) who will do their best to answer your questions. If you remain unhappy and wish to complain formally you can do this by contacting the Research Supervisor (Dr. Luai Ahmed (luai.ahmed@uaeu.ac.ae) or Dr Linda Durbow Marshall (l.dubrow-marshall@salford.ac.uk). If the matter is still not resolved, please forward your concerns to Professor Susan McAndrew, Chair of the Health Research Ethical Approval Panel, Room MS1.91, Mary Seacole Building, Frederick Road Campus, University of Salford, Salford, M6 6PU. Tel: 0161 295 2278. E: s.mcandrew@salford.ac.uk.

Will my taking part in the study be kept confidential?

The researchers will need to collect personal data about you, which may be sensitive (for instance, date of birth and relevant health information). The researchers may also need to get some of your health information from your medical records. Any personal or health information will be kept private and confidential. It will be stored securely and accessible to authorised persons to be kept confidential. Your study details will be given a number so that your identity will not be apparent. The study records will be kept in a locked filing cabinet in the researcher's office at Tawam Hospital during the study and *in a locked archive for at least 10 years from the time the study is closed and will be destroyed at any time thereafter.*

Authorised representatives of the study and the Research Ethics Committees may require access to your study records to verify study procedures and/or data. In all cases when dealing with your information, these people are required to comply with privacy laws that protect you. We will ensure that all the information you give us will be held in strictest confidence and will not be passed on to a third party in a form which can lead to the identification of individuals. All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised.

Any data from the questionnaires and interviews will be kept on a secure university drive for three years, unless you ask for the information to be destroyed within 30 days of your participation. Your confidentiality will be further maintained by assigning a code number instead of your name to the information which you have provided either in the surveys or in the interviews.

What will happen if I don't carry on with the study?

If you withdraw from the study all the information and data collected from you, to date, will be destroyed provided you withdraw 30 days after your participation and your name will be removed from all the study files. There will be no negative consequences to you for withdrawing, and you will continue with your cancer care follow up plan as per normal department follow up.

What will happen to the results of the research study?

You will be sent a summary of the findings from this study. The results of the research will be made available to health professionals through medical journals or meetings, but you will not be identifiable in these communications. By taking part in this study you agree not to restrict the use of any data but only if you withdraw within thirty days.

Who is organising or sponsoring the research?

The Al Ain medical district Institution Board Review (IRB) committee and Salford University's School of Health and Society Research Ethics Committee have reviewed this study and given approval for this research. If you have any ethical concerns regarding the study, you can contact the secretary at the Tawam Hospital Institution Board Review (IRB) committee at Research Office on telephone number (+971 03 707 4739).

Further information and contact details

The study is conducted by the student Maria Aamir who is undertaking the research at the University of Salford, UK.

Contact persons:

Should you have questions about the study you may contact: Maria Aamir Phone No 037072686 email: maamir@seha.ae

APPENDIX 4b: PATIENT INFORMATION SHEET – ARABIC

نموذج معلومات المريض

نحن ندعوك للمشاركة في الدراسة البحثية التي أعدّها مجموعة من المهنين العاملين في مجال الصحة داخل مستشفى توام بغرض البحث والكشف عن احتياجات الناجيات من سرطان الثدي ومن أجل تقديم أفضل وأعلى مستوى للرعاية لمرضى السرطان في المستشفى.

ماء الباحثين:

ماريا عامر

يرجى أخذ وقتك لقراءة المعلومات التالية بعناية والاتصال بنا للحصول على أي سؤال إذا كان جزء من المعلومات غير واضح لك أو إذا كنت ترغب في مزيد من المعلومات. يرجى قراءة هذا قبل التوقيع على نموذج الموافقة هذا.

من يقوم بهذه الدراسة؟

هذه دراسة لمستشفى توام لفهم احتياجات مرضى السرطان ولتطوير تدخل يلبي تلك الاحتياجات غير الملباة. أجريت الدراسة في الأساس من قبل الدكتورة ماريا عامر التي تجري البحث في مستشفى توام.

للتنسيق والاتصال:

إذا كانت لديك أسئلة حول الدراسة ، فيمكنك الاتصال بـ: د. ماريا عامر هاتف رقم 2686 707-03

سيتم تزويد جميع المشاركين في الدراسة بنسخة من ورقة المعلومات والموافقة نموذج لسجلاتهم الشخصية.

قد تقرر أن تكون في الدراسة أو لا تشارك على الإطلاق. إذا قررت المشاركة في هذه الدراسة ، فيمكنك التوقف في أي وقت. ومع ذلك ، قبل أن تقرر ، من المهم أن تفهم سبب إجراء هذا البحث وما الذي سيتضمنه.

لن يؤدي قرارك إلى أي عقوبة أو التأثير على رعايتك الطبية المنتظمة أو أي فائدة يحق لك الحصول عليها.

تشرح ورقة المعلومات التالية الدراسة وستتضمن تفاصيل مثل:

- **لماذا هذه الدراسة قد تكون مناسبة لك**
- **طبيعة مشاركتك**

- حقوقك ومسؤولياتك

ما هو الغرض من الدراسة؟

تهدف الدراسة إلى استكشاف الاستخدام المحتمل لمنظمة العفو الدولية للتنبؤ بنتائج سرطان الثدي وتطوير خطط الرعاية الآلية بناءً على الاحتياجات الفريدة للناجين.

ما هي مشاركتي في هذه الدراسة؟

إذا قررت المشاركة في هذه الدراسة ، فسيتم إرسال نموذج الموافقة الذي ستوقعه بالموافقة على المشاركة في هذه الدراسة طواعية. مع هذا ، ستحتاج إلى ملء استبيان سيستغرق استكماله حوالي 45 دقيقة إلى ساعة. ستساعدنا ردودك على فهم ما هو مهم بالنسبة لك والذي قد يخفف من حياتك. سيتم طرح المعلومات حول:

- احتياجاتك بما في ذلك المعلومات ، والمالية ، والطبية ، والعلاقات ، والعاطفية وأي حاجة أخرى تعتقد أنها مهمة بالنسبة لك.
- التفاصيل الشخصية مثل عمرك وجنسك ونوع السرطان ونوع علاج السرطان ومتى بدأت العلاج سيتم جمعها أيضًا.
- سوف تتوقف مشاركتك في الدراسة بعد الانتهاء من الاستبيان.

هل هناك أي أسباب لا ينبغي أن أكون في هذه الدراسة؟

لا

ما هي التكاليف بالنسبة لي؟

لن يتم تكبد أي تكاليف شخصية.

ما هي فوائد ممكنة من المشاركة؟

قد لا تكون هناك فائدة مباشرة للمشاركة في هذه الدراسة ولكن قد تجد أنها تجربة إيجابية للمشاركة في هذا البحث لأن مشاركتك يمكن أن تفيدك أنت والآخرين الذين لديهم أعراض مماثلة وتعاني من نفس التحديات من خلال مرضهم. كما ستوفر الدراسة فرصة لتحسين خدمات السرطان ورعاية المرضى من خلال فهم الأنواع المختلفة للاحتياجات التي تحتاج إليها من أجل تحسين طريقة تقديم الرعاية وإعداد الأفراد بشكل أكثر ملاءمة في المستقبل.

كيف سيتم ضمان سلامتي؟

لن تؤثر المشاركة في هذه الدراسة على سلامتك الشخصية لأنك سترد على الاستبيان عن بُعد.

ما هي البدائل التي يجب علي الذهاب إليها في هذه الدراسة؟

نود منك المشاركة ، ولكن إذا كنت لا ترغب في ذلك ، فلديك مطلق الحرية في الرفض. وبالمثل ، إذا كنت قد وافقت في البداية ، ثم رغبت في الانسحاب ، فيمكنك القيام بذلك دون أي مشكلة. في كلتا الحالتين لن نطلب أي تفسير ، ولن تكون هناك أي آثار سلبية على الإطلاق بالنسبة لك. لن يؤثر هذا على الرعاية الحالية أو العلاج الطبي الذي تتلقاه بأي شكل من الأشكال.

ما هي الآثار الجانبية المحتملة والمخاطر ومضايقات المشاركة؟

سنحاول أن نكون حذرين للغاية فيما يتعلق بالأسئلة المطروحة ، لكن هذا موضوع حساس للكثيرين وفي بعض الأحيان ، قد يجده البعض كتجربة عاطفية أو مرهقة. في هذه الظروف ، إذا احتجت إلى إحالتك إلى أخصائي صحي للحصول على الدعم العاطفي ، فسوف يضمن الباحث حدوث ذلك في أقرب وقت ممكن. سيتم تقديم هذا الدعم دون أي تكلفة.

ماذا يحدث إذا غيرت رأيي بعد أن أرسلت إجاباتي وأرغب في الانسحاب من الدراسة؟

إذا قررت الانسحاب من الدراسة بعد الانتهاء من الدراسة ، ثم أخبر الباحث ببساطة وسيتم حذف إجاباتك وسيتم إتلاف جميع المعلومات ذات الصلة ، ولن يتم استخدام أي من معلوماتك في الدراسة.

ماذا يحدث في نهاية الدراسة؟

في نهاية الدراسة ، سوف تستمر في متابعة خطة متابعة العناية بالسرطان حسب متابعة القسم المعتادة.

هل تبقى مشاركتي في هذه الدراسة سرية؟

سيحتاج الباحثون إلى جمع بيانات شخصية عنك ، والتي قد تكون حساسة (على سبيل المثال ، تاريخ الميلاد والمعلومات الصحية ذات الصلة). قد يحتاج الباحثون أيضًا إلى الحصول على بعض المعلومات الصحية الخاصة بك من سجلاتك الطبية. سيتم الاحتفاظ بأي معلومات شخصية أو صحية خاصة وسرية. سيتم تخزينه بشكل آمن ومتاح للأشخاص المخولين للحفاظ على سريته. سيتم إعطاء تفاصيل دراستك رقماً حتى لا تكون هويتك واضحة. سيتم الاحتفاظ بسجلات الدراسة في خزانة ملفات مغلقة في مكتب الباحث في مستشفى توام أثناء الدراسة وفي أرشيف مغلق لمدة 10 سنوات على الأقل من وقت إغلاق الدراسة وسيتم إتلافها في أي وقت بعد ذلك.

قد يطلب الممثلون المعتمدون للدراسة ولجان أخلاقيات البحث الوصول إلى سجلات الدراسة للتحقق من إجراءات الدراسة و/ أو البيانات. في جميع الحالات عند التعامل مع معلوماتك ، يتعين على هؤلاء الأشخاص الامتثال لقوانين الخصوصية التي تحميك. سنضمن أن جميع المعلومات التي تقدمها لنا سيتم الاحتفاظ بها بسرية تامة ولن يتم نقلها إلى جهة خارجية في شكل يمكن أن يؤدي إلى تحديد هوية الأفراد.

هل سأكتشف نتائج الدراسة؟

سيتم إرسال ملخص للنتائج التي توصلت إليها هذه الدراسة. ستتاح نتيجة البحث للمهنيين الصحيين من خلال المجلات الطبية أو الاجتماعات ، لكنك لن تكون محددًا في هذه الاتصالات. بالمشاركة في هذه الدراسة ، فإنك توافق على عدم تقييد استخدام أي بيانات ولكن فقط في حالة الانسحاب.

من سيراجع الدراسة؟

ستقوم لجنة مراجعة مجلس إدارة مستشفى توام بمراجعة هذه الدراسة وإعطاء الموافقة على إجراء هذا البحث. إذا كانت لديك أية مخاوف أخلاقية بشأن الدراسة ، فيمكنك الاتصال بلجنة مراجعة مجلس أمين السر (IRB) على رقم الهاتف (+971 03 7072686)

بمن أتصل وكيف إذا كان لدي أي أسئلة؟

إذا كان لديك أي أسئلة حول الدراسة ، يمكنك الاتصال بـ: Maria Aamir Tel: +971 03 707 2686 (من 7:00 ص إلى 4:00 م) ؛ البريد الإلكتروني: maamir@tawamhospital.ae

APPENDIX 5a: CANCER SURVIVORS’ NEED SURVEY – ENGLISH

Version 1, dated 03.10.18

We invite you to take part in a research study at Tawam Hospital. This study is conducted by the group of health professionals to investigate the needs of breast cancer survivors to help provide the optimal and high-quality cancer care at the hospital.

First, we want you to know that taking part in this study is entirely voluntary and you may receive no benefit from taking part. Nevertheless, your contribution to this research is very important as this research will provide us knowledge that may help people and their health in the future.

There are ten major sections to complete in this questionnaire. It requires you to simply selecting the most appropriate answer from the choices given. The questionnaire will not take more than 30 minutes to answer. Please **complete this survey** carefully by giving your answers accurately and as fully as possible. Please be assured that all replies will be anonymised and you will not be identified at any stage to any third party. Your answers to this questionnaire will be strictly **CONFIDENTIAL** to the Tawam Hospital Research team only and will not be given to anyone else without your written permission. We would like to **THANK YOU** for taking part in the study.

Please complete this survey and return to the researcher. If you have difficulty in interpreting any question, please ask the researcher or the coordinator.

Thank you again. If you would like to have further information regarding any aspect of this study, please contact our research team and we would be delighted to provide you further information.

WHAT ARE YOUR NEEDS?

This survey of needs will provide awareness and insight into the needs of cancer survivors and provide leaders with valuable information needed to provide appropriate resources and plan supportive programs. Whether you completed treatment ten days or ten years ago, or continue to receive treatment, it's important we hear from you. Please take a few moments to complete this survey and share your thoughts with us.

Thank you.

SECTION 1: DEMOGRAPHICS (7 Items)

- Age: ______(Yrs)
- Nationality:
    - ○ Emirati (1)
    - ○ Expatriate (2)
- Year of cancer diagnosis __________
- Type of cancer _______________
- Stage of cancer _______________ (I, II, III IV, Unknown)
- Type of treatment received (check all that apply)
    - ○ Surgery (1)
    - ○ Radiation (2)
    - ○ Chemotherapy (3)
    - ○ Hormonal (4)
    - ○ Other (8)
- Currently receiving treatment?
    - ○ Yes (1)
    - ○ No (0)

SECTION 2: QUALITY OF LIFE (1 Item)

Please circle the number (0-10) that describes your overall Quality of Life during the past week, including today:

0 1 2 3 4 5 6 7 8 9 10

As bad as **As good as**

it can be **it can be**

As a cancer survivor you may experience some lasting side effects from your treatment. Please rate each topic according to how much concern it is causing you **today**.

Please circle the number on the **scale from 0 (no concerns) to 5 (extreme concerns).**

SECTION 3: PHYSICAL CONCERNS (20 Items)

	No Concerns					Extreme Concerns
	0	**1**	**2**	**3**	**4**	**5**
Pain						
Fatigue						
Sleep disturbance						
Memory and concentration						
Nausea / Vomiting						

Poor appetite						
Trouble swallowing						
Dental or mouth problems						
Weight changes						
Balance / Walking / Mobility						
Loss of strength						
Tingling or numbness in feet & hands (neuropathy)						
Swelling in legs or arms (lymphedema)						
Osteoporosis / Bone health						
Hair and skin care concerns						
Body changes						
Bowel or bladder changes						
Hot flashes						
Sexual concerns						
Fertility concerns						

SECTION 4: INFORMATION CONCERNS (7 Items)

	No Concerns					Extreme Concerns
	0	**1**	**2**	**3**	**4**	**5**
Being fully informed about my cancer and treatment						
Being fully informed about potential side effects and long-term adverse effects						
Being fully informed about any familial risk						
Being fully informed about any symptom appear (recurrence/new primary)						
Being fully informed about who to contact if any symptom appears (recurrence/new primary)						
Being fully informed about next follow-up date, place and physician						
Being fully informed about the Psychosocial support and resources to other support services						

SECTION 5: SOCIAL & FINANCIAL CONCERNS (6 Items)

	No Concerns					Extreme Concerns

	0	1	2	3	4	5
Managing household activities						
Caring for family members						
Talking about cancer with family and friends						
Returning to work						
Health insurance						
Financial concerns						

SECTION 6: EMOTIONAL CONCERNS (14 Items)

	No Concerns					Extreme Concerns
Defining a new sense of normal	**0**	**1**	**2**	**3**	**4**	**5**
Managing difficult emotions: anger, fear, sadness, depression, guilt, anxiety)						
Coping with grief and loss						
Living with uncertainty						
Fear of recurrence						
Managing stress						
Isolation / Feeling alone						
Intimacy issues						
Looking for the bright side: gratitude, forgiveness, love, happiness, contentment						
Having a sense of well being						
Changing relationships with spouse, family, and others						
Finding support resources						
Connecting to counseling services						
Genetic counseling (worry about your children getting cancer)						

SECTION 7: SPIRITUAL/RELIGIOUS CONCERNS (4 Items)

	No Concerns					Extreme Concerns
Religious or spiritual support	**0**	**1**	**2**	**3**	**4**	**5**
Religious or spiritual distress						
Loss of faith						

End of life concerns						

SECTION 8: OTHER CONCERNS (1 Items)

Any other concerns that you may have, please specify	

SECTION 9: Please indicate how you prefer to learn about the following topics. Check all that apply (4 Items)

	Written Materials	Class	**Video**	Healthcare Specialist	Cancer Survivor	Internet
Physical issues						
Social issues						
Emotional issues						
Spiritual issues						

SECTION 10: What specific topics are you interested in learning about? (Circle topics of interest) (4 Items)

HEALTHY LIVING CHOICES:	Nutrition	Safe exercise	Smoking cessation
FINANCIAL CONCERNS:		Living wills	Disability
ENHANCING COMMUNICATION:	With your doctors	With your spouse or significant other	
HEALTH SCREENINGS:	Cancer	Heart	

SECTION 11: What has been your primary source of strength during your cancer experience? (1 Items)

Additional comments:

Thank you for completing this survey. Your comments will be beneficial as we plan for the future needs of cancer survivors.

For more information regarding this survey, please contact Maria Aamir at 037072686 or maamir@seha.ae

APPENDIX 5B: CANCER SURVIVORS’ NEED SURVEY - ARABIC

نحن ندعوك للمشاركة في الدراسة البحثية التي أعدّها مجموعة من المهنين العاملين في مجال الصحة داخل مستشفى توام بغرض البحث والكشف عن احتياجات الناجيات من سرطان الثدي ومن أجل تقديم أفضل وأعلى مستوى للرعاية لمرضى السرطان في المستشفى.

في البداية نودُ أن نشير بأن المشاركة في هذه الدراسة ستكون طوعية تمامًا ولن يتحصل المشارك على أي استحقاق أو مكافأة مقابل الإجابة أو المشاركة في هذا الاستبيان.

ومع ذلك فتعتبر مشاركتك في هذه الدراسة مهمّة جدًا لأنها سوف توفر لنا المعلومات والمعرفة التي ستسهم في مساعدة الكثير من الناس وصحتهم في المستقبل.

يحتوي هذا الاستبيان على 10 أقسام رئيسة، تتطلب الإجابة واستكمال البيانات. وسيتطلب منك الاستبيان وبشكل مبسط أن تقوم باختيار الإجابة الأكثر ملائمة من الخيارات المقدمة.

لن تستغرق منك الإجابة على الاستبيان أكثر من 30 دقيقة.

نرجو منك الإجابة على الاستبيان بشكل دقيق وكامل بقدر المستطاع.

نوّد أن نؤكد لكم بأنه لن يتم التعريف أو الكشف عن هويتك أو شخصك عند أي مرحلة ولأي فرد من أفراد الطرف الثالث.

وسيحتفظ فريق قسم الأبحاث في مستشفى توام بجميع إجابتك بشكل سرّي، ولن يتم تداولها مع أي شخص آخر من دون الحصول مسبقًا على إذن كتابي منك. ونحن نتقدم لك بجزيل الشكر على المشاركة في هذه الدراسة.

فضلًا بعد استكمال الإجابة على الاستبيان يرجي تسليمه للباحث، وفي حال واجهتك أي صعوبات في فهم الأسئلة أو ترجمتها يرجى الرجوع للباحث أو المنسّق لطلب المساعدة.

شكرًا لك مجددًا وللمزيد من الأسئلة أو المعلومات المتعلّقة بهذه الدراسة يرجى الاتصال بفريق البحث وسنكون سعداء عند تقديم المزيد من المعلومات والمساعدة.

ماهي احتياجاتك؟

إن هذه الدراسة والاستبيان المتعلّق باحتياجاتك سوف يوفر التوعية وسيسهم في إلقاء نظرة فاحصة على احتياجات الناجين من السرطان كما ستقدم للمسؤولين المعلومات القيّمة والمفيدة لتوفير الموارد المناسبة وبرامج خطط الدعم .

رأيك وإجاباتك تهمنا، سواء أكملت العلاج منذ 10 أيام أو 10 سنوات أو لاتزال تتلقّى العلاج.

فضلًا خصص بعضًا من وقتك للإجابة عن الاستبيان وشاركنا أرائك ومقترحاتك.

شكرًا

القسم الأول: المعلومات الديمغرافية (7 بنود)

القسم 1:

العمر: ....سنة

الجنسية:

- ○ إماراتي (1)
- ○ وافد (2)

سنة تشخيص إصابتك بالسرطان :...............

نوع السرطان:............................

نوع العلاج الذي تتلقاه (يرجى وضع إشارة عند كل ماينطبق)

الجراحة (1)

العلاج الإشعاعي (2)

العلاج الكيمائي (3)

العلاج الهرموني (4)

أنواع أخرى من العلاج (8)

هل تتلقى العلاج حاليًا؟

- ○ نعم
- ○ لا

القسم (2): نوعية الحياة (بند 1):

فضلًا ضع دائرة على الأرقام من 0-10 والتي تصف نوعية حياتك بشكل عام أثناء الأسبوع السابق بمافي ذلك اليوم :

0	1	2	3	4	5	6	7	8	9	10
أسوء مايمكن										أفضل مايمكن

قد تصاب بأعراض دائمة ناتجة عن العلاج كمريض / مريضة ناجي/ة من السرطان. فضلّا يرجى تقييم كل موضوع بناءًا على مدى مقدار المخاوف والقلق الذي سببته لك هذه الأعراض اليوم

يرجى وضع دائرة حول الرقم على المقياس من 0 (ليس هناك مخاوف أو قلق) إلى رقم 5 (مخاوف شديدة)

القسم 3 المخاوف البدنية (20 بندًا)

المخاوف و القلق الشديد من	**لاتوجد مخاوف 0**	**1**	**2**	**3**	**4**	**المخاوف والقلق الشديد 5**
الألم						
الأعياء والتعب						
اضطراب النوم						
الذاكرة وقلة التركيز						
الغثيان / القيئ (الاستفراغ)						
ضعف الشهية						
صعوبة ومشاكل في البلع						
مشاكل في الفم أو الأسنان						
تغييرات في وزن الجسم						

التوازن / المشي / الحركة						
فقدان القوة						
الشعور بالخدران والوخز في الأقدام واليدين (اعتلال عصبي)						
تورّم الساقيين أو الذراعين (استسقاء لمفاوي)						
هشاشة العظام / صحة العظم						
مخاوف وقلق بشأن صحة الشعر والجلد						
تغييرات في الجسم						
تغييرات في المثانة والأحشاء (الأمعاء)						
هَبَّةُ الحَرارَة (هوت فلاش)						
شواغل ومخاوف جنسية						

القسم الرابع : المخاوف والقلق المعلوماتي 7بنود

	لاتوجد مخاوف 0	1	2	3	4	المخاوف والقلق الشديد 5
على علم تام بشأن إصابتي بمرض السرطان والعلاج المقرر لي						
على علم تام بالأضرار الجانبية المحتملة						
على علم تام بإحتمالات خطورة الإصابة الوراثية						
على علم تام بإمكانية ظهور أعراض (معاودة / جديدة وأولية)						
على علم تام بالشخص الذي يجب التواصل معه عند ظهور						

أي أعراض (معاودة أو جديدة وأولية)						
على علم تام بتفاصيل الموعد التالي للمتابعة : تاريخه ومكانه واسم الطبيب						
على علم تام عن الدعم الإجتماعي والنفسي وموارد خدمات الدعم الأخرى						

القسم الخامس : المخاوف والمشاغل الإجتماعية والمالية: (6 بنود)

	لاتوجد مخاوف 0	1	2	3	4	المخاوف والقلق الشديد 5
المقدرة على القيام بالأعمال المنزلية						
رعاية أفراد الأسرة						
التحدث مع الأسرة والأصدقاء عن السرطان						
العودة للعمل						
التأمين الصحي						
المخاوف والقلق الخاص بالأمور المالية						

القسم السادس : المخاوف والمشاغل العاطفية 14 بند

المخاوف والقلق الشديد من	لاتوجد مخاوف 0	1	2	3	4	المخاوف والقلق الشديد 5
وجود شعور جديد طبيعي						
التغلب على المشاعر الصعبة : الغضب والخوف والحزن والاكتئاب والشعور بالذنب والقلق)						
التغلب على مشاعر الحزن والخسارة						
عدم وجود استقرار معيشي						
الخوف من تكرار الإصابة أو معاودة المرض)						
التغلب على التوتر						
العزلة / الشعور بالوحدة						
مشاكل في العلاقة الحميمية						
البحث عن الجانب الإيجابي : الشكر والعفو / التسامح والحب والفرح والقناعة						
الشعور بالارتياح والرفاهية						

حدوث تغيير في العلاقة مع الشريك في الحياة أو الأسرة أو الأخرين						
وجود مصادر للدعم						
الانضمام إلى خدمات المواساة والدعم						
الاستشارة الجينية (القلق من إصابة الأطفال بالسرطان)						

القسم السابع : المخاوف والمشاغل الدينيةوالروحانية (اربع بنود)

المخاوف والقلق الشديد من	لاتوجد مخاوف 0	1	2	3	4	المخاوف والقلق الشديد 5
وجود دعم روحي و ديني						
الضائقة الروحية والدينية						
فقدان الإيمان						
المخاوف المتعلقة بنهاية الحياة						

القسم الثامن :اهتمامات ومخاوف أخرى بند واحد

هل لديك أي مخاوف أو اهتمامات أخرى، فضلًا أذكرها :	

القسم التاسع : : فضلًا أذكر كيف تفضل أن نخبرك عن المواضيع التالية التي تهمك، ضع علامة أمام الموضوع الذي يهمك (4 بنود):

وجود الدعم الروح والديني	المواد التثقيفية المكتوبة	محاضرة/ الصف	الفيديو	اختصاصي الرعاية الصحية	أحد الناجين من السرطان	عن طريق شبكة المعلومات الإلكترونية

المشاكل الجسدية والبدنية						
المشاكل الإجتماعية						
المشاكل العاطفية						
المشاكل الروحانية						

القسم العاشر : فضلًا حدد المواضيع التي تشغلك وترغب بمعرفة المزيد عنها، ضع علامة أمام الموضوع الذي يهمك (4 بنود):

خيارات الحياة الصحية	التغذية	التمارين الآمنة	الامتناع عن التدخين
المشاكل المادية		وصايا البقاء	العجز
تعزيز التواصل	مع أطبائك	مع شريكك في الحياة أو أشخاص مهمين آخرين	
الفحص الكشفي الصحي	السرطان	القلب	

القسم 11 أذكر مصدر قوتك الأساسي أثناء فترة معانتك من مرض السرطان؟ بند واحد

ملاحظات إضافية :

نشكر لك مشاركتك في هذا الاستبيان، إجاباتك وملاحظاتك سوف تفيدنا في خطتنا للإحتياجات المستقبلية الخاصة بالناجيين من السرطان:

للمزيد من الأسئلة والإستفسارات الخاصة بهذا الاستبيان يمكنكم الاتصال بالدكتورة ماريا عامر:

037072686 maamir@seha.ae

APPENDIX 6: DATA COLLECTION FORM CANCER REGISTRY

DEMOGRAPHICS	
AGE	
MARITAL STATUS	
FORMAL EDUCATION	
OCCUPATION	
NATIONALITY	
EMIRATE AT DIAGNOSIS	
EMIRATE CURRENT	
INSURANCE	
MOBILE/TELEPHONE	
CANCER INFORMATION	
DIAGNOSIS	
HISTOLOGY	
STAGE	
LATERALITY	
GRADE	
DIAGNOSTIC CONFIRMATION	

DATE OF INITIAL DIAGNOSIS	
DATE 1ST CONTACT WITH THE FACILITY	
DATE OF REFERRAL	
REFERRED HOSPITAL	
REFERRED PHYSICIAN	
MANAGING PHYSICIAN	
FOLLOWING PHYSICIAN	
TREATMENT INFORMATION	
TREATMENT STATUS	
SURGERY (Type & Date)	
CHEMOTHERAPY (Type & Date)	
RADIOTHERAPY (Type & Date)	
HORMONAL THERAPY (Type & Date)	
IMMUNOTHERAPY (Type & Date)	
PALLIATIVE CARE (Type & Date)	
ANY OTHER TREATMENT	Specify: _______________
Reviewer Information:	
Reviewer Name	
Tracking Number	

APPENDIX 7: RISK ASSESSMENT FORM

Version 1, dated 03.10.18

ALL projects MUST include a risk assessment. If this summary assessment of the risk proves insignificant, i.e., you answer 'no' to all of the questions, then no further action is necessary. However, if you identify any risks then you must identify the precautions you will put in place to control these.

1. What is the title of the project?

An exploration of psychosocial needs of breast cancer survivors and its association with cultural differences and clinical indicators – A mixed method study in a hospital setting

2. Is the project purely literature based? **YES/NO**

NO. It is supported by the literature.

3. Please highlight the risk(s) which applies to your study:

Hazards	**Risks**	**If yes, consider what precautions will be taken to minimise risk and discuss with your Supervisor**
Use of ionising or non-ionising radiation	*Exposure to radiation* ***NO***	*Obtain copy of existing risk assessment from place of research and attach a copy to this risk assessment summary.*
Use of hazardous substances	*Exposure to harmful substances* ***NO***	*Obtain copy of existing risk assessment from place of research and attach a copy to this risk assessment summary.*
Use of face-to-face interviews *Interviewees could be upset by interview and become aggressive or*	*Interviewing …*	***NB:*** *Greater precautions are required for medium & high-risk activities* ***Consider:***

violent toward researcher	*Own classmates=Low risk* ***NO*** *Other University students=Medium risk* ***NO*** *Non-University personnel=High risk* ***No***	
Use of face-to-face interviews *Participants or* *interviewees could become upset by interview and suffer psychological effects*	***YES***	***Consider:*** ***A separate application will be made for face-to-face interviews, but I have completed this at this time in regard to the planned interviews.*** Participants will be contacted through the hospital source and an official number will be given for communication. The interviews will be held in a safe environment at Breast care centre at Tawam Hospital. Interviews will be conducted very cautiously with the questions asked but this is a sensitive topic for many and at occasion, some may find it as an emotional or stressful experience. In those circumstances, if a participant needs to be referred to a health professional for emotional support, the researcher will ensure this occurs as soon as possible. This support will be offered at no cost to you. Additionally, if any participant has a concern about any aspect of this study, she should ask to speak to the researcher (x y, contact: 1234) who will do their best to answer your questions. If participants remain unhappy and wish to complain formally you can do this by contacting the Research Supervisor c d, contact: 5678 or e f (e.f@salford.ac.uk). If the matter is still not resolved, participants can forward their concerns to Professor Susan McAndrew, Chair of the Health Research Ethical

		Approval Panel, Room MS1.91, Mary Seacole Building, Frederick Road Campus, University of Salford, Salford, M6 6PU. Tel: 0161 295 2278. E: s.mcandrew@salford.ac.uk'.
Sensitive data	*Exposure to data or information which may cause* *upset or distress to the researcher* ***YES***	***Consider:*** The researchers will collect personal data about the participants, which may be sensitive (for instance, date of birth and relevant health information). The researchers may also need to get some of patient's health information from participant's medical records. Any personal or health information will be kept private and confidential. It will be stored securely and accessible to authorised persons to be kept confidential. Participants will be given a number so that their identity will not be apparent. The study records will be kept in a locked filing cabinet in the researcher's office at Tawam Hospital during the study and in a locked archive for at least 10 years from the time the study is closed and will be destroyed at any time thereafter.
Physical activity	*Exposure to levels of exertion unsuitable for an individual's level of fitness* ***NO***	***Consider:***
Equipment	*Exposure to faulty or unfamiliar equipment.* ***NO***	***Consider****:*
Sensitive issues i.e., Gender/Cultural *e.g., when observing or dealing with undressed members of the opposite sex*	*Exposure to vulnerable situations/ sensitive issues that may cause distress to interviewer or interviewee* ***YES***	***Consider:*** Translators will be placed for native speakers mainly for Emiratis who need clarification for any questions either with regards to questions in the in the study or any aspect of the study.
Children	***NO***	

Manual handling activities	*Exposure to an activity that could result in injury* ***NO***	

If you have answered 'YES' to any of the hazards in section 3, then please list the proposed precautions below:

Please see notes above.

Signature of student: Maria Aamir Date: 03/10/2018………………………

Signature of Supervisor: Linda Dubrow-Marshall Date: 03/10/2018………………………

APPENDIX 8: RISK ASSESSMENT FORM

TAWAM HOSPITAL مستشفى تـــــوام
IN AFFILIATION WITH JOHNS HOPKINS MEDICINE بالإشتراك مع جونـــــز هوبكنز الطبيـــــة

Tawam Cancer Registry Data Confidentiality Agreement

You have inquired about obtaining access to the Cancer Data. Maintaining confidentiality of the cancer data in our Registry is of paramount importance and is upheld with great respect. For this reason, it is very important that you as the requestor specify your need for requested cancer data and the intent of their usage to avoid ever-present potential of its misuse.

By signature below TAWAM CANCER REGISTRY make such binding commitments, the requestor firm assures compliance with the below conditions.

The data will be treated as strictly confidential.

The data will not be used for any purpose other than that specifically set forth above.

The data will not be made available to any other individual, agency, institution, or firm and controls will be maintained to prevent unauthorized access.

No follow back of any type will be made to any individual, institution, or firm without prior approval.

All results will be restricted to study only and will not contact any individual, institution, or firm.

Confidential data will be destroyed or returned to the TAWAM CANCER REGISTRY after serving the purpose set forth above unless specific IRB is granted for their retention.

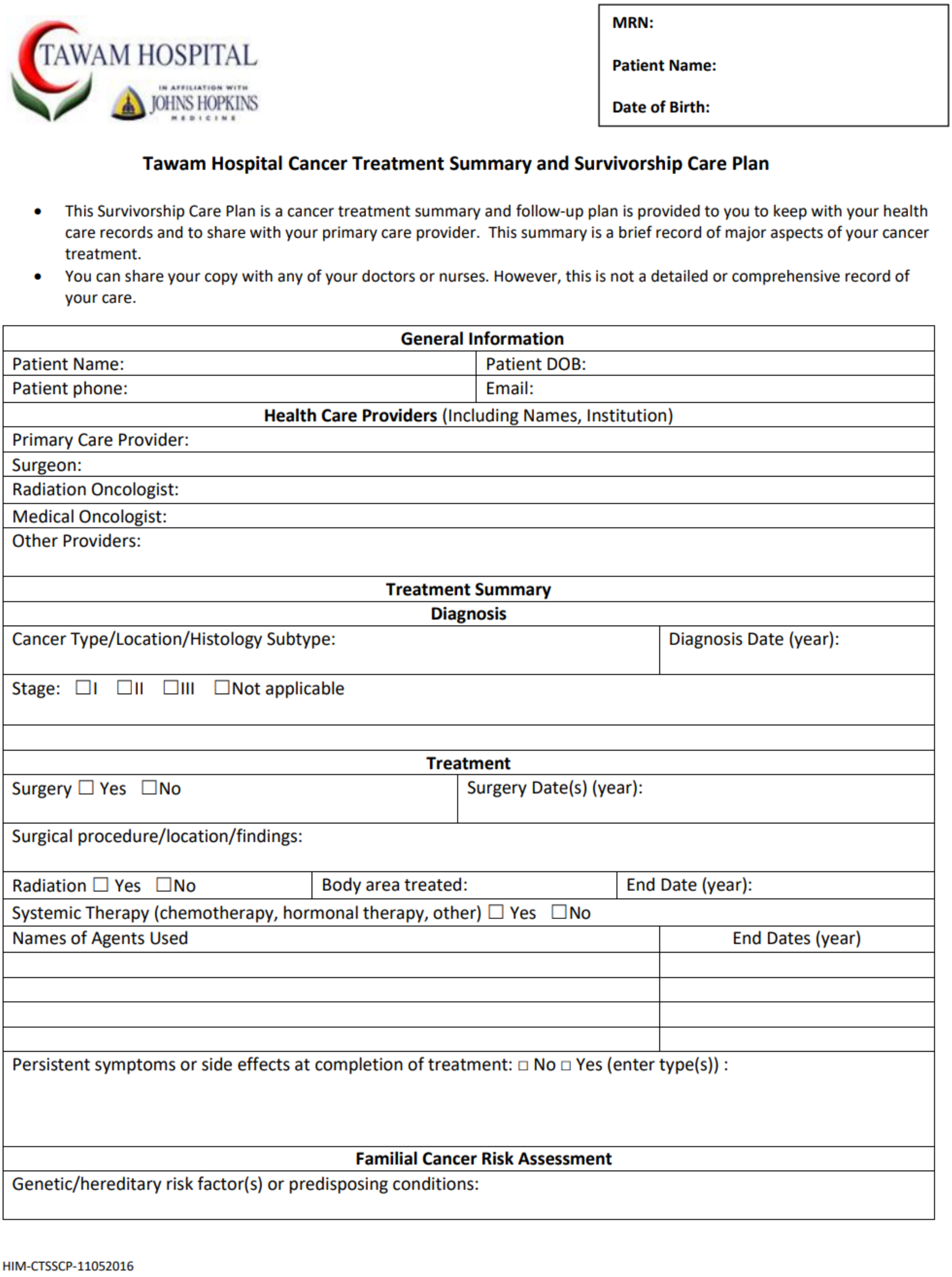
The Tawam Cancer Registry will be credited as the source of the data.

Authorship may be required when TCR makes substantial contribution to the data.

A copy of the results of the study will be furnished to the Tawam Cancer Registry within 60 days of the completion of the project.

Principal Investigator: Maria Aamir **Date: __03/10/2018______________________**

APPENDIX 9: SURVIVORSHIP CARE PLAN



TAWAM HOSPITAL
IN AFFILIATION WITH JOHNS HOPKINS MEDICINE

MRN:

Patient Name:

Date of Birth:

Tawam Hospital Cancer Treatment Summary and Survivorship Care Plan

- This Survivorship Care Plan is a cancer treatment summary and follow-up plan is provided to you to keep with your health care records and to share with your primary care provider. This summary is a brief record of major aspects of your cancer treatment.
- You can share your copy with any of your doctors or nurses. However, this is not a detailed or comprehensive record of your care.

General Information		
Patient Name:	Patient DOB:	
Patient phone:	Email:	
Health Care Providers (Including Names, Institution)		
Primary Care Provider:		
Surgeon:		
Radiation Oncologist:		
Medical Oncologist:		
Other Providers:		
Treatment Summary		
Diagnosis		
Cancer Type/Location/Histology Subtype:	Diagnosis Date (year):	
Stage: ☐I ☐II ☐III ☐Not applicable		
Treatment		
Surgery ☐ Yes ☐No	Surgery Date(s) (year):	
Surgical procedure/location/findings:		
Radiation ☐ Yes ☐No	Body area treated:	End Date (year):
Systemic Therapy (chemotherapy, hormonal therapy, other) ☐ Yes ☐No		
Names of Agents Used	End Dates (year)	
Persistent symptoms or side effects at completion of treatment: □ No □ Yes (enter type(s)) :		
Familial Cancer Risk Assessment		
Genetic/hereditary risk factor(s) or predisposing conditions:		

HIM-CTSSCP-11052016

Genetic counseling: ☐ Yes ☐ No Genetic testing results:

Follow-up Care Plan

Need for ongoing (adjuvant) treatment for cancer ☐ Yes ☐ No

Additional treatment name	Planned duration	Possible Side effects

Schedule of next visits

Physician/Clinic Name	When/How often	Related Tests

Please continue to see your primary care provider for all general health care recommended for a (man) (woman) your age, including cancer screening tests. Any symptoms should be brought to the attention of your provider:

1. Anything that represents a brand new symptom
2. Anything that represents a persistent symptom
3. Anything you are worried about that might be related to the cancer coming back.

Possible late- and long-term effects that someone with this type of cancer and treatment may experience:

Cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

☐ Emotional and mental health ☐ Fatigue ☐ Weight changes ☐ Stopping smoking
☐ Physical Functioning ☐ Insurance ☐ School/Work ☐ Financial advice or assistance
☐ Memory or concentration loss ☐ Parenting ☐ Fertility ☐ Sexual functioning
☐ Other

A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:

☐ Tobacco use/cessation ☐ Diet
☐ Alcohol use ☐ Sun screen use
☐ Weight management (loss/gain) ☐ Physical activity

Resources you may be interested in:

Other comments:

Prepared by: Name ____________________ Date: ____________
Signature & Stamp ________________

Approved by: Name ____________________ Date: ____________
Signature & Stamp _______________

APPENDIX 10: QUANTITATIVE DATA EXTRACTION FILES

Descriptive Analysis

			Statistic	Std. Error
Physical Concerns	Mean		6.14	.857
	95% Confidence Interval for Mean	Lower Bound	4.45	
		Upper Bound	7.83	
	5% Trimmed Mean		3.97	
	Median		1.00	
	Variance		150.619	
	Std. Deviation		12.273	
	Minimum		0	
	Maximum		61	
	Range		61	
	Interquartile Range		6	
	Skewness		2.843	.170
	Kurtosis		7.801	.338
Information Concerns	Mean		27.99	.770
	95% Confidence Interval for Mean	Lower Bound	26.47	
		Upper Bound	29.51	
	5% Trimmed Mean		29.13	
	Median		35.00	
	Variance		121.441	
	Std. Deviation		11.020	
	Minimum		0	
	Maximum		35	
	Range		35	
	Interquartile Range		12	
	Skewness		-1.420	.170
	Kurtosis		.593	.338
Social_Financial_Concerns	Mean		7.13	.442
	95% Confidence Interval for Mean	Lower Bound	6.26	
		Upper Bound	8.00	
	5% Trimmed Mean		6.71	
	Median		6.00	
	Variance		39.974	
	Std. Deviation		6.323	
	Minimum		0	
	Maximum		28	
	Range		28	

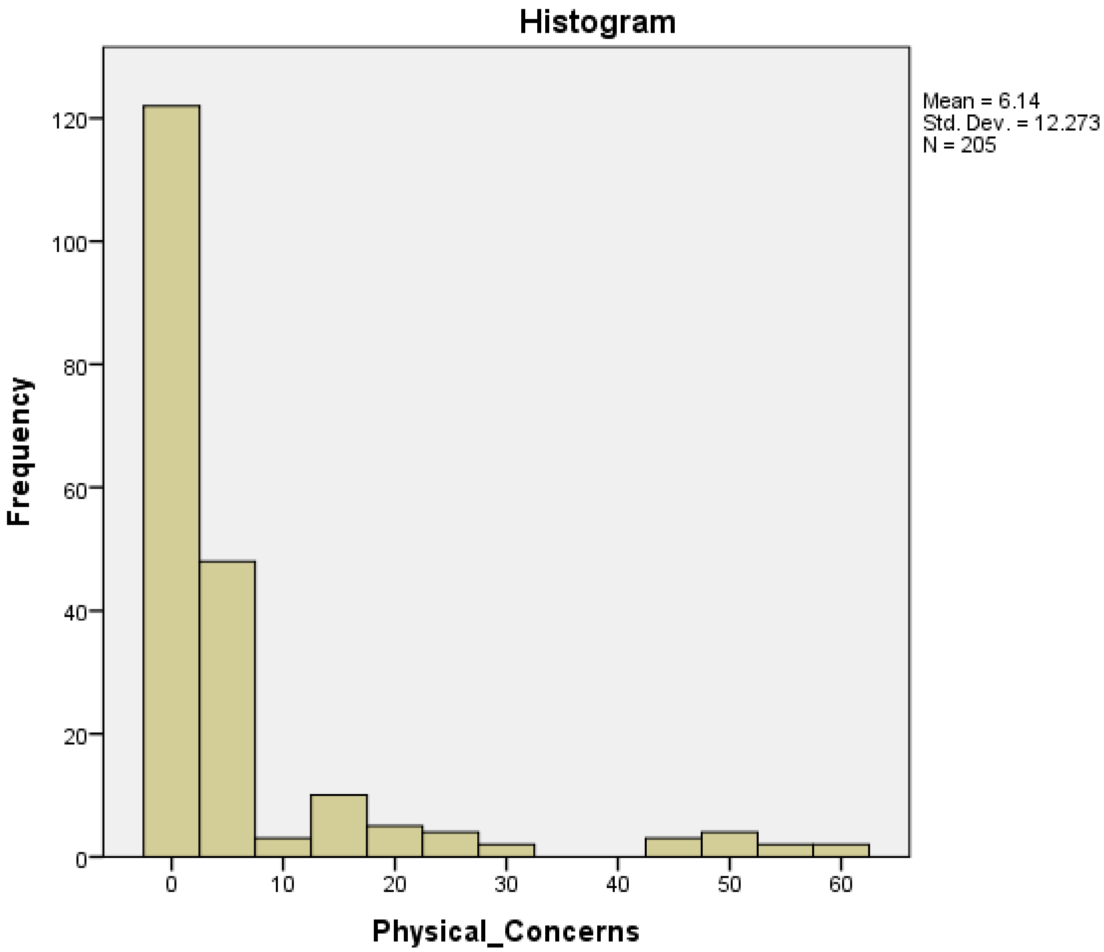
	Interquartile Range		12	
	Skewness		.726	.170
	Kurtosis		-.065	.338
Emotional Concerns	Mean		15.05	.761
	95% Confidence Interval for Mean	Lower Bound	13.55	
		Upper Bound	16.55	
	5% Trimmed Mean		14.49	
	Median		13.00	
	Variance		118.733	
	Std. Deviation		10.896	
	Minimum		0	
	Maximum		54	
	Range		54	
	Interquartile Range		17	
	Skewness		.672	.170
	Kurtosis		-.006	.338
Spiritual/Religious Concerns	Mean		.20	.064
	95% Confidence Interval for Mean	Lower Bound	.07	
		Upper Bound	.33	
	5% Trimmed Mean		.02	
	Median		.00	
	Variance		.837	
	Std. Deviation		.915	
	Minimum		0	
	Maximum		8	
	Range		8	
	Interquartile Range		0	
	Skewness		5.718	.170
	Kurtosis		36.577	.338

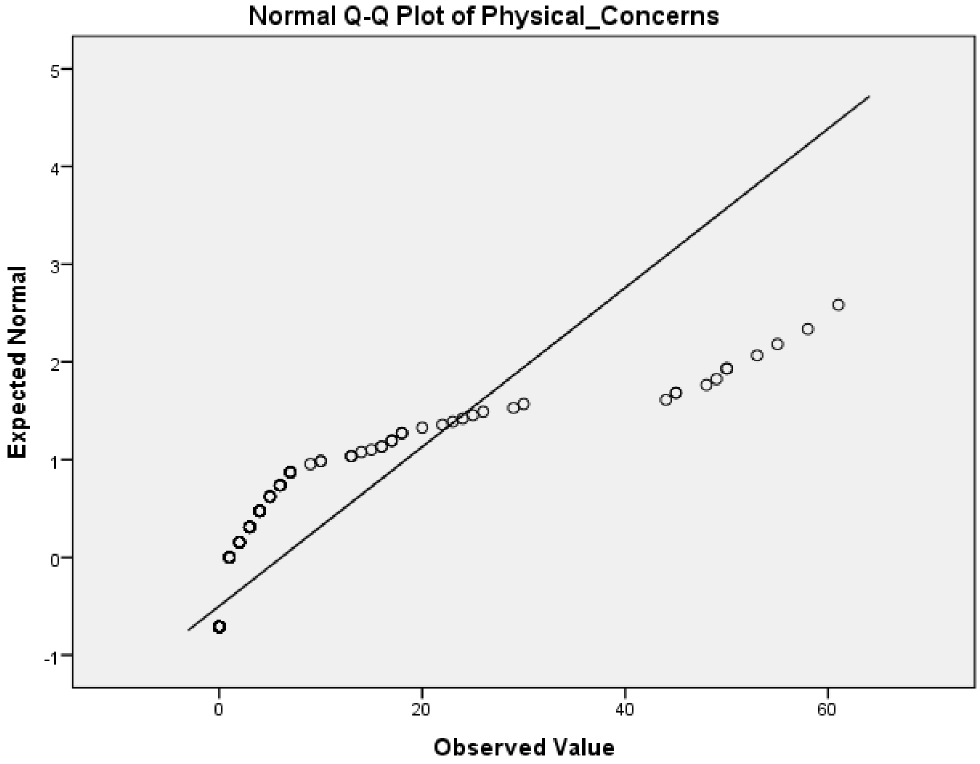
Tests of Normality

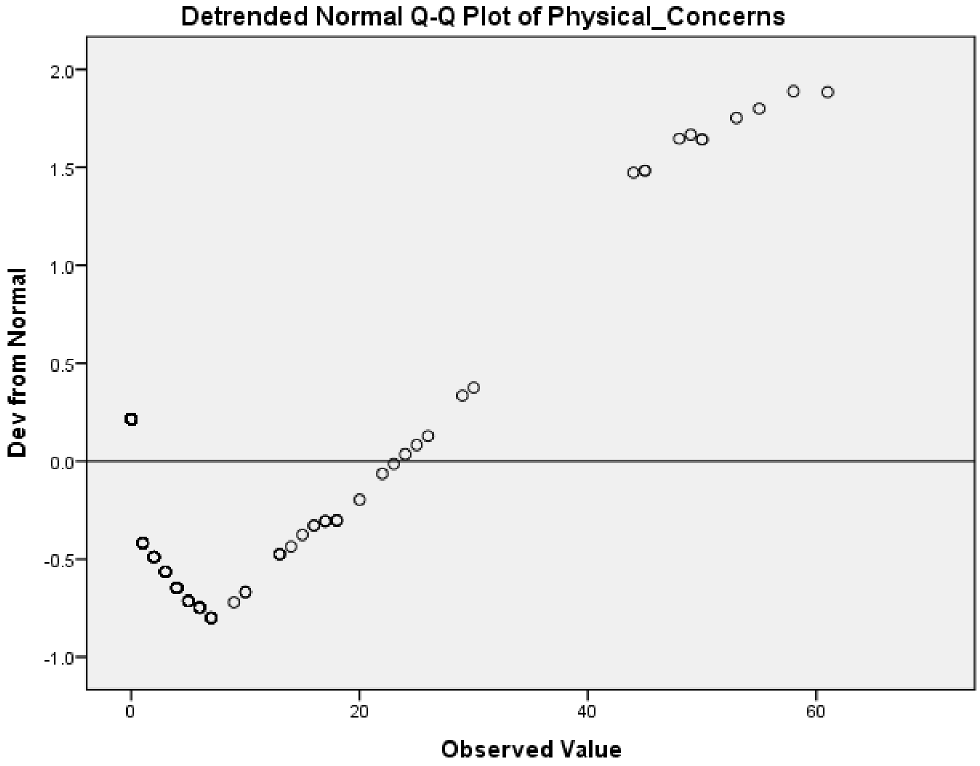
	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Physical_Concerns	.309	205	.000	.551	205	.000
Information_Concerns	.313	205	.000	.679	205	.000
Social_Financial_Concerns	.130	205	.000	.915	205	.000
Emotional_Concerns	.091	205	.000	.951	205	.000
Spiritual_Relegious_Concerns	.518	205	.000	.232	205	.000

a. Lilliefors Significance Correction

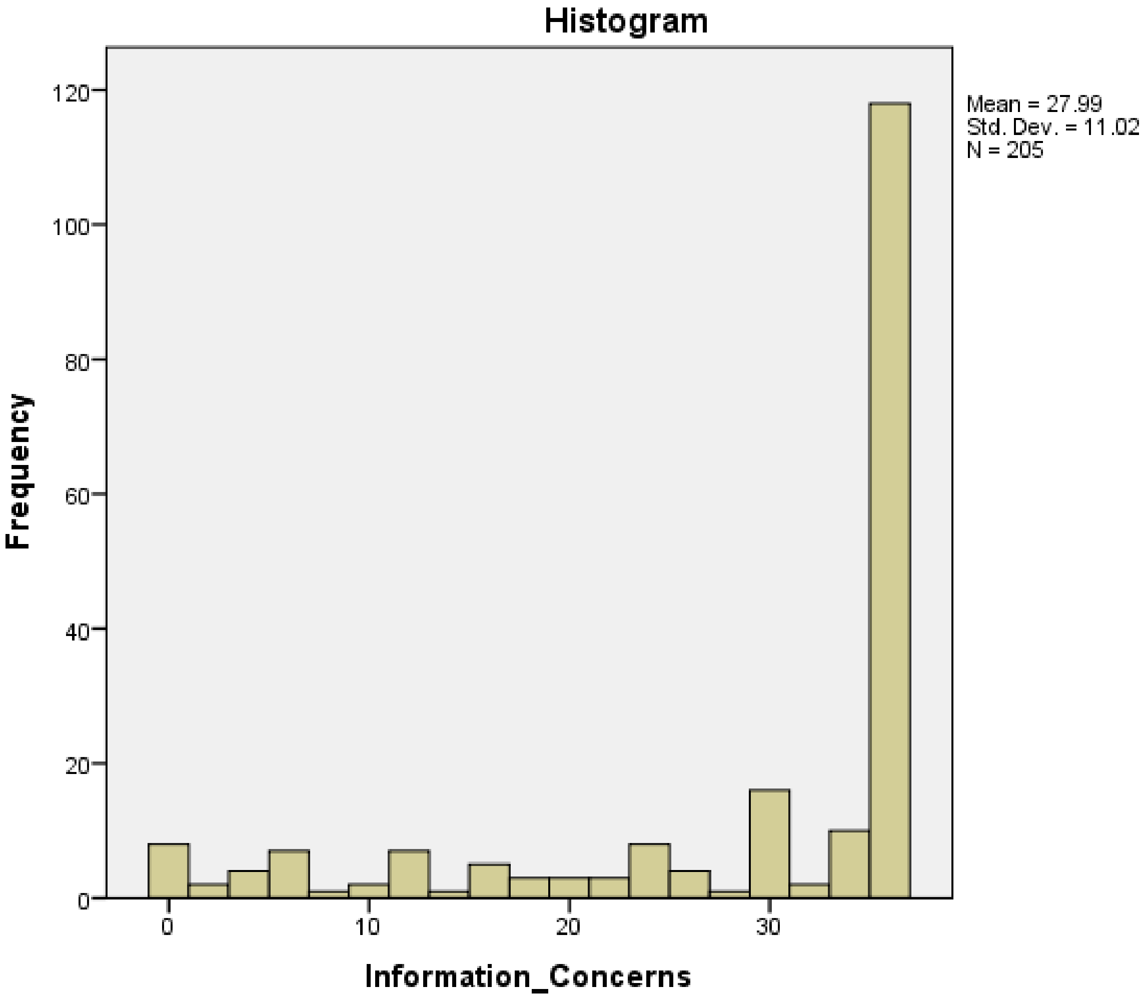
Physical Concerns

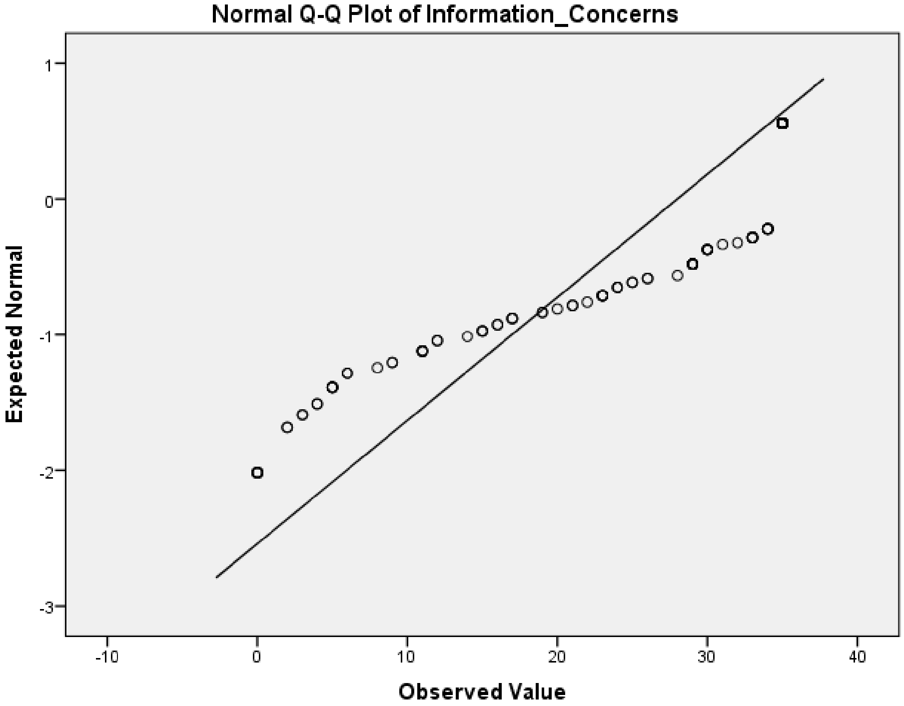


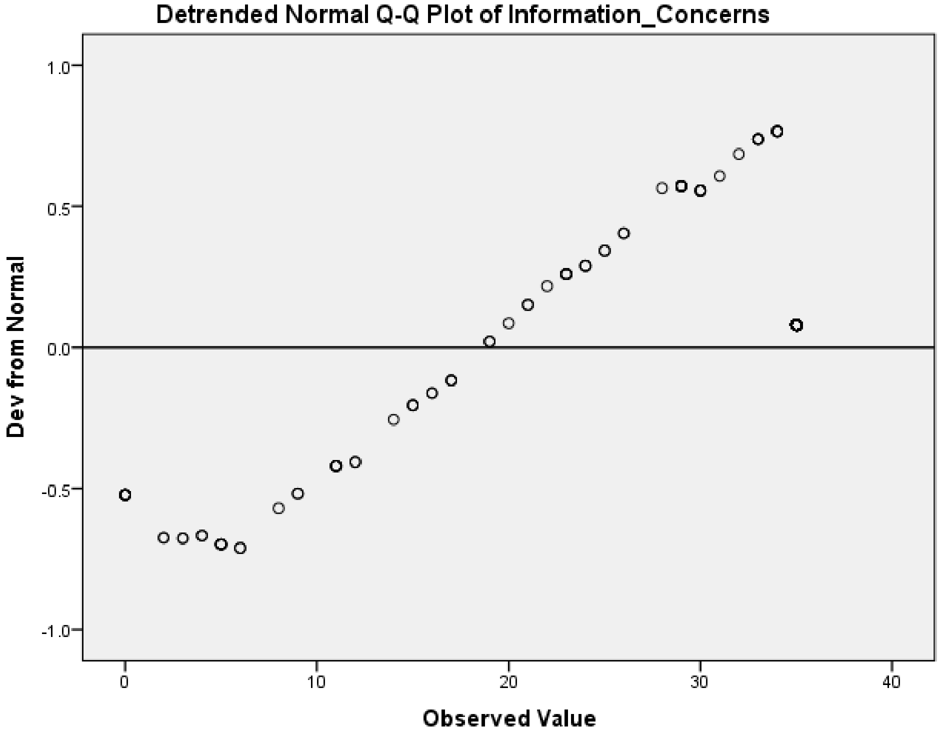

Normal Q-Q Plot of Physical_Concerns
Expected Normal
5
4
3
2
1
0
-1
0
20
40
60
Observed Value


Detrended Normal Q-Q Plot of Physical_Concerns
Dev from Normal
2.0
1.5
1.0
0.5
0.0
-0.5
-1.0
0
20
40
60
Observed Value

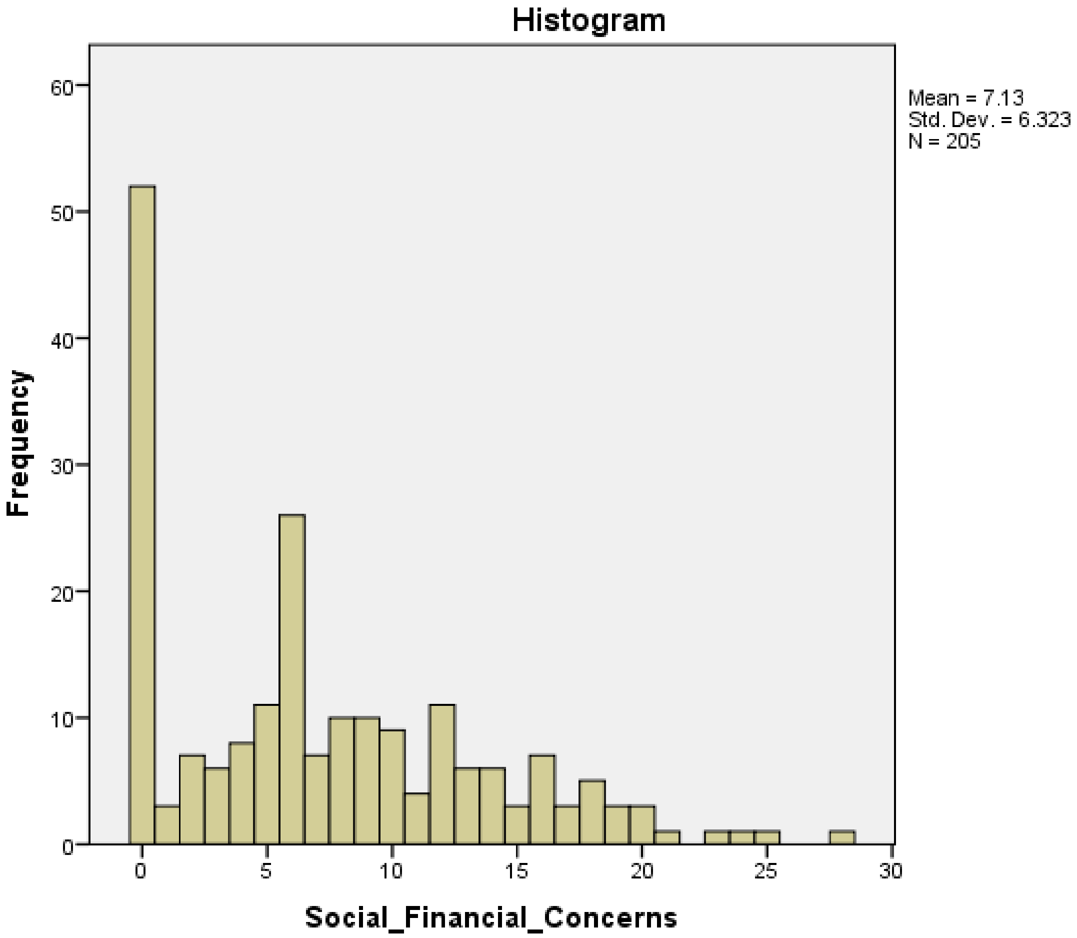
Information Concerns

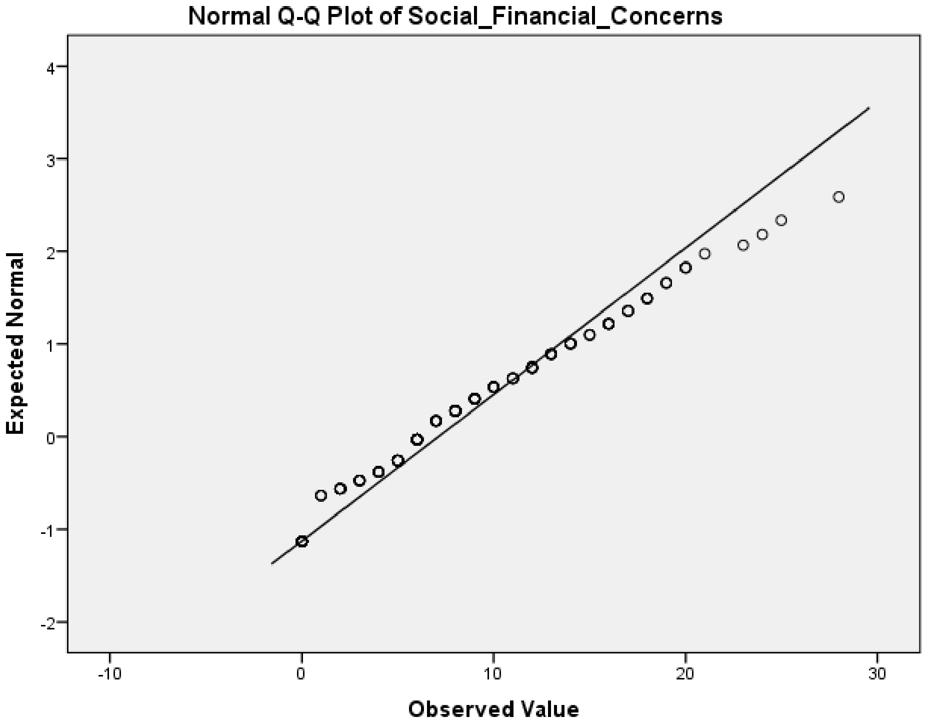


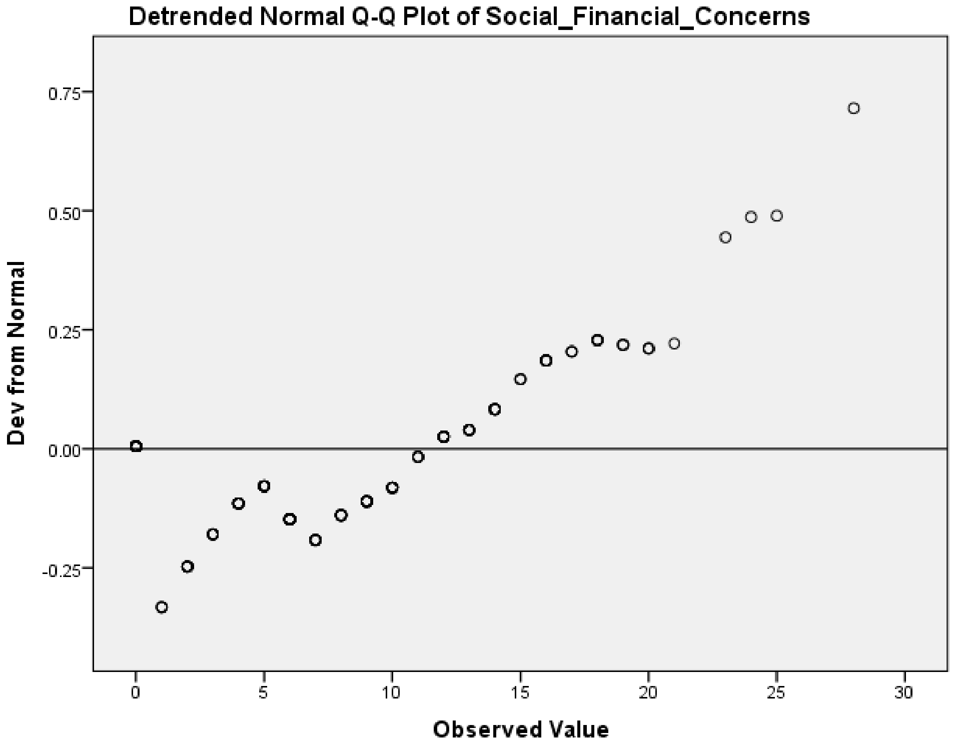

Normal Q-Q Plot of Information_Concerns
Expected Normal
1
0
-1
-2
-3
-10
0
10
20
30
40
Observed Value


Detrended Normal Q-Q Plot of Information_Concerns
Dev from Normal
1.0
0.5
0.0
-0.5
-1.0
0
10
20
30
40
Observed Value

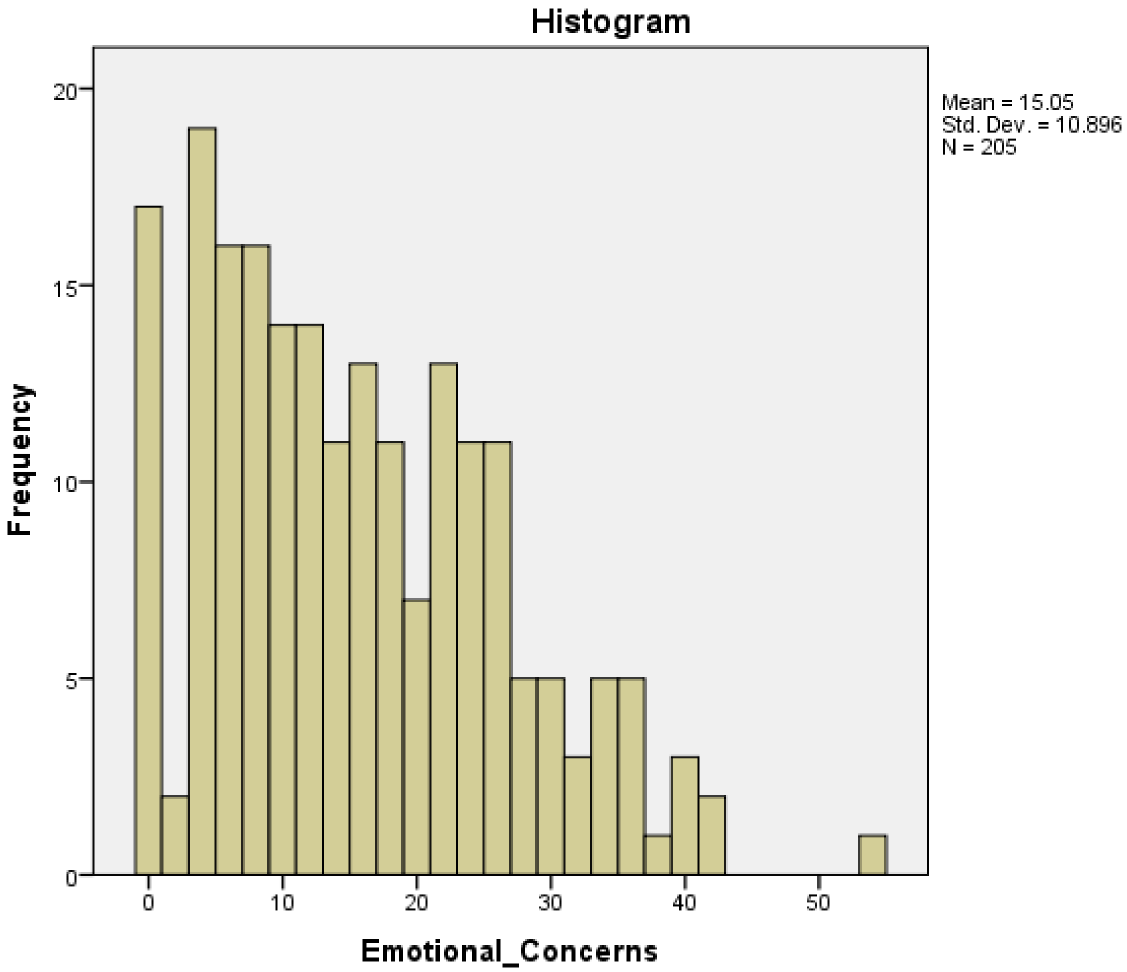
Social or **Financial Concerns**

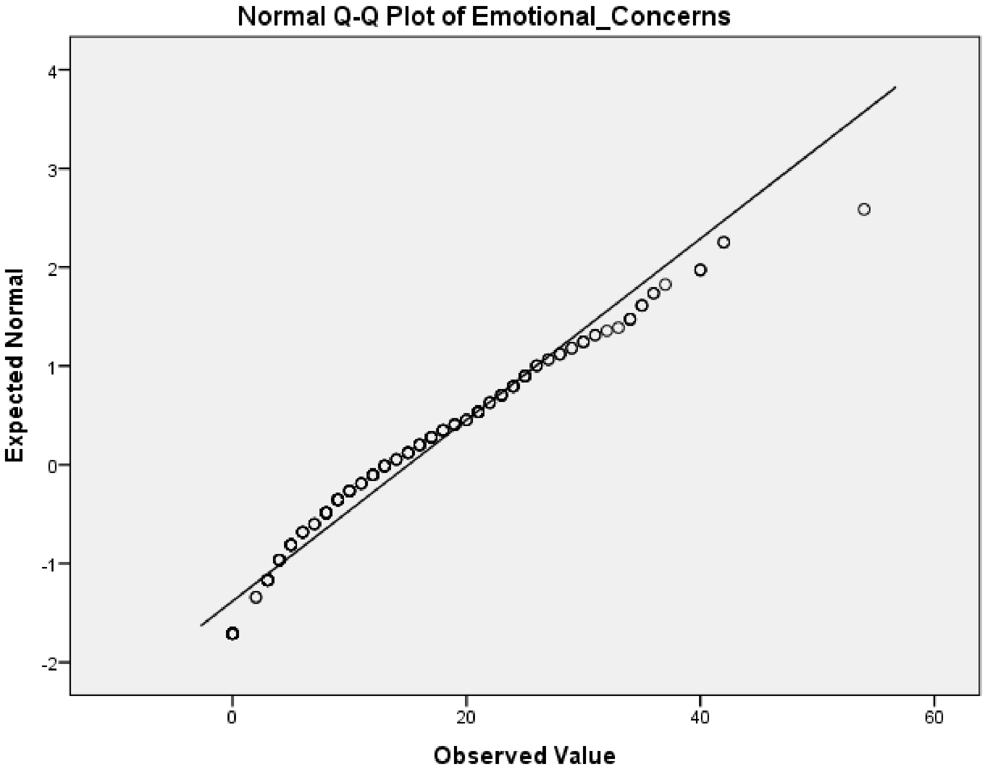


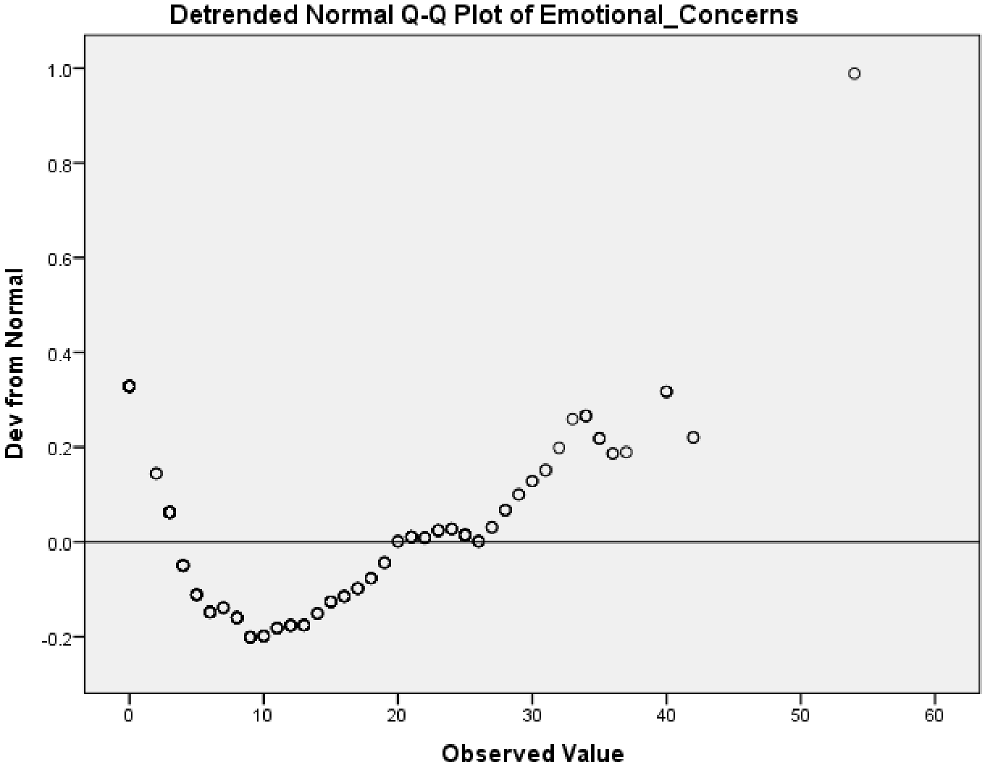

Normal Q-Q Plot of Social_Financial_Concerns
Expected Normal
4
3
2
1
0
-1
-2
-10
0
10
20
30
Observed Value


Detrended Normal Q-Q Plot of Social_Financial_Concerns
Dev from Normal
0.75
0.50
0.25
0.00
-0.25
0
5
10
15
20
25
30
Observed Value

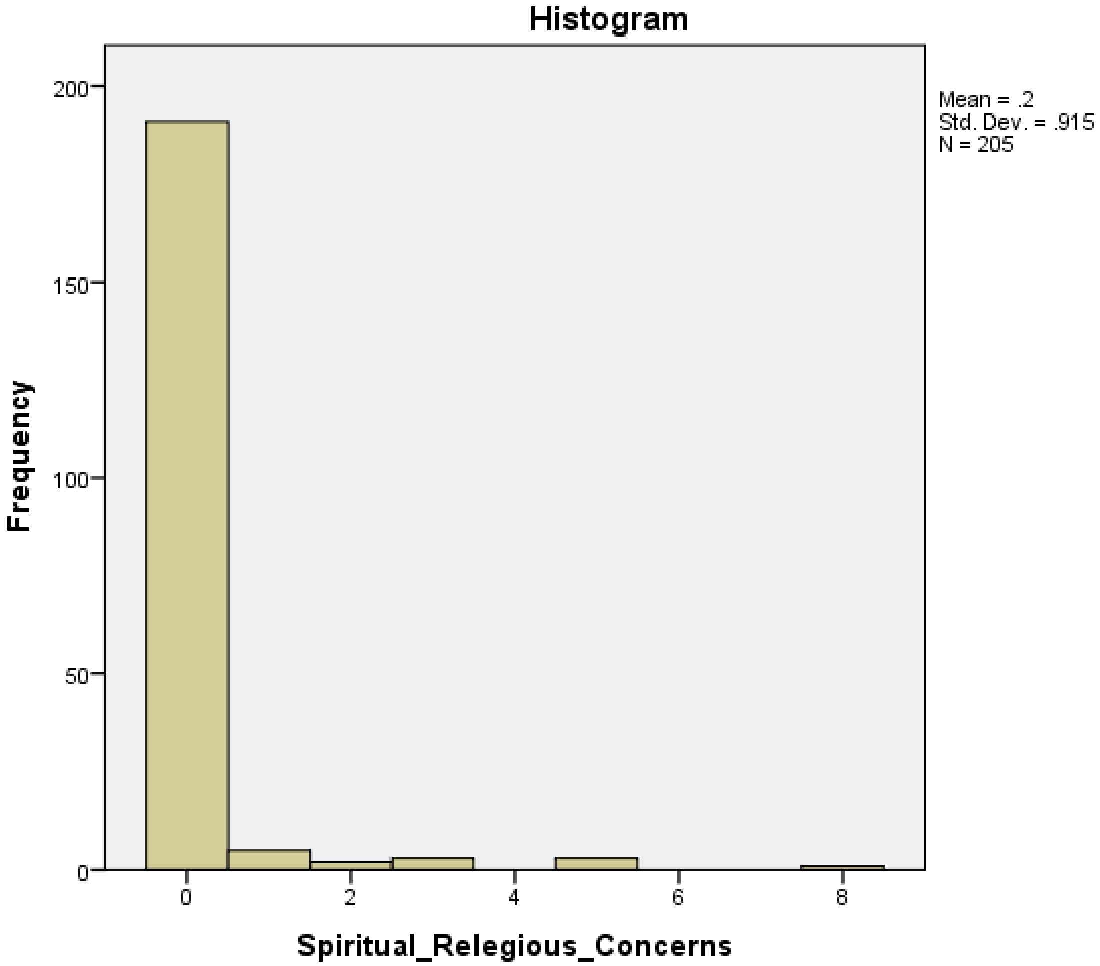
Emotional Concerns

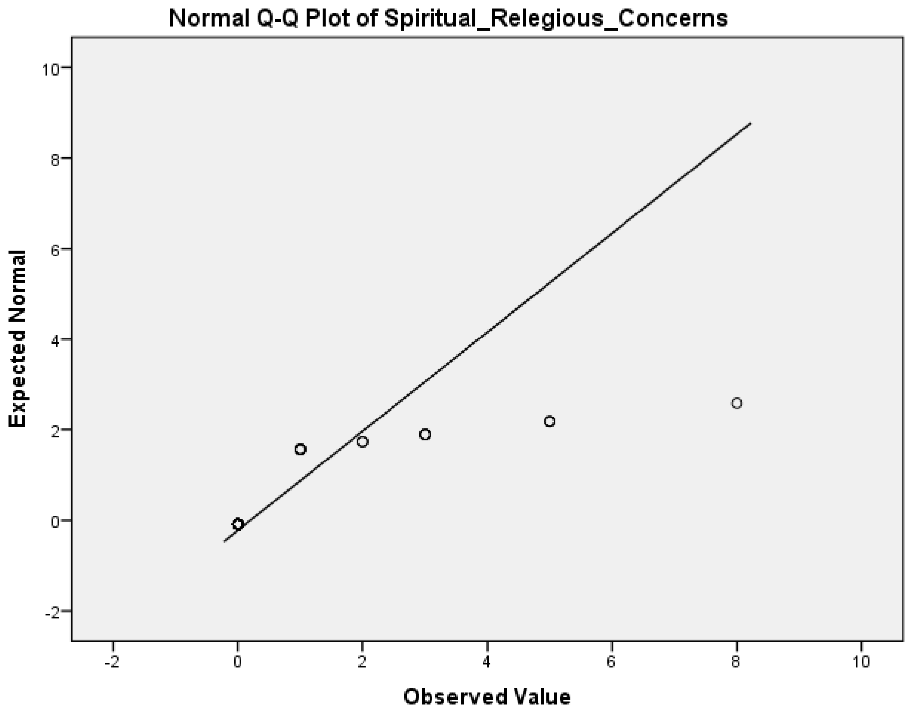


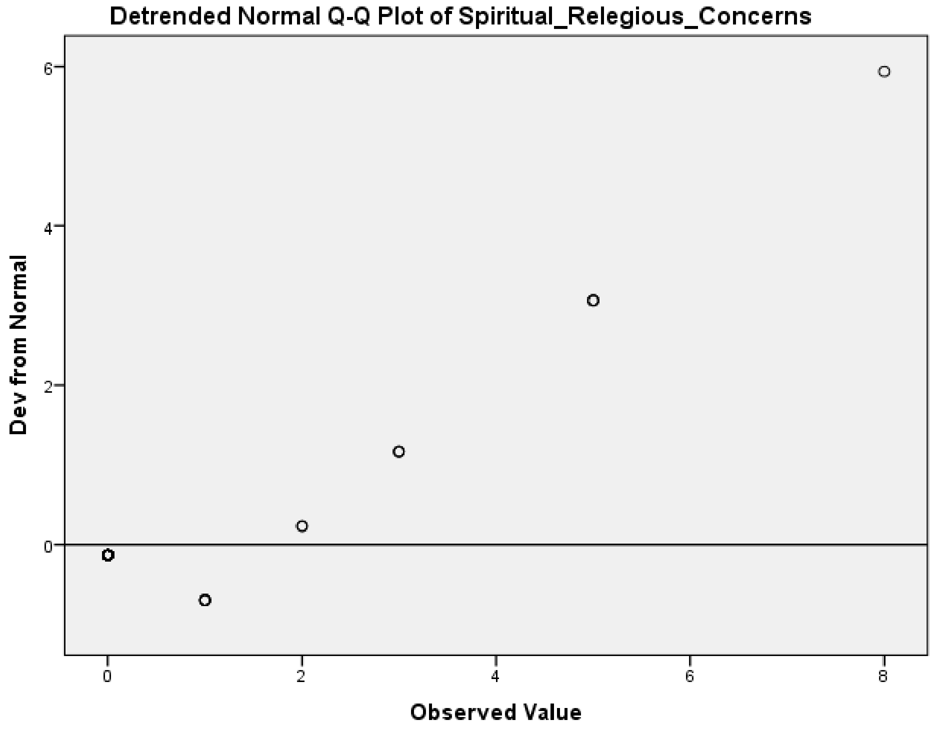

Normal Q-Q Plot of Emotional_Concerns
Expected Normal
4
3
2
1
0
-1
-2
0
20
40
60
Observed Value


Detrended Normal Q-Q Plot of Emotional_Concerns
Dev from Normal
1.0
0.8
0.6
0.4
0.2
0.0
-0.2
0
10
20
30
40
50
60
Observed Value

Spiritual Or Religious Concerns




Normal Q-Q Plot of Spiritual_Relegious_Concerns
Expected Normal
10
8
6
4
2
0
-2
-2
0
2
4
6
8
10
Observed Value


Detrended Normal Q-Q Plot of Spiritual_Relegious_Concerns
Dev from Normal
6
4
2
0
0
2
4
6
8
Observed Value

DESCRIPTIVE STATISTICS - SEVERITY OF BREAST CANCER SURVIVORS' PSYCHOSOCIAL CONCERNS

	N	Mean	Std. Deviation
PHYC1	205	.64	1.274
PHYC2	204	.69	1.286
PHYC3	205	.38	1.044
PHYC4	203	.26	.760
PHYC5	203	.26	.760
PHYC6	205	.22	.803
PHYC7	203	.26	.760
PHYC8	203	.14	.625
PHYC9	205	.35	.992
PHYC10	203	.29	.912
PHYC11	200	.29	.899
PHYC12	204	.19	.631
PHYC13	204	.15	.588
PHYC14	203	.28	.903
PHYC15	203	.47	1.166
PHYC16	205	.36	.983
PHYC17	202	.33	.969
PHYC18	203	.33	1.073
PHYC19	205	.09	.404
PHYC20	205	.21	.786
INF_CONCERN1	205	3.89	1.829

INF_CONCERN2	205	4.35	1.479
INF_CONCERN3	201	4.04	1.691
INF_CONCERN4	202	4.06	1.692
INF_CONCERN5	203	3.97	1.778
INF_CONCERN6	204	3.96	1.776
INF_CONCERN7	204	3.95	1.791
SFC1	205	.85	1.204
SFC2	201	.86	1.168
SFC3	197	.61	1.052
SFC4	202	.94	1.420
SFC5	205	1.96	1.860
SFC6	205	1.96	1.860
EC1	205	1.04	1.380
EC2	204	.78	1.202
EC3	203	.40	.908
EC4	199	1.45	1.839
EC5	205	3.44	1.966
EC6	202	.98	1.250
EC7	203	.41	.915
EC8	205	.26	.718
EC9	200	.61	1.089
EC10	202	1.05	1.543
EC11	201	.29	.804
EC12	201	.46	1.104

EC13	200	.55	1.150
EC14	203	3.48	1.968
SRC1	205	.02	.279
SRC2	205	.02	.279
SRC3	205	.00	.000
SRC4	202	.16	.738
Valid N (listwise)	139		

Breast cancer survivors’ most prevalent concerns by year of diagnosis

0–1 year since diagnosis, >=2018 (n =122)

	N	Mean	Std. Deviation
Physical_Concerns	122	7.00	13.368
Information_Concerns	122	26.60	11.582
Social_Financial_Concerns	122	6.30	6.160
Emotional_Concerns	122	13.89	10.570
Spiritual_Relegious_Concerns	122	.23	1.019
Valid N (listwise)	122		

2–5 years since diagnosis, 2012-2017 (n = 80)

	N	Mean	Std. Deviation
Physical_Concerns	80	4.31	8.710
Information_Concerns	80	29.96	9.995
Social_Financial_Concerns	80	8.27	6.410
Emotional_Concerns	80	17.04	11.302
Spiritual_Relegious_Concerns	80	.16	.754
Valid N (listwise)	80		

6 and earlier since diagnosis (n = 3)

	N	Mean	Std. Deviation
Physical_Concerns	3	19.67	33.201

Information_Concerns	3	32.00	5.196
Social_Financial_Concerns	3	10.00	7.211
Emotional_Concerns	3	9.33	4.041
Spiritual_Relegious_Concerns	3	.00	.000
Valid N (listwise)	3		

ASSOCIATION BETWEEN BREAST CANCER SURVIVORS' NATIONALITY & AGE

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Age group * Nation	205	100.0%	0	0.0%	205	100.0%

Age group * Nation Crosstabulation

			Nation		Total
			Emirati	Expatriate	
Age group	22-32	Count	1	11	12
		Expected Count	3.2	8.8	12.0
		% within Age group	8.3%	91.7%	100.0%
	33-43	Count	20	44	64
		Expected Count	16.9	47.1	64.0
		% within Age group	31.3%	68.8%	100.0%
	44-54	Count	14	50	64
		Expected Count	16.9	47.1	64.0
		% within Age group	21.9%	78.1%	100.0%
	55-65	Count	15	30	45
		Expected Count	11.9	33.1	45.0
		% within Age group	33.3%	66.7%	100.0%

	>65	Count	4	16	20
		Expected Count	5.3	14.7	20.0
		% Within Age group	20.0%	80.0%	100.0%
Total		Count	54	151	205
		Expected Count	54.0	151.0	205.0
		% Within Age group	26.3%	73.7%	100.0%

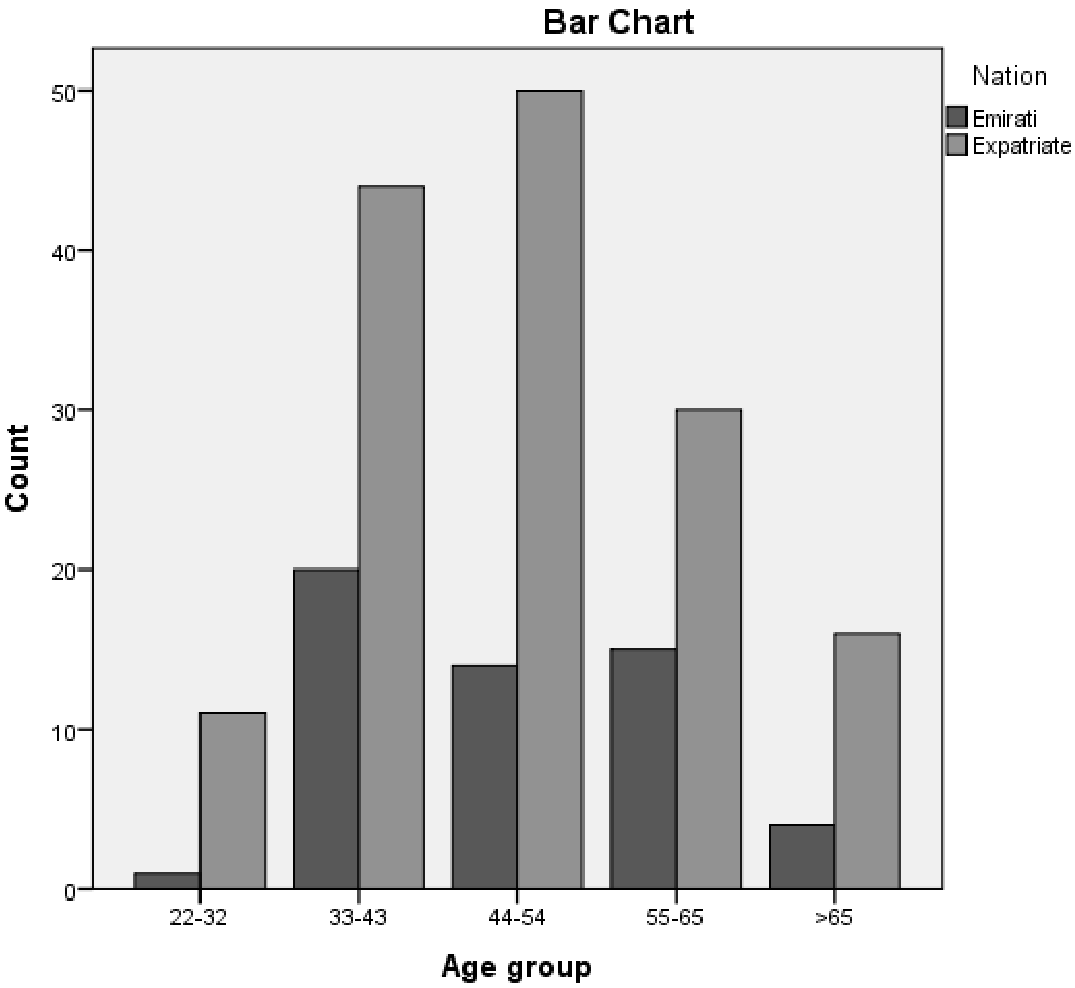
Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	5.007[a]	4	.287
Likelihood Ratio	5.479	4	.242
Linear-by-Linear Association	.069	1	.792
N of Valid Cases	205		

a. 1 cells (10.0%) have expected count less than 5. The minimum expected count is 3.16.

Symmetric Measures

		Value	Approximate Significance
Nominal by Nominal	Phi	.156	.287
	Cramer's V	.156	.287
N of Valid Cases		205	


Bar Chart
Count
50
40
30
20
10
0
22-32
33-43
44-54
55-65
>65
Age group
Nation
Emirati
Expatriate

ASSOCIATION BETWEEN BREAST CANCER SURVIVORS' STAGE OF CANCER & NATIONALITY

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Stage * Nation	205	100.0%	0	0.0%	205	100.0%

Stage * Nationality Crosstabulation

			Nation		
			Emirati	Expatriate	Total
Stage	In-Situ	Count	5	8	13
		Expected Count	3.4	9.6	13.0
		% Within Stage	38.5%	61.5%	100.0%
	Stage I	Count	12	27	39
		Expected Count	10.3	28.7	39.0
		% Within Stage	30.8%	69.2%	100.0%
	Stage II	Count	31	74	105
		Expected Count	27.7	77.3	105.0
		% Within Stage	29.5%	70.5%	100.0%
	Stage III	Count	6	42	48
		Expected Count	12.6	35.4	48.0
		% Within Stage	12.5%	87.5%	100.0%
Total		Count	54	151	205

		Expected Count	54.0	151.0	205.0
		% Within Stage	26.3%	73.7%	100.0%

Stage * Nationality Crosstabulation

			Nation		Total
			Emirati	Expatriate	
Stage	In-Situ	Count	5	8	13
		Expected Count	3.4	9.6	13.0
		% Within Stage	38.5%	61.5%	100.0%
	Stage I	Count	12	27	39
		Expected Count	10.3	28.7	39.0
		% Within Stage	30.8%	69.2%	100.0%
	Stage II	Count	31	74	105
		Expected Count	27.7	77.3	105.0
		% Within Modified Stage	29.5%	70.5%	100.0%
	Stage III	Count	6	42	48
		Expected Count	12.6	35.4	48.0
		% Within Modified Stage	12.5%	87.5%	100.0%
Total		Count	54	151	205
		Expected Count	54.0	151.0	205.0
		% Within Modified Stage	26.3%	73.7%	100.0%

Chi-Square Tests

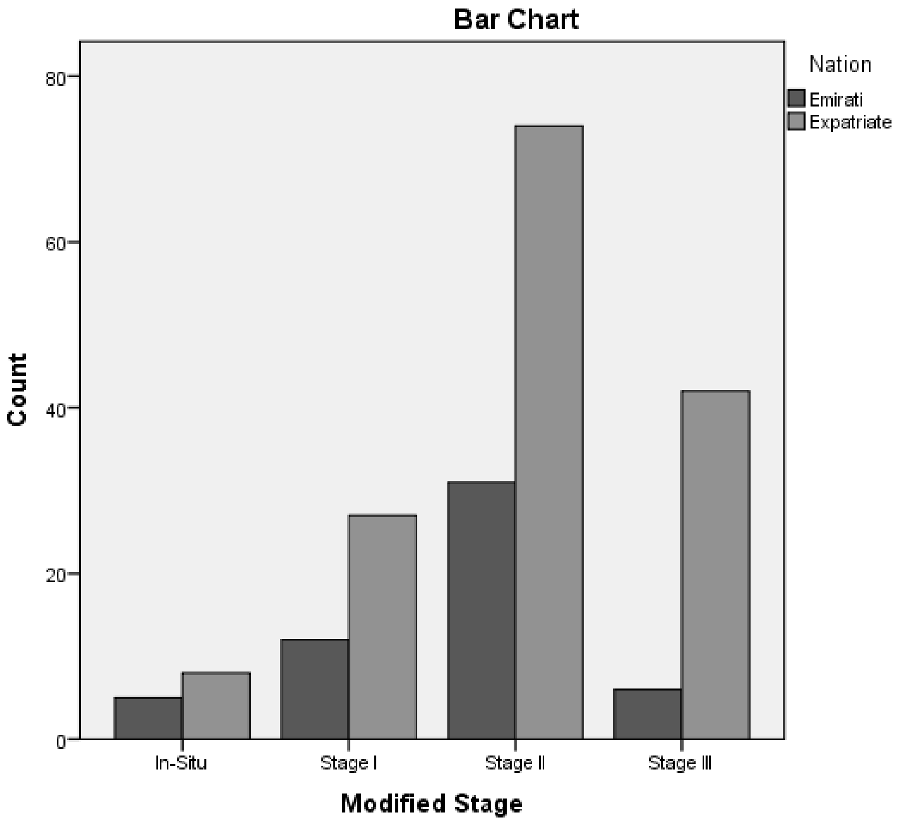
	Value	df	Asymptotic Significance (2-sided)

Pearson Chi-Square	6.666[a]	3	.083
Likelihood Ratio	7.344	3	.062
Linear-by-Linear Association	4.949	1	.026
N of Valid Cases	205		

a. 1 cells (12.5%) have expected count less than 5. The minimum expected count is 3.42.

Symmetric Measures

		Value	Approximate Significance
Nominal by Nominal	Phi	.180	.083
	Cramer's V	.180	.083
	N of Valid Cases	205	



T-Test – Psychosocial Concerns

Group Statistics

	Nation	N	Mean	Std. Deviation	Std. Error Mean
Physical_Concerns	Emirati	54	3.57	8.878	1.208
	Expatriate	151	7.05	13.183	1.073
Information_Concerns	Emirati	54	26.41	14.395	1.959
	Expatriate	151	28.56	9.524	.775
Social_Financial_Concerns	Emirati	54	3.59	3.839	.522
	Expatriate	151	8.39	6.561	.534
Emotional_Concerns	Emirati	54	17.17	10.056	1.368
	Expatriate	151	14.29	11.116	.905
Spiritual_Relegious_Concerns	Emirati	54	.28	.960	.131
	Expatriate	151	.17	.900	.073

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Physical_Concerns	Equal variances assumed	7.160	.008	-1.798	203	.074	-3.479	1.935	-7.295	.337
	Equal variances not			-2.153	139.000	.033	-3.479	1.616	-6.673	-.284

	assumed									
Information_Concerns	Equal variances assumed	23.772	.000	-1.231	203	.220	-2.149	1.745	-5.590	1.292
	Equal variances not assumed			-1.020	70.284	.311	-2.149	2.107	-6.350	2.053
Social_Financial_Concerns	Equal variances assumed	17.379	.000	-5.067	203	.000	-4.798	.947	-6.665	-2.931
	Equal variances not assumed			-6.423	159.920	.000	-4.798	.747	-6.273	-3.323
Emotional_Concerns	Equal variances assumed	2.102	.149	1.671	203	.096	2.875	1.720	-.516	6.267
	Equal variances not assumed			1.753	102.519	.083	2.875	1.640	-.378	6.129
Spiritual_Relegious_Concerns	Equal variances assumed	1.864	.174	.727	203	.468	.106	.145	-.181	.392

	Equal variances not assumed			.705	88.480	.483	.106	.150	-.192	.403

Group Statistics – Physical Concerns

	Nation	N	Mean	Std. Deviation	Std. Error Mean
PHYC1	Emirati	54	.33	.911	.124
	Expatriate	151	.75	1.366	.111
PHYC2	Emirati	54	.41	.981	.134
	Expatriate	150	.79	1.367	.112
PHYC3	Emirati	54	.07	.428	.058
	Expatriate	151	.49	1.171	.095
PHYC4	Emirati	54	.09	.351	.048
	Expatriate	149	.32	.855	.070
PHYC5	Emirati	54	.09	.351	.048
	Expatriate	149	.32	.855	.070
PHYC6	Emirati	54	.19	.803	.109
	Expatriate	151	.24	.806	.066
PHYC7	Emirati	54	.09	.351	.048
	Expatriate	149	.32	.855	.070
PHYC8	Emirati	54	.02	.136	.019
	Expatriate	149	.19	.720	.059
PHYC9	Emirati	54	.26	.915	.125
	Expatriate	151	.38	1.019	.083
PHYC10	Emirati	54	.17	.795	.108
	Expatriate	149	.34	.949	.078
PHYC11	Emirati	53	.19	.810	.111
	Expatriate	147	.32	.929	.077
PHYC12	Emirati	54	.04	.191	.026
	Expatriate	150	.24	.721	.059
PHYC13	Emirati	54	.02	.136	.019
	Expatriate	150	.20	.676	.055

PHYC14	Emirati	53	.15	.533	.073
	Expatriate	150	.32	.999	.082
PHYC15	Emirati	53	.49	1.325	.182
	Expatriate	150	.46	1.109	.091
PHYC16	Emirati	54	.37	1.104	.150
	Expatriate	151	.35	.939	.076
PHYC17	Emirati	54	.17	.505	.069
	Expatriate	148	.39	1.086	.089
PHYC18	Emirati	54	.24	.950	.129
	Expatriate	149	.36	1.115	.091
PHYC19	Emirati	54	.06	.408	.056
	Expatriate	151	.11	.403	.033
PHYC20	Emirati	54	.15	.627	.085
	Expatriate	151	.23	.836	.068

Independent Samples Test – Physical Concerns

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
PHYC1	Equal variances assumed	14.017	.000	-2.105	203	.037	-.422	.200	-.817	-.027
	Equal variances not assumed			-2.532	140.405	.012	-.422	.167	-.751	-.092
PHYC2	Equal variances assumed	8.278	.004	-1.904	202	.058	-.386	.203	-.786	.014
	Equal variances not assumed			-2.217	130.338	.028	-.386	.174	-.730	-.042

PHYC3	Equal variances assumed	27.524	.000	-2.547	203	.012	-.416	.163	-.738	-.094
	Equal variances not assumed			-3.725	202.879	.000	-.416	.112	-.636	-.196
PHYC4	Equal variances assumed	14.765	.000	-1.857	201	.065	-.223	.120	-.459	.014
	Equal variances not assumed			-2.628	198.024	.009	-.223	.085	-.390	-.056
PHYC5	Equal variances assumed	14.765	.000	-1.857	201	.065	-.223	.120	-.459	.014
	Equal variances not assumed			-2.628	198.024	.009	-.223	.085	-.390	-.056
PHYC6	Equal variances assumed	.574	.450	-.417	203	.677	-.053	.128	-.305	.198
	Equal variances not assumed			-.418	93.791	.677	-.053	.127	-.306	.200
PHYC7	Equal variances assumed	14.765	.000	-1.857	201	.065	-.223	.120	-.459	.014
	Equal variances not assumed			-2.628	198.024	.009	-.223	.085	-.390	-.056
PHYC8	Equal variances assumed	12.466	.001	-1.715	201	.088	-.169	.099	-.364	.025
	Equal variances not assumed			-2.740	173.892	.007	-.169	.062	-.291	-.047
PHYC9	Equal variances assumed	2.124	.147	-.793	203	.429	-.125	.157	-.435	.186
	Equal variances not assumed			-.835	103.255	.406	-.125	.150	-.422	.172
PHYC10	Equal variances assumed	4.880	.028	-1.168	201	.244	-.169	.145	-.454	.116

	Equal variances not assumed			-1.268	111.218	.207	-.169	.133	-.433	.095
PHYC11	Equal variances assumed	2.939	.088	-.910	198	.364	-.131	.144	-.415	.153
	Equal variances not assumed			-.970	104.630	.334	-.131	.135	-.399	.137
PHYC12	Equal variances assumed	17.960	.000	-2.041	202	.043	-.203	.099	-.399	-.007
	Equal variances not assumed			-3.157	192.150	.002	-.203	.064	-.330	-.076
PHYC13	Equal variances assumed	16.240	.000	-1.957	202	.052	-.181	.093	-.364	.001
	Equal variances not assumed			-3.119	178.120	.002	-.181	.058	-.296	-.067
PHYC14	Equal variances assumed	5.699	.018	-1.173	201	.242	-.169	.144	-.453	.115
	Equal variances not assumed			-1.542	169.747	.125	-.169	.110	-.385	.047
PHYC15	Equal variances assumed	.614	.434	.164	201	.870	.031	.187	-.338	.399
	Equal variances not assumed			.150	79.250	.881	.031	.203	-.374	.435
PHYC16	Equal variances assumed	.195	.659	.124	203	.901	.019	.156	-.289	.327
	Equal variances not assumed			.115	82.064	.909	.019	.169	-.316	.355
PHYC17	Equal variances assumed	9.031	.003	-1.466	200	.144	-.225	.154	-.528	.078
	Equal variances not assumed			-2.000	188.903	.047	-.225	.113	-.447	-.003

PHYC18	Equal variances assumed	1.577	.211	-.674	201	.501	-.115	.171	-.451	.222
	Equal variances not assumed			-.726	109.369	.469	-.115	.158	-.429	.199
PHYC19	Equal variances assumed	2.315	.130	-.787	203	.432	-.050	.064	-.177	.076
	Equal variances not assumed			-.782	92.316	.436	-.050	.064	-.178	.078
PHYC20	Equal variances assumed	1.688	.195	-.670	203	.503	-.084	.125	-.330	.162
	Equal variances not assumed			-.767	124.190	.445	-.084	.109	-.300	.132

Group Statistics – Social & Financial Concerns

	Nation	N	Mean	Std. Deviation	Std. Error Mean
SFC1	Emirati	54	.63	.917	.125
	Expatriate	151	.93	1.284	.104
SFC2	Emirati	54	.69	.886	.121
	Expatriate	147	.92	1.252	.103
SFC3	Emirati	50	.34	.519	.073
	Expatriate	147	.70	1.167	.096
SFC4	Emirati	53	.64	1.178	.162
	Expatriate	149	1.05	1.486	.122
SFC5	Emirati	54	.67	1.046	.142
	Expatriate	151	2.42	1.871	.152
SFC6	Emirati	54	.67	1.046	.142
	Expatriate	151	2.42	1.871	.152

Independent Samples Test – Social & Financial Concerns

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
SFC1	Equal variances assumed	6.631	.011	-1.600	203	.111	-.304	.190	-.679	.071
	Equal variances not assumed			-1.868	130.649	.064	-.304	.163	-.626	.018
SFC2	Equal variances assumed	10.268	.002	-1.256	199	.210	-.233	.186	-.599	.133
	Equal variances not assumed			-1.468	133.223	.144	-.233	.159	-.547	.081
SFC3	Equal variances assumed	16.425	.000	-2.113	195	.036	-.361	.171	-.697	-.024
	Equal variances not assumed			-2.979	181.820	.003	-.361	.121	-.600	-.122
SFC4	Equal variances assumed	7.888	.005	-1.795	200	.074	-.405	.226	-.851	.040
	Equal variances not assumed			-2.002	114.574	.048	-.405	.203	-.807	-.004
SFC5	Equal variances assumed	44.090	.000	-6.540	203	.000	-1.757	.269	-2.287	-1.227
	Equal variances not assumed			-8.431	166.559	.000	-1.757	.208	-2.169	-1.346
SFC6	Equal variances assumed	44.090	.000	-6.540	203	.000	-1.757	.269	-2.287	-1.227

	Equal variances not assumed			-8.431	166.559	.000	-1.757	.208	-2.169	-1.346

RELATIONSHIP BETWEEN (a) DEMOGRAPHIC FACTORS & PSYCHOSOCIAL CONCERNS

Relationship	**Correlation (R-value)**	**Significance level (P-value)**
Age and physical concern	-0.114	0.104
Stage of cancer and physical concern	-0.041	0.562
Receiving treatment and physical concern	0.117	0.095

Relationship	**Correlation (R-value)**	**Significance level (P-value)**
Age and social financial concern	-0.060	0.394
Stage of cancer and social financial concern	0.157	0.025*
Receiving treatment and social financial concern	0.246	0.000*

Model	Predictor variable	Standardised regression coefficient beta	T-value	P(significance level)
Model1	Receiving treatment	0.246	3.622	0.000
Model 2	Receiving treatment	0.239	3.545	0.000
	Stage of cancer	0.145	2.151	0.033

Relationship	**Correlation (R-value)**	**Significance level (P-value)**
Age and emotional concern	0.133	0.058
Stage of cancer and emotional concern	0.037	0.602
Receiving treatment and emotional concern	0.240	0.001*

Model	Predictor variable	Standardised regression coefficient beta	T-value	P(significance level)
Model	Receiving treatment	0.240	3.524	0.001

Relationship	**Correlation (R-value)**	**Significance level (P-value)**
Age and spiritual concern	0.45	0.523

Stage of cancer and spiritual concern	-0.069	0.325
Receiving treatment and spiritual concern	-0.024	0.734

ORRELATION BETWEEN QUALITY OF LIFE & PSYCHOSOCIAL CONCERNS OF BREAST CANCER SURVIVORS

		Overall_QOL	Physical_Concerns	Information_Concerns	Social_Financial_Concerns	Emotional_Concerns	Spiritual_Relegious_Concerns
Overall_QOL	Pearson Correlation	1	-.483**	.221**	-.282**	-.360**	-.166*
	Sig. (2-tailed)		.000	.001	.000	.000	.017
	N	205	205	205	205	205	205
Physical_Concerns	Pearson Correlation	-.483**	1	-.308**	.306**	.373**	.324**
	Sig. (2-tailed)	.000		.000	.000	.000	.000
	N	205	205	205	205	205	205
Information_Concerns	Pearson Correlation	.221**	-.308**	1	.107	.163*	-.192**
	Sig. (2-tailed)	.001	.000		.127	.019	.006
	N	205	205	205	205	205	205
Social_Financial_Concerns	Pearson Correlation	-.282**	.306**	.107	1	.524**	.104

	Sig. (2-tailed)	.000	.000	.127		.000	.138
	N	205	205	205	205	205	205
Emotional_Concerns	Pearson Correlation	-.360**	.373**	.163*	.524**	1	.246**
	Sig. (2-tailed)	.000	.000	.019	.000		.000
	N	205	205	205	205	205	205
Spiritual_Relegious_Concerns	Pearson Correlation	-.166*	.324**	-.192**	.104	.246**	1
	Sig. (2-tailed)	.017	.000	.006	.138	.000	
	N	205	205	205	205	205	205

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

MULTIPLE REGRESSION

Descriptive Statistics

	Mean	Std. Deviation	N
Overall_QOL	9.40	1.262	205
Physical_Concerns	6.14	12.273	205
Information_Concerns	27.99	11.020	205
Social_Financial_Concerns	7.13	6.323	205
Emotional_Concerns	15.05	10.896	205
Spiritual_Relegious_Concerns	.20	.915	205

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	Physical_Concerns	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
2	Emotional_Concerns	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
3	Information_Concerns	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: Overall_QOL

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate

1	.483[a]	.234	.230	1.108
2	.521[b]	.271	.264	1.083
3	.540[c]	.292	.281	1.070

a. Predictors: (Constant), Physical_Concerns

b. Predictors: (Constant), Physical_Concerns, Emotional_Concerns

c. Predictors: (Constant), Physical_Concerns, Emotional_Concerns, Information_Concerns

Coefficients[a]

		Unstandardized Coefficients		Standardized Coefficients		
Model		B	Std. Error	Beta	t	Sig.
1	(Constant)	9.700	.087		112.084	.000
	Physical_Concerns	-.050	.006	-.483	-7.864	.000
2	(Constant)	10.015	.129		77.538	.000
	Physical_Concerns	-.042	.007	-.405	-6.259	.000
	Emotional_Concerns	-.024	.007	-.209	-3.231	.001
3	(Constant)	9.551	.230		41.495	.000
	Physical_Concerns	-.035	.007	-.337	-4.817	.000
	Emotional_Concerns	-.030	.008	-.261	-3.868	.000
	Information_Concerns	.018	.008	.160	2.427	.016

a. Dependent Variable: Overall_QOL

Excluded Variables[a]

Model	Beta In	t	Sig.	Partial Correlation	Collinearity Statistics

						Tolerance
1	Information_Concerns	.079[b]	1.231	.220	.086	.905
	Social_Financial_Concerns	-.147[b]	-2.308	.022	-.160	.906
	Emotional_Concerns	-.209[b]	-3.231	.001	-.222	.861
	Spiritual_Relegious_Concerns	-.011[b]	-.168	.867	-.012	.895
2	Information_Concerns	.160[c]	2.427	.016	.169	.815
	Social_Financial_Concerns	-.067[c]	-.946	.345	-.067	.712
	Spiritual_Relegious_Concerns	.019[c]	.290	.772	.020	.877
3	Social_Financial_Concerns	-.084[d]	-1.184	.238	-.083	.706
	Spiritual_Relegious_Concerns	.044[d]	.683	.495	.048	.855

a. Dependent Variable: Overall_QOL

b. Predictors in the Model: (Constant), Physical_Concerns

c. Predictors in the Model: (Constant), Physical_Concerns, Emotional_Concerns

d. Predictors in the Model: (Constant), Physical_Concerns, Emotional_Concerns, Information_Concerns

RELATIONSHIP BETWEEN PHYSICAL CONCERNS AND DEMOGRAPHIC FACTOR

Relationship	Correlation (R-value)	Significance level (P-value)
Age and physical concerns	-0.114	0.104
Stage of cancer and physical concerns	-0.041	0.562
Receiving treatment and physical concerns	0.117	0.095

ELATIONSHIP BETWEEN INFORMATION CONCERNS AND DEMOGRAPHIC FACTOR

Relationship	Correlation (R-value)	Significance level (P-value)
Age and information concerns	0.182	0.009
Stage of cancer and information concerns	0.044	0.528
Receiving treatment and information concerns	0.179	0.010

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	Age	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
2	Current receiving treatment	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: Information_Concerns

Model Summary

					Change Statistics				
	R	**R Square**	**Adjusted R Square**	**Std. Error of the Estimate**	**R Square Change**	**F Change**	**df1**	**df2**	**Sig. F Change**
1	**.182**[a]	**.033**	**.028**	**10.863**	**.033**	**6.956**	**1**	**203**	**.009**
2	**.252**[b]	**.063**	**.054**	**10.718**	**.030**	**6.549**	**1**	**202**	**.011**

a. Predictors: (Constant), Age

b. Predictors: (Constant), Age, Current receiving treatment

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	820.813	1	820.813	6.956	.009[b]
	Residual	23953.168	203	117.996		
	Total	24773.980	204			
2	Regression	1569.709	2	784.854	6.832	.001[c]
	Residual	23204.272	202	114.873		
	Total	24773.980	204			

a. Dependent Variable: Information_Concerns

b. Predictors: (Constant), Age

c. Predictors: (Constant), Age, Current receiving treatment

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	19.732	3.222		6.125	.000
	Age	.169	.064	.182	2.637	.009
2	(Constant)	13.767	3.945		3.490	.001
	Age	.165	.063	.177	2.602	.010
	Current receiving treatment	3.888	1.523	.174	2.553	.011

a. Dependent Variable: Information_Concerns

RELATIONSHIP BETWEEN SOCIAL & FINANCIAL CONCERNS AND DEMOGRAPHIC FACTOR

Relationship	*Correlation (R-value)*	*Significance level (P-value)*
Age and Social financial concerns	-0.060	0.394
Stage of cancer and Social financial concerns	0.157	0.025
Receiving treatment and Social financial concerns	0.246	<0.001

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	Current receiving treatment	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
2	Modified Stage	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: Social_Financial_Concerns

Model Summary

					Change Statistics				
	R	**R Square**	**Adjusted R Square**	**Std. Error of the Estimate**	**R Square Change**	**F Change**	**df1**	**df2**	**Sig. F Change**
1	**.246[a]**	**.061**	**.056**	**6.143**	**.061**	**13.118**	**1**	**203**	**.000**
2	**.286[b]**	**.082**	**.073**	**6.089**	**.021**	**4.625**	**1**	**202**	**.033**

a. Predictors: (Constant), Current receiving treatment

b. Predictors: (Constant), Current receiving treatment, Stage

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	494.960	1	494.960	13.118	.000[b]
	Residual	7659.742	203	37.733		
	Total	8154.702	204			
2	Regression	666.418	2	333.209	8.988	.000[c]
	Residual	7488.285	202	37.071		
	Total	8154.702	204			

a. Dependent Variable: Social_Financial_Concerns

b. Predictors: (Constant), Current receiving treatment

c. Predictors: (Constant), Current receiving treatment, Modified Stage

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	5.262	.670		7.851	.000
	Current receiving treatment	3.160	.872	.246	3.622	.000
2	(Constant)	2.055	1.632		1.259	.209
	Current receiving treatment	3.069	.866	.239	3.545	.000
	Modified Stage	1.118	.520	.145	2.151	.033

a. Dependent Variable: Social_Financial_Concerns

RELATIONSHIP BETWEEN EMOTIONAL CONCERNS AND DEMOGRAPHIC FACTOR

Relationship	Correlation (R-value)	Significance level (P-value)
Age and emotional concerns	0.133	0.058
Stage of cancer and emotional concerns	0.037	0.602
Receiving treatment and emotional concerns	0.240	0.001

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	Current receiving treatment	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: Emotional_Concerns

Model Summary						Change Statistics			
	R[a]	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
Model	.240	.058	.053	10.604	0.58	12.417	1	203	.001

a. Predictors: (Constant), Current receiving treatment

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	1396.120	1	1396.120	12.417	.001[b]
	Residual	22825.392	203	112.440		
	Total	24221.512	204			

a. Dependent Variable: Emotional_Concerns

b. Predictors: (Constant), Current receiving treatment

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	11.917	1.157		10.300	.000
	Current receiving treatment	5.306	1.506	.240	3.524	.001

a. Dependent Variable: Emotional_Concerns

RELATIONSHIP BETWEEN RELIGIOUS OR SPIRITUAL CONCERNS AND DEMOGRAPHIC FACTORS

Relationship	Correlation (R-value)	Significance level (P-value)
Age and religious or spiritual religious **concerns**	0.045	0.523
Stage of cancer and religious or spiritual religious **concerns**	-0.069	0.325
Receiving treatment and religious or spiritual **concerns**	-0.024	0.734

RELATIONSHIP BETWEEN PSYCHOSOCIAL CONCERNS AND OVERALL QUALITY OF LIFE

Relationship	Correlation (R-value)	Significance level (P-value)
Quality of life & physical concern	-0.481	<0.0001
Quality of life & information concern	0.208	0.003
Quality of life & social financial concern	-0.271	<0.0001
Quality of life & emotional concern	-0.366	<0.0001
Quality of life & spiritual concern	-0.166	<0.0001

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	Physical_Concerns	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
2	Emotional_Concerns	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
3	Information_Concerns	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: Overall QOL

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.483[a]	.234	.230	1.108
2	.521[b]	.271	.264	1.083
3	.540[c]	.292	.281	1.070

a. Predictors: (Constant), Physical_Concerns

b. Predictors: (Constant), Physical_Concerns, Emotional_Concerns

c. Predictors: (Constant), Physical_Concerns, Emotional_Concerns, Information_Concerns

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	75.894	1	75.894	61.848	.000[b]
	Residual	249.101	203	1.227		
	Total	324.995	204			
2	Regression	88.135	2	44.068	37.582	.000[c]
	Residual	236.860	202	1.173		
	Total	324.995	204			
3	Regression	94.880	3	31.627	27.625	.000[d]

	Residual	230.115	201	1.145		
	Total	324.995	204			

a. Dependent Variable: Overall QOL

b. Predictors: (Constant), Physical_Concerns

c. Predictors: (Constant), Physical_Concerns, Emotional_Concerns

d. Predictors: (Constant), Physical_Concerns, Emotional_Concerns, Information_Concerns

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	9.700	.087		112.084	.000
	Physical_Concerns	-.050	.006	-.483	-7.864	.000
2	(Constant)	10.015	.129		77.538	.000
	Physical_Concerns	-.042	.007	-.405	-6.259	.000
	Emotional_Concerns	-.024	.007	-.209	-3.231	.001
3	(Constant)	9.551	.230		41.495	.000
	Physical_Concerns	-.035	.007	-.337	-4.817	.000
	Emotional_Concerns	-.030	.008	-.261	-3.868	.000
	Information_Concerns	.018	.008	.160	2.427	.016

a. Dependent Variable: Overall QOL

APPENDIX 11a: QUALITATIVE INTERVIEWS – COMPILED TRANSCRIPTS

1- PARTICIPANT - EMIRATI

Interview	Exploratory comments
I: Can you tell me what has happened since the moment you were diagnosed with breast cancer? P: Yeah, I discovered this disease before one year and half. Yeah, and how? it was by sudden. I put my hand on my breast and felt something is not normal, something hard like a bone in my breast….so, I talked to my husband and he insisted me to go to the hospital and check. I went to Al-Zahra hospital in Sharja before coming to Tawam. Doctor at Al-Zahra hospital checked with her hand and asked me to do the biopsy. I felt that she was not happy and was worried. She asked me to take the biopsy because she wasn't sure and wasn't quite happy with the condition of my breast. And I got the biopsy near here and they told me that you have this breast cancer. And after that I decided to go to Tawam hospital to complete my treatment.	*Cancer as a shock and unanticipated experience* Open relationship with husband/Family support Seeking care in different facility, lack of trust in one facility; health decision-making Willingness to get treatment
I: What were your thoughts and feelings when you were told you had breast cancer? P: What they told me? Of course, I was not happy because there were some worries and things to be worried about but you Muslim always has faith so I said alhamdullila; it worked for me so I should say alhamdullila as I have faith. So, that was from my husband, I was strong hamdullila.	Feeling unhappy Feeling worried Feeling strong Expressing gratitude Feeling strong

	Having faith, religion as source of faith and positivity Praising Allah often Support from husband Source of support
I: What are your experiences with having breast cancer, its treatment, side effects and care that you received at the hospital? P: of course, there were some difficulties especially throughout the mechanical treatment. All the side effects that I faced was in the chemo. The side effects were on my skin, darkness on my face, on my arms, on my neck…and the food…my appetite was very bad, I couldn't eat. I lost weight, I lost weight around five kilos. My eye brows started falling during the treatment, there was all the time movement but now I stopped chemo, things are better now alhamdullila.	Problems due to treatment Health decision-making Skin changes, body changes outlook change Health went down Weight loss Unable to eat Feeling better
I: What physical changes or difficulties you faced? P: About physical problems, the main problem I faced was the outlook and changes in my face and my skin; there were no eyebrows, no hair, like this….	Changes in physical appearance
I: Did you face any difficulties in obtaining or getting information about your disease or care?	Access to information Sources of information

P: For information, of course now a days, there is no difficulty if you want to know anything; just google and YouTube and you will know everything.	Ease of getting information
I: Did you have any social or emotional concerns with the either family, friend or relatives? P: I have found so much support from my family, from my relatives that's why they gave us strength hamdulilla**.**	Supportive family and friends/relationships Source of strength
I: Did you have any financial concerns during the disease management? P: No, I had no financial problems as it is covered hamdullila.	No financial issues, Health coverage by the government. Praising God
I: Did you have any spiritual or religious concerns while having disease? P: When we have faith, it helps us pass through all the difficulties hamdullila. I feel sorry for Non-Muslims. I think how non-Muslims face the problems in their lives hamdullila, Islam is a gift, it is really a gift. It helps us to pass everything and I feel happy because you know the coming thing is better.	Describing value of faith/reliance on God Describing how faith helps in facing difficulties Praising Allah Describing the importance of importance of religion Praising religion/Islam Faith as hope

	Faith as source of positivity Feel happy and positive/hopeful
1: Tell me about the treatment choices and life changes you made after the treatment; how breast cancer impacted your life. P: I finished chemotherapy, I finished surgery, I finished the radiation and now I am on the hormonal treatment. You know that it lasts for five years. The main problems I face with Chemo treatment mainly physical and outlook change. It was difficult but I found a way to deal with it through my faith and my family **support.**	Multimodality treatment Willingness of treatment Long-term treatment Physical issues Outlook issues *Expressing difficulty* Faith helped in dealing with the disease Supportive family
I: Can you tell me what were your main concerns or biggest challenges; (prompt: focusing physical, information, social, emotional, spiritual or any other) P: My major concern was physical appearance like, no hair, skin change…	
I: How those influenced your breast cancer experience? (prompt: health, family, work, relationships). P: Of course, as I said, it was challenging to deal the problems but hamdullila I managed all with my family and my doctor and most importantly with my faith in	*Expressing difficulty.* Expressing an ability to manage/feeling strong Faith as source of strength/reliance on God

Allah, there were difficulties but I managed all hamdullila.	Praising Allah Family support Support from Doctor
I: How did you manage to deal with them or from where you received the support? P: My family and my faith in Allah made me pass through all difficulties.	Praising Allah Family support
I: What do you think and what elements of the service delivery and care at the hospital you were satisfied or not satisfied with? P: I was satisfied and I am still satisfied especially with my Doctor Mouza Al Ameri. She is very nice doctor. We don't feel like her as a doctor, she is like a friend or sister. She even calls us at our home to make sure and to do the check. So, I am very satisfied with the whole thing.	Feeling confined Support from the doctor
I: What change or improvement you would expect if possible or what kind of support you need? (prompt: what comes to your mind, what do you want in terms of support that can make you feel better or to improve your experience). P: I really needed a Nutritionist. You just need someone to advise you how can one deal with appetite. What should we eat and what we shouldn't eat? That is what I	Expectations Information seeking Source of information

needed most. I am very far from the hospital (Al Ain). I am from Kalba it is two and half hour. So sometime I cannot reach to the doctor and in that case, internet helps me.	Location very far to access healthcare
2- PARTICIPANT - EMIRATI	
Interview	**Exploratory comments**
I: What were your thoughts and feelings when you were told you had breast cancer? P: Before three or four years, I had something under my arm, like small pimple and also my breast is not equal like my other one (yaani/means) something different I feel it. Then I said, it happened but it will go. But it took time and there was wedding of my sister and then I said not now till my sister's wedding is over. You know then after that I went to see the doctor here in Sharjah. They do the screening campaign to check the breast and when I went there to see the doctor without an appointment and thought they will see me and they will say nothing and I will return hamdullila. The doctor wrote me to do the mammogram after which he will see me. Then he did the mammogram and asked for how many days you are suffering from this and he said it's better to take the biopsy. He said directly that it's no good but we should take a biopsy and I will tell you exactly what you have. They took the biopsy and then they discovered that I have a cancer type (stage) II. Before they did the biopsy, I was all the time thinking if they will tell me something bad, what I will do…. But when he told me, I feel that the God gave me something	**Breast as abnormal in feel and look** **Considering light, delayed seeking medical advice** **Not a planned visit to the doctor** **Not thinking or expecting a health issue/disease** **Feeling light/not taking it serious** **Suspicion of disease by doctor** **Diagnosed after visiting the doctor** **Fear of having bad news** **Initial worry of bad news** **Feeling fearless**

like power. I don't know, I wasn't afraid when I heard. I thought maybe I will cry. I said khalas (done), this is the moment, I will let. If this is what, God want it. Directly I asked what I should do and he said I will start do an operation, it's better directly.	**Feeling strong and fearless by Allah** **Power given by Allah** **Allah's decision**
I: What physical changes or difficulties you faced? P: See like, it was more pain on the left side, they took too much flesh from my left side but hamdullila I have my two son and daughter, they are with me. They told me, do like this, don't eat like this, put me in a good way you know for my food, my exercise. Every night I stayed in the hotel in Al Ain and I did exercise like walking hamdullila they were with me and I managed. I had no issues with my physical appearance … (laughs) I don't care…this is the last thing I care about. Also, my all family, all my sisters, they were all with me. I had an operation and radiation but I have been alright during and after the treatments hamdullila. You don't know what happened to me after operation, they did wrong operation on me, wallah. They didn't remove the lymph node under my arm. They took like half from my breast and the doctor said, khalas, you are ok and like this. When they took the biopsy, it written in the result, there are no lymph nodes involved and only the fat and my doctor, Dr. Riyad was so much angry because its wrong operation and they should have removed everything. When I saw my doctor, directly I	**Pain and feeling lack of flesh after operation** **Family support,** **Looking after herself** **Family helped in managing the disease** **Physical look is the least priority** **Supportive family** **Unsatisfactory care** **Incomplete operation quoted as wrong by patient** **Seeking advice from another doctor showing lack of trust**

went to Hurrya kaabi, she is a very good doctor. She did the mammogram again for me and scanning and everything and she said its better to remove all and the second one; even if you don't have a cancer in that, remove it. Directly I went to Tawam to see Dr. Mouza and she made the surgery for me and I said remove both. She said you don't have a cancer in other one and I said, it's better for me to do it both.	**Revising the investigation showing lack of trust in the received healthcare** **Different opinions from healthcare providers** **Sought multiple opinions showing lack of trust in health providers** **Self-decision making to remove both breast**
I: Did you face any difficulties in obtaining or getting information about your disease or care? P: You know Dr. Hurrya, she explained to me everything and also Dr. Mouza. I had no problems with obtaining information at all.	**No problems in accessing information** **Satisfied with the given information**
I: Did you have any social or emotional concerns with the either family, friend or relatives? P: No, alhamdullila, they are all big now and they are the one taking care of me. I don't have a husband, he passed away. Also, my husband, he had a cancer when he passed away. I was with him and I know everything. Like this, I don't want to suffer when I think about him, I don't want to be like him. He was too much depressed. He couldn't control himself. That's is why he didn't even take the medicine. There are patients sometimes, they give up and say khalas…if I will die, I will just die. For me, No. I said myself, I will fight. Because I love	**Lost her husband due to cancer** **Known to cancer experience** **Want to avoid depression since she had this experience with the husband** **Self-motivation to fight cancer** **Want to live for children**

my children, I want to see their children and become a grandmother. How you think, its very important. Think in a good way.	**Thinking positive**
I: Did you have any financial concerns during the disease management? P: No, I had no financial or social issues. My healthcare is covered by insurance alhamdullilah.	**No financial or social issues** **Have full health coverage with insurance**
I: Did you have any spiritual or religious concerns while having disease? P: When I think about this, I said, may be Allah loves me. I discovered so many good things…people…like this….	**Feeling close to Allah** **Faith brings opportunities/good things**
I: Can you tell me what were your main concerns or biggest challenges; (prompt: focusing physical, information, social, emotional, spiritual or any other) P: The difficult part was after operation. I had pain and sometime I was about to vomit. I suffered from this part so mainly physical.	**Difficulty in living with cancer** **Most challenging was the physical concern**
I: How did you manage to deal with them or from where you received the support? P:: Mainly from my children, my family and my sisters. I had lots of support from my family. I managed well with their support.	**Supportive family** **Managed the disease well because of family support**
I: What do you think and what elements of the service delivery and care at the hospital you were satisfied or not satisfied with?	**Confined with the care received at Tawam**

P: Yes, I am satisfied with the care I received, how they treated me a good way. All the people are good even when I had radiation, they were helpful people hamdullilah.	
I: What change or improvement you would expect if possible or what kind of support you need? (prompt: what comes to your mind, what do you want in terms of support that can make you feel better or to improve your experience). P: I didn't take chemotherapy, only radiation. The radiation department is nice but for chemotherapy when I had some appointment, there is too much rush. Sometimes, I have an appointment at one O'clock, I see the doctor at three O' clock. I don't know why. So timing to see the doctor must be reduced.	**Self-selection of the treatment or shared decision-making** **Long waiting time, Timing should be reduced**
3- PARTICIPANT - EMIRATI	
Interview	**Exploratory comments**
I: What were your thoughts and feelings when you were told you had breast cancer? P: When I was told I had cancer; I was sort of shocked. Like I paused. First, I was little depressed of course it's not good news but later I accepted the reality. I felt my life changed to slow and I became more thoughtful and considerate towards my family than myself. As I told you earlier, it was not what I was expecting or I thought I would ever face but of course I later accepted as part of the reality. I was not angry or sad but shocked you can say as it hit me from nowhere, something	**Diagnosis was shocking** **Bad news** **Feeling depressed** **Unanticipated, shocking news**

unexpected that you never thought of it. I just accepted that it happened, what else I could do.	
I: What physical changes or difficulties you faced? P: Pain was the main problem. Also, I was having sleep disturbance but it was also because I lost my son. I had a good feed so I didn't lose weight. I would say I managed with the support of my family and my doctors. It was sure not easy and sometimes pain and other disturbances were too much for me to handle but I managed somehow. As I said, I did not have much difficulty but of course after Surgery I suffered pain. But that didn't impact my life as much when I lost my son. His loss made me emotional and low. I dealt with the cancer but his loss was the **most challenging** in my life because I was the one with him and taking care while he was ill.	**Pain was the most challenging** **Sleep difficulties** **Son death made her very emotional** **Family and doctor support helped a lot to manage the disease** **Suffered from pain** **Son death made her emotional** **Son death was more challenging than cancer**
I: Did you face any difficulties in obtaining or getting information about your disease or care? P: No, I was fully informed and multiple times about the side effects of medications I had. I was fully informed of the symptoms I had. Healthcare department was calling me regularly and asking me how I am doing, how I am progressing.	**No information concerns** **Was fully informed** **Health facility was approaching her regularly**
I: Did you have any social or emotional concerns with the either family, friend or relatives?	**Not very difficult**

P: There was no as such difficulty. My sister in law had a cancer so I was comfortable talking to her and get the support I needed. I do not have much friend but I spoke to my family and they were all with me to support me. Well, I wasn't going out much and I was bit down so I was always with my family. But I had a fear of recurrence because I was diagnosed and then later, I was diagnosed for another cancer on other side so I was always having this fear that I might get another cancer. My husband was very supportive thought and I had no issue talking to him about it.	**Sister in law had a cancer so got all the support within family** **Supportive family** **Feeling isolated/Not many friends** **Always with family/relying on family** **Fear of having cancer comeback again** **Fear of having another cancer** **Husband was supportive and open to talk about issues**
I: Did you have any financial concerns during the disease management? P: I no financial problem; my healthcare was covered by insurance.	**No financial issue** **Health coverage by isurance**
I: Did you have any spiritual or religious concerns while having disease? P: I managed it all with my faith in Allah and Allah made it easy for me. I found more peace and courage with my strong faith in Allah and in my religion.	**Reliance and faith in Allah gave peace and strength**
I: Can you tell me what were your main concerns or biggest challenges; (prompt: focusing physical,	**Son's death was the biggest challenge than cancer**

information, social, emotional, spiritual or any other) P: The biggest challenge was, my son passed away and that was more concerning to me than my own health. He had a comorbidity and was bed-ridden for a long time and I was taking care of him and he passed away just two months before I was diagnosed with cancer. When I was taking care of him, I knew I had a lump but when he passed away after that I decided to go and see the doctor. Before that I was ignoring my condition. This was the part that impacted me most and even now I think of my son that more than my condition.	**Son's death impacted her emotionally more than cancer** **Intentionally delayed in seeking medical care because of other life priorities (son)**
I: How did you manage to deal with them or from where you received the support? P: I did not have many health issues and my family was very supportive. I do not work and I have few friends but my relationship and my life were not altered due to cancer. I had other life challenges. Mainly family, my family was very supportive	**Not very social and have few friends** **Cancer was not the priority but other life challenges mainly son's health and death effected deeply** **Very supportive family**
I: What do you think and what elements of the service delivery and care at the hospital you were satisfied or not satisfied with? P: I was fully satisfied with the care I received. Everything was good and doctor kept on checking about everything.	**Fully confined with the care and health providers**
I: What change or improvement you would expect if possible or what kind of support you need? (prompt: what comes to your mind, what do you want in terms	**Meet all expectation, fully satisfied**

of support that can make you feel better or to improve your experience). P: I don't think there is anything missing from the healthcare department. I received all the updates I needed from my doctors and nurses and the doctor was calling me to check on me how I am doing so I got the sufficient support from the healthcare department.	**Doctors were asking and updating regularly** **Sufficient support by health providers**

4- PARTICIPANT - EMIRATI

Interview	**Exploratory comments**
I: What were your thoughts and feelings when you were told you had breast cancer? P: I was surprised but it was my destiny. What I was going to do. I was scared though because I have small kids, I was worried and of course unhappy but it's from Allah and it took it easy.	**Feeling scared because of kids who are young** **Feeling worried** **Feeling unhappy** **Was not expecting cancer** **From Allah's believing he is the owner of our destinies** **Accepted it**
I: What physical changes or difficulties you faced? P: I had chemotherapy, my eye-sight dropped and I couldn't see particularly at night. Mainly the left eye. At night I had all blurry vision. I got pain in my bones and body. When I was taking her chemo, my hair fell. And	**Had multimodality treatments, surgery, chemo radiation** **Had pain, blurry vision, hair fall**

then I took radiation for a month. I lost weight. When I had radiation on breast, I had pain on the area where I had surgery but it wasn't that much. So that was all. Sure, I had difficulties but I was able to manage my daily life and tasks as normal.	**Lived with difficulties but managed daily life**
I: Did you face any difficulties in obtaining or getting information about your disease or care? P: They were clear and I had no difficulty in obtaining information. I was told everything.	**Was fully informed, had no problems obtaining information**
I: Did you have any social or emotional concerns with the either family, friend or relatives? P: Everything and everyone was good and supportive. I had no emotional or social concerns hamdullila. In our family, there are lots of people who have cancer. My sister also has breast cancer so it wasn't that much. Also, my work was OK and flexible and they knew my condition and allowed me to leave at twelve because I couldn't stay more as I got tired. They told me; you can leave early. My family treated me very normally. Of course, it was hard for them to know that I have cancer but they didn't treat me as something is abnormal. Hamdullila, I didn't experience any psychological or emotional issues with family or with my friend or colleagues.	**Good supportive family** **No emotional or social issues** **Family has cancer history so it was ok to talk about it and family treated her normally not something abnormal** **At work, people and employer were supportive and considerate towards her condition**

I: Did you have any financial concerns during the disease management? P: No, I had no issues with finance, it is covered and they did everything.	**No financial difficult, had heath insurance**
I: Did you have any spiritual or religious concerns while having disease? P: when I was diagnosed with cancer, since then I got much closer to Allah. During my disease and while I was receiving my treatment, I found myself closer to Allah.	**Got closer to Allah due to disease**
I: Can you tell me what were your main concerns or biggest challenges; (prompt: focusing physical, information, social, emotional, spiritual or any other) P: I think the most difficult for me was, I was away from my kids because I had my surgery done in the Germany and this was the biggest challenge for me to be apart from kids. It wasn't easy.	**The biggest challenge was not the cancer but being away from family because of cancer treatment**
I: How did you manage to deal with them or from where you received the support? P: Mainly I got all support from Allah and my family.	**Reliance on Allah** **Supportive family**
I: What do you think and what elements of the service delivery and care at the hospital you were satisfied or not satisfied with?	**Fully satisfied with the received care**

P: I was satisfied with the care I received. I didn't have any issue really.	
I: What change or improvement you would expect if possible or what kind of support you need? (prompt: what comes to your mind, what do you want in terms of support that can make you feel better or to improve your experience). P: Tawam pharmacy services are very slow, I think that should be improved for faster services and better delivery.	**Pharmacy services to be improved for efficiency**
5- PARTICIPANT - EMIRATI	
Interview	**Exploratory comments**
I: What were your thoughts and feelings when you were told you had breast cancer? **P:** I don't know, I was expecting that. I don't know why. I felt that I was having a breast cancer soon. Doctor was hesitating to tell me and I told her, I am having breast cancer and she said yes. Nothing, not because of anything, just like this, I just felt I was having a breast cancer. My sister had a breast cancer and she passed away but it doesn't relate to the fact that because my sister had it.	**It was not a shock but expected** **Her sister had it but she didn't have a feeling that she was having because of her.** **It was a feeling she will have it**
I: What physical changes or difficulties you faced? **P:** Pain was the most of difficult. Since I did the radiation, my skin turned darker at that place. I had the	**Had multimodality treatment, radiation, surgery, hormone therapy.**

surgery. Plus, the look of the surgery is very bad. It is affecting me psychologically. They told me that pain will go away after one year. It has been more than one year and I am having that pain, seriously unbearable pain but they just gave me sick leave for just six months and then they let me go and said I am fit but I was not fit. And since I was taking this hormone therapy, I was having my periods more than twenty days, so my health became very bad. I am having flue frequently. Most days I have this flue. There is no day when I don’t have congestive nose. My immune system became down and I told them and they said everything is fine. How? I wasn’t like this! Whole night I couldn’t sleep because of my congestive nose, how could I do daily work. Also, I am having asthma so it effects my chest so until now I am suffering from this.	**Pain was the most challenging** **Surgery affected her physiologically** **Sleep disturbance**
I: Did you face any difficulties in obtaining or getting information about your disease or care? P: Well, all doctors are like they remember in the university and they are coming to say to you. They don’t know the result; they think I don’t have anything so their answers were not convenient to me at all. Some words were related to me but others not especially my health was going down and they didn’t answer me. They said, you are fine and this is normal. What’s normal? Normal is when people can do and practice daily life. They can go and come as they wish. This is not normal! I don’t think they told me my health would be like this. They just told me that I need to do the radiation. We	**Lack of information provided by doctors** **Not being normal or do normal day work**

need to do the operation, radiation. We need to do the hormone therapy which I didn't complete because I had this period for long time and I was outside the country and when I came back, I told my doctor this and she said, you are just saying…of course I am saying, I am not doing something from my mind that I am sick or something. Even if I am another country and I told you that I have this, how could you know that that I am having this or I don't have. You won't see inside me. What is this. Doctors have to believe what patients is saying. I am not creating these things.	**Lack of understanding by doctors** **Lack of trust in doctors** **Lack of support from doctors**
I: Did you have any social or emotional concerns with the either family, friend or relatives? **P:** I couldn't tell my mother; I am having this disease. I used to tell her that I am going outside for my studies and I used to hide in my sister's house. When I used to be back home, I still used to have this pain but I had to hide it. My mother passed away and I couldn't even tell her, you know. They saw it affected me too much and after two months, my sister who had a cancer, she also died. That is like destroyed me really.	**Had to be silent, couldn't share** **Feeling regret** **Family death effected a lot (mother and sister both died)**
I: Did you have any financial concerns during the disease management? P: Alhamdullila no, I didn't have any financial problem because this is all from the government.	**No financial prob** **Health coverage by the government**
I: Did you have any spiritual or religious concerns while having disease?	**Faith became stronger** **Praising God** **Reliance on God**

P: this disease made my faith into God stronger. Because the way God stands with me, nobody can be with me. In this situation, you will feel how God is closest to you.	
I: Can you tell me what were your main concerns or biggest challenges; (prompt: focusing physical, information, social, emotional, spiritual or any other) P: Pain, physical concerns for sure. This was the biggest challenge because the pain, pain on the chest cannot let you sleep and you have to be on drugs and drugs also not good for you. Its like, you have to manage your pain plus you have to go to the work. How could you go to the work like this? Until now, you know I cannot wear the bra. It's very hard for me to wear the bra because when I wear the bra, my pain increases. For example, until now when my nieces and nephews come and hug me, my breast is like somebody hit me or something like this slightly and I feel pain. I had a radiation; surgery and I started this hormone therapy then I stopped it as I told you and all doctors are like take it…take it…how can I take it? Even I asked them, did you have a patient like me, this happened and they said let's try. What's let's try? I am asking them give me information. Did it happen before, is it something naturally happening? Do you have other cases or not? So, in that situation, they just want to do what they learned.	**Pain was the biggest concern** **Sleep disturbance** **Difficulty in managing work life balance due to drugs** **Difficult living** **Multimodality treatment** **Decided to stop hormone therapy** **Lack of trust in doctors** **Demand of information** **Unsatisfied delivery from doctors**
I: How did you manage to deal with them or from where you received the support?	**Lack of support from people** **Colleagues at work were supportive**

P: I didn't have the support except people at my work helped me. Still I am suffering that I have to go to work and I still don't have a reason that could stop me to go the work, even the doctors didn't support me in this. However, I had all the support from my sisters but I couldn't tell them what is in my heart because you know they were also going through this tragedy. And they also lost one sister because of cancer. I have to be careful what I am saying to them and all this thing.	**Problems in managing work and life** **Supportive family** **Hide emotions** **Family had several deaths**
I: What do you think and what elements of the service delivery and care at the hospital you were satisfied or not satisfied with? P: Cancer speciality compare to others; people are very caring. You have very good treatment so you cannot say that you didn't have a good care but lack of information from the doctors, this affects.	**Satisfied with care received** **Information from doctors lacking**
1 – EXPAT PARTICIPANT	
Interview	**Exploratory comments**
I: What were your thoughts and feelings when you were told you had breast cancer? P: I was shocked and devastated to hear that I have cancer. It was sense of denial in the beginning as I never thought myself being in that situation. I had no idea, it is gonna be that tough.	**Cancer was a shocking news** **Couldn't believe** **Unexpected news**
I: What physical changes or difficulties you faced?	

P: My life has changed including me, my appearance, my feelings, my priorities. Everything has changed to the extent that its all just new. It has changed my life completely. I put myself into forum mainly because of the effects chemo has had on me. It was after the first chemo session. It was like I was devastated. As I explained to you, I associated myself with the forum and doctors explained to me. I did start my chemo on Wednesday and it was only on Sunday when I woke up, I started vomiting and diarrhoea and my stomach was so tortured. Nothing prepared me for that. Yes, I prepared myself for that but not to that level that will float me. I had read, I had researched but I did not know that it was such a fine balance that you had to run between diarrhoea and normal bathroom needs that needs to be there…. that was not there. That was so like today I am going to bathroom and after that I couldn't go back to it and it was escalated so much so first time, I was just float. My whole face showed it. I was just in my bed; I couldn't do anything just couldn't do anything. Pain in terms of I do not take the tablet, the yellow tablet, I do not take one. The intensity of pain and cramps; having all your periods and childbirth is just nothing like that swear to God. And other was fatigue, I couldn't leave my pillow…that was the level of fatigue. And Inability of sleep, I was just awake. I would sleep one hour and then awake. My hair went off. I was just showing to my nephew the picture of my pillow after my second chemo. And my pillow, it was just full of hair, that was the amount of hair I lost. I just went to the bath room, I didn't have the shaver, I just put the Veet all over	**Life changed after cancer in all aspects** **Joined the forum** **Feeling devastated** **Joined the forum** **Vomiting and diuarrhoea were intense** **No one prepared her for those intensed physical symptoms** **Unable to go to the bathroom, was not able to do anything** **Had intense pain just like childbirth** **Sleep problems due to fatigue** **Had hair fall that her pillow was covered with hair that she had to remove all and used veet cream** **Because of chemotherapy had bad taset in mouth** **Also because of chemo, she lost 7 kilos** **Show herself strong and positive**

my head. And taste in mouth, anything I eat, it tastes off, I couldn’t eat anything and whole six months of chemo because of that and because of side effects of chemo I lost 7 kilos. I have a ten-year-old daughter so I had to be brave and strong for her. You know what I mean so I tried to get myself positive as I could. Having said that I had lots of friend assisting me. My principle was assisting me. I am a teacher so she took away some of my classes so it won’t drain me out. She put another teacher with me in the class so if I can’t do anymore, she takes over. Everybody was most helpful. My quality of life was just, I just lived for weekend so I could just stay in bed. I just did the most essential groceries in my house and put like noodles, easy things for my daughter to make for herself. It had also psychological effect, I became very depressed	**Supportive friends** **Supportive employer** **Difficult living** **Effected psychology**
I: Did you face any difficulties in obtaining or getting information about your disease or care? P: Yes, I was fully informed. My doctor, my oncologist she explained to me what’s going to happen but as I said I didn’t own it. I didn’t realise that’s gonna be you that’s gonna happen to you like other people. Everybody experience is different for example sense of taste was terrible. My memory was gone. I was fully informed about the side effects of chemo; I remember my doctor told me all. I was fully informed about all the symptoms and side effects. When you are first diagnosed, if you speak to a doctor in her office, her time is gonna be limited because there	**Was fully informed but didn’t own it** **Sense of taste and memory loss** **Doctor’s time is limited to get all kind of information**

will be more patients waiting outsider her room, you know what I mean. You know all my questions were answered, I have to say that but like I have had time to think about it and I have more questions so whose gonna follow that. It cannot be the doctor because she has other patients to see. So, example, having my double mastectomy, when do I stop it? Yes, I was told and I remember everything what the doctor said at that time but there was time when I was like what do I do now? How to empty it and everything. They go very efficient in everything but the psychological and emotional side, nobody said you are gonna be depressed as afterwards. If you are gonna see the mirror for the first time, you are gonna break down in tears no body prepared you for that. Side effects, yes gonna be there but to what level……I cannot say questions answered but addressed. I am here alone with my daughter, it's difficult because I have to be strong for her. The only time, I can be myself is when she is gone to bed and I can lie and I can cry into my pillow. The side effects of the chemo, to use a bad word…just terrible it is. Side effects are long, its like, one time I found myself its like crawl to the bathroom like I have diarrhoea. Tell me these things, I don't want to hear that you are gonna be OK cause you are not going to be OK. Your life just will not be the same again. For example, when I recovered, fifty percent of the hair has grown back. One person said, after one year of chemo, she cannot still remember how she coped till today. She had to rely on people to tell her oh, this is what happened and so. So, be clear like my doctor said chemo will not but the side effects throw you. I didn't feel like I want to go my friends and	**Cancer patient has lots of questions** **Usually healthcare providers miss psychological and emotional aspect** **You are unaware and not prepared for lots of questions** **Live with only daughter and have to be strong for her** **Cry alone** **Had bad side effects of chemo, diarrhoea** **Severe side effects must be informed earlier** **Life will not be the same** **side effects of chemo are severe and that should be informed by doctors** **cannot go and feel like telling her situation to friends and colleagues** **cancer survivors should feel safe to talk about their issues**

colleagues to tell them like I feel this, like they have enough of them. So, if there is like a forum, if there are people who have gone through the same things, they can relate. I feel like I cannot go to them all the time, I feel like I cannot vent out my story. There should be a safe place to speak about it, you know what I mean. I think it is for every cancer survivor, every sufferer, everyone who has gone through cancer. Its such a big thing, its like a paradigm shift, its never the same. Like before, I would like, oh look at this line, you know that was the main concern, health wise. It was so shallow; you got other things now. I couldn't be bothered anymore.	**cancer is a big shift and changes life**
I: Did you have any social or emotional concerns with the either family, friend or relatives? P: I was also informed of all the services available if needed. I will tell you what they gave me, I have it in my purse. I laminated this card so if anything is wrong with me because once I had to come to ER on Friday evening. After 9, I had to call my friend, I had fever. I just showed that so I went to him. But it wasn't covered where to go or whom to speak to if I have any social needs. When those people who have cancer if they can come around together and tell, listen this is what you need to look for and this is how you gonna feel. There was a lady and she was on her first session when I was on my 3rd or 4th session, she came from Fujairah to Tawam. She asked me how does it feel now where you are and what you need to look for and I told her listen look for this and this and this and then after couple of sessions down the line, we landed up together in the same room and she said the same thing with her. She	**Was informed about the available services** **Services which are not covered must be informed, was not informed what to do where to go** **Other cancer survivors can help by sharing information or their experience**

said she did on Wednesday. She said from the Sunday to Thursday she couldn't do anything so what I had told her so basically prepared her for that so we need that. **I: Did you have any financial concerns during the disease management?** P: Dr. Mouza will tell you the issues I had with NEXtCare which is my provider from Ministry of education. Sometimes I would come and the approval will not go through entirely so couple of sessions I had to miss. Dr Daniela also knows about it. So, when I had started my chemotherapy, the first session had to be postponed because they didn't approve it. They said go to the social worker and speak to the social worker and they asked if I had insurance and I said yes, I have insurance and they said then you cannot have it, go to the principle. So, I went to the principle, there is a special person from NEXtCare to speak to from insurance side. The code that they had to put in for insurance from Tawam hospital side was wrong because I am not supposed to pay for anything and they told that I have to pay ten thousand and I said I can't do that…I can't afford it. So, when I had my first chemo session and the tablet that I am going to eat, it was about six to seven hundred dirhams and you need this lonesten injection which is two thousand dirhams and I said I don't have two thousand dirhams. They did not cover because that insurance wanted to block patients so they kinda wangle it so it would be inpatient so they (hospital) can give it to me in the hospital and I didn't have to pay for it. So, hospital was very accommodating.	**Problem with the insurance approval** **Hospital had to work out for her so her insurance could cover it** **Had to postpone the treatment because it wasn't approved** **Having her health coverage is like taken the burden off, showing gratitude**

Lot of the time, initially first few weeks of my chemo, I didn't do it. After that it had to be postponed to next Wednesday because it wasn't approved. I have had a lot of issues in the beginning. I can show you my phone calls; every time I come for chemo, I have learned that the day before I had to call them to ask them if it is approved. The ladies here, they are putting the request and then tell me that I put it in ten days ago and say they are still working on it. It is ridiculous! But to be honest, I would be at home and it would have been coming out of my pocket, I am extremely grateful that I am here in the UAE. That burden has been taken of me because I work for the ministry of education. My chemo is basically paid for, alhamdullila totally alhamdullila. And I am so lucky that people who are coming to my life especially Dr Mouza has been brilliant.	
I: Did you have any spiritual or religious concerns while having disease? P: We need religion like something to hold onto. Since the birth of my daughter, before that I was kind of wild. Conception was an issue with me and I kind of made a bet if I had a baby and I could carry it to the term then I would change my life. I went into hijab after that and I kind of decided…I have always been a Muslim but now I am gonna be a stonged Muslim. I made a lot of Tahajjud (night prayer) and salah in the Ramadan. I just sit on my muslaah (prayer mat) and cry… cry in the middle of the night. I have done more sunna prayers. I have recited the Quran. I have had two more religion,	**Religion to hold to during difficult time** **Being survivor made her practice even more** **Being survivor made her cry while praying** **Religion guides you**

but in an effort to sooth myself. Because if you don't have religion, you are lost. You know what I mean, so yes, I have gone closer to my God	**Being survivor make you close to God**
I: Can you tell me what were your main concerns or biggest challenges; (prompt: focusing physical, information, social, emotional, spiritual or any other) P: I had double mastectomy and my breast were removed. After that I had chemotherapy and hormonal. At this point of my life, as you can see, even the small thing will affect your life. It effects your sexuality. You know what I mean. It effects how you dress. Like inside my apartment, I would go without my Sheila (scarf) but even in the balcony, I am gonna cover myself because I just don't want everybody to see. I have become more comfortable not having breast but it's difficult. It affects me what I choose to wear. It is long sleeve, it is not tight fitted, I don't wear my swim wear, you know, its changed. Every aspect of your life changes drastically. It was my face. Because it's like I would have conversation with my gardener; I can't do this anymore. This is too difficult. That is always at the back of my mind, tomorrow I can lose my job and then what do I do? Physical concerns and emotional concerns were the most important issues I had to deal with the cancer. The psychological and emotional impact it had on me, I didn't know how this will affect my life like the first	**Had both breast removed and chemo and hormonal therapy after that** **Anything afftect you after treatment even little thing** **Her sexuality was effected** **Covered herself so people can't see** **Choice of dress became difficult** **Couldn't have conversation with people, became very difficult** **Fear of losing job** **The highest concerns were physical and emotional** **Lot of psychological and emotional effect on her, thought it will be easy** **Didn't take hormone tablets thinking it wont happen to me**

time I had lump on my side so I thought, they will take it out and I will be good. I didn't realise taking the hormonal tablets after. I did not think its gonna happen to me.	**When it came on the other side then wanted to talk to someone**
You're always like it is gonna be the next person. So, when it recurred on the other side, I was like, no, this is really serious and that point, I needed to speak to someone.	**No network available to help her**
I did not have the financial ability, there is no network that tells you that someone you can speak to. I didn't have it.	**Decision to remove both breasts was intense, wanted to speak to someone**
The decision to remove both of my breast, it was such an immense step; I needed someone to speak to.	**Self-perception changed**
Because my view of myself changed and it was going to change immensely after and coming to terms to my new body, I can tell you at this point that I do not have partner in my life but this is gonna impact me having one again.	**Will affect me finding a partner**
I don't wanna share as I said I have daughter, I didn't want her to let her see because first I had to own it to myself, I had to look at it and I didn't after the operation. I would just not look into the mirror. And I had a mirror the one full body mirror which I put it in my room and now I have just small round one and I needed to speak to someone. And I feel my daughter needed to speak to	**It was difficult to show her daughter** **Self-acceptance was imp at first** **Didn't want mirror to show full body** **It was devastating for daughter too** **Daughter wanted support too**

someone apart from me because we have been here alone for ten years and because my nephew came and he is with us here now and we didn't have anyone. And this was devastating for her. Because I had lost my best friend, she had colon cancer. Feb 22nd, she passed away so she thought immediately that was gonna happen to her. So, I feel she needs someone, she needs just to speak to let it out.	**Non-locals had little information about places and people who could support** **Supportive employer and co-workers**
Also, because I am an expat, if it was a local lady, they would know who to speak because they know the place and connections. Because I am not from here, I do not know, I can go there or go there. It would be an immense help.	
I am blessed with a very good principle alhamdullila and she has been immensely supportive. Like I said, the accommodation they made for me, me to have absence, absence, absence so she said, I could come to the school. If I had to use my key, come in and sign in so like I am not absent. Not letting Ministry of education, they have basically covered me alhamdullila but this is because of the calibre of person she is. But to be honest the previous principle, she is the new one; the previous would had done the same. But I don't know the Ministry of education, what is their policy, you know what I mean. Of course, you are conflicting stories. Luckily, I would be put in the position where I was, I had to face that.	**Supportive healthcare providers. Colleagues** **Received lots of support from friends**
When I came for my first operation, Dr. Mouza said, almost like my entourage, there was always someone with me. A friend of mine Amina, we were together so I went for my operation, I was unable to cook anything	**Fear of having cancer again**

so we have like EMT in school, English medium teachers and they made like every night a different person will come and bring me lunch or dinner then my friend Amina she is local, she said No, No…she is my sister. I am not lying, I swear to God, every day I had lunch, I had dinner. It would be left at my door. Every day she sent, somebody from cleaning company, every day my apartment got cleaned because I cannot, I must not do anything. Alhamdullia she took me like her sister and she did it for the whole of my period when I was recovering till I do it and I said Amina, I can do it and only then she did stop. I am so blessed, absolutely blessed but I might be the exception, you know what I mean. This may not happen to others. The fear of recurrence that it will come back, it was always there in the back of my mind that I have to do revisions for my daughter if I am not there anymore and I have to prepare her for that situation and like we never know what will happen so we talked about it. As I told her she need to speaks about her fears or concerns like anytime she has a question, she needs to ask me. **I was satisfied with the care but there should be an improvement in information delivery**	**Preparing her daughter emotionally so she can speak about her fears** **Satisfied with care** **Provision of information must be improved**
PARTICIPANT 2- EXPAT	
Interview	**Exploratory comments**
I: What were your thoughts and feelings when you were told you had breast cancer?	**Cancer was a shock, sad news** **It was scary**

P: First, I remember, I was sitting down and cry. It was a complete surprise for me that such a thing happened to me. Second, what I have to do. And of course, when you don't know what is chemo, how does it affect you. This scared you because you don't know anything. I cannot explain in few words. My friend she started reading about it. I cannot forget, I couldn't read about it, I couldn't hear about it. I don't know how to explain, this is something related to something you are going to do, know about it. She told me Nadia, there are some steps: First you are going to accept this and then will define everything. When I had the treatment, I understood it's my life now. Of course, it was angry, like sadness, fears, it was like no emotions at all. So, all, emotions or mixed emotions…I am not a kind of person who will sit angry why it happened to me or I am scared, what I am scare of? Yes of course, it can happen to anyone, of course if you are standing next to the God and you are thinking, I am ready yet, actually I will believe. It's difficult to explain emotions. If you compare me one and half year back and now it is different	**Life changed after treatment** **Mixed emotion** **Life changed as it was in past**
I: What physical changes or difficulties you faced? P: Mainly fatigue was the biggest challenge. I didn't have any other problems from any treatment. I was very lucky.	**Fatigue was the biggest issue** **No other major issues**
I: Did you face any difficulties in obtaining or getting information about your disease or care?	

P: We are living in the world of information. We can open the google and check on whatever we want. Also, we are not living out of social world. In my case I can say that, it was someone, I didn't know anything and even you offer me all the information which is enough for me but it all must be for my doctor. See if I have information what I am going to do with that. Of course, I understand what you mean for example, if I know something, it will change my life but no, it will not change my life. If my doctor doesn't know some information, it will affect me but if I don't know some information, I don't think it will change my life. I think yes, I was fully informed, even more I needed to know for example, Dr. Mouza she did not explain to me what was the treatment, she approximately explained to me but all what I needed to know deeply, Dr. Danijela explained to me and of course she is my oncologist. She actually explained to me more than I needed to know.	**Information is easy to obtain these days** **Information must be sought from doctors** **Doctors should have correct information as it can impact lives** **Was fully informed**
I: Did you have any social or emotional concerns with the either family, friend or relatives? P: You know through this sickness, almost all my people changed, people whom I was with and thought they are close and I thought they are my relative, I am not talking about my husband, I am talking about my friends, close friends. Some of them they chill out with me but I can say they are not so many and mostly I don't see them. Because they show themselves that actually they are not my friends. They are scared more than me, they have decided to stay away from me.	**People changed after cancer** **Do not have many friends, not very supportive** **Appreciating God's help** **Supportive employer**

You know I think God is with me cause the treatment did not affect me that I had to stop the work. My director in the school, he knows what happened to me. Actually, he gave me one month off when I started my chemo so I can continue my job. Thanks God, may be because of my job because I knew that I needed to go, I needed to wake up, I had to go to my children to teach them; maybe it is some stamina that helps you in this I did 12 chemo then now 6 cycles of chemo tablet and tomorrow will be last day of tablet. Then I will go to Dr. Danijella to know what is next. That's why I did scan to see if all is alright and then next week Dr. Danijella will tell me, what will happen in my life.	**Had chemotherapy**
I: Did you have any financial concerns during the disease management? P: Actually, my insurance doesn't work here, it was given from my job. Because I am from Abu Dhabi. I have SEHA mandate. It is really hard for me for example in my case; I will tell you what Dr. Danijella and Dr. Mouza explained to me, it is genetic case. I did here some genetic analysis. Dr. Mouza helped me with this. I remember my mother told me about it but we didn't discuss what kind of sickness it is. When it happened to me, the doctor started asking me and I asked my mother and she told me yes, she has a cancer but the other one. In my case, I have to think of my breast and also, I have gynaecological cancer. Because I do not have a mandate approved from Abu Dhabi for the gynaecological	**Treatment covered under government mandate** **Insurance didn't cover** **Mandate was approved for one cancer only not for other cancer** **Wants to get the treatment for both of her cancer at single**

cancer. They said, if you have a cancer of Breast, we can help you with that but we cannot cover this gynaecological cancer care. For example, from my doctor, it is most comfortable that if I get the gynaecologist here, I cannot pay two thousand dirhams for gynaecologist. I did this once here but this is, in my job, it is quite expensive. So, this is the challenge I faced here, because I would like to be here but I cannot afford it this amount. I hope my financial stuff gets better and I can afford it. For example, if it is possible to see some particular cases, if it's really needed and you just don't just concentrate what you have, it's about overall health. For example, I want to send someone no need to go to this doctor; you need to go and see the doctor and you cannot afford it but they cannot cover so this is kind of financial stuff. My gynaecology is not covered here. Its not going to affect me as such. I actually really appreciate all what has happened to me the chemo, the doctors, all covered, its really big help and it saved my life. I really appreciate you know. For example, they said go to some social services and my doctor said its good if I have some gynaecologist. here, she trusts doctors here who is really like know much more about cancer than outside. I am going to try and find which suits my insurance. You understand, its not about complain because it will be easy for all of them	**facility but not covered for other cancer** **Mandate was covered for at least one cancer which is a great help**
I: Did you have any spiritual or religious concerns while having disease?	**Prayers remove fears**

P: You know when you pray, it releases your fears. Through prayers, the words you read in a particular way, it already gives your brain a different world and of course the feelings, when you are in this situation and your really are going to think about this. For me it's easier and I think I got more closer to the God. Actually, I never go out of his sight but may be before I prayed and I didn't cry but this time I pray and I cry so this I can say it's different. I think I am closed to the God. We are different people and with me it's like see when you are happy, you are closed to the God, if you are sad, you are closed to the God. I was waiting for something like it will be horrible and I wouldn't be able to wake up from the bed but thanks God. 90% is his job.	**Prayers have positive effect on brain** **Now became much sensitive unlike past, cries more** **Been more close to God**
I: Can you tell me what were your main concerns or biggest challenges; (prompt: focusing physical, information, social, emotional, spiritual or any other) P: Dealing with emotions, may be, was the biggest challenge for me because you need lots of strength and it is very important for you to have supportive people.	**Emotions were the biggest challenge** **Must have supportive people**
I: How did you manage to deal with them or from where you received the support? P: The main support I got it from myself, though I am very weak emotionally. I put myself through lots of thing. Sometimes its better not feel anything. May be sometimes we don't know how strong we are and may be this is the case God shows us but I don't know, future	**Not to feel anything is better sometimes/having no emotions is better** **Praising God for not having other side effects of treatment**

will tell us. Really this is a miracle that I really didn't get any bad effects from the treatment and I think it is from God.	
I: What do you think and what elements of the service delivery and care at the hospital you were satisfied or not satisfied with? P: I went to the hospital and I was told don't worry, she is a nice doctor. Actually, when I started with Dr. Danijella, I didn't know that Dr. Mouza is my surgeon so it's really fun. I was like, she is really fun, I didn't know where I needed to go but already, I know where to go but that time…. she talked to me (both of them). Of course, she explained to me like when I came, she was very concerned, she was next to me when they standing next to my bed when they researched about whether it is true or not. All the doctors, nurses, they have like become more concerned than my friends as I told you. From the first step when I started here, I see faces that are smiling saying you will be ok. I do remember, the first chemo, there was Syrian nurse, she did my first chemo. I cried; I don't know how to explained. I felt there is something in body, I don't know, I felt I won't wake up. She was standing right next to me and said why are you crying, are you missing someone. Everything will be OK. I really appreciate SEHA or whoever created this program for expatriate to get this treatment because for example, what about me. You know I am living here for quite long and job is here like my life is here. For example, if I didn't get the treatment here. I really	**Friendly and supportive health providers** **Supportive doctor showed concerns** **Expressing gratitude to health providers/government** **Suggesting enhanced coverage** **Feeling happy about the care received**

appreciate and thanks from the heart really. I told you there are so many people who have cancer but for example people like in my case who are living in Abu Dhabi; I have two ways of my surgery so plastic doesn't come under mandate approved treatment but in my case, better to go for this operation. So, for some patients, like in my case like something to do with the increase or enhanced coverage. But I am so happy, so happy about my doctors, it's a new world to me. I am so happy about the nursers and researchers. I can say that they are with us in this. It's their job and people can do their job in different way, see here it's really helpful. Because see, doctors smile, nurse smile and every time they ask how are you so its fortunate.	
I: What change or improvement you would expect if possible or what kind of support you need? (prompt: what comes to your mind, what do you want in terms of support that can make you feel better or to improve your experience). P: Expand the mandate, this will help me of course but will help my doctor as well. Of course, it will make me happier. I have told you if possible, in cases of research if you add such mandates to cover other co-existing problems, it will help. It's not just helpful, it's very helpful. I think nobody can help you. I didn't go to the psychologist, I didn't. I don't remember but I don't think I was told if I face such and such issues, I can go to this person or that person but I think this is something you	**Suggesting enhanced coverage under mandate to cover co-existing condition** **Was not informed who to see and where to go for if something you need**

need. I think like it must be next to the doctor like psychologist	
PARTICIPANT 3- EXPAT	
Interview	**Exploratory comments**
I: What were your thoughts and feelings when you were told you had breast cancer? P: When I heard the first time, I was shocked, sure it was a shock for me but later I said its ok Alhamdulillah, I will pray and I told my god I agree for everything I have so my sister brought my mother. This gave me strength. Also, my sister is with me, my husband …NO, he is X. he didn't stand up with me. For gave myself the strength, my mother, my sister is with me.	**Cancer was a shocking news** **Considered as from God and accepted it** **Mother and sister were supportive** **Didn't receive support from husband**
I: What physical changes or difficulties you faced? P: Everything changed for me hair, body, everything. I had also lots of difficulty with my stomach, my hand, my mouth but after sessions I went to work. Because my manager she told me, you can sit no problem; your salary is OK but for me I said, No, I should go to work because I don't want to think too much and if I will sit at home and I will think too much and I will feel I am weak. I didn't want to feel this. Also, I can see from my mother's eyes, she is very sad about me. For me, I will show her, I am good, I am strong.	**Everything changed after cancer** **Faced difficulty with stomach, mouth and hand** **Supportive co-workers** **Didn't want to feel weak so tried to engaged herself with work** **Had to be strong for mother as she was sad for her** **Life changed after treatment**

After the treatment, everything changed for me. Also, my hand got too much black and my colleague told me Shaima why your hand is like this, you want to wash your hand and I told them No, its from the treatment.	**Hand discolouration due to treatment**
My another colleague told me why you told her about it and I said no problem, its time and InshAllah it will pass.	**Showed positivism and hope**
On the first session, I was tired for sure	**Tiredness after chemo**
but you know, I am driving from Abu Dhabi to Al Ain and its considerably very far for a patient	**Hospital very far from residence**
when I have session and after that my mother sat with me for nine months. I come along with my mother and after that,	**Support from mother**
I took my treatment, it was concentrated chemo.	**Had chemo treatment**
After I had session, I drove back to Abu Dhabi to Al Ain. OK, I felt so much pain and tiredness but I did manage. On the first session, after three days, I was little bit OK but because I had so much problem with my stomach, I was vomiting, also my mouth, for sure my hair fell but for me I would put make up at least. And also, my family would see me that I am OK at least.	**Pain and tiredness after treatment** **Stomach pain, vomiting and hairfall after treatment** **wearing makeup to show people I am OK**
I: Did you face any difficulties in obtaining or getting information about your disease or care?	
P: On the session, they gave me some medication and I slept. I was not informed I feel but after that yes, sometimes I went to emergency, three times because I had too much headache and vomiting. The nurse gave me a book and told me if you have fever you should go	**Was informed about the treatment after effects** **Had often vomiting and headache after treatment**

to emergency or something. Hamdullila I didn't go to emergency but after that I changed my treatment and when I changed my treatment, I took radiation and my treatment together. I had some days, I couldn't stand because, I had too much vomiting, I took water, I vomited, I had too much headache and I went to emergency may be three times. **I: Did you have any social or emotional concerns with the either family, friend or relatives?** P: From my husband, No, there was no support. I felt support from my mother, from my sister. Actually, from my family. When I see any other patient with me, they say, you are my hero, you give me positive energy. So, my family gave me this not my husband. I have two kids and my husband but he didn't support me emotionally, he didn't support me financially. It is difficult for me, my husband has money, he could have given me money for my surgery but he didn't give me. He let me go to Hilal Ahmar (Charity) like this to manage my surgery. It was difficult for me. After that, I will be in front of him even more strong because he wanted to see I am weak. No …even I am, I will not show him I am weak. **I: Did you have any financial concerns during the disease management?** P: My insurance is very bad, now I took treatment under mandate because my insurance doesn't cover anything. Also, for my surgery I had money problems and I couldn't manage the money for surgery.	**Changed treatment added radiation therapy with chemo** **Some days had very bad vomiting and headache that had to go to emergency** **No support from husband** **Mother and sister were supportive only** **Husband didn't support emotionally** **Didn't want to show to husband as weak person** **No insurance coverage** **Covered by government mandate** **Financial problems to get the surgery done** **Became close to God**

I: Did you have any spiritual or religious concerns while having disease? P: Alhamdullila, I got more closer to Allah. From the beginning, I accepted, I prayed and I told my Allah, I agree with all I have.	**Accepted cancer as it is God’s decision**
I: Can you tell me what were your main concerns or biggest challenges; (prompt: focusing physical, information, social, emotional, spiritual or any other) P: I would say physical and emotional, two. I prefer if I receive more support from health providers about the physical issues I have. May be doctors can also provide emotional support. I have too much pain and you know I work in sales and I should stand for hours but hamdullila I try to manage not that I can manage but I try to manage every day. It’s difficult to accept, also I told you about the medicine, the hormonal treatment, I didn’t feel anything. Its difficult for me…… I didn’t think too much about depression and I tell to myself, now I am taking treatment, lets live now. I will put tomorrow up to God. Because I accepted all from the beginning. I had surgery, I removed my breast and its difficult for me but I accepted so I agree for everything.	**Main concerns were physical and emotional** **Anticipate further support from doctors for physical and emotional domains** **Had lots of pain and physical issues** **It was difficult to accept** **Hormone treatment didn’t help** **Tried to strengthen herself and start living** **For future, leave it to God** **Had breast removal, it was difficult decision**
I: How did you manage to deal with them or from where you received the support?	

P: I got the main support from my God Alhamdullila after that my mother.	**Got the strength from God and mother**
I: What do you think and what elements of the service delivery and care at the hospital you were satisfied or not satisfied with? P: Hamdullila, it is from my God, I had too much support here. You know before I came here, maybe I took two months from Abu Dhabi to Sharjah to Dubai to get the right treatment. After I came here, hamdullila from my God, I feel I am comfortable and I am friends with everybody here.	**Support from God** **Satisfied with care**
I: What change or improvement you would expect if possible or what kind of support you need? (prompt: what comes to your mind, what do you want in terms of support that can make you feel better or to improve your experience). P: May be if doctors can provide emotional support	**Anticipate emotional support from doctors**
PARTICIPANT 4 - EXPAT	
Interview	**Exploratory comments**
I: What were your thoughts and feelings when you were told you had breast cancer? P: In Oct 2018, I was diagnosed with breast cancer with stage II cancer. When I heard the news, I didn't feel bad, I was positive and I felt normal.	**It was normal, didn't feel bad when she heard had cancer**
I: What physical changes or difficulties you faced?	**Received chemo**

P: First I received the chemotherapy. I had lots of side effects mainly vomit but I managed. After chemotherapy, I started maintenance for Herceptin for two months. On March 11th, I did my surgery. After surgery, I had radiation on my right Breast. In 2019, I took Femara for hormonal treatment until now. I have had mild pain in my knee, not too much and I have become fatty. Before I was sixty-five kilos and now, I am seventy-two. I have no problems as such in daily tasks or daily living, its normal.	**Lots of side effect mainly vomiting** **Had hormonal therapy, had surgery and radiation too** **Mild pain** **Weight gain** **Daily life wasn't altered, normal daily living**
I: Did you face any difficulties in obtaining or getting information about your disease or care? P: yes, I was given all sorts of information and I had no issues with that.	**No problems in obtaining in formation**
I: Did you have any social or emotional concerns with the either family, friend or relatives? P: I didn't find any emotional or social issues. My family has been very supportive and they supported me all.	**No emotional or social concerns** **Supportive family**
I: Did you have any financial concerns during the disease management? P: I had no problems financially because my treatment is covered by Daman (insurance). I don't work, I manage my four children.	**Had insurance coverage** **No financial problems**

I: Did you have any spiritual or religious concerns while having disease? P: no, I rather got closer to God and my religion.	**Got closer to God and religion**
I: Can you tell me what were your main concerns or biggest challenges; (prompt: focusing physical, information, social, emotional, spiritual or any other) P: I would say none was challenging for me, my life didn't change much. I am happy with my family and I managed all.	**Life didn't change much** **Supportive family**
I: How did you manage to deal with them or from where you received the support? P: My God and my family really supported me.	**Support from God and family**
I: What do you think and what elements of the service delivery and care at the hospital you were satisfied or not satisfied with? P: I was fully satisfied with care I received. For me its all good, the service Tawam hospital provided. Today I am a survivor because of all the doctors and staff at Tawam Hospital Oncology department.	**Satisfied with care received at hospital**
I: What change or improvement you would expect if possible or what kind of support you need? (prompt: what comes to your mind, what do you want in terms of support that can make you feel better or to improve your experience).	**Suggested enhanced coverage**

P: If hospital can provide enhanced coverage for those who cannot afford the treatment, this would be very helpful. But it is all good and I think they are doing all fine.	
PARTICIPANT 5- EXPAT	
Interview	**Exploratory comments**
I: What were your thoughts and feelings when you were told you had breast cancer? P: I was scared, I was shocked, I was shocked really. The doctor told me that I need to remove my breast; I had no other choice. There was a shock in the beginning when doctor told me to remove my breast completely but you know my family, they were there for me. Look, there were some women/patients out there, they were waiting out there; they also had an appointment with the doctor so I told her I need five minutes I need to stay alone. I went there and there were three of them; they also did the same surgery; they removed the breast. So, they told me that, its fine, its so easy. It won't take like more than three day.	**Was scared and cancer was a shock** **Supportive family**
I: What physical changes or difficulties you faced? P: There were no side effects. I didn't take any chemo; I just had my surgery done. There was pain but after surgery two to three weeks, everything was fine. It was so easy, no difficulty like I didn't do anything.	**Had no adverse effects from drug** **Had chemo and surgery** **Had a little pain but after surgery but manageable**

I would say it didn't change for me even one percent, I went to my work as same after the surgery. I am doing my life activity as before, nothing changed for me at all. Even like two months, there was little difficulty in activities say for walking, sitting, you know but after that it was ok, nothing changed. Everything was like the past. But there was difficulty like when I saw myself in the mirror, it was a bit psychological or say emotional. Treatment that I am taking now; the doctor told me that I have to take the tablets for five years at least.	**Life didn't change, it is as same as before** **There were some difficulties after the treatment but later it was all ok** **Everything is as it was in the past** **Couldn't see herself in the mirror. It was psychologically disturbing** **Have to take tablets for 5 years (currently on hormone therapy)**
I: Did you face any difficulties in obtaining or getting information about your disease or care? P: The doctor told me everything, every single detail about the treatment, everything to do. All the information I got and the details also.	**Was fully informed about treatment and everything.**
I: Did you have any social or emotional concerns with the either family, friend or relatives? P: See, it didn't impact me at all. I didn't tell anything about it. I only told my daughter, my son and that's it.	**Cancer didn't impact her life** **Didn't tell anyone about cancer only daughter and son** **Didn't tell anyone, kept it to herself**

I didn't tell anyone about it because you know, they would be worried about me, I didn't want that so I kept it to myself. And you know when people about it they will be shocked; oh, how would you do it, it is dangerous. I didn't want that negativity. My husband passed away seven year ago but I got all the support from my family. I can't believe it has been one year and half since I did it, it was so easy alhamdullila. The best thing that I did it alhamdulliah because if I didn't do it, I would be suffering from it for. If I didn't remove it, it may have gone to other place and I didn't know what would happen so I am really happy that it was removed. I don't regret anything.	**People could be shocked and it could be negative** **Husband died but has full supportive family** **Had no problems due to cancer even after a year** **Made a timely decision to be treated** **Pleased with herself that she did the surgery, has no regrets**
I: Did you have any financial concerns during the disease management? P: I had my insurance and it was totally fine. I had no problems anything alhamdulilla.	**Had no insurance problems**
I: Did you have any spiritual or religious concerns while having disease? P: I believe if anything happens to anyone, it is for a reason so Allah he knows what is better for you so it was totally fine. It made me closer to God.	**Believe in Allah that everything has reasons** **Became close to God**
I: Can you tell me what were your main concerns or biggest challenges; (prompt: focusing physical,	**Main concern was physical**

information, social, emotional, spiritual or any other) P: May be the physical concerns were more challenging in term of like surgery made something happened to me, it was dangerous to my life, I thought like this. This is the only thing. Because I am old so I thought surgery is dangerous for me, may be anaesthesia is not good for me…only that.	
I: How did you manage to deal with them or from where you received the support? P: My daughter and my son, really. Maybe they encouraged me so much to do. They were more scared about it; I was like I will do it anyways but they were scared about it.	**Supportive kids**
I: What do you think and what elements of the service delivery and care at the hospital you were satisfied or not satisfied with? P: The care I received was perfect. I was satisfied with everything. I got the care that I need and even more really	**Satisfied with care received**
I: What change or improvement you would expect if possible or what kind of support you need? (prompt: what comes to your mind, what do you want in terms of support that can make you feel better or to improve your experience). P: you know, if I had to choose the chemotherapy, I would take the tablet not chemotherapy so it was good for me. I didn't take chemo or radiation so it was just	**Decided not to take chemotherapy or radiation** **Made a choice to get hormonal treatment**

fine with me. It was just the best that I didn’t do these two treatments. I am satisfied that I am on tablets/hormonal treatment, it is easier.	

APPENDIX 11b: SELECTED FIELD NOTES FROM PARTICIPANTS INTERVIEWS

SITE: Breast Cancer Centre	**EXPATRIATES**				
Interview date	**02 Mar 2020**	**4 Mar 2020**	**3rd Mar 2020**	**29 Jul 2020**	**4 Sep 2020**
Participant ID	**Participant 1**	**Participant 2**	**Participant 3**	**Participant 4**	**Participant 5**
Interview Questions	***What were your thoughts and feelings when you were told you had breast cancer?***	***Can you tell me what your main concerns or biggest challenges were; (prompt: focusing physical, information, social, emotional, spiritual or any other?***	***What physical changes or difficulties you faced?***	***Did you have any financial concerns during the disease management?***	***How did you manage to deal with them or from where you received the support?***
Field Notes	Sounds recalling with lots of pauses yet very decisive about answers. She provides about as much detail on her experience on her own, her family, work and family is a	Very positive women, lots of clarity in her thoughts but upon asking about the biggest challenge seems like she has been upset with friend who left her during crisis.	Looks very occupied and struggling due to cancer and trying to explain how tired she is due to cancer and long-distance drive to visit her doctor. Sound relief while talking about her employment and	Sounds positive and hopeful. Talks lots of positive, using Gods name a lot. Lots of appreciation toward family and God.	Raised hands for dua (prayer) as gesture of gratitude toward God. Very calm and collective. Looks quite satisfied and answering positively to most questions

	the main worry for her being a single mother who had relied on her.		supportive workplace		
SITE: Breast Cancer Centre	**EMIRATIS**				
Interview date	**29 Jul 2020**	**15 Sep 2020**	**27 Sep 2020**	**9 Nov 2020**	**4th Oct 2020**
Participant ID	**Participant 1**	**Participant 2**	**Participant 3**	**Participant 4**	**Participant 5**
Field Notes	Using Allahs name with lots of gratitude. I sensed that 'religion' is a big part of her life. She is firm in beliefs that God's been with her through the difficult times	Answered expressing painful memories. Raising hands closing eyes, nodding head, all are signs.	She lost her son, and it seems that this is the heaviest than her disease. Looks low and tired but normal. She paused several times and I sense she is still in grief of her son's death. I should not explore the question where she is quite and getting sensitive.	N/A (praising God)	Happy laughing and very engaged. Smiling and positive to most answers with lots of gratitude and using Allah's name. Most of her support came from her family.

APPENDIX 11c: CODING & THEMES

CODING OF INTERVIEWS (COLOUR CODING)
Theme 1: Living experience with Breast Cancer
Sub-theme 1: Diagnosis of Cancer
Sub-theme 2: Living with cancer
Sub-theme 3: Difficulty in access to health care
Sub-theme 4: Health decision-making
Theme 2: Breast Cancer Survivors' Concerns
Sub-theme 1: Physical concerns
Sub-theme 2: Information concerns
Sub-theme 3: Social & Financial concerns
Sub-theme 4: Emotional concerns
Sub-theme 5: Spiritual/Religious concerns
Theme 3: Expectations or support needed

Theme 1: Living experience with Breast Cancer									
Sub-theme 1: Diagnosis of Cancer									
(Emirati) Participant 1	**(Emirati) Participant 2**	**(Emirati) Participant 3**	**(Emirati) Participant 4**	**(Emirati) Participant 5**	(Expat) **Participant 6**	(Expat) **Participant 7**	(Expat) **Participant 8**	(Expat) **Participant 9**	(Expat) **Participant 10**
It was by sudden	something differe	When I was told I had	I was surprised but it	I don't know, I was	I was shocked and devasta	It was a complete	When I heard the first	In Oct 2018, I was diagno	I was shocked, I was shocke

	nt I feel it	cancer; I was sort of shocked. Like I paused	was my destiny **it's from Allah and it took it easy.**	expecting that. I felt that I was having a breast cancer soon. Doctor was hesitating to tell me and I told her, I am having breast cancer and she said yes. I just felt I was having a	ted to hear that I have cancer	surprise for me that such a thing happened to me.	time, I was shocked, sure it was a shock for me but later I said its ok Alhamdulillah, I will pray	sed with breast cancer with stage II cancer. When I heard the news, I didn't feel bad, I was positive and I felt normal.	d really. The doctor told me that I need to remove my breast; I had no other choice.

				breast cancer. My sister had a breast cancer and she passed away but it doesn’t relate to the fact that because my sister had it.					
something is not normal	He (Doctor) said directly that it’s no good	It was not what I was expecting or I thought I would		It was sense of denial					There was a shock in the beginning when doctor told me to remove

		ever face but of course I later accepted as part of the reality. I was not angry or sad but shocked you can say as it hit me from nowhere, something unexpected that								my breast completely

		you never thought of it.							
something hard like a bone in my breast	they discovered that I have a cancer type (stage) II	I was diagnosed and then later, I was diagnosed for another cancer on other side		I never thought myself being in that situation					
She (Doctor) was not happy and was worried									

She (Doctor) wasn't sure and wasn't quite happy with the condition of my breast									
They told me that you have this breast cancer									

Sub-theme 2: Living with difficulties									
It was difficult	I have been alright during and after the treatments hamdullila.	I felt my life changed to slow and I became more thoughtful and considerate towards my family than myself.	I had difficulties but I was able to manage my daily life and tasks as normal.		I had no idea, it is gonna be that tough	. If you compare me one and half year back and now it is different	After the treatment, everything changed for me	: I would say none was challenging for me, my life didn't change much	I would say it didn't change for me even one percent, I went to my work as same after the surgery. I am doing my life activity as before, nothing changed for me at all
It was challenging		I just accepted		They just gave	My life has change	When I had the	.	I have no proble	Everything was

to deal with the problems		that it happened, what else I could do.		me sick leave for just six months and then they let me go and said I am fit but I was not fit	d including me, my appearance, my feelings, my priorities. Everything has changed to the extent that its all just new. It has changed my life completely.	treatment, I understood it’s my life now		ms as such in daily tasks or daily living, its normal.	like the past.
There were some difficulties especi		It was sure not easy and somet			My quality of life was just, I just		Everything changed for me hair,		I can’t believe it has been one year

ally throughout the mechanical treatment.		imes pain and other disturbances were too much for me to handle but I managed somehow			lived for weekend so I could just stay in bed. I just did the most essential groceries in my house and put like noodles, easy things for my daughter to make for herself		body, everything		and half since I did it, it was so easy alhamdullila
Now I am on		There was			Your life just				

the hormonal treatment. You know that it lasts for five years		no as such difficulty			will not be the same again. For example, when I recovered, fifty percent of the hair has grown back. One person said, after one year of chemo, she cannot still remember how she coped till today.				

					She had to rely on people to tell her oh, this is what happened and so.				
There were difficulties but I managed all hamdullila				They said, you are fine and this is normal. What’s normal? Normal is when people can do and practice daily life.	Its such a big thing, its like a paradigm shift, its never the same. Like before, I would like, oh look at this line, you know				

				They can go and come as they wish. This is not normal!	that was the main concern, health wise. It was so shallow; you got other things now. I couldn’t be bothered anymore				
				They said, you are fine and this is normal. What’s normal?	At this point of my life, as you can see, even the small thing will affect				

				Normal is when people can do and practice daily life. They can go and come as they wish. This is not normal!	your life. You know what I mean. It effects how you dress. Like inside my apartment, I would go without my Sheila (scarf) but even in the balcony, I am gonna cover myself because I just				

					don't want everybody to see. I have become more comfortable not having breast but it's difficult Every aspect of your life changes drastically				
				Until now, you know I cannot wear the bra.	It was my face. Because it's like I would				

				It's very hard for me to wear the bra because when I wear the bra, my pain increases. For example, until now when my nieces and nephews come and hug me, my breast is like somebody hit me or	have conversation with my gardener; I can't do this anymore. This is too difficult.				

				something like this slightly and I feel pain					
				Still I am suffering that I have to go to work and I still don’t have a reason that could stop me to go the work	Because my view of myself changed and it was going to change immensely after and coming to terms to my new body, I can tell you at this point				

					that I do not have partner in my life but this is gonna impact me having one again.				
				I told my doctor this and she said, you are just saying …of course I am saying, I am not doing					

				something from my mind that I am sick or something. **Doctors have to believe what patients is saying. I am not creating these things.** **How could you know that that I am**					

				having this or I don't have. You won't see inside me.					
Sub-theme 3: Difficulty in access to healthcare									
I am very far from the hospital (Al Ain)	they did wrong operation on me, wallah.			all doctors are like take it…take it…how can I take it? Even I asked them, did you have a patient like me, this	When you are first diagnosed, if you speak to a doctor in her office, her time is gonna be limited because there		you know, I am driving from Abu Dhabi to Al Ain and its considerably very far for a patient		

				happened and they said let's try. What's let's try	will be more patients waiting outsider her room,				
Sometime I cannot reach to the doctor	They didn't remove the lymph node under my arm								
	my doctor, Dr. Riyad was so much angry because its wrong operation and they								

	should have removed everything								
Sub-theme 4: Health decision-making									
I went to Al-Zahra hospital in Sharja before coming to Tawa	Then I said, it happened but it will go	When I was taking care of him, I knew I had a lump but when he passed away after that I decided to go and	I had chemo therapy	I did the radiation	I put myself into forum mainly because of the effects chemo has had on me.	I did 12 chemo then now 6 cycles of chemo tablet and tomorrow will be last day of tablet.	I took my treatment, it was concentrated chemo	First I received the chemo therapy	I didn’t take any chemo; I just had my surgery done.

		see the doctor.							
I decided to go to Tawam hospital to complete my treatment.	But it took time and there was wedding of my sister and then I said not now till my sister's wedding is over. You know then after that I went	Before that I was ignoring my condition	I was taking her chemo	I had the surgery	I associated myself with the forum		I changed my treatment and when I changed my treatment, I took radiation and my treatment together.	After chemotherapy, I started maintenance for Herceptin for two months. On March 11th, I did my surgery. After surgery, I had radiation on my	Treatment that I am taking now; the doctor told me that I have to take the tablets for five years at least.

	to see the doctor here in Sharjah							right Breast .	
but now I stopped chemo	when I went there to see the doctor without an appointment and thought they will see me and they will say nothing and I will return		I had surgery	I was taking this hormone therapy	I had double mastectomy and my breast were removed. After that I had chemotherapy and hormonal	I did 12 chemo then now 6 cycles of chemo tablet and tomorrow will be last day of tablet	I had surgery, I removed my breast and its difficult for me but I accepted so I agree for everything.	In 2019, I took Femara for hormonal treatment until now	The best thing that I did it alhamdulliah because if I didn't do it, I would be suffering from it for.
I finishe	I had an		I took radiati	We need to	. I didn't				: you know,

d chemotherapy, I finished surgery, I finished the radiation and now I am on the hormonal treatment	operation and radiation		on for a month	do the hormone therapy which I didn't complete	realise taking the hormonal tablets after				if I had to choose the chemotherapy, I would take the tablet not chemotherapy so it was good for me. I didn't take chemo or radiation so it was just fine with me. It was just the best that I didn't

									do these two treatments. I am satisfied that I am on tablets/ hormonal treatment, it is easier.
And I got the biopsy near here	I went to Hurryakaabi, she is a very good doctor. She did the mammogram again for me and scanni			I had a radiation; surgery and I started this hormone therapy then I stopped it	So, if there is like a forum, if there are people who have gone through the same things, they can				

	ng and everything				relate.. There should be a safe place to speak about it,				
	she (Doctor) said its better to remove all and the second one; even if you don’t have a cancer in that, remove it				When those people who have cancer if they can come around together and tell, listen this is what you need to look for and this is how you				

					gonna feel				
	I went to Tawam to see Dr. Mouza and she made the surgery for me				There was a lady and she was on her first session when I was on my 3rd or 4th session, she came from Fujairah to Tawam. She asked me how does it feel now where you are and what you				

					need to look for and I told her listen look for this and this and this and then after couple of sessions down the line, we landed up together in the same room and she said the same thing with her. She said she did on				

					Wednesday. She said from the Sunday to Thursday she couldn’t do anything so what I had told her so basically prepared her for that so we need that.				
	I said remove both (breast). She								

	said you don't have a cancer in other one and I said, it's better for me to do it both								
	I didn't take chemotherapy, only radiation								
Theme 2: Breast Cancer Survivors' Concerns									
Sub-theme 1: Physical concerns									
The side effects were	I had something under my	Pain was the main	my eye-sight dropped and	Pain was the most of difficult	That was so like today I am	Mainly fatigue was the	Everything changed for me	I had lots of side effects mainly	There were no side effects.

on my skin	arm, like small pimple and also my breast is not equal like my other one	problem	I couldn't see particularly at night. Mainly the left eye. At night I had all blurry vision.		going to bathroom and after that I couldn't go back to it and it was escalated so much so first time, I was just float. My whole face showed it. I was just in my bed; I couldn't do anything just couldn'	biggest challenge. I didn't have any other problems from any treatment. I was very lucky	hair, body, everything. I had also lots of difficulty with my stomach, h, my hand, my mouth but after sessions I went to work.	vomit but I managed.	

					t do anything.				
darkness on my face, on my arms, on my neck	I had no issues with my physical appearance	I was having sleep disturbance	I got pain in my bones and body	Whole night I couldn’t sleep	I did start my chemo on Wednesday and it was only on Sunday when I woke up, I started vomiting and diarrhoea and my stomach was so tortured		my hand got too much black and my colleague told me Shaima why your hand is like this, you want to wash your hand and I told them No, its from	I have had mild pain in my knee, not too much and I have become fatty. Before I was sixty-five kilos and now, I am seventy-two.	There was pain but after surgery two to three weeks, everything was fine. It was so easy, no difficulty like I didn’t do anything.

							the treatment.		
my appetite was very bad, I couldn’t eat	) I don’t care… this is the last thing I care about.		my hair fell	I had this period for long time	Pain in terms of I do not take the tablet, the yellow tablet, I do not take one. The intensity of pain and cramps; having all your periods and childbirth is just nothing like		After I had session, I drove back to Abu Dhabi to Al Ain. OK, I felt so much pain and tiredness but I did manage. On the first session, after three days, I was little		like two months, there was little difficulty in activities say for walking, sitting, you know but after that it was ok, nothing changed

					that swear to God		bit OK but because I had so much problem with my stomach, I was vomiting, also my mouth, for sure my hair fell		
I lost weight , I lost weight around five kilos.	They took like half from my breast and the doctor		. I lost weight.	Pain, physical concerns for sure.	other was fatigue, I couldn’t leave my pillow …that		sometimes I went to emergency, three times becaus		May be the physical concerns were more challenging in

	said, khalas, you are ok				was the level of fatigue.		e I had too much headache and vomiting.		term of like surgery made something happened to me, it was dangerous to my life, I thought like this
The main problem I faced was the outlook and changes in my face and		I had a good feed so I didn’t lose weight	I had pain on the area where I had surgery but it wasn’t that much	This was the biggest challenge because the pain, pain on the chest cannot let you sleep	Inability of sleep, I was just awake. I would sleep one hour and then awake		On the first session, I was tired for sure		

my skin		As I said, I did not have much difficulty but of course after Surgery I suffered pain.							
	Pain and feeling lack of flesh after operation			They told me that pain will go away after one year. It has been more than one	It effects your sexuality.				

				year and I am having that pain, seriously unbearable pain I was having my periods more than twenty days, so my health became very bad					
My eye brows started falling during the	The difficult part was after operation. I			I am having flue frequently. Most days I	My hair went off. I was just showing to my		sometimes I went to emergency, three		

treatment	had pain and sometime I was about to vomit. I suffered from this part so mainly physical			have this flue. There is no day when I don’t have congestive nose. My immune system became down and I told them and they said everything is fine. How? I wasn’t like this!	nephew the picture of my pillow after my second chemo. And my pillow, it was just full of hair, that was the amount of hair I lost. I just went to the bath room, I didn’t have the shaver, I just put the Veet all over		times because I had too much headache and vomiting		

					my head				
There were no eyebrows, no hair				Whole night I couldn’t sleep because of my congestive nose, how could I do daily work. Also, I am having asthma so it effects my chest so until now I am suffering from this.	And taste in mouth, anything I eat, it tastes off, I couldn’t eat anything and whole six months of chemo because of that		I had some days, I couldn’t stand because, I had too much vomiting, I took water, I vomited, I had too much headache and I went to emergency may be		

							three times.		
The main problems I face with Chemo treatment mainly physical and outlook change.					because of side effects of chemo I lost 7 kilos		Physical concerns were the highest.		
All the side effects that I faced was in the chemo					Physical concerns and emotional concerns were the most				

					important issues I had to deal with the cancer.				
					The side effects of the chemo, to use a bad word… just terrible it is. Side effects are long, its like, one time I found myself its like crawl to the		I told you about the medicine, the hormonal treatment, I didn't feel anything. Its difficult for me		

					bathroom like I have diarrhoea				
My major concern was physical appearance like, no hair, skin change							I have too much pain and you know I work in sales and I should stand for hours but hamdullila I try to manage not that I can manage but I try to		

							manage every day.		
							also I told you about the medicine, the hormonal treatment, I didn’t feel anything. Its difficult for me……		
Sub-theme 2: Information concerns									
There is no difficulty if you want	Dr. Hurrya, she explained to me	I was fully informed and multi	They were clear and I had no difficu	they think I don’t have anything so	Nothing prepared me for that. Yes, I	We are living in the world of inform	On the session, they gave me some	I was given all sorts of inform	The doctor told me everything, every

to know anything	everything and also Dr. Mouza. I had no problems with obtaining information at all	ple times about the side effects of medications. I was fully informed of the symptoms I had. Healthcare department was calling me regularly and asking me how I	lty in obtaining information. I was told everything	their answers were not convenient to me at all	prepared myself for that but not to that level that will float me.	ation. We can open the google and check on whatever we want.	medication and I slept. I was not informed	ation and I had no issues with that	single detail about the treatment, everything to do. All the information I got and the details also

		am doing, how I am progressing							
Just google and YouTube and you will know everything				Some words were related to me but others not especially my health was going down and they didn’t answer me	I had read, I had researched but I did not know that it was such a fine balance that you had to run between diarrhoea and normal bathroom needs	I didn’t know anything and even you offer me all the information which is enough for me but it all must be for my doctor			

					that needs to be there…. that was not there				
Internet helps me				I am asking them give me information. Did it happen before, is it something naturally happening? Do you have other cases or not? So, in that	Yes, I was fully informed. My doctor, my oncologist she explained to me what’s going to happen but as I said I didn’t own it. I didn’t realise that’s gonna	if I know something, it will change my life but no, it will not change my life. If my doctor doesn’t know some information, it will affect me but if I			

				situation, they just want to do what they learned.	be you that's gonna happen to you like other people	don't know some information, I don't think it will change my life.			
What should we eat and what we shouldn't eat? That is what I needed most				lack of information from the doctors, this affects.	I was fully informed about the side effects of chemo; I remember my doctor told me all. I was fully informed about	, I was fully informed, even more I needed to know			

					all the symptoms and side effects.				
					You know all my questions were answered, I have to say that but like I have had time to think about it and I have more questions so whose gonna follow that, It cannot be the	I don’t remember but I don’t think I was told if I face such and such issues, I can go to this person or that person but I think this is something you need			

					doctor because she has other patients to see.				
					having my double mastectomy, when do I stop it? Yes, I was told and I remember everything what the doctor said at that time but there				

					was time when I was like what do I do now?				
					They go very efficient in everything but the psychological and emotional side, nobody said you are gonna be depressed as afterwards				

					If you are gonna see the mirror for the first time, you are gonna break down in tears no body prepared you for that.				
					Side effects, yes gonna be there but to what level……I cannot say questions				

					answered but addressed				
					. Tell me these things, I don’t want to hear that you are gonna be OK cause you are not going to be OK				
					So, be clear like my doctor said chemo will not but the side effects				

					throw you				
					I was also informed of all the services available if needed.				
					once I had to come to ER on Friday evening. After 9, I had to call my friend, I had fever. I just				

					showed that so I went to him. But it wasn't covered where to go or whom to speak to if I have any social needs				
					Because I am not from here, I do not know, I can go there or go there				
Sub-theme 3: Social & Financial concerns									

I had no financial problems	No, I had no financial or social issues	no financial problem	Everything and everyone was good and supportive. I had no emotional or social concerns hamdullila	no, I didn’t have any financial problem because this is all from the government.	Dr. Mouza will tell you the issues I had with NEXtC are which is my provider from Ministry of education.	I have SEHA mandate. It is really hard for me for example in my case;	My insurance is very bad, now I took treatment under mandate because my insurance doesn’t cover anything.	I had no problems financially because my treatment is covered by Daman (insurance).	I had my insurance and it was totally fine. I had no problems anything alhamdulilla.
It is covered	healthcare is covered by insurance alhamdullilah	my healthcare was covered by insurance	my work was OK and flexible and they knew my condit	: I didn’t have the support except people at my work	Sometimes I would come and the approval will not go through entirely so	Because I do not have a mandate approved from Abu Dhabi	, for my surgery I had money problems and I couldn’t manag	I don’t work, I manage my four children	

			ion and allowed me to leave at twelve because I couldn’t stay more as I got tired. They told me; you can leave early.	helped me.	couple of sessions I had to miss	for the gynaecological cancer. They said, if you have a cancer of Breast, we can help you with that but we cannot cover this gynaecological cancer care	e the money for surgery.		
					when I had started my chemot				

					herapy, the first session had to be postponed because they didn’t approve it				
					They said go to the social worker and speak to the social worker and they asked if I had insurance and I said yes, I have	it is most comfortable that if I get the gynaecologist here, I cannot pay two thousand dirhams for gynaecologist. I did			

					insurance and they said then you cannot have it, go to the principle	this once here but this is, in my job, it is quite expensive. So, this is the challenge I faced here, because I would like to be here but I cannot afford it this amount			
					they told that I	My gynaecology			

					have to pay ten thousand and I said I can’t do that…I can’t afford it.	is not covered here. Its not going to affect me as such. I actually really appreciate all what has happened to me the chemo, the doctors, all covered, its really big help and it saved my life			

					They did not cover because that insurance wanted to block patients so they kinda wangle it so it would be inpatient so they (hospital) can give it to me in the hospital and I didn’t have to pay for it. So,				

					hospital was very accommodating.				
					Lot of the time, initially first few weeks of my chemo, I didn't do it. After that it had to be postponed to next Wednesday because it wasn't approved. I				

					have had a lot of issues in the beginning				
					every time I come for chemo, I have learned that the day before I had to call them to ask them if it is approved. The ladies here, they are putting the request				

					and then tell me that I put it in ten days ago and say they are still working on it. It is ridiculous!				
					But to be honest, I would be at home and it would have been coming out of my pocket, I am				

					extremely grateful that I am here in the UAE… But to be honest, I would be at home and it would have been coming out of my pocket, I am extremely grateful that I am here in the UAE				
I talked	my two	My sister	No, I had no	the doctors	I had lots of	You know	I have so my	I am happy	you know

to my husband	son and daughter, they are with me. They told me, do like this, don't eat like this, put me in a good way you know for my food, my exercise	in law had a cancer so I was comfortable talking to her and get the support I needed.	issues with finance, it is covered and they did everything	didn't support me in this	friend assisting me..	through this sickness, almost all my people changed, people whom I was with and thought they are close and I thought they are my relative	sister brought my mother. This gave me strength.	with my family and I managed all.	my family, they were there for me
That was from my	they were with me and	I spoke to my famil	My family treated me	I had all the support from	My principle was assisting	Some of them they	Also, my sister is with	My family has been	My daughter and my son,

husband, I was strong	I managed	y and they were all with me to support me.	very normally. Of course, it was hard for them to know that I have cancer but they didn't treat me as something is abnormal	my sisters	g me. I am a teacher so she took away some of my classes so it won't drain me out. She put another teacher with me in the class so if I can't do anymore, she takes over.	chill out with me but I can say they are not so many and mostly I don't see them. Because they show themselves that actually they are not my friends. They are scared more than me,	me, my husband …NO, he is X. he didn't stand up with me.	very supportive and they supported me all.	really. Maybe they encouraged me so much to do. They were more scared about it; I was like I will do it anyways but they were scared about it.

						they have decided to stay away from me.			
I have found so much support from my family , from my relatives that’s why they gave us strength hamdullila	my all family, all my sisters, they were all with me	My husband was very supportive thought and I had no issue talking to him about it.	Mainly I got all support from Allah and my family		Everybody was most helpful	My director in the school , he knows what happened to me. Actually, he gave me one month off when I started my chemo so I can contin	Because my manager she told me, you can sit no problem; your salary is OK but for me I said, No, I should go to work		My husband passed away seven year ago but I got all the support from my family

						ue my job			
I found a way to deal with it through my faith and my family support	Mainly from my children, my family and my sisters. I had lots of support from my family. I managed well with their support	my family was very supportive			I am blessed with a very good principle alhamdullila and she has been immensely supportive	I do remember, the first chemo, there was Syrian nurse, she did my first chemo. I cried; I don't know how to explained. I felt there is something in body, I don't know, I felt I	when I have session and after that my mother sat with me for nine months.		. I didn't tell anything about it. I only told my daughter, my son and that's it

						won't wake up. She was standing right next to me and said why are you crying, are you missing someone. Everything will be OK			
I managed all with my family		Mainly family, my family was				All the doctors, nurses, they have	From my husband, No, there was no		

and my doctor		very supportive				like become more concerned than my friends	support. I felt support from my mother, from my sister. Actually, from my family.		
My family and my faith in Allah made me pass through all difficulties		I have few friends			When I came for my first operation, Dr. Mouza said, almost like my entourage, there was always someon		So, my family gave me this not my husband. I have two kids and my husband but he		

					e with me. A friend of mine Amina, we were together so I went for my operation,		didn’t support me emotionally, he didn’t support me financially. It is difficult for me, my husband has money, he could have given me money for my surgery but he didn’t give me. He		

							let me go to Hilal Ahmar (Charity) like this to manage my surgery. It was difficult for me.		
Doctor Mouza Al Ameri, she is a very nice doctor. We don’t feel like her as a doctor, she is					I am not lying, I swear to God, every day I had lunch, I had dinner. It would be left at my door.		Alhamdullila after that my mother		

like a friend or sister					Every day she sent, somebody from cleaning company, every day my apartment got cleaned because I cannot, I must not do anything. Alhamdullia she took me like her sister and she did it for the whole				

					of my period when I was recovering till I do it and I said Amina, I can do it and only then she did stop.				
He insisted me to go to the hospital and check						it is very important for you to have supportive people			
						She (doctor) is really fun			

						she (doctor) was very concerned, she was next to me when they standing next to my bed when they researched about whether it is true or not.			
Sub-theme 4: Emotional concerns									
I was not happy	I was all the time	, I was little	I was scared thoug	the look of the	I have a ten-year-	First, I remember, I	because I don't	I was scared	But there was

because there were some worries and things to be worried about but you	thinking if they will tell me something bad, what I will do	depressed of course it's not good news but later I accepted the reality	h because I have small kids,	surgery is very bad. It is affecting me psychologically	old daughter so I had to be brave and strong for her.	was sitting down and cry	want to think too much and if I will sit at home and I will think too much and I will feel I am weak. I didn't want to feel this. Also, I can see from my mother's eyes,		difficulty like when I saw myself in the mirror, it was a bit psychological or say emotional

							she is very sad about me. For me, I will show her, I am good, I am strong		
Things are better now alhamdullila.	I wasn't afraid when I heard	it was also because I lost my son	I was worried and of course unhappy	I couldn't tell my mother; I am having this disease. I used to tell her that I am going outside for my studies	I tried to get my self positive as I could	Sometimes its better not feel anything.	After that, I will be in front of him even more strong because he wanted to see I am weak. No	I didn't find any emotional or social issues	I didn't tell anyone about it because you know, they would be worried about me, I didn't want that so I kept it

				and I used to hide in my sister's house. When I used to be back home, I still used to have this pain but I had to hide it			…even I am, I will not show him I am weak.		to myself. And you know when people about it they will be shocked; oh, how would you do it, it is dangerous. I didn't want that negativity.
I was satisfied and I am still satisfied	my husband, he had a cancer when he passed	I after Surgery I suffered pain. But that	I didn't experience any psychological or	My mother passed away and I couldn't even tell	It had also psychological effect, I became very	what I have to do. And of course, when you don't	but for me I would put make up at least. And		If I didn't remove it, it may have gone to other

	away. I was with him and I know everything	didn't impact my life as much when I lost my son. His loss made me emotional and low	emotional issues with family or with my friend or colleagues.	her, you know.	depressed	know what is chemo, how does it affect you. This scared you because you don't know anything.	also, my family would see me that I am OK at least.		place and I didn't know what would happen so I am really happy that it was removed. I don't regret anything.
	I don't want to suffer when I think about him, I don't want to be like him.	I dealt with the cancer but his loss was the **most challengin**	. I had no emotional or social concerns hamdullila	They saw it affected me too much and after two months, my sister who	It was like I was devastated.	Of course, it was angry, like sadness, fears, it was like no emotions at all. So,	I would say physical and emotional		

	He was too much depressed	**g** in my life because I was the one with him and taking care while he was ill.		had a cancer, she also died. That is like destroyed me really.		all, emotions or mixed emotions			
	. I said myself, I will fight.	I do not have much friend	In our family, there are lots of people who have cancer. My sister also has breast	I couldn't tell them what is in my heart because you know they were also going	I am here alone with my daughter, it's difficult because I have to be strong for her.	before I prayed and I didn't cry but this time I pray and I cry so this I can say it's	It's difficult to accept		. If I didn't remove it, it may have gone to other place and I didn't know what would

			cancer so it wasn’t that much.	through this tragedy.		different			happen so I am really happy that it was removed. I don’t regret anything.
	I love my children, I want to see their children and become a grand mother	I wasn’t going out much and I was bit down so I was always with my family	I think the most difficult for me was, I was away from my kids because I had my surgery done in the	And they also lost one sister because of cancer. I have to be careful what I am saying to them and all this thing.	The only time, I can be myself is when she is gone to bed and I can lie and I can cry into my pillow.	Dealing with emotions, may be, was the biggest challenge for me because you need lots of strength and	My another colleague told me why you told her about it and I said no problem, its time and InshAl		

			Germany and this was the biggest challenge for me to be apart from kids. It wasn’t easy			it is very important for you to have supportive people.	lah it will pass.		
					That is always at the back of my mind, tomorrow I can lose my job and then		I didn’t think too much about depression and I tell to myself, now I am		

					what do I do?		taking treatment, lets live now		
	How you think, its very important. Think in a good way	I had a fear of recurrence			I didn’t feel like I want to go my friends and colleagues to tell them like I feel this, like they have enough of them				
		I was always having this fear			I feel like I cannot go to them all the				

		that I might get another cancer			time, I feel like I cannot vent out my story				
		The biggest challenge was, my son passed away and that was more concerning to me than my own health.			. I just sit on my muslaah (prayer mat) and cry… cry in the middle of the night				

		I was taking care of him and he passed away just two months before I was diagnosed with cancer			. The decision to remove both of my breast, it was such an immense step; needed someone to speak to				
		This was the part that impacted me most			As I told her she need to speaks about her fears or concer				

		and even now I think of my son that more than my condition			ns like anytime she has a question, she needs to ask me.				
					The fear of recurrence that it will come back, it was always there in the back of my mind that I have to do revisions for				

					my daughter if I am not there anymore and I have to prepare her for that situation and like we never know what will happen so we talked about it.				
					And I feel my daughter needed to speak to				

					someone apart from me because we have been here alone for ten years and because my nephew came and he is with us here now and we didn’t have anyone. And this was devastating for her. I feel she				

					needs someone, she needs just to speak to let it out.				
					I don’t wanna share as I said I have daughter, I didn’t want her to let her see because first I had to own it to myself, I had to look at it and I didn’t				

					after the operation. I would just not look into the mirror. And I had a mirror the one full body mirror which I put it in my room and now I have just small round one and I needed to speak to				

					someone.				
					emotional concerns were the most important issues I had to deal with the cancer.				
					The psychological and emotional impact it had on me, I didn't know how this				

					will affect my life like the first time I had lump on my side so I thought, they will take it out and I will be good				
Sub-theme 5: Spiritual/Religious concerns									
Muslim always has faith so I said alhamdullila	when he told me, I feel that the God gave me something	I managed it all with my faith in Allah	when I was diagnosed with cancer, since then I got much closer	this disease made my faith into God stronger.	We need religion like something to hold onto	You know I think God is with me cause the treatment did not affect	I told my god I agree for everything	My God and my family really supported me.	I believe if anything happens to anyone, it is for a reason so

	like power		to Allah.			me that I had to stop the work.			Allah he knows what is better for you so it was totally fine. It made me closer to God.
It worked for me so I should say alham dullila as I have faith	If this is what, God want it.	Allah made it easy for me	During my disease and while I was receiving my treatment, I found myself closer to Allah	Because the way God stands with me, nobody can be with me.	I have always been a Muslim but now I am gonna be a stonged Muslim. I made a lot of Tahajjud (night prayer) and	You know when you pray, it releases your fears.	Alhamdullila, I got more closer to Allah. From the beginning, I accepted, I prayed and I told my	My religious belief really helped me through the disease and to cope up	

					salah in the Ramadan		Allah, I agree with all I have.		
When we have faith, it helps us pass through all the difficulties hamdullila	Allah loves me.	I found more peace and courage with my strong faith in Allah and in my religion	Mainly I got all support from Allah and my family	In this situation, you will feel how God is closest to you.	I have done more sunna prayers	Through prayers, the words you read in a particular way, it already gives your brain a different world and of course the feelings, when you are in	.		

						this situation and your really are going to think about this.			
I think how non-Muslims face the problems in their lives hamdullila	I discovered so many good things …people				Because if you don't have religion, you are lost.	I think I got more closer to the God	I will put tomorrow up to God. Because I accepted all from the beginning.		
Islam is a gift; it is really a gift.					I have gone closer to my God	when you are happy, you are	I got the main support from		

It helps us to pass everything						closed to the God, if you are sad, you are closed to the God.	my God		
I found a way to deal with it through my faith						Really this is a miracle that I really didn't get any bad effects from the treatment and I think it is from God.	Hamdullila, it is from my God, I had too much support here		
Most import									

antly with my faith in Allah, there were difficulties but I managed all hamdullila									
my faith in Allah made me pass through all difficulties									
Theme 3: Expectations or support needed									
Muslim always	Yes, I am satisfie	I was fully satisfi	I was satisfied	You have very	**I was satisfied with**	I am so happy about	May be if doctor	I was fully satisfi	The care I receive

has faith so I said alhamdullila	d with the care I received	ed with the care I received	with the care I received. I didn't have any issue really	good treatment so you cannot say that you didn't have a good care	**the care but there should be an improvement in information delivery**	the nurses and researchers. I can say that they are with us in this. It's their job and people can do their job in different way, see here it's really helpful!	**s can provide emotional support**	ed with care I received. For me its all good, the service Tawam hospital provided. Today I am a survivor because of all the doctors and staff at Tawam Hospital Oncol	d was perfect. I was satisfied with everything. I got the care that I need and even more really

								ogy department.	
It worked for me so I should say alhamdullila as I have faith	they treated me a good way	Everything was good and doctor kept on checking about everything.	Tawam pharmacy services are very slow, I think that should be improved for faster services and better delivery.	**Lack of information from the doctors, this affects**		I have two ways of my surgery so plastic surgery doesn't come under mandate approved treatment but in my case, better to go for this operation. So, for some patient	I prefer if I receive **more support** from health providers about the physical issues I have. May be doctors can also **provide emotional**	If hospital **can provide enhanced coverage** for those who cannot afford the treatment, this would be very helpful. But it is all good and I think they	

						s, like in my case like something to do with the **increase or enhanced coverage**	**support**.	are doing all fine.	
I was satisfied, and I am still satisfied especially with my Doctor	All the people are good even when I had radiation, they were helpful people hamdullilah.	I don’t think there is anything missing from the healthcare department.				**Expand the mandate, this will help me of** course but will help my doctor as well.	After I came here, hamdullila from my God, I feel I am comfortable		

						I have told you if possible, in cases of research if you add such mandates to cover other co-existing problems, it will help. It’s not just helpful, it’s very helpful			
	I have an	I recei				I really apprec			

	appointment at one O'clock, I see the doctor at three O' clock **So timing to see the doctor must be reduced.**	ved all the updates I needed from my doctors and nurses and the doctor was calling me to check on me how I am doing so I got the sufficient support				iate SEHA or whoever created this program for expatriate to get this treatment			

		from the healthcare department							

APPENDIX 12: GLOSSARY OF TERMS USED (ABBREVIATIONS)

ACS: American Cancer Society

Adjuvant therapy: Additional treatment(s) that are offered after a surgical procedure, designed to target microscopic traces of tumour which may have been left behind.

Advanced Stage: Mainly Stage IV, advanced breast cancer means that a cancer that began in the breast has spread to another part of the body.

ALND (Axillary Lymph Node Dissection): An axillary lymph node dissection (ALND) is surgery to remove lymph nodes from the armpit (underarm or axilla).

Arabs: Those who speak Arabic as their native tongue. Arabs are not a distinct ethnic group, since there are both white Arabs and black Arabs. Majority of Arabs are Muslims, but some are Jews and Christians too. In this research Arabs are considered as Muslims.

Aromatase Inhibitors: A type of hormonal therapy that reduces the levels of oestrogen in the body by blocking aromatase, an enzyme which helps to form oestrogen from other steroids. Examples include Anastrozole (Arimidex), Letrozole and Exemestane.

ASCO: American Society of Clinical Oncology

Brachytherapy: It is a form of radiotherapy where a sealed radiation source is placed inside or next to the area requiring treatment.

Breast reconstruction: The formation of a breast shape after a total mastectomy (see mastectomy), using a synthetic implant or tissue from the woman’s body.

Chemotherapy: The use of anti-cancer drugs to destroy cancer cells. This treatment can be given alone or as part of adjuvant therapy.

Clinical factors: This research will focus on clinical attributes including primary site, cancer stage and treatment modalities.

DoH: Department of Health (Abu Dhabi)

UAE: United Arab Emirates

HAAD: Health Authority Abu Dhabi

Early Stage: Breast cancer that has not spread beyond the breast or the axillary lymph nodes. This includes ductal carcinoma in situ and stage I, stage IIA, stage IIB, and stage IIIA breast cancers.

Emirati Nationals: UAE citizens/nationals

Expatriate: Any non-UAE National who has entered the Emirate of Abu Dhabi for the purpose of work or residence under a permanent or temporary work or residence permit issued by the State. The term “Expatriate Resident” shall also include the resident families and dependants of the Expatriate Resident who enter the Emirate for the purpose of residence.

FOCP: Friends of Cancer Patients

Herceptin: Also known as Trastuzumab, it is a type of biological therapy used to reduce the risk of breast cancer coming back in women with HER2 positive breast cancer (type of breast cancer).

Hormonal Therapy: Type of treatment used to inhibit the growth of hormones in the body which are responsive to cancer cells (also see: Arimidex, Aromatase inhibitors and Tamoxifen).

Invasive Breast Cancer: Type of breast cancer where the cancer cells have spread outside the lining of the ducts or lobules into the surrounding breast tissue.

IARC: International Agency for Research on Cancer-GLOBOCAN

IOM: Institute of Medicine

Lumpectomy: It is a surgery to remove cancer (the lump) and some other abnormal tissue from your breast. Lumpectomy is a form of “breast-conserving” or "breast preservation" surgery.

Lymphoedema: Swelling of the arm or breast due to a build-up of lymphatic fluid.

Mastectomy: It is the removal of the whole breast. **Metastasis:** The spread of cancer to other organs in the body.

MoH: Ministry of Health

MOHAP: Ministry of Health and Prevention

Multiple Primary (MP): Multiple primary cancers are usually defined as primary malignant tumours of different histological origins in one person. In Breast, multiple tumours with the same histologic type appearing in the breast and in a different site are regarded as multiple primary tumours unless stated as metastatic tumours.

Muslims: Those who follow or practice Islam (religion).

Nationality: Representation of the passport held by an individual. However, in this study the term nationality is used in cultural context classified into two groups: Emirati Nationals and Expatriates

NCCN Guidelines: National Comprehensive Cancer Network Guidelines

Neoadjuvant therapy: Treatment given as a first step to shrink a tumour before the main treatment, which is usually surgery, is given.

Primary Breast Cancer: It is a cancer that hasn't spread beyond the breast or the lymph nodes under the arm.

Prophylactic contralateral mastectomy: It is a risk-reducing mastectomy performed for the patient diagnosed with an invasive or a non-invasive breast cancer.

Psychosocial Concerns: This research will cover psychosocial issues including physical, informational or educational, social and financial, emotional and spiritual or religious concerns which are translated into patients' needs issues of cancer, beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life.

Quran: Muslims Holy book

Radiotherapy: Type of treatment which uses high energy x-rays to destroy cancer cells.

Recurrence: Cancer that has recurred (come back), usually after a period of time during which the cancer could not be detected.

SEHA: Abu Dhabi Health Services

Survivor: An individual diagnosed with cancer from the time of initial diagnosis until his or her death.

Survivorship: In cancer, survivorship focuses on the health and life of a person with cancer post treatment until the end of life. However, in this research the term survivorship encapsulates the survivors' experience/needs throughout cancer trajectory starting from the diagnosis.

Tamoxifen: Type of hormonal therapy which uses an anti-oestrogen drug to prevent oestrogen in the body from attaching to breast cancer cells

WHO: World Health Organisation.

APPENDIX 13: MAYO CLINIC APPROVAL FOR THE USAGE OF SURVEY

From: Cancer Education Program
Sent: Thursday, June 25 6:29 PM
To: 'Maria Aamir'
Subject: RE: Permission to use cancer needs survey for the PhD dissertation

Dear Dr. Aamir,

Thank you for your note and interest in the Cancer Survivorship Survey Tool that was developed at Mayo Clinic. We are happy to share the tool. I am attaching the survey in English and Spanish. You have permission to use as-is or adapt the survey for your research. Our only request is to credit Mayo Clinic for the tool, please reference the survey development from our program. Original survey developed by the Cancer Education Program, Mayo Clinic Cancer Center – Cancer Survivor Survey of Needs. I also attached a copy of our survey results/study manuscript from 2013.

I would love to hear back from you if you decide to publish, the survey results would be interesting also to our group.

Kind Regards,

Wendy

From: Maria Aamir [mailto:drmaria75@hotmail.com]
Sent: Thursday, June 25 7:03 AM
To: Cancer Education Program
Subject: [EXTERNAL] Permission to use cancer needs survey for the PhD dissertation

Hi,

I am writing you to ask permission if I can use the cancer needs survey developed by PeterMac Mayo clinic to be used to assess cancer patients needs in the UAE (in a hospital setting). I am not intended to change any of the items apart from nationality classification into local emiratis and non-local expatriates.

Kindly if I can have some information about the internal validity of the survey how it was validated and what is the validity of it while developing the instrument (attached). Kindly if you could get me in touch with the authors or who could provide me the above information along with the permission to use it.

I look forward to obtain the approval to use it for my PhD studies.

Dr. Maria Aamir

+971508550292

My professional profile can be accessed through the below link:

https://www.linkedin.com/in/dr-maria-aamir-89b70415