# Symptom Experience and Quality of Life of Patients With Breast Cancer Receiving Chemotherapy in Bangladesh

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## ABSTRACT

This study aims to describe symptom experience and quality of life of patients with breast cancer, and the relationships between symptom experience and quality of life of patients receiving chemotherapy at different stages of breast cancer in Bangladesh. The study was conducted at the National Institute of Cancer Research and Hospital (NICRH), in Dhaka, Bangladesh and approached 130 participants. The data were collected by using the Chemotherapy Symptom Assessment Scale (C-SAS) and the Functional Assessment of Cancer Therapy-Breast (FACT-B) Scale version 4. The internal consistency reliability coefficients of the Bengali version of the C-SAS and the FACT-B scale yielded values of .88 and .80, respectively.

The female participants participating in this study had age ranging from 24 to 70 years (*Mdn* = 45 years). The majority of them were at stage four. All of the participants were currently receiving chemotherapy. The symptom experience was measured by asking the participants to recall their experience of a 7-day period after receiving chemotherapy of the previous cycle. On the 7-day period, the participants experienced, on average seventeen symptoms (*M* = 17.32, *SD* = 2.01, *Min-Max* = 12-22). The top ten symptoms commonly reported by the most participants included

feeling unusually tired, feeling weak, feeling anxious/worried, changes to appetite /taste, feeling low or depressed, difficulty sleeping, hair loss, mouth/throat problems, nausea, and skin/nails problems. The patients with breast cancer in Bangladesh experienced both symptom severity ($M$ = 2.27, $SD$ = 0.25) and symptom distress ($M$ = 2.88, $SD$ = 0.41) at a moderate level. Overall, the level of quality of life of the participants was at a moderate level ($M$ = 2.02, $SD$ = 0.39). The physical well-being had the lowest score ($M$ = 1.17, $SD$ = 0.66) while the social well-being had highest score compared to other subscales. The mean scores of functional well-being, emotional well-being and additional concerns of breast cancer subscales were at a moderate level. Moreover, the relationships between symptom experience and quality of life was significantly and negatively correlated; symptom severity ($r$ = -.48, $p$<.01) and symptom distress ($r$ = -.50, $p$ < .01).

The findings of the study are useful to provide basic information to health care professionals to recognize the symptoms related to breast cancer and chemotherapy side effects and appropriate plan of care should be made to reduce the symptoms.

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# CHAPTER 1

# INTRODUCTION

## Background and Significance of the Problem

Breast cancer is the most common female cancer. In the year 2012, the American Cancer Society (APPPCS) projected that approximately 226,870 women would be diagnosed as new cases of invasive breast cancers (American Cancer Society [ACS], 2012). It has been predicted that there are about 30,000 new breast cancer patients each year in Bangladesh (Story et al., 2012). The increasing occurrences of breast cancer in South Asia are subject to the combination of increased life expectancy, population growth and adoption of western lifestyles (Story et al., 2012).

Surgery, radiation, chemotherapy, and hormonal therapy are considered as the standard treatments for breast cancer and can be used either singly or in combination with one another. Though surgery remains the primary therapy for most operable breast cancers, some patients may develop micro-metastases and recurrence of their disease suggesting a combination of treatment modalities is more effective to control the disease (ACS, 2011). Recently, chemotherapy has been used before surgery (neo-adjuvant chemotherapy) in order to lessen extensive surgery, or after surgery (adjuvant chemotherapy) to reduce the risk of breast cancer recurrence (ACS, 2011). In general, chemotherapy is most effective when it is used with more than one drug. Oncologists provide chemotherapy drugs in cycles with an optimal duration of 3 - 6 months depending on each regimen which is often followed by a two-week rest period (day 15 to 28). Although chemotherapy works against cancer

cells or provides the benefit of survival, it has many side effects including dramatic effects on physical and psychosocial well-being (ACS, 2011).

Patients with cancer experience several symptoms throughout the course of cancer trajectory and patients with breast cancer are no exception. It is also evident that chemotherapy is one treatment modality resulting in several unpleasant symptoms as a result of the drug side effects. It has been reported that 13 out of 28 symptoms were reported in more than 50% of patients with breast cancer undergoing chemotherapy (Sitzia & Huggins as cited in Suwisith et al., 2008). The most common symptoms were alopecia (91%), fatigue (89%), weight gain (68%), and the most bothersome problems were fatigue and nausea followed by difficulty sleeping and sore eyes (Sitzia & Huggins, 2002). In a descriptive study involving 320 women with breast cancer receiving chemotherapy, Suwisith et al. (2008) found that women reported a mean of 17.4 symptoms with mild to moderate level of symptom severity.

Reported symptoms vary according to various factors, including types of chemotherapeutic agents patients have received. The following symptoms have been commonly reported. Cancer-related fatigue or lack of energy or feeling tired was reported by up to 40% of patients at diagnosis and about 80% of patients undergoing chemotherapy (Golan-Vered & Pud, 2012; Hofso, Miaskowski, Bjordal,Cooper, & Rustøen, 2012; Prigozin, Uzeily, & Musgrave, 2010; Zachariae et al., 2007). The prevalence of chemotherapy-induced fatigue is even higher in breast cancer population with a reported 80% to 100% in those receiving different types of regimen that included either cyclophosphamide, methotrexate and 5- fluorouracil (CMF) or cyclophosphamide, epirubicin, and 5-fluorouracil (CEF) (Prigozin et al., 2010; Zachariae et al., 2007). Breast cancer patients ($N = 303$) experienced nausea and/or

vomiting during the course of chemotherapy either during an acute phase (within 24 hours after the administration of chemotherapy) or delayed phase (after the first 24 hours) which is twice the number who experienced delayed nausea (from 47% and 45% to 82% and 74%, respectively) (Lee, Dibble, Pickett, & Luce, 2005). The most frequent and severe symptom is sleep disturbance or difficulty sleeping observed in doxorubicin-based chemotherapy (Golan-Vered & Pud, 2012; Hofso et al., 2012; Prigozin et al., 2010). The occurrence of hot flushes or menopausal symptoms is high in patients with breast cancer who are receiving adjuvant chemotherapy and hormonal therapy (Downie, Fan, De-Tchen, Yi, & Tannock, 2006; Savard, Savard, Quesnel, & Ivers, 2009), and was reported by 65% in pre-treatment and found to be 80% to 94% post-treatment.

Pain is another common problem in a cancer population. Fifty-three percent of cancer patients surveyed had experienced pain since being diagnosed (Fortner, Okon, & Portenoy, 2002) and that pain had one of the highest symptom experiences in patients with breast cancer who received chemotherapy (Byar, Berger, Bakken, & Cetak, 2006; Hofso et al., 2012). It is found that pain was also the most distressing symptom in patients with breast cancer who received doxorubicin-based chemotherapy (Byar et al., 2006). Pain is a common and debilitating symptom found in patients with breast cancer receiving chemotherapy and that pain can lead to poor quality of life (Fiorentino, Rissling, Liu, & Ancoli-Israel, 2012).

Quality of life (QoL) is the well-being of patients with breast cancer. It depends on many subjective aspects and is related to side effects of chemotherapy regimen. Byar et al. (2006) found that women reported a higher level of fatigue in the daytime in seven of eight domains of QoL: physical, role physical, role emotional,

social, mental, vitality and general health at 60 days after completion of chemotherapy than in baseline evaluation. The researchers found baseline fatigue affected four domains of QoL: physical, role emotional, mental, and vitality. They also found that women experienced more fatigue intensity than the baseline and at 60 days, patients reported lower levels of QoL in role physical, social, mental, vitality and general health.

Quality of life of patients with breast cancer may be different across countries due to different social and cultural factors. It is observed that the country factor effects physical QoL of patients with breast cancer (Shim et al., 2006). They found that domains of QoL differed across countries, with the German and Japanese breast cancer patients having higher scores of QoL compared to the South Korean patients. There are three types of chemotherapy regimen used to treat breast cancer in Bangladesh. These are CMF (cyclophosphamide, methotrexate and 5-FU), AC (doxorubicin /cyclophosphamide), and TAC (doxorubicin + cyclophosphamide followed by paclitaxel). A regimen is selected based on medical history, physical examination, breast ultrasound noting, laboratory staging in following high income country-based guidelines. It is also used in the context of specific medical circumstances (International Breast Cancer Research Foundation [IBCRF], 2012). Akin, Can, Durna, and Aydiner (2008) revealed that patients with breast cancer had experienced negative changes to their QoL throughout the course of breast cancer treatment in many types of chemotherapy regimen including 5-Fluorouracil (5-FU), doxorubicin, cyclophosphamide (FAC)/5-FU, epirubicin, cyclophosphamide (FEC)/doxorubicin, cyclophosphamide (AC)/epirubicin, cyclophosphamide (EC), docetaxel, paclitaxel, and navelbin (vinorelbine) at various stages of the disease. A

study of early stage breast cancer found that the impact of disease and treatment on QoL is changed by age, level of education and marital status after primary treatment (King, Kenny, Shiell, Hall, & Boyages, 2000). It was found that the QoL of patients with breast cancer fluctuated according to the patient's knowledge and level of education (Uzun, Aslan, Selimen, & Koc, 2004). Uzun et al. reported that there was statistically significant difference between educational level and QoL; patients with breast cancer who had a college level of education had better QoL than those who had a lower level of education. The results of reviewed studies explained the importance of symptom experience in patients with breast cancer on their daily life in different contexts.

Although the studies on symptom experience and QoL have so far only been conducted in other countries, studies of breast cancer conducted in Bangladesh included very limited information about symptom experience and QoL of patients with breast cancer receiving chemotherapy (Chowdhury & Sultana, 2011; IBCRF, 2012). Bangladesh is an developing Asian country where people are from different races and cultures. These are social factors which mean, different values are found to a significant extent in individuals' lives, e.g., influencing how patients perceive health or illness. By considering the lack of studies in Bangladesh, this study is being undertaken to investigate the symptom experience and QoL of patients with breast cancer receiving chemotherapy. In addition, the occurrence, severity and distress of symptoms, and the QoL are individual processes that are influenced by many factors, especially the patients' demographic, health and illness, and environment (Dodd et al., 2001). Therefore, the proposed study is expected to provide results regarding the

relationship between symptom experience and QoL of patients with breast cancer receiving chemotherapy in the context of Bangladesh.

## Objectives of the Study

This study aims to:

1. Identify symptom experience of patients with breast cancer receiving chemotherapy in items of

    1.1 The number of symptoms

    1.2 The level of symptom severity

    1.3 The level of symptom distress

2. Examine the level of quality of life of patients with breast cancer receiving chemotherapy

3. Examine the relationships between symptom severity and symptom distress, and quality of life of patients with breast cancer receiving chemotherapy

## Research Questions

The research questions of this study are as follows:

1. What are the symptom experience of patients with breast cancer receiving chemotherapy in terms of the number of symptoms, the level of symptom severity and the level of symptom distress?

2. What is the level of quality of life of patients with breast cancer receiving chemotherapy?

3. Are there any relationships between symptom severity and symptom distress, and quality of life of patients with breast cancer receiving chemotherapy?

## Conceptual Framework of the Study

This study aimed to describe symptom severity and symptom distress, and QoL and examine the relationships between symptom experience and quality of life of patients with breast cancer receiving chemotherapy. The Symptom Management Model (SMM) was chosen to guide the conceptualization of the study variables: symptom experience and QoL of patients with breast cancer receiving chemotherapy. The SMM is composed of three dimensions; (1) symptom experience, (2) symptom management strategies, and (3) outcomes. Moreover, the SMM has three domains and these domains contribute to the three symptom dimensions. This part presents only two dimensions which are related to the study. The SMM is described in the second chapter. In addition, related literature has also been integrated.

### Symptom Experience

Symptom experience is a dynamic process that has been described as patient's perception, evaluation of the symptom and response to the symptom. Perception of symptom refers to a patient's or individual's feeling or recognition of symptom. People evaluate their symptom by expression of opinion about the severity, distress, cause, and impact of on their lives. Response to symptom includes physiological, psychological, socio-cultural and behavioral aspects (Dodd et al., 2001).

**Perception of symptom.** Perception of symptom can help understand the way of noticing the individual's occurrence and behavioral signals of symptoms. In this study perception of symptom is used to recognize the occurrence of chemotherapy complications which are generally experienced by patients with breast cancer. For example, a patient receiving chemotherapy begins to feel or perceive the symptom signal through nausea, vomiting, pain, fatigue, or sleep disturbances etc. In addition the perception of symptom can cause changes in the individual's or patient's normal body functions that is noticed through symptom occurrence.

**Evaluation of symptom.** Evaluation of symptom is the extent of symptom that the individual already feels with regard to its intensity, location, temporal nature, frequency and affective mood. In this study symptom intensity was selected to represent this dimension as it is commonly used for evaluating the effectiveness of symptom management. An 'experienced' individual often learns to catalogue various, discrete and subtle sensations involved with symptoms and the quality of symptoms.

**Response to symptom.** Response to symptom is how an individual would respond to a recognized symptom. These can be physiological, psychological, socio-cultural and behavioral responses. In this study psychological response measured by symptom distress was selected because it can be reported and closely related to symptom intensity.

## Quality of Life

Quality of life is one of eight main variables described as outcomes in the revised SMM. The impact of breast cancer treatment, particularly symptom

experience can influence the patients. QoL is a subjective and multidimensional concept. The definition of QoL is the feeling of satisfaction or dissatisfaction concerning patients' health related to domains including physical well-being (i.e., disease symptoms, side effects of treatment, general physical functioning), functional well-being and social well-being (i.e., one's ability to carry out daily activities associated with personal, work-related, and social needs), emotional well-being (i.e., well-being associated with links, close friends, families, partner, etc), the additional concerns to assess breast-cancer specific concerns of patients with breast cancer receiving chemotherapy (Brady et al., 1997).

Dodd et al. (2001) stated that there are relationships between symptom experience, symptom management strategies and outcomes. Since this study is considered to be a starting point to test the SMM in the context of Bangladesh, only two variables were explored: symptom experience and outcomes (Hofso et al., 2012; So et al., 2009). The relationship between symptom experience and outcomes, quality of life of patients with breast cancer in particular, is investigated.

## Research Hypothesis

There are negative relationships between symptom severity and quality of life and between symptom distress and quality of life of patients with breast cancer receiving chemotherapy.

## Definition of Terms

### Symptom Experience

Symptom experience refers to the perception, the evaluation and the response to symptom of patients with breast cancer receiving chemotherapy. Symptom experience is measured by using the modified Chemotherapy Symptom Assessment Scale (C-SAS) originally developed by Brown et al. (2001) where the higher score means the more symptom experience. It measures the occurrence (perception), the severity (evaluation) and distress (response) of symptoms with different rating scales. The occurrence was measured as yes = 1, and no = 0; symptom severity was measured on a 3-point rating scale ranging from 1 = mild to 3 = severe; and the symptom distress was measured on a 4-point scale, ranging from 1 = not at all to 4 = very much (Pinar, Pinar, & Ayhan, 2012). The symptom experience was measured by asking the participants to recall their experience of a 7-day period after receiving chemotherapy of the previous cycle.

### Quality of Life

Quality of life refers to the patients' perception of their health and well-being regarding four characteristics including additional concerns during a 7-day period after receiving chemotherapy of the previous cycle. These are comprised of physical, social/family, emotional and functional well-being and the additional concerns of patients with breast cancer receiving chemotherapy. The QoL was measured by using the Functional Assessment of Cancer Therapy-Breast (FACT-B) scale version 4 in which a high score indicates better QoL (Brady et al., 1997).

## Scope of the Study

In this study the researcher used descriptive research to identify the number of symptom, to describe the level of symptom severity and symptom distress, and examine the level of QoL. Moreover, the researcher examined relationships between symptom experienced and QoL of patients with breast cancer receiving chemotherapy. This study was conducted at the National Institute of Cancer Research and Hospital, Dhaka, Bangladesh. The patients with breast cancer undergoing chemotherapy included patients receiving the second cycle of the chemotherapy and more. Only patients who attended the selected hospital between January 28, 2014 and March 14, 2014 were recruited.

## Significance of the Study

This study was useful to provide basic information to health care professionals to recognize the symptoms related to breast cancer and chemotherapy side effects. The study findings could be used for future experimental research related to symptom and QoL of patients with breast cancer receiving chemotherapy. Moreover, the expected output might be useful to prevent the side effects of breast cancer associated treatment. Furthermore, knowledge gained from the results regarding symptom occurrence, symptom severity and symptom distress could be used to decrease the impact and instance of symptoms and improve the QoL of patients with breast cancer.

# CHAPTER 2

# LITERATURE REVIEW

This chapter provides a review of literature and presents a critical synopsis of knowledge relevant to the proposed study. The available literature is organized into three major parts: overview of the breast cancer and its treatments, symptom experience and quality of life of patients with breast cancer receiving chemotherapy.

1. Overview of breast cancer and its treatments
2. The Symptom Management Model
3. Symptom experience of patients with breast cancer receiving chemotherapy
    - 3.1 Common symptoms of patients with breast cancer receiving chemotherapy
    - 3.2 Factors related to symptom experience of patients with breast cancer receiving chemotherapy
    - 3.3 Assessment of symptom experience of patients with breast cancer receiving chemotherapy
4. Quality of life (QoL) of patients with breast cancer receiving chemotherapy
    - 4.1 Concepts of QoL
    - 4.2 QoL of the patients with breast cancer receiving chemotherapy

4.3 Factors related to QoL of patients with breast cancer receiving chemotherapy

4.4 Assessment of QoL of patients with breast cancer

5. Relationship between symptom experience and QoL

6. The Health Care System in Bangladesh

7. Summary

# Overview of Breast Cancer and Its Treatments

## Breast Cancer

Breast cancer is the most common disease experienced by women and it is the second leading cause of death in women. Comparative study results have shown that the same disease of breast cancer is similar in Asian and Western countries according to epidemiologic and clinical data (Leong et al., 2010). However, it is more noticeable in ages between 40 and 50 years in Asian countries, and 60 and 70 years in Western countries. Moreover, according to the "Breast Surgery International Symposium at International Surgical Week" 2007 (Leong et al., 2010) there is an increasing mortality rate from breast cancer in Asia, where in Western countries the incidence rate of breast cancer is increasing, but the mortality rate is decreasing.

The breast cancer disease grows due to many kinds of factors similar to other human diseases. These factors can be divided into two groups non-modifiable and modifiable. Sex, age, family history, early menarche, and late menopause are non-modifiable factors whereas postmenopausal obesity, use of combined estrogen and progestin menopausal hormones, cigarette smoking, and alcohol consumption are modifiable factors. There is related to another risk factor of breast cancer known as estrogen receptor(ER) + /luminal A subtype (ACS, 2013).

There are naturally no symptoms found in breast cancer when tumor size is small. The most prominent sign is a painless lump or swelling that can be felt in screening at an early stage of the disease. Less common signs and symptoms are breast pain or heaviness; changes in the breast; and nipple abnormalities such as spontaneous discharge, erosion, inversion, or tenderness (ACS, 2011). It could be

found that ulcerated and infected breast, smell and discharge are noticed by family members in the late stage breast cancer (Story et al., 2012). The study participants stated that the signs and symptoms of breast cancer were spontaneous, clear or bloody discharge in accordance of their knowledge (Chowdhury & Sultana, 2011). Their study participants were illiterate and house wives and did not know the best time of breast-self examination because they have lack of awareness. It has been shown that poorly defined mass or asymmetric density, calcification, larger tumor size, lymph-node involvement and lesions are signs and symptoms by the histopathology and mammography reports (Hofvind, Geller, & Skaane, 2010).

Histopathology and other reports are important measurements for the diagnosis of breast cancer. Breast cancer is a fatal disease similar to all of other cancers. These pathological reports are related to staging of breast cancer disease. There are four stages of breast cancer according to the sixth edition of the American Joint Committee on Cancer (AJCC) staging manual (Singletary & Connolly, 2006).

In the first half of the 20th century, clinicians advocated that all breast cancers had different prognosis and required various treatments and decisions were made to aggressively treat tumors which had distinguishing characteristics. The German physician Steinthal recommended that breast cancer be separated into three prognostic stages that included small tumors that appeared to be localized to the breast (Stage I), larger tumors that involved the axillary lymph nodes (Stage II), and tumors that had clearly invaded tissues around the breast (Stage III).The fourth-stage, representing disease that had metastasized throughout the body was later introduced by Columbia Clinical Classification System (Singletary & Connolly, 2006). It was later reclassified as:

Stage 0: Carcinoma in situ

Stage I: Tumor of under 2 cm with negative nodes

Stage IIA: Tumor of 0-2 cm with positive nodes

Stage IIB: Tumor of 2 to 5 cm with positive nodes or greater than 5 cm with negative nodes

Stage IIIA: No evidence of primary tumor or tumor of less than 2 cm with involved fixed lymph nodes or tumor greater than 5 cm with involved movable or non-movable nodes

Stage IIIB: Tumor of direct extension to chest wall or skin, with or without involved lymph nodes, or any size tumor with involved internal mammary lymph nodes

Stage IV: Any distant metastasis (as cited in Crane-Okada & Loney, 2007).

**Breast Cancer Treatments and Their Side Effects**

The principles of treatments for breast cancer are similar to treatments for other types of cancer with different treatment options available. The best treatment is decided on by assigned oncologists, patients and their relatives. The majority of women with breast cancer need to have (1) surgery combined with (2) radiation therapy, (3) systemic therapy: chemotherapy, hormonal therapy, and/or (4) targeted therapy (ACS, 2011). Oncologists would prefer breast cancer treatments based on the stage of disease after considering the related advantages and disadvantages. However, the negative effects produced by treatments are not able to be avoided. Each treatment is described in details as follows:

**Surgery.** There are many types of surgery such as breast conserving therapy, mastectomy and axillary and sentinel lymph node dissection. The goal of breast conserving therapy is to minimize the risk of local recurrence. It is referred to as lumpectomy, segmental mastectomy, partial mastectomy, quadrantectomy, wide local excision, tylectomy etc (Morrow, as cited in Focson, Letmer, & Felder, 2011). The principles of the surgery are to control the primary cancer. According to the patients' view this treatment is acceptable to maintain body image. However, complications can arise which are arm edema, seroma formation, wound infection, shoulder dysfunction, upper extremity weakness, fatigue and limitation in mobility. Modified radical mastectomy is indicated for larger, and/or multicentric disease where cosmesis could not be achieved with conservative therapy. This type of surgery has many side effects such as wound infection, flap necroses and seroma formation as well as shoulder stiffness. The main reason to perform axillary and sentinel lymph node dissection is to help determine prognosis and to prevent risk of recurrence. Complications that come from axillary and sentinel lymph node dissection are pain, numbness, swelling, weakness and stiffness, lymphedema and decreased QoL (Focson et al., 2011).

Mastectomy and lumpectomy are the two kinds of surgery that are involved in breast cancer treatment; removing cancerous tissue with border of normal tissue regarded as the lumpectomy and removal of the total breast and lymph regarded as the mastectomy. The primary goals of breast surgery are to remove the cancer from the breast and to assess the stage of disease. The lumpectomy followed by radiation therapy, is expected to result in longer survival similar to mastectomy, but without the possibility of recurrence of cancer like mastectomy (ACS, 2011). Radical mastectomy

is indicated for patients who have small lesions (< 2 cm) instead of mastectomy. It has shown a high rate of local recurrence after primary treatment that has been reported by several authors (Anderson et al., 2006).

**Radiation therapy.** The role of radiation therapy in the treatment of cancer and noncancerous conditions has expanded dramatically. The role of radiation is the minimized to localized breast cancer that has developed over and over again from the point of the surgical area. It is indicated to use radiation therapy in post mastectomy and in women who are at high risk of local or regional recurrence, those who have large tumors greater than 5 cm, tumors that invade the skin of the breast or chest wall, or those with more than 4 positive axillary nodes. Radiation therapy is used to destroy cancer cells in the breast, chest wall or underarm after lumpectomy. It is also used after mastectomy and even in lymph node cancer. It is generally used for 5 to 6 weeks (ACS, 2011); but recent studies have suggested that a duration of 3 weeks is the most effective (Whelan et al., 2010). So, radiation therapy is used in all phases of the disease localized in advanced, metastatic stages and before chemotherapy, preoperative and post operative phases.

The acute effects that develop from external beam radiation therapy are skin changes including itching, dryness, scaling, redness, tenderness, burning, discoloration of skin, and later in breast swelling, arm swelling and pain. Rare complications of radiation therapy are dry cough and low grade fever as in pneumonitis (Focson et al., 2011). Moreover, development of ulceration (mucositis) is one of the most adverse reaction by radiation therapy may also be observed (Naidu et al., 2004). It is noteworthy that women with breast cancer experienced symptoms by the radiation therapy that were pain, fatigue, sleep disturbance, depression, perceived

change in appearance, cognitive disturbance, and gastrointestinal symptoms (Matthews, Schmiege, Cook, & Sousa, 2012).

**Systematic therapy.** Systemic therapy consists of endocrine therapy, chemotherapy and targeted therapy. Systemic therapy can potentially destroy circulating tumor cells. Prospective clinical trials have found that it could reduce node negative recurrence breast cancer by 20% to 50% through administration of adjuvant therapy (Carlson et al., as cited in Focson et al., 2011).

In systemic therapy, anti-cancer drugs are administered, either intravenously or orally that acts on all parts of the body through blood circulation. Systemic therapy includes targeted therapy (attacking specific parts of cancer cells), chemotherapy (attacking cancer cells), and hormonal therapy (attacking natural hormones which sometimes act to promote cancer growth) that is used before surgery to reduce the size of the cancerous cells and is known as neo-adjuvant therapy (ACS, 2011). This treatment is used after surgery to destroy any invisible tumor as in adjuvant therapy. For patients who suffer from metastatic breast cancer, systemic therapy is mainly used. Chemotherapy will later be discussed in more detail.

***Adjuvant endocrine therapy*.** Hormonal therapy is given to patients who are breast cancer test positive for hormone receptors to reduce estrogen level, and to block the effects of estrogen in breast cancer cells. Common hormonal therapy drugs are tamoxifen, toremifene (fareston), and fulvestrant (faslodex) that are used to reduce the number of estrogen receptors in breast tumors. letrozole, anastrozole, and exemestane are used in early and advanced hormone receptor positive breast cancer, which are known as aromatase inhibitors (AIs) (ACS, 2011). These drugs are also used in postmenopausal women to block an enzyme to produce the required amount

of estrogen. It is evidently demonstrated that there is a clear advantage of using either an AIs or Tamoxifen for average a total period of four years disease free survival or switching to an AIs after several years of tamoxifen, as opposed to tamoxifen alone for five years (Howell et al., 2004).

Tamoxifen is a non-steroidal anti estrogen drug that binds estrogen and modulates the functions arbitrated by the receptor system. By blocking the binding of the estrogen, it blocks the cell cycle transit in the gap 1 phase and inhibits tumor growth. It is used generally in greater ER positivity, the greater the response rate to endocrine therapy. It can be used in premenopausal and postmenopausal patients. It decreases the recurrence and death rates. It has several side effects such as hot flashes, night sweats, vaginal discharge, vaginal dryness, mood swings, leg cramps, weight gain, bloating and swelling, hirustism, hair loss, acne, deepening of the voice and increased libido (Focson et al., 2011).

***Adjuvant targeted-trastuzumab therapy.*** Ajuvant targeted-trastuzumab therapy is used in HER2 /neupositive patients to increase survival rate. Cardiotoxicity is the side effect of trastuzumab (Focson et al., 2011). Breast cancer is produced by the growth-promoting protein HER2/neu (human epidermal growth factor receptor 2) that develops a tumor around 15% to 30% faster than a recurrence tumor. Tratuzumab is a monoclonal antibody that directly targets the HER*2* protein of breast tumors and increases the survival rate of women with breast cancer. Metastatic breast cancer is treated with Tratuzumab in the first stage and early stages where HER2-positive breast cancer reduces the risk of recurrence decline, and death from 52% to 33% compared with chemotherapy. It is found that women who have HER2-positive

advanced stages of breast cancer used lapatinib (tykerb) to delay progression and is used in patients who are resistant to Trastuzumab (ACS, 2011).

There are many complications of target therapy. The most common effects of Lapatinib are diarrhea and rash where the effect of Bevacizumab results in hypertension, headache and vomiting as common side effects. Fatigue, hypertension, and skin manifestations neutropenia, febrile neutropenia are found to be common reactions to Sunitinib, and dermatitis/skin rash, hand-foot syndrome (pain, swelling, numbness, tingling, or redness of the hands or feet), and hypertension result from Sorafenib. Hypertension, headache, thrombosis are the adverse effects commonly resulting from Vandetanib. Febrile neutropenia, fatigue, stomatitis, diarrhea, and hypertension were observed from increase of axitinib. The most commonly reported adverse effects of temsirolimus include mucositis, maculopapular rash, and nausea. Fatigue, nausea, and vomiting have been reported in the case of polymerase inhibitors (Alvarez, Valero, & Hortobagyi, 2010).

***Chemotherapy***. In most breast cancer diseases chemotherapy is used as adjuvant and neoadjuvant treatment, and is the most effective when used in combination with other chemotherapy regimens. Though different combinations of drugs and chemotherapy are applied together to treat the breast cancer, there is no evidence concerning which single combination is the best. To find the most effective treatment against breast cancer disease, different experimental studies are ongoing. The chemotherapy regimens most commonly used that are as follows (ACS, 2013):

1. CMF: Cyclophosphamide (cytoxan), methotrexate, and 5-fluorouracil (5-FU)

2. CAF (FAC): Cyclophosphamide, doxorubicin (adriamycin), and 5-FU

3. AC (DC): Doxorubicin (adriamycin) and cyclophosphamide

4. EC: Epirubicin (ellence) and cyclophosphamide

5. TAC: Docetaxel (taxotere), doxorubicin (adriamycin), and cyclophosphamide

6. C (T): Doxorubicin (adriamycin) and cyclophosphamide followed by paclitaxel (taxol) or docetaxel (taxotere). Trastuzumab (herceptin) may be given with the paclitaxel or docetaxel for HER2/neu positive tumors

7. A (CMF): Doxorubicin (adriamycin), followed by CMF

8. CEF (FEC): Cyclophosphamide, epirubicin, and 5-fluorouracil followed by docetaxel

9. TC: Docetaxel (taxotere) and cyclophosphamide

10. TCH: Docetaxel, carboplatin, and trastuzumab (herceptin) for HER2/neu positive tumors (ACS, 2013).

There are many causes which are adherent to chemotherapy. These are cancer size, number of lymph nodes, and presence of hormone receptors. Cancer cells are made by those factors. It has been recognized that combined chemotherapy is more effective than a single drug for breast cancer treatments in research studies. These common drugs are cyclophosphamide, methotrexate, fluorouracil, doxorubicin (adriamycin), epirubicin, paclitaxel (taxol), and docetaxol (taxotere). Chemotherapy is required for a-duration of three to six months. It is needed to complete a full dose and cycle of drugs for maximum effectiveness. The chemotherapy regimens might be used

to make lesser a cancer that has metastasized (ACS, 2011). Chemotherapy is not only used to shrink a cancer, but also used to increase survival rates of the cancer patients.

*Neo-adjuvant chemotherapy***.** The treatment used before primary or main treatment is called neoadjuvant therapy. It can be chemotherapy, radiotherapy, or hormone therapy. The preoperative or neoadjuvant chemotherapy is an opportunity of patients for early-stage breast cancer (Schott & Hayes, 2012). It was evaluated that standard, postoperative adjuvant chemotherapy with increasing survival and easy to surgery by neoadjuvant chemotherapy. They also suggested that it can be used in locally advanced breast cancer for surgery. However, the patient with breast cancer who needs chemotherapy, the standard care is adjuvant chemotherapy after surgery.

*Adjuvant chemotherapy*. The main purpose of the adjuvant therapy is to reduce the chance of recurrence and increase survival rate in patients with breast cancer (Focson et al., 2011). Adjuvant therapy or endocrine therapy is in part to reduce the risk of breast cancer recurrence (Goldhirsh et al., as cited in Focson et al., 2011). It is found to prolong survival in women with stage I-II breast cancer disease although it can cause both long-term and short-term side effects.

For Bangladeshi women, CMF and doxorubicin, cyclophosphamide (DC) plus pacllitaxel chemotherapy regimen is used for treatment of different types of breast cancer including surgery and radiation therapy. Tamoxifen is used in pre and post-menopausal women with estrogen receptor negative/positive and progesterone receptor negative/positive tumors (IBCRF, 2012). These treatment regimens are accompanied by physical symptoms, psychological symptoms and social well-being that in turn affect patients' them-selves.

Symptom experience or side effects rely on various regimens. Combined chemotherapy regimens are currently being used to treat loco-regional breast cancer. Drugs that are used in adjuvant breast cancer include doxorubicin, cyclophosphamide, paclitaxel, doxetaxel, fluororacil and methotrexate. Various types of chemotherapy regimen found in the National Comprehensive Cancer Network Concensus-Based Guidelines (2009) include (1) docetaxel, doxorubicin and cyclophosphamide (TAC); (2) doxorubicin and cyclophosphamide (AC); (3) doxorubicin and cyclophosphamide dose dense or every 2 weeks followed by paclitaxel dose dense; (4) doxorubicin and cyclophosphamide followed by weekly paclitaxel; (5) docetaxel plus cyclophosphamide (TC) (Carlson et al., as cited in Focson et al., 2011).

Chemotherapy has many side effects depending on the particular regimen being used such as nausea, vomiting, nitropenia, anemia, peripheral neuropathy, arthragias, and myalgias, myelodyplastic syndrome, leukemia, cardiomyopathy and bladder cystitis (Focson et al., 2011). Even though chemotherapy used to result in improvements in the cancer disease, it accordingly, has many complications. Adjuvant chemotherapy has been used by breast cancer patients in order to compare the regimen of chemotherapy toxicity. These regimens were doxorubicin (A), paclitaxel (T), and cyclophosphamide (C) with concurrent doxorubicin and cyclophosphamide (AC) followed by paclitaxel. Researchers designed their chemotherapy regimens in four schedules as regimen (1): Sequential doxorubicin, paclitaxel and cyclophosphamide every three weeks, regimen (2): Sequential doxorubicin, paclitaxel and cyclophosphamide every two weeks, regimen (3): concurrent AC every weekly followed by paclitaxel every three weeks, and

regimen (4): Concurrent doxorubicin and cyclophosphamide followed by paclitaxel every two weeks. Findings revealed that febrile neutropenia, Grade 3 or greater emesis, cardiomyopathy, myelodysplastic syndrome, acute myelogenous leukemia, cardiotoxicity, neurotoxicity, ductal carcinoma-in-situ, all resulted from the four regimens of chemotherapy (Citron et al., 2003).

Different regimens are responsible for various toxicities. A comparison of breast cancer treatment, chemotherapy and goserelin was used to compare disease free survival and overall survival, and toxicities of that treatment. They found that many toxicities of adjuvant chemotherapy between two regimens of goserelin and cyclophosphamide, methotrexate, and fluorouracil (CMF) (Jonat et al., 2002). These toxic effects identified short-term toxic and long-term associated with premature menopause. Amenorrhea experienced 95% of goserelin patients where 58.6% in CMF participants. The amenorrhea was permanently experienced in the group of CMF patients. Moreover, the higher chemotherapy-related side effects experienced in CMF patients were nausea/vomiting, alopecia, and infection. Vaginal dryness and hot flashes were found in two separate chemotherapy regimens (Jonat et al., 2002). Other comparative study results illustrated that many clinical manifestations came from the CMF and FAC chemotherapy regimen. The participant in the study reported significantly increased treatment-induced manifestations of emesis, mucositis, alopecia and cardiotoxicity in FAC regimen. On the hand, CMF treatment induced significantly more conjunctivitis and weight gain. However, both groups reported amenorrhea equally (Martin et al., 2003).

Secondary side effects or general well-being effects come from toxicity of chemotherapy which later decreases patients' QoL of life such as physical,

emotional, social and functional well-being. One study about the effect of chemotherapy regimens reported that patients who received epirubicin plus classic CMF reported more severe symptoms than those who received classic CMF. The findings of the study illustrated that severe side effects of chemotherapy lead to less improvement in global health (Poole et al., 2006). It is evidently found that the patients who received FAC and AC regimen followed by Paclitaxel the physical well-being, emotional well-being and additional concerns subscales were more negatively affected by the breast cancer treatment (Akin et al., 2008). Martin et al. (2003) found that patients who received FAC regimen reported significantly higher treatment induced symptoms perceived.

It is true that development of disease either comes from natural sources, and the occurrence of symptoms in patients with breast cancer may emerge from complications resulting from chemotherapy. Whilst those symptoms are abundant, severe and distressing they disrupt patients' lives physically, psychologically, socially or emotionally.

## The Symptom Management Model

This section discusses the symptom management model (SMM). It is served as the conceptual framework in this study. It is consisted of three bidirectional dimensions and three related factors (Dodd et al., 2001). These dimensions are symptom experience, symptom management strategies and outcomes. The three related factors are personal, health and illness, and environmental. It is described in more details as follows.

**Dimensions of Symptom Management Model**

The Dodd et al.'s symptom management model (SMM) consists of three dimensions including symptom experience, symptom management strategies, and symptom outcome (Dodd et al., 2001). The symptom management model initially developed by Larson and colleagues (1994), focused on biology, psychological and social aspects of life functioning, feeling or cognition of an individual change to symptom experience. Moreover, signs and symptoms are the problems of the individual and need the attention of patients and nursing personnel. The aim of this model was symptom management as it has been examined in research and extended by the developer's discussions in the School of Nursing Centre at the University of California San Francisco (UCSF). Initially the model was composed of three core domains. There are three core dimensions: (1) symptom experience, (2) symptom management strategies, and (3) outcomes. There are main factors contributing to the three core elements: (1) person (2) health and illness, and (3) environment added during the model revision (Dodd et al., 2001).

According to Dodd et al. (2001), there are three related dimensions describing how people live when they experience health-related symptoms: symptom experience, symptom management and outcomes. Each dimension is described in the following section and examples found in patients with breast cancer are given.

**Symptom experience.** It is a dynamic process that has been described as the patient's perception, evaluation of the meaning and response to the symptom. Perception of symptom refers to a patient's or individual's feelings. People are used to evaluate their symptom by expression of opinion about the severity, occurrence, distress, cause, and impact on their lives. Responses to a symptom include

physiological, psychological, socio-cultural and behavioral aspects (Dodd et al., 2001). For instance, nausea/vomiting are commonly found in patients with breast cancer causing patients to feel discomfort. Thereafter, the patients can evaluate the toxicity of a symptom and in turn respond with distress which can be a risk to physical health and may hamper daily activities or functions. Women with breast cancer are mostly alarmed in the diagnostic phase, adjuvant phase and initial recovery phase. During these phases, women with breast cancer might experience many symptoms which result from the primary disease and/or the treatment of the disease. The term symptom experience has been used to describe the multiplicity of symptom in patients with breast cancer (as cited in Denieffe & Gooney, 2011).

**Symptom management strategies.** All symptoms need to be managed depending on the symptom severity. Symptom management is the process used to relieve such symptoms. It is started through assessment from the patient's viewpoint and then symptom management strategies are utilized. The aim of symptom management is to prevent or delay the negative outcomes through biomedical, professional and self-caring strategies (Dodd et al., 2001). Interventions are targeted at one or more symptom experience to achieve expected results. Besides, different people express the symptom experience in different ways, so when the symptom occurs, they may respond and apply different symptom management strategies. Symptom management is the method used to reduce that symptom and refers to the detection approach ("what?", and "why?"), and develops and establishes a symptom management strategy ("how?", "when?", "where?", "how much?" and "to whom?") (Dodd et al., 2001). For example, breast cancer patients who receive chemotherapy

develop fatigue during treatment and reduce fatigue through doing stress management training.

**Outcomes.** Outcomes are results of symptom management strategies and the symptom experience. These include eight main variables in the revised SMM. These outcomes are symptom status, functional status, emotional status, self-care ability, costs, QoL, and morbidity and mortality. A new outcome "cost" includes financial status and health services utilization dimensions of the original in addition to receipt of workers compensation. This study explored one aspect of these outcomes, quality of life. The reason was that QoL is a multidimensional construct that has some dimensions overlap such as functional status or emotional status. Moreover some dimension may be biasedly measured if the study was conducted as cross-section.

## Factors Contributing to Symptom Experience

Dodd et al. (2001) further explained that three sets of factors or domains contribute to the symptom dimensions. They are person, health and illness, and environment.

### Subheading of Factors

**Person domain.** Person domain includes demographic, psychological, sociological, physiological and developmental areas that are related to an individual's vision and response to the symptom experience. It describes the impact of the developmental stage; the menopausal symptoms affect quality of sleep in midlife of women (Dodd et al., 2001). So, each one responds to symptom severity and symptom

distress in various ways such as through demographic, psychological, sociological, physiological and developmental factors.

**Health and illness domains**. This domain is composed of the state of health or illness and collected risk factors, injuries or disabilities of an individual. It can affect direct or indirect symptom experiences in patients with breast cancer (Dodd et al., 2001), and depends on type of disease, progression of disease (stage) and remedial therapy. For example, contra-lateral prophylactic mastectomy (CPM) significantly increased among young aged breast cancer patients (Tuttle, Habermann, Grund, Morris, & Virnig, 2007). They found women who were previously diagnosed cancer displayed higher rates of CPM associated with larger tumor size and all stages of breast cancer.

**Environmental domain.** The environmental domain refers to the combined situation or the cultural milieu within a symptom that includes physical, social and cultural variables. The physical environment includes home, work place and hospital; the social environment includes one's social support and interpersonal relationships and finally the cultural aspects of the environment includes beliefs, values and practices that are a cluster of the individual's ethnic, racial, or religious group (Dodd et al., 2001). So, patients experience symptom in different ways

## Symptom Experience of Patients With Breast Cancer Receiving Chemotherapy

### Common Symptom Experience of Patients With Breast Cancer Receiving Chemotherapy

This part is a review of the symptoms which are usually experienced by patients with breast cancer receiving chemotherapy. Many studies have described

that breast cancer patients receiving chemotherapy recognize symptom severity and symptom distress, reporting of short and long duration of symptoms and stages of disease which are explained according to the period of illness. The majority of studies were conducted while the patients were receiving chemotherapy at breast cancer stage I-IV.

The common symptom experienced by patients with breast cancer while receiving chemotherapy were fatigue (Golan-Vered & Pud, 2012; Hofso et al., 2012; Prigozin et al., 2010), sleep disturbance (Golan-Vered & Pud, 2012; Hofso et al., 2012; Prigozin et al., 2010), drowsiness (Hofso et al., 2012; Prigozin et al., 2010), distress (Prigozin et al., 2010), menopausal symptoms of hot flashes (Prigozin et al., 2010), premature menopause (Rosenberg & Partridge, 2013), sadness (Prigozin et al., 2010), night sweats, worrying, hair loss, skin changing, and difficulty in swallowing (Hofso et al., 2012), pain (Golan-Vered & Pud, 2012; Saibil et al., 2010), gastrointestinal symptom, nausea, difficulty concentrating (Byar et al., 2006), depression (Golan-Vered & Pud, 2012; So et al., 2010), tingling and numbness (Golan-Vered & Pud, 2012), taste change (Williams & Schreier, 2004), eye problems (Eisner & Luoh, 2011), and anxiety (So et al., 2010). Headache was found in patients with metastatic breast cancer (Shmueli, Wigler, & Inbar, 2004). Weight loss or weight gain was also observed while patients received chemotherapy (Thivat et al., 2010). Signs of infection were found in those participants who received denosumab and zoledronic acid-based chemotherapy (Stopeck et al., 2010).

The most frequently observed proportion of symptoms was fatigue, followed by sleep disturbance, drowsiness, distress, sadness, menopausal of hot flashes, sweats at stage I-II breast cancer (Prigozin et al., 2010). Patients who were

treated with adriamycin and cyclophosphamide (AC) followed by either four or eight courses of paclitaxel found that they experienced pain, sleep disturbance, fatigue, and depression (Golan-Vered & Pud, 2012).

Chemotherapy-induced neuropathy (CINP) is commonly reported in certain chemotherapy regimen. Peripheral neuropathy is highly frequent and associated with paclitaxel chemotherapy treatment. Adriamycin and cyclophosphamide (AC) are followed by either 4 or 8 courses of paclitaxel and users frequently endure neuropathic pain (CINP) and neural damage. Patients who were diagnosed with CINP show a higher frequency of neuropathic symptoms than non-CINP. The observed symptoms include burning, painful cold, electric shocks, tingling, and pins and needles from 30% to 70%, numbness and itching 50% and 45% respectively, in the CINP subgroup (Golan-Vered & Pud, 2012). The most common symptom was headaches found in patients with breast cancer who were trastuzumab users (Shmueli et al., 2004). However, less common symptoms were gait disturbances and dizziness. Fatigue was experienced and increased while receiving the course of radiotherapy (Donovan et al., 2008). However, Donovan and colleagues reported severe fatigue in early stage of breast cancer and it was found that more severity of fatigue was related to chemotherapy than radiotherapy. They also found that receiving chemotherapy previous to radiotherapy could induce fatigue, and the patients who received combined chemotherapy and radiotherapy reported significantly more fatigue than patients who only received radiotherapy. Hines et al. (2009) found that the patients with breast cancer experienced many severe symptoms. These symptoms were anemia, acute respiratory distress syndrome, dyspnea, fever, headache, hypotension, leukopenia, neutropenia, and thrombosis. However, the most common

symptoms found in their participants were headache, abdominal pain, flatulence, diarrhea, constipation, arthralgia, and chest pain. All those symptoms were found in patients who received anthracyclines, taxanes, or cyclophosphamide based chemotherapy (Hines et al., 2009).

Adjuvant chemotherapy led to development of premature menopausal symptoms for patients with breast cancer. The participants of Rosenberg and Partridge's study (2013) reported that they had faced loss of fertility and physiologic symptoms, for example night sweats, hot flashes, vaginal dryness, and weight gain. The researchers advocated that these distressing symptoms could negatively affect both health-related and psychosocial quality of life of young breast cancer patients (Rosenberg & Partridge, 2013). Fatigue, nausea and vomiting, and taste change were the most repeated symptom experience found in patients with breast cancer using cyclophosphamide, methotrexate, and fluorouracil or doxorubicin and cytoxan (AC) (Williams & Schreier, 2004). The average number of symptoms was 6.8, with five most common symptoms after completion of their surgery, radiation therapy and chemotherapy as their primary treatment (Janz et al., 2007). These were systemic therapy side effects (87.7%), fatigue (81.7%), breast symptoms (72.1%), sleep disturbance (57.1%), and arm symptoms (55.6%). More severe symptoms were found in patients who were younger age who had poorer health status in seven QoL dimensions (Janz et al., 2007). The majority of participants (87%) who received anthracycline or the taxane-based chemotherapy reported having pain. The pain characteristics were arthralgias, myalgias, and peripheral neuropathy. These kinds of pain were found in fingertips and toes (39%), lower back (30%), legs (29%), upper back (26%), arms (20%), chest (14%), abdomen (8%), and head (8%). There was so

much pain that they needed to take narcotics (Saibil et al., 2010). The patients with breast cancer received antracycline-based chemotherapy after surgery. The researchers stated their participants reported that weight loss or weight gain were observed significantly while receiving chemotherapy (Thivat et al., 2010). Stopeck et al.'s study (2010) identified twenty adverse events in patients who used denosumab and zoledronic acid-based chemotherapy. Among these, 18 symptoms were more common with zoledronic acid, including pyrexia, bone pain, arthralgia, renal failure, and hypercalcemia; two were more common with denosumab, including toothache and hypocalcemia. These side effects were expected in acute phase reactions of the treatment, renal toxicity, and osteonecrosis of the jaw. Acute-phase reactions occurred within first three days after receiving treatment which were composed of flu-like syndrome including pyrexia, chills, flushing, bone pain, arthralgias, and myalgias (Stopeck et al., 2010).

Many types of eye problems are experienced by the patients with breast cancer who received hormonal therapy. The participants of the study who used cytotoxic chemotherapy experienced many types of eye problems such as epiphora by inducing canalicular stenosis and ocular surface irritation (Eisner & Luoh, 2011). Tamoxifen can lead to posterior subcapsular cataract and affects the optic nerve as a result swelling, retinopathy, macular holes, and perception of colorful flashing lights could be developed. Anastrozole increases tractional force between the vitreous and retina, as consequence increased risk of traction-related vision loss could occur (Eisner & Luoh, 2011).

The patients with breast cancer had about 38% anxiety at a moderate to severe level and the same population had depression at a moderate to severe level,

about 22% from their first diagnosis of breast cancer disease and after completion of their breast surgery (Mehnert & Koch, 2008). However, they reported that the participants of their study had psychological comorbidity had also suggested that the patients who had psychological comorbidity they had higher levels of anxiety and higher levels of anxiety lead to lower QoL.

## Factors Related to Symptom Experience of Patients With Breast Cancer Receiving Chemotherapy

**Personal factor**. Demographic variables threaten symptoms development and some demographic variables were reported to be correlated with symptom experience. There is a significant relationship among the symptom severity and education (Prigozin et al., 2010). Younger patients experienced more menopausal symptoms. No significant differences have been found between marital status and symptom severity on either the M. D. Anderson Symptom Inventory (MDASI) or the Breast Cancer Prevention Trail Hot Flashes Symptom Subscales (BCPT-HFS) (Prigozin et al., 2010). The younger aged patients experienced menopausal symptoms and had higher risk of disability (Hofso et al., 2012). No correlations have been found between symptom distress and age, marital status, educational level, job, income or insurance. However, a significant correlation has been noted between distress and hospitalization in female patients, and distress and transportation problems within male patients (Omran, Ahmad, & Simpson, 2012).

There may be gender difference in symptom experience. Omran and colleagues (2012) conducted a descriptive correlation study using a convenience sample of 112 adult Jordanian patients with various types of cancer. They were receiving chemotherapy as the primary supportive therapy. The researchers found that

there was a strong correlation among fear, sadness and distress in female patients. Although for physical symptoms, such as nausea, anorexia, fatigue and daily activity disorder the relationships with distress were similar for both gender.

**Health and illness factors.** Greater symptom severity is found in patients who received doxorubicin/adriamycin + cyclophosphamide (AC) and doxorubicin + cyclophosphamide + fluorouracil (CEF) types of chemo regimen and less symptom severity found in those who used doxorubicin/adriamycin + cyclophosphamide (AC) + paclitaxel type of regimen (Prigozin et al., 2010). Hofso et al. (2012) compared the symptom experience of patients who were receiving radiation therapy in between the groups who received chemotherapy (CTX) prior to radiation therapy and who did not receive chemotherapy prior to radiation therapy (RT). The longitudinal study found patients who received chemotherapy prior to radiation therapy had experienced a higher number of symptoms ($M$ = 12.6) than those who did not receive CTX ($M$ = 6.3) prior to RT in a scale where the score ranged from'0' (none), 1- 4 (mild), 5 - 6 (moderate), 6 -10 (severe). Eighteen out of thirty two symptoms occurred more frequently and significantly in patients who received CTX prior to RT compared to those who did not receive CTX (Hofso et al., 2012). Experience of CTX and CTX induced symptoms would greatly contribute to current cancer treatment as frequency of past treatments and current a number of chemotherapy cycles have been significantly correlated with distress (Omran et al., 2012).

Chemotherapy-related symptoms were very severe. The researchers observed higher severity of symptom in the epirubicin plus CMF group and CMF group of regimen (Poole et al., 2006). The participants in Poole et al.'s study reported

significantly higher severity of symptoms which were alopecia, nausea, vomiting, constipation and stomatitis in the epirubicin plus CMF group in the National Epirubicin Adjuvant Trial (NEAT). Patients of NEAT reported severe diarrhea, infection, fatigue, neutropenia or thrombocytopenia between the epirubicin plus CMF group and CMF group. The adverse effects of nausea, vomiting, stomatitis, diarrhea, infection and fatigue were reported in the BR9601 trial by the participants. Patients in both groups reported 73% of total participants occurrences of chemotherapy-related amenorrhea (in NEAT, 71% for epirubicin plus CMF and 74% for CMF alone; in the BR9601 trial, 73% for epirubicin plus CMF and 74% for CMF alone) (Poole et al., 2006).

Chemotherapy was reversely related to comorbidity. It was shown that the incidence of anemia increased in patients with breast cancer and ovarian cancer on chemotherapy. The short- and long-term bone marrow toxicities (BMT) were consistent between chemotherapeutic regimens (CMF, platinum/taxanes therapy or CAF). The CAF regimen causes thrombocytopenia. Bone marrow suppression was found in patients who received 20 cycles of chemotherapy (Nurgalieva, Liu, & Du, 2011).

Anxiety and depression in chemotherapy were more severe in those experienced by the radiotherapy group (So et al., 2010). During diagnosis breast cancer patients with poor health status showed more symptoms with a mean value 6.5 symptoms, including the five most common symptoms: systemic therapy side effects (87.7%), fatigue (81.7%), breast symptoms (72.1%), sleep disturbance (57.1%), and arm symptoms (55.6%) (Janz et al., 2007).

The influence of emotional factors on symptom severity has been explained in that negative emotions are associated with the illness, for instance, unhappiness, discomfort, un- easiness, influence fatigue (Tsai Lin, Chao, & Lin, 2009). These negative emotions directly or indirectly exaggerate regular activities in family due to uncertainty; stress and psychological burden, and patients are not always treated. It was found that patients who had conflicts with their children as they struggled with their treatment, suffered raised emotional stress and the resulting. The accumulation of those negative impacts worsened fatigue (Tsai et al., 2009).

In a longitudinal study, Doxorubicin-based chemotherapy was investigated and results found that stable fatigue during treatment resulting in recovery after one year of chemotherapy (Byar et al., 2006). However, the observed the condition reoccurred again and again at the fourth cycle treatment. Participants reported fatigue was stable during treatment and at lower levels after treatment. A sleep disturbance and pain baseline was found as the most frequent side effect during the first chemotherapy treatment where sleeping disturbance was found after every treatment. Gastrointestinal symptoms and nausea was observed after the treatment, developing concentration disturbance was observed along with the decrease of nausea. Sleep disturbance was more intense from first treatment to the final treatment. So, sleep disturbance, pain and difficulty in concentration were the most intense symptoms. The most bothersome (distressing) were pain and sleep disturbance before and after chemotherapy, both are related to concentration disturbances found during or after the final treatment. So, physical symptoms, intensity and distress changed over time. Anxiety changed overtime but depression was lower at baseline and higher at the 4th treatment (Byar et al., 2006).

The study population reported that breast cancer patients who received Taxane-based chemotherapy to treat breast cancer, showed symptom experienced at the end of 4-6 cycles (Speck et al., 2012). They experienced three symptoms after first infusion; routine activities, functions and behavior impacted by chemotherapy-induced peripheral neuropathy (CIPN). CIPN symptoms included sleeping, driving, standing, walking, climbing stairs, loss of balance, opening containers, holding onto things, cooking, cleaning, flipping pages of paper, wearing certain shoes and jewelry, exercising, and socializing. Women who received docetaxel found decreasing hand strength and coordination, upper and lower body muscle weakness and general restlessness. Paclitaxel users felt numbness, tingling and pain on patients' work day. Commonly, women with or without CIPN were similar in the quantity and other types of side effects. Most of the study population reported that six or more side effects were experienced as non-CIPN, these were swelling in the legs or arms, hot flashes, weight loss or gain, nausea, stomach pain, diarrhea, constipation, indigestion, or acid reflux, mouth sores, loss of appetite, alteration in smell, bone and joint pain, muscle pain and fatigue, breathlessness, lack of sexual interest, depression and anxiety (Speck et al., 2012).

Newly diagnosed patients with breast cancer experienced many symptoms. It is indicated that patients who were newly diagnosed had high distress levels due to emotional cause (100%) related to breast cancers that included worry (89%), fear (82%), nervousness (78%), sadness (61%), and depression (50%) (Hegel et al., 2006).They stated that distress was associated with uncertainty about treatment (96%), physical symptoms (81%), practical life problems (63%), family problems (52%), and spiritual crises (9%).

**Environmental factor.** A review study revealed that poor socio-cultural environment might be responsible for developing depression among breast cancer patients. For that reason they made decision to delay treatment for consultation and screening the breast lump which had developed (Reich, Lesur, & Perdrizet-Chevallier, 2008). Social support improved the impacts of clinical symptoms. A cross sectional study found that a higher level of mood disturbance led to a higher level of symptoms when social support was average or low while receiving chemotherapy (Lee, Chung, Park, & Chun, 2004). The researchers reported that the majority of patients experienced low to moderate level of symptom and mood disturbance. However, their findings shown that the most of the study population were received moderately high level of social support. Another study suggested that insufficient social support influenced higher levels of physical and psychological symptoms patients with breast cancer receiving chemotherapy unlike patients who had minor symptoms (So et al., 2009).

## Assessment of Symptom Experience of Patients With Breast Cancer Receiving Chemotherapy

Many assessment instruments are used to assess the symptom experience of patients under chemotherapy. Among these, the Memorial Symptoms Assessment Scale (MSAS), the Chemotherapy Symptom Assessment scale (C-SAS), the M. D. Anderson Symptom Inventory (MDASI), the Edmonton Symptom Assessment Scale (E-SAS) are most commonly used in different studies. The scales are briefly described below.

**The Memorial Symptoms Assessment Scale (MSAS)**. The Memorial Symptoms Assessment Scale is a general tool which was originally developed in 1994

to assess and calculate a large range of physical and psychological symptoms in advanced cancer patients (Portenoy, Thaler, & Kornblith, 1994). It consists of 32 symptoms that occur as a result of cancer or its treatment. For each symptom, patients will be asked to indicate whether they recognize the symptom during the treatment week (i.e., occurrence). If they experience the symptom, they will be asked to rate its frequency, severity. Symptom frequency is rated using a 4-point likert scale (1 = rarely, 2 = occasionally, 3 = frequently, 4 = almost constantly), and severity (1 = slight, 2 = moderate, 3 = severe, 4 = very severe). The MSAS total score (on 32 scales) is categorized into three main symptoms groups and a number of sub-groups. The major groups are composed of psychological symptoms and physical symptoms. Internal consistency was high in the physical symptoms (PHYS H) and psychological symptoms (PSYC H) groups (Cronbach's alpha coefficients of .88 and .83), moderate in the physical symptoms (PHYS L) group ($\alpha$ = .58). The MSAS scale has shown high correlation with clinical symptoms including a brief Global Distress Index. The MSAS scale is widely used reliable and valid instrument for assessment of symptom prevalence, characteristics and distress (Kutner, Kassner, & Nowels, 2001).

**The Chemotherapy Symptom Assessment Scale (C-SAS).** The Chemotherapy Symptom Assessment Scale was originally developed in 2000 for the routine assessment of symptom experienced by patients who were receiving cytotoxic chemotherapy (Brown et al., 2001). The process of this scale development was validated and revealed the clinical usefulness of the scale. Forty-eight patients and twenty-one health professionals rated the importance of 44 symptoms on a 4-point ordinal scale from 'very severe' to 'not severe at all'. The aim of this process was to reduce the number of items through the views of both health care providers and

patients. The highest ranked symptoms were included in the final version of the C-SAS. The C-SAS was rated for both severity and distress for observing the multidimensional nature of symptom experience. Symptom severity is rated on a 3-point rating scale (mild = 1, moderate = 2 and severe = 3); and symptom distress will be rated using a 4-point scale (1 = not at all, 2 = a little, 3 = quite a bit, and 4 = very much). The total score of C-SAS scale is 24 which distinguished all symptoms that are composed of psychological symptoms and physical symptoms. Consistency was ranked highest by the authors in all items (Brown et al., 2001).

**The M. D. Anderson Symptom Inventory (MDASI).** Cleeland and colleagues developed the M. D. Anderson Symptom Inventory (MDASI) that was designed to measure symptom severity and symptom interference (as cited in Prigozin et al., 2010). This tool includes two subscales, symptom severity and symptom interference. Symptom severity includes 13 parameters and symptom interference includes 6 parameters. The symptom severity scale is rated on an 11-point scale which starts from 0 (not present) to 10 (as bad as you can imagine) for each symptom. The symptom interfere subscale is rated on same scale but using different terms to explain the rank 0 meaning “did not interfere” 10 meaning “completely interfere”. This scale has been used by several authors in their studies (Prigozin et al., 2010). The scale is validated in several languages. The MDASI has two subscales reliabilities; .83 for the severity scale and .87 for the interference scale.

**The Edmonton Symptom Assessment Scale (E-SAS)**. The Edmonton Symptom Assessment Scale was developed in 1991 and was specially developed to give palliative care through symptom assessment. Patients rated their nine symptoms by using the Edmonton Symptom Assessment Scale that includes

pain, activity, nausea, depression, anxiety, drowsiness, lack of appetite, well-being, and shortness of breath. This scale is a nine-item visual analogue scale with 11-point on the scale. Symptom severity is ranked from 0 means (no pain, no activity, no nausea, no depression, no anxiety, no drowsiness, no lack of appetite, best well-being, no shortness of breath) to 10 means (worst possible pain, worst possible activity, worst possible nausea, worst possible depression, worst possible anxiety, worst possible drowsiness, worst possible lack of appetite, worst possible well-being, worst possible shortness of breath). Cronbach's alpha score for this instrument use is .79 (Chang, Hwang, & Feuerman, 2000).

In conclusion, the Chemotherapy Symptom Assessment Scale (C-SAS) is a specific tool to assess the symptom experience of patients with breast cancer receiving chemotherapy. This scale is easy to understand and, takes only 15 minutes to complete, so it is less time consuming and has been found to have a 91% participation rate from a pilot study to ensure consistency. Moreover, the C-SAS has shown to be valid and reliable with a Cronbach's alpha of .75 and responsiveness to clinical change (Pinar et al., 2012). Therefore, the C-SAS will be used in this study.

## Quality of Life of Patients With Breast Cancer Receiving Chemotherapy

### Concepts of quality of life

The concept of quality of life (QoL) is a multidimensional construct that covers the whole of life, and is a useful parameter for outcomes in oncology nursing. It has been stated that QoL is a concept that exclusively contributes to nursing science and practice. QoL is not only restricted to clinical trials of therapeutic agents but it is also ranges of cancer care, including palliative care, end-of- life care,

and long-term survivorship. So, oncology nurses focus on all aspects of life which are affected by cancer and their treatment, such as physical symptoms, treatment toxicities, mental and physical functioning, body image, psychological state, work and role responsibilities, social and family life, and spiritual concerns (Focson et al., 2011).

Quality of life (QoL) is a person's common sense of well-being that is divided into satisfaction or dissatisfaction and includes the various concepts of life that are most important to them (Ferrans, as cited in Sammarco & Konecny, 2009). QoL refers to "global well-being," that includes physical, emotional, mental, social, and behavioral components of life (Boscolo-Rizzo, Maronato, Marchiori, Gava, & Mosto, 2008). Brady et al. (1997) also defined QoL of as physical, social/family, emotional and functional well-being.

According to Ferran's, QoL is an individual's sense that originates from satisfaction and dissatisfaction of well-being that includes health and functioning, socio-economic, psychological and spiritual and family as well as depending on a person's milieu (Ferrans, as cited in Sammarco & Konecny, 2009). Moreover, QoL among women in advanced stage disease of patients with breast cancer are described as self analytic in response to treatment and survival time (Aranda et al., 2005). The terms "QoL" and "health-related QoL" refer to the physical, psychological, and social domains of health, perceived as dissimilar areas that are influenced by a person's experiences, beliefs, expectations, and perceptions of health (as cited in Testa & Simonson, 1996). It is found that physical symptoms, uncertainty, distress, disruptions in social and family relationships, loss of control,

changes in self-image and concerns about the finances and employment define the terms of quality of life (Knobf, as cited in Sammarco & Konecny, 2009).

It is stated that the related QoL of patients with breast cancer consists of well-being which consists of physical, social, emotional and functional well-being. In addition, concerns of breast cancer were added from a patients' symptom experiences.

**Quality of Life of the Patients With Breast Cancer Receiving Chemotherapy**

The definition of QoL is personal view of life values, objectives, standards, and interests in the framework of culture, according to WHO (Dehkordi, Heydarnejad, & Fatehi, 2009). The QoL refers to "global well-being," including physical, emotional, mental, social, and behavioral components. Depression related with a lower quality of life in all areas reported by the patients with breast cancer (Reich et al., 2008). Various studies have clearly shown that depression and its associated symptoms such as dissatisfaction and less quality of life, affect compliance with medical therapies and reduce survival rate. However, impacts of depression on body image, physical, emotional and social dimensions of their quality of life but there was no finding that depression affects family functioning (Reich et al., 2008). The patients with breast cancer who received different types of chemotherapy regimen such as 5-FU, FAC, EFC, AC, EC, docetaxel, paclitaxel, and navelbin (vinorelbine), they had poor QoL at all the dimensions throughout their course of treatment (Akin et al., 2008). They found that in negative effect on physical well-being, emotional well-being and breast cancer (additional concerns) subscales compared with pretreatment findings, during the chemotherapy. However, emotional

well-being was more negatively affected in second and third cycle of chemotherapy (Akin et al., 2008). The researchers reported that fatigue was the most distressing symptom of newly diagnosed patients with breast cancer prior to primary treatment. However, it was found that the most significant factors were fatigue, limited shoulder function and perceived poor appearance which changed the QoL. It was also reported that the QoL of life changed to the poorest level in the first month after surgery (Cheng et al., 2012). Patients, who received primary treatment and chemotherapy, had no better QoL in several domains. The reason many symptoms were developed was reported by the patients with breast cancer. In this regard, patients perceived poorer quality of life (Ganz et al., 2004). They found that the severity of symptom was statistically significantly associated with mental and physical health. Younger breast cancer patients were at risk of chemotherapy-related premature menopause. This symptom was related to poorer QoL and decreased sexual functioning. They reported that menopausal symptom distress, psychosocial distress was related to fertility concerns, infertility, and uncertainty about late effects of premature menopause (Knobf, 2006).

## Factors Related to QoL of Patients With Breast Cancer Receiving Chemotherapy

**Demographic factor.** Socio-demographic variables influence patients' with breast cancer QoL. They consist of educational level, employment status, marital status, race/ethnicity, income, religion, gender, ages, others contributing factors. Educational background and employment status is reported to be significantly related to QoL of patients with having breast cancer (Uzun et al., 2004). The researchers found employed patients had better QoL than those who were unemployed or retired:

general well-being, physical symptoms and activity, cognitive function, social contracts and work performance, and patients who had college level of education stated better quality of life than those who had a lower level of education in four subscales of QoL. In a comparative study, participants were often depressed due to economic situation, medically underserved, lack of health insurance and lack of adequate access to health care (Sammarco & Konecny, 2009), factors that all led to poorer QoL.

Health-related QoL is influenced by different methods of recruitment, demographic and socio-cultural factors that varied from country to country (Pekmezovic, Gavrilovic, Tepavcevic, & Golubicic, 2009). Women who were diagnosed with breast cancer at 45-64 years had better quality of life in all dimensions than older participants were diagnosed at 65 + years of age (Pekmezovic et al., 2009).

Women with college level of education stated better QoL in four subscales which were general well-being ($M$ = 12.79), sleep dysfunction ($M$ = 10.15), cognitive function ($M$ =12.58), and social contacts and work performance ($M$ = 14.05) than patients who had a lower level of college education. Women involved in a job also showed better QoL in general well-being ($M$ = 10.42), physical symptoms and activity ($M$ =13.36), cognitive function ($M$ = 7.44), social contacts and work performance ($M$ = 10.61) (Uzun et al., 2004). Breast cancer survivors showed worse health related QoL compared with the healthy women in the control group (Pekmezovic et al., 2009).

**Health and illness factors.** Health and illness factors are usually added breast cancer patient's well-being. These factors are composed of stage of disease, type of treatment regimen, functional status to perform daily activity, family

history of breast cancer, or other contributing (comorbid disease) factors. QoL is affected by types of chemotherapy. It is significantly evident that Capecitabine users had better QoL than patients who received standard chemotherapy (i.e., CMF and AC regimen) in early stage of breast cancer (Kornblith et al., 2011). Kornblith et al. found that capecitabine had a significantly better global QoL score at mid-treatment and end of treatment than those patients with breast cancer who were treated with standard chemotherapy. In comparison, a longitudinal study revealed that patients who were treated with capecitabine had significantly better QoL in role function, and social function, fewer systemic adverse effects, less psychological distress, and less fatigue during and at the completion of treatment in longitudinal analysis at 12 months and 24 months (Kornblith et al., 2011). Treatments' type caused fluctuations in QoL as perceived from long term treatment such as body image, sexual functioning, and physical symptoms (Montazeri et al., 2008; Salonen, Kellokumpu-Lehtinen, Tarkka, Koivisto, & Kaunonen, 2011). Morbidity influences physical and psychological well-being with breast cancer such as in newly diagnosed cases exaggerated by both surgery and chemotherapy. These might deteriorate women's physical and psychosocial well-being in addition to their QoL (Badger et al., as cited in Salonen et al., 2011).

A prospective longitudinal study showed that elderly aged patients with breast cancer had low QoL in all the functional well-being areas (Hurria et al., 2006). They have more symptom experience about the treatment side effects including thrombotic complication, cerebrovascular accident, deep vein thrombosis and pulmonary embolism, speech impairment (Hurria et al., 2006). The prospective study found that for the patients with breast cancer who received primary treatment,

their functioning and global QoL fluctuated (Montazeri et al., 2008). They reported physical that functioning was enhanced (5.8 points, range from 0 - 100) after 18 months follow-up. They also reported while physical functioning improved global QoL scores elevated by three assessments which were 59.2 at baseline, 71.3 at 3-month follow-up and 32.0 at 18-months follow-up (Montazeri et al., 2008). The QoL was related to disease such as with physical symptoms, uncertainty, distress, disruptions in social and family relationships, loss of control, changes in self-image and concerns about finances and employment (Knobf, as cited in Sammarco & Konecny, 2009). The conserved group showed lower QoL compared with the mastectomy group (Dubashi, Vidhubala, Cyriac, & Sagar, 2010). QoL is deteriorated by primary and combined treatment. It is has been evidently stated that there is no improvement in body image during the study period in patients with breast cancer who had breast conservation surgery (Dubashi et al., 2010).

It was evident that low QoL in EORTC QLQ-30 functioning scale which gained 50 or below represented worse quality of life. On the global health status scale about 27% to 30% women scored 50 or less on physical, role and social functioning (Aranda et al., 2005). They stated that symptom scale that obtained scores over 50 on the fatigue indicate higher scores of pain and insomnia symptoms. It indicated worse QoL. This longitudinal study showed the decreased body image of participants after six months of surgery due to systematic side effects (Salonen et al., 2011). Pearson correlation found lower levels of QoL in four domains: physical role, emotional, mental and vitality/energy. On the 60th day patients experienced higher levels of daytime fatigue after treatment and lower levels of QoL in seven physical symptoms (except pain). After one year, women experienced fatigue similar to the

beginning of chemotherapy, which showed higher intensity and poorer QoL (Byar et al., 2006). Patients having radical mastectomy or lumpectomy showed lower QoL than patients who had total mastectomies (Uzun et al., 2004).

It is found that the QoL was negatively affected in patients with breast cancer as reported by 69% of patients with breast cancer who were treated with adjuvant chemotherapy composed of fluorouracil, epirubicin, cyclophosphamide (FEC) in dose step -2 and -1(Iiristo, Wiklund, Wilking, Bergh, & Brandberg, 2011). They found higher mean scores in cognitive functioning in dose step -2 (fluorouracil 300mg/$m^2$, epirubicin 38 mg/$m^2$, cyclophosphamide 450 mg /$m^2$) and dose step -1 (fluorouracil 600 mg/$m^2$, epirubicin 60 mg/$m^2$, cycophosphamide 600 mg/$m^2$) than patients at dose step 1(fluorouracil 600mg/m2, epirubicin 75mg/$m^2$, cyclophosphamide 900mg/$m^2$) and between those groups who received chemotherapy and hormonal therapy as adjuvant therapy (Salonen et al., 2011).

Furthermore, participants described that they suffered from pain continuous or discontinuous for first or second weeks after surgery. Even if there was no significant statistical difference between with or without pain, negative correlation was observed (Uzun et al., 2004). The study participants reported that patients who had radical mastectomies or lumpectomies had lower QoL scores than patients who had other mastectomies. Patients showed that functional status significantly fluctuated during chemotherapy treatment. Patients demonstrated physical function, role physical, general health, vitality, and social functioning deteriorated while bodily pain and mental health status were significantly improved after 2 cycles of chemotherapy (Lee et al., 2005). They reported that the majority of participants were able to carry out their usual activities, 27.7% in the first cycle and 23.3% in the second cycle.

**Environmental factor**. Socio-economic condition and ethnicity is often related to poor QoL. It is revealed that the Latina participants with breast cancer had poorer QoL than Caucasian (Sammarco & Konecny, 2009). It was observed that breast cancer is the major problem in developing countries where the lack studies in quality of life (Pekmezovic et al., 2009). These negative factors were associated to declining the QoL of patients with breast cancer (Pekmezovic et al., 2009). It is evidently reported that emotional support at baseline and at 5-month follow-up were significantly associated with patients' health-related QoL and self efficacy outcomes in the breast cancer population (Arora, Rutten, Gustafson, Moser, & Hawkins, 2007).

## Assessment of QoL of Patients With Breast Cancer

"A state of complete physical, mental, and social well-being not merely the absence of disease" has been stated by the World Health Organization (World Health Organization [WHO], 1997) as the definition of health and the effects of health care by assessment. It is not only changes the frequency and severity of diseases, but also estimates well-being to improve quality of life (WHO, 1997). Many assessment instruments are used to assess the quality of life of patients receiving chemotherapy. Among these tools the European Organization and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-CO), Palliative Outcome Scale (POS) and Functional Assessment of Cancer Therapy-Breast (FACT-B) are worthy of mention.

## QoL Instruments

***The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-CO)***. The European Organization for Research and Treatment of Cancer Quality of life Questionnaire (EORTC QLQ-CO) is a HR QoL questionnaire that was developed in 1993 by Aaronson and colleagues (as cited in Iiristo et al., 2011). It was constructed for the measurement of QoL of cancer patients and is composed of 33 items within three subscales. Five functional scales (physical functioning, role functioning, cognitive functioning, emotional functioning and social functioning); nine symptom scales (fatigue, nausea/vomiting, pain, dyspnea, insomnia, appetite loss, constipation, diarrhea and financial difficulties); one global health and QoL scale. The scale is rated by a 4-point likert scale; 1 (“Not at all”) to 4 (“Very much”). Global quality of life items are scored on 1 (“Very poor”) to 7 (“Excellent”) point scales. The validity and reliability of the Swedish version was ensured by developers (Iiristo et al., 2011).

***Palliative Outcome Scale (POS).*** The Palliative Outcome Scale (POS) was developed by Hearn and Higginson to measure palliative outcome of patients and care givers from a range of cultures and clinicians (Hearn & Higginson, 1999). It measures the concept of "total pain" including pain and other symptoms, emotional, social, and spiritual/existential and communication/information. It was rated on a 5-point likert scale ranging from 0 (not at all) to 4 (overwhelming). For instance, "Over the last three days have you been feeling anxious or worried about your illness or treatment?” The scale is used directly by the patient about their symptoms and whether or not information needs are met or the caregiver was asked to assess

conditions. Care givers scale consists of 22 items rated on a 5-point likert scale (never = 0, nearly always = 4). In Kappa tests; slight (0.0 –0.20), fair (0.21 – 0.40), moderate (0.41–0 .60), substantial (0.61 – 0.80) and perfect agreement (>.80) are measured (Landis & Koch, as cited in Higginson & Gao, 2008).

***Functional Assessment of Cancer Therapy-Breast (FACT-B).*** The Functional Assessment of Cancer Therapy-Breast Cancer (FACT-B) version 4 consists of two parts, the general subscale on cancer (FACT-G) and additional concerns the breast cancer-specific subscale (BCS). The FACT-G includes 4 subscales: physical well-being (PWB 7 items), social/family well-being (SWB, 7 items), emotional well-being (EWB, 6 items), functional well-being (FWB, 7 items) and the breast cancer specific subscale (BCS, 10 items).

The BCS contains items specific to the concerns of women with breast cancer to rate well-being. It is rated using a 5-point likert scale (0 = not at all, 1 = a little bit, 2 = somewhat, 3 = quite a bit, 4 = very much). In Akin et al.'s study (2008), Cronbach's alpha reliability coefficients for physical well-being subscale was.71, social/family well-being subscale was.76, emotional well-being subscale was .73, functional well-being subscale was .77, breast cancer (additional concerns) subscale was .57, Functional Assessment of Cancer Therapy-Breast Trail Outcome Index (FACT-BTOI) was .67, FACT-G was .79 and for the total scale .89. It was translated to the Chinese version of the FACT-B to assess QoL of 376 patients having breast cancer. The psychometric testing of this tool showed that its' test-retest reliability and internal consistency for five domains and the overall scales showed optimum values (Wan et al., 2007).

In summary, it is stated that to complete the assessment of QoL in breast cancer patients, nurses need to ask and observe the QoL by using assessment scales with the full details of components of QoL. In this study FACT-B will be used to measure the patient's QoL as this instrument is commonly used to measure general well-being as well as the other types of well-being specific to breast cancer. The scale was used with all participants ensuring the validity and internal consistency reliability of the five components.

## Relationships Between Symptom Experience and QoL

The symptom experience and QoL are made relationships. The impacts of symptom decreased the QoL of patients with breast cancer receiving chemotherapy. The longitudinal study found that higher fatigue (symptom) was significantly correlated with lower QoL in several domains during and after chemotherapy. Lower QoL found in physical, role physical, role emotional, social, mental, vitality and general health domains (Byar et el., 2006). The other study reported that fatigue, menopausal symptoms, and cognitive function in the 1-year and 2-year period follow-up of patients with breast cancer after receiving chemotherapy in Canada showed that strong correlation associated between fatigue, menopausal symptoms, and overall QoL. However, there was found no relationship between fatigue, menopausal symptoms, and cognitive function from any other assessment (Fan et al., 2005).

Patients with higher education have less severe symptoms than the low or non-educated patients (Prigozin et al., 2010; Stanton, Bernaards, & Ganz, 2005). However, no relationship has been found between menopausal symptoms and

education, although there was a significant relationship between age and menopausal symptoms. It is found that the patients having breast lump emerged depressive disorder. This depressive disorder might be correlated in ethnic minority women (e.g. Southern California), low-income women, pain, anxiety and health-related quality of life (Reich et al., 2008). Another correlational study found that mood disturbance was positively correlated with symptom experience reported by the patients with breast cancer receiving chemotherapy. However, there was found a significant negative relationships but low correlation observed between social support and mood disturbance (Lee et al., 2004). A longitudinal study found that body image declined significantly after six months of surgery (Salonen et al., 2011), stating that patients who had under aged children showed significant association with negative QoL.

It is noteworthy that there are distinguishing views regarding the experience of symptom associated with QoL in patients with breast cancer receiving chemotherapy. Therefore, symptom experience needs to be further examined in QoL of patients with breast cancer receiving chemotherapy.

## The Health Care System in Bangladesh

Bangladesh is a developing county in South Asia. The total population averages to be 150 million with 964 persons living per square kilometer where the total area is only 147,570 square kilometers. Three-quarters of the Bangladeshi population (74.5%) live in rural areas and the rest in urban areas (25.5%) (Health Bulletin, 2011). The health system is controlled by the Ministry of Health and Family Welfare (MOHFW), which is separated into two sections, one is Population and Family Planning and the other deals with Health. There is a government healthcare

service network throughout the country from the capital city to village level (Rahman, Ashaduzzaman, & Rahman, 2005). According to the health bulletin (2011, p.25), there are three levels of health care delivery system in Bangladesh.

It is very challenging for health care systems of Bangladesh to deliver health care to the population (Mahmood, 2012). Even though there are still three main health care systems in Bangladesh, it has a shortage of doctors and nurses, as well as lack of drugs supplies and other facilities, the nurse to physician ratio is one nurse to three doctors (Mahmood, 2012). In addition, Sarker et al. (2012) observed 1242 patients with breast cancer attended appointments and treatments at NICRH in 2010, in Bangladesh. They also stated that patients with breast cancer were gradually increasing in each year. Researchers found the figure of patients with breast cancer on year ways by using cancer registry data, 2008, 2009 and 2010 was 759 (10.2%), 1196 (12.3%) and 1242 (12.3%), respectively.

According to Health Bulletin, the United Nations Population Fund has supported the Ministry of Health and Family Welfare to run a cervical and breast cancer screening program. That program was being coordinated from the Department of Obstetrics and Gynecology at the Bangabandhu Sheikh Mujib Medical University (BSMMU), Dhaka. It is found that non-communicable diseases, focusing on chronic diseases (i.e., DM, hypertension etc.) have been prevented through the control and management strategy being developed and being implemented. Whereas, cancer diseases including breast cancer which is a non-communicable disease was not receiving a priority since there was no mentioning of expenditure for chemotherapy and drug regimen for breast cancer. Nevertheless, there was a running Breast Cancer Screening Training program. It was established by the BSMMU and funding support

from the Ministry of Health and Family Welfare (MOHFW) which was very small (550.00 lakh) (Health Bulletin, 2014).

Bangladesh is the seventh most over populated country in the world, where 89% of the population is Muslim and it is the third largest Muslim country. It is a low-income country, with a gross national income less than US$ 1005 per capita. Approximately, fifty percent of population are employed in the agricultural sector, 40% of the population have inconsistent jobs such as, laborer working only few hours per week. Sixty percent of women are illiterate and 27% of the population is undernourished. Primary health care is provided by the government and nongovernment rural clinics with a referral system from divisional to secondary or tertiary level of care. Tertiary health care, however, can rarely be received at the Division level or district due to lack of trained health care providers, treatment facilities, and patient resources (Story et al., 2012).

**Breast Cancer Treatment in Bangladesh**

It is noteworthy that the treatment available for cancer treatments are surgery, radiotherapy and chemotherapy used alone or in combination. It is suggested that breast cancer is found to be malignant among adult women more than other types of cancer, in Bangladesh. Cancer patients presented with chemotherapy-induced side effects and these side effects were managed with relative medications (Fukhrul, Nazmul, Ara, Sharmin, & Binte, 2012). There are about 1.5 million cancer patients in Bangladesh and the prevalence of cancer diagnosis in Bangladesh is about 200,000 persons for various types of cancer annually. It is evidently found that the majority of female cancer is uterine or breast both of which are associated with reproductive and

sexual factors. There are many chemotherapeutic regimens available to treat cancer patients. However, there is no found specific chemotherapy regimen to treat breast cancer. One hundred and fifty qualified oncologists have been placed in different parts of Bangladesh, but there are no trained oncology nurses (Hussain, 2013).

In addition, the treatment of cancer patients in various areas in Bangladesh is facing numerous problems. These issues include financial constraints, late diagnosis, poor radiotherapy facilities, unavailability of a cancer-specialized hospitals, poor funding support from government for cancer treatment, lack of NGOs to tackle the problems, lack of cancer registries, and low level of awareness. There are many initiatives taken to improve the cancer scenario in Bangladesh. For example, (1) to create awareness, (2) to attain early clinical diagnosis (ECD), (3) to extend the therapy by introducing minimal therapy, (4) widening the coverage and reach of human resources and supplying necessary drugs and equipment to district level, (5) collaborating with NGOs for the home care service, (6) to improve the QoL for cancer patients and their family through support, rehabilitation, and palliative care and others (Hussain, 2013).

## Summary

The majority of patients with breast cancer experience symptoms after receiving chemotherapy. Literature has shown that symptom experience and QoL are related. The symptom experience and QoL were described in the Symptom Management Model established by Dodd et al. (2001). Symptom experience refers to a person's perceptions of, evaluation of and response to a symptom.

Numerous studies have been conducted based on the experienced symptoms in patients with breast cancer receiving chemotherapy such as physical, psychological and chemotherapy-induced neuropathy in both developed and developing countries. Among symptoms fatigue, sleep disturbance, menopausal symptoms of hot flashes, sadness, worry, hair loss, skin changing, pain, nausea, depression, taste change, burning, painful cold, electric shocks, tingling, and pins and needles, numbness and itching were found in various kind of chemotherapy regimen. These symptoms affect the well-beings of patients with breast cancer.

Previous studies have shown the changeable QoL of patients with breast cancer while receiving chemotherapy. In Dodd et al.'s model (2001) the person, health/illness, and environmental factors influence symptom experience and outcomes. Thereafter, by considering the different cultural contexts and health care system in Bangladesh, this study provides significant evidence for improvement that may influence the QoL of patients with breast cancer while receiving chemotherapy and post chemotherapy.

# CHAPTER 3

# RESEARCH METHODOLOGY

This chapter presents the research design, population, setting, sample instrumentation, ethical consideration, data collection procedure, and data analysis.

## Research Design

This study was conducted by using a descriptive, correlational design to examine symptom experience and QoL of patients with breast cancer receiving chemotherapy and the relationships between the two variables.

## Population

The target population of this study was patients with breast cancer who were currently receiving chemotherapy. All participants attended an outpatient department or were admitted in an inpatient department of a medical college hospital in Bangladesh.

## Setting

There are 15 government medical college hospitals in Bangladesh. Among these, few medical college hospitals have oncology units that offer specific cancer care. For this study, one government hospital was purposively selected: the National Institute of Cancer Research and Hospital (NICRH), Dhaka. This particular hospital was selected as it is the top level referral hospital, and has the high level of

technology required for providing chemotherapy for patients with breast cancer in Bangladesh. Eligible participants who met the inclusion criteria were recruited.

## Sample

### Estimation of Sample Size

The sample size was estimated using power analysis based on a previous study entitled "Impact of adjuvant breast cancer chemotherapy on fatigue, other symptoms, and quality of life" (Byar et al., 2006). This study found higher fatigue was associated with lower QoL in several domains such as physical, role physical, role emotional, social, mental, vitality and general health. The effect size was determined by using the lowest correlation coefficient *(r*) = .40 which matches the proposed study. In this study smaller effect size is anticipated because of the different culture and study setting. The researcher used the effect size: $r = .25$. According to Polit and Beck (2012, *p*. 425), using this effect size with the accepted alpha ($\alpha$) of .05 and the power of .80, the estimated total sample size was 123. During the data collection, 130 eligible participants were approached.

### Sampling Technique

A total of 130 patients with breast cancer were recruited. The sample was composed of patients with breast cancer who were receiving chemotherapy as adjuvant therapy or neoadjuvant therapy (either completed surgery or radiotherapy) at the National Institute of Cancer and Research Hospital (NICRH) in Dhaka, Bangladesh. A convenience sampling technique was used to select a sample who met

the following inclusion criteria during the study period in order to homogenize the study participants.

1. Newly diagnosed with breast cancer
2. Age 18 years or older
3. Receive chemotherapy at least one cycle and is now on the second cycle or more
4. Understand and speak Bengali language

## Instrumentation

### Instruments

The self-report questionnaires composed of closed and open-ended questions were used. There were three parts; Part-1: the Demographic and the Health-Related Questionnaire (Appendix B), Part-2: the Chemotherapy Symptom Assessment Scale (C-SAS) (Appendix C), and Part-3: the Functional Assessment of Cancer Therapy-Breast (FACT-B) (Appendix D).

**Part-1: Demographic and Health-Related Questionnaire**. The Demographic Data Form was designed to collect the following data: (1) age, (2) gender, (3) living place, (4) marital status, (5) religion, (6) education, (7) occupation, (8) monthly income.

The Health-Related Information Form consisted of health-related variables. These were (1) current chemotherapy cycle, (2) functional status/ability to perform daily activity, (3) duration of illness since breast cancer diagnosis, (4) breast cancer stage, (5) family history of breast cancer, (5) chemotherapy, (6) conventional treatment, (7) chemotherapy regimen, (8) symptom prophylaxis (drugs), (9) comorbid

disease, (10) place where symptoms start to occur, (11) having family caregivers to provide support, and (12) economic support. These details were obtained from the patient's and medical record.

**Part 2: The Chemotherapy Symptom Assessment Scale (C-SAS).** The Chemotherapy Symptom Assessment Scale was originally developed by Brown et al. (2001) for use as a routine assessment scale in a clinical setting, specifically for patients receiving cytotoxic chemotherapy. The researcher modified the C-SAS by adding one dimension asking the subjects to rate if they experienced each listed symptom first (1 = yes, 2 = no). If they did, then they were further asked to rate both symptom severity and symptom distress. By doing this, all three concepts of the symptom experience: perception of symptom (occurrence), evaluation (severity), and response (distress) could be captured. Symptom severity was further rated using a 3-point scale (1 = mild, 2 = moderate, 3 = severe) and symptom distress was rated using a 4-point scale (1 = not at all, 2 = a little, 3 = quite a bit and 4 = very much). The C-SAS was a 24-item scale covering physical and psychological symptoms. It has been evidently found that the C-SAS showed adequate levels of both validity and reliability (Cronbach's alpha = .75) (Pinar et al., 2012). In administering the C-SAS, the participants were asked to think of their symptom experience during a 7-day period after receiving chemotherapy of the previous cycle (recalled experience).

**Scoring of the C-SAS.** Three subscales of the C-SAS were scored and interpreted separately as follows. For the occurrence subscale, the symptoms rated as yes were summed; the higher the scores on this subscale indicated the more symptoms being experienced. For the severity of symptom, each experienced symptom was scored and interpreted separately. The averaged scores were computed and interpreted

as follows: mild = 1.00 – 1.66, moderate = 1.67 - 2.33, and severe = 2.34 – 3.00. For the distress subscale, each experienced symptom was scored and interpreted separately similar to symptom severity. The averaged scores were computed using a standard procedure [(highest score – lowest score) divided by the number of levels] and interpreted as follows: low = 1.00 – 2.00, moderate = 2.01 – 3.00, and high = 3.01 – 4.00.

**Part 3: The Functional Assessment of Cancer Therapy-Breast (FACT-B) Version 4.** The Functional Assessment of Cancer Therapy-Breast (FACT-B) was developed by Brady et al. (1997). The FACT-B version 4 consists of two parts, the Functional Assessment of Cancer Therapy-General (FACT-G, 27 items) and additional concerns on breast cancer-specific subscale (BCS, 10 items). The FACT-G included 4 subscales: physical well-being (PWB, 7 items), social/family well-being (SWB, 7 items), emotional well-being (EWB, 6 items), and functional well-being (FWB, 7 items). The BCS contained items specific to the concern of women with breast cancer. So, the FACT-B is composed of 37 items in various domains. There were 17 positive items and 20 negative items. The FACT-G was rated using a 5-point likert scale (0 = not at all, 1 = a little bit, 2 = somewhat, 3 = quite a bit, 4 = very much). In Akin et al.'s study (2008), internal consistency reliability representing with a Cronbach's alpha coefficient for physical well-being subscale was .71, social/family well-being subscale was .76, emotional well-being subscale was .73, functional well-being subscale was .77, and additional concerns on breast cancer-specific subscale was .57. The FACT-B has been translated in to Chinese to assess the QoL of 376 patients with breast cancer. The psychometric testing of this tool represented by its test-retest reliability and internal consistency for five domains and the overall scale

resulted in reliable values (Wan et al., 2007). The alpha coefficient (internal consistency) for the FACT-B total score was high (α = .90), with subscale alpha coefficients ranging from .63 to .86 (Brady et al., 1997). Similar to the C-SAS, in administering the FACT-B, the participants were asked to think of their health and well-being during a 7-day period after receiving chemotherapy of the previous cycle (recalled QoL).

**The scoring of FACT-B.** Total scores of the FACT-G were PWB (4 multiply 7 divided by the number of symptoms); SWB (4 multiply 7 divided by the number of symptoms); EWB (4 multiply 6 divided by the number of symptoms); and FWB (4 multiply7 divided by the number of symptoms). The breast cancer subscale (BCS 10 items) and the scores of the BCS were 4 multiplied by 10 divided by the number of symptoms. So, the FACT-B score was equal to both scores of FACT-G and BCS. In the FACT-B version 4, there were the negative items that must be reversed. Negatively stated scores were reversed (items GP1, GP2, GP3, GP4, GP5,GP6, GP7; GE1, GE3, GE4, GE5, GE6;B1, B2, B3, B5, B6, B7, B8, B10) seven items of physical well-being, five items of emotional well-being except GE2, and eight items from breast cancer-specific subscale except B4 and B9. The scores of FACT-G and BCS were determined by 0 (not at all) to 4 (very much) and three levels were classified as that are low (0 – 1.33), moderate (1.34 – 2.67) and high (2.68 – 4.00).

## Validity and Reliability of the Instruments

The two clinical instruments (C-SAS & FACT-B) were tested for quality through validity and reliability before carrying out the actual study.

**Validity of the instruments**. The instruments were validated by three experts. They were recognized as competent scholars and practitioners in the oncology field. They included a lecturer of the Faculty of Nursing, Prince of Songkla University; an advanced practice nurse (APN) on palliative care from Songklanagarind Hospital in Thailand and an oncologist from Bangladesh. The experts assessed the contents to determine whether or not the items on the questionnaires are accurate, appropriate, and congruent with the conceptual definitions. The proportions of expert team rating of quite relevant and highly relevant were added then divided by the number of content validity experts (Polit & Beck, 2006). Thus, the researcher calculated the Scale-level Content Validity Index (S-CVI) for the C-SAS and the FACT-B yielding values of .93 for the C-SAS [(Oncologist + Lecturer + Advanced Practice Nurse) = (.792 + 1 + 1 = 2.792 /3)] and .90 for the FACT-B [(Oncologist + Lecturer + Head Nurse) = (.703 +1 + 1 = 2.703 /3)]. The questionnaires were revised according to the experts' opinions and recommendations.

**Reliability of the instruments.** The researcher examined the Bengali version of the tools that were piloted with 20 patients with breast cancer. The Cronbach's alpha coefficients for the C-SAS and the FACT-B were .88 and .80, respectively.

**Translation of the instruments.** The original instruments were developed in English. The English version of the C-SAS was translated into Bengali by a bilingual translator; it was further translated from Bengali to English. Finally, the researcher with help from an English language expert compared two English versions (the original and translated English versions) by to check English language consistency and appropriateness of the meaning of the instruments. After that, the

Bengali version was reviewed by an oncologist to check its cultural relevancy with the context. When the two English versions were consistent, the instruments were tested on 20 patients with breast cancer who met the inclusion criteria.

The FACT-B version 4 (Bengali version) was used and permission was obtained from the developers (D. Cella) through personal contact on August, 10, 2013 (Appendix G).

## Ethical Consideration

This study was conducted after gaining approval from the Research Ethics Committee (REC) of the Faculty of Nursing, Prince of Songkla University and permission from the Ethics Committee of the National Institute of Cancer Research and Hospital, Dhaka, Bangladesh. The head nurses of each ward introduced the researcher to potential participants of this study. Prospective participants who were willing to participate in this study were asked to sign a consent form. The identities of the participants were coded in order to ensure confidentiality and anonymity. The participants were informed that they have the choice of whether or not to participate in the program and that they may withdraw from the study at any time, if they wish. There were also informed that it is possible that symptoms or problems may arise during interviews and if they felt any discomfort, the researcher would stop the interview. Seven participants experienced some symptoms (e.g., nausea, vomiting, cough and dyspnea) during the interview. The researcher then provided mental support, and consulted ward staff or physicians. Two participants decided to withdraw from the study because of respiratory distress and fatigue from vomiting.

## Data Collection Procedure

Data were collected from January 28, 2014 to March 14, 2014. Data collection procedures were composed of two phases: preparatory phase and implementing phase.

### Preparatory Phase

1. The researcher submitted the study proposal to the Research Ethics Committee (REC) of the Faculty of Nursing, Prince of Songkla University, Thailand.

2. After obtaining approval from the Research Ethics Committee (REC) of the Faculty of Nursing, Prince of Songkla University, the proposal was presented to the Ethics Committee (EC) and nursing superintendent of a selected hospital to obtain permission.

3. The researcher explained the purposes of the study and data collection process to the head nurses and doctors of the oncology department in order to obtain their support.

### Implementing Phase

1. The researcher obtained information from staff nurses on the number and availability of patients in inpatient departments (IPD) and outpatient departments (OPD) that might be eligible for participating in the study.

2. The researcher was introduced by the nurse in-charge to the participants and explained the objectives of the study to them. The researcher collected the data if patients were receiving a second cycle of chemotherapy and every second or third day infusion of chemotherapy using a face-to-face approach.

3. The researcher assured each participant concerning the rights of being a study participant in order to maintain ethical integrity. Written informed consent was obtained after each of them had received comprehensive information and indicated a willingness to participate voluntarily.

4. The researcher explained to the participants how to complete the questionnaires and allowed time to complete the questionnaires. All participants, both the IPD participants ($n$ = 22, 16.9%) and the OPD participants ($n$ = 108, 83.1%) requested the researcher to read the questionnaires to them and completed the form for them. It took, on average, 45 minutes to one hour to complete the data collection.

5. The researcher gave a code number instead of the actual name of each participant on the questionnaires to ensure the anonymity of the participants.

## Data Analysis

Data were analyzed using descriptive statistics and inferential statistics. Descriptive statistics were used to examine and illustrate the patients' demographic data by using frequency, percentage, median and interquartile range; and patients' clinical characteristics of (1) symptom experience: symptom occurrence, symptom severity and symptom distress and (2) quality of life of patients with breast cancer receiving chemotherapy by using frequency, percentage, mean and standard deviation. The researcher tested the assumptions of the normality and linearity of the following variables: symptom severity, symptom distress, and quality of life.

The normal distribution was determined by visual inspection and statistical procedure. Skewness and kurtosis distributions were visually examined. Furthermore, the skewness ratio and kurtosis ratio were calculated by dividing its statistical value with standard error. The distribution was considered normal if the value was within the range of ± 3. For this study, the C-SAS and FACT-B scores were normally distributed. All other variables also met assumptions of normality.

Linearity is the assumption that there is a straight line between two variables. It is checked between two variables which are evaluated by the inspection of scatter plots. This was employed to determine whether or not the relationship between symptom experience and quality of life was linear. Finally, the Pearson's Product-Moment Correlation Coefficient was applied to examine the relationships between symptom experience and quality of life.

# CHAPTER 4

# RESULTS AND DISCUSSION

## Results

In this chapter, descriptions of the sample and the results of the analysis matching the objectives are presented. There are three parts presented as follows: (1) demographic and health-related characteristics, (2) symptom experience, (3) quality of life, and (4) the relationships between symptom experience and quality of life.

### Demographic and Health-related Characteristics of the Patients

The demographic characteristics of 130 patients are shown in Table 1. The median age of the patients was 45 years old (*IQR* = 10) with ages ranging from 24 to 70 years. All of the patients in this study were female (100%). The majority of them were married (80.8%) and more than half (53.1%) had no formal education. Only two patients had completed a master degree. Most of them (93.1%) were Muslim, whereas 66.2% lived in rural areas with their family.

For health-related characteristics, approximately two-thirds (64.6%) of the patients received chemotherapy in the second to fourth cycle where most of the cases (51.5%) had AC regimen. More than half (52.3%) of the patients reported that they needed partial help from others to carry out their daily activities. Even though 70.8% of patients had stage IV breast cancer disease, 92.3% had no family history of breast cancer and they were diagnosed within less than one year (63.8%).

The largest proportion (86.2%) of the study participants reported that they have a low income and there were a few patients (3.1%) who received full support from the hospital for breast cancer treatment (Table1). Maximum patients with breast cancer were recruited from OPD (83.1%) whereas IPD accounted for only 16.9%.

Table 1

*Demographic and Health-related Characteristics of Patients (N = 130)*

| Variable | Frequency (*n*) | Percentage (*%*) |
|---|---|---|
| Age (years) | | |
| 24 - 35 | 27 | 20.8 |
| 36 - 47 | 65 | 50.0 |
| 48 - 59 | 32 | 24.6 |
| 60 - 70 | 6 | 4.6 |
| *Mdn* (*IQR*): | 45 (10) | |
| Min – Max: | 24 - 70 | |
| Gender | | |
| Female | 130 | 100 |
| Marital status | | |
| Single | 1 | 0.8 |
| Married | 105 | 80.8 |
| Widowed | 19 | 14.6 |
| Divorced | 5 | 3.8 |
| Education | | |
| No formal education | 69 | 53.1 |
| Primary school | 42 | 32.3 |
| Secondary school | 11 | 8.5 |
| Higher secondary school | 6 | 4.6 |
| Master | 2 | 1.5 |
| Religion | | |
| Islam | 121 | 93.1 |
| Hindu | 9 | 6.9 |
| Living place | | |
| Rural | 86 | 66.2 |
| Urban | 44 | 33.8 |
| Functional status | | |

Table 1 (*continued*)

| Variable | Frequency (*n*) | Percentage (*%*) |
|---|---|---|
| Independent | 5 | 3.8 |
| Partially dependent | 68 | 52.3 |
| Fully dependent | 57 | 43.8 |
| Breast cancer stage | | |
| Unknown | 11 | 8.5 |
| Second | 6 | 4.6 |
| Third | 21 | 16.2 |
| Fourth | 92 | 70.8 |
| Family history of breast cancer | | |
| Yes | 10 | 7.7 |
| No | 120 | 92.3 |
| Current chemotherapy cycle | | |
| 2nd to 4th cycle | 84 | 64.6 |
| 5th to 7th cycle | 42 | 32.3 |
| 8th to 9th cycle | 4 | 3.1 |
| Chemotherapy regimen | | |
| CMF | 1 | 0.8 |
| AC | 67 | 51.5 |
| C | 32 | 24.6 |
| Capecitabine | 1 | 0.8 |
| CAF | 11 | 8.5 |
| GC | 3 | 2.3 |
| PC | 3 | 2.3 |
| TC | 1 | 0.8 |
| 5FU + CPL | 7 | 5.4 |
| DCP | 2 | 1.5 |
| PD | 1 | 0.8 |
| EC | 1 | 0.8 |
| Family monthly income (Taka) 70 Taka = | 1US$ | |
| 1000 - 20000 | 112 | 86.2 |
| 21000 - 40000 | 8 | 6.2 |
| 41000 - 60000 | 4 | 3.1 |
| 61000 - 80000 | 1 | 0.8 |
| 81000 - 100000 | 2 | 1.5 |
| 101000 - 200000 | 3 | 2.3 |
| *Mdn (IQR)*: | 10000 (5000) | |
| Min – Max: | 1000 - 200000 | |
| Economic support | | |

Table 1 (*continued*)

| Variable | Frequency (*n*) | Percentage (*%*) |
|---|---|---|
| Hospital | 4 | 3.1 |
| Patient payment | 75 | 57.7 |
| Patient payment + hospital | 51 | 39.2 |
| Occupation | | |
| House wife | 123 | 94 |
| Private employee | 1 | 0.8 |
| Retired | 4 | 3.1 |
| Others (Homeo-therapist, maid servant) | 2 | 1.5 |
| Duration of illness since breast cancer diagnosis (months) | | |
| 02 - 11 | 83 | 63.8 |
| 12 -21 | 33 | 25.4 |
| 22 -31 | 11 | 8.5 |
| 32 - 41 | 1 | 0.8 |
| 42 - 51 | 1 | 0.8 |
| 52 - 60 | 1 | 0.8 |
| Chemotherapy | | |
| Neoadjuvant | 19 | 14 |
| Adjuvant | 110 | 84.6 |
| Concurrent chemo + radiation | 1 | 0.8 |
| Conventional treatment | | 86.2 |
| Surgery | 112 | 100 |
| Chemotherapy | 130 | 3.8 |
| Radiotherapy | 5 | |
| Symptom prophylaxis | | |
| Anti-emetics | 130 | 100 |
| H2 blocker | 130 | 100 |
| Oradexon | 130 | 100 |
| Sleeping pill | 84 | 64.6 |
| Pain killers | 54 | 41.5 |
| Iron, Vita, Neoro-B | 41 | 31.4 |
| Comorbid diseases | | |
| Yes | 37 | 28.5 |
| No | 93 | 71.5 |
| Having family caregivers in hospital and home | 130 | 100 |

*Note.*CMF = Cyclophosphamide (CPA) + Methotrexate + 5-Fluorouracil; AC = CPA + Doxorubicine; C = Paclitaxel; CAF = 5FU + CPA + Doxorubicin; GC = Gemcitabine + Carboplatin; PC = Paclitaxel + Carboplatin; TC = Docetaxel + CPA; 5FU + CPL= 5-Fluorouracil + Cisplatin; DCP = Doxorubicin + CPA + Paclitaxel; PD

= Paclitaxel + Doxorubicin; EC = Endoxan + Cisplatin; *Mdn* = Median; *IQR* = Interquartile Range.

## Symptom Experience

**Symptom occurrence.** The majority of the patients reported more than twelve symptoms in a 7-day period after receiving chemotherapy of the previous cycle with an average number of 17 symptoms (*M* = 17.32, *SD* = 2.01, *Min-Max* = 12-22). The top ten symptoms commonly reported by most participants (88.5% - 100%) were feeling weak, feeling anxious/ worried, changes to appetite or taste, feeling low or depressed, difficulty sleeping, feeling unusually tired, hair loss, mouth or throat problems, nausea, and skin or nails problems (Table 2). The ten symptoms lowest number of participants reported their occurrences (3.8% - 68.5%) were nausea or vomiting before treatment, bleeding/bruising, shortness of breath, diarrhea, changes in periods, signs of infection, changes to sexual relationships, weight loss or gain, vomiting and constipation (Table 3).

Table 2

*The Highest Occurrence of Symptoms in Patients With Breast Cancer Receiving Chemotherapy (N = 130)*

| Symptoms | Frequency (*n*) | Percentage (%) |
|---|---|---|
| Feeling weak | 130 | 100 |
| Feeling anxious or worried | 130 | 100 |
| Changes to appetite or taste | 130 | 100 |
| Feeling low or depressed | 130 | 100 |
| Difficulty sleeping | 130 | 100 |
| Feeling unusually tired | 129 | 99.2 |
| Hair loss | 128 | 98.5 |
| Mouth or throat problems | 124 | 95.4 |
| Nausea | 117 | 90.0 |
| Skin or nails problems | 115 | 88.5 |

Table 3

*The Lowest Occurrence of Symptoms in Patients With Breast Cancer Receiving Chemotherapy (N = 130)*

| Symptoms | Frequency (*n*) | Percentage (*%*) |
|---|---|---|
| Nausea or vomiting before treatment | 5 | 3.8 |
| Bleeding/bruising | 12 | 9.2 |
| Shortness of breath | 29 | 22.3 |
| Diarrhea | 45 | 34.6 |
| Changes in periods | 66 | 50.8 |
| Signs of infection | 76 | 58.5 |
| Changes to sexual relationships | 82 | 63.1 |
| Weight loss or gain | 85 | 65.4 |
| Vomiting | 89 | 68.5 |
| Constipation | 90 | 69.2 |

**Symptom severity.** Concerning the severity of each symptom, Table 4 illustrates the most common symptoms analyzed to determine the severity of each symptom occurrence in a 7-day period. It was found that the top ten ranking order of the most common symptoms rated as severe were: (1) feeling unusually tired (79.8%), (2) feeling anxious or worried (75.4%), (3) feeling weak (75.4%), (4) changes to appetite or taste (73.8%), (5) feeling low or depressed (71.5%), (6) difficulty sleeping (64.6%), (7) nausea (71.8%), (8) mouth/throat problems (58.1%), (9) skin or nails problems (46.1%), and (10) hair loss (38.3%). Overall, the patients reported the severity scores at a moderate level with a mean of 2.27 (*SD* = 0.25) (Table 6).

Table 4

*The Number of Participants and Percentage Classified by the Level of Symptom Severity*

| Symptoms | *Mdn* (*IQR*) | *M* (*SD*) | *n* (%) | | |
|---|---|---|---|---|---|
| | | | Mild | Moderate | Severe |
| | | | 1.00 – 1.66 | 1.67 – 2.33 | 2.34 – 3.00 |
| Feeling unusually tired | 3.0 (3.0) | - | 5 (3.9) | 21 (16.3) | 103 (79.8) |
| Feeling anxious/worried | 3.0 (3.0) | 2.75 (0.44) | 0 (0.0) | 32 (24.6) | 98 (75.4) |
| Feeling weak | 3.0 (3.0) | - | 4 (3.1) | 28 (21.5) | 98 (75.4) |
| Changes to appetite/taste | 3.0 (3.0) | - | 3 (2.3) | 31 (23.8) | 96 (73.8) |
| Feeling low/depressed | 3.0 (3.0) | 2.72 (0.52) | 0 (0.0) | 37 (28.5) | 93 (71.5) |
| Difficulty sleeping | 3.0 (3.0) | 2.61 (0.57) | 5 (3.8) | 41 (31.5) | 84 (64.6) |
| Nausea | 3.0 (3.0) | 2.68 (0.54) | 4 (3.4) | 29 (24.8) | 84 (71.8) |
| Mouth/throat problems | 3.0 (3.0) | 2.56 (0.55) | 3 (2.4) | 49 (39.5) | 72 (58.1) |
| Skin or nails problems | 2.0 (2.0) | 2.30 (0.74) | 19 (16.5) | 43 (37.4) | 53 (46.1) |
| Hair loss | 2.0 (2.0) | 2.21 (0.72) | 22 (17.2) | 57 (44.5) | 49 (38.3) |
| Bleeding or bruising | 2.0 (2.0) | 2.08 (0.67) | 2 (16.7) | 7 (58.3) | 3 (25.0) |
| Nausea or vomiting before treatment | 2.0 (2.0) | 2.0 (1.0) | 2 (40.0) | 1 (20.0) | 2 (40.0) |

*Note*. Percentage was computed based on total number of participants experienced that symptom.

**Symptom distress.** Regarding the distress of each symptom, Table 5 demonstrates that within the 7-day period symptoms were analyzed to determine the distress of the patients' commonly reported symptoms. The top ten symptoms reported as high distress were: (1) feeling unusual tired (69.0%), (2) feeling weak (64.6%), (3) changes to appetite or taste (61.5%), (4) feeling low or depressed (56.9%), (5) feeling anxious or worried (56.9%), (6) nausea (54.61%), (7) difficulty sleeping (52.3%), (8) mouth or throat problems (47.6%), (9) hair loss (30.5%), and (10) skin or nails problems (32.2%). Overall, the distress scores were at a moderate level with a mean of 2.88 (*SD* = 0.41) (Table 6).

Table 5

*The Number of Participants and Percentage Classified by the Level of Symptom Distress*

| Symptoms | *Mdn* (*IQR*) | *M* (*SD*) | *n* (%) | | |
|---|---|---|---|---|---|
| | | | Low | Moderate | High |
| | | | 1.00 – 2.00 | 2.01- 3.00 | 3.01 - 4.00 |
| Feeling unusually tired | 3.0 (3.0) | - | 14 (10.9) | 26 (20.2) | 89 (69.0) |
| Feeling weak | 3.0 (3.0) | - | 16 (12.3) | 30 (23.1) | 84 (64.6) |
| Changes to appetite or taste | 3.0 (3.0) | 3.46 (0.77) | 18 (13.8) | 32 (24.6) | 80 (61.5) |
| Feeling low or depressed | 3.0 (3.0) | 3.48 (0.67) | 10 (7.7) | 46 (35.4) | 74 (56.9) |
| Feeling anxious or worried | 3.0 (3.0) | 3.45 (0.73) | 14 (10.8) | 42 (32.3) | 74 (56.9) |
| Nausea | 3.0 (3.0) | - | 12 (10.3) | 34 (29.1) | 71(54.61) |
| Difficulty sleeping | 3.0 (3.0) | 3.36 (0.79) | 17 (13.1) | 45 (34.6) | 68 (52.3) |
| Mouth or throat problems | 3.0 (3.0) | 3.23 (0.85) | 29 (23.4) | 36 (29.0) | 59 (47.6) |
| Hair loss | 3.0 (3.0) | 2.21 (0.72) | 49 (38.3) | 40 (31.2) | 39 (30.5) |
| Skin or nails problems | 3.0 (3.0) | 2.82 (0.99) | 47 (40.9) | 31 (27.0) | 37(32.2) |
| Nausea or vomiting before treatment | 2.0 (2.0) | 2.60 (1.35) | 3 (60.0) | 0 (0.00) | 2 (40.0) |
| Bleeding/bruising | 3.0 (3.0) | 2.75(0.76) | 5 (41.7) | 5 (41.7) | 2 (16.7) |

*Note*. Percentage was computed based on total number of participants experienced that symptom.

Table 6

*Overall Level of Severity and Distress of Patients With Breast Cancer Receiving Chemotherapy (N = 130)*

| Subscale | *M* (*SD*) | Min - Max | Skewness | Kurtosis | Level |
|---|---|---|---|---|---|
| Severity | 2.27 (0.25) | 2 – 3 | -0.99 | -1.14 | Moderate |
| Distress | 2.88 (0.41) | 2 – 4 | -2.00 | -0.71 | Moderate |

*Note: M* = Mean; *SD* = Standard Deviation; Min = Minimum; Max = Maximum

**Quality of Life**

Table 7 shows the total score and subscales of the FACT-B including additional concerns. The domain with the highest score was social well-

being/relationships (*M* = 3.14, *SD* = 0.66), while the physical well-being had the lowest score (*M* = 1.17, *SD* = 0.66). In addition the mean score of other domains were: emotional well-being (*M* = 1.38, *SD* = 0.61), functional well-being (*M* = 2.05, *SD* = 0.65), and additional concerns of breast cancer (*M* = 2.34, *SD* = 0.45). The overall results demonstrate the total FACT-B mean scores was at a moderate level (*M* = 2.02, *SD* = 0.39).

Table 7

*The Quality of Life of Patients With Breast Cancer Receiving Chemotherapy (N = 130)*

| Subscales | Min - Max | *M(SD)* | Skewness | Kurtosis | Level |
|---|---|---|---|---|---|
| PWB | 0 – 3 | 1.17 (0.66) | 3.57 | 1.12 | Low |
| SWB | 2 - 4 | 3.14 (0.66) | -1.91 | -1.76 | High |
| EWB | 0 – 3 | 1.38 (0.61) | 1.71 | 0.26 | Moderate |
| FWB | 1 – 4 | 2.05 (0.65) | 3.57 | -0.62 | Moderate |
| ACB | 1 – 3 | 2.34 (0.45) | -4.22 | 2.39 | Moderate |
| Total | 1 – 3 | 2.02 (0.39) | 2.10 | -0.22 | Moderate |

*Note.* PWB = Physical Well-being; SWB = Social Well-being; EWB = Emotional Well-being; FWB = Functional Well-being; ACB = Additional concerns of breast cancer.

Shown in Table 8 is the highest score of the FACT-B subscales. Three items taken from each dimension were rated by the participants very highly. These dimensions were (1) physical well-being: pain, nausea and lack of ability to fulfill family needs; (2) social/family well-being: feeling close to partner, family accepted their illness and satisfaction with family communication about their illness; (3) emotional well-being: satisfied through coping with their illness, having hope to fight against illness and concerned about the condition to get worse; and (4) functional well-being: coping with illness, satisfy toward present quality of life and fulfilling home demand.

Moreover, three items regarding additional concerns of breast cancer in the breast cancer subscale: 'feelings of femininity', 'bothered by a change in weight', and 'certain parts of body where experience pain', were rated at a high level where as the item, 'one or both of arms are swollen or tender,' was at a moderate level (Table 8).

Table 8

*Items With Highest Scores From Each Subscale of the FACT-B*

| Subscales | Min - Max | *M* (*SD*) | *Mdn* (*IQR*) | Skewness | Kurtosis |
|---|---|---|---|---|---|
| **Physical well-being** | | | | | |
| Pain | 0 - 4 | 2.18 (1.28) | | -0.85 | -2.06 |
| Nausea | 0 - 4 | 1.85 (1.26) | | 1.21 | -1.73 |
| Lack of ability to fulfilling the family needs | 0 - 4 | 1.21(1.20) | | 3.19 | -1. 03 |
| **Social/family well-being** | | | | | |
| Feeling close to partner | 2 - 4 | - | 4.0 (0.0) | -15.08 | 20.81 |
| Family accepted illness | 0 - 4 | 3.78(0.69) | 4.0 (0.0) | -16.17 | 28.18 |
| Satisfaction with family communication regarding illness | 2 - 4 | 3.64(0.70) | - | -7.76 | 2.68 |
| **Emotional well-being** | | | | | |
| Satisfaction through coping with illness | 0 - 4 | 2.63 (1.17) | - | -1.73 | -1.74 |
| Having hope to fight against their illness | 0- 4 | 1.58 (1.19) | - | 1.24 | -1.48 |
| Concerned about the condition to get worse | 0 - 4 | 1.12 (1.16) | - | 2.42 | -2.38 |
| **Functional well-being** | | | | | |
| Coping with illness | 1 - 4 | - | 4.0 (0.0) | -16.99 | 31.47 |
| Satisfy toward present quality of life | 0 - 4 | 1.98 (1.10) | - | 3.50 | -1.65 |
| Fulfilling homework | 0 – 4 | 1.89 (1.14) | - | 3.14 | 0.001 |
| **Additional concerns of breast cancer (ACB)** | | | | | |
| Feelings of femininity | 0 - 4 | - | 4.0 (0.0) | -28.47 | 93.98 |
| Bothered by a change in weight | 0 - 4 | - | 4.0 (0.0) | -8.90 | 7.36 |
| Certain parts of body where experience pain | 0 - 4 | - | 4.0 (0.0) | -7.78 | 5.08 |
| One or both of arms are swollen or tender | 0 - 4 | 2.73 (1.30) | - | -3.59 | -1.23 |

The lowest scores reported by participants rating in each subscale of the FACT-B version 4 are shown in Table 9. Among these, items "lack of energy" was rated the lowest (*M* = 0.61, *SD* = 0.89), followed by "feeling ill" (*M* = 0.65, *SD* = 0.84) "feeling sad" (*M* = 0.73, *SD* = 0.85), "forced to go to bed" (*M* = 0.79, *SD* = 0.84), "worried about dying" (*M* = 1.11, *SD* = 1.26), "feeling nervous/anxious" (*M* = 1.12, *SD* = 1.09), and "ability to work" (*M* = 1.29, *SD* = 0.84). The lowest scores of all seven items in the physical well-being, emotional well-being, and functional well-being subscales were rated at a low level (with a mean less than 1.33) whereas the lowest scores of three items of the social/family well-being subscale were at a moderate level. Two lowest score items of the breast cancer subscale were at a low level: worry about the effect of stress and worry about the risk of cancer in other family members.

Table 9

*Items with Lowest Scores From Each Subscale of the FACT-B*

| Subscales | Min - Max | *M* (*SD*) | *Mdn* (*IQR*) | Skewness | Kurtosis |
|---|---|---|---|---|---|
| **Physical Well-being** | | | | | |
| Lack of energy | 0 – 4 | 0.61 (0.89) | - | 5.99 | 2.02 |
| Feeling ill | 0 – 4 | 0.65 (0.84) | 0.0 (1.0) | 6.22 | 3.94 |
| Forced to go to bed | 0 – 3 | 0.79 (0.84) | - | 3.08 | 1.38 |
| **Social/Family Well-being** | | | | | |
| Feeling close to friends (Neighbor and relatives) | 0 – 4 | 2.25 (1.28) | - | 0.10 | -3.66 |
| Satisfied with conjugal life | 0 – 4 | 2.25 (1.79) | - | -1.26 | -4.10 |
| Supported by friends | 0 – 4 | 2.51 (1.24) | | -0.15 | -3.45 |
| **Emotional Well-being** | | | | | |
| Feeling sad | 0 – 3 | 0.73 (0.85) | | 3.70 | -1.15 |
| Feeling nervous/anxious | 0 – 4 | 1.12 (1.09) | | 3.78 | 0.35 |
| Worried about dying | 0 – 4 | 1.11(1.26) | | 3.83 | -1.25 |
| **Functional Well-being** | | | | | |
| Ability to work | 0 – 4 | 1.29 (0.84) | | 3.96 | 2.21 |

Table 9 (continued)

| Subscale | Min-Max | *M* (*SD*) | *Mdn* (*IQR*) | Skewness | Kurtosis |
|---|---|---|---|---|---|
| Ability to enjoy life | 0 – 4 | 1.61 (1.06) | - | 4.54 | 0.84 |
| Enjoying the fun | 0 – 4 | 1.85 (1.08) | - | 3.76 | -1.09 |
| **Additional concerns of breast cancer (ACB)** | | | | | |
| Worry about the effect of stress on illness | 0 – 4 | 1.18 (1.16) | - | 2.93 | -1.27 |
| Worry about the risk of cancer in other family members | 0 – 4 | 1.23 (1.29) | - | 3.13 | -1.76 |
| I am bothered by hair loss | 0 – 4 | 1.86 (1.38) | - | 0.34 | -2.91 |
| Shortness of breath | 0 – 4 | 1.87(1.33) | - | 0.58 | -2.29 |
| Self-consciousness about cloths | 0 - 4 | 2.73 (1.30) | - | -0.97 | -1.24 |

**Relationship Among the Variables: Physical Well-being, Social Well-being, Emotional Well-being, Functional Well-being, Additional concerns of breast cancer, Symptom Severity and Symptom Distress**

Pearson's Product-Moment correlation was used to analyze the relationships among the variables. The findings are presented in Table 10. There were negative relationships between symptom severity and distress and quality of life: (1) symptom severity and total QoL ($r$ = -.48, $p$ < .01), (2) symptom severity and physical well-being ($r$ = -.40 and $p$ < .01), (3) symptom severity and social well-being ($r$ = -.30 and $p$ < .01), (4) symptom severity and emotional well-being ($r$ = -.20 and $p$ < .01), (5) symptom severity and functional well-being ($r$ = -.48 and $p$ < .01), (6) symptom severity and breast cancer-specific subscale ($r$ = -.08, $p$ > .01), (7) symptom distress and total QoL ($r$ = -.50, $p$ < .01), (8) symptom distress, and physical well-being ($r$ = -.40, $p$ < .01), (9) symptom distress and social well-being ($r$ = -.31, $p$ < .01), (10) symptom distress and emotional well-being ($r$ = -.28, $p$ < .01), (11) symptom distress and functional well-being ($r$ = -.52, $p$ < .01), and (12) symptom distress and breast cancer-specific (additional concerns) subscale ($r$ = .01, $p$>.01).

There was a negative and non-significant relationship found in symptom severity and breast cancer-specific (additional concerns) subscale ($r$ = -.08, $p$>.01), and a positive and non-significant relationship found in symptom distress and breast cancer-specific (additional concerns) subscale ($r$ = .019, $p$ > .01).

Table 10

*Correlation of Symptom Severity, Symptom Distress, Physical Well-Being, Social Well-Being, Emotional Well-Being, Functional Well-Being, Additional Concerns of Breast Cancer, and QoL* (*N = 130*)

| | Symptom Severity | Symptom Distress | Total QoL | PWB | SWB | EWB | FWB | ACB |
|---|---|---|---|---|---|---|---|---|
| Symptom Severity | 1 | | | | | | | |
| Symptom Distress | .86** | 1 | | | | | | |
| Total QoL | -.48** | -.50** | 1 | | | | | |
| PWB | -.40** | -.40** | .74** | 1 | | | | |
| SWB | -.30** | -.31** | .58** | .19* | 1 | | | |
| EWB | -.20** | -.28** | .70** | .41** | .16** | 1 | | |
| FWB | -.48** | -.52** | .70** | .37** | .41** | .31 | 1 | |
| ACB | -.08 | .019 | .48** | .38** | -.02 | .39** | 0.18 | 1 |

*Note*. **$p$ < .01; *$p$<.05

## Discussion

### Demographic Characteristics of the Sample

All patients with breast cancer receiving chemotherapy were female. They were middle aged adults with a median age of 45 years (*IQR* = 10), had received AC based chemotherapy following paclitaxel, the majority of participants (80.8%) were married, and the majority of them had no formal education (53.1%) or low level (32.3%). These findings are comparable with a previous study conducted in Israel of which they found that the mean age of the study sample was 45 years (*SD* = 9.3), the

majority of study participants (87.5%) were married or had a partner and were treated with AC regimen following paclitaxel. However, most of the study participants (62.5%) were college graduates which were different from the present study. They found a cluster of four symptoms: pain, sleep disturbance, fatigue and depression to be at a high level (37.5%) (Golan-Vered & Pud, 2013). All of participants in this present study received chemotherapy and were married which was consistent with other developing countries in Jordan and East Carolina, USA (Omran et al., 2012; Williams & Schreier, 2004). The results showed that more than half the participants (53.1%) had no formal education. The lowest number of participants (2 patients) had completed a master degree. The majority of participants were Muslim in the present study, whereas 66.2% of patients lived in a rural area with their family.

The majority of the participants (70.8%) had metastasis breast cancer (Stage IV). The findings of the present study matched the opinion of the oncologist who was the head of the department in the target hospital (NICRH). According to oncologist consultation nearly all patients are continuously diagnosed in Stage III and Stage IV which was consistent with a previous study conducted in Bangladesh (Story et al., 2012). Cancer is often not stated a priority for health care expenditures in countries with limited resources including Bangladesh. As infectious diseases typically dominate the health care agendas of such countries, cancer control efforts generally fall behind other priorities of the national health authorities. Although the majority of cancers are curable if detected and treated in the early stages, about 80% of all patients with breast cancer in the developing world have advanced stage disease at initial presentation (Anderson et al., 2006).

Breast cancer is the highest burden of mortality in the lowest-income African countries. The mortality rate was 69% in Africa, compared with 19% in North America. This high ratio partly results from incomplete reporting of disease and largely reflects the high proportion of women who present with late-stage disease, which is not curable even in wealthy countries (Porter, 2008). The findings of this present study showed more than half of the patients who had no family history of breast cancer disease were diagnosed within less than one year at the fourth stage of the breast cancer disease. The current finding of the study was a partial consistent with previous study (Fokhrul et al., 2012). They stated that the majority of participants had no family history of breast cancer.

Low socioeconomic status may contribute to limited accessibility to health education for breast cancer prevention and early detection of women with breast cancer in this present study. This reason may be applied to the findings in this present study that the majority of participants (94%) were housewives or their spouse had work casually (car or rickshaw driver, or dependent on others temporary jobs). Many women who believe fatalism fall into social isolation and accept the poor outcome in countries with limited resources. In resource-limited countries, the knowledge of most women about breast cancer and its warning signs are very limited. This factor may also influence the delay in referral for treatment and increase in the incidence of late stage disease presentation. Social fears of breast cancer, cultural taboos and myths and a lack of adequate public health educational resources are major obstacles in countries of limited resources (Masood, 2007). In spite of the setting being the National Institute of Cancer Research and Hospital, only a small amount of IPD patients with breast cancer received chemotherapy (16.9%).

## Symptom Experience

Symptoms identified during therapy are considered to be due to treatments, specifically chemotherapy. Although chemotherapy works against cancer cells or provides the benefit of survival, it has many side effects including dramatic effects on physical and psychosocial symptoms (ACS, 2011; Byar et al., 2006). All participants in the present study were currently receiving neo-adjuvant, adjuvant chemotherapy or radiotherapy. They experienced several symptoms which were evaluated and rated as symptom severity. Once symptoms were recognized, individuals responded to these symptoms and expressed these in terms of symptom distress. In this study, the researcher gained insights about symptoms experienced by Bangladeshi women with breast cancer during chemotherapy treatments. Symptom experiences, conceptualized based on the Symptom Management Model (SMM) (Dodd et al., 2001) and findings from related, previous studies guided an interpretation and discussion of the study findings as follows.

**Symptom occurrence.** The prevalence of symptom occurrence was high among the newly diagnosed patients with breast cancer. On average, 17 symptoms were experienced concurrently by each participant with a range of 12 to 22 symptoms during a 7-day period after receiving chemotherapy from the previous cycle. The findings of the present study are comparable with a previous study evaluating of differences of symptom occurrence, severity, and distress among the patients with breast cancer receiving chemotherapy (Hofso et al., 2012). Hofso et al. reported that 23 symptoms occurred out of 32 listed in the questionnaire and 5 symptoms with the highest occurrence were lack of energy, worrying, difficulty sleeping, feeling drowsy, and sweats. This is considered comparable to this present

study in which feeling weak, feeling anxious or worried, changes to appetite or taste, feeling low or depressed, and difficulty sleeping were reported by all participants (Table 2).

The occurrence of symptoms being experienced depends largely on types of chemotherapy. It is noteworthy that study findings of newly diagnosed patients with breast cancer receiving doxorubicin based chemotherapy regimen developed a number of physical and psychological symptoms (Byar et al., 2006) that could occur at their first chemotherapy (Williams & Schreier, 2004). Williams and Schreier reported that the patients with breast cancer who received CMF or AC based chemotherapy developed fatigue, nausea and vomiting, and taste change most frequently. Seven common symptoms; feeling a lack of energy, decrease in physical strength/weakness, headaches, difficulty sleeping, feeling blue of depressed, hot flushes, and night sweats were found in approximately 90% of the study participants who had completed primary treatment, received adjuvant chemotherapy and Stage I to Stage IV breast cancer diseases (Bender, Ergun, Rosenzweig, Cohen, & Sereika, 2005).

Another contributing factor to symptom experience is the number of time patients had received chemotherapy (chemotherapy cycles) All participants in this present study had a history of receiving more than one cycle of chemotherapy. The top ten symptoms found in this study were congruent with another review study (Kim, Dodd, Aouizerat, Jahan, & Miaskowski, 2009). Kim et al.'s summarized the prevalence of symptoms in patients with breast cancer and other cancers based on their review of 18 studies in which the top ten symptoms were reported in at least five of the studies. Fatigue, worrying, feeling nervous, dry mouth, insomnia, feeling

sad/mood, feeling irritable, pain, drowsiness, and distress occurred in more than 22% to 30% of these cancer patients. They found that occurrence of multiple symptoms decreased the functional status and QoL of patients with advanced stage cancer. Feeling weak was one of the most frequent symptoms reported by the patients with breast cancer in the present study. It is one kind of fatigue. Hofman, Ryan, Figueroa-Moseley, Jean-Pierre, and Morrow (2007) described the characteristics of fatigue as feelings of tiredness, weakness, and lack of energy, or drowsiness. The cause of fatigue may come from cancer disease and chemotherapy. Hofman et al. found that it was early symptom of malignant cancer reported by the cancer patients at the diagnostic phase. Another study found that fatigue occurred concurrently with other symptoms (Cheng & Lee, 2011). Cheng and Lee found that fatigue was a significant most predicting factor of changes in quality of life.

Feeling anxious or worried was reported by all participants in present study. This finding was consistent with a previous study (Baqutayan, 2012). Baqutayan reported that anxiety was a common feeling for patients with breast cancer and stated that anxiety could increase after breast cancer is diagnosed. It might be increased by breast cancer or its treatment. So, anxiety was not only the most psychological threats but also it can lead to both physical and psychological symptoms such as worry and tension, restlessness, irritability, muscle tension, headaches, sweating, difficulty concentration, nausea, tiredness, etc (as cited in Baqutayan, 2012). Anxiety reduced the quality of life.

The occurrence of changes to appetite is one of the most common symptoms. It is found that the occurrence of changes to appetite or taste in this study was a major concern at the time of a 7-day period on the list of symptoms experienced

by the patients with breast cancer receiving chemotherapy. It is found that the taste change was most frequently reported by patients with breast cancer (Williams & Schreier, 2004). Another reviewed study showed that alterations of taste and odor disorders were the result of breast cancer and its therapy. These alterations affected the daily quality of life and led to patient malnutrition and significant morbidity reported by the breast cancer patients. The researchers also reported that the patients with breast cancer receiving chemotherapy and radiotherapy developed unpleasant metallic and bitter sensations (Hong et al., 2009).

The most commonly occurring symptoms of feeling low or depressed and difficulty sleeping found in this present study were reported by all of the study participants. This finding is comparable to a previously reviewed study (Bower, 2008). Bower showed that a common side effect of breast cancer diagnosis and treatment were disturbances in energy, sleep, mood, and cognition. The researcher stated that these symptoms caused serious disruption in patients' quality of life and were persistent for long time after chemotherapy. In addition, some rationales may explain the differences in the number of symptoms between the findings of this present study and other studies. First, symptom assessment scales list different numbers of symptoms. For examples, the Anderson Symptom Inventory (MDASI) and the Edmonton Symptom Assessment Scale (E-SAS), the most commonly used scales, list less than 20 cancer related symptoms and that may help the patients to easily explore their symptoms. This present study used the Chemotherapy Symptom Assessment Scale (C-SAS) enlisting 24 general symptoms of patients with breast cancer who underwent chemotherapy (Brown et al., 2001). In addition, an open-ended question was utilized to provide the opportunity for the study participants to indicate

other symptoms stemming from breast cancer treatment. The majority of study participants added at least twelve symptoms. This may contribute to more average numbers of symptoms compared to that of other studies. Next, having enough time to fill the questionnaires allowed patients to report the presence of their symptoms which was preferable to other studies where physicians or nurses were interviewed regarding common symptoms (Teunissen et al., 2007). The symptoms referred to only covered areas such as fatigue, pain, lack of energy, weakness, and appetite loss.

**Symptom severity.** The severity of symptoms reported by the participants in this study was averaged to be at a moderate level (Table 6). Examining each symptom severity by looking at number of participants who rated the identified symptom at each level of symptom severity (mild, moderate, or severe), it was revealed that there were eight symptoms more than half of the participants who experienced each individual symptom rated them as "severe" (Table 4). The highest number of participants rated the following three symptoms as "severe": feeling unusually tired, feeling anxious or worried, and feeling weak (*Mdn* = 3). Feeling unusually tired and feeling weak can be considered to be "fatigue." This is consistent with a study conducted by Huang et al. (2013) who found that the severity score was high in fatigue. Fatigue refers to feeling unusually tired and feeling weak. In Breen et al.'s study (2009), they found that the participants reported the most severe symptoms to be pain, difficulty sleeping, and feeling unusually tired. For psychological symptoms: feeling anxious/worried as well as feeling low or depressed, nearly 80% of participants who reported these symptoms rated them as severe (Hofso et al, 2012). The researchers showed that three symptoms (i.e., hair loss, problems with sexual interest, and ''I don't look like myself'') caused the highest severity that were

associated to change in body image reported by patients with breast cancer who received CTX prior to RT.

Changes to appetite or taste was another symptom nearly three-fourths of them who experienced this symptom rated it as severe. Williams and Schreier (2004) found that patients who received cyclophosphamide, methotrexate, and fluorouracil or doxorubicin and cytoxan (AC) based regimen reported to have fatigue, nausea and vomiting, and taste change. Difficulty sleeping was reported to be severe by about two-thirds (64.6%) of those experienced it. This was comparable to a previous study (Hofso et al., 2012), and the severity of difficulty sleeping influenced the use of chemotherapy prior to radiation therapy. Hofso et al. found that the severity was due to from lack of energy, worrying, feeling drowsy, sweats, and pain were less than the difficulty sleeping. The severity of these symptoms suggested a poorer functional status and a higher comorbidity (Hofso et al., 2012).

Nausea was one common symptom rated as severe by the majority of the participants having this symptom (71.8%). This finding was congruent with a previous study (Bloechl-Daum, Deuson, Mavros, Hansen, & Herrstedt, 2006) which found that the significantly greater severity of nausea in cancer patients who had cisplatin, and dacarbazine chemotherapy regimen (49.3%), particularly during two to five days after administration were breast cancer patients. Mouth or throat problems are a general symptom reported to be severe by more than half of the participants experienced it in the present study. This can be found in patients with cancer receiving various types of standard chemotherapy (Naidu et al., 2004). Naidu et al. reported that mucositis would be increased if patients received high doses of chemotherapy. This might limit the patient's ability to tolerate chemotherapy or

radiation therapy, and affect their nutritional status and quality of life. Hair loss is another symptom reported to be severe by more than one-third of the participants in the present study, comparable to Hofso et al.'s study (2012).

Moreover, skin/nails problems is another symptom that nearly half of participants experiencing this symptom in this present study rated it as severe. Segaert and Cutsem (2005) showed that dermatological side-effects most frequently developed included xerosis, eczema, fissures, telangiectasia, hyperpigmentation, hair changes and paronychia with pyogenic granuloma in patients who used monoclonal antibodies. Many treatment options are available to prevent and treat the severity of symptom, but none of them can completely prevent or treat. The following symptoms were those reported as severe by lower number of participants: bleeding or bruising (25%), and nausea or vomiting before treatment (40%). Anticipatory nausea and vomiting (ANV) occurs before treatment is actually given. It is a conditioned and learned phenomenon which was reported to occur in approximately 25% of patients at the fourth chemotherapy cycle (Roscoe, Morrow, Aapro, Molassiotis, & Olver, 2011). More than 73.8% of participants reported symptom severity on "changes to appetite or taste" in current study, it is consistent with a previous study (Gamper et al., 2012). They suggested that the highest severity of taste alterations in breast cancer patients treated with epirubicin/docetaxel/capecitabine. They also showed that the severity of taste alteration was associated to reduce certain QoL domains. Nausea increased in duration post-treatment and projected greater severity for younger adult female patients (Kim & Morrow, 2003; Roscoe et al., 2011). The overall, symptom severity level was at a moderate (2.27, $SD = 0.25$) in this present study which was consistent with a previous study (Suwisith et al., 2008).

**Symptom distress**. Symptom distress was found in the present study through symptoms analyzed from a 7-day period after receiving chemotherapy from the previous cycle. These common distress symptoms found in the present study were feeling unusually tired, feeling weak, changes to appetite/taste, feeling low/depressed, feeling anxious or worried, nausea, difficulty sleeping, mouth or throat problems, hair loss, and skin or nails problems.

The symptom distress in the present study comparable with a previous study (Borjeson, Starkhammar Unosson, & Bertero, 2012). Borjeson et al. observed nine distressing symptoms with other cancer patients. Each symptom was assessed by observing the number of patients depending on the level of symptom distress (low, moderate, or high). There were seven symptoms rated as high by more than half of the participants ranging from 52.3% - 69% (Table 5). More than 60% of participants rated symptoms feeling unusually tired, feeling weak and changes to appetite or taste as "high". Concerning the distressing of psychological symptoms, 56.9% of patients reported feeling low or depressed and feeling anxious or worried rated as "high" like a previous study (Breen et al., 2009). According to their findings 45% and 25% of patients reported anxiety and depression respectively. Participants experienced symptom distress could be the results of concurrent symptoms complying with the previous study showed the participants with 10 - 23 symptoms had higher levels of symptom distress (Sarenmalm, Ohlen, Jonsson, & Gaston-Johansson, 2007)

In addition, other researchers have reported that physical symptoms caused the most distress (Breen et al., 2009), and these physical symptoms were pain, constipation, and nausea. However, their regression analysis results found that symptom distress has come from malaise, nutritional and gastrointestinal factors

which were independent predictors of depression. The changes to appetite/taste found another common distressing symptom approximately sixty percent of participants reported at a high level in the current study. This finding was congruent with Bernhardson, Tishelman, and Rutqvist study (2009). The researchers advocated that high distress was a cause of taste/smell changes (TSC) in the patients who received chemotherapy. They also showed that TSC-related distress effects daily life and their findings stated that high levels of distress could cause a significant impact on daily life, affecting psychological and somatic or mental aspects (Bernhardson et al., 2009).

Hair loss is a common distressing symptom found in this study, distress of hair loss consistently ranked the most troublesome side effect after receiving chemotherapy (Lemieux, Maunsell, & Provencher, 2008). Alopecia is a common symptom experience and it evidently found that it was ranked the most prevalent side effect of chemotherapy and it was suggested that some breast cancer patients refused to continue their chemotherapy due to its effects. However, it was rarely reported by the breast cancer patients. In addition, skin or nails problems symptoms found in nearly half of the participants were reported at a high level. This was found in studies by Borjeson and colleagues (2012) and Roche et al. (2006). Borjeson and colleagues identified a number of distressing symptoms in patients with breast cancer which were fatigue, changed bowel habits, nausea, loss of appetite, skin and mucous membrane problems, pain and other and these symptoms affected mental well-being. Roche and colleagues were observed stomatitis, edema, and nail disorders and attributed these symptoms to FEC regimen followed by Docetaxel which were graded 3 or 4 (Roche et al., 2006).

Breast cancer-related fatigue (CRF) is characterized by feelings of tiredness, weakness, lack of energy, and drowsiness (Hofman et al., 2007), and those were found at all the stages of breast cancer disease reported by the patients with breast cancer (Ancoli-Israel et al., 2006). Hofman et al. (2007) found that cancer-related fatigue notably was associated with psychological distress and it can be barrier of patient's ability to work.

The distress of nausea was reported by half of patients during a 7-day period was at a high level. This common symptom could be related other symptoms for example, nausea-related with gastrointestinal symptoms which found the most distressing for patients with breast cancer (Byar et al., 2006). The researchers found that the prevalence of nausea symptom was related to family conflicts and that was associated with the patient's age (younger adult patients) and gender (female patients) (Tsai et al., 2009; Roscoe, et al., 2011). Overall, the distress score were ranked at a moderate level (2.88, *SD* = 0.41). This similarity was found in Knobf (2001) who stated that the study participants reported symptom distress at a moderate to high level.

The majority of patients were middle aged or above 40 years, the present study findings were congruent in a previous study (Kim & Morrow, 2003). These personal characteristics may contribute to the perception of symptom. For example, symptoms were found in higher levels in unemployed patients, reported symptoms varied from culture to culture, younger patients reported higher levels of symptoms than older patients with breast cancer, patients with very recent diagnosis reported higher levels of symptoms (Henry et al., 2008). The findings of the previous study (Henry et al., 2008) and this present study related with Dodd et al.'s model

which explained that personal characteristics would influence the experience of symptom.

Culture might also influence the symptom occurrence, severity and distress. This could be that attitude and the female nature in a culture was the factor influencing symptom experience particularly in the present study. The majority of patients in the present study complained of massive white discharge, and felt very bothered by this physical symptom. Therefore, chemotherapy also leads premenopausal symptoms at a very early age. The majority participants in this study were Muslim and have no formal education or very low educational level. People in rural areas simply do not explain about physical and psychological problems. Differences in symptom severity and symptom distress score were found in women who received chemotherapy in this study. Severity of the symptoms was at a moderate level as was distress level, but with a slightly higher score. There was no variation of symptom severity and symptom distress found between Muslim and followers of other religions. So, overall symptom experience (severity and distress) reported by the patients with breast cancer receiving chemotherapy was at a moderate level in this current study.

Finally, the severity and distress was found at a moderate level. This was because all of the study participants received different types of symptom preventive medication. These findings supported in a study conducted previously (Pandya, Morrow, Roscoe, & Hickok, 2005). The researchers suggested that the gabapentin was used to reduce hot flash in patients with breast cancer who received systemic therapy. They showed that the frequency and severity of hot flashes declined from baseline (21% to 15%). So, their finding proved that gabapentin medicine

controlled the hotflashes (Pandya et al., 2005). Warr et al. (2005) showed that the patients who used aprepitant one hour before chemotherapy had no vomiting during acute and delayed phases during the 5-days after administered of intravenous AC and CMF regimen. However, overall, the patients reported less or no impact on their daily living (Warr et al., 2005).

**Quality of Life of Patients With Breast Cancer Receiving Chemotherapy**

The QoL of Bangladeshi patients with breast cancer receiving chemotherapy in this study was at a moderate level. The mean score under the domain of social relationship and additional concern of breast cancer subscale were higher than the overall QoL mean scores (Table 7). The domain of social relationship consists of feeling close to partner, family accepted illness, and satisfaction with family communication regarding illness. These three subscale scores were high (Table 8). The higher rating of the social relationship demonstrates that the patients with breast cancer receiving chemotherapy had better social well-being. The findings of social relationships were consistent with a previous study (Gokgoz et al., 2011). They found that the patients who were aged 50 and older had the highest scores in emotional, social functioning and body image. Another finding also observed the patients who had local and axilliary breast cancer had better cognitive and sexual function. On the other hand, the researchers observed the patients who experienced symptoms more repeatedly such as fatigue, nausea/vomiting, insomnia, appetite loss, systemic therapy side effects and breast symptoms had lower sexual functioning and sexual enjoyment. The participants in this study who were currently receiving chemotherapy and who had been diagnosed for one year or less, mentioned symptoms

were more likely to occur. This finding is partial congruent with a previous study (Gokgoz et al., 2011). Their findings showed that advanced stages of breast cancer had lower physical, social and sexual functioning than those in the early stages. moreover, lower QoL was observed in patients who used chemotherapy.

Moreover, it was rated high may be because of the participants social relationship with their family members and friends that may play a significant role in Bangladeshi people. Most of the participants lived in rural areas with their families and as a consequence they received social support (Uzun et al., 2004). Even though they have insufficient economic solvency they visit patients together or individually to provide emotional support. In fact this type of comfort is important for patients with breast cancer and mood disturbance and social support had a significant interaction effect on symptom experience (Lee et al., 2004).

In addition, the participants of this study who reported highest social relationship in the social well-being domain had higher social support. This was consistent with a previous study (Rao, Debb, Blitz, Choi, & Cella, 2008). The researchers suggested that the emotional well-being is associated with social support. Social support may not help to improve physical symptoms, however, it can help patients with breast cancer to cope better with their illness. The support from the family gave them strength to cope with and endure the illness. The friendship and neighborly culture in Bangladesh are markedly observed when someone is sick at home or hospitalized. Another important point is that the race and cultural difference may be varied to improve social relationships. This finding is supported by a comparative study (Rao et al., 2008), where reflected subscale level between two different ethnicities of patients with breast cancer. They reported that overall physical,

social, and functional well-beings were poorer but better emotional well-being was found in African American participants than in European American participants.

The three subscales of social domain are feeling close to friends, satisfied with conjugal life and supported by friends. These three subscales were reported at moderate level by the patients in this study. The moderately rated social relationship shows that the patients with breast cancer were negatively affected. The results of the present study are comparable with the previous study conducted in Turkey (Akin et al., 2008). Their study reported that the patients with breast cancer received chemotherapy as AC or FAC regimen and their social well-being domain was affected by demographic factors such as marital status, stage of disease and duration of having breast cancer.

Moreover, the level of physical well-being is the lowest found in the present study. The reason is the majority of the patients completed primary treatment as surgery and they received adjuvant chemotherapy. This finding was consistent with a previous study (Ganz et al., 2004). They stated the participants who had a mastectomy had the poorest physical functioning at registration and at enrollment for chemotherapy. The participants in the current study perceived lower QoL in physical, emotional and functional well-being than social well-being and breast cancer subscale score. Ganz et al. study (2004) showed that physical functioning, emotional functioning , and sexual functioning were poor in patients who completed surgery and chemotherapy. However, poorest physical functioning was observed in patients who had mastectomy. Emotional functioning and physical functioning were disrupted in patients with breast cancer who had significantly higher symptom severity and distress reported by study participants who lived in rural areas (Omran et al., 2012). It

is found that the lower scores of QoL found in all the well-being domains on physical well-being, social/family well-being, emotional well-being, functional well-being and breast cancer subscale (Park, Lee, Lee, Lee, & Hwang, 2011). Park et al. reported lower QoL related to age was found in patients with breast cancer who were more than 50 years old. Reed, Simmonds, Haviland, and Corner study (2012) showed that symptom burden was associated with lower QoL and found in metastasis breast cancer patients. Another longitudinal study results showed that poorest physical functioning was observed in the mastectomy group during registration and appointment. Significantly poor physical functioning and emotional well-being was also reported by patients the end of primary treatment. They reported many physical symptoms i.e., muscle stiffness, breast sensitivity, aches and pains, tendency to take naps, and difficulty concentrating, at the admission. Significantly worse sexual functioning was found in patients who received chemotherapy (Ganz et al., 2004)

The occurrence of the symptoms, symptom severity and symptom distress particularly prohibited the patients' ability to fulfill their family needs and about the two-fifth of patients were not able to meet their family needs at all, and in some cases only had a low level QoL. In parallel, the present study findings were supported in a study by Ogce and Ozkan (2008), it was determined that there was reduced physical activity, physical strength and functional status, because of a statistically significant increase in presence of physical and psychological symptoms after chemotherapy. Finally, the present study findings were supported by Dodd et al.'s model with regard to existence of symptoms as a result of health and illness factors and change in patient's QoL.

**Relationship Between Symptom Experience and QoL**

Based on the study framework, the relationship between symptom experience and QoL is discussed. The patients with breast cancer perceived moderate level symptom experience and poor QoL in the current study. This study showed a significantly negative correlation among symptom severity and QoL, and symptom distress and QoL. Moreover, a number of correlations were found between symptom severity, symptom distress, physical well-being, social well-being, emotional well-being, functional well-being and breast cancer-specific (additional concerns) subscale. Eleven pairs of negative relationships in bivariate correlation were found between symptom severity, symptom distress, subscales of well-being, and quality of life. These were symptom severity and total QoL, symptom severity and physical well-being, symptom severity and social well-being, symptom severity and emotional well-being, symptom severity and functional well-being, symptom severity and breast cancer-specific subscales, symptom distress and total QoL, symptom distress and physical well-being, symptom distress and social well-being, symptom distress and emotional well-being, symptom distress and functional well-being, and symptom distress and breast cancer-specific subscales. The negative correlations of symptom severity and QoL, and symptom distress and QoL of the current study were congruent with Sarenmalm et al.'s study (2007).

There was a significant negative relationship found among physical well-being, social well-being emotional well-being and functional well-being, and total QoL with symptom severity and symptom distress. There was evidently found sufficient correlation. For example, a previous study reported an average occurrence rate of 10 - 23 symptoms (Sarenmalm et al., 2007). The study also reported that lower

coping capacity had higher prevalence of symptoms, experienced higher levels of distress, and experienced worse condition of health, and concluded that this may decrease their health-related quality of life. Patients who have higher symptom severity and distress had worse physical and emotional well-being (Huang et al., 2013). However, there was negative and non-significant relationship observed between symptom severity and breast cancer-specific (additional concerns) subscale ($r$ = -.08), and positive and non-significant relationship found between distress and breast cancer (additional concerns) subscale ($r$ = .019, $p$ > .01).

Again the participants have many social relationships, but they were not trained. Thus, participants in this study had inadequate social support, and experienced at a moderate level of symptom and were more likely to have a poorer QoL (So et al., 2009). The two dimensions of the SMM, symptom experience and QoL are dynamic over time (Dodd et al., 2001). Moreover, symptom distress was found that the highest influence on QoL with correlation coefficients on total effect ($r$) of -.50. The findings of the study indicated that the patients with breast cancer receiving chemotherapy can obtained QoL through symptom experience. Symptom experience, mainly symptom distress, comes across to direct affect patient's QoL mostly. In addition, the symptom severity of mood swings and irritability were the symptoms most strongly associated with a decrease in QoL (Ochayon, Zelker, Kaduri, & Kadmon, 2010). One a reviewed study found that the symptom distress of hair loss has been reported to be associated with lower QoL (Lemieux et al., 2008). Similarly, the two domains are interrelated.

# CHAPTER 5

# CONCLUSION AND RECOMMENDATIONS

The chapter presents a summary of the research findings, the recommendations for future intervention study and strengths and weaknesses of the study.

## Conclusion

The objectives of the descriptive study were to describe the level of symptom experience, quality of life, and to examine the relationships between symptom experience and quality of life of patients with breast cancer receiving chemotherapy in Bangladesh. The sample used in this study consisted of 130 patients with breast cancer receiving chemotherapy by convenience sampling technique adapted to draw the sample. Data were collected through face to face interview using the Demographic and health-related questionnaire, the Chemotherapy Symptom Assessment Scale (C-SAS) and the Functional Assessment of Cancer Therapy-Breast version 4 (FACT-B).

Data were analyzed by using descriptive statistics including frequency, percentage, mean, standard deviation, median, interquartile range and parametric statistics including the Pearson's Product-Moment Correlation Coefficient. The patients with breast cancer receiving chemotherapy in Bangladesh experienced both symptom severity ($M = 2.27$, $SD = 0.25$) and symptom distress ($M = 2.88$, $SD = 0.41$) at a moderate level, where average occurrence rate was 17. The level of QoL of patients with breast cancer was at a moderate ($M = 2.02$, $SD = 0.39$) level. Symptom

severity ($r$ = -.48, $p$ < .01) and symptom distress ($r$ = -.50, $p$ < .01) had a significantly negative correlation with QoL.

The majority of the participants underwent surgery either lumpectomy or mastectomy and all of the patients obviously received chemotherapy in different regimen in this study. Therefore, it is concluded that symptom experience deteriorated the patient's with breast cancer quality of life in various dimensions.

## Strengths and Limitations

This study was the first descriptive study in Bangladesh which explored two variables: symptom experience and quality of life of patients with breast cancer receiving chemotherapy. This study was conducted at the top level referral hospital, and has the high level of technology required for providing chemotherapy for patients with breast cancer in Bangladesh. It was also a tertiary level hospital, where the study participants were appeared from city and rural areas. With this regard, the study findings are considered to have high generalizability.

In spite of these strengths, this study also has a limitation to be acknowledged. Using "recall" response of symptom experience and QoL may limit true scores as some participants may not fully recall such experience.

## Recommendations

### Nursing Practice

Clinical nurses are facing difficulties in reducing symptom experience and promoting well-beings of patients with breast cancer receiving chemotherapy. They are always in front line of health services, because of their close relationships

with women during chemotherapy administration. Thus, findings of this study provide baseline evidence on symptom occurrence, symptom severity and symptom distress to help clinical nurses understand this group of patients. This would lead to their initiation to help reduce such symptoms. When taking care of patients with breast cancer with symptoms, nurses should assess the symptom carefully and avoid making judgments based only on their responses. Another finding was the study patients with breast cancer had a moderate level of QoL and that there were negative relationships between symptom severity and distress and QoL. These findings have important implications for nursing practice. Reducing symptom severity and distress would help improve QoL.

**Nursing Education**

The findings of this study can be utilized by nurse educators as fundamental information to teach about symptoms, and chemotherapy's influence on symptoms to their nursing students. This kind of knowledge is very helpful for students and other nurses to understand the symptoms in relation to symptom experience. In addition, nurse educators and administrators may consider to provide in-service training for nurses working with patients with breast cancer to increase their awareness and understanding of this phenomenon. So that further innovative interventions can be designed to help the patients.

**Nursing research**

This study was conducted by using a quantitative approach to investigate the level of symptom experience, QoL, and to see relationships between

the symptom experience and quality of life. As the importance of these aspects has been emphasized, future intervention study is needed to manage the lived symptom experience of patients with breast cancer receiving chemotherapy. Through further study, better understanding of the differences in symptom experience and QoL can be obtained. An innovative intervention targeted on relieving symptom experience can be proposed and tested in further study.

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# APPENDICES

# APPENDIX A

## Informed Consent

Dear participant,

I am Mosammat Shamsun Naher Begum, working at Chittagong Medical College Hospital, Chittagong, Bangladesh, as senior staff nurse. I am studying Master of Nursing Science, Faculty of Nursing, Prince of Songkla University, Thailand. As a part of my course I am going to conduct a research on "symptom experiences and quality of life of patients with breast cancer receiving chemotherapy" in Bangladesh. I would like to ask some questions about symptom experiences and quality of life of patients with breast cancer receiving chemotherapy.

The reason for the study is to identify the number of symptoms, the symptom severity and symptom distress of patients with breast cancer receiving chemotherapy and to know the level of quality of life of patients with breast cancer receiving chemotherapy. The findings of the study will give basic information to health professionals and to develop future intervention research related to symptoms of patients with breast cancer and their quality of life.

Your participation in this study will be completely voluntary. You can participate in this study or not depend on your decision. In this regard, your decision will be respected and (family opinion) making no difference to your family. You have the right to stop or withdraw from the study at any time without any reason. If you agree to participate in this study, you will be asked to complete the self-reported questionnaire including demographic data, symptom experiences and quality of life of patients with breast cancer receiving chemotherapy. This will take 30 minutes. All of your information will be kept strictly secret. Your anonymity will be guaranteed and

your identity will not be reflected in any part of the document. The raw data will be permanently destroyed after once data analysis will be finished and published report. If you have any question about this study, please feel free to contact me. My address is Mosammat Shamsun Naher Begum, Master of Nursing Science (International Program), faculty of nursing, Prince of Songkla University,Thailand. During data collection, you can communicate to me at Mobile No 01815563848(Bangladesh) and e-mail address is shamsun_naher2000@yahoo.com.On the above mentioned information, I agree to participate in this study.

| | |
|---|---|
| Date | Date |
| ……. | …… |
| Signature of | Signature of |
| Participant…… | Researcher……. |
| Name of | Name of |
| Participant……. | Researcher…….. |

ID.....

Place of the data collection: ☐ 1. OPD ☐2. IPD (Oncology hospital)

## APPENDIX B

### Part 1: Demographic and Health-related Questionnaire

I will ask you some personal data including demographic and health related questionnaire, please answer the best choice and put mark ( ) in the bracket

**Date:…….**

| **Section 1** | **Demographic Data** | |
|---|---|---|
| Age | :……...years | |
| Gender | : ☐1. Male | ☐ 2. Female |
| Living place | : ☐1. Rural | ☐ 2.Urban |
| Marital status | : ☐1. Single<br>☐2.Married | ☐3.Widowed<br>☐4. Divorced |
| Religion | : ☐1.Muslim<br>☐2. Hindu | ☐ 3. Buddhist<br>☐ 4. Christian |
| Education | : ☐1. No formal education<br>☐2. Primary education<br>☐3. SSC(secondary school) | ☐ 5.HSC (Higher Secondary school)<br>☐ 6.Masters/PhD |
| Occupation | :☐1.House Wife<br>☐2.Public Job<br>☐3.Private Job | ☐4.Business<br>☐5.Retired<br>☐6.Others (identity)… |
| Family Monthly income | :……Taka | |
| **Section 2** | **Health and Illness Data (**This section will be filled by the researcher from medical record of the subjects) | |
| Current chemotherapy cycle | :☐ 2. 2nd cycle<br>☐ 3. 3rd cycle<br>☐ 4.4th cycle<br>☐ 5. 5th cycle | ☐ 6. 6th cycle<br>☐ 7. 7th cycle<br>☐ 8. 8th cycle<br>☐ 9. 9th cycle |
| Functional status/ ability to perform daily activity | : ☐1.Independent(fully be able to perform daily activities)<br>☐2.Partial dependent(need some help from others)<br>☐3.Fully dependent(need full help from others) | |

| | | |
|---|---|---|
| Duration of illness since breast cancer diagnosis | : ☐ 1. Months……..... ☐ 2.Years……. | |
| Breast cancer stage | : ☐ 1.Stage I ☐ 2.Stage II | ☐ 3.Stage III ☐ 4.Stage IV |
| Family history of breast cancer | : ☐ 1.Yes ☐ 2. No | |
| Chemotherapy | : ☐ 1. Neoadjuvant ☐ 2. Adjuvant | ☐ 3. Concurrent (chemo+radiation) |
| The conventional treatment | : ☐ 1. Radiotherapy…….. Date……. ☐ 2. Surgery: Type……. Date …… ☐ 3. Chemotherapy: Regimen …….Date……..... ☐ 4. Others specify please…….. | |
| Symptom prophylaxis (drugs) | : ☐ 1.No ☐ 2.Yes, If yes please Specify: | 1.1 Ante-emetics 2.2 Pain medication 2.3 Iron 2.4 Others |
| Comorbid disease | : ☐ No ☐ Yes | |
| Place where symptoms start to occur | : ☐ 1. Hospital ☐ 2. Home | ☐ 3.Work place ☐ 4.Others |
| Having family caregivers to provide support | At hospital: ☐ 1. No ☐ 2.Yes If yes, please specify..... | At home : ☐ 1. No ☐ 2.Yes If yes, please specify..... |
| Economic support | : ☐ 1. *Samaz Kollan tahbil* Islamic social fund (medical) ☐ 2. Private | ☐ 3. Hospital ☐ 4.Patient payment ☐ 5. Patient +Hospital |

## APPENDIX C

### Part 2: The Chemotherapy Symptom Assessment Scale (C-SAS)

The following items of symptom are commonly found in patients with breast cancer receiving chemotherapy. Please give the mark (√) on the column that best fit to your symptom experience and symptom bother from the chemotherapy. If you choose "yes", then you follow to the severity and bother columns. The severity of symptoms describes 3-point rating scale as follows:

3 = Severe

2 = Moderate

1 = Mild

The bother of symptoms describe at 4-point rating scale including:

4 =Very much

3 = quite a bit

2 = a little

1 = Not bother at all

| No | Items | 1 Yes | 0 No | (Severity) How severe was the symptom? | | | (Distress) How much did the symptom bother you? | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | 3 severe | 2 moderate | 1 mild | 4 very much | 3 quite a bit | 2 a little | 1 not at all |
| 1. | Nausea following treatment | | | | | | | | | |
| 2. | Vomiting following treatment | | | | | | | | | |
| 3. | Constipation | | | | | | | | | |
| 4. | Diarrhea | | | | | | | | | |
| 5. | Weight loss or gain | | | | | | | | | |
| 6. | Problems with your mouth or throat(e.g. sore or dry mouth or throat, mouth ulcers) | | | | | | | | | |
| 7. | A change in your appetite or taste | | | | | | | | | |
| 8. | Hair loss | | | | | | | | | |
| 9. | Problems with your skin or nails e.g. dry, itchy or inflamed | | | | | | | | | |

| No | Items | 1 Yes 0 No | (Severity) How severe was the symptom? 3 severe | 2 moderate | 1 mild | (Distress) How much did the symptom bother you? 4 very much | 3 quite a bit | 2 a little | 1 not at all |
|---|---|---|---|---|---|---|---|---|---|
| | skin, sun sensitivity, changes in your nails, vein marking | | | | | | | | |
| 10. | Problems with your eyes e.g. sore, scratchy, dry or watery eyes | | | | | | | | |
| 11. | Feeling unusually tired | | | | | | | | |
| 12. | Feeling weak | | | | | | | | |
| 13. | Pins and needles, or numbness of your hands or feet | | | | | | | | |
| 14. | Nausea or vomiting before treatment | | | | | | | | |
| 15. | Headaches | | | | | | | | |
| 16. | Changes in your periods e.g., periods stopping, becoming irregular, spotting | | | | | | | | |
| 17. | Signs of infection .e.g., feeling unusually hot or cold 'flu-like feelings, high temperature, pain when urinating | | | | | | | | |
| 18. | Pain or discomfort(state where) | | | | | | | | |
| 19. | Bleeding or bruising e.g. nose bleeds, rectal bleeds, blood in urine, bruising | | | | | | | | |
| 20. | Difficulty sleeping | | | | | | | | |
| 21. | Feeling low or depressed | | | | | | | | |
| 22. | Feeling anxious or worried | | | | | | | | |
| 23. | Changes in your intimate or sexual relationships e.g. decreased sexual interest | | | | | | | | |
| 24. | Shortness of breath | | | | | | | | |

## APPENDIX D

### Part 3: The Functional Assessment of Cancer Therapy-Breast (FACT-B) (Version 4)

The following items are quality of life in patients with breast cancer receiving chemotherapy. Please give the mark (√) on the column that best fit to your QoL from the course of chemotherapy cycles. It will measure a 7-day period. The quality of life describes 5- point rating scale as follows: Though some questions of FACT-B similar to C-SAS questionnaire's questions. They are different from each other questions. The C-SAS are overlapped the FACT-B.

0 = Not at all

1 =A little bit

2 = Somewhat

3 = Quite a bit

4= Very much

| No | Items | (0) Not at all | (1) A little bit | (2) Somewhat | (3) Quite a bit | (4) Very much |
|---|---|---|---|---|---|---|
| | **Physical well-being** | | | | | |
| GP1 | I have a lack of energy | | | | | |
| GP2 | I have nausea | | | | | |
| GP3 | Because of my physical condition, I have trouble meeting the needs of my family | | | | | |
| GP4 | I have pain | | | | | |
| GP5 | I am bothered by side effects of treatment | | | | | |
| GP6 | I feel ill | | | | | |
| GP7 | I am forced to spend time in bed | | | | | |
| | **Social/family well-being** | | | | | |
| GS1 | I feel close to my friends | | | | | |
| GS2 | I get emotional support from my family | | | | | |
| GS3 | I get support from my friends | | | | | |
| GS4 | My family has accepted my illness | | | | | |
| GS5 | I am satisfied with family | | | | | |

| No | Items | (0 ) Not at all | (1) A little bit | (2) Somewhat | (3) Quite a bit | (4) Very much |
|---|---|---|---|---|---|---|
| | communication about my illness | | | | | |
| GS6 | I feel close to my partner (or the person who is my main support) | | | | | |
| GS7 | I am satisfied with my sex life | | | | | |
| | **Emotional well-being** | | | | | |
| GE1 | I feel sad | | | | | |
| GE2 | I am satisfied with how I am coping with my illness | | | | | |
| GE3 | I am losing hope in the fight against my illness | | | | | |
| GE4 | I feel nervous | | | | | |
| GE5 | I worry about dying | | | | | |
| GE6 | I worry that my condition will get worse | | | | | |
| | **Functional well-being** | | | | | |
| GF1 | I am able to work(include work at home) | | | | | |
| GF2 | My work (include work in home) is fulfilling | | | | | |
| GF3 | I am able to enjoy life | | | | | |
| GF4 | I have accepted my illness | | | | | |
| GF5 | I am sleeping well | | | | | |
| GF6 | I am enjoying the things I usually do for fun | | | | | |
| GF7 | I am content with the quality of my life right now | | | | | |
| | **Additional concerns** | | | | | |
| B1 | I have been short of breath | | | | | |
| B2 | I am self-conscious about the way I dress | | | | | |
| B3 | One or both of my arms are swollen or tender | | | | | |
| B4 | I feel sexually attractive | | | | | |
| B5 | I am bothered by hair loss | | | | | |
| B6 | I worry about the risk of cancer in other family members | | | | | |
| B7 | I worry about the effect of stress | | | | | |

| No | Items | (0 ) Not at all | (1) A little bit | (2) Somewhat | (3) Quite a bit | (4) Very much |
|---|---|---|---|---|---|---|
| | on my illness | | | | | |
| B8 | I am bothered by a change in weight | | | | | |
| B9 | I am able to feel like a women | | | | | |
| P2 | I have certain parts of my body where I experience pain | | | | | |

Table 11

*Frequency and Percentage of Symptom Occurrence of Patients With Breast Cancer Receiving Chemotherapy (N= 130)*

| No | Items | Yes | No |
|---|---|---|---|
| | | n (%) | n (%) |
| 1 | Nausea following treatment | 117 (90.0) | 13 (10.0) |
| 2 | Vomiting following treatment | 90 (69.2) | 40 (30.8) |
| 3 | Constipation | 90 (69.2) | 40 (30.8) |
| 4 | Diarrhea | 45 (34.6) | 85 (65.4) |
| 5 | Weight loss or gain | 86 (66.2) | 44 (33.8) |
| 6 | Problems with your mouth or throat e.g. sore or dry mouth or throat, mouth ulcers | 124 (95.4) | 6 (4.6) |
| 7 | A change in your appetite or taste | 130 (100.0) | 0 (0.0) |
| 8 | Hair loss | 128 (98.5) | 2 (1.5) |
| 9 | Problems with your skin or nails e.g. dry, itchy or inflamed skin, sun sensitivity, changes in your nails, vein marking | 115 (88.5) | 15 (11.5) |
| 10 | Problems with your eyes e.g. sore, scratchy, dry or watery eyes | 90 (69.2) | 40 (30.8) |
| 11 | Feeling unusually tired | 129 (99.2) | 1 (0.8) |
| 12 | Feeling weak | 130 (100.0) | 0 (0.0) |
| 13 | Pins and needles, or numbness of your hands or feet | 106 (81.5) | 24 (18.5) |
| 14 | Nausea or vomiting before treatment | 5 (3.8) | 125 (96.2) |
| 15 | Headaches | 114 (87.7) | 16 (12.3) |
| 16 | Changes in your periods e.g. periods stopping, becoming irregular, spotting | 66 (50.8) | 64 (49.2) |
| 17 | Signs of infection .e.g. feeling unusually hot or cold, 'flu-like feelings, high temperature, pain when urinating | 76 (58.5) | 54 (41.5) |
| 18 | Pain or discomfort(state where) | 97 (74.6) | 33 (25.4) |
| 19 | Bleeding or bruising e.g. nose bleeds, rectal bleeds, blood in urine, bruising | 12 (9.2) | 118 (90.8) |
| 20 | Difficulty sleeping | 130 (100.0) | 0 (0.0) |
| 21 | Feeling low or depressed | 130 (100.0) | 0 (0.0) |
| 22 | Feeling anxious or worried | 130 (100.0) | |
| 23 | Changes in your intimate or sexual relationships e.g. decreased sexual interest | 83 (63.8) | 47 (36.2) |
| 24 | Shortness of breath | 28 (21.5) | 102 (78.5) |

Table 12

*Frequency and Percentage of Symptom Severity of Patients with Breast Cancer Receiving Chemotherapy (N = 130)*

| No | Items | (0) None | (1) Mild | (2) Moderate | 3) Severe |
|---|---|---|---|---|---|
| | | n (%) | n (%) | n (%) | n (%) |
| 1 | Nausea following treatment | 13 (10) | 4 (3.1) | 29 (22.3) | 84 (64.6) |
| 2 | Vomiting following treatment | 41 (31.5) | 13 (10.0) | 28 (21.5) | 48 (36.9) |
| 3 | Constipation | 40 (30.8) | 9 (6.9) | 46 (35.4) | 35 (26.9) |
| 4 | Diarrhea | 85 (65.4) | 9 (6.9) | 22 (16.9) | 14 (10.8) |
| 5 | Weight loss or gain | 45 (34.6) | 64 (49.2) | 18 (13.8) | 3 (2.3) |
| 6 | Problems with your mouth or throat e.g. sore or dry mouth or throat, mouth ulcers | 6 (4.6) | 3 (2.3) | 49 (37.7) | 72 (55.4) |
| 7 | A change in your appetite or taste | 0 (0.0) | 3 (2.3) | 31 (23.8) | 96 (73.8) |
| 8 | Hair loss | 2 (1.5) | 22 (16.9) | 57 (43.8) | 49 (37.7) |
| 9 | Problems with your skin or nails e.g. dry, itchy or inflamed skin, sun sensitivity, changes in your nails, vein marking | 15 (11.5) | 19 (14.6) | 43 (33.1) | 53 (40.8) |
| 10 | Problems with your eyes e.g. sore, scratchy, dry or watery eyes | 40 (30.8) | 28 (21.5) | 35 (26.9) | 27 (20.8) |
| 11 | Feeling unusually tired | 1 (0.8) | 5 (3.8) | 21 (16.2) | 103 (79.2) |
| 12 | Feeling weak | 0 (0.0) | 4 (3.1) | 28 (21.5) | 98 (75.4) |
| 13 | Pins and needles, or numbness of your hands or feet | 24 (18.5) | 23 (17.7) | 52 (40.0) | 31 (23.8) |
| 14 | Nausea or vomiting before treatment | 125 (96.2) | 2 (1.5) | 1 (0.8) | 2 (1.5) |
| 15 | Headaches | 16 (12.3) | 34 (26.2) | 54 (41.5) | 26 (20.0) |
| 16 | Changes in your periods e.g. periods stopping, becoming irregular, spotting | 64 (49.2) | 49 (37.7) | 16 (12.3) | 1 (0.8) |
| 17 | Signs of infection .e.g. feeling unusually hot or cold, 'flu-like feelings, high temperature, pain when urinating | 54 (41.5) | 37 (28.5) | 33 (25.4) | 6 (4.6) |
| 18 | Pain or discomfort(state where) | 33 (25.4) | 35 (26.9) | 45 (34.6) | 17 (13.1) |

Table 12 (*continued*)

| | Items | (0) None | (1) Mild | 2) Moderate | (3) Severe |
|---|---|---|---|---|---|
| 19 | Bleeding or bruising e.g. nose bleeds, rectal bleeds, blood in urine, bruising | 118 (90.8) | 2 (1.5) | 7 (5.4) | 3 (2.3) |
| 20 | Difficulty sleeping | 0 (0.0) | 5 (3.8) | 41 (31.5) | 84 (64.6) |
| 21 | Feeling low or depressed | 0 (0.0) | 0 (0.0) | 37 (28.5) | 93 (71.5) |
| 22 | Feeling anxious or worried | 0 (0.0) | 0 (0.0) | 32 (24.6) | 98 (75.4) |
| 23 | Changes in your intimate or sexual relationships e.g. decreased sexual interest | 48 (36.9) | 39 (30.0) | 31 (23.8) | 12 (9.2) |
| 24 | Shortness of breath | 101 (77.7) | 17 (13.1) | 10 (7.7) | 2 (1.5) |

Table 13
*Frequency and Percentage of Symptom Distress of Patients with Breast Cancer Receiving Chemotherapy (N = 130)*

| No | Items | (0) None | (1) Not at all | (2) A little | (3) Quite a bit | (4) Very much |
|---|---|---|---|---|---|---|
| | | n (%) | n (%) | n (%) | n (%) | n (%) |
| 1 | Nausea following treatment | 13 (10.0) | 3 (2.3) | 9 (6.9) | 34 (26.2) | 71 (54.6) |
| 2 | Vomiting following treatment | 40 (30.8) | 3 (2.3) | 23 (17.7) | 21 (16.2) | 43 (33.1) |
| 3 | Constipation | 40 (30.8) | 6 (4.6) | 26 (20.0) | 35 (26.9) | 23 (17.7) |
| 4 | Diarrhea | 85 (65.4) | 6 (4.6) | 16 (12.3) | 14 (10.8) | 9 (6.9) |
| 5 | Weight loss or gain | 45(34.6) | 41(31.5) | 35 (26.9) | 8 (6.2) | 1(0.8) |
| 6 | Problems with your mouth or throat e.g. sore or dry mouth or throat, mouth ulcers | 6 (4.6) | 2 (1.5) | 27 (20.8) | 36 (27.7) | 59 (45.4) |
| 7 | A change in your appetite or taste | 0(0.0) | 2 (1.5) | 16 (12.3) | 32 (24.6) | 80 (61.5) |
| 8 | Hair loss | 2 (1.5) | 14 (10.8) | 35 (26.9) | 40 (30.8) | 39 (30.0) |
| 9 | Problems with your skin or nails e.g. dry, itchy or inflamed skin, sun sensitivity, changes in your nails, vein marking | 15 (11.5) | 11 (8.5) | 36 (27.7) | 31 (23.8) | 37 (28.5) |
| 10 | Problems with your eyes e.g. sore, scratchy, dry or watery eyes | 40 (30.8) | 17 (13.1) | 35 (26.9) | 12 (9.2) | 26 (20.0) |
| 11 | Feeling unusually tired | 1 (0.8) | 3 (2.3) | 11 (8.5) | 26 (20.0) | 89 (68.5) |
| 12 | Feeling weak | 0 (0.0) | 3 (2.3) | 13 (10.0) | 30 (23.1) | 84 (64.6) |
| 13 | Pins and needles, or numbness of your hands or feet | 24 (18.5) | 13 (10.0) | 40 (30.8) | 31 (23.8) | 22 (16.9) |
| 14 | Nausea or vomiting before treatment | 25 (96.2) | 1 (0.8) | 2 (1.5) | 0 (0.0) | 2 (1.5) |
| 15 | Headaches | 16(12.3) | 18(13.8) | 41(31.5) | 42 (32.3) | 13(10.0) |
| 16 | Changes in your periods e.g. periods stopping, becoming irregular, spotting | 64 (49.2) | 35 (26.9) | 26 (20.0) | 5 (3.8) | 0 (0.0) |
| 17 | Signs of infection .e.g. feeling unusua hot or cold, 'flu-like feelings, high temperature, pain when urinating | 54 (41.5) | 24 (18.5) | 31 (23.8) | 15 (11.5) | 6 (4.6) |
| 18 | Pain or discomfort(state where) | 33 (25.4) | 16 (12.3) | 45 (34.6) | 29 (22.3) | 7 (5.4) |
| 19 | Bleeding or bruising e.g. nose bleeds, rectal bleeds, blood in urine, bruising | 118 (90.8) | 0 (0.0) | 5 (3.8) | 5 (3.8) | 2 (1.5) |
| 20 | Difficulty sleeping | 0 (0.0) | 4 (3.1) | 13 (10.0) | 45 (34.6) | 68 (52.3) |
| 21 | Feeling low or depressed | 0 (0.0) | 1 (0.8) | 9 (6.9) | 46 (35.4) | 74 (56.9) |
| 22 | Feeling anxious or worried | 0 (0.0) | 2 (1.5) | 12 (9.2) | 42 (32.3) | 74 (56.9) |
| 23 | Changes in your intimate or sexual relationships e.g. decreased sexual interest | 47 (36.2) | 20 (15.4) | 46 (35.4) | 15 (11.5) | 2 (1.5) |
| 24 | Shortness of breath | 02 (78.5) | 4 (3.1) | 16 (12.3) | 8 (6.2) | 0 (0.0) |

Table 14

*Frequency and Percentage of Quality of Life of Patients with Breast Cancer Receiving Chemotherapy (N= 130)*

| | Items | (0) Not at all | (1) A little bit | (2) Somewhat | (3) Quite a bi | (4) Very muc |
|---|---|---|---|---|---|---|
| | | *n* (%) | *n* (%) | *n* (%) | *n* (%) | *n* (%) |
| | **Physical well-being** | | | | | |
| GP1 | I have a lack of energy | 80 (61.5) | 20 (15.4) | 24 (18.5) | 5 (3.8) | 1 (0.8) |
| GP2 | I have nausea | 19 (14.6) | 27 (20.8) | 47 (36.2) | 14 (10.8) | 23 (17.7) |
| GP3 | Because of my physical condition, I have trouble meeting the needs of my family | 47 (36.2) | 27 (20.8) | 34 (26.2) | 13 (10.0) | 9 (6.9) |
| GP4 | I have pain | 16 (12.3) | 15 (11.5) | 43 (33.1) | 28 (21.5) | 28 (21.5) |
| GP5 | I am bothered by side effects of treatment | 60 (46.2) | 34 (26.2) | 27 (20.8) | 7 (5.4) | 2 (1.5) |
| GP6 | I feel ill | 70 (53.8) | 39 (30.0) | 15 (11.5) | 4 (3.1) | 2 (1.5) |
| GP7 | I am forced to spend time in bed | 58 (44.6) | 42 (32.3) | 26 (20.0) | 4 (3.1) | 0 (0.0) |
| | **Social/family well-being** | | | | | |
| GS1 | I feel close to my friends | 2 (1.5) | 41 (31.5) | 26 (20.0) | 19 (14.6) | 42 (32.3) |
| GS2 | I get emotional support from my family | 0 (0.0) | 3 (2.3) | 21 (16.2) | 14 (10.8) | 92 (70.8) |
| GS3 | I get support from my friends | 2 (1.5) | 34 (26.2) | 33 (25.4) | 18 (13.8) | 43 (33.1) |
| GS4 | My family has accepted my illness | 1 (0.8) | 2 (1.5) | 7 (5.4) | 4 (3.1) | 116 (89.2) |
| GS5 | I am satisfied with family communication about my illness | 0 (0.0) | 0 (0.0) | 16 (12.3) | 15 (11.5) | 99 (76.2) |
| GS6 | I feel close to my partner (or the person who is my main support) | 0 (0.0) | 0 (0.0) | 8 (6.2) | 4 (3.1) | 118 (90.8) |
| GS7 | I am satisfied with my sex life | 44 (33.8) | 3 (2.3) | 18 (13.8) | 6 (4.6) | 59 (45.4) |
| | **Emotional well-being** | | | | | |
| GE1 | I feel sad | 65 (50.0) | 37 (28.5) | 24 (18.5) | 4 (3.1) | 0 (0.0) |
| GE2 | I am satisfied with how I am coping with my illness | 6 (4.6) | 14 (10.8) | 43 (33.1) | 26 (20.0) | 41 (31.5) |
| GE3 | I am losing hope in the fight against my illness | 31 (23.8) | 26 (20.0) | 47 (36.2) | 15 (11.5) | 11 (8.5) |
| GE4 | I feel nervous | 48 (36.9) | 33 (25.4) | 34 (26.2) | 8 (6.2) | 7 (5.4) |

Table 14 (*continued*)

| | Items | (0) Not at all | (1) A little bit | (2) Somewhat | (3) Quite a bit | (4) Very much |
|---|---|---|---|---|---|---|
| | | *n* (%) | *n* (%) | *n* (%) | *n* (%) | *n* (%) |
| GE5 | I worry about dying | 60 (46.2) | 22 (16.9) | 23 (17.7) | 18 (13.8) | 7 (5.4) |
| GE6 | I worry that my condition will get worse | 57 (43.8) | 18 (13.8) | 34 (26.2) | 19 (14.6) | 2 (1.5) |
| | **Functional well-being** | | | | | |
| GF1 | I am able to work(include work at home) | 16 (12.3) | 74 (56.9) | 28 (21.5) | 10 (7.7) | 2 (1.5) |
| GF2 | My work (include work in home) is fulfilling | 4 (3.1) | 61 (46.9) | 28 (21.5) | 19 (14.6) | 18 (13.8) |
| GF3 | I am able to enjoy life | 10 (7.7) | 65 (50.0) | 34 (26.2) | 8 (6.2) | 13 (10.0) |
| GF4 | I have accepted my illness | 0 (0.0) | 2 (1.5) | 4 (3.1) | 8 (6.2) | 116 (89.2) |
| GF5 | I am sleeping well | 5 (3.8) | 39 (30.0) | 63 (48.5) | 13 (10.0) | 10 (7.7) |
| GF6 | I am enjoying the things I usually do for fun | 3 (2.3) | 62 (47.7) | 33 (25.4) | 16 (12.3) | 16 (12.3) |
| GF7 | I am content with the quality of my life right now | 1 (0.8) | 55 (42.3) | 40 (30.8) | 13 (10.0) | 21 (16.2) |
| | **Additional concerns** | | | | | |
| B1 | I have been short of breath | 25 (19.2) | 18 (13.8) | 41 (31.5) | 19 (14.6) | 27 (20.8) |
| B2 | I am self-conscious about the way I dress | 24 (18.5) | 24 (18.5) | 33 (25.4) | 46 (35.4 | 3 (2.3) |
| B3 | One or both of my arms are swollen or tender | 11 (8.5) | 8 (6.2) | 20 (15.4) | 38 (29.2) | 53 (40.8) |
| B4 | I feel sexually attractive | 34 (26.2) | 10 (7.7) | 22 (16.9) | 20 (15.4) | 44 (33.8) |
| B5 | I am bothered by hair loss | 28 (21.5) | 22 (16.9) | 28 (21.5) | 32 (24.6) | 20 (15.4) |
| B6 | I worry about the risk of cancer in other family members | 55 (42.3) | 22 (16.9) | 28 (21.5) | 16 (12.3) | 9 (6.9) |
| B7 | I worry about the effect of stress on my illness | 50 (38.5) | 29 (22.3) | 34 (26.2) | 12 (9.2) | 5 (3.8) |
| B8 | I am bothered by a change in weight | 5 (3.8) | 4 (3.1) | 8 (6.2) | 32 (24.6) | 81 (62.3) |
| B9 | I am able to feel like a women | 1 (0.8) | 1 (0.8) | 1 (0.8) | 4 (3.1) | 123 (94.6) |
| P2 | I have certain parts of my body where I experience pain | 3 (2.3) | 3 (2.3) | 16 (12.3) | 28 (21.5) | 80 (61.5) |

# APPENDIX E

## Experts of the Validity Test

Three experts examined the Scale-Content Validity Index (S-CVI) of the Chemotherapy Symptom Assessment Scale (C-SAS) and The Functional Assessment of Cancer Therapy-Breast Cancer (FACT-B).

1. Asst. Prof. Dr. Hathairat Sangchan
   Lecturer, Faculty of Nursing, Prince of Songkla University
   Thailand
2. Ms. Orapan Chaipet
   Advanced Practice Nurse (APN) on palliative care, Sonklanagarind Hospital
   Thailand
3. Asst. Prof. Dr. Mohammad Sajjad Yusuf
   Oncologist, Chittagong Medical College and Hospital,
   Bangladesh

# APPENDIX F

## Back Translators of the Instruments

Three persons worked on the translation of the instruments: the Demographic Data Form and Chemotherapy Symptom Assessment Scale (C-SAS). These three language experts are:

For English Version of the Bengali Version

1. MD. Sazzad Hossain, M Sc. in Nursing (Paediatric)
   Lecturer, Chittagong Nursing College
   Chittagong, Bangladesh

For Bengali Version of the English original instruments

2. Md Belal Uddin Ahmed, MPH (HE)
   Lecturer, North East Nursing College
   Sylhet, Bangladesh

For discrepancy and clarity of two Versions questionnaires

3. Saifullah Mohammed Saem
   Teacher, Faculty of English, IPeace School & College
   BA Hons in English, International Islamic University Chittagong

## APPENDIX G
## Asking Permission of the Instrument

**From:** David Cella [mailto:d-cella@northwestern.edu]
**Sent:** Saturday, August 10, 2013 9:40 AM
**To:** shamsun naher; Jason Bredle
**Cc:** W P
**Subject:** RE: Prayer for asking permission to use questionnaire

Hi Shamsun,

No problem, here you go. Let me know if you need anything else.

Thanks,
Jason

Jason Bredle
FACIT.org
+1.773.807.9094

**From:** shamsun naher [mailto:shamsun_naher2000@yahoo.com]
**Sent:** Monday, August 12, 2013 3:00 AM
**To:** d-cella@northwestern.edu; Jason Bredle
**Cc:** W P
**Subject:** Re: Prayer for asking permission to use questionnaire

Dear Professor Cella and Jason,

I am very grateful for your kind support. Yes, I would like to have the Bengali version of the FACT-B to use in my thesis work with Bangladeshi patients with breast cancer receiving chemotherapy.

I am looking forward to hearing from you again and I will follow your suggestion strictly.

Sincerely Yours,
Mosammat Shamsun Naher Begum

---

**From:** Jason Bredle <jbredle@facit.org>
**To:** shamsun naher <shamsun_naher2000@yahoo.com>
**Cc:** W P <pwongcha@hotmail.com>
**Sent:** Monday, August 12, 2013 4:45 AM
**Subject:** RE: Prayer for asking permission to use questionnaire

Hi Shamsun,

If you register on the website, you should be able to download the English questionnaire and scoring directly from the Questionnaires page. Let me know if you need a translated version, and I can send it to you if it's available – we have it in Bengali if you need it.

Kind regards,
Jason

Jason Bredle
FACIT.org
+1.773.807.9094

**From:** David Cella [mailto:d-cella@northwestern.edu]
**Sent:** Saturday, August 10, 2013 9:40 AM
**To:** shamsun naher; Jason Bredle
**Cc:** W P
**Subject:** RE: Prayer for asking permission to use questionnaire

Yes, you have permission. Specifics on administration and scoring are on website (www.facit.org) or from jason bredle (copied) if you require a non-English version. There will be a license fee if this is commercially-sponsored, but it appears it is your academic work, which will not carry any fee.

Dave cella

David Cella, PhD
http://www.mss.northwestern.edu/faculty/cella.html

**From:** shamsun naher [mailto:shamsun_naher2000@yahoo.com]
**Sent:** Saturday, August 10, 2013 8:29 AM
**To:** David Cella
**Cc:** W P
**Subject:** Prayer for asking permission to use questionnaire

Dear Professor David F. Cella,

With due respect to you, I am Mosammat Shamsun Naher Bagum from Bangladesh. I am a master student at department of Medical/Surgical Nursing, Faculty of Nursing, Prince of Songkla University, Thailand. I am proposing to conduct a thesis, entitled "Symptom Experience and Quality of Life of Breast Cancer

Patients Receiving Chemotherapy in Bangladesh." Now I am processing of developing the instrument to collect data.

I have reviewed your article entitled "Reliability and Validity of the Functional Assessment of Cancer Therapy-Breast Quality-of-Life Instrument" (1993) and consider it to be appropriate for use in my study. Therefore, I would like to ask for permission to use the FACT-B. If you grant me to use permission, please also advice it's scoring and interpretation. I am hoping that you would kindly consider this request. If you have any queries regarding this request, you can also contact my supervisor, Assistant Professor Dr. Wongchan Petpichetchian at wongchan-p@psu.ac.th

Sincerely

Mosammat Shamsun Naher Begum
Master student
Department of Medical/ Surgical Nursing,
Faculty of Nursing,
Prince of Songkla University,
Hat Yai, Songkla,Thailand.
E-mail: shamsun_naher2000@yahoo.com

# VITAE

**Name** Mosammat Shamsun Naher Begum
**Student ID** 5510420024

## Educational Attainment

| Degree | Name of Institution | Year of Graduation |
|---|---|---|
| Bachelor of nursing science | Bangladesh open University | 2006 |
| Diploma in midwifery | Nursing Institute, Chittagong | 1991 |
| Diploma in Nursing | Nursing Institute, Chittagong | 1992 |

## Scholarship Award during Enrollment

2012 - 2014 Scholarship for the Degree of Master of Nursing Science (International Program), Faculty of Nursing, Prince of Songkla University, funded by the Government of the People's Republic of Bangladesh

## Work-Position and Address

**Work-Position** Senior staff nurse, Chittagong Medical College and Hospital, Bangladesh
**Phone** 8801815563848
**E-mail** shamsun_naher2000@yahoo.com