EFFECTIVENESS OF PSYCHO-EDUCATION INTERVENTION PROGRAM ON QUALITY OF LIFE, COPING STRATEGIES AND PSYCHOLOGICAL DISTRESS AMONG JORDANIAN WOMEN DIAGNOSED WITH BREAST CANCER

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by

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LIST OF SYMBOLS

μ	Mean
t	Time
m1	Mean intervention group
m2	Mean control group
Sd1	Standard deviation intervention group
Sd2	Standard deviation control group
t(df)	t test

LIST OF ABBREVIATIONS

AIC	Akaike Information Criterion
BIC	Bayesian Information Criterion
CATPCA	Categorical Principal Components Analysis
CI	Confidence Interval
CS	Coping Strategies
EORTC	European Organization for the Research and Treatment of Cancer
GLMM	Generalized Linear Mixed Models
HADS	Hospital Anxiety Depression Scale
IQR	Inter Quartile Rang
JMOH	Jordan Ministry of Health
PEIP	Psycho-Education Intervention Program
QOL	Quality of life
SD	Standard Deviation
SEI	Socio Economic Index
SPSS	Statistical Package for Social Sciences
WHO	World Health Organization
TNM	Tumor, Node, Metastasis

KEBERKESANAN PROGRAM INTERVENSI PENDIDIKAN PSIKOLOGI TERHADAP KUALITI HIDUP, STRATEGI DAYA TINDAK DAN GANGGUAN PSIKOLOGI DALAM KALANGAN WANITA JORDAN YANG MENGHIDAP KANSER PAYUDARA

ABSTRAK

Diagnosis kanser payudara adalah satu peristiwa menyedihkan dan menghancurkan yang berkemungkinan menimpa kaum wanita. Ia dianggap sebagai peristiwa besar yang mengancam semua aspek kehidupan seorang wanita dan boleh dianggap sebagai cabaran dari segi nilai, kepercayaan dan matlamat, fungsi hidup dan menggugat jati diri. Semasa diagnosis, perasaan ingin tahu pesakit tidak terpenuhi dan mereka menzahirkan keinginan untuk berbicara dengan seseorang yang pernah menghidapi penyakit yang sama dan telah mengatasinya. Dalam kajian ini, maklumat berkaitan dan perkongsian pengalaman akan disediakan kepada pesakit kanser payudara dengan tujuan untuk meningkatkan penilaian pesakit terhadap keadaan yang menimbulkan tekanan, dan seterusnya dapat mengurangkan gangguan psikologi dan menambahbaik kualiti hidup melalui peningkatan strategi daya tindak. Objektif kajian ini adalah untuk menentukan keberkesanan program intervensi pendidikan psikologi terhadap kualiti hidup, strategi daya tindak dan gangguan psikologi dalam kalangan wanita Jordan yang menghidap kanser payudara. Kajian rawak terkawal dan buta binari telah dilakukan yang melibatkan 200 peserta dari Hospital Al-Bashir di bandaraya Amman. Peserta kajian adalah pesakit wanita Jordan yang berumur antara 20-65 tahun dan menghidap kanser payudara tahap 0, I, II atau III. Peserta yang memenuhi syarat kelayakan telah dipilih secara rawak, yang kemudiannya dibahagikan kepada kumpulan intervensi atau kumpulan kawalan dengan

menggunakan janaan rawak blok pemilih atur bersaiz sama. Kumpulan intervensi seterusnya menyertai sesi dua hari pendidikan kesihatan mengenai kanser payudara berpandukan modul Fawzy Fawzy. Terdapat empat bahagian modul: 1) pendidikan kesihatan; 2) latihan kemahiran daya tindak; 3) pengurusan tekanan; dan 4) sokongan psiko-sosial. Hasil kajian dinilai menggunakan: Kaji Selidik EORTC QLQ-C30 dan QLQ-BR23 untuk mengukur kualiti hidup, Skala Brief COPE untuk menilai strategi daya tindak dan Skala Kerisauan dan Kemurungan Hospital (HADS) untuk menilai tahap kerisauan dan kemurungan dalam kalangan wanita kanser payudara di Jordan. Model Campuran Linear Umum (GLMM) dilakukan untuk menilai kesan intervensi yang disesuaikan untuk pemboleh ubah yang membaur. Hasil kajian menunjukkan kumpulan intervensi telah mencapai peningkatan yang bererti dalam kualiti hidup: QLQ-C30 (β=0.137, P=0.006), QLQ-BR23 (β=0.190, P=0.001) dan kemahiran daya tindak mudah suai (β=0.921, P<0.001); dan penurunan yang bererti bagi tahap kerisauan (β=-0.378, P<0.001) dan kemurungan (β =-0.525, P<0.001) berbanding dengan peserta kumpulan kawalan. Intervensi ini berkesan secara positif dalam mempengaruhi kualiti hidup, strategi daya tindak dan gangguan psikologi. Program ini dicadangkan untuk digunapakai sebagai sebahagian daripada pendidikan kesihatan rutin di klinik onkologi di Jordan.

Kata Kunci: kanser payudara, pendidikan kesihatan, pendidikan psikologi, kualiti hidup, strategi daya tindak, gangguan psikologi, Jordan

EFFECTIVENESS OF PSYCHO-EDUCATION INTERVENTION PROGRAM ON QUALITY OF LIFE AND COPING STRATEGIES AND PSYCHOLOGICAL DISTRESS AMONG JORDANIAN WOMEN DIAGNOSED WITH BREAST CANCER

ABSTRACT

The diagnosis of breast cancer is distressing and devastating events that may befall women. It is considered a major stressful event that threats all aspects of woman's' life and can regarded as a challenge to women's basic values, beliefs and goals, life functions and threatening their sense of identity. At the time of diagnosis, the patients face unmet knowledge needs and they express the greatest need to speak with someone who has experienced and overcame the same disease. In this study, related to knowledge and sharing experience that will be provided to the breast cancer patients with aim of enhance the reappraisal of stressful situation that reduce the psychological distress, and promote quality of life through enhance coping strategy. The objective of this study was to determine the effectiveness of psycho-education intervention program on quality of life, coping strategies, psychological distress among Jordanian women diagnosed with breast cancer.A randomized controlled trial, double-blind study was conducted with 200 participants from Al-Bashir Hospital in Amman city. The participants include all Jordanian women in aged 20-65 years and had diagnosis of breast cancer in stage 0, I, II or III. The participants who met the eligibility criteria was selected randomly after which they were evenly randomized using randomly generated permuted blocks of equal sizes into one of either the intervention or control group. The intervention group then underwent two-day health education session on breast cancer, which was strictly guided by the Fawzy Fawzy module. This comprised

of four components: 1) health education; 2) coping skills training; 3) stress management; and 4) psychosocial support. The outcomes were measured by using EORTC QLQ-C30 and QLQ-BR23 questionnaires to assess the quality of life, Brief COPE scale to assess coping strategy, and Hospital Anxiety Depression Scale (HADS) to assess the anxiety and depression among Jordanian breast cancer women. Generalised Linear Mixed Models was conducted to evaluate the effect of the intervention adjusted for confounding variables. The results showed that the intervention group was significant in increasing the quality of life: QLQ-C30 (β=0.137, *P*=0.006), QLQ-BR23 (β=0.190, *P*=0.001); adaptive coping skills (β=0.921, *P*<0.001), and decreasing anxiety score (β=-0.378, *P*<0.001) and depression score (β=-0.525, *P*<0.001) compared to the control group. The intervention was effective in positively affecting the QOL, adaptive coping strategies and psychological distress. It is recommended for adoption as part of routine health education given at oncology clinics in Jordan.

Keywords: breast cancer, health education, psycho-education, quality of life, coping startegy, psychological distress, Jordan

CHAPTER 1

INTRODUCTION

1.1 Introduction

Women with breast cancer face challenges in different aspects of their lives as the drastic changes in their psychological needs can be distressful. With the intention of helping these women to cope after the diagnosis, there has been an emphasis in providing psychological support and interventions to enhance quality of life (QOL) and survival rate (Lim *et.al*., 2015). It is imperative to investigate the psychological and psychosocial factors interrupting quality female cancer patients' life and well-being with the intention of providing them with proper treatment and therapeutic intervention. Psycho-education is a form of therapeutic intervention for patients and their families. The purpose of this intervention is to provide information on the course of treatment, side effects to the patients and educate the family members to have a better understanding on what the illness is. Most importantly, psycho-education helps the families to learn to cope with the changes that would affect their lives entirely.

Breast cancer in the Hashemite Kingdom of Jordan is the most prevalent among women between 20 and 49 years of age (45%) and in women 50 years of age and older (34.8%) (Sharkas *et.al*, 2015). The median age of women exposure of breast cancer is between 45-50 years as compared to 63 years in developed countries (El Saghir *et al*., 2007; Howlader *et al*., 2013). It is likely to spread among young age groups (Montgomery and McCrone, 2010). The incidence rate is 52.6 per 100,000 among Jordanian women (Registry, 2010; Cancer, 2015; Ferlay *et al*., 2015a). Breast cancer in women ranked first

among all cancers from 1996-2010 in Jordan (Abu-Helalah *et al*., 2014; Sharkas *et.al*, 2015) and it accounted for about 37.4% (n=941) of all female cancers in 2010 (Sharkas *et.al*, 2015). There were 978 cases of breast cancer in both genders, 27 cases in situ and 951 cases of invasive breast cancer (Sharkas *et.al*,. 2015). This indicated that the most breast cancer cases were invasive (advanced stages) and in females. Breast cancer staging ranged from 34% stage I and stage II (localized disease); 45% age II (regional disease); 9% stage IV (distant metastasis), 2% in situ; to 8% unknown (Sharkas *et.al*, 2015). It mainly affects young women (Nimri and Al-Sayaideh, 2012; Sharkas *et.al*, 2015).

Jordan is considered as the fourth Arabic country after Bahrain, Tunisian, and United Arab Emirates (UAE) with poor QOL among women with cancer (Abu-Helalah *et al*., 2014). Breast cancer patients need help with transport, symptoms observation and a rise in domestic chores due to disease progression (Bakas & Parson, 2001). Patients may also face some social problems that may interfere with their inability to cope as they want to avoid public sympathy. They will also tend to isolate themselves. Hence, family support is crucial for these patients (Kleponis, 2006).

Currently, there has been no studies determining the effectiveness of psycho-education intervention program on QOL, coping strategy (CS) and psychological distress among breast cancer patients from a medical perspective in Jordan. Moreover, there is a lack of research evidence on basic knowledge of the disease and experiences shared by Jordanian breast cancer survivors within the Jordanian scientific and clinical community. The current gaps in Jordanian knowledge constitute a clinical barrier to identifying survivor needs that accompany the unresolved symptoms and hardships. Jordanian women

providing support by sharing personal experiences battling breast cancer may assist other patients to cope with the disease.

Psychosocial support is found effective to improve breast cancer indications and psycho-educational support to improve emotional health within six month of post intervention (Nishimoto *et al*., 2014). Takahasi *et.al* (2008) stated that psychopathological symptoms, for example anxiety and depression, are common among patients with cancer. Their findings substantiated a study by Avelar *et.al.* (2004) who revealed that anxiety and depression levels among pre and post surgery women with breast cancer were notably maintained after pyscho-educational intervention.

The purpose of this study is to provide findings beneficial in developing specific psycho-education intervention to enhance the nature and quality of breast cancer survival. Breast cancer patients are susceptible to experiencing emotional distress which could bring bouts of depression and anxiety (Ng *et.al.*, 2017). These psycho-education may improve coping with the diagnosis, effective management of daily stressors by using problem-focused CS (adaptive coping) and increase the overall QOL of Jordanian women breast cancer survivors.

1.2 Background of the Study

One of the most frequently diagnosed cancer among women is breast cancer (Steponaviciene *et.al*., 2019). The World Health Organization (WHO) justified that approximately 30% of all cancers among women is breast cancer (Bener *et al*., 2017). The Global Cancer Statistics (2018) showed that in 2018 alone, two million cases of breast cancer were reported. Breast cancer is considered as a global public health concern in

both developed and developing countries as most cases of breast cancer are fatal (Rivera Franco and Leon-Rodriguez, 2018). At the global scale, breast cancer is ranked fifth in cancer-related deaths (Ferlay *et.al*, 2015a). The survival rate varies as cancer survivors in developing countries are lower compared to developed countries. The lower survival rates are caused by insufficient early detection programs, which resulted in most women being diagnosed at advanced stages (Rivera Franco and Leon-Rodriguez, 2018). Rivera Franco and Leon-Rodriguez (2018) also projected that in 2020, 1.7 million of new breast cancer cases and due to unavailability key preventive methods, 70% deaths was expected to occur. Hence, this stresses on the importance of early detection.

1.2.1 Breast Cancer in Jordan

In Jordan, women with breast cancer do not have easy access to adequate cancer care due to to a shortage of oncology trained healthcare professionals. Imbalance in ratio of doctors to patients in Jordan (KHCFUSA, 2009; Sharkas *et.al*, 2015) may also lead to insufficient counselling time for patients (Institute of Medicine and National Research Council, 2004; Sharkas *et.al*, 2015). Lack counselling time may also lead to incidences where the healthcare professionals become unaware with their patients' concerns (Farrell *et al.*, 2005; Parker *et al.*, 2009). Generally, one doctor sees approximately 100 patients daily in the outpatient department where one patient is estimated to have only 3 minutes of consultation with the doctor. Furthermore, information provided to patients frequently does not meet the patients' individual needs within the disease's trajectory (Harrison *et al.*, 2009; Park and Hwang, 2012).

The much needed supportive services such as mental health services cancer centers for these women are also lacking in the country (Abu-Helalah *et al*., 2014). Most studies utilized the cognitive, and behavioral approaches, psychotherapeutic (group and individual), psychopharmacologic to help patients cope with the sudden change of lifestyles. Few interventions have been utilized in the psycho-educational and sharing experience support to help these patients. Nevertheless, despite majority of studies focused on stress management during the treatment period or survival life, yet few focused on the patients at the time of diagnosis, where patients, during this period, are more prone to stress (Holland and Weiss, 2010). The systemic review also showed that most studies have assessed the effectiveness of interventions over time on psychological distress, CS, and QOL, but few studies were carried out on the psycho-education intervention program efficiency in predicting QOL, CS, and psychological distress over time. Moreover, there is a lack of studies on determining psycho-education intervention program efficiency on QOL, CS, and psychological distress among women diagnosed with breast cancer in Jordan (Younis *et al*., 2020).

1.2.2 Breast Cancer Burden in Jordan

Figure 1.1 shows the current statistics from the WHO's International Agency for Research on Cancer (IARC) revealed that in Jordan, breast cancer is one of the top five cancers with total cases of 2,143 and is considered as the most common causes of death due to neoplasms among females (IARC, 2018).

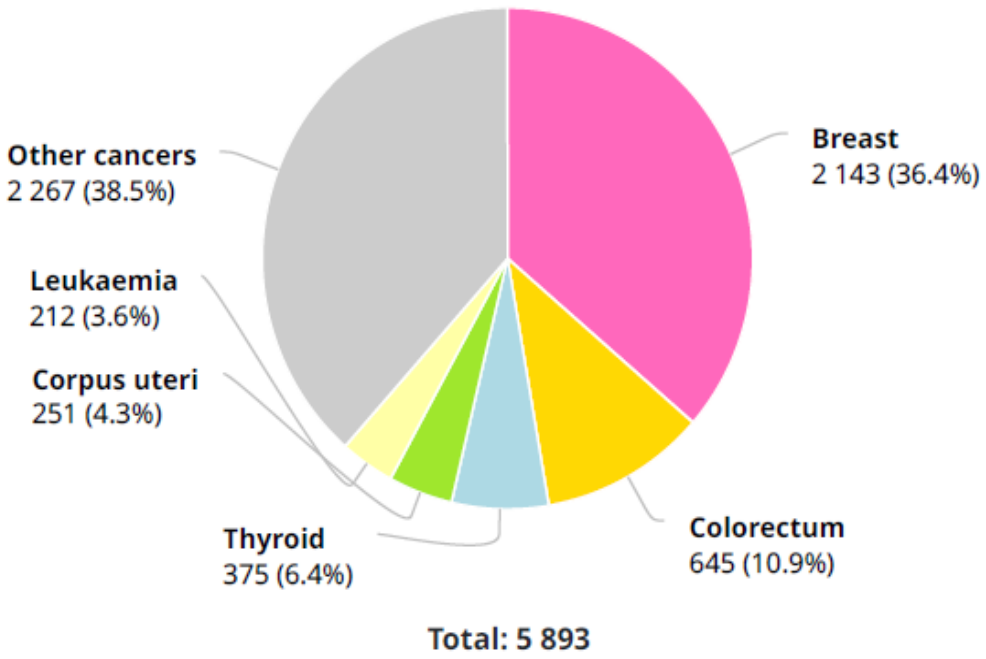

Figure 1.1 Number of new breast cancer cases among females in Jordan
(Source: IARC, 2018)

Jordan is divided into three regions: the north, central and south regions with a total of 12 governorates (Taha *et al*., 2012) (Figure 1.2). The division of its administration is identified as central, north, and south regions with an urban population of 82.6% with approximately two thirds of the residents living in the central district. 10% of the population lives in Amman (Department of Statistics, 2011).

Figure 1.2 Map of Jordan
(Source: https://www.lonelyplanet.com/maps/middle-east/jordan/)

For breast cancer cases by regions, the highest rate in 2010 was found in the central area (n=1,918; 36.7% of all cases) followed by the north area (n=462; 37.4%), and the lowest number of cases occurred in the south area (n= 135; 45.9%) (Sharkas *et.al.*, 2015). Many risk factors contribute to the increase in breast cancer occurrence in Jordan such as rapid growth in population, poverty, smoking (Ismail *et al*., 2013); lack of exercise (El Saghir *et al*., 2007); increased life expectancy (MacMahon, 2006); marriage at an older age and first pregnancy in the late twenties and adoption of unhealthy lifestyles (MacMahon, 2006; El Saghir *et al*., 2007; Najjar and Easson, 2010; Jemal *et al*., 2011; Ismail *et al*., 2013).

The overall of the five-year survival rate among those diagnosed with breast cancer in Jordan was 64.2% with 82.7% stage I, 72.2% stage II, 58.7% stage III, and 34.6% stage

IV (Tarawneh *et al*., 2011). About 97.6% of these women were diagnosed by biopsy or histology of the primary site (Jordan Cancer Registry , 2009). Despite the existence of a Jordanian cancer registry, there is no available data on the percentage of mastectomy, partial/lumpectomy, and reconstruction, or rates of chemotherapy, radiation, and/or hormonal therapy. Based on previous study involving 838 participants, it was reported that 47% (n=394) of women with breast cancer received combined treatment of surgery, chemotherapy and radiotherapy (Arkoob *et al*., 2010). Overall, these statistics showed that breast cancer patients in Jordan are usually treated using a combination of surgery, radiation therapy and chemotherapy.

1.2.3 Psychological Effects Among Women with Breast Cancer

Women with breast cancer is prone to psychological effect (Crist and Grunfeld, 2013). No less than one-third of cancer patients suffers from psychological distress, and women and young people are at higher risk (Khalili *et al*., 2013; Ghaffari *et al*., 2014). In general, these women see breast cancer as a significant stressor where previous studies found that most common concerns of breast cancer survivors were their status, femininity, employment, their roles in the family, fear of relapse and death (Ziner and Bell, 2012; Anusasananun *et al*., 2013; Leal and Cohen, 2015). It has been reported in other studies that Jordanian cancer patients mentioned that they experienced many unmet needs, it is essential to implement appropriate intervention programs with additional need supportive care services for these patients in Islamic countries (Joulaee *et al*., 2012; Khalili *et al.*, 2013; Obaidi *et al*., 2013; Abdollahzadeh & Pakour, 2014; Ghaffari *et al*., 2014; Abu-Helalah *et al*., 2014).

Breast cancer threatens the patient's life, causing a state of fear, anxiety and sadness, making it difficult to see the patient psychologically stable, and remains in constant psychological disorder due to persistent thinking of the disease and the results. The disease also affects the female patients in establishing social relations with her surroundings as a result of the increased sensitivity and feeling ashamed and embarrassed by the removal of one of her breasts. This is not only reflected on the people around her but also on the marital relationship because of the gap between the couple is caused by the patients' loss of self-confidence and self-rejection (Alhusban, 2019).

Living with breast cancer is perilous as the cancer's adversative properties and treatment have damaging influence on the patients' QOL. Patients are burdened with the seriousness of the disease and may require assistance to perform daily activities. Despite the need to understand ways to help these patients, the review indicated that research on QOL among breast cancer patients is poorly established in Arab countries (Perry and Chang, 2007).

From the whole facts mentioned above, it can be said that patients with cancer are challenged psychologically. They face various emotional unpleasantry that affects their capability of coping with the disease, the indications and treatment (Abrahamson, 2010). Two main CS may use by patients: problem-focused (adaptive coping) and emotional-focused (avoidant coping). Problem-focused strategies involve constructive actions to reduce or change traumatic situations. Emotion–focused attempts in regulating emotional concerns of demanding circumstances and establishing effective and emotional balance through emotional control (Carver and Weintraub, 1989; Carver *et al*., 1993). The ability to cope can help patients to persevere throughout the course of treatment and improve survival rates (Khalili *et al*., 2013).

Having the capacity to cope is one of the traits to enhance QOL (Tuncay, 2014). It is worth mentioning that the women with breast cancer use different ways to cope and is dependent on the cancer's current stage, treatment, individual's self-beliefs and attitude towards the situation affect how they choose to cope psychologically with the battle (Cebeci, 2012; Hopman, 2015). In fact, most people in Jordan's society are likely to have a fatalist viewpoint regarding any new situation in their lives due to their religious views. Nevertheless, women have significant needs for supportive care that are often unmet, mostly including information needs and unmet needs in the areas of their physical wellbeing and everyday lives (Abu-Helalah, 2014). Various studies showed a certain connection between CS and QOL among women with breast cancer (McCaul *et al.*, 1999; Stanton *et al.*, 2000; Sehlen *et al.*, 2003; Avis *et al.*, 2005).

Two studies by Avis *et al.*(2005) and Lehto *et al*. (2005) showed that having a good way of coping with the situation is better than being dependent of medical or treatment when forecasting a patient's QOL. The cross-sectional outcomes showed that women with breast cancer who chose to think positively, accepted the circumstances and are emotionally strong have better QOL compared to those who prefer to take the condition passively by avoiding discussing their conditions (Lazarus and Folkman, 1984; Stanton *et al.*, 2000; Avis *et al.*, 2005).

Coping plays a significant role in psycho-social adaptation to chronic illnesses and disabilities, including breast cancer. People can use coping efforts to psycho-social adaptation both directly and indirectly (Livneh and Martz, 2012). People need to help patients learn active CS and reduce avoiding CS in improving overall QOL.

The breast cancer patients' psychological is growing with the improvement of psychological intervention in the past few decades. Edwards *et. al.* (2008) suggested that there were four types of psycho-social intervention available for cancer patients and psycho-educational therapy is one of the suggested intervention.

1.2.4 Psycho-educational Intervention Program Effects on Women with Breast Cancer

One of the most operative psycho-social approaches to cancer patients is psycho-education (Dastan, 2012). Psycho-education is important as it is a process that provides education and information to individuals who seek or receive mental health services such as individuals with seriously or terminally ill and their family member. The program normally includes health education, stress management, coping skills, and psychological support.

Psycho-education intervention program's objective is to help people to understand of mental situation and adapt to the changes caused by the illness. Understanding the types of challenges can help patients, in this case, women with breast cancer, to have better knowledge of the physical and emotional changes they will face, identify their own strengths to help them cope better with the treatment and have more control over their own health.

In general, psycho-education intervention should aid women with breast cancer in coping with their stressors by enhancing the score of QOL domains, and encouraging adaptive coping outcomes. CS can help patients diagnosed with breast cancer to decrease psychological distress like anxiety and depression, and to enhance their QOL. However,

while the association between QOL, CS and psychological distress has been studied extensively, little research has been undertaken to examine the effectiveness of psycho-education intervention program in enhancing reappraisal of stressful situations among Jordanian women diagnosed with breast cancer and undergoing different treatments. Limited data are available regarding CS, and there is no program as intervention to perceive QOL, CS and psychological distress among Jordanian women with breast cancer.

Besides, psycho-education intervention is significant in improving well-being and reducing psychological distress like depression, stress, and anxiety among Jordanian breast cancer survivors (Younis *et al.*, 2020). Psycho-education therapy assists women with breast cancer with these effects of the disease on their QOL, psychological distress, and how to select proper CS. Most importantly, family members need to be included in the programs to help counter the undesirable effects of the recurring disease on their mental fitness, and to allow them to continuously act as operative caregivers (Laurel *et al*., 2002).

1.3 Problem Statements

Women with breast cancer have the tendency of experiencing serious mental and emotional consequences than other types of cancers (Sharif Nia *et. al*., 2017). Being diagnosed with breast cancer can be devastating to the patient as it could lead to fears, depression and thoughts of death (Kai-na *et.al*., 2011; Jafari *et.al*. 2018). The diagnosis leads to other sources of stressors such as financial difficulties (Parker *et al*., 2003; Yan *et al*., 2019); anxiety, depression and fear (Reyes-Gibby *et al*., 2012; Llewellyn *et al*., 2019). Additional stressors include physical problems (Rustøen and Begnum, 2000; Parker *et al*., 2003), worries for future recurrence (Maheu *et al*., 2019), and the detrimental

side effects of their cancer treatments (Browall, 2008; Ashing-Giwa *et al*., 2013; Smit *et al*., 2019). Hardships associated with female breast cancer survivorship may occur throughout the diagnosis, therapy, post-therapy recovery, stable disease, relapses, wellness or chronicity, and end-of-life.

Most women see breast cancer as life-limiting and threatening (Stevenson *et al*., 2004; Holland and Weiss, 2010), and a form of a death sentence (Holland, 2002). Being diagnosed with breast cancer affects a woman's confidence where the cancer attacks the breast, which is aesthetically important to her physical being. The breast represents a woman's femininity, motherhood and love in her life (Galjchen, 1999; Kunkel *et al*., 2002; Lewis *et al*., 2012; Ohaeri, 2012) and a change in body structure through hair loss and removal or disfigurement of one or both breasts is equivalent to the loss of femininity and brings about a sense of inferiority (Enache, 2012).

This study looked into an intervention program that was developed and implemented among Jordanian women diagnosed with non-metastatic breast cancer. The program consists of two main parts, i.e. medical education of CS and sharing experiences support part. The cancer-related educational themes was provided by an oncologist physician, and the sharing experience support session was offered by a breast cancer survivor. The selected breast cancer survivor would provide the support as she had the experience overcoming the disease. The effectiveness of the psycho-education intervention was assessed across time on repeated measures and the interaction factor with psycho-education intervention and related predictors were determined.

1.4 Research Questions

i. What are the level of QOL, CS and psychological distress among Jordanian women diagnosed with breast cancer in Al-Bashir hospital, Amman?

ii. Is the psycho-education intervention program effective in improving the QOL scoring among Jordanian women diagnosed with breast cancer in Al-Bashir hospital, Amman?

iii. Is the psycho-education intervention program effective in improving the CS scoring, among Jordanian women diagnosed with breast cancer in Al-Bashir hospital, Amman?

iv. Is the psycho-education intervention program effective in reducing psychological distress scoring among Jordanian women diagnosed with breast cancer in Al-Bashir hospital, Amman?

1.5 Research Objective

The general objective of this study was determining the effectiveness of psycho-education intervention program on QOL, CS and psychological distress among women diagnosed with breast cancer in Al-Bashir Hospital, Jordan. The specific objectives are as follows.

i. To determine the level of QOL, CS and psychological distress among Jordanian women diagnosed with breast cancer in Al-Bashir Hospital, Amman.

ii. To determine the effectiveness of psycho-education intervention program in improving QOL among Jordanian women diagnosed with breast cancer in Al-Bashir Hospital, Amman.

iii. To determine the effectiveness of psycho-education intervention program in improving CS among Jordanian women diagnosed with breast cancer in Al-Bashir Hospital, Amman.

iv. To determine the effectiveness of psycho-education intervention program in reducing psychological distress among Jordanian women diagnosed with breast cancer in Al-Bashir Hospital, Amman.

1.6 Research Hypotheses

i. The psycho-education intervention significantly improved QOL score of the intervention group compared to control group with regard of time among Jordanian women diagnosed with breast cancer in Al-Bashir Hospital, Amman.

ii. The psycho-education intervention significantly improved CS score of the intervention group compared to control group with regard of time among Jordanian women diagnosed with breast cancer in Al-Bashir Hospital, Amman.

iii. The psycho-education intervention significantly reduced the psychological distress score of the intervention group compared to control group with regard of time among Jordanian women diagnosed with breast cancer in Al-Bashir Hospital, Amman.

1.7 Justification of the Study

The motivation of this study was to carry out a study that specifically focused on psycho-education intervention program and its effectiveness among Jordanian women with breast cancer. Apart from filing the gaps to enhance QOL using psycho-education intervention program, this study is necessary as more understanding is needed on the role of health

education intervention in preparing the patients with the treatment plans and provide information to help them understand any possible complications that may arise during the process.

One of the important benefits of this study is that the information obtained from the participants were used to refer them for clinical psychiatric review, particularly participants who complained of severe depression based on initial analyses of baseline survey. These findings can be used to provide feedback needed to improve health care system in Jordanian Ministry Of Health for breast cancer patients. The study's finding would contribute to the development of curriculum health education and health training courses for medical and health care personnels.

The last systematic review and meta-analysis concluded that the psycho-educational intervention program from Middle East countries, especially the Arab region, need to investigate the efficacy of the psycho-educational intervention to improve the emotional disturbance, anxiety and QOL of breast cancer patients. Further research concentrating of evaluating the efficacy of long-term psycho-educational intervention strategies and exploring the intervention's impact on patients with cancer's survival. (Younis et al., 2020).

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter reviews literature related to the investigated topic which are psycho-education intervention program, psychological distress such as depression and anxiety, QOL and CS among breast cancer patients. The efficacy of psycho education intervention program in managing psychological distress among women diagnosed with breast cancer, improving their QOL and CS has been discussed extensively in western literature, particularly United States and European countries. However, in the context of Arabic countries, there is a relatively small number of researches involving Jordanian women with breast cancer available. This chapter also reviews the current information on breast cancer survivorship in Jordan and examines quantitative and qualitative studies on breast cancer conducted in Jordan. The review begins with a discussion of the search strategies utilized to obtain the literature and is followed by an explanation of the conceptual framework chosen for this thesis. The study's conceptual framework and the significance of the Lazarus theory used as the analytic lens theory are explained before the chapter concludes with a discussion of the impact of educational interventions on aspects of cancer survivorship like QOL, CS and psychological distress**.**

2.1.1 Literature Search Strategies

The comprehensive search was conducted in Google Scholar, PubMed, MEDLINE, and CINAHL plus with FT-EBSCO databases. Over 150 articles in Western and Arabic countries were initially reviewed to inform the significance and background of this thesis

and its specific aims. A separate search in English for abstracts from 2007 to 2020 regarding different topics related to breast cancer was conducted using the web search engine “Google”. The search also included other unpublished literature resources using the following key words: QOL, women with breast cancer, CS, psycho-education program, Jordan and Psychological distress with breast cancer.

1. "breast cancer" or "breast carcinoma"or"breast tumour "AND
2. "coping strategies "or" quality of life" AND
3. "psychological distress"or"anixty"or"depressation"or"stress"AND/OR
4. "psychological distress" or" psycho education intervention" AND
5. "International"or"Jordan"

The titles, which were publications written in English, were searched using Boolean Method (Table 2.1). Eighty articles focusing on treatment and post-treatment survivorship issues were chosen based on their relevancy. The eighty articles were organized into six categories forming the literature review’s organizational framework. These included the conceptual/theoretical framework, Jordanian population characteristics, breast cancer QOL, psychological aspects of breast cancer survivorship, CS in breast cancer survivorship, and the effectiveness of educational aspects among breast cancer survivorship on QOL, CS, and psychological distress in the Jordanian context.

Table 2.1 Literature Search Resultsusing Google Scholar, PubMed, MEDLINE, CINAHL plus with FT-E BSCO SEARCH ENGINES

Phrases used	Google Scholar	PubMed	MEDLINE EBSCO	CINAHL plus with FT-EBSCO
Psycho-Education Intervention and Quality of Life and Coping Strategies and Psychological Distress	14,200	2	1,374	218
Psycho-Education Intervention and Quality of Life and Coping Strategies and Psychological Distress among Breast cancer	1,900	0	3,085	375
Psycho-Education Intervention and Quality of Life and Coping Strategies and Psychological Distress among Breast Cancer Jordan	234	0	3,087	274
Using Boolean Operators and Keywords				
"breast cancer " AND "coping strategies " AND " quality of life"	23,900	35	4,369	281
"breast cancer" AND "Psychological distress" AND "Psycho educational intervention"	32,100	2	2,561	271

2.2 Breast Cancer Experience Among Women

2.2.1 Breast Cancer Experience Among Women in The Arab Region

Three qualitative studies conducted in Arabic countries explored and described the experience of Arabic women with breast cancer (Al-Azri et al., 2014; Doumit et al., 2010; Nizamli et al., 2011). In Lebanon, Doumit et al. (2010) aimed to better understand the experience of 10 Lebanese women with breast cancer with stages (I-III) disease and mean age was 51.3 years (no Standard Deviation reported). The themes described were: (a)

living with losses (e.g., the loss of a normal life, hair, and a breast); (b) guilt feelings from the fear that this cancer may develop in their daughters and granddaughters because of heredity; (c) fears that their cancer may reoccur, separation from loved one, fear of being pitied by others and about the uncertainty of their futures; and (d) the need to know more about their cancer and to share that knowledge with those with similar experience.

In Syria, Nizamli *et al.* (2011) described the chemotherapy experiences of 17 Syrian female stages II-IV breast cancer survivors (Mean age = 37 years, no Standard Deviation reported). They found four main themes: (a) psychological discomfort (i.e., negative emotions from fear of death and uncertainty, loss of control and powerlessness, body image from hair loss and change in breast appearance, and depressive symptoms from loss of dependence and autonomy; (b) physical problems associated with their chemotherapy (pain, fatigue, nausea, and vomiting); (c) social dysfunction associated with the negative views of society (i.e., social isolation and lack of marriage opportunities if patient were unmarried or single); and (d) failure in the family role (i.e., difficulties in doing the mother's role for taking care of their children and household chores and fear from changes in sexual relationship with their husbands such as loss of sexual drive).

In Oman, Al-Azri *et al.* (2014) explored the psychosocial impact of breast cancer diagnosis in 19 Omani female breast cancer stages I – IV disease survivors (Mean age 40 years). Time elapsed from the initial breast cancer diagnosis ranged from two month to 36 month. They found four major themes: (a) psychological distress and uncertainty (i.e., worry and fear of death, work and family responsibilities' disruptions, hope of a cure from breast cancer, and travelling aboard from their home country for better care and

treatments); (b) family members' reactions (i.e., shock, sad, togetherness, pressures related to travel aboard for treatment or seek local traditional treatments) and their relationships became stronger after diagnosis and more supportive; (c) how they were viewed by society (i.e., pity from others, limited their social interactions and isolation from people, keeping the news of their diagnosis confidential and sharing it with close family members); and lastly; (d) worries and fears about their future (i.e., chemotherapy's impact, metastasis, effect on their daughters by heredity).

In relation to earlier breast cancer studies conducted in Jordan, the quantitative and qualitative studies on breast cancer did not investigate and describe a broad spectrum of psychological distress and QOL dimensions of breast cancer survivorship from the perspective of Jordanian women breast cancer survivors (Alqaissi and Dickerson, 2010; Obeidat *et al*., 2013; Abu-Helalah *et al*., 2014; Obeidat and Lally, 2014; Obeidat, 2015; Obeidat and Khrais, 2015). Furthermore, the extant evidence supports the conclusion that the multifaceted burdens of breast cancer as lived by younger Arabic women with breast cancer have not been investigated enough and should be a research priority (Najjar and Easson, 2010).

2.2.2 Jordanian Population Characteristics

The Jordanian population and demographic characteristics proffer a context for situating breast cancer. Jordan (The Hashemite Kingdom of Jordan) is an Arab country located in the Middle East with an open and culturally diverse environment. Its population of 10,491,243 as of September 2019 is rapidly undergoing modernization and change (Jordan Department of Statistics, 2019). Jordan's population of is 90% Muslims with the

distribution of Christians, and other religions. While Arabic is the official language, English is obligatorily taught in public and private schools. The population is highly urbanized with approximately 84.13 of the Kingdom's population living in urban areas (Jordan Department of Statistics, 2019).

Literacy rate in Jordan as of 2015 was reported at 98.01% (Jordan Human Development Report, 2015). The unemployment rate was 18.5% in 2017 while the poverty ratio was 14.4% in 2010; the average income per month for males was 429 JD (606.27$) and for females 379 JD (535.61$) in 2011 (Jordan Department of Statistics, 2012). Of Jordan's population, 4,851,000 are female; 55.8 % are married; and 83.8% are homemakers (Jordan Department of Statistics, 2019). The statistics reported that a majority of Jordanian women work as professionals (62.8%), the mean marriage age is 22.7 years; and the average number of children is 2.6 per woman (Jordan Department of Statistics, 2018). About 62.6% of Jordanian women are 15 years of age or older; life expectancy is 76 years for women and is 72.7 years for men (WHO, 2018).

Khader et.al. (2018) reported that from 2000 to 2013, breast cancer is the most common cancer diagnosed among Jordanian women at 35.6% (Table 2.2). The percentage of women diagnosed with cancer was also significantly higher than males during the same period at 68.4%.

Table 2.2 Ten Most Common Cancers Diagnosed in Men and Women of Jordan

Male			Female			Total		
Primary Site	N	%	Primary Site	N	%	Primary Site	N	%
Colorectal	3532	12.3	Breast	10780	35.6	Breast	10957	18.6
Lung	3332	11.6	Colorectal	2912	9.6	Colorectal	6444	10.9
Lymphoma	2546	8.9	Lymphoma	2083	6.9	Lymphoma	4629	7.9
U.bladder	2384	8.3	Thyroid	1623	5.4	Lung	4033	6.8
Prostate	2267	7.9	Uterus	1532	5.1	Leukemia	3484	5.9
Leukemia	2008	7.0	Leukemia	1476	4.9	U.bladder	2723	4.6
brain	1263	4.4	Ovary	986	3.3	Prostate	2267	3.8
Stomach	1129	3.9	Brain	833	2.7	Thyroid	2112	3.6
Larynx	1040	3.6	Stomach	712	2.3	Brain	2096	3.6
Kidney	772	2.7	Lung	701	2.3	Stomach	1841	3.1
Others	8331	29.1	Others	6668	22.0	Others	18324	31.1
Total	28604	100.0	Total	30306	100.0	Total	58910	100.0

Source: Khader *et.al.* (2018)

2.2.3 European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Version 3.0 and Breast Cancer-Specific Quality of Life Questionnaire. EORTC QLQ-C30 and QLQ-BR23 as Tools to Measure Quality of Life among Women with Breast Cancer

Despite the existence of review articles on breast cancer patients' QOL, few systematic reviews with limited objectives discussed this topic. The articles and systematic reviews utilized different data collection instruments commonly used by researchers and clinician to measure QOL and based on the findings, the validity and reliability of the tools were proven. For this review, the researcher focused on six (n=6) articles which used QLQ-C30 and QLQ-BR23 as tools to measure QOL for women with breast cancer.

In any forms of intervention programs, its effectiveness is determined by the QOL of women with breast cancer. Several studies, which were carried out qualitatively, were reviewed to gain more insights on improving QOL of breast cancer patients as the findings allowed a deeper interpretation on the patients' lives after their diagnosis and throughout the course of their treatment until completion (Beckjord and Compas, 2007). Beckjord and Compas (2007) stated that 60% of women with breast cancer, especially those who had undergone mastectomy, reported that their QOL, particularly their body image and sexual functions, was affected by the surgical procedures they had to undergo. Their findings echoed Malinovskaya (2006) who highlighted that breast cancer patients reported of sexual dysfunction due to their diagnosis treatments.

Apart from sexual dysfunction, Lehto et.al (2005) explained the patients' QOL were also affected by external factors such as age, education levels, spousal support, employment, finances and stage of their diagnosis. A study by Alawadi and Ohaeri (2009) showed that women with breast cancer had low QOL due to treatments which affected them physically, psychologically and socially. These women reported that their QOL were negatively affected by arm morbidity, anxiousness, depression, constant state of pain and tiredness. More recent findings from Huijer and Abboud (2012) corrobrated their findings based on their investigation involving Lebanese women with breast cancer, who apart from associating their low QOL with functional abilities, medical care, spirituality and relationship, also associated their QOL with anxiety, sadness and fatigue.