Name	DR. NORLEY SHUIB
Matric No.	MGC090001
Title of thesis	SEXUAL DYSFUNCTION, BODY IMAGE DISTRESS AND MARITAL DISSATISFACTION IN BREAST CANCER PATIENTS OF UNIVERSITY MALAYA MEDICAL CENTRE (UMMC)
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SEXUAL DYSFUNCTION, BODY IMAGE DISTRESS AND MARITAL DISSATISFACTION IN BREAST CANCER PATIENTS OF UNIVERSITY MALAYA MEDICAL CENTRE (UMMC)

BY

DR. NORLEY SHUIB

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Department of Psychological Medicine

Faculty of Medicine

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ORIGINAL LITERARY WORK DECLARATION

Name of candidate : Dr. Norley Shuib IC No:

Matric No : MGC090001

Name of degree : Master of Psychological Medicine (MPM)

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Field of study : Psychological Medicine

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PROF. DR. NOR ZURAIDA ZAINAL
CONSULTANT PSYCHIATRIST
DEP. OF PSYCHOLOGICAL MEDICINE
FACULTY OF MEDICINE
UNIVERSITY MALAYA

ABSTRACT

Sexual dysfunction, body image distress and marital dissatisfaction in breast cancer patients of University Malaya Medical Centre (UMMC)

Introduction: Breast cancer is the commonest cancer amongst Malaysian women. Recent literature has shown that, the disease itself and adverse effects of the cancer treatment were associated with sexual dysfunction, body image distress and marital dissatisfaction.

Aim: The aim of the study is to determine the prevalence of sexual dysfunction in breast cancer patients who are in remission attending follow-up at the breast clinic in UMMC.

Method: This is a cross-sectional study conducted at the breast clinic in UMMC. The patients were given self-reported questionnaires, the Female Sexual Function Index (FSFI), Breast Impact of Treatment Scale (BITS), Golombok Rust Inventory of Marital State (GRIMS), Hospital Anxiety and Depression Scale (HADS) and Psychological General Well-Being Index (PGWBI). Socio-demographic, clinical, disease and marital data were obtained by interviewing the patients and also reviewing the medical notes. Ethical approval for the study was obtained from the Ethics Committee of UMMC.

Results: A total of 100 breast cancer patients were recruited. The prevalence of sexual dysfunction as assessed by the Female Sexual Function Index (FSFI) with the cut-off score of ≤ 26.6 was 90.0%. By using the Breast Impact of Treatment Scale (BITS), the prevalence of body image distress was 42.9%. The prevalence of marital dissatisfaction determined by the Golombok Rust Inventory of Marital State (GRIMS) was 55.0%. The Hospital Anxiety and Depression Scale (HADS) was used to assess depression (prevalence of 9.0%) and anxiety (prevalence of 27.0%).

Actual age of disease onset, total GRIMS score (marital dissatisfaction) and HADS-D sub-scale score (depression) were found to be independently associated with sexual dysfunction.

Conclusion: Breast cancer survivors experienced great level of sexual dysfunction, body image distress, marital dissatisfaction, depression and anxiety. These findings serve as an alarm for health care providers for early and routine assessment of these matters. A prompt referral to the mental health services may be required for further evaluation and appropriate treatment when indicated.

ABSTRAK

Disfungsi seksual, tekanan berkaitan imej tubuh dan ketidakpuasan dalam perkahwinan di kalangan pesakit kanser payudara Pusat Perubatan Universiti Malaya (PPUM)

Pengenalan: Kanser payudara adalah merupakan kanser yang paling lazim dihidapi oleh wanita Malaysia. Kajian terkini telah mendapati bahawa kanser payudara sendiri dan kesan sampingan dari rawatan kanser mempunyai perkaitan dengan disfungsi seksual, tekanan berkaitan imej tubuh dan ketidakpuasan dalam perkahwinan.

Objektif: Objektif utama kajian ini dijalankan adalah untuk menentukan prevalens disfungsi seksual yang dialami oleh pesakit kanser payudara yang berada dalam remitan yang menghadiri rawatan susulan di klinik payudara di PPUM.

Kaedah: Ini adalah kajian keratan rentas yang dijalankan di klinik payudara di PPUM. Pesakit diberikan borang kajian soal selidik yang perlu dijawab sendiri, yang terdiri dari borang “Female Sexual Function Index” (FSFI), “Breast Impact of Treatment Scale” (BITS), “Golombok Rust Inventory of Marital State” (GRIMS), “Hospital Anxiety and Depression Scale” (HADS) dan “Psychological General Well-being Index” (PGWBI). Data sosio-demografik, klinikal, penyakit dan perkahwinan diperolehi dengan menemubual pesakit dan juga menyemak nota perubatan pesakit. Kebenaran untuk menjalankan kajian ini telah diperolehi daripada Ahli Jawatankuasa Etika PPUM.

Keputusan: Seramai 100 orang subjek telah menyertai kajian ini. Prevalens disfungsi seksual diperolehi dengan menggunakan “Female Sexual Function Index” (FSFI) pada jumlah skor ≤ 26.6 adalah 90.0%. Prevalens tekanan berkaitan imej tubuh adalah 42.9% dengan menggunakan “Breast Impact of Treatment Scale” (BITS). “Golombok Rust Inventory of Marital State” (GRIMS) telah digunakan untuk memperolehi prevalens ketidakpuasan dalam perkahwinan, iaitu sebanyak 55.0%. Prevalens untuk kemurungan dan keresahan dengan menggunakan “Hospital Anxiety and Depression Scale” (HADS) adalah sebanyak 9.0% dan 27.0% masing-masing.

Usia ketika permulaan kanser, jumlah skor bagi GRIMS (ketidakpuasan dalam perkahwinan) dan skor bagi skala HADS-D (kemurungan) menunjukkan perkaitan yang bebas dengan disfungsi seksual.

Kesimpulan: Subjek yang menghidapi kanser payudara yang menghadiri rawatan susulan di klinik payudara di PPUM mempunyai tahap disfungsi seksual, tekanan berkaitan imej tubuh, ketidakpuasan dalam perkahwinan, kemurungan dan keresahan yang tinggi. Keputusan yang diperolehi menunjukkan bahawa kakitangan perubatan harus peka dan berwaspada terhadap permasalahan ini. Penilaian awal dan berkala adalah perlu untuk pengesanan awal. Rujukan kepada pakar kesihatan mental haruslah dibuat pada kadar segera bagi tujuan penilaian lanjut dan seterusnya rawatan jika perlu.

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CHAPTER ONE

INTRODUCTION

Breast cancer is the commonest cancer affecting women. Both women from developed and less developed countries are affected by it (WHO, 2014). It is the second most commonly diagnosed cancer worldwide, after lung cancer, with an estimate of 1.38 million cases (10.9%) in 2008 based on the GLOBOCAN report. Although it ranks the fifth as cancer-related death in 2008, with 458,000 deaths (6.1%) recorded, breast cancer is still the commonest cause of cancer death in women globally (Ferlay et al, 2010). Almost 50% of breast cancer cases and 58% of deaths were recorded in less developed countries, even though breast cancer is said to be a disease of the developed countries (GLOBOCAN, 2008).

The lifetime risk for breast cancer is 1 in 20 women in Malaysia and breast cancer is the commonest malignancy in women (Lim and Halimah, 2003). Based on the National Cancer Registry 2007, breast cancer ranked number one among the top ten cancers in Malaysia. A total of 3292 cases were diagnosed in 2007, which was 18.1% of all cancer cases (National Cancer Registry, 2007). Commonly, women in Malaysia presented with bigger tumour size and at more advanced stages of the disease. These may be due to certain health beliefs, inaccurate information, and insufficient health care facilities that prohibited routine early detection and treatment of breast cancer (Yip and Omar, 2003).

The diagnosis of breast cancer and its treatment modalities tremendously affect the patient’s life. Survivorship of the disease has improved over the years with greater use of screening mammography and advances in its treatment modalities (American Cancer Society, 2009; Bloom et al, 2004; Taylor et al, 2002; Qaseem et al, 2007). In the

United States alone, more than 2.9 million breast cancer survivors are recorded in the 2012 (Siegel et al, 2012). Improvement in the survivorship of the disease has transformed breast cancer from a terminal illness to a disease with a chronic course (Sherman and Hossfeld, 1990). Breast cancer does not only affect the patient physically, but it also has psychological and social impact (Bloom et al, 2004; Ganz et al, 2002). Its impact on quality of life is an increasing important area of study with the improvement of the survival rates (Taylor et al, 2002). Literature has reported a wide range of disturbances in the daily living secondary to the diagnosis of breast cancer (Rowland and Massie, 2009). Women with breast cancer may experience physical changes to their body as a result of cancer treatment. The disease may also lead to change in body image, self-esteem and psychological distress. Other psychosocial impacts of breast cancer are financial, relationship and work related issues.

This disease threatens an organ that is closely related to attractiveness, femininity, sexuality, motherhood, and consequently with body and self- image, and self-esteem (Abdul Rahim, 2010). Cancer patients were found to have significant fears associated with the effects of surgery on the body and side effects due to chemotherapy (Farooqui et al, 2011). Common adverse effects of chemotherapy, radiation therapy, breast cancer surgery, and hormonal therapy are vaginal irritation and dryness, dyspareunia, decreased sexual desire, alopecia, nausea, vomiting, early onset menopause, and significant emotional disturbances (Bakewell and Volker, 2005). Cancer-related traumatic stress symptoms may be seen in 50% of breast cancer patients (Butler et al, 1999) and as high as 45% of early stage breast cancer patients suffer from anxiety or depression (Henson, 2002).

Women with breast cancer were found to be more self-conscious (Walsh, Manuel and Avis, 2005), less attractive (Henson, 2002), and have poorer body images compared to normal controls (Mock, 1993). Surgical treatment either modified radical mastectomy or segmental mastectomy are associated with some level of breast loss or breast change. However, these options are less disfiguring compared to the previous Halstead radical mastectomy which involves the *"amputation of the breast with a wide excision of the pectoral muscles and axillary lymph nodes"* (Frierson, Thiel and Andersen, 2006). Altered body image is associated with breast cancer surgeries (Collins et al, 2011). Breast disfigurement and body image dissatisfaction can lead to psychological disturbances in women with breast cancer (Falk et al, 2010; Hemls et al, 2008).

Breast cancer treatments also have a substantial effect on sexual function, with as high as 50% to 76% of women with the disease experienced sexual difficulties after breast cancer treatment (Burbie and Polinsky, 1992; Goldfarb et al, 2009). Adverse effects of breast cancer treatments such as sex hormone deficiency (Buijs et al, 2008; Joly et al, 2000; Meyerowitz et al, 1999; Schover, 2008) or body image changes (Arora et al, 2001; Janz et al, 2005) may affect sexual functioning of women with breast cancer.

The disease does not only affect the patient, but it also can be intensely distressing for the family (Ganz et al, 1998; Henson, 2002; Schover, 1991). Substantial amount of strains were experienced in relationships during breast cancer. A study conducted by Walsh and colleagues (2005) found that 25% of women suffering from breast cancer experienced difficulties in their relationship, 35% felt that their spouses were emotionally absent, and 12% reported separation. This study also found that the separations were mostly instigated by men who were not able to handle the issues pertaining to their wives' or spouses' cancer (Walsh, Manuel and Avis, 2005).

In this study, the breast cancer patients who are in clinical remission attending follow up at the breast clinic in University Malaya Medical Centre (UMMC) will be given a set of questionnaires after an informed and written consent was obtained. This study is to look at the interactions between, sexual dysfunction, body image distress, and marital dissatisfaction in breast cancer survivors who have been attending follow up at the breast clinic. These pertinent issues may be inter-related to each other which may affect the quality of life of breast cancer survivors. Hence, the aim of this study is to look at sexual dysfunction and its association with body image distress, marital dissatisfaction and other confounding factors in breast cancer survivors (BCS). Sexual dysfunction and psychological aspects associated with it may persist even long after completion of breast cancer therapy and during clinical remission, thus play a vital part in the quality of life and survival of women with breast cancer. To date, there are no published data or studies regarding sexual dysfunction, body image distress, and marital dissatisfaction among BCS in Malaysia.

CHAPTER TWO

LITERATURE REVIEW

2.1 EPIDEMIOLOGY OF BREAST CANCER

Breast cancer is rapidly increasing globally. In 2002, there were 1.15 million cases of breast cancer recorded in the world (Parkin et al, 2005). In 2008, there was an increase in the incidence of the disease detected to 1.38 million and breast cancer is the second most common cancer type diagnosed in the world after lung cancer, which is 10.9% of all new cancer cases and 23% of all female cancers. It is the commonest cancer type in women both in the developed and less developed countries (WHO, 2014). There is geographical variation of the incidence rates around the world, with a higher incidence of greater than 80 per 100, 000 in more developed countries reported than in the developing countries. Less developed countries recorded lower incidence rate of less than 40 per 100, 000. Each region reported an estimate of 690, 000 new cases with the population ratio of 1:4 (GLOBOCAN, 2008). North America has the highest incidence rate of breast cancer with the age standardized rates of 99.4 per 100, 000 population. The Eastern Europe, South America, Southern Africa, and Western Asia regions have moderate incidence rates and most African countries recorded the lowest incidence rates (Jemal et al, 2004). Breast cancer is associated with significant morbidity and mortality. Based on a report, 1 out of 8 women in the United States (US) are at risk to develop breast cancer throughout their lifetime (US Breast Cancer Statistics, 2013). According to the Breast Cancer Facts and Figures 2013-2014 by the American Cancer Society, an estimated of 232, 340 American women will be newly diagnosed with invasive breast cancer in 2013. It was also estimated that there will be 39, 620 breast cancer deaths in US in the 2013, and breast cancer is the second cause of cancer-related deaths in women, just behind lung cancer (American Cancer Society, 2014). Globally, it ranked as the fifth killer from cancer overall with 458, 000 deaths recorded in 2008. However, breast cancer is still the most common cause of death in women worldwide, with 189, 000 deaths in the developed regions and 269, 000 deaths in the less developed regions (GLOBOCAN, 2008).

In Asia, the rates of breast cancer are lower compared to the Western countries. The incidence rates of breast cancer in the Asian region varied from 15 to 50 per 100, 000 population based on a report by the International Agency for Research on Cancer in 2007 (Curado et al, 2007). The “more westernized” areas in Asia such as Singapore, Japan and Hong Kong recorded highest incidence rates whereas India, Korea and Thailand had the lowest rates in 2007 (Curado, 2011). Despite the lower incidence rates, breast cancer is still the commonest cancer and cause of cancer-related deaths in Asian women (Curado, 2011).

In Malaysia, 3738 new cases of breast cancer were recorded in 2003 based on the National Cancer Registry (NCR) with age standardized incidence rate (ASR) of 46.2 per 100, 000 women. An estimate of 1 in every 20 women in the country has risk of developing breast cancer throughout their lifetime. The ASR in the Chinese population is the highest, with 59.7 per 100, 000 population, and this is followed by the Indians and the Malays, with ASR of 55.8 per 100, 000 population and 33.9 per 100, 000 population respectively. Approximately 1 in 16 Chinese, 1 in 16 Indian and 1 in 28 Malay women has the risk of developing breast cancer throughout their lives (Lim and Halimah, 2003).

According to the National Cancer Registry, breast cancer is ranked number one among the top ten cancers in Malaysia in 2007 with the incidence of 3292 cases diagnosed (18.1% of all cancers). It accounted for 32.1% of all female cases diagnosed with cancer. It is the commonest cancer among Malaysian women, regardless of their ethnic origin and is also the most common cause of cancer-related deaths among women in this country. The Chinese has the highest incidence rate with the age standardized incidence rate (ASR) of 38.1 per 100, 000 population, and this is followed by the Indians with the ASR of 33.7 per 100, 000 population. The lowest incidence of breast cancer is observed in the Malays with the ASR of 25.4 per 100, 000 population. The most susceptible age group for breast cancer among Malaysian women are seen in between 50 to 59 years (National Cancer Registry, 2007).

Based on an epidemiological study of breast cancer conducted in University Malaya Medical Centre (UMMC), the commonest age of presentation is between 40 to 49 years among women in the country. Women below the age of 50 years represented just over 50% of the cases, 16.8% below 40 years and 2% below 30 years of age (Yip, Taib and Mohamed, 2006). From 1993 to 2004, presentation at the early stages (Stages 1 and 2) of the disease was seen in about 60-70% of women and 30-40% presented with advanced stages (Stages 3 and 4) of breast cancer. Lump in the breast through breast self-examination was the most common presenting complaint which is over 90% of the cases. The average tumour was 4.2cm. Malaysian women who were symptomatic waited for 3 months prior to seeking professional medical advice on the average. Malays were the highest presenting with advanced stage of the disease, with 40% reported to be in Stage 3 and 4 at the time of diagnosis. This was followed by the Indians, 20% and the Chinese, 15%. Malaysian women presents at later stages of the disease compared to the Western countries, where more than 80% of women presented with early stage of breast cancer and smaller tumour size with the mean diameter of 2.0 cm resulting in poorer outcome (Yip, Taib and Mohamed, 2006). The latest data based on the NCR showed that 58% presented at Stage 1 and 2 of the disease and 42% presented at an advanced stage (Stages 3 and 4) in the year 2007 (National Cancer Registry, 2007). Infiltrating ductal carcinoma is the commonest histological type of breast cancer seen in Malaysian women in both age groups of below and above 50 years (Sheikh et al, 2012).

2.2 SURVIVORSHIP OF BREAST CANCER

Prevention, early detection and improvements in breast cancer treatments have led to positive changes with regards to the prognosis, outcome, and survivor of breast cancer patients. Breast cancer survivor was defined differently in the literatures. As an example, breast cancer survivor used to define only those patients who were in remission for at least 5 years after being diagnosed. The term has now evolved to be more comprehensive which include anyone who has been diagnosed with the illness until death which includes those who are asymptomatic or those living with recurrence of the illness (Ganz and Hahn, 2008; Hewitt, Greenfield and Stovall, 2005; Pagani et al, 2010). In 2009, there were at least 2.4 million breast cancer survivors in the United States (Katz et al, 2009). The number of survivors had increased to an estimate of 2.8 million in 2013 based on the report produced by the American Cancer Society. The 10 year-survival rate for breast cancer patients from a hospital based study conducted in Nottingham Hospital was reported to have improved from 55% to

77% recently (Blamet et al, 2007). Globally it is reported that there are 4.4 million breast cancer survivors living 5 years after the diagnosis of the illness (Epplein et al, 2011). The number of survivors is reported to be on the rise (Hickey et al, 2009).

The survival of breast cancer patients depends on many factors. The essential prognostic factors determining the survival of patients with breast cancer are tumour stage at the point of diagnosis, tumour size, menstrual status and the histopathology of the cancer itself. The population structures which consist, the population age structure and ethnicity, socioeconomic background, the availability of an effective health care system and accessibility to high quality treatment are amongst other factors that could have influenced the survival of breast cancer patients (Hortobagyi et al, 2005; Tan et al, 2007).

In a study conducted in University Malaya Medical Centre (UMMC), the overall 5 year survival rate was 59.1% among 413 patients diagnosed with breast cancer between 1993 to 1997 (Taib et al, 2008). A retrospective cohort study conducted in Hospital Kuala Lumpur, Malaysia, indicated that the overall survival rate was the lowest in the Malay ethnic group with 39.7%, followed by the Indians and the Chinese, with survival rates of 47.2% and 48.2% respectively. Other factors that were accounted for poor survival identified in this study are larger tumour size, lymph node involvement, HER 2 and ERPR status, both breasts involvement and delayed presentation (Ibrahim et al, 2012). A study involving 166 breast cancer patients who were followed up for a period of 18 and 34 months in University Malaya Medical Centre (UMMC) found the mortality rate of 20.7% and recurrence rate of 10.3% (Yip and Looi, 1996). Based on a report produced by the International Cancer Screening Network, the annual breast cancer mortality rate for Malaysia was 14.7 per 100, 000 population in 2008.

A more recent population-based retrospective cohort study conducted in Malaysia involving breast cancer patients who were diagnosed with the disease between the year 2000 to 2005, reported that the overall 5-year survival rate was 49.4%. The median survival time for the 10, 230 breast cancer patients recruited into the study was 68.1 months. Indian women have the highest 5-year survival rate of 54.2%, and this is followed by Chinese women with the survival rate of 49.1%. Malay women reported the lowest 5-year survival rate of 45.1% among the 3 main ethnics in Malaysia. The study also demonstrated that younger women aged less than 50 years have a significantly better survival compared to those aged above 50 years (Abdullah et al, 2013).

Based on the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) database 2003-2009, 61% of patients were diagnosed with localized breast cancer, 32% with regional spread, 5% distant spread and 2% unknown or unstaged breast cancer. The 5-year survival for localized breast cancer is 98.6%, and this is followed by regional spread and unstaged breast cancer, with 84.4% and 50.0% respectively. Distant spread has the lowest 5-year survival of 24.3% (Howlader, 2012). In another study conducted in Izmir, Turkey, out of 1786 patients with breast cancer recruited from 1995 to 2008, the average survival was 36.98 months with a maximum of 168 months. The overall survival rate for the first 5 years was 90%, and 77% after 14 years of diagnosis. Early-stage patients have a higher survival rate compared to the advance-stage patients. Stage I have been reported to have the highest 5-year survival rate of 98%, and this are followed by Stage IIa with 93%. The lowest overall survival rate was seen in Stage IIIb with 93%. The same observation was also made in the 14-year survival rate with 94% for Stage I, 84% for Stage IIa, 64% for Stage IIb, 74% for Stage IIIa, and 64% for Stage IIIb (Gokce, Karadogan and Akçay, 2011).

Local recurrence of breast cancer is defined as *"a tumour that occurs in the original tumour bed (from residual cells) that has the same histopathologic features as the primary tumor"* (Odle, 2011). The local recurrence rate for breast cancer is in between 1% to 2% per year (Usmani et al, 2010). Depending on cancer and treatment type, a woman with history of breast cancer has 7% to 30% risk of recurrence and a 45% to 90% risk of distant metastases (Pan et al, 2010).

Despite the increase in the number of survivors, breast cancer is still the commonest cause of cancer death in women worldwide. An estimation of around 458, 500 female deaths in 2008 is related to breast cancer or nearly one in seven of all cancer deaths in women. Eastern Asia has the lowest female breast cancer mortality rates while Southern and Western Africa have the highest, with an around three-fold variation in the mortality rates between the regions of the world (Ferlay et al, 2008).

2.3 SEXUALITY AND SEXUAL FUNCTION IN BREAST CANCER

Sexuality is an important aspect of life. It involves a complex interaction between the physical, psychological, interpersonal, and behavioural aspects of a person (National Cancer Institute, 2013). Sexuality is subjective and has a wide range of normality. The factors that have important roles in the determination of sexuality by individual patient and his/ her spouse are sex, age, personal attitudes, and religious, and cultural background (National Cancer Institute, 2013). *"Sexuality is a personal expression of one's self and one's relationship with others"* (Pelusi, 2006). *"Sexuality encompasses feelings about one's own body, the need for touch, interest in sexual activities, communication of one's needs to a partner, and the ability to engage in satisfying sexual activities"* (Henson, 2002). Factors that are important in ensuring healthy sexuality are women's perceptions, different gender roles and feelings of femininity (Wilmoth, 2001). In contrast, sexual functioning involves desire, arousal, lubrication and orgasm. Sexual health is defined as *"the ongoing process towards physical, psychic and socio-cultural well-being connected with sexuality"* (World Health Organization and Sexology, 2000). Sexuality and sexual functioning are closely related to each other. Different types of cancer could cause sexual dysfunction. It is also a common adverse effect of cancer treatments, with an estimate of 40% to 100% after various cancer therapies (Derogatis and Kourlesis, 1981).

Breasts are considered as erogenous part of the body and play an essential role in the female sexuality. The diagnosis of breast cancer threatened women's normal femininity by affecting their sense of self, body image and emotional health (Gibert, Ussher, and Perz, 2010; Spence, 1995; Young, 1992).

Patients with breast cancer and its treatment alone could have a tremendous influence on woman's sexuality. The changes to sexual function and health can potentially be the most troublesome areas of life after breast cancer even following successful treatment of the disease (Anderson, 2009; Bertero et al, 2007; Burwell et al, 2006). It is also often associated with serious physical and psychological consequences (Langellier and Sullivan, 1998). Women with breast cancer have reduced sexual satisfaction and struggled to maintain their sexual life when compared to their same-aged healthy counterparts (Speer et al, 2005).

The specific sexual well-being disturbances experienced by breast cancer survivors are pain, fatigue, reduced vaginal lubrication, nausea, hot flushes, night sweats, vomiting, vaginal irritation, painful sexual intercourse, reduced sexual libido, vaginal atrophy, reduced sexual arousal, numbness in previously sensitive breasts and problems with orgasm (Avis, Crawford and Manuel, 2004; Fobair et al, 2006; Ganz et al, 1998; Ganz et al, 2003; Knobf, 2001; Wilmoth, 2001). Archibald et al (2006) found that some survivors of breast cancer had positive changes with regards to their sexuality after the disease. On the contrary to this finding, most literature concluded that women with breast cancer experience a spectrum of psychological adverse effects, such as depression and anxiety (Garussi and Faezee, 2008). These women also experience changes in their sexual self (Wilmorth, 2001). In an online survey conducted in Australia, 1259 women with breast cancer participated by answering an open-ended question asking about subjective experience of alterations to sexual health after breast cancer. The commonest concerns identified are those related to psychological disturbances, physical changes, perceptions of themselves as being unattractive or less feminine, self- acceptance of changes, concerns related to spouse or relationship, and spousal support and relationship improvement (Ussher, Perz and Gilbert, 2012).

2.4 PREVALENCE OF SEXUAL DYSFUNCTION IN BREAST CANCER SURVIVORS

Sexual dysfunction is commonly related to different types of cancer and cancer treatments. Sexual dysfunction is defined as *"a lack of healthy/ expected/ normal, sexual response/ interest where psychological, biological, interpersonal, and contextual factors may contribute"* (Basson et al, 2003). Sexual dysfunction after various cancer therapies is estimated to be in the range of 40% to 100% across sites (Derogatis and Kourlesis, 1981). Surgery, chemotherapy, radiotherapy and hormonal therapy are treatment modalities available for breast cancer. Sexual dysfunction is a recognized complication of breast cancer therapy that can affect women regardless of their menopausal status and their quality of life. Sexual function can be affected by consequences of breast cancer therapies such as sex hormone deficiency (Buijs et al, 2008; Joly et al, 2000; Meyerowitz et al, 1999; Schover, 2008) or by changes in body image (Arora et al, 2001; Janz et al, 2005). The commonest sexual problems experienced by women with cancer are decreased sexual desire, painful sexual intercourse, changes in genital sensation secondary to pain or loss of sensation and numbness, and difficulties in achieving orgasm (Schover, Montague and Lakin, 1997). These problems can cause sexual dissatisfaction secondary to pain and frustration, also leading to decreased frequency of sexual activity (Bre´dart et al, 2011). Even though it is considered as a common adverse effect of the disease itself and its different treatment modalities, sexual dysfunction is among the least talked about issues in cancer survivors (Dizon, 2009). Sexual disorders do not only occur during treatment of breast cancer but also persist after completion of treatment (Katz, 2011). Hence, this could possibly explain the high prevalence (90%) of sexual dysfunction observed in women with breast cancer, with some studies reporting that almost all women experience some form of sexual complaints after therapy of breast cancer (Krychman, 2006).

In a survey conducted involving 509 women with breast cancer at different stage of the disease and receiving therapy, 76% of the respondents experienced sexual dysfunction attributed to breast cancer or its therapies, defined as a Female Sexual Function Index (FSFI) score < 26. Majority of these patients (79%) perceived their sexual symptoms to be bothersome. 51% reported moderate or severe levels of bother with a FSFI score of 5 and less (Goldfarb et al, 2009). In a separate study conducted in France involving 378 breast cancer survivors (BCS), the prevalence of sexual problems were found to be significantly higher in BCS than the adjusted data from a French female representative sample ($p < 0.0001$). These include differences in frequency of sexual intercourses in the past month, dyspareunia, problems with sexual libido, and difficulty with regards in reaching orgasm (Bre´dart et al, 2011).

Based on another research done, long-term sexual dysfunction is seen in about 50% of women with breast cancer (Ganz et al, 1998). The similar proportion was also observed in women who have had gynaecological cancer (Andersen, 1995). In a prospective cohort study carried out in Seoul National University Bundang Hospital (SNUBH) involved 191 breast cancer patients who had undergone surgery, more moderate to severe problems with sexual desire (30.1%, 27.7%, and 26.0% vs. 17.5%) and sexual activity (13.3%, 12.7%, and

11.4% vs. 6.0%) at 3, 6, and 12 months following breast cancer surgery were reported among these women compared with the pre-treatment levels. Sexual interest or desire, that was assessed by the Beck Depression Inventory item 21 (BDI 21), and also sexual activity, as assessed by the Disability of the Arm, Shoulder, and Hand item 21 (DASH 21) demonstrated significant deterioration at each follow up post-surgery compared with pre-treatment data ($p<0.001$ in all cases for both) (Yang et al, 2011).

A cross-sectional survey of breast cancer outpatients was conducted in Japan in 2005. The data from 85 patients, who were sexually active before breast cancer operation and were without recurrence were analysed. Although 73 patients had resumed sexual activity after surgery, 43 recorded a decrease in the frequency of sexual activity. Majority (72 women) reported at least one sexually related changes, which includes decreased sexual interest, hesitation to be naked in front of partner, reduced sexual pleasure, physical distress described as pressure to the chest during sexual intercourse, dyspareunia, and uncomfortable sensation when touched at the surgical scar (Takashi et al, 2008). A qualitative and quantitative online survey conducted in Australia found that the majority of the 1956 participants with breast cancer (98% were women) recorded a reduction in frequency of sex (78%), energy for sex (76%), sexual arousal (74%), feeling desirable (73%), sexual libido (71%), sexual pleasure (64%), sexual satisfaction (62%), and intimacy (60%). The same study also identified fatigue (71%), vaginal dryness (63%), hot flushes (51%), and feeling unattractive (51%) were the most frequent areas of breast cancer or breast cancer therapies that were thought to have an impact on sexual health (Ussher, Perz and Gilbert, 2012).

2.5 FACTORS ASSOCIATED WITH SEXUAL DYSFUNCTION IN BREAST CANCER SURVIVORS

2.5.1 PATIENT'S AGE

A French study involving 378 breast cancer survivors reported that 29% (109) of the subjects had absence of sexual activity at the time of the survey. Age more than 55 years was identified as a factor associated with no sexual activity or sexual dissatisfaction based on univariate analysis conducted on the total sample in the same study. Age of greater than 50 years was also associated with reduced frequency of sexual activity, reduced sexual pleasure (Sexual Activity Questionnaire (SAQ)- Pleasure sub-scale), or greater sexual discomfort (SAQ- Discomfort sub-scale) in 268 women reporting current sexual activity (Bre´dart et al, 2011).

Speer and colleagues conducted a study among 55 breast cancer survivors (BCS) who were not having recurrence and who had completed their initial breast cancer therapy, which found that women who were more than 70 years old have very low sexual functioning scores based on the Female Sexual Function Index (FSFI) used. The amount of lubrication and sexual pain experienced by BCSs were related to age (Speer et al, 2005).

Another study done in Sudan looked at sexual health issues involving 100 breast cancer patients and 100 controls. The patients were at different stages of breast cancer and had undergone different cancer treatment options. Out of the 100 patients, 60 patients had received hormonal therapy and were in the follow-up period, and 40 patients had yet to receive hormonal therapy and were having chemotherapy and/ or radiation therapy. Watts Sexual Function

Questionnaire was used in the outcome assessment. A negative correlation (*r*= -0.188, df= 98, p= 0.03) was found between sexual function and patients' age (Abasher, 2009).

2.5.2 STAGE OF CANCER

A longitudinal study was conducted to look at the variations in sexual problems over time comparing women with early stage breast cancer and healthy controls. This study had involved 1033 participants of which, 17.3% was Stage 0, 33.4% was Stage I or IIA and 49.3% was healthy women. Four interviews were carried out at 4-6 months (T1), 6 months (T2), 1 year (T3), and 2 years (T4) after surgery for breast cancer patients or a negative/ benign screening mammogram for the control group. This study reported that women with early stage breast cancer are more likely to experience problems related to sexual attractiveness compared to their healthy counterparts at the initial phase of the disease (4-6 months). Problems related to sexual attractiveness were reported less by these women as the time progresses (Pérez et al, 2010).

In a different study, involving 191 newly diagnosed breast cancer patients, 60% of the sample indicated interruption in their sexual quality of life. Advanced stage of the disease was among the factors reported to lead to disruption in sexual quality of life among these women during breast cancer therapy (Beckjord and Campas, 2007).

2.5.3 MEDICAL COMORBIDITY

Sexual functioning can be affected by chronic medical illness. Neurological, vascular, endocrinological, musculoskeletal, or psychological are the mechanism that maybe involved in the disturbances of sexual functioning (Nusbaum, Hamilton and Lenehan, 2003). Few, if any, chronic illnesses require limitation of sexual activity, even though sexual activity involves high physical demands (Kaplan, 1974; Kolodny, Masters and Johnson, 1979). Nevertheless, changes to sexual activity to accommodate physiological or mechanical limitations may be carried out by couples (Nusbaum, Hamilton and Lenehan, 2003). Patients with chronic illness may not be interested in sex or may become sexually inactive because of misunderstandings about their capability to have sex or the safety of having sexual relations, or due to body image worries or grief related to the diagnosis of their illness (Carter, 1990). Treatments for chronic illnesses such as medications and surgery can also cause disruption in sexual functioning (Nusbaum, Hamilton and Lenehan, 2003)

Bre´dart and colleagues (2011) had carried out a research to examine the prevalence and determinants of sexual activity, sexual difficulties, and sexual satisfaction in French breast cancer survivors (BCSs). The participants consisted of 378 women, with early-stage breast cancer, post-treatment of 6 months to 5 years, aged 18-70 years, and they were randomly chosen from an appointment list. They filled in questionnaires assessing the quality of life (EORTC QLQ-C30 and QLQ-BR23), body image scale, and sexuality (Sexual Activity Questionnaire- SAQ, Relationship and Sexuality Scale, and French Sexual Behaviour Scale- CSF). Presence of concomitant disease(s) was among the factors identified to be associated with no sexual activity or sexual dissatisfaction in BCSs who participated in the research using univariate analysis (Bre´dart et al, 2011).

2.5.4 SURGICAL INTERVENTIONS

Surgery is one of the treatment modalities available for treatment of breast cancer. In a prospective study carried out in Morocco, 120 patients who were diagnosed with breast cancer from a medical oncology department at University Military Hospital of Instruction at Rabat were enrolled into the study. Female Sexual Function Index (FSFI) was used to examine sexual functioning in the subjects. A total of 80 patients (66.5%) had undergone radical mastectomy and 40 patients (33.5%) had breast conserving surgery (BCS). Majority of the subjects (91.5%) reported an absence of sexual dysfunction before the diagnosis and therapy of breast cancer. However, of these, 100% indicated deterioration of the symptomatology after various treatment modalities. In this sub-sample, 78% has reported that they had no previous history of sexual dysfunction prior to the cancer treatment. Of the sexual dysfunctions, 9% was observed after surgery (Sbitti et al, 2011).

Of 186 women with Stage I or II breast cancer who have had lumpectomy, 57% reported lubrication disorder, 53.8% were dissatisfied with their sexual health, desire disorder in 42.5%, and arousal disorder in 37.0% (all patients vs. 204 healthy controls $p< 0.01$). This study indicated that lumpectomized breast cancer women experienced significantly marked difficulties in their sexual functioning (Safarinejad, Shafiei and Safarinejad, 2013).

Biglia and colleagues (2010) conducted a study involving 35 women with a premenopausal diagnosis of breast cancer who are waiting for adjuvant treatment. They were assessed at baseline which is during first follow up post-surgery (T0), then post chemotherapy or at least 6 months of hormonal therapy (T1), and after a year (T2). The participants completed validated scales on menopausal symptoms, sexuality, partner relationship, depression, body image, and cognitive functions. The types of surgery that the participants had undergone are lumpectomy (91.4%), mastectomy (8.6%), sentinel lymph node (51.4%), and axillary dissection (48.6%). Half of the participants had McCoy Female Sexuality Questionnaire (MFSQ) scores below the normal range already at baseline. The mean score related to the sexuality domain was significantly impaired after 1 year of follow-up (-12.7, p= 0.022) (Biglia et al, 2010).

In a study carried out by Pérez and colleagues, patients with mastectomy (35.7%) have 2.7 times greater odds to report sexual difficulties on the 9 items measuring sexual interest, sexual attractiveness, and ability to enjoy sexual relations (arousal, dyspareunia/ discomfort, orgasm, and satisfaction) at 2-year follow-up compared to baseline (p= 0.0339) (Pérez et al, 2010). Patients who had undergone mastectomy also were reported to have low sexual desire and were only slightly satisfied with their sex life in a different study involving 123 Turkish patients who had mastectomy (Karabulut, 2009).

A prospective study involving 223 women with early-stage breast cancer, found that on average, women who had undergone breast conserving therapy (BCT), had lower quality of sexual life (QOSL) scores compared to those who had mastectomy. Women who had mastectomy also had higher sexual functioning (SF) scores than to those who had undergone BCT (Den Oudsten et al, 2010).

On a contrary, a study conducted in Turkey involving 75 breast cancer survivors (50 patients received total mastectomy alone and 25 had total mastectomy and breast reconstruction surgery), and 50 healthy controls, found that the type of surgery has no effect on sexual satisfaction as indicated by similar mean scores of the Golombok Rust Inventory of Sexual Satisfaction (GRISS) between the three groups (Elbi Mete, Noyan and Alper, 2004). This finding is further supported by another study done in Korea involving 191 women diagnosed with breast cancer who were interviewed at baseline (prior to surgery), and then at 3, 6, and 12 months follow up post-surgery. Among the domains assessed in the survey are sexual desire, sexual activity, sexual satisfaction, sexual attractiveness, body image, medical illness, symptoms of upper limb dysfunction, and socio-demographic data. 60.2% (115 patients) had undergone conservative surgery (CS), whilst 39.8% (76 patients) had undergone extensive surgery (ES). The type of surgery had no significant effect on the sexual health (Burwell et al, 2006; Ganz et al, 1992; Yang et al, 2010).

2.5.5 CHEMOTHERAPY

A woman's physical and psychological health can be seriously affected by chemotherapy, which may affect the quality of life (Arora et al, 2001; Kaplan 1992; Lindley et al, 1998; Makar et al, 1997). Longstanding impairments in sexual functioning have been associated with chemotherapy (Dorval et al, 1998; Dow et al, 1996; Ganz et al, 1998; Ganz et al, 1996; Young et al, 1996). Sexuality can be affected by chemotherapy directly, through gonadal and hormonal changes, or indirectly, by inducing feelings of fatigue, apathy, nausea, vomiting and malaise, and sleep or appetite changes that lead to interruption of sexual libido (Kaplan, 1992).

Researches that investigated the effects of adjuvant chemotherapy on the quality of life have reported significant impacts on sexual dysfunction (Alfonso et al, 1997; Arora et al, 2001; Dorval et al, 1998; Dow et al, 1996; Ganz et al, 1998; Ganz et al, 1996; Kaplan, 1992; Lindley et al, 1998; Makar et al, 1997; Rose and Davis, 1980; Wilmoth and Ross, 1996; Young, 1996). These include dyspareunia, vaginal dryness, impaired sexual activity, and reduced libido (Lindley et al, 1998; Makar et al, 1996; Wilmoth and Ross, 1996; Young, 1996).

Previous literature had identified that between 50-60% of women with breast cancer who had completed chemotherapy experienced sexual dysfunction past 12 months post treatment (Curran et al, 1998; Lindley et al, 1998). In a separate study involving 120 Moroccan women with breast cancer, as high as 90% of the participants reported sexual dysfunction after chemotherapy (Sbitti et al, 2011).

A longitudinal Korean study involving 191 women with breast cancer found that chemotherapy cause changes in sexual desire and sexual activity only at the early stage post therapy ($p < 0.05$) (Yang et al, 2011). A recent systemic review of literature investigating the changes in sexuality after breast cancer reported that women who had undergone adjuvant chemotherapy are at increased risk for sexual dysfunction compared to those who had not received such treatment. Disorders of arousal, lubrication, orgasm, and dyspareunia were most significantly associated with the sexual dysfunction observed (Emilee, Ussher and Perz, 2010).

A study observed that patients who undergone surgery (lumpectomy or mastectomy) followed by chemotherapy had higher rates of reporting an adverse effect on their sex life, with 48% for lumpectomy and 51% for mastectomy. The patients who had surgery only, reported rates of 18% and 25% for lumpectomy and mastectomy respectively (Ganz et al, 2004 and 2005).

Women who received high doses of chemotherapy are at greater risk of developing sexual dysfunction compared to those who received conventional doses (Arora et al, 2001; Makar et al, 1997). Women who became menopausal secondary to chemotherapy experienced more prominent changes in sexual functioning after chemotherapy (Curran et al, 1998; Ganz et al, 1998; Young, 1996).

2.5.6 RADIOTHERAPY

Among short-term side effects of adjuvant radiotherapy to the breast are breast tenderness and skin redness. These side effects have no significant impact on sexual functioning in breast cancer patients (Kissane et al, 2004). Sexual function was significantly less affected by radiotherapy as the primary adjuvant treatment when compared to adjuvant chemotherapy as reported by multiple studies (Beckmann et al, 1983; Carroll, 1991; Cohen, Kahn and Steeves, 1998; Dunn et al, 1998; Greer and White, 1977; Lasry et al, 1987; Meyer and Aspegren, 1988; Morris et al, 1980; Rosenqvist, Sandelin and Wickman, 1996; Steginga et al, 1998; Wellisch et al, 1989).

There were no literature found that indicated extensive increases in psychosexual problems after radiation therapy (Kissane et al, 2004). A study reported 75% of women who chose primary radiation therapy before surgery had unchanged or good sexual quality of life (Lasry et al, 1987).

In another study involving 120 Moroccan diagnosed with breast cancer, dyspareunia (65%) is the commonest sexual dysfunction reported. Problems with lubrication are seen in 54% of women and the absence or reduction of sexual libido (48% and 64%, respectively).Orgasmic problems (40%), sexual dissatisfaction (37%), short duration of intercourse and arousal (38%) were seen in about one third of the participants. Before the diagnosis and treatment of breast cancer, sexual dysfunction were absent in 91.5% of women and worsening of the symptoms after breast cancer therapies were seen in all of these patients. Sexual dysfunction was reported in only 3% of the women receiving radiotherapy (Sbitti, 2011). The incidence of sexual dysfunction after radiotherapy was also reported being as low as 6% (Barni and Mondin, 1997).

2.5.7 HORMONAL TREATMENT

Hormonal treatment are divided into non-steroidal anti-oestrogens (tamoxifen, toremifene, droloxifene, and raloxifene), steroidal anti-oestrogens (faslodex), luteinizing hormone-releasing hormone agonists (goserelin), selective aromatase inhibitors (anastrozole, letrozole, vorozole, formestane, and fadrozole), progestins (medroxyprogesterone acetate), and androgens/ antiandrogens (Buzdar and Hortobagyi, 1998). The most common side effects observed are hot flushes, increased weight, nausea, fatigue, and vaginal bleeding, discharge or irritation. Rate of thromboembolic events is 1% and the risk for endometrial cancer is 2 cases per 1000 patients yearly with tamoxifen (Buzdar and Hortobagyi, 1998).

Tamoxifen has been the most frequently researched. Although anecdotal reports describe tamoxifen both increases and decreases sexual desire, these are very rare events occurring (Barni and Ardizzoia, 1998; Leonard, Lee and Harrison, 1996). The National Cancer Institute (NCI) conducted a large survey on sexual functioning involving American breast cancer survivors with an average of three years post diagnosis. Nearly half of the participants were presently on tamoxifen. Tamoxifen did not significantly affect sexual functioning (Ganz et al, 1998).

A cross-sectional study involving 85 Japanese women with breast cancer also found that there were no statistically significant correlations between having a history of hormonal therapy with reduced sexual libido, reduced sexual pleasure, and dyspareunia (Takahashi et al, 2007). This finding was further supported by a Moroccan study where none of the subjects on hormonal therapy reported problem in their sexual function (Sbitti, 2011).

2.5.8 BODY IMAGE

"Body image is defined as the mental picture of one's body, an attitude about the physical self, appearance, and state of health, wholeness, normal functioning, and sexuality. Body image is a component of a larger concept of self that for women includes feeling feminine and attractive (Carver et al, 1998; Cohen et al, 1998; Hopwood, 1993; Mock, 1993; White, 2000) *enjoying one's body as a symbol of social expression, and as a way of being in the world*" (Cohen et al., 1998). Higher levels of self-confidence in coping with breast cancer are seen in women with positive body image perceptions (Pikler and Winterowd, 2003). Sexual function can also be affected by psychological responses to cancer through mood and body image changes and disturbances in established patterns of achieving physical pleasure and intimacy (Fobair et al, 2006; Frierson et al, 2006).

Lam and colleague (2012) conducted a study to examine the degree and factors associated with change in body image and sexuality throughout the first year after breast cancer diagnosis. A total of 363 Chinese women undergoing surgery for breast cancer were assessed at baseline, 1 month, 4 months, and 8 months post-surgery. The modalities that were assessed at baseline were psychological disturbances, treatment decision making (TDM) difficulties, satisfaction with outcome of therapy, optimism, and self-efficacy. Self-image and sexuality was assessed at every follow-up. A total of 211 out of the 363 original participants were successfully traced and assessed 6 years later. High-stable, recovery, and high-deteriorating were the different trajectories of self-image and sexuality recognized from the study. Stable levels of self-image and sexuality scores were seen in most women (64% self-image; 58% sexuality).

Those with high-stable level of self-image had the best 6-year self-image and sexuality. High and stable self-image and sexuality were indicated by low TDM difficulties and high treatment outcome satisfaction.

In a Danish study involving a total of 214 patients who were treated with breast conserving therapy (BCT), among the participants, 15% reported reduction in femininity, 25% experience reduction in sexual attractiveness, and 28% of patients had changed their dressing habits secondary to the disease or breast cancer therapy (Lyngholm et al, 2013).

Fobair and colleagues (2006) carried out a study involving a sample of 549 women who were assessed seven months of diagnosis with breast cancer (in situ, local, or regional). The study observed that half of the participants reported body image issues, with 33% had two or more body image issues some of the time, and 17% at least one problem much of the time. Out of the 360 sexually active women, half (52%) experienced a little problem in two or more areas of sexual functioning (24%), or a definite or serious problem in at least one area (28%). This study also showed the association between body image problems and sexual difficulties faced by women with breast cancer (Fobair et al, 2006). A Korean study also identified that low perceived sexual attractiveness early post-surgery was associated with higher overall sexual problems (Yang et al, 2011). Similar finding was also observed in the research conducted by Bre´dart and colleagues (2012).

2.5.9 MENOPAUSE

Menopause is a sequel of surgical removal of the ovaries or the adverse effect of chemotherapy, which can disrupt ovarian function, leading to anovulation and impairment in fertility (Kissane et al, 2004). Reduction in oestrogen levels and the classical symptoms of vaginal dryness, and painful sexual intercourse are experienced by postmenopausal women, which may possibly lead to reduction of sexual activity (Hentschel, 2001), also seen in women treated for breast cancer (Couzi, Helzlsouer and Fetting, 1995).

Women who do not experience pre-mature menopause post therapy for breast cancer were found to have better sexual functioning, with the presence of normal libido, sexual satisfaction and better marital adjustment (Ghizzani et al, 1995). Interruption of normal ovarian function affects body image and sexual adjustment after adjuvant chemotherapy (Bines, Oleske and Cobleigh, 1996). Premature menopause was also the main association between chemotherapy and sexual dysfunction in other studies (Burwell et al, 2006; Schover, 1994).

Based on a study conducted online involving young Dutch women (45 years of age and less) with breast cancer, premature menopause has been found to have led to the occurrence of genital arousal disorder in the samples (Kedde et al, 2013).

2.5.10 MARITAL RELATIONSHIP

Interruptions and changes in the daily living resulting from breast cancer diagnosis were described in a growing literature (Rowland and Massie, 2009). Marriage is an important element in the woman’s adaptation process to the diagnosis and therapy of breast cancer (Bloom et al, 2001). Treatment phase is a period when patients are at increased risk to develop psychological distress and in great need of support. A study suggests that the relationship with their spouse is a very important source of support during this phase. Hence this provides a probable explanation for the strong associations observed between marital quality, intimacy, and women’s psychological quality of life (PQoL) (Moreira et al, 2011).

Majority of women with breast cancer experienced body image and sexual problems at the initial phase after the diagnosis of the disease, with greater sexual and body image problems were associated with the partner’s difficulty in understanding the patient’s feelings (Fobair et al, 2006).

Bre´dart and colleagues (2011) identified that no, and reduced frequency of sexual activity, sexual dissatisfaction, reduced sexual pleasure, and higher sexual discomfort were all associated with perceived emotional separation in the spouse or spousal fear of sexual intercourse among breast cancer survivors.

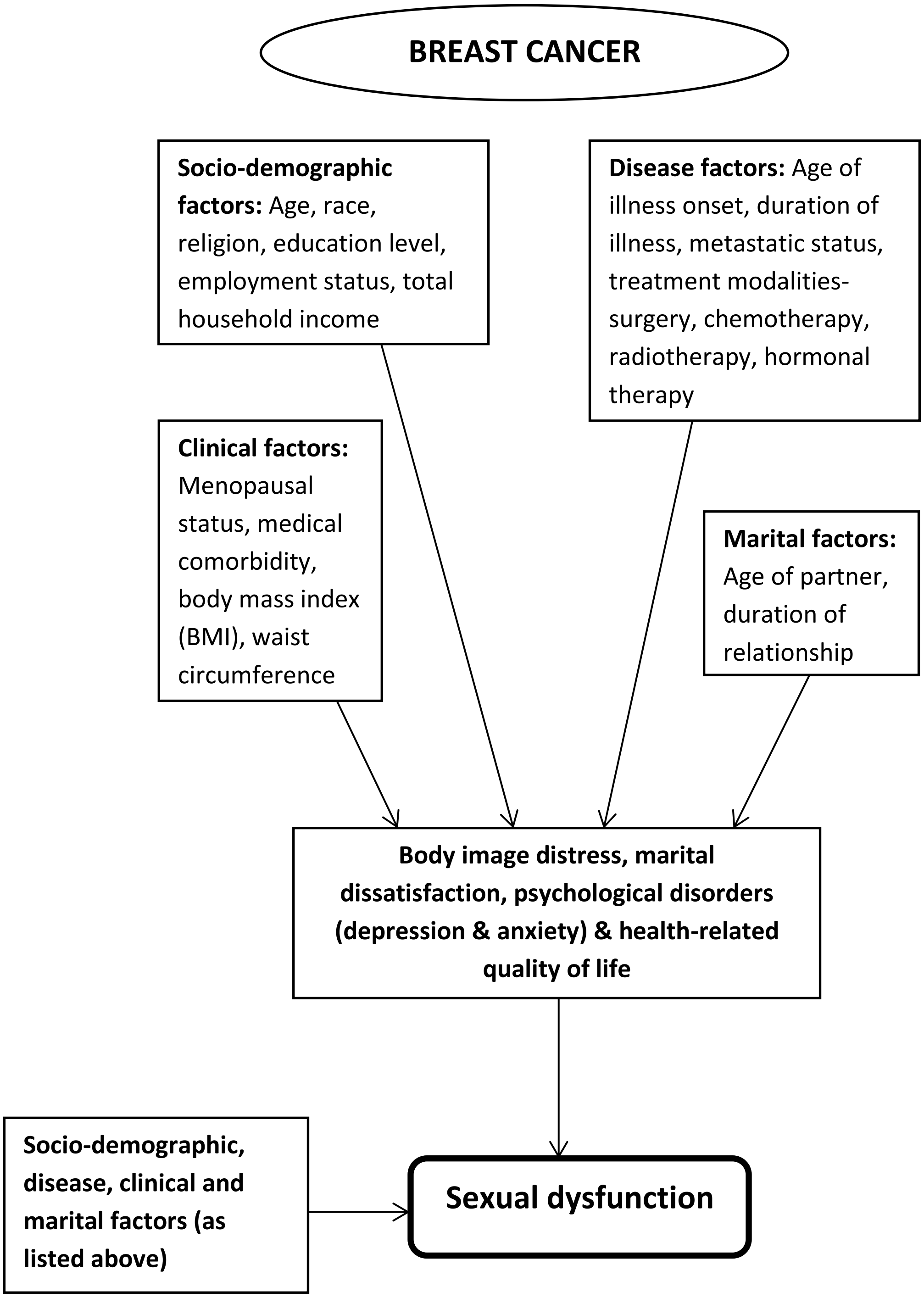
2.5.11 PSYCHOLOGICAL STATUS

The diagnosis of cancer and its treatment do not only have physical impacts but also psychosocial and financial consequences surrounding it (Pumo et al, 2012). Patients diagnosed with cancer commonly experienced anxiety and depression, with double the risk of psychological problems compared to the general population (Hinz et al, 2010). Interruption in all angles of life, reduction in the patient's coping capability to their illness, and interference with relationships, rehabilitation, and enjoyment of their remaining life span are among the consequences of untreated anxiety, depression, and sexual disorders (Pumo et al, 2012).

Out of 167 breast cancer survivors enrolled in their study, Pumo and colleagues (2012) found that 72.4% of the participants reported psychological effects and sexual problems were identified in 65.9% of the participants. This study also noted an association between frequency of psychological problems and seriousness of sexual difficulties. Anxiety, depression, fear, and cognitive and affective disorders were the psychological problems experienced by the samples in this study. Young patients, those who were married, and those with low education were the factors associated with high psychological disorders (Pumo et al, 2012).

2.6 CONCEPTUAL FRAMEWORK

Figure 2.1 Conceptual framework



CHAPTER THREE

RATIONALE AND OBJECTIVES

3.1 RATIONALE OF THE STUDY

Sexual well-being is a vital component of quality of life. Thus, its assessment is vital in order to be able to provide a holistic care for patients with breast cancer. History taking process should incorporate a short enquiry about sexual function for both, women who are newly diagnosed with breast cancer and also those who are attending regular follow ups. Time restrictions, deficiency in the health care providers' training with regards to assessment of sexual function and issues related to it, or the uncomfortable feeling associated with discussing sexual issues commonly hinder both the physician and the patient in doing so. As a result, sexual problems amongst breast cancer survivors are often neglected even though it is a recognized adverse effect of the disease itself and also treatments for breast cancer.

In Malaysia, there is lack of published data regarding sexual dysfunction among breast cancer survivors (BCS). We only have published data from other countries. As sexual satisfaction may be influenced by socio-religious values, this study is very important in providing the much needed baseline information regarding sexual dysfunction in BCS. This study will also determine the associated factors related to sexual dysfunction that will provide clues to those survivors who are at risk of sexual dysfunction. This study serves as a stepping stone towards a more relevant planning of an intervention program in order to provide a more comprehensive care for BCS.

3.2 GENERAL OBJECTIVE

The aim of the study is to determine the prevalence of sexual dysfunction in breast cancer patients who are in remission attending follow-up at the breast clinic at the Department of Surgery in University Malaya Medical Centre (UMMC).

3.3 SPECIFIC OBJECTIVES

1. To determine the severity of marital dissatisfaction experienced by the survivors and its relationship with sexual dysfunction.

2. To determine the severity of body image distress experienced by the survivors and its relationship with sexual dysfunction.

3. To determine the significant associations of biological factors, psychosocial factors, disease-related factors, depression, anxiety, body image distress, marital dissatisfaction, and health related quality of life with sexual dysfunction in breast cancer survivors.

3.4 RESEARCH QUESTIONS

1. What is the prevalence of sexual dysfunction in breast cancer survivors attending the outpatient follow-up at the breast clinic in UMMC?
2. What are the factors associated with sexual dysfunction in breast cancer survivors attending the outpatient follow-up at the breast clinic in UMMC?
3. What is the level of body image distress in these breast cancer survivors?
4. What is the severity of marital dissatisfaction among these breast cancer survivors?
5. What is the interaction between sexual dysfunction, body image distress and marital dissatisfaction in these breast cancer survivors?

3.5 RESEARCH HYPOTHESES

1. There is a difference of sexual function between breast cancer survivors (BCS) with body image distress and those without body image distress.
2. There is a difference of sexual function between BCS experiencing marital dissatisfaction and those without marital dissatisfaction.

CHAPTER FOUR

METHODOLOGY

4.1 STUDY SETTING

This study was conducted at the breast clinic in the Department of Surgery of University Malaya Medical Centre (UMMC). UMMC is a tertiary hospital and one of the organizations under the Ministry of Higher Education. UMMC is part of the University of Malaya (UM). It was founded in 1962 and is the first teaching hospital in the country which provides teaching and training of medical and paramedic staff to cater the health demands of the local population. Health services, learning, and research are the main objectives of UMMC. The hospital has 1200 beds equipped with modern medical facilities and is rapidly expanding to meet the health demands of the Klang Valley area. The Breast Unit in UMMC was started in 1993 which provides clinical services, teaching and training, and also conducts research activities. The breast clinic in UMMC provides multidisciplinary clinical services involving staff from various medical departments such as surgery, radiology, oncology, psycho-oncology, palliative medicine, pathology, breast care nurse, and rehabilitative medicine. Since it started in 1993, there were nearly 4000 patients who were registered in the UMMC Breast Cancer Database in the year 2009.

UMMC is situated at the border of Kuala Lumpur and one of the densely populated town in the state of Selangor called Petaling Jaya. Kuala Lumpur is the capital of Malaysia with a population of 1.67 million people (Department of Statistics, 2010). Petaling Jaya is a city comprising mostly of residential areas and some industrial areas with a population exceeding 600,000 people in 2010. Half of the population are Chinese, and this is followed by the Malays, and the Indians. UMMC serves as a health centre for both Kuala Lumpur and Selangor, especially for the community of Petaling Jaya.

4.2 STUDY DESIGN

This is a cross-sectional study involving patients who have been diagnosed with breast cancer and attended the follow-up at the breast clinic in UMMC. Convenience sampling was used in this study where every patient that fulfilled the inclusion criteria during the study period was invited to participate.

4.3 PERIOD OF STUDY

This study was conducted from August 2012 until December 2012 for the period of 4 months.

4.4 STUDY POPULATION

The subjects were the patients, diagnosed with breast cancer who attended follow-up at the breast clinic in UMMC during the study period.

4.5 INCLUSION CRITERIA

1. Female breast cancer patients who attended breast outpatient clinics in UMMC.
2. Patients aged 65 and below.
3. Patients had a living spouse during enrolment into the study.
4. Three months after any active treatment (surgery, chemotherapy, or radiotherapy) other than hormonal therapy.
5. Patients who were able to give informed consent.
6. Patients who were able to understand, read and communicate in English adequately well.

4.6 EXCLUSION CRITERIA

1. Patients who were single or spouse not staying together.
2. Patients who were on chemotherapy or radiotherapy during enrolment into the study.

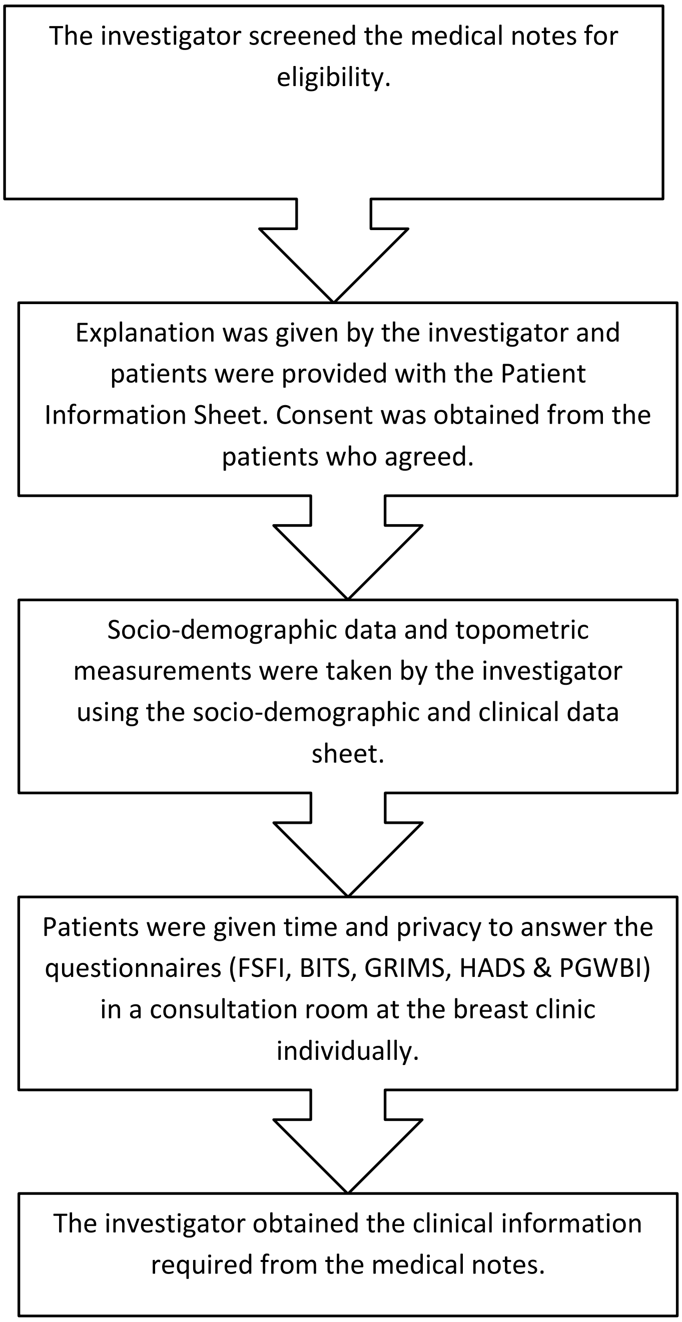
4.7 DATA COLLECTION

The patients with breast cancer were identified in the breast clinic at the Department of Surgery. Their medical notes were screened. Those who were qualified for the study will be approached to participate in the study. The selected patients were taken into a consultation room in the breast clinic individually to ensure their privacy as sexual matter is considered to be a private and sensitive matter to discuss. An explanation about the study was then given to the patients. Patients were reassured of the confidentiality of the information given in this study. The Research Information and Patient Consent Form sheets were given to the patients. Informed consent was obtained if the patient agreed to be enrolled in the study. The socio-demographic data was recorded by the investigator based on the data sheets prepared. Her height, weight, and waist circumference were measured. The readings were than recorded on the Patient Data sheet.

The patients were then given self-rated questionnaires- Female Sexual Function Index (FSFI), Breast Impact of Treatment Scale (BITS), Golombok Rust Inventory of Marital State (GRIMS), Hospital Anxiety and Depression Scale (HADS), and Psychological General Well-being Index (PGWBI). The questionnaires were all in English language to standardize the scoring of each scale. They were requested to answer the questionnaires independently. They were given privacy to answer the questionnaires and in their own time. The patients were allowed to ask clarification from the investigator when the language is a problem. The investigator provided assisted guidance on answering the questionnaire that would not in any way influence the patient's selection of answers and introduce bias. Care was also taken not to cause much embarrassment to the patients and thus, prevented dishonesty in their answers. During the data collection, every patient who participated in the study was also given information about the walk-in psychiatry clinic that is available daily from Monday to Friday mornings. This was done as the investigator did not know which of these participants is experiencing difficulties in their marriage, sexual relationship or psychological problems, especially anxiety or depression that could possibly have detrimental effect on them. Apart from the participants, the doctors in the breast clinic were also reminded to routinely enquire about these issues during their consultation. All patients who were suspected to experience difficulties were advised to be referred for expert assessment and further management. The doctors were also provided with the information about the walk-in psychiatry clinic available in UMMC. The clinical information was obtained by tracing the patients' medical notes.

Figure 4.1 below illustrated the flow chart of the subject recruitment process for the study.

Figure 4.1 Flow chart of the subject recruitment process for the study



The investigator screened the medical notes for eligibility.

Explanation was given by the investigator and patients were provided with the Patient Information Sheet. Consent was obtained from the patients who agreed.

Socio-demographic data and topometric measurements were taken by the investigator using the socio-demographic and clinical data sheet.

Patients were given time and privacy to answer the questionnaires (FSFI, BITS, GRIMS, HADS & PGWBI) in a consultation room at the breast clinic individually.

The investigator obtained the clinical information required from the medical notes.

4.8 SAMPLE SIZE

The sample size for research question 1 was calculated by using the Sample Size Calculator for Prevalence Studies (Naing, Winn and Rusli. Sample Size Calculator for Prevalence Studies, Version 1.0.01):

Level of confidence = 95%
Expected prevalence, $P = 0.75$
Population size, $N = 96$
Precision, $d = 0.05$

There is no published local study on sexual dysfunction in breast cancer survivors. In this study, the prevalence rate was taken as 76% based on a study conducted by Goldfarb and colleagues (2009).

Thus form the Sample Size Table:

Sample size, $n = 73$ (with Finite Population Correction)
An additional of 20% was added for non-respondents:
$n = 73 + (0.2 \text{ x } 73)$
So, $n = 88$ breast cancer patients.

The sample size for research question 2 was calculated using the two proportion formula as below:

$$n = \frac{P_1(1 - P_1) + P_2(1 - P_2)}{(P_1 - P_2)^2} (Z_\alpha + Z_\beta)^2$$

Where,

P_1 = 0.68 i.e. expected proportion of females who have sexual difficulties (Philips, 2000)

P_2 = 0.30 i.e. proportion of females who have sexual difficulties in the general population (Philips, 2000)

$Z_\alpha = 1.96$

$Z_\beta = 0.84$

Therefore,

$$n = \frac{0.68(0.32) + 0.30(0.70)}{0.38^2} (2.8)^2 = 24$$

An additional of 20% was added for non-respondents:

$n = 24 + (0.2 \times 24) = 28$

So, $n = 28 \times 2 = 56$ breast cancer patients

For this study, a sample of 100 breast cancer survivors was taken.

4.9 INSTRUMENTS

4.9.1 SOCIO-DEMOGRAPHIC AND CLINICAL DATA

A set of data sheet was devised to collect information from the patients. The data sheet is divided into four parts.

The first part is to obtain the identification and socio-demographic information such as the registration number, age, race, religion, employment status, educational background, and monthly household income. The second part of the data sheet is to gather marital information such as the partner's age, duration of marriage, and presence of any marital problems.

The third part is for the clinical information like the age at the onset of illness, duration of illness, clinical stage of the disease, treatment(s) that the patients has had or is having at the point of the study (surgery, chemotherapy, radiotherapy, or hormonal therapy), presence of any other medical comorbidity, presence of any metastasis of the disease itself, and menopausal status. The last part is to record the patients' weight, height, body mass index, and abdominal circumference.

4.9.2 FEMALE SEXUAL FUNCTION INDEX (FSFI)

The FSFI is a 19 self-administered items multidimensional scale for examining sexual function in women (Wiegel, Meston and Rosen, 2005). In a study conducted by Rosen and colleagues (2000), the scale was given to 131 normal controls and 128 age-matched subjects with female sexual arousal disorder (FSAD) involving five research centres. A total of 6 domains were identified, which consisted desire, subjective arousal, lubrication, orgasm, satisfaction, and pain. The scale recorded a high general test-retest reliability coefficients for each separate domains (*r*= 0.79 to 0.86). It also has a good internal consistency (Cronbach’s alpha values of 0.82 and higher). The scale also has good construct validity. In addition, divergent validity with a scale of marital satisfaction (Locke-Wallace Marital Adjustment Test) was also observed. These findings indicated that the FSFI is a valid and reliable clinical instrument in assessing female sexual dysfunction and also the specific domains related to it (Rosen et al, 2000).

The scale has been cross-validated in 568 samples of women with mixed sexual dysfunctions. Out of the 568 participants, a total of 307 women has a mixed of sexual dysfunction diagnoses and 261 women were non-dysfunctional controls. The internal reliability for the total score and the six individual domain scores were found to be between good to excellent, with Cronbach’s alpha of > 0.9 for the combined sample and above 0.8 for the sexually dysfunction and non-dysfunctional women. Discriminant validity testing concluded that the FSFI total score and the scores of its individual domains were able to differentiate those with female sexual dysfunction and those with normal sexual function. A total score of 26.55 on the FSFI scale were found to be the optimal cut-off indicating the presence of female sexual dysfunction. This study identified that 70.7% of women has sexual dysfunction based on this cut-off score and 88.1% of women with normal sexual function in the cross-validation sample were correctly identified (Wiegel, Meston and Rosen, 2005).

Baser and colleagues (2012) have also conducted a study of psychometric validation of the FSFI in cancer survivors. The data from 3 separate institutional review board-approved studies of the psychosexual adjustment of women cancer survivors carried out at the Memorial Sloan-Kettering Cancer Center were combined. Psychometric analysis was done to the FSFI responses from 181 women consisting of 4 cohorts, including survivors of gynaecological cancer (all types; 2 cohorts), malignancies requiring bone-marrow/ stem cell transplantation and early stage cervical cancer. The internal consistency reliability was 0.94 for the FSFI total score and ranged from 0.85 to 0.94 for the domain scores. The total score recorded a range from 0.44 to 0.79 and the domain scores recorded a range from 0.62 to 0.88 for the corrected item-total correlations. The FSFI exhibited strong psychometric properties and was a useful tool for evaluating sexual dysfunction, and cancer-related dysfunction in sexually active women with cancer (Baser, Li and Carter, 2012).

The FSFI is divided into six domains, including desire, arousal, lubrication, orgasm, satisfaction, and pain. The scoring for the separate domains of the FSFI and full scale score is illustrated in Table 4.1 below. Attention should be given that within the separate domains, a domain score of zero indicates that the subject reported the absence of sexual activity during the past month. In this study, the cut-off total score of 26.6 (rounded to one decimal point) based on the study done by Wiegel and colleagues (2005), was taken to differentiate breast cancer survivors (BCS) with sexual dysfunction and those without sexual dysfunction.

FSFI has been translated to Malay language and its psychometric properties have been explored (Sidi et al, 2007). They found that for the Malay version of the FSFI, the cut-off score for a 'case' of female sexual dysfunction was 55 which is not similar to the original version. Hence, this study intents to use the original FSFI.

Table 4.1 Domains, item cluster, and scoring of the FSFI

Domain	Item cluster	Score range	Factor	Minimum score	Maximum score
Desire	1, 2	1-5	0.6	1.2	6.0
Arousal	3, 4, 5, 6	0-5	0.3	0	6.0
Lubrication	7, 8, 9, 10	0-5	0.3	0	6.0
Orgasm	11, 12, 13	0-5	0.4	0	6.0
Satisfaction	14, 15, 16	0(or 1)-5	0.4	0.8	6.0
Pain	17, 18, 19	0-5	0.4	0	6.0
		Full scale score range		2.0	36.0

4.9.3 BREAST IMPACT OF TREATMENT SCALE (BITS)

The BITS was constructed from previous breast cancer studies examining the worries of women post breast cancer surgery (Frierson, Thiel and Andersen, 2006). The authors offered a different conceptualization called the body change stress. Body change stress is defined as the subjective psychological distress, thoughts, and behaviours experienced by women following breast cancer and/ or breast surgeries. Body change stress is directly correlated to body dissatisfaction and the magnitude of body image (Zainal et al, 2013). Evaluation of more than 50 items from various scales used in previous studies had generated the 13 items in the BITS. The BITS can be considered as a ‘gold standard’ tool as it includes body image satisfaction, sexual behaviour, sexual affects, and cancer-related thoughts and behaviour in respond to traumatic stress (Frierson, Thiel and Andersen, 2006).

The BITS was translated to the Malay language. The Malay version of the BITS (MVBITS) was validated in a study involving 70 women with breast cancer who undergone chemotherapy in the Oncology Clinic of University Malaya Medical Centre (UMMC). The MVBITS has good reliability with internal consistency, Cronbach’s alpha of 0.945. The test-retest reliability after the 3-weeks interval was still high and stable (Zainal et al, 2013). However, the original English version of the BITS was used in this study.

The BITS entails of 13 items, each item is scored in 4 points scale (0= not at all, 1= rarely, 3= sometimes, and 5= often). The total score ranges from 0 to 65 with the cut-off point of 26. Higher score indicated more body change stress as the following: 0 to 25- mild, 26 to 43- moderate, and 44 and above- severe. The internal consistency was between 0.84 to 0.91, and it has good validity (Frierson, Thiel and Andersen, 2006; Yurek, Farrar and Andersen, 2000).

Table 4.2 Score range of the BITS and its interpretation

Score range	**Interpretation**
0 to 25	Mild body change stress
26 to 43	Moderate body change stress
44 and above	Severe body change stress

4.9.4 GOLOMBOK RUST INVENTORY OF MARITAL STATE (GRIMS)

The GRIMS was developed based on the conceptual blueprint of marital discord. It assesses the overall quality of a couple's relationship (Rust et al, 1990). The items were generated based on specific areas of distress identified by both marital therapists and their clients (Rust et al, 1986). This was conducted among 57 couples who participated in a marital therapy study (Bennun, 1985). At the beginning, 183 items were generated, and this was narrowed down to 28 items after a pilot study was conducted involving 60 couples (120 subjects) who attended marital therapy and marriage guidance clinic. The mean score on the scale for men was 46.88 (SD= 10.99), and for women was 42.66 (SD= 11.26). The scale has split half reliability of 0.92 for men, and 0.90 for women. Both, the content and face validity were also high (Rust et al, 1986).

The English version of the GRIMS in examining marital satisfaction was validated in our local population by Quek and colleagues (2002). The study was done in University Malaya Medical Centre (UMMC) involving 60 respondents with benign prostatic hyperplasia (BPH). The validity and reliability of the scale were studied in two different groups of the subjects, one without lower urinary tract symptoms (LUTS) which is the control group (N= 30), and one group with LUTS who were admitted for transurethral resection of the prostate (TURP) which represents the surgical group (N= 30). Most of the items in the scale had high internal consistency, which indicated a high level of homogeneity between them. Test-retest reliability was assessed in 30 patients following a 12-week period. The intra-class correlation coefficient (ICC) and Pearson's product moment correlation of the total GRIMS score was 0.87 ($p< 0.001$) and 0.78 ($p\leq 0.01$) respectively, in the assessment of the test-retest reliability conducted in 30 patients after a 12-week interval. The study also found that all items in the scale have high sensitivity and specificity to the effects of treatment. The scale also has good discriminant validity (Quek et al, 2002).

Quek and colleagues (2001) also conducted a study to validate the Malay version of the GRIMS (Mal-GRIMS) involving 37 urological patients. The scale recorded an excellent internal consistency with the Cronbach's alpha value of 0.43 to 1.00. It also have highly significant test-retest coefficient and ICC (ICC= 0.51 and above) in most of the items. The total scores of the Mal-GRIMS also showed high sensitivity and specificity (Quek et al, 2001).

The GRIMS consists of 28 items, of which 14 items are reversely scored, and 14 are directly scored. The reversed items of the GRIMS are 3, 6, 7, 8, 11, 13, 16, 18, 19, 21, 23, 24, 26, and 28. Each item is scored on a 4-point scale, ranging from 'strongly disagree' to 'strongly agree.' Higher total score of the GRIMS indicates the more severe the relationship problem (Rust et al, 1988).

Table 4.3 Item cluster and scoring of the GRIMS

Item cluster	Scoring
3, 6, 7, 8, 11, 13, 16, 18, 19, 21, 23, 24, 26, 28	Reversely scored
1, 2, 4, 5, 9, 10, 12, 14, 15, 17, 20, 22, 25, 27	Directly score

Table 4.4 Total score range and interpretation of the GRIMS

Total score range	Interpretation
16 or less	Undefined
17-21	Very good
22-25	Good
26-29	Above average
30-33	Average
34-37	Poor
38-41	Bad
42-46	Severe
47 and above	Very severe

4.9.5 HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS)

The HADS is a self-administered questionnaire that provides a reliable and valid assessment of anxiety and depression in medical outpatient clinics (Herrmann, 1997; Zigmond and Snaith, 1983). It is not a diagnostic scale, and is best used for screening purposes of general hospital patients who need further psychiatric assessment and further intervention (Herrmann, 1997). They measure the severity of symptoms that suggest the likelihood that a patient may have the disorder (Zainal et al, 2007; Zigmond and Snaith, 1983).

Kjaergaard and colleagues (2013) conducted a study to evaluate the psychometric properties of the Beck Depression Inventory-II (BDI), the Montgomery and Åsberg Depression Rating Scale (MADRS), and the Hospital Anxiety and Depression Scale (HADS) in a sample from a healthy population for screening of Major Depressive Episode (MDE). MDE was diagnosed using the Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV Axis I Disorders-Clinician Version (SCID-CV). Out of the 357 subjects, a current MDE was diagnosed in 20 subjects (6%). High area under the receiver operating characteristics curve (ROC) was recorded by all the three scales including the depression domain for the HADS (AUC 0.84-0.87). All scales also had high internal consistency (0.75-0.89). The optimal cut-off score for MDE was $\geq$ 12 for BDI-II, MADRS $\geq$ 8, total HADS $\geq$ 9, and HADS-D $\geq$ 4, with sensitivities of 0.85 and specificity of 0.75. All depressions scales had low diagnostic accuracy (Cohen's kappa= 0.20-0.40), which indicated that these scales are acceptable as screening instruments (Kjaedgaard, Arfwedson Wang and Waterloo, 2013).

A cross-sectional survey was conducted in Norway involving 1,781 patients attending 41 general practitioner practices to assess the usefulness of the HADS for general practitioners (GPs). The study found that the HADS-A had optimal cut-off ≥ 8 (sensitivity 0.89; specificity 0.75), area under the curve (AUC) of 0.88. 76% of the patients were correctly identified in relation to generalized anxiety disorder (GAD). The HADS-D had optimal cut-off ≥ 8 (sensitivity 0.80; specificity 0.88), AUC of 0.93. 87% of the patients were correctly identified in relation to Major Depressive Episode (MDE) (Olssøn, Mykletun and Dahl, 2013). In a different study done to examine the psychometric properties of the HADS in a large population, Mykletun and colleagues (2001) concluded that the basic psychometric properties of the HADS are quite good in terms of factor structure, inter-correlation, homogeneity, and internal consistency. Both domains (anxiety and depression) were found to have good internal consistency, with Cronbach's alpha of 0.80 and 0.76 respectively (Mykletun, Stordal and Dahl, 2001).

The English version of the HADS was validated in the Malaysian population in a study conducted by Fatt and colleagues (2007). A total of 267 participants were involved in the study. They were recruited from urological (those presented with pre-mature ejaculation (PE)) and primary care (those presented with other medical symptoms- controls) clinics. All the items in the HADS recorded good internal consistency and this observation was made in both groups, those with PE and those without PE (Cronbach's alpha > 0.800). Both groups also had intraclass correlation coefficient (ICC) of > 0.800. These observations indicated that the items in the HADS have high reliability and consistency. A significant difference was recorded for the scores of all the items of both sub-domains (anxiety and depression) when comparison was made between the 2 groups involved in the study. This indicated that the HADS has good discriminant validity.

It is divided into 2 domains, which are the anxiety and depression domain. The HADS consisted of seven questions that evaluate anxiety and seven questions that evaluate depression. It is rated on a four-point Likert scale (0 to 3). The minimum score of ‘0’ indicates the lowest stress while the maximum score of ‘3’ indicates the maximum stress for that particular question in the scale. The score of the individual domain ranges from 0 to 21. The sum of the ratings for the 7 questions that assess anxiety and depression separately will give the score for the individual domain. Presence of problems was indicated by higher scores. Patients who scored more than 7 on the anxiety domain would be categorized as ‘anxious’ while those who scored more than 7 on the depression domain would be categorized as ‘depressed.’ The total HADS score was obtained by summing the ratings for all the 14 questions (Zigmond and Snaith, 1983). An indication that the patient may have anxiety or depressive disorder is when a total score of 15 or more, or a score of 8 or more is obtained on the domain(s). The two domains have been found to be independent measures. The scale has been suggested for use in cancer research because it did not include items on physical aspects of psychiatric disorder (eg. fatigue) (Maguire and Selby, 1989).

Table 4.5 Domains and item cluster of the HADS

Domain	Item cluster	Score range
Anxiety	1, 3, 5, 7, 9, 11, 13	0-3
Depression	2, 4, 6, 8, 10, 12, 14	0-3

Table 4.6 Scoring of the individual domain of the HADS and its interpretation

Domain	Score	Interpretation
Anxiety	8 and above (≥ 8)	Anxious
Depression	8 and above (≥ 8)	Depressed

4.9.6 PSYCHOLOGICAL GENERAL WELL-BEING INDEX (PGWBI)

The PGWBI questionnaire is a 22 self-administered items validated Health Related Quality of Life (HRQoL) measure, commonly used in medical-related studies and epidemiological researches to provide an overall assessment of self-perceived psychological health and well-being (Boman et al, 2001; Havelund et al, 1999; Hunt and McKenna, 1992; Omvik et al, 1993; Rasmussen, Norholm, and Bech, 1999; Reddy et al, 2000; Walle et al, 1994; Wilkund and Kalrberg, 1991; Wilkund et al, 1992). The Psychological General Well-Being Schedule, a scale consisting of 68 questions was developed by Harold Dupuy, a psychologist at the National Centre of Health Statistics in the late sixties, to assess the degree of ‘happiness’ of the American population or the probability of psychological distress (Grossi et al, 2006). It was considered to be one of the earliest generic assessments for health-related quality of life with particular attention to mental health (Grossi et al, 2006). A revision of the scale and a final version of 22 selected items were validated under the name of PGWBI by Dupuy and John E some years later. An extensive reference data of this version were generated in the US general population and was published in 1984 (Dupuy, 1984).

A database that consist the observations on 8536 patients from 11 studies conducted in 19 countries and 16 languages were compiled by investigators working with the MAPI Research Institute as part of the International Health-Related Quality of Life Outcomes Database (IQOD). These can be used as reference values that can help the interpretation of scores in other studies (Chassany et al, 2004).

Lundgren-Nilsson and colleagues (2013) conducted a study to evaluate the construct validity of the PGWBI. The study involved 179 patients who attended a tertiary stress clinic. These patients were treated for stress-related exhaustion. The PGWBI was administered as part of the routine clinical assessment at baseline and 3 months. After 3 months, a vast improvement in well-being was reported among the participants. This study concluded that the PGWBI questionnaire has satisfactory internal construct validity (Lundgren-Nilsson et al, 2013).

It is assessed on a 6-point scale, which examine the psychological health and general well-being of the respondents. It is divided into six HRQoL domains: anxiety, depressed mood, positive well-being, self-control, general health, and vitality. Each item was scored in between 0 to 5, with the lowest value (0) indicating the most distress and the highest value (5) indicating the highest level of well-being. Hence, the total score of the PGWBI ranged from 0 to 110 (Chassany et al, 2004).

Table 4.7 Dimensions and item cluster of the PGWBI

Dimensions	**Item cluster**	**Range**
Anxiety	5, 8, 17, 19, 22	0-25
Depressed mood	3, 7, 11	0-15
Positive well-being	1, 9, 15, 20	0-20
Self-control	4, 14, 18	0-15
General health	2, 10, 13	0-15
Vitality	6, 12, 16, 21	0-20
Global score		**0-110**

4.9.7 WEIGHT, HEIGHT, WAIST CIRCUMFERENCE, AND BODY MASS INDEX (BMI)

The patients' weight was measured and recorded in kilograms (kg) to the nearest 0.1kg and the height recorded in meters (m) to the nearest 0.01m. The BMI will be calculated as:

$$\text{BMI} = \frac{\text{Weight (kg)}}{\text{Height}^2\ (\text{m}^2)}$$

The waist circumference was obtained using a standard measuring tape. It was taken at the mid-point between the rib cage and the iliac crest. Both the waist circumference and BMI were classified according to the Malaysia Clinical Practice Guideline (CPG) in Management of Obesity (2004).

Table 4.8 Waist circumference classification for Asian populations (WHO, 2004)

Gender	Waist circumference (cm)
Male	≥ 90 cm- high risk
Female	≥ 80 cm- high risk

Table 4.9 Classification of weight by BMI for Asian populations (WHO, 2004)

BMI range (kg/m^2)	Classification
≤ 18.4	Underweight
18.5-22.9	Normal weight
23.0-27.4	Overweight
≥ 27.5	Obese

These classifications were adopted because Asian populations are at higher risk of developing medical comorbidities at a lower BMI and the Asians also have a higher body fat percentage compared to non-Asians (Malaysia CPG on Management of Obesity, 2004).

4.10 STATISTICAL ANALYSIS

The data was analysed using the Statistical Package for Social Sciences (SPSS) version 21.0.

Descriptive analysis was conducted for socio-demographic, clinical, disease and marital variables. Descriptive analysis was also done for sexual dysfunction, body image distress, marital dissatisfaction, depressive, and anxiety symptoms and quality of life. The prevalence for sexual dysfunction, body image distress, marital dissatisfaction, possible depression, and anxiety cases were obtained. Severity of body image distress and marital dissatisfaction experienced by breast cancer patients recruited in the study were also analysed. The cut-off scores for sexual dysfunction, body image distress, marital dissatisfaction, probable depression, and anxiety cases were used to examine the correlation with socio-demographic, clinical, disease and marital variables. For quality of life, the median score was used to assess correlation. Variables such as age, race, religion, educational level, total monthly household income, age of disease onset, duration of illness, body mass index, waist circumference, partner's age and duration of relationship were re-categorised. Chi square test and Fisher's exact test, wherever appropriate was used.

The correlation between dependent and independent variables were obtained. Further multivariate analysis was conducted between sexual dysfunction as the dependent variable and significant independent variables from the univariate analysis using multivariate linear regression analysis.

4.11 ETHICAL CONSIDERATION

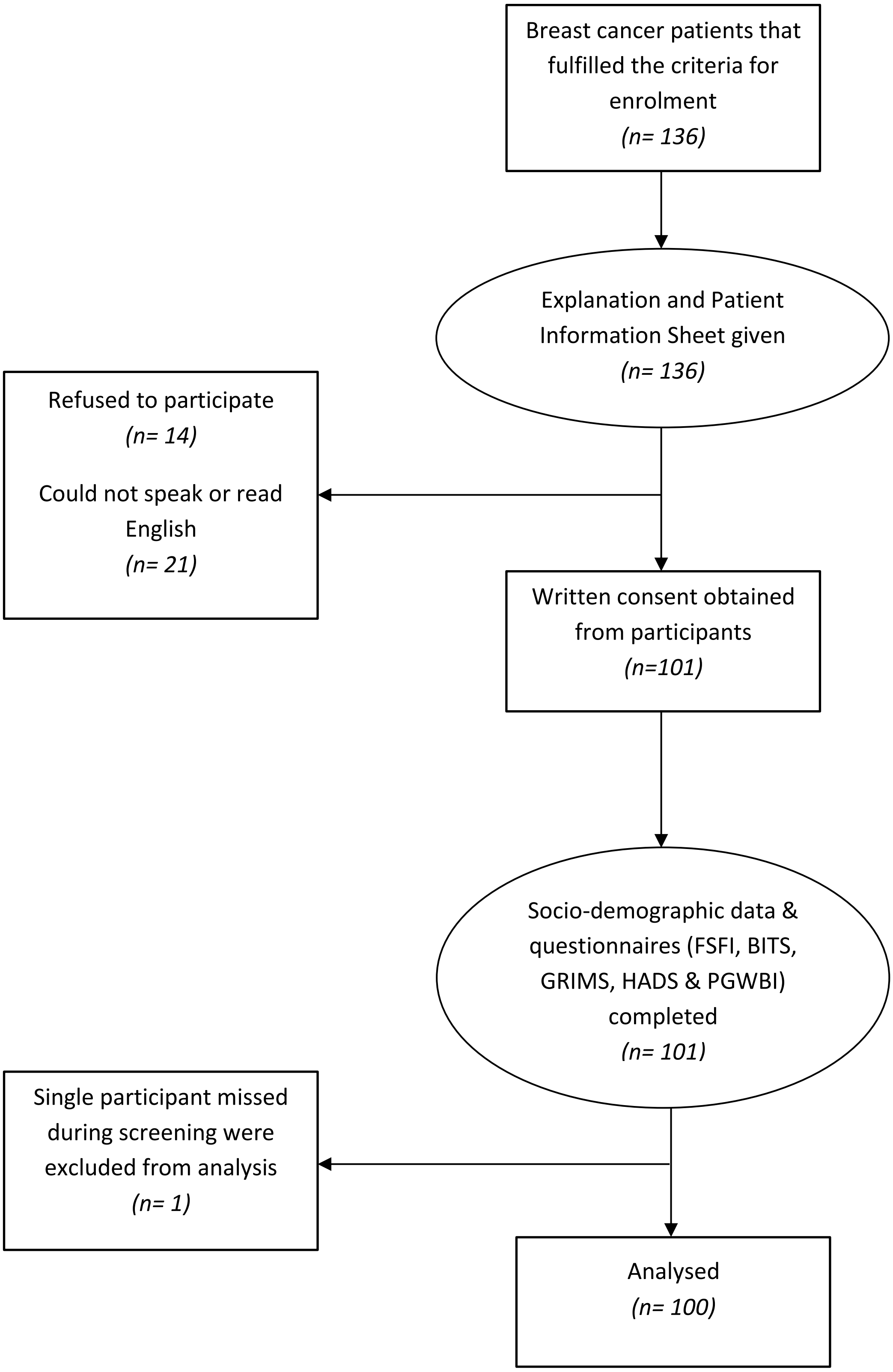
This study was approved by the Research Committee, Department of Psychological Medicine in July 2011 and the Ethics Committee, University Malaya Medical Centre in September 2011. An informed and written consent was obtained from all of the study participants.

CHAPTER FIVE

RESULTS

This was a cross-sectional study of sexual dysfunction, body image distress, and marital dissatisfaction in breast cancer survivors attending follow up at the breast clinic in University Malaya Medical Centre (UMMC). It was conducted over a four-month period, starting from August 2012 to December 2012. During this study period, a total of 136 breast cancer patients were approached to participate in the study. However, 35 patients refused to participate, with 14 patients refused to give consent, and the other 21 could not speak and read English. All the remaining 101 patients managed to complete the questionnaires required in the study, but 1 patient was found to be single. Therefore, a total of 100 breast cancer patients were included in the data analysis. Figure 5.1 illustrated the flow chart of the study participants.

Figure 5.1 Flow chart of the study participants



5.1 DESCRIPTIVE STATISTICS

5.1.1 DESCRIPTIVE STATISTICS OF PATIENTS' SOCIO-DEMOGRAPHIC CHARACTERISTICS

Table 5.1 describes the descriptive statistics of the patients' socio-demographic characteristics. The mean age for the subjects was 52.64 years with a standard deviation of 7.54 years. Of all the participants 43.0% were Chinese. This is followed by Malay and Indian, with 37.0% and 20.0% respectively. More than half of these women had a minimum of secondary education (61.0%). Almost half of them were working either part time or full time (46.0%). The participants mostly had a household income of RM 3000 and below per month with 55.0%.

Table 5.1 Socio-demographic characteristics of the breast cancer patients attending follow up at the breast clinic in UMMC

Socio-demographic characteristics	**Frequency (%)**
Age (years)	
≤ 50	40 (40.0)
> 50	60 (60.0)
Minimum 33	
Maximum 65	
Mean ± sd (52.64 ± 7.54)	
Race	
Malay	37 (37.0)
Chinese	43 (43.0)
Indian	20 (20.0)
Religion	
Islam	37 (37.0)
Buddhism	33 (33.0)
Hinduism	12 (12.0)
Christianity	18 (18.0)
Education level	
No formal education	3 (3.0)
Primary education	6 (6.0)
Secondary education	61 (61.0)
Tertiary education	30 (30.0)
Employment status	
Unemployed/ housewives	37(37.0)
Working part time/ full time	46 (46.0)
Pensioner/ retiree	17 (17.0)
Household income range (per month)	
≤ RM 3000	55 (55.0)
> RM 3000	45 (45.0)

5.1.2 DESCRIPTIVE STATISTICS OF PATIENTS' DISEASE CHARACTERISTICS

Table 5.2 shows the disease profile of the subjects. Most of the women had onset of breast cancer at the age of 50 years and below with 59.0%. The mean age of onset of the disease was 47.77 years, with a standard deviation of 7.93 years. Majority of these participants had duration of illness of 5 years and below (70.0%). The mean time of diagnosis to their enrolment in the study was 4.99 years, with the standard deviation of 4.73 years. Majority of the participants (49.0%) were diagnosed with Stage II breast cancer at first consultation with the breast team. This is followed by Stage I (38.0%), Stage III (11.0%) and Stage IV (2.0%). Only 3.0% of these women had distant metastasis of the disease at the point of enrolment into the study. More than half of the women had undergone mastectomy 64.0% as compared to lumpectomy 35.0% and 1 patient did not have any surgical intervention. 75.0% of these patients had chemotherapy and hormonal therapy while 72% had radiotherapy therapy.

Table 5.2 Disease characteristics of breast cancer patients attending follow up at the breast clinic in UMMC

Disease characteristics	**Frequency (%)**
Age of onset (years)	
≤ 50	59 (59.0)
> 50	41 (41.0)
Mean ± sd (47.77 ± 7.93)	
Median 48.50	
Minimum 32	
Maximum 63	
Duration of illness (years)	
(From diagnosis to enrolment into the study)	
≤ 5	70 (70.0)
> 5	30 (30.0)
Mean ± sd (4.99 ± 4.73)	
Median 3.00	
Stage of cancer at first consultation	
Stage I	38 (38.0)
Stage II	49 (49.0)
Stage III	11 (11.0)
Stage IV	2 (2.0)
Distant metastatic status	
(At the enrolment into the study)	
Metastasis	3(3.0)
Non-metastasis	97 (97.0)
Breast cancer surgery	
Mastectomy	64 (64.0)
Lumpectomy	35 (35.0)
No	1 (1.0)
Chemotherapy	
Yes	75 (75.0)
No	25 (25.0)
Chemotherapy regime	
FEC regime	66 (88.0)
TAC regime	1 (1.3)
Others	8 (10.7)
Radiotherapy	
Yes	72 (72.0)
No	28 (28.0)

Table 5.2 Continued

Disease characteristics	**Frequency (%)**
Hormonal therapy	
Yes	75 (75.0)
No	25 (25.0)
Current hormonal therapy	
Tamoxifen	68 (90.7)
Femara (Letrozole)	4 (5.3)
Aromasin (Exemastane)	1(1.3)
Others	2 (2.7)

5.1.3 DESCRIPTIVE STATISTICS OF THE PATIENTS' CLINICAL CHARACTERISTICS

Table 5.3 shows the clinical characteristics of the participants enrolled in the study. Most of the participants were menopausal with 77.0% compared to those who were non-menopausal (23.0%). The mean duration of menopause was 7.38 years, with a standard deviation of 5.40 years. A high proportion of these women had no underlying medical illness (67.0%). More than half of them were within the overweight and obese category in terms of their body mass index (BMI) with 67.0%. The mean weight and height of the participants was 61.70 kg and 1.55 m respectively. A total of 58.0% of these women with breast cancer had a waist circumference of 80 cm and above.

Table 5.3 Clinical characteristics of breast cancer patients attending follow up at the breast clinic in UMMC

Clinical characteristics	Frequency (%)
Menopausal status	
Yes	77 (77.0)
No	23 (23.0)
Duration of menopause (years)	
(From the onset to enrolment in the study)	
Mean ± sd (7.38 ± 5.40)	
Medical comorbidity	
Yes	33 (33.0)
No	67 (67.0)
Body mass index (kg/m^2)	
Underweight	5 (5.0)
Normal weight	28 (28.0)
Overweight	39 (39.0)
Obese	28 (28.0)
Mean weight (kg) ± sd (61.70 ± 10.72)	
Mean height (m) ± sd (1.55 ± 0.06)	
Waist circumference (cm)	
< 80	42 (42.0)
≥ 80	58 (58.0)
Mean ± sd (81.40 ± 9.68)	

5.1.4 DESCRIPTIVE STATISTICS OF PATIENTS' MARITAL PROFILES

Table 5.4 shows the marital profiles of the breast cancer participants. Most (69.0%) of the partners were above 50-years of age. Majority of the patients have a long duration of relationship (> 20 years) with 73 out of 100 patients. The mean duration of relationship was 27.37 with a standard deviation of 8.75.

Table 5.4 Marital profiles of breast cancer patients attending follow up at the breast clinic in UMMC

Marital profiles	**Frequency (%)**
Age of partner (years)	
≤ 50	31 (31.0)
> 50	69 (69.0)
Mean ± sd (56.44 ± 9.04)	
Minimum 37	
Maximum 75	
Duration of relationship (years)	
≤ 20	27 (27.0)
> 20	73 (73.0)
Mean ± sd (27.37 ± 8.75)	

5.1.5 DESCRIPTIVE STATISTICS OF SCORE FOR SEXUAL DYSFUNCTION

Figure 5.2 illustrate the descriptive statistics of score for sexual dysfunction as assessed by the Female Sexual Function Index (FSFI). A total of 90 out of 100 women reported sexual dysfunction as indicated by total FSFI scores of ≤ 26.6. Therefore, the prevalence of sexual dysfunction among breast cancer survivors who participated in this study was 90.0%.

Figure 5.2 Descriptive statistics of sexual dysfunction in breast cancer patients attending follow up at the breast clinic in UMMC

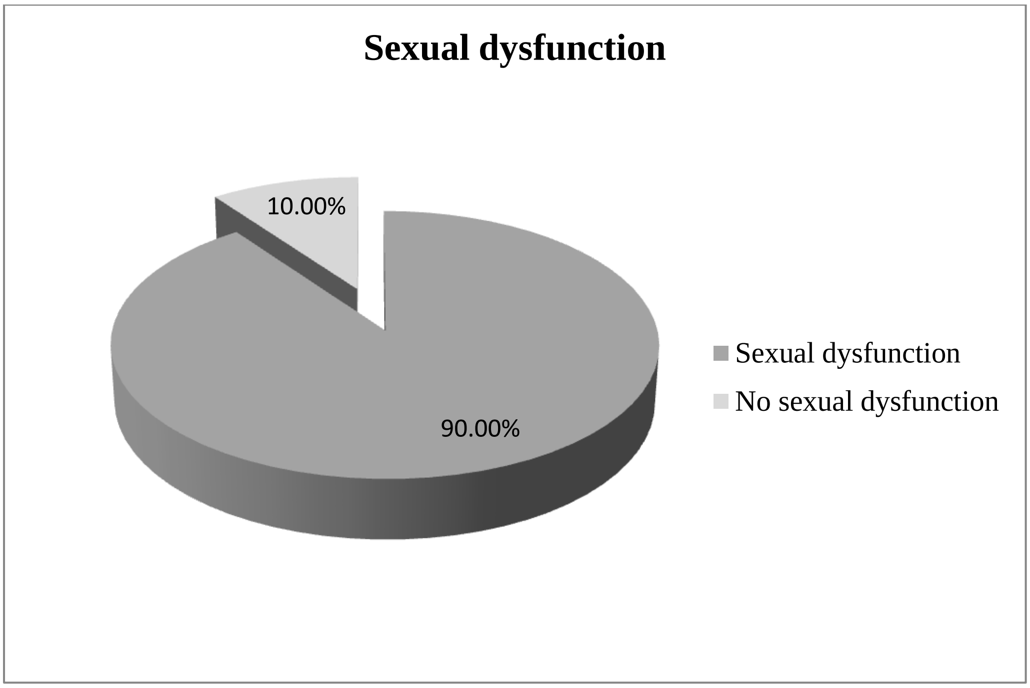
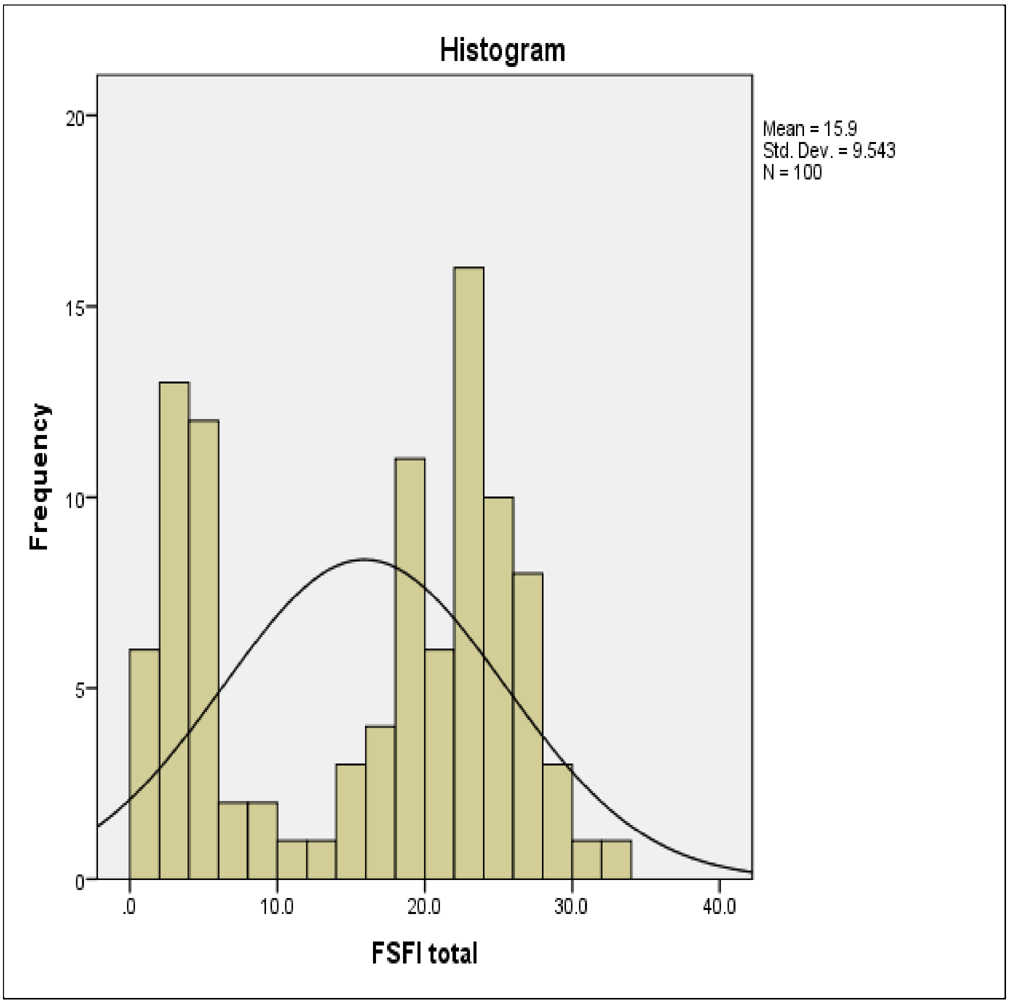


Figure 5.3 showed the distribution of the total FSFI scores among the participants. The participants had a mean total FSFI score of 15.90 with a standard deviation of 9.54. The median score was 19.05.

Figure 5.3 Distribution of total FSFI scores of breast cancer patients attending follow up at the breast clinic in UMMC



5.1.6 DESCRIPTIVE STATISTICS OF DOMAINS OF SEXUAL FUNCTION

Table 5.5 shows the mean score of specific domains of sexual function as assessed by the FSFI reported by women who participated in this study.

Table 5.5 Mean score of specific domains of sexual function as assessed by the FSFI in breast cancer patients attending follow up at the breast clinic in UMMC

Domains of sexual function	Mean ± sd
Sexual desire	2.54 ± 1.01
Sexual arousal	2.30 ± 1.42
Lubrication	2.46 ± 1.99
Orgasm	2.58 ± 2.07
Sexual satisfaction	3.15 ± 1.80
Pain	2.87 ± 2.13

5.1.7 DESCRIPTIVE STATISTICS FOR BODY IMAGE DISTRESS

Figure 5.4 illustrates the descriptive statistics for body image distress experienced by the participants as assessed by the Breast Impact of Treatment Scale (BITS). The cut-off point of 26 and above indicated body image distress. Among the 100 participants in the study, a total of 9 patients did not complete the entire questionnaire. A total of 39 (42.9%) women reported body image distress and 52 (57.1%) patients did not have body image distress. The mean total score for the BITS was 21.96 with a standard deviation of 15.78. Therefore, the prevalence of body image distress experienced by the breast cancer survivors included in this study was 42.9%.

Figure 5.4 Descriptive statistics for body image distress among breast cancer patients attending follow up at the breast clinic in UMMC

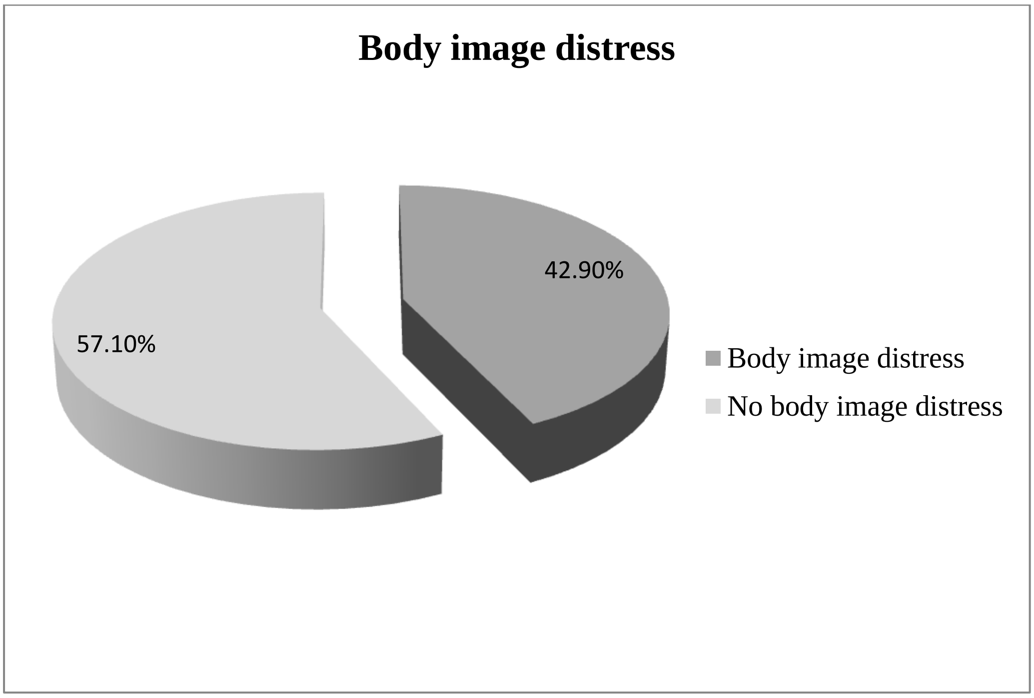


Figure 5.5 shows the histogram of the BITS total score among the participants of the study.

Figure 5.5 Distribution of the BITS total score in breast cancer patients attending follow up at the breast clinic in UMMC

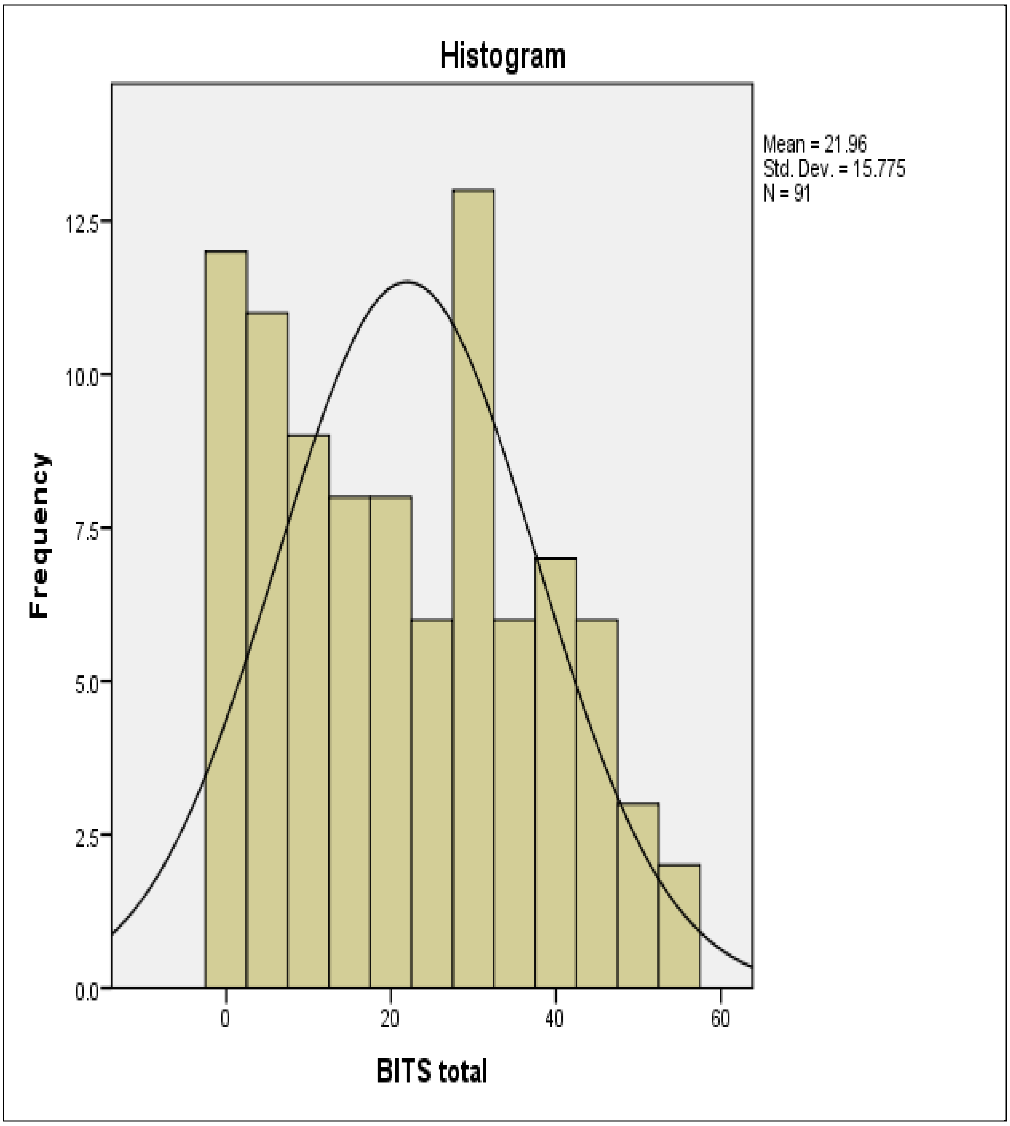
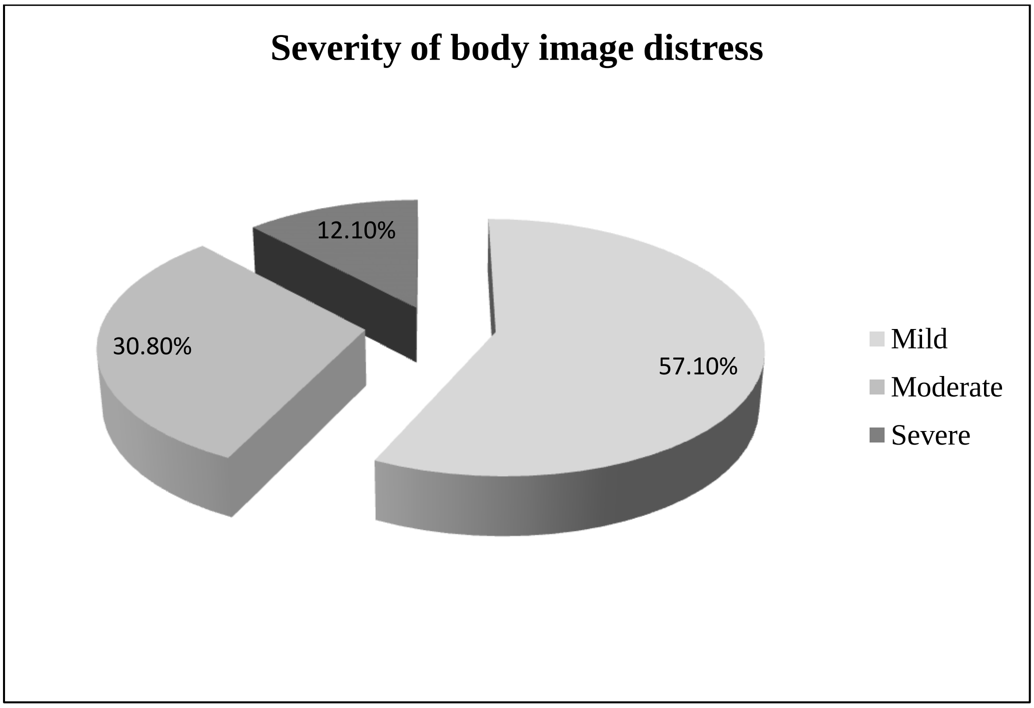


Figure 5.6 illustrates the severity of body image distress experienced by the breast cancer survivors in the study. 30.8% of these women experienced moderate severity of body image distress, while 12.1% had severe body image distress.

Figure 5.6 Descriptive statistics of the severity of body image distress in breast cancer patients attending follow up at the breast clinic in UMMC



5.1.8 DESCRIPTIVE STATISTICS FOR THE HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS) SCORE

Figure 5.7 and 5.8 represent the descriptive statistics of the HADS sub-scales score. Figure 5.7 indicated that 9 out of 100 patients with breast cancer scores ≥ 8 on the HADS depression sub-scale. The prevalence of these women that may have had depression was 9.0%. Figure 5.8 showed that 27 out of 100 patients who participated in this study had scores of ≥ 8 on the HADS anxiety sub-scale, indicating the prevalence of 27.0% that may possibly have had anxiety. For both depression and anxiety sub-scales, 7 out of 100 patients scored ≥ 8.

Figure 5.7 Possible cases of depression in breast cancer patients attending follow up at the breast clinic in UMMC

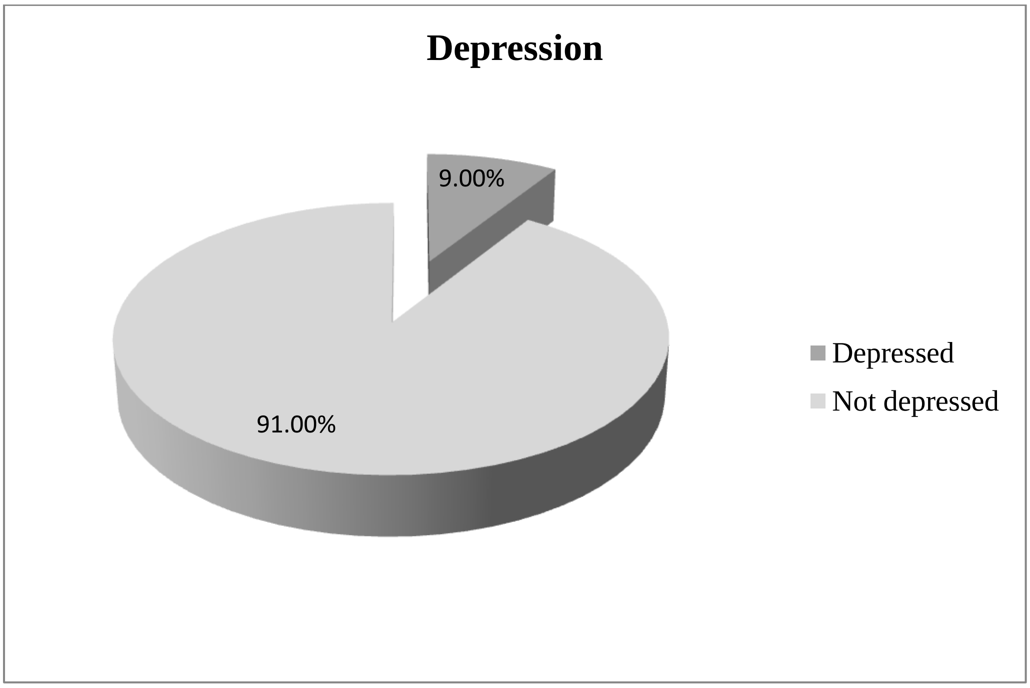


Figure 5.8 Possible cases of anxiety in breast cancer patients attending follow up at the breast clinic in UMMC

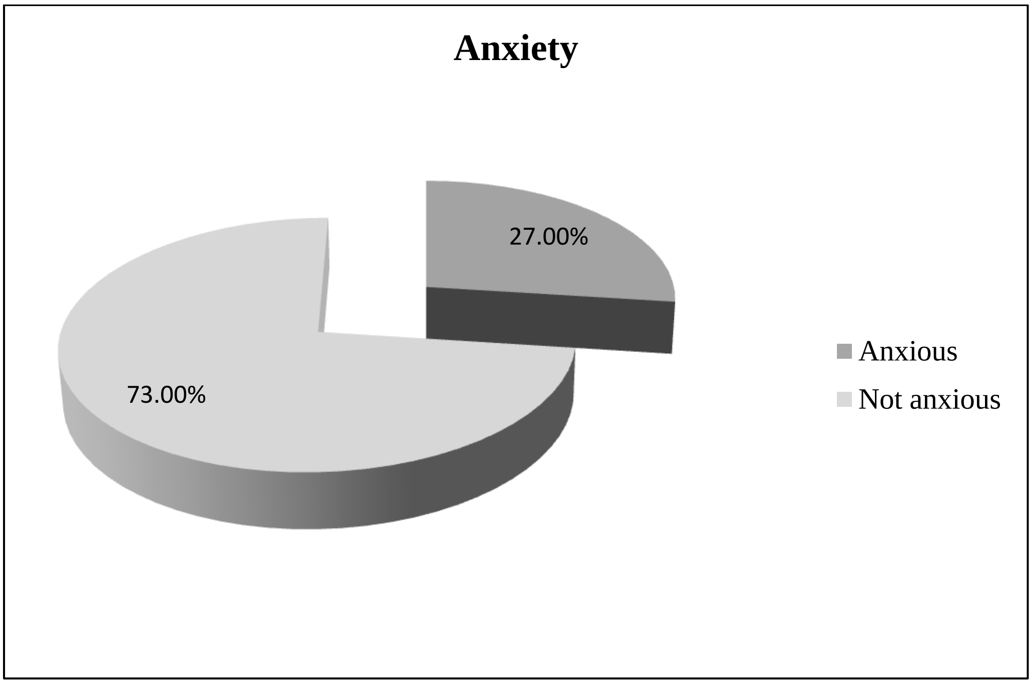


Figure 5.9 and 5.10 showed the distribution of depression and anxiety sub-scale scores respectively.

Figure 5.9 Distribution of the depression sub-scale scores in breast cancer patients attending follow up at the breast clinic in UMMC

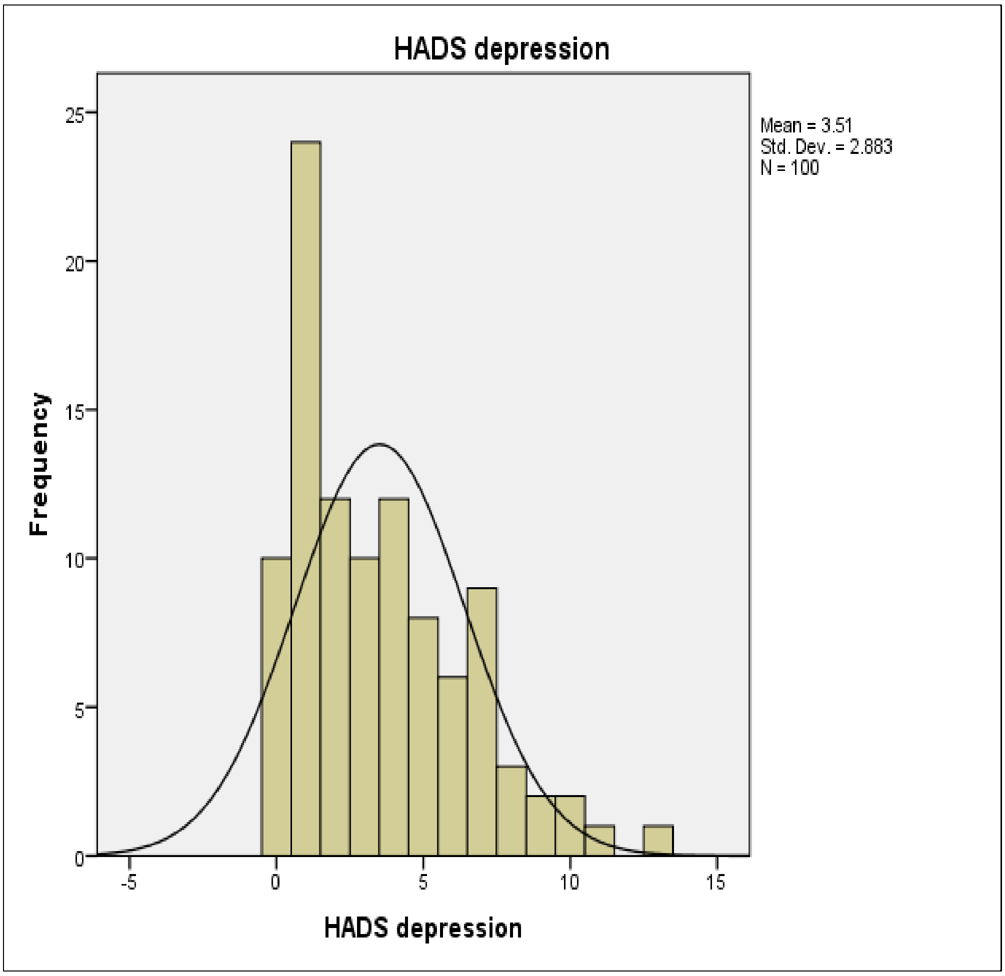
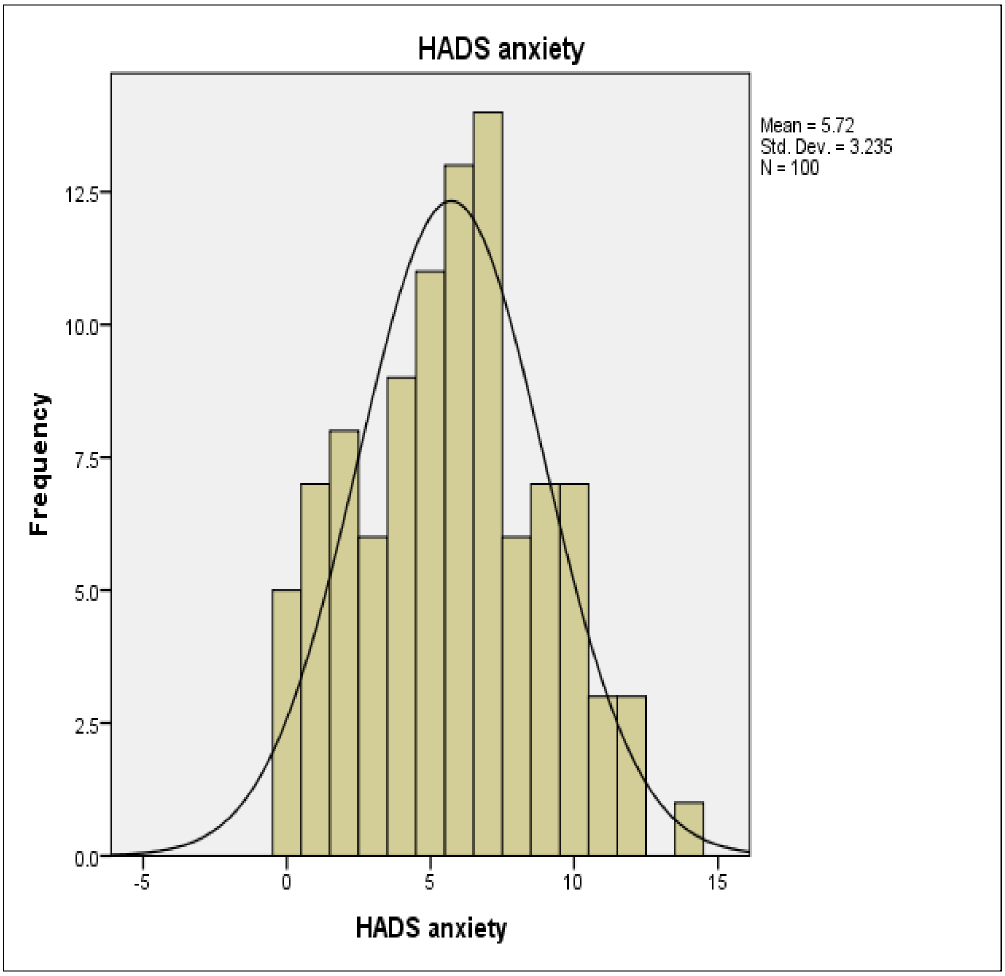


Figure 5.10 Distribution of the anxiety sub-scale scores in breast cancer patients attending follow up at the breast clinic in UMMC



5.1.9 DESCRIPTIVE STATISTICS FOR THE GOLOMBOK-RUST INVENTORY OF MARITAL STATE (GRIMS) SCORE

Table 5.6 describes the descriptive statistics of marital satisfaction among the participants based on the GRIMS total score. Poor marital satisfaction was reported by 22 out of the 100 women who participated in the study. Half of these women, which is 55.0% had at least poor to very severe marital problems.

Table 5.6 Descriptive statistics of marital satisfaction in breast cancer patients attending follow up at the breast clinic in UMMC

Independent variables	Frequency (%)
Marital satisfaction	
Undefined	5 (5.0)
Very good	8 (8.0)
Good	8 (8.0)
Above average	10 (10.0)
Average	14 (14.0)
Poor	22 (22.0)
Bad	15 (15.0)
Severe	11 (11.0)
Very severe	7 (7.0)

Figure 5.11 illustrates the descriptive statistics for marital dissatisfaction in breast cancer participants based on the total GRIMS score. Marital dissatisfaction was considered if the total GRIMS score was ≥ 34. A total of 55 out of the 100 women reported marital dissatisfaction. The mean total GRIMS score was 33.39 with a standard deviation of 10.06. Therefore, the prevalence of marital dissatisfaction reported by the participants in this study was 55.0%.

Figure 5.11 Descriptive statistics for marital dissatisfaction in breast cancer patients attending follow up at the breast clinic in UMMC

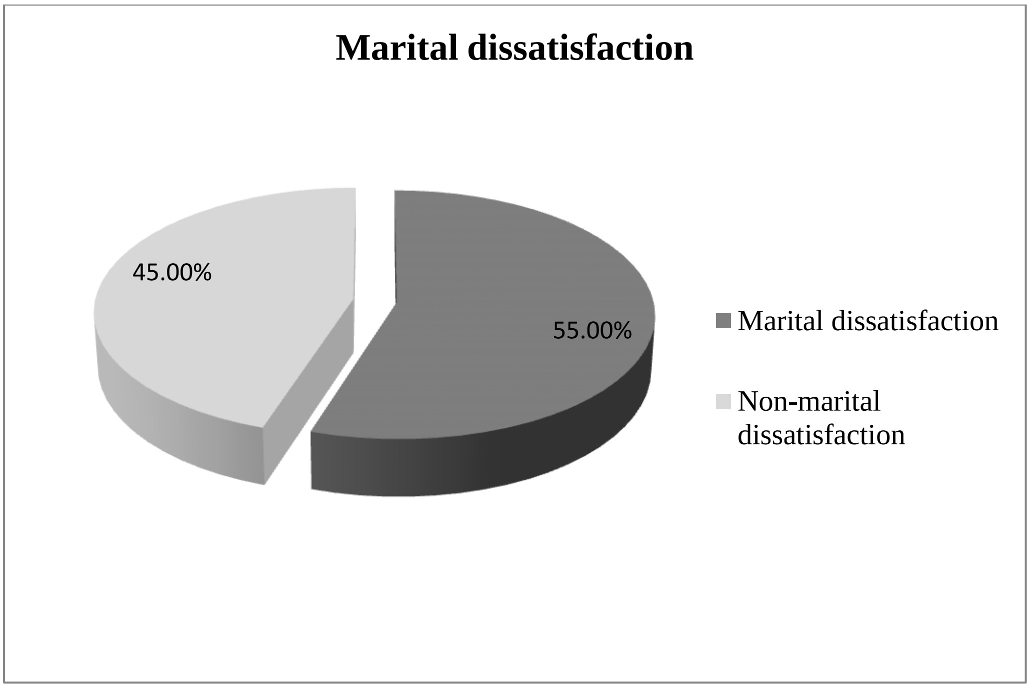
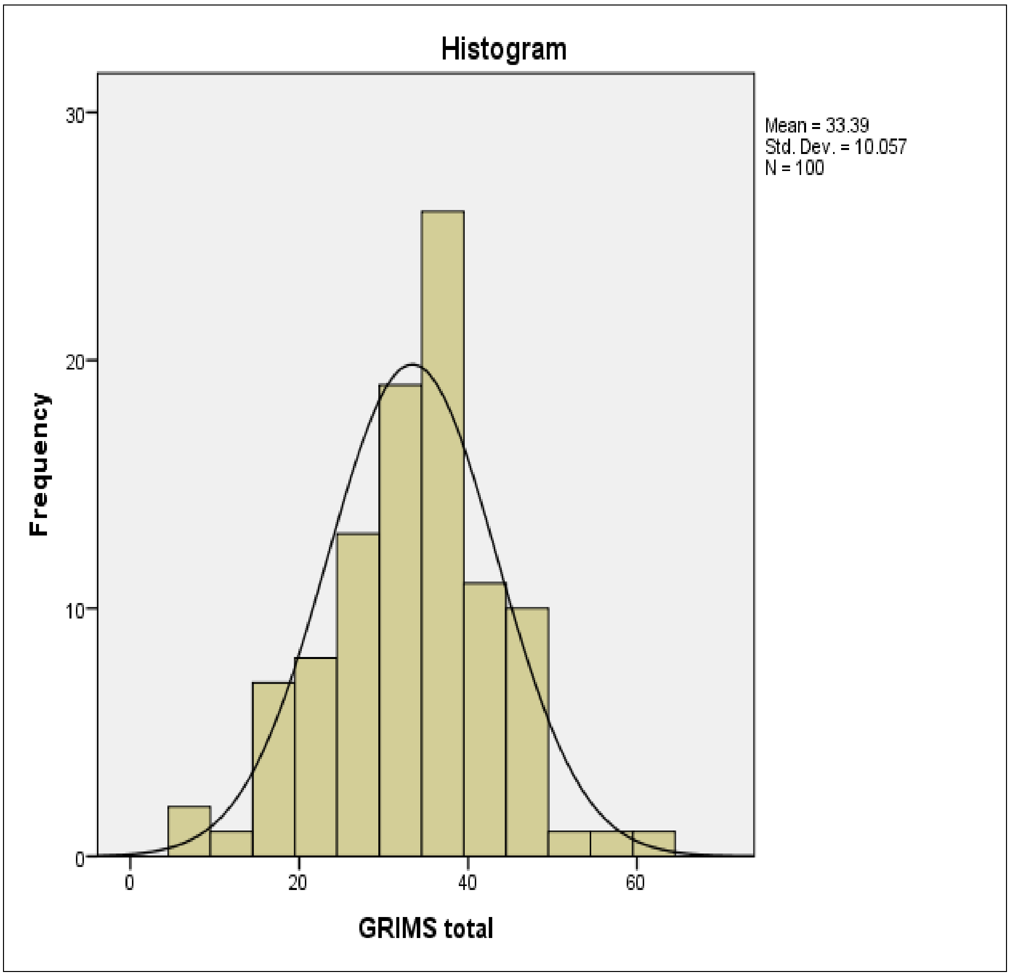


Figure 5.12 shows the distribution of the GRIMS total score among the participants which was rather normally distributed.

Figure 5.12 Distribution of the GRIMS total score in breast cancer patients attending follow up at the breast clinic in UMMC



5.1.10 DESCRIPTIVE STATISTICS OF THE PSYCHOLOGICAL GENERAL WELL BEING INDEX (PGWBI) SCORE

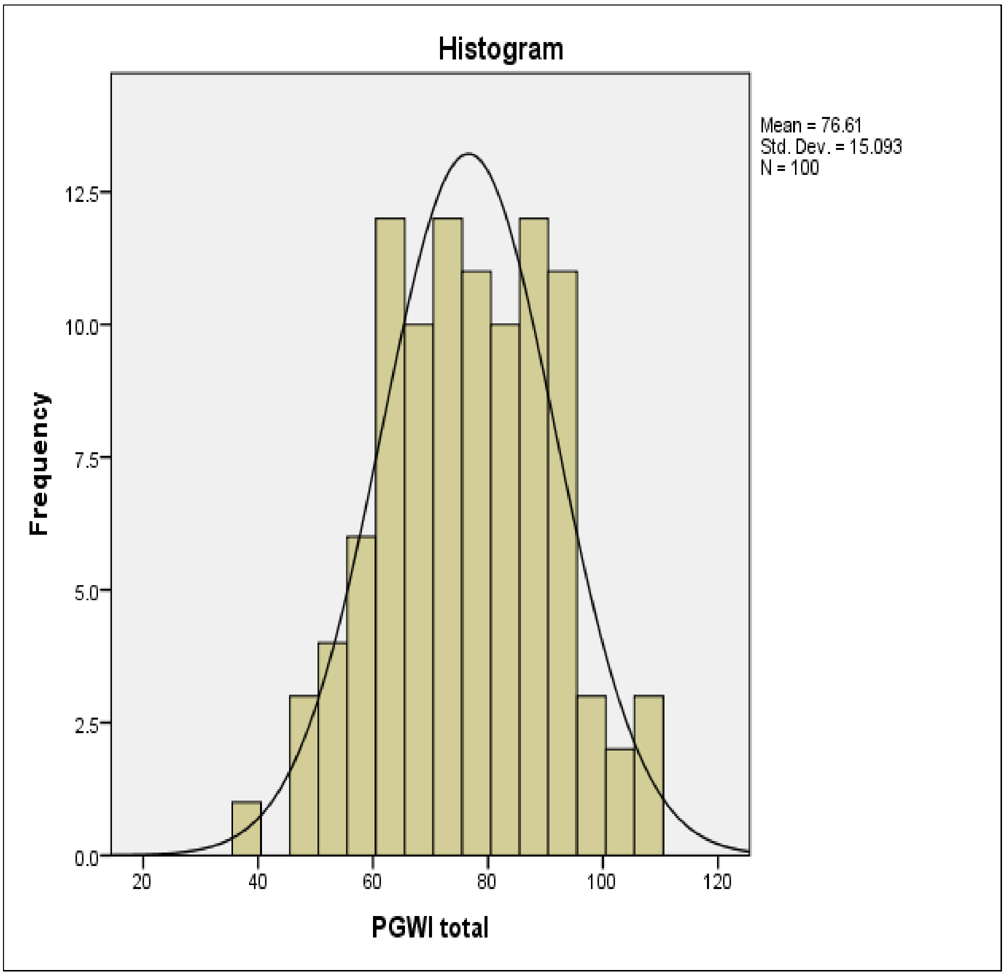
Table 5.7 shows the descriptive statistics for specific domains and total score of the PGWBI.

Table 5.7 Descriptive statistics of specific domains and total score of the PGWBI in breast cancer patients attending follow up at the breast clinic in UMMC

Domains	Minimum score	Maximum score	Median	Mean	Standard deviation
Anxiety	5	25	19.00	17.91	4.00
Depressed mood	7	15	12.00	12.05	2.04
Positive well-being	2	20	13.00	12.51	3.67
Self-control	5	15	11.00	11.00	2.66
General health	3	15	10.00	9.75	2.38
Vitality	5	20	14.00	13.39	3.14
Total score	**38**	**110**	**76.00**	**76.61**	**15.09**

Figure 5.13 shows the distribution of the total PGWBI score of the participants which was more or less normally distributed. The mean of the total PGWBI score was 76.61 with standard deviation of 15.09.

Figure 5.13 Distribution of the total PGWBI score in breast cancer patients attending follow up at the breast clinic in UMMC



5.2 ASSOCIATION AND REGRESSION

5.2.1 UNIVARIATE ANALYSIS OF SEXUAL DYSFUNCTION AND STUDY VARIABLES

Table 5.8 Socio-demographic profiles with sexual dysfunction in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	Sexual dysfunction (n= 90)	No sexual dysfunction (n= 10)	x^2 value	OR	95% CI	p value
Age (years)						
≤ 50 (%)	35 (87.5)	5 (12.5)	¥	1.571	0.424-5.824	0.515
> 50 (%)	55 (91.7)	5 (8.3)				
Race						
Malay (%)	35 (94.6)	2 (5.4)	¥	0.393	0.079-1.958	0.315
Non-Malay (%)	55 (87.3)	8 (12.7)				
Religion						
Muslim (%)	35 (94.6)	2 (5.4)	¥	0.393	0.079-1.958	0.315
Non-Muslim (%)	55 (87.3)	8 (12.7)				
Education level						
Secondary and below (%)	63 (90.0)	7 (10.0)	¥	1.000	0.240-4.161	1.000
Tertiary (%)	27 (90.0)	3 (10.0)				
Employment						
Employed (%)	40 (87.0)	6 (13.0)	¥	1.875	0.495-7.102	0.506
Unemployed (%)	50 (92.6)	4 (7.4)				
Household income (per month)						
≤ RM 3000 (%)	52 (94.5)	3 (5.5)	¥	0.313	0.076-1.290	0.108
> RM 3000 (%)	38 (84.4)	7 (15.6)				

* Significance level: $p < 0.05$

¥ Fisher's Exact Test

Table 5.8 shows the socio-demographic profiles with sexual dysfunction. None of the socio-demographic variables were found to be significantly associated with sexual dysfunction. Breast cancer patients who are 50-years and below, and those who are employed appear to have higher odds of experiencing sexual dysfunction. However these associations are not statistically significant.

Table 5.9 Clinical and disease profiles with sexual dysfunction in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	**Sexual dysfunction (n= 90)**	**No sexual dysfunction (n= 10)**	**x^2 value**	**OR**	**95% CI**	**p value**
Age of onset (years)						
≤ 50 (%)	50 (84.7)	9 (15.3)	¥	7.200	0.875-59.233	0.044*
> 50 (%)	40 (97.6)	1 (2.4)				
Duration of illness (years)						
≤ 5 (%)	63 (90.0)	7 (10.0)	¥	1.000	0.240-4.161	1.000
> 5 (%)	27 (90.0)	3 (10.0)				
Surgery						
Yes (%)	89 (89.9)	10 (10.1)	¥			1.000
No (%)	1 (100.0)	0 (0.0)				
Chemotherapy						
Yes (%)	66 (88.0)	9 (12.0)	¥	3.273	0.394-27.215	0.444
No (%)	24 (96.0)	1 (4.0)				
Radiotherapy						
Yes (%)	66 (91.7)	6 (8.3)	¥	0.545	0.142-2.101	0.460
No (%)	24 (85.7)	4 (14.3)				
Hormonal therapy						
Yes (%)	67 (89.3)	8 (10.7)	¥	1.373	0.272-6.940	1.000
No (%)	23 (92.0)	2 (8.0)				

* Significance level: $p < 0.05$

¥ Fisher's Exact Test

Table 5.9 Continued

Variables	Sexual dysfunction (n= 90)	No sexual dysfunction (n= 10)	x^2 value	OR	95% CI	p value
Distant metastasis						
Metastasis (%)	3 (100.0)	0 (0.0)	¥			1.000
Non-metastasis (%)	87 (89.7)	10 (10.3)				
Medical comorbidity						
Yes (%)	32 (97.0)	1 (3.0)	¥	0.201	0.024-1.662	0.159
No (%)	58 (86.6)	9 (13.4)				
Menopausal status						
Yes (%)	71 (92.2)	6 (7.8)	¥	0.401	0.103-1.568	0.232
No (%)	19 (82.6)	4 (17.4)				
BMI (kg/m^2)						
Underweight/ normal weight (%)	31 (93.9)	2 (6.1)	¥	0.476	0.095-2.379	0.490
Overweight/ obese (%)	59 (88.1)	8 (11.9)				
Waist circumference (cm)						
< 80 cm (%)	36 (85.7)	6 (14.3)	¥	2.250	0.593-8.538	0.314
≥ 80 cm (%)	54 (93.1)	4 (6.9)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.9 shows the clinical and disease profiles with sexual dysfunction. Based on this table, there was significant association between younger age of disease onset (≤ 50 years) with sexual dysfunction, with an odds ratio of 7.200, p= 0.044. This would indicate that younger women diagnosed with breast cancer were at greater odds of experiencing sexual dysfunction compared to older women diagnosed with breast cancer.

Women who has had chemotherapy, hormonal therapy and those with waist circumference of less than 80 cm appear to have greater odds of experiencing sexual dysfunction but these associations are not statistically significant.

Table 5.10 Marital profiles with sexual dysfunction in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	**Sexual dysfunction (n= 90)**	**No sexual dysfunction (n= 10)**	**x^2 value**	**OR**	**95% CI**	**p value**
Partner's age (years)						
≤ 50 (%)	26 (83.9)	5 (16.1)	¥	2.462	0.657-9.221	0.277
> 50 (%)	64 (92.8)	5 (7.2)				
Duration of relationship (years)						
≤ 20 (%)	23 (85.2)	4 (14.8)	¥	1.942	0.503-7.498	0.452
> 20 (%)	67 (91.8)	6 (8.2)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.10 shows the marital profiles with sexual dysfunction. From this table, women with younger partner (≤ 50-years of age) and those with shorter duration of relationship (≤ 20 years) appeared to have higher odds of experiencing sexual dysfunction. However, the associations were not statistically significant.

5.2.2 UNIVARIATE ANALYSIS OF BODY IMAGE DISTRESS AND STUDY VARIABLES

Table 5.11 Socio-demographic profiles with body image distress in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	Body image distress (n= 39)	No body image distress (n= 52)	x^2 value	OR	95% CI	p value
Age (years)						
≤ 50 (%)	18 (48.6)	19 (51.4)	0.854	0.672	0.288-1.565	0.355
> 50 (%)	21 (38.9)	33 (61.1)				
Race						
Malay (%)	12 (36.4)	21 (63.6)	0.891	1.524	0.634-3.664	0.345
Non- Malay (%)	27 (46.6)	31 (53.4)				
Religion						
Muslim (%)	12 (36.4)	21 (63.6)	0.891	1.524	0.634-3.664	0.345
Non-Muslim (%)	27 (46.6)	31 (53.4)				
Education level						
No formal education/ primary/ secondary (%)	26 (40.6)	38 (59.4)	0.439	1.357	0.549-3.354	0.508
Tertiary (%)	13 (48.1)	14 (51.9)				
Employment						
Employed (%)	19 (45.2)	23 (54.8)	0.181	0.835	0.363-1.920	0.671
Unemployed (%)	20 (40.8)	29 (59.2)				
Household income (per month)						
≤ RM 3000 (%)	23 (45.1)	28 (54.9)	0.238	0.812	0.351-1.879	0.626
> RM 3000 (%)	16 (40.0)	24 (60.0)				

* Significance level: $p < 0.05$

¥ Fisher’s Exact Test

Only 91 out of the 100 participants completed the BITS questionnaire entirely. When the BITS total score ≥ 26 was used, none of the socio-demographic variables were found to be associated with body image distress as shown in Table 5.11. Malay, Muslim and those with lower education level (secondary or primary or no formal education) were found to have higher odds to develop body image distress. However, these associations were not statistically significant.

Table 5.12 Clinical and disease profiles with body image distress in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	Body image distress (n= 39)	No body image distress (n= 52)	x^2 value	OR	95% CI	p value
Age of onset (years)						
≤ 50 (%)	24 (45.3)	29 (54.7)	0.305	0.788	0.338-1.836	0.581
> 50 (%)	15 (39.5)	23 (60.5)				
Duration of illness (years)						
≤ 5 (%)	31 (47.7)	34 (52.3)	2.172	0.487	0.186-1.279	0.141
> 5 (%)	8 (30.8)	18 (69.2)				
Surgery						
Yes (%)	39 (43.3)	51 (56.7)	¥			1.000
No (%)	0 (0.0)	1 (100.0)				
Chemotherapy						
Yes (%)	31 (45.6)	37 (54.4)	0.819	0.637	0.238-1.699	0.365
No (%)	8 (34.8)	15 (65.2)				
Radiotherapy						
Yes (%)	28 (43.1)	37 (56.9)	0.004	0.969	0.386-2.432	0.947
No (%)	11 (42.3)	15 (57.7)				
Hormonal therapy						
Yes (%)	31 (45.6)	37 (54.4)	0.819	0.637	0.238-1.699	0.365
No (%)	8 (34.8)	15 (65.2)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.12 Continued

Variables	Body image distress (n= 39)	No body image distress (n= 52)	x^2 value	OR	95% CI	p value
Distant metastasis						
Metastasis (%)	1 (50.0)	1 (50.0)	¥	0.745	0.045-12.295	1.000
Non-metastasis (%)	38 (42.7)	51 (57.3)				
Medical comorbidity						
Yes (%)	11 (34.4)	21 (65.6)	1.450	1.724	0.708-4.202	0.229
No (%)	28 (47.5)	31 (52.5)				
Menopausal status						
Yes (%)	30 (42.9)	40 (57.1)	0.000	1.000	0.373-2.679	1.000
No (%)	9 (42.9)	12 (57.1)				
BMI (kg/m^2)						
Underweight/ normal weight (%)	13 (46.4)	15 (53.6)	0.811	1.426	0.331-1.987	0.646
Overweight/ obese (%)	26 (41.3)	37 (58.7)				
Waist circumference (cm)						
< 80 cm (%)	17 (44.7)	21 (55.3)	0.094	0.877	0.378-2.033	0.759
≥ 80 cm (%)	22 (41.5)	31 (58.5)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.12 shows the clinical and disease profiles with body image distress. From this table, none of the clinical and disease profiles had statistically significant association with body image distress.

Table 5.13 Marital profiles with body image distress in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	Body image distress (n= 39)	No body image distress (n= 52)	x^2 value	OR	95% CI	p value
Partner's age (years)						
≤ 50 (%)	15 (53.6)	13 (46.4)	1.896	0.533	0.217-1.312	0.169
> 50 (%)	24 (38.1)	39 (61.9)				
Duration of relationship (years)						
≤ 20 (%)	10 (41.7)	14 (58.3)	0.019	1.068	0.415-2.747	0.891
> 20 (%)	29 (43.3)	38 (56.7)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.13 illustrates the marital profiles with body image distress. Even though breast cancer patients with shorter duration of relationship (≤ 20 years) have higher odds of developing body image distress, none of the marital profiles were significantly associated with body image distress.

5.2.3 UNIVARIATE ANALYSIS OF MARITAL DISSATISFACTION AND STUDY VARIABLES

Table 5.14 Socio-demographic profiles with marital dissatisfaction in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	Marital dissatisfaction (n= 55)	No marital dissatisfaction (n= 45)	x^2 value	OR	95% CI	p value
Age (years)						
≤ 50 (%)	25 (62.5)	15 (37.5)	1.515	0.600	0.265-1.357	0.218
> 50 (%)	30 (50.0)	30 (50.0)				
Race						
Malay (%)	17 (45.9)	20 (54.1)	1.945	1.788	0.787-4.061	0.163
Non- Malay (%)	38 (60.3)	25 (39.7)				
Religion						
Muslim (%)	17 (45.9)	20 (54.1)	1.945	1.788	0.787-4.061	0.163
Non-Muslim (%)	38 (60.3)	25 (39.7)				
Education level						
No formal education/ primary/ secondary (%)	40 (57.1)	30 (42.9)	0.433	0.750	0.318-1.769	0.511
Tertiary (%)	15 (50.0)	15 (50.0)				
Employment						
Employed (%)	26 (56.5)	20 (43.5)	0.080	0.892	0.404-1.968	0.778
Unemployed (%)	29 (53.7)	25 (46.3)				
Household income (per month)						
≤ RM 3000 (%)	32 (58.2)	23 (41.8)	0.500	0.751	0.340-1.660	0.480
> RM 3000 (%)	23 (51.1)	22 (48.9)				

* Significance level: $p < 0.05$

¥ Fisher's Exact Test

Table 5.14 shows the socio-demographic profiles with marital dissatisfaction. Malay patients and those practising Islam have greater odds of having marital dissatisfaction compared to the non-Malays and non-Muslim devotees. However, these associations are not statistically significant. There are no significant differences in marital dissatisfaction with regards to the socio-demographic profiles (age, race, religion, employment status, education level, and household income) of the participants in the study.

Table 5.15 Clinical and disease profiles with marital dissatisfaction in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	**Marital dissatisfaction (n= 55)**	**No marital dissatisfaction (n= 45)**	**x^2 value**	**OR**	**95% CI**	**p value**
Age of onset (years)						
≤ 50 (%)	35 (59.3)	24 (40.7)	1.086	0.653	0.293-1.458	0.297
> 50 (%)	20 (48.8)	21 (51.2)				
Duration of illness (years)						
≤ 5 (%)	42 (60.0)	28 (40.0)	2.357	0.510	0.214-1.212	0.125
> 5 (%)	13 (43.3)	17 (56.7)				
Surgery						
Yes (%)	55 (55.6)	44 (44.4)	¥			0.450
No (%)	0 (0.0)	1 (100.0)				
Chemo-therapy						
Yes (%)	42 (56.0)	33 (44.0)	0.121	0.851	0.343-2.109	0.728
No (%)	13 (52.0)	12 (48.0)				
Radio-therapy						
Yes (%)	44 (61.1)	28 (38.9)	3.880	0.412	0.168-1.007	0.049*
No (%)	11 (39.3)	17 (60.7)				
Hormonal therapy						
Yes (%)	41 (54.7)	34 (45.3)	0.013	1.055	0.424-2.625	0.908
No (%)	14 (56.0)	11 (44.0)				

* Significance level: $p < 0.05$
¥ Fisher’s Exact Test

Table 5.15 Continued

Variables	**Marital dissatisfaction (n= 55)**	**No marital dissatisfaction (n= 45)**	**x^2 value**	**OR**	**95% CI**	**p value**
Distant metastasis						
Metastasis (%)	2 (66.7)	1 (33.3)	¥	0.602	0.053-6.865	1.000
Non-metastasis (%)	53 (54.6)	44 (45.4)				
Medical comorbidity						
Yes (%)	16 (48.5)	17 (51.5)	0.845	1.480	0.640-3.420	0.358
No (%)	39 (58.2)	28 (41.8)				
Menopausal status						
Yes (%)	40 (51.9)	37 (48.1)	1.260	1.734	0.659-4.564	0.262
No (%)	15 (65.2)	8 (34.8)				
BMI (kg/m^2)						
Under-weight/ normal weight (%)	20 (60.6)	13 (39.4)	0.625	0.711	0.305-1.658	0.429
Overweight/ obese (%)	35 (52.2)	32 (48.8)				
Waist circum-ference (cm)						
< 80 cm (%)	23 (54.8)	19 (45.2)	0.002	1.017	0.458-2.259	0.968
≥ 80 cm (%)	32 (55.2)	26 (44.8)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.15 shows the clinical and disease profiles with marital dissatisfaction. Women who had hormonal therapy, menopause, presence of medical comorbidity, and have a smaller waist circumference (< 80cm) have greater odds of having marital dissatisfaction, but these associations are not statistically significant. Those who were diagnosed with breast cancer at a younger age (≤ 50 years), and shorter duration of illness (≤ 5 years) have lower odds of experiencing marital dissatisfaction. However, these associations are also statistically insignificant. Women who had radiotherapy have lower odds of experiencing marital dissatisfaction and this association is statistically significant with p= 0.049.

Table 5.16 Marital profiles with marital dissatisfaction in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	Marital dissatisfaction (n= 55)	No marital dissatisfaction (n= 45)	x^2 value	OR	95% CI	p value
Partner's age (years)						
≤ 50 (%)	19 (61.3)	12 (38.7)	0.689	0.291	0.291- 1.634	0.397
> 50 (%)	36 (52.2)	33 (47.8)				
Duration of relationship (years)						
≤ 20 (%)	16 (59.3)	11 (40.7)	0.271	0.789	0.322- 1.930	0.603
> 20 (%)	39 (53.4)	34 (46.6)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.16 shows the marital profiles with marital dissatisfaction. There are no differences with marital dissatisfaction with regards to the partners' age and the duration of the relationship.

5.2.4 UNIVARIATE ANALYSIS OF HADS-D AND STUDY VARIABLES

Table 5.17 Socio-demographic profiles with depressive symptoms in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	Depressed (n= 9)	Not depressed (n= 91)	x^2 value	OR	95% CI	p value
Age (years)						
≤ 50 (%)	4 (10.0)	36 (90.0)	¥	0.818	0.206-3.253	1.000
> 50 (%)	5 (8.3)	55 (91.7)				
Race						
Malay (%)	2 (5.4)	35 (94.6)	¥	2.188	0.430-11.134	0.478
Non- Malay (%)	7 (11.1)	56 (88.9)				
Religion						
Muslim (%)	2 (5.4)	35 (94.6)	¥	2.188	0.430-11.134	0.478
Non-Muslim (%)	7 (11.1)	56 (88.9)				
Education level						
No formal education/ primary/ secondary (%)	9 (12.9)	61 (87.1)	¥			0.054
Tertiary (%)	0 (0.0)	30 (100.0)				
Employment						
Employed (%)	4 (8.7)	42 (91.3)	¥	1.071	0.270-4.250	1.000
Unemployed (%)	5 (9.3)	49 (90.7)				
Household income (per month)						
≤ RM 3000 (%)	6 (10.9)	49 (89.1)	¥	0.583	0.137-2.477	0.508
> RM 3000 (%)	3 (6.7)	42 (93.3)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.17 describes the socio-demographic data with depressive symptoms based on the HADS-D score of ≥ 8. Women who are working have higher odds of developing depressive symptoms, but this association is not statistically significant. Being Malay and practising Islam were also noted to have higher odds of developing depressive symptoms. However, these associations are not statistically significant too. There are no differences in depressive symptoms with regards to the participants' age, educational level and the monthly household income.

Table 5.18 Clinical and disease profiles with depressive symptoms in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	**Depressed (n= 9)**	**Not depressed (n= 91)**	**x^2 value**	**OR**	**95% CI**	**p value**
Age of onset (years)						
≤ 50 (%)	6 (10.2)	53 (89.8)	¥	0.697	0.164-2.965	0.733
> 50 (%)	3 (7.3)	38 (92.7)				
Duration of illness (years)						
≤ 5 (%)	7 (10.0)	63 (90.0)	¥	0.643	0.126-3.292	0.720
> 5 (%)	2 (6.7)	28 (93.3)				
Surgery						
Yes (%)	9 (9.1)	90 (90.9)	¥			1.000
No (%)	0 (0.0)	1 (100.0)				
Chemo-therapy						
Yes (%)	7 (9.3)	68 (90.7)	¥	0.845	0.164-4.359	1.000
No (%)	2 (8.0)	23 (92.0)				
Radio-therapy						
Yes (%)	6 (8.3)	66 (91.7)	¥	1.320	0.306-5.686	0.707
No (%)	3 (10.7)	25 (89.3)				
Hormonal therapy						
Yes (%)	8 (10.7)	67 (89.3)	¥	0.349	0.041-2.938	0.444
No (%)	1 (4.0)	24 (96.0)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.18 Continued

Variables	Depressed (n= 9)	Not depressed (n= 91)	x^2 value	OR	95% CI	p value
Distant metastasis						
Metastasis (%)	0 (0.0)	3 (100.0)	¥			1.000
Non-metastasis (%)	9 (9.3)	88 (90.7)				
Medical comorbidity						
Yes (%)	3 (9.1)	30 (90.9)	¥	0.984	0.230-4.207	1.000
No (%)	6 (9.0)	61 (91.0)				
Menopausal status						
Yes (%)	9 (11.7)	68 (88.3)	¥			0.113
No (%)	0 (0.0)	23 (100.0)				
BMI (kg/m^2)						
Under-weight/ normal weight (%)	3 (9.1)	30 (90.9)	¥	0.984	0.230-4.207	1.000
Overweight/ obese (%)	6 (9.0)	61 (91.0)				
Waist circum-ference (cm)						
< 80 cm (%)	3 (7.1)	39 (92.9)	¥	1.500	0.353-6.374	0.730
≥ 80 cm (%)	6 (10.3)	52 (89.7)				

* Significance level: $p < 0.05$
¥ Fisher’s Exact Test

Table 5.18 shows the clinical and disease profiles with depressive symptoms. Women who had radiotherapy and those with waist circumference of < 80cm have greater odds of developing depressive symptoms, but these associations are not statistically significant. There are no differences in depressive symptoms in terms of both the clinical and disease profiles of the participants.

Table 5.19 Marital profiles with depressive symptoms in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	**Depressed (n= 9)**	**Not depressed (n= 91)**	**x^2 value**	**OR**	**95% CI**	**p value**
Partner's age (years)						
≤ 50 (%)	2 (6.5)	29 (93.5)	¥	1.637	0.320-8.374	0.717
> 50 (%)	7 (10.1)	62 (89.9)				
Duration of relationship (years)						
≤ 20 (%)	1 (3.7)	26 (96.3)	¥	3.200	0.381-26.874	0.438
> 20 (%)	8 (11.0)	65 (89.0)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.19 shows the marital profiles with depressive symptoms. When the total HADS-D was taken at ≥ 8, there are no differences in depressive symptoms with regards to the participants' marital profiles.

5.2.5 UNIVARIATE ANALYSIS OF HADS-A AND STUDY VARIABLES

Table 5.20 Socio-demographic profiles with anxiety symptoms in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	Anxious (n= 27)	Not anxious (n= 73)	x^2 value	OR	95% CI	p value
Age (years)						
≤ 50 (%)	16 (40.0)	24 (60.0)	5.716	0.337	0.136-0.836	0.017*
> 50 (%)	11 (18.3)	49 (81.7)				
Race						
Malay (%)	7 (18.9)	30 (81.1)	1.946	1.993	0.749-5.305	0.163
Non- Malay (%)	20 (31.7)	43 (68.3)				
Religion						
Muslim (%)	7 (18.9)	30 (81.1)	1.946	1.993	0.749-5.305	0.163
Non-Muslim (%)	20 (31.7)	43 (68.3)				
Education level						
No formal education/ primary/ secondary (%)	19 (27.1)	51 (72.9)	0.002	0.976	0.372-2.563	0.961
Tertiary (%)	8 (26.7)	22 (73.3)				
Employment						
Employed (%)	17 (37.0)	29 (63.0)	4.284	0.388	0.156-0.964	0.038*
Unemployed (%)	10 (18.5)	44 (81.5)				
Household income (per month)						
≤ RM 3000 (%)	14 (25.5)	41 (74.5)	0.148	1.190	0.491-2.883	0.700
> RM 3000 (%)	13 (28.9)	32 (71.1)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.20 shows the socio-demographic data with anxiety symptoms. When the total HADS-A was taken at ≥ 8, younger breast cancer patients (≤ 50 years) are at lower odds of experiencing depressive symptoms compared to older patients, with an odds ratio of 0.337, p= 0.017. Those who are employed are also at lower odds of developing anxiety symptoms compared to those who are not working, with an odds ratio of 0.388, p= 0.038. None of the other socio-demographic variables were significant with anxiety symptoms.

Table 5.21 Clinical and disease profiles with anxiety symptoms in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	Anxious (n= 27)	Not anxious (n= 73)	x^2 value	OR	95% CI	p value
Age of onset (years)						
≤ 50 (%)	19 (32.2)	40 (67.8)	1.977	0.510	0.198-1.314	0.160
> 50 (%)	8 (19.5)	33 (80.5)				
Duration of illness (years)						
≤ 5 (%)	20 (28.6)	50 (71.4)	0.292	0.761	0.282-2.052	0.589
> 5 (%)	7 (23.3)	23 (76.7)				
Surgery						
Yes (%)	27 (27.3)	72 (72.7)	¥			1.000
No (%)	0 (0.0)	1 (100.0)				
Chemo-therapy						
Yes (%)	21 (28.0)	54 (72.0)	0.152	0.812	0.285-2.314	0.696
No (%)	6 (24.0)	19 (76.0)				
Radio-therapy						
Yes (%)	23 (31.9)	49 (68.1)	3.190	0.355	0.110-1.143	0.074
No (%)	4 (14.3)	24 (85.7)				
Hormonal therapy						
Yes (%)	20 (26.7)	55 (73.3)	0.017	1.069	0.389-2.942	0.897
No (%)	7 (28.0)	18 (72.0)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.21 Continued

Variables	Anxious (n= 27)	Not anxious (n= 73)	x^2 value	OR	95% CI	p value
Distant metastasis						
Metastasis (%)	1 (33.3)	2 (66.7)	¥	0.732	0.064-8.421	1.000
Non-metastasis (%)	26 (26.8)	71 (73.2)				
Medical comorbidity						
Yes (%)	7 (21.2)	26 (78.8)	0.837	1.581	0.590-4.233	0.360
No (%)	20 (29.9)	47 (70.1)				
Menopausal status						
Yes (%)	20 (26.0)	57 (74.0)	0.179	1.247	0.448-3.471	0.672
No (%)	7 (30.4)	16 (69.6)				
BMI (kg/m^2)						
Under-weight/ normal weight (%)	7 (21.2)	26 (78.8)	0.837	1.581	0.590-4.233	0.360
Overweight/ obese (%)	20 (29.9)	47 (70.1)				
Waist circum-ference (cm)						
< 80 cm (%)	9 (21.4)	33 (78.6)	1.140	1.650	0.655-4.154	0.286
≥ 80 cm (%)	18 (31.0)	40 (69.0)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.21 illustrates the clinical and disease profiles with anxiety symptoms. Breast cancer patients who have had hormonal therapy, medical comorbidity, menopausal, under or normal weight and those with waist circumference < 80 cm are at greater odds to develop anxiety symptoms compared to those who did not undergo radiation therapy. However these associations are not statistically significant. None of the clinical and disease profiles are statistically significant with anxiety symptoms, when the total HADS-A score was taken at ≥ 8.

Table 5.22 Marital profiles with anxiety symptoms in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	Anxious (n= 27)	Not anxious (n= 73)	x^2 value	OR	95% CI	p value
Partner's age (years)						
≤ 50 (%)	10 (32.3)	21 (67.7)	0.630	0.687	0.271- 1.742	0.427
> 50 (%)	17 (24.6)	52 (75.4)				
Duration of relationship (years)						
≤ 20 (%)	10 (37.0)	17 (63.0)	1.890	0.516	0.199- 1.336	0.169
> 20 (%)	17 (23.3)	56 (76.7)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.22 shows the marital profiles with anxiety symptoms. Breast cancer patients with younger partners (≤ 50 years) and those with the duration of relationship of 20 years and less have lower odds of experiencing anxiety symptoms. However, these associations are not statistically significant.

5.2.6 UNIVARIATE ANALYSIS OF TOTAL PGWBI SCORE AND STUDY VARIABLES

The PGWBI has no cut-off point, hence the median score (76.00) was used in the analysis.

Table 5.23 Socio-demographic profiles with total PGWBI score in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	**PGWBI ≥ 76 (n= 52)**	**PGWBI < 76 (n= 48)**	**x^2 value**	**OR**	**95% CI**	**p value**
Age (years)						
≤ 50 (%)	15 (37.5)	25 (62.5)	5.616	2.681	1.175-6.118	0.018*
> 50 (%)	37 (61.7)	23 (38.3)				
Race						
Malay (%)	26 (70.3)	11 (29.7)	7.854	0.297	0.125-0.706	0.005**
Non-Malay (%)	26 (41.3)	37 (58.7)				
Religion						
Muslim (%)	26 (70.3)	11 (29.7)	7.854	0.297	0.125-0.706	0.005**
Non-Muslim (%)	26 (41.3)	37 (58.7)				
Education level						
No formal education/ primary/ secondary (%)	39 (55.7)	31 (44.3)	1.290	0.608	0.257-1.440	0.256
Tertiary (%)	13 (43.3)	17 (56.7)				
Employment						
Employed (%)	19 (41.3)	27 (58.7)	3.904	2.233	1.001-4.982	0.048*
Unemployed (%)	33 (61.1)	21 (38.9)				
Household income (per month)						
≤ RM 3000 (%)	30 (54.5)	25 (45.5)	0.317	0.797	0.362-1.755	0.573
> RM 3000 (%)	22 (48.9)	23 (51.1)				

* Significance level: $p < 0.05$
** Significance level: $p < 0.01$
¥ Fisher's Exact Test

Table 5.23 shows the socio-demographic profiles with the total PGWBI score. Younger women (≤ 50 years of age) and those who are working have greater odds of obtaining higher PGWBI total score, with odds ratio of 2.681 and 2.233 respectively. These associations are statistically significant, with p= 0.018 and p= 0.048 respectively. Whereas Malay and Muslim women have lower odds of obtaining higher PGWBI total score, with odds ratio of 0.297 and p= 0.005.

Table 5.24 Clinical and disease profiles with total PGWBI score in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	**PGWBI ≥ 76 (n= 52)**	**PGWBI < 76 (n= 48)**	**x^2 value**	**OR**	**95% CI**	**p value**
Age of onset (years)						
≤ 50 (%)	25 (42.4)	34 (57.6)	5.343	2.623	1.148-5.995	0.021*
> 50 (%)	27 (65.9)	14 (34.1)				
Duration of illness (years)						
≤ 5 (%)	35 (50.0)	35 (50.0)	0.374	1.308	0.553-3.093	0.541
> 5 (%)	17 (56.7)	13 (43.3)				
Surgery						
Yes (%)	51 (51.5)	48 (48.5)	¥			1.000
No (%)	1 (100.0)	0 (0.0)				
Chemo-therapy						
Yes (%)	42 (56.6)	33 (44.0)	1.923	0.524	0.209-1.316	0.166
No (%)	10 (40.0)	15 (60.0)				
Radio-therapy						
Yes (%)	36 (50.0)	36 (50.0)	0.412	1.333	0.553-3.213	0.521
No (%)	16 (57.1)	12 (42.9)				
Hormonal therapy						
Yes (%)	40 (53.3)	35 (46.7)	0.214	0.808	0.326-1.999	0.644
No (%)	12 (48.0)	13 (52.0)				

* Significance level: $p < 0.05$

¥ Fisher’s Exact Test

Table 5.24 Continued

Variables	**PGWBI ≥ 76 (n= 52)**	**PGWBI < 76 (n= 48)**	**x^2 value**	**OR**	**95% CI**	**p value**
Distant metastasis						
Metastasis (%)	1 (33.3)	2 (66.7)	¥	2.217	0.195-25.271	0.606
Non-metastasis (%)	51 (52.6)	46 (47.4)				
Medical comorbidity						
Yes (%)	19 (57.6)	14 (42.4)	0.613	0.715	0.309-1.657	0.433
No (%)	33 (49.3)	34 (50.7)				
Menopausal status						
Yes (%)	43 (55.8)	34 (44.2)	1.982	0.508	0.196-1.315	0.159
No (%)	9 (39.1)	14 (60.9)				
BMI (kg/m^2)						
Under-weight/ normal weight (%)	13 (39.4)	20 (60.6)	3.136	2.143	0.915-5.016	0.077
Overweight/ obese (%)	39 (58.2)	28 (41.8)				
Waist circum-ference (cm)						
< 80 cm (%)	16 (38.1)	26 (61.9)	5.609	2.659	1.173-6.026	0.018*
≥ 80 cm (%)	36 (62.1)	22 (37.9)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.24 shows the clinical and disease profiles with the total PGWBI score. Breast cancer patients with younger age of disease onset (≤ 50 years of age) and waist circumference < 80 cm were at greater odds of obtaining higher total PGWBI score and these associations are statistically significant, with p= 0.021 and p= 0.018 respectively.

Table 5.25 Marital profiles with the total PGWBI score in breast cancer patients attending follow up at the breast clinic in UMMC

Variables	PGWBI ≥ 76 (n= 52)	PGWBI < 76 (n= 48)	x^2 value	OR	95% CI	p value
Partner's age (years)						
≤ 50 (%)	12 (38.7)	19 (61.3)	3.179	2.184	0.918-5.195	0.075
> 50 (%)	40 (58.0)	29 (44.0)				
Duration of relationship (years)						
≤ 20 (%)	10 (37.0)	17 (63.0)	3.318	2.303	0.928-5.714	0.069
> 20 (%)	42 (57.5)	31 (42.5)				

* Significance level: $p < 0.05$
¥ Fisher's Exact Test

Table 5.25 illustrates the marital profiles with the total PGWBI score. The participants' marital profiles are not significantly associated with the total PGWBI score.

5.2.7 CORRELATION BETWEEN DEPENDENT MEASURE AND INDEPENDENT MEASURES

Table 5.26 Correlation between body image distress (BITS), marital dissatisfaction (GRIMS), depressive symptoms (HADS-D), anxiety symptoms (HADS-A), and quality of life (PGWBI) with sexual dysfunction (FSFI)

		BITS	GRIMS	HADS-D	HADS-A	PGWBI
Sexual dysfunction (FSFI)	**Correlation co-efficient, *r***	-0.13	-0.49	-0.34	-0.10	0.24
	p value	0.226	< 0.001***	0.001**	0.301	0.140

** Significance level: p < 0.01
*** Significance level: p < 0.001

Table 5.26 shows the correlation between body image distress, marital dissatisfaction, depressive, and anxiety symptoms and quality of life with sexual dysfunction. There is significant correlation between measures of marital dissatisfaction and depressive symptoms with the primary outcome measure of sexual dysfunction, with p< 0.001 and p= 0.001 respectively. Body image distress (*r*= -0.13), marital dissatisfaction (*r*= -0.49), anxiety, and depressive symptoms (*r*= -0.10, -0.34 respectively) scores are inversely correlated with sexual dysfunction.

Table 5.27 Correlation between sexual dysfunction (FSFI), marital dissatisfaction (GRIMS), depressive symptoms (HADS-D), anxiety symptoms (HADS-A), and quality of life (PGWBI) with body image distress (BITS)

		FSFI	GRIMS	HADS-D	HADS-A	PGWBI
Body image distress (BITS)	**Correlation co-efficient, *r***	-0.13	0.34	0.37	0.45	-0.41
	p value	0.226	0.001**	<0.001***	<0.001***	<0.001***

** Significance level: p < 0.01
*** Significance level: p < 0.001

Table 5.27 shows the correlation between sexual dysfunction, marital dissatisfaction, depressive, and anxiety symptoms and quality of life with body image distress. Measures of marital dissatisfaction, depressive, and anxiety symptoms and quality of life showed significant correlation with body image distress.

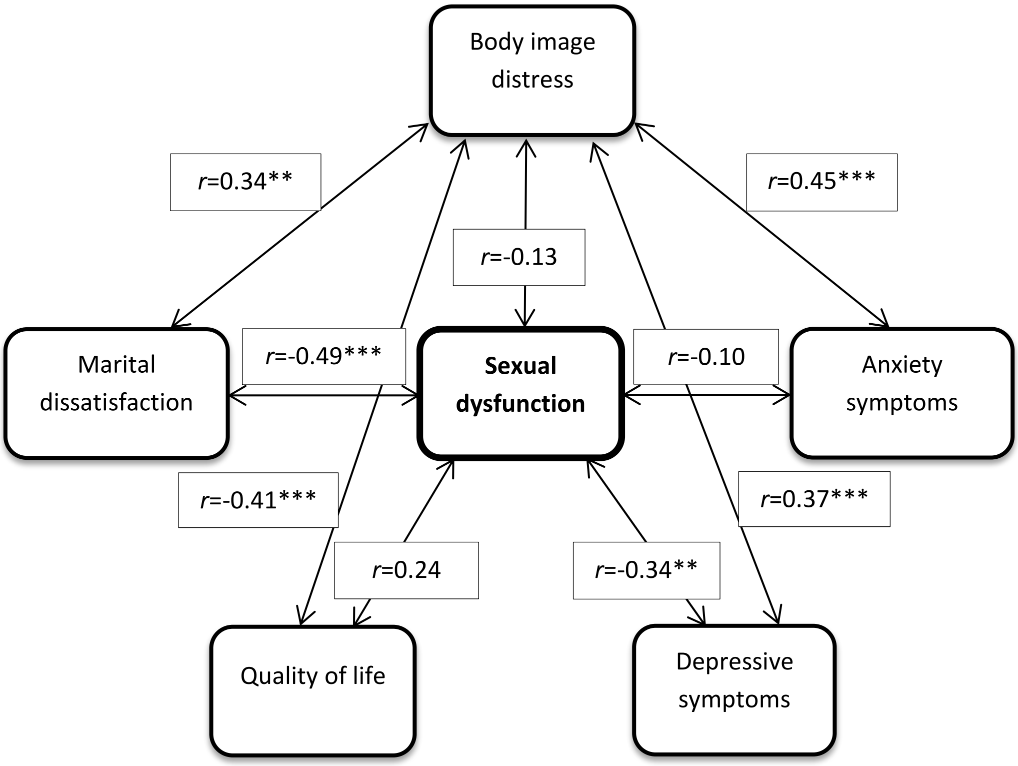
Table 5.28 Correlation between sexual dysfunction (FSFI), body image distress (BITS), depressive symptoms (HADS-D), anxiety symptoms (HADS-A), quality of life (PGWBI) with marital dissatisfaction (GRIMS)

		FSFI	BITS	HADS-D	HADS-A	PGWBI
Marital dis-satisfaction (GRIMS)	**Correlation co-efficient, *r***	-0.49	0.34	0.39	0.38	-0.40
	p value	<0.001***	0.001**	<0.001***	<0.001***	<0.001***

** Significance level: $p < 0.01$
*** Significance level: $p < 0.001$

Table 5.28 shows the correlation between sexual dysfunction, body image distress, depressive and anxiety symptoms, and quality of life with marital dissatisfaction. Measures of sexual dysfunction, body image distress, depressive and anxiety symptoms, and quality of life are significantly correlated with marital dissatisfaction.

Figure 5.14 Summary of correlation between dependent measures and independent measures



5.2.8 MULTIVARIATE LINEAR REGRESSION ANALYSIS BETWEEN SEXUAL DYSFUNCTION AND INDEPENDENT MEASURES

Table 5.29 Multivariate linear regression analysis of independent variables with sexual dysfunction

Variables	Unstandardized coefficients, B	Standardized coefficients, Beta	p value	95% CI
Age of disease onset	-0.423	-0.351	< 0.001***	-0.616 to -0.231
Total GRIMS score	-0.353	-0.371	< 0.001***	-0.518 to -0.189
HADS-D subscale score	-0.669	-0.202	0.022*	-1.240 to -0.098
R = 0.623				
R^2 = 0.388				
Adjusted R^2 = 0.368				

* Significance level: $p < 0.05$
*** Significance level: $p < 0.001$

From the univariate analysis conducted, the patients who experienced sexual dysfunction showed significant association with age of disease onset, the total GRIMS score and HADS-D sub-scale score, with p< 0.05. Multivariate linear regression was conducted as shown in Table 5.29 above. For every year increase in the age of disease onset, the total FSFI score was expected to decrease by -0.423 point, holding all other variables constant, with p< 0.001. The coefficient for the total GRIMS score was -0.353, which indicated that for every point increase in the total GRIMS score, the total FSFI score was expected to decrease by -0.353 point, with p< 0.001. For every 1 point increase in the HADS-D sub-scale, the total FSFI score was expected to decrease by -0.669, with p= 0.022. All the independent variables (age of disease onset, GRIMS total score and

HADS-D score) were statistically significant with total FSFI score. The adjusted R^2 is 0.368, which indicated that 37% of the total variability of the FSFI total score is explained by age of disease onset, GRIMS total score and HADS-D score.

Table 5.30 Stepwise multivariate linear regression analysis of independent variables with sexual dysfunction

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.489[a]	.239	.231	8.3664	.239	30.812	1	98	.000
2	.594[b]	.353	.340	7.7541	.114	17.089	1	97	.000
3	.623[c]	.388	.368	7.5838	.034	5.405	1	96	.022

a. Predictors: (Constant), GRIMS total

b. Predictors: (Constant), GRIMS total, Actual age of onset

c. Predictors: (Constant), GRIMS total, Actual age of onset, HADS depression

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B	
		B	Std. Error	Beta			Lower Bound	Upper Bound
1	(Constant)	31.392	2.914		10.772	.000	25.608	37.175
	GRIMS total	-.464	.084	-.489	-5.551	.000	-.630	-.298
2	(Constant)	49.759	5.200		9.570	.000	39.439	60.079
	GRIMS total	-.429	.078	-.452	-5.505	.000	-.584	-.274
	Actual age of onset	-.409	.099	-.340	-4.134	.000	-.605	-.213
3	(Constant)	50.257	5.090		9.874	.000	40.154	60.361
	GRIMS total	-.353	.083	-.372	-4.260	.000	-.518	-.189
	Actual age of onset	-.423	.097	-.351	-4.366	.000	-.616	-.231
	HADS depression	-.669	.288	-.202	-2.325	.022	-1.240	-.098

a. Dependent Variable: FSFI total

Table 5.30 showed the stepwise multivariate linear regression that was carried out for the independent variables with sexual dysfunction. Model 1 which included only the GRIMS total score for 23% of the variance (adjusted R^2= 0.231). The inclusion of actual age of disease onset in model 2 resulted in additional 11% of the variance being explained (R^2 change= 0.114). The final model 3 also included HADS-D sub-scale score, and this model accounted for 37% of the variance (adjusted R^2= 0.368). Hence using the stepwise method, a significant model emerged, with adjusted R^2= 0.368. Significant variables are GRIMS total score (B= -0.372, p< 0.001), actual age of disease onset (B= -0.351, p< 0.001) and HADS-D sub-scale score (B= -0.202, p= 0.022).

CHAPTER SIX

DISCUSSION

This is a cross-sectional study examining the prevalence of sexual dysfunction amongst breast cancer survivors attending follow up at the breast clinic in University Malaya Medical Centre (UMMC) from August 2012 to December 2012. Other aims were to determine the severity of body image distress and marital dissatisfaction amongst the participants and their associations with sexual dysfunction as well as the associated socio-demographic and clinical variables.

6.1 SOCIO-DEMOGRAPHIC, CLINICAL, DISEASE AND MARITAL CHARACTERISTICS OF THE STUDY PARTICIPANTS

In this study, Table 5.1 showed that the majority of the participants were more than 50 years of age (60%) and the mean of age was 52.64 with a standard deviation of 7.54. This finding was similar to a study done on the survival analysis of women with breast cancer in Malaysia which was based in UMMC by Taib et al, (2003). Out of the 413 breast cancer survivors that were included in the study, 241 women (58%) were between 41 to 59 years of age and 95 women (23%) were 60 years of age and above.

More Chinese breast cancer survivors were noted from the study with 43%, and this was followed by the Malays and the Indians, with 37% and 20% respectively. This was surprising as the Malay ethnic origin usually makes up the majority of the population in the country. The possible explanation for this observation is that the Chinese has the highest incidence of breast cancer, with 1 in 16 Chinese women will develop breast cancer during their lifetime, followed by 1 in 16 Indian women and 1 in 28 Malay women (Lim and Halimah, 2004). Similar findings were also reported in the National Cancer Statistics 2007. Chinese women with breast cancer were also found to have higher 5-year survival probability of 0.635 compared to the Indian and Malay women, with 0.574 and 0.475 respectively (Taib, Yip and Mohamed, 2003). Having said that, according to the hospital statistics, Chinese patient attendees are over-represented in UMMC.

Religion is still an important aspect of most Malaysians regardless of their ethnicity. In this study, the majority of the participants were Muslims with 37%, and this was followed by Buddhism (33%), Christianity (18%) and Hinduism (12%). This finding correlates with Islam as being the largest religion in Malaysia. It was also noted that in this study, there were 43 Chinese patients but only 33 patients who were Buddhist devotees. The explanation to this disparity observed could be the fact that occasionally Chinese may have other religious practise such as Christianity.

Amongst the breast cancer survivors that were included in this study, 61% had completed secondary education while 30% had tertiary education. A low percentage of these women (3%) had no formal education and only 6% had only completed primary education. Even though the 2 participants have never had formal schooling, they were still able to understand and read English language. Thus, they were still able to complete the questionnaires which were self-administered scales.

Almost half (46%) of the breast cancer patients in this study were either working full time or part time. Out of the 100 participants, 37 were either unemployed or a housewife. Pensioner or retiree made up 17% of the participants. Majority of these women had a low total household income of RM3000 and below per month (55%).

In the study population, majority (59%) of these women were 50 years and younger at the onset of breast cancer. The mean for age of onset was 47.77 years with a standard deviation of 7.93. This was higher compared to the findings in an epidemiological study conducted by Yip and colleagues (2003) which reported that out of 3738 cases of breast cancer seen in Malaysia that year, about 50% were below the age of 50 years. The mean age of onset of 47.77 years was also younger compared to the mean age of onset of 51 years in a study conducted by Taib and colleagues (2008). Majority of these women had duration of illness of 5 years and below (70%). The mean duration of breast cancer from the time of diagnosis to their recruitment into the study was 4.99 years with median of 3.00 years and standard deviation of 4.73.

Only 3 out of the 100 breast cancer survivors had distant metastasis of the disease at the point of enrolment into the study. This could be due to public awareness campaign through the mass media. The early screening programs which allow for detection of the disease at an early stage, and also advances in the treatment modalities of breast cancer is accessible to most Malaysians. 99 out of the 100 breast cancer patients in this study had breast cancer surgery, of which 64 had a mastectomy and the remaining 35 had lumpectomy. 75% of the women had chemotherapy, 72% had radiotherapy, and 75% had hormonal therapy. Of those that were still on hormonal therapy during participation in the study, 68 (90.7%) were on Tamoxifen.

Majority of these women with breast cancer were menopausal (77%). The mean duration from the onset of menopause to their participation into the study was 7.38 years with a standard deviation of 5.40. Only a minority of them (33%) had other medical comorbidity which was mainly a history of diabetes mellitus or hypertension. With regards to the body mass index (BMI) of the participants, only 28% had normal BMI compared to 39% who were considered overweight and 28% who were in the obese category. The mean weight of the participants was 61.70kg with a standard deviation of 10.72. 58% of these women had waist circumference of 80cm and above with the mean of 81.40cm and standard deviation of 9.68.

In this study, Table 5.4 illustrated the marital profiles of the participants which indicated that majority (69%) of the partners were above 50 years of age with the mean of 56.44 years and standard deviation of 9.04. The youngest partner was 37 years of age, and the oldest partner was 75 years of age.

6.2 SEXUAL DYSFUNCTION AND SOCIO-DEMOGRAPHIC VARIABLES

The prevalence of sexual dysfunction amongst breast cancer survivors in this study was 90% with the total FSFI score of ≤ 26.6 taken as an indication of the presence of sexual dysfunction. This was higher compared to the 75% prevalence of sexual dysfunction in breast cancer patients reported in a study done in the United States by Goldfarb et al (2009). In their cross-sectional study, Goldfarb and colleagues (2009) had recruited 100 women with breast cancer from an outpatient clinic of a breast centre. The subjects had mean age of 52 (range 26-75 years of age) and the FSFI with a cut-off score of less than 26 was also used to assess for sexual dysfunction. In a different survey also conducted in the United States by Raggio and colleagues (2014), 83 breast cancer survivors with a median of 7 years post diagnosis were included in the study. 77% of all the subjects were found to have sexual dysfunction as identified also by the FSFI. In another cross-sectional study conducted by Capodice and colleagues (2008), the prevalence of sexual dysfunction as assessed by using the FSFI was reported to be at 57%. This particular study had recruited a total of 117 women with breast cancer, with the median age of 52 years (range 29-82 years of age). Kedde and colleagues (2013) carried out a cross sectional study looking at sexual dysfunction amongst Dutch women with breast cancer and found that the prevalence of sexual dysfunction to be 64% in those still receiving treatment for cancer and 45% in those who had completed their treatment.

The possible reason for the discrepancy observed in the prevalence of sexual dysfunction in this current study compared to previous papers would be the difference in the study population. All the above cited studies were conducted in Western countries. In Asian countries like Malaysia, female sexual dysfunction is rarely talked about amongst the general public and considered relatively new (Sidi el at, 2007). Hence, the awareness about this issue amongst the general public especially Malaysian women might be scarce as compared to their Western counterparts. This could be a contributing factor to explain the high prevalence of sexual dysfunction observed in this study compared to the ones involving Western populations.

Higher number of Malay women with breast cancer and thus Muslim women (94.6%) were found to have sexual dysfunction compared to their non-Malay and non-Muslim counterparts (87.3%) based on this study. The cultural and religious beliefs amongst these women could also be a probable contributing factor to the high prevalence of sexual dysfunction observed. Muslim women are not encouraged to talk about their sexual relationship with other people except with their husband. Women might feel uneasy and uncomfortable discussing their sexual difficulties with their husband, fearing that the issue could jeopardize their relationship. They might also perceived that the difficulties that they are facing is normal, thus preventing them from consulting about the sexual problems. Also it is not an uncommon practise amongst Malaysian, particularly in the Malays, to seek traditional methods of treatment for sexual problems, either by visiting traditional healers or by consuming traditional medications or preparations. This cultural belief and practise could also provide a possible explanation for the high prevalence rate of sexual dysfunction amongst Malaysian women with breast cancer that was recruited in this study.

The observation made in this study was similar to the findings of a study conducted on sexual dysfunction amongst Malaysian women by Sidi et al (2007). In this study involving a total of 230 married women, the authors found that amongst the risk factors significantly associated with female sexual dysfunction was Malay ethnicity. 61.8% of the Malay women recruited in the study were found to have sexual dysfunction. Yusoff and colleagues (2012) had done a qualitative study on 10 husbands of breast cancer women, of whom 7 were Malays. Amongst the marital challenges narrated by the 3 Malay husbands were their wives' perception of being unattractive post-surgery, feelings of insecurity, not wanted and unappreciated. These women were also described to feel inadequate and unworthy for not being able to fulfil their husband's needs. In other instances, the husbands found them to be overly sensitive and jealous. Husband's engagement in extra-marital affair after the wife was diagnosed with breast cancer was also described as part of the marital challenges faced. The challenges encountered by the Malay couples described in this study could lead to strain in their relationship and could also possibly have implication to their sexual relationship. These marital adversities could provide a possible explanation to the higher number of observed cases of sexual dysfunction in Malay women with breast cancer compared to the non-Malays in this study.

The menopause rate amongst the subjects of this study was considerably high at 77% which could also contribute to the high prevalence of sexual dysfunction observed. Pre-mature menopause secondary to breast cancer treatment could result in sexual dysfunction in women with breast cancer. Post-menopausal status either early or late onset has been found to be strongly associated with sexual dysfunction in breast cancer survivors (Capodice et al, 2008).

"Female sexual dysfunction (FSD) is characterized by disturbances in the process of a normal sexual response cycle or dyspareunia" (Mat Napes et al, 2013). *"A normal sexual response cycle includes stages of desire, arousal/ excitement, orgasm and resolution"* as described by Masters and Johnson (1966) and revised by Kaplan (1969). In FSD, one or more stages of the sexual response cycle can be disturbed (Basson, 2005). The diagnosis and treatment of breast cancer can have tremendous effects on women sexuality and sexual function. Breast cancer patients may experience fatigue, decreased sexual desire, reduced physiological arousal in response to sexual stimuli, dyspareunia as a result of vaginal dryness secondary to reduced oestrogen levels during the treatment of breast cancer and at times persisted across the trajectories of the disease (Katz, 2011). Concerns about cancer recurrence and potential result of

breast cancer treatment are often the main priorities in many women compared to potential changes in sexuality and sexual function (Anllo, 2000). However, it is detrimental that breast cancer survivors recognize that the disease and the treatment modalities can have a tremendous impact on their sexual relationship that may persist for long duration of time (Katz, 2011).

Sexual dysfunction was also found to be greater in the older age group (> 50 years of age) with 91.7% compared to younger patients (≤ 50 years of age) with 87.5%. A possible explanation to this observation is that the frequency of sexual activity declines as the age progresses amongst Malaysian couples. Chronic medical comorbidity, side effects of medications and physical limitations could also be contributing factors to sexual dysfunction experienced by older patients with breast cancer. This observation was similar to the finding in a study conducted in France by Bre´dart and colleagues (2011) where amongst sexually active women with breast cancer, age of above 50 years was associated with lower frequency of sexual activity, reduced sexual pleasure or greater sexual discomfort.

Higher sexual dysfunction was reported amongst those who were unemployed (92.6%) compared to those who are working with only 87%. Those with lower economic status (total household income of ≤ RM 3000 per month) had higher sexual dysfunction with 94.5% compared to those with high monthly total household income with only 84.4%. Lower socio-economic status and financial difficulties can put these women at risk for developing psychological distress. Financial problems could also lead to strain in the relationship between the woman with breast cancer and her spouse, thus affecting the sexual function and relationship. The similar finding was observed in a study on depression and sexual adjustment following breast cancer in low income Hispanic and non-Hispanic White (Christie, Meyerowitz and Maly, 2010). Hispanic women had poorer sexual function compared to the non-Hispanic, even after controlling for significant covariates. They had significantly lower sexual libido, more difficulty relaxing and enjoying sex, and more difficulties in sexual arousal and orgasms compared to the non-Hispanic White women.

6.3 SEXUAL DYSFUNCTION AND CLINICAL, AND DISEASE VARIABLES

In this study, Table 5.9 showed the analysis of clinical and disease variables with sexual dysfunction. Young age of breast cancer onset (≤ 50 years of age) was found to be significantly associated with sexual dysfunction with p= 0.044. Sexual dysfunction was 7 times more common in younger women diagnosed with breast cancer with an odds ratio of 7.200. 84.7% of women from this age group reported sexual dysfunction. This was higher compared to the findings of a study conducted by Kedde et al (2013) which reported the prevalence of sexual dysfunction amongst women with breast cancer who were 45 years of age or younger to be 64% in those still receiving treatment for the disease and 45% in those who had completed their treatment.

The diagnosis of breast cancer is more distressing for young women compared to older women because of more severe psychosocial worries secondary to the negative reproductive effects of the treatment modalities (Bakewell and Volker, 2005; Ganz et al, 2003). Women younger than 45 years of age experienced pre-mature menopause secondary to the adjuvant chemotherapy or hormonal therapy, which in turn led to disturbances in sexual functioning and infertility problems that may induce additional psychological distress (Arora et al, 2001; Bardwell et al, 2006; Ganz et al, 2003; Hopwood et al, 2007).

Sexual dysfunction between women with short duration of illness (≤ 5 years) and those with longer duration of illness (> 5 years) was noted to be equal (90%). Amongst breast cancer participants who had undergone surgery, sexual dysfunction was reported to be 89.9%.

Sexual dysfunction was observed in 67 out of 75 (89.3%) participants who have had hormonal therapy. Majority of them (90.7%) were on Tamoxifen. Tamoxifen is the most frequently used anticancer agent globally (Mortimer et al, 1999). The agent led to hot flushes and night sweats in acute toxicities, which also suggests that Tamoxifen produces symptoms of menopause (Fisher et al, 1989). Reduction of oestrogen level after menopause resulted in the decrease of vaginal lubrication and vaginal dryness, which can lead to pain during sexual intercourse (Leiblum et al, 1983; Semmens & Wegner; 1982). These symptoms could possibly have negative impacts on sexual function of women with breast cancer. In a study conducted by Mortimer and colleagues (1999) which involved a total of 57 women with breast cancer who received Tamoxifen between 2 to 24 months period, the authors found that 54% of the patients experienced pain, burning, or discomfort during sexual intercourse. The finding of this study confers with the observation made by Mortimer and colleagues (1999).

Majority (97%) of those participants with medical comorbidity experienced sexual dysfunction compared to only 86.6% of those without any comorbid medical illness. This finding was in keeping with the observation made in a study done by Bre'dart and colleagues (2011) which found that the absence of sexual activity and sexual dissatisfaction were associated with comorbidities in breast cancer patients. Menopausal women were also noted to have higher sexual dysfunction cases with 92.2% compared to non-menopausal women with 82.6%. However, this was not statistically significant difference. Pre-mature menopause can be a complication of breast cancer treatment which leads to vaginal dryness, an important cause for sexual functioning problems in women with breast cancer (Bloom, Peterson and Kang, 2007; Ganz et al, 1998; Kornblith and Ligibel, 2003). Nonetheless, in this study menopausal stage per se was not associated with sexual dysfunction. There must be other factors which influence the high prevalence of sexual dysfunction in these women.

6.4 SEXUAL DYSFUNCTION AND MARITAL VARIABLES

Older spousal age (> 50 years) was noted to have higher cases of sexual dysfunction with 92.8% compared to those with younger spouse with 83.9%. This could possibly be due to reduction in sexual activity as the couple grew older. Presence of medical comorbidity in the spouse and some of its treatment could also contribute to sexual problems amongst older couples.

Those with longer duration of relationship (> 20 years) recorded more cases of sexual dysfunction compared to participants with shorter duration of relationship (≤ 20 years), with 91.8% and 85.2% respectively.

6.5 ASSOCIATION OF BODY IMAGE DISTRESS WITH SEXUAL DYSFUNCTION

The Breast Impact of Treatment Scale (BITS) was used to assess body image distress in this study. The cut-off point of ≥ 26 indicated the presence of body image distress. Higher total score also indicated a greater degree of body image distress.

In this study, the prevalence of body image distress amongst breast cancer participants was 42.9%. The prevalence in this study was lower compared to the finding of a study conducted by Fobair and colleagues (2006) where half of the 546 women were reported to experience two or more body image problems some of the time (33%), or at least one problem much of the time (17%). In a different study conducted amongst breast cancer patients who had undergone breast conserving therapies, assessment of body image found that 15% felt less feminine, 25% felt less sexually attractive, and 28% of these women had changed their clothing habits secondary to the disease or treatment (Lyngholm et al, 2013).

Women with better body image were found to have a higher level of confidence and were able to cope better with cancer (Pikler and Winterowd, 2003). Perceived loss of femininity and body integrity, hesitance to look at one’s self naked, feeling sexually unattractive, self-consciousness about appearance, and dissatisfaction with surgical scars are negative perceptions of body image that might be experienced by breast cancer survivors (Bartelink et al, 1985; Beckmann et al, 1983; Cohen et al, 1998; de Haes et al, 1986; Ganz et al, 1992 & 2003; Hopwood, 1993; Kemeny et al, 1988; Lasry et al, 1987; Pozo et al, 1992; Sanger and Reznikoff, 1981; Steinberg et al, 1985; Wellisch et al, 1989).

From multivariate linear regression analysis conducted in this study, body image distress was not significantly associated with sexual dysfunction. The observation made in this study replicated the findings from previous literature (Ashcroft et al, 1985; Ganz et al, 1987; Goldberg et al, 1992; Penman et al, 1986).

6.6 ASSOCIATION OF MARITAL DISSATISFACTION WITH SEXUAL DYSFUNCTION

In this study, marital satisfaction was measured by using the Golombok Rust Inventory of Marital State (GRIMS) with a higher score indicating greater degree of marital dissatisfaction.

Spouses are often considered as the primary sources of support after the diagnosis of life threatening illness (Lasry et al, 2003). The disease does not only affect the women diagnosed with breast cancer but also involves the partners and other family members as a whole. The marital relationship plays a vital part in the woman's adaptation process to the diagnosis and therapy of breast cancer (Bloom et al, 2001). Literature have illustrated that the quality of the marital relationship is significantly associated with the women's psychological adaptation to the illness (Giese-Davis et al, 2000; Manne and Glassman, 2000; O'Mahoney and Carroll, 1997). The illness experience and treatment regime are strong enough to bring about these emotional disturbances (Iqbal et al, 2001). Both cross-sectional and longitudinal studies have reported increased levels of spousal distress such as anxiety and depressed mood, and difficulties in marital communication (Baider et al, 2003; Carlson et al, 2000; Foy and Rose, 2001; Lewis, 1997; Lewis and Deal, 1995; Northouse and Swain, 1987; Omne-Poten et al, 1993; Ptacek el at, 1994; Toseland et al, 1995). In another study conducted by Rodrigue and Hoffman (1994), as high as 29% of sampled couples who had been receiving cancer therapies showed clinically high levels of psychological distress. Couples battling with breast cancer also reported more strain and conflict in their relationship (Carter et al, 1993; Northouse et al, 1998; Wai Ming, 2002). Couples with pre-existing marital problems were at increased risk of marital breakdown when faced with the illness due to greater demands and strain added on to their relationship (Carter et al, 1993; Lewis and Hammond, 1992; Litchman et al, 1987; Morris et al, 1977; Northouse, 1989).

Marriage may protect from increased social isolation, psychological disturbances, and pain following the diagnosis of cancer in a woman (Katz et al, 2005). Emotional support includes empathising, listening, comforting and communicating with the loved ones. While informational support involves giving advice, guidance and feedback about a problem. Instrumental support entails physical aids such as helping with house chores, managing the bills or finances and transportation (Kinsinger et al, 2011). The association between partner’s emotional support and adjustment to cancer is well-recognised in the literature (Alferi et al, 2001; Helgeson, 2003; Helgeson and Cohen, 1996). A study conducted by Pistrang and Barker (1995) showed that support from other sources from the patient’s social network could not replace for the loss of support from a spouse.

Slower recovery process, worse health condition and performance status are associated with marital distress (Yang and Schuler, 2009). Among a sample of high risk women awaiting genetic testing for hereditary breast and ovarian cancer, unhappily married women were found to have experienced more distress than either unmarried or happily married women (Coyne and Anderson, 1999). Couples struggling with the disease were found to experience marital distress, which is than expressed in sexual relationships and their communication forms (Northouse, Cracchiolo-Caraway and Appel, 1991). Studies also found that, the diagnosis of breast cancer can lead to disturbances in marital intimacy and reduction in frequency, and enjoyment of sexual activity (Hughes, 1996; Kadmon et al, 2008). Greater spousal distress is also associated with higher distress levels in women with breast cancer (Kim et al, 2008; Segrin et al, 2007).

Sexual difficulties are experienced by women with breast cancer up to 3 years following the diagnosis (Ganz et al, 1996). Factors that play important role in women's psychosexual functioning include medical factors (surgical disfigurement and adverse effects of adjuvant therapies), psychological factors (body image, psychological problems) and relationship variables (spouse's reaction to illness and its therapy) (Kinsinger et al, 2011). A husband's supportive response to the disease can protect against relationship difficulties (Ghizzani et al, 1995; Holmberg et al, 2001; Manne et al, 2004; Skerrett, 1998; Wimberly et al, 2005). In a study done by Ghizzani and colleagues (1995), women were found to be more open to romance and sexuality when their spouses were perceived to be emotionally supportive. The feeling that a spouse is emotionally available also adds to feelings of femininity and attractiveness positively and leads to better marital satisfaction (Wimberly et al, 2005).

Husbands often reported that they were unable to function and struggled to help their wives to cope with the disease and therapy (Sabo, Brown and Smith, 1990). In a study conducted by Maguire (1981), 25%-33% of husbands reported that the surgical treatment for breast cancer had adversely affected their sexual relationship and marital intimacy. In a different study involving 50 Israeli husbands whose wives were diagnosed with breast cancer, 75% of the subjects reported changes in their relationship, more than a third had a reduction in communication with their families and 72% had change in their sexual activity, with 13% experienced moderate difficulty and 59% had slight difficulty in terms of their sexual activity (Kadmon et al, 2008).

Communication in couples is important in battling with breast cancer. The amount and quality of communication regarding the worries and stressors encountered has vital implication on the couples’ adjustment to cancer and also the satisfaction of the marital relationship. Two basic communication patterns were identified in couples when dealing with psychological issues related to early stage of breast cancer. Couples who perceived that talking was essential talked openly and demonstrated fewer problems in their communication (Hilton, 1994). A longitudinal study was conducted by Manne and colleagues (2006) involving 147 patients with early stage of breast cancer and 127 partners during cancer treatment and 9 months later to examine the association between types of communication strategies to handle stressors and psychological distress and relationship satisfaction. Distress and relationship satisfaction were associated with the couples’ perceptions of their communication with regards to cancer-related issues and difficulties. Lower level of distress and higher relationship satisfaction for both partners was associated with constructive communication between them. The demand-withdraw communication (*one partner pressures the other partner to talk about the cancer-related issue while the other partner withdraw*) demonstrated greater level of distress and lower marital satisfaction for both partners. Struggles in a relationship and marital dissatisfaction can also be an outcome of partners' different perceptions about their communication behaviours (Gottman, 1979). Alterations in partner communication and responsiveness were also found to be associated with sexuality and intimacy after a diagnosis of breast cancer (Manne et al, 2004; Wimberly et al, 2005), hence affecting sexual response in breast cancer survivors.

"Cancer-related demands of illness are defined as the concerns attributed to the cancer experienced by spouses" (Haberman et al, 1990). In a cross-sectional study conducted among 151 partners of women newly diagnosed with non-metastatic breast cancer, 5 groups of cancer-related demands were recognized. These are worries related to their own ability to function, their role as a source of support to their wives, sexual relationship, wife's general health and the outcome of cancer therapies, and also the family members including the children's general health. Partners were worried about themselves, including their own mortality, the necessity to rearrange their life priorities and felt unprepared to handle the uncertainties and often ruminate on how they were facing and tackling the situation. They were also worried about their wives' cancer treatment outcome, wanted more information about the therapies and were tremendously engrossed about metastasis of the disease and failure of detection by the doctor, even when their wives are on active cancer treatment. They were also concerned about the impacts on their sexual relationship with their wives which includes the quality, frequency, and the lack of time to be sexually intimate with their wives. The family's well-being such as what would happen to their family and their children were also identified as the spouses' concern. They were worried about the likelihood that their children might be at risk of developing the illness or might need psychological support more than they do. They were also worried about their capabilities to help their wives

fighting the battle with breast cancer and they were often concerned about defending their wives from stress. This study also found that spouses who had more depressive symptoms, lack of confidence in their capability to self-manage the cancer and the inability to avoid negative thoughts during communication about the cancer with their wives had higher amount of breast cancer-related concerns (Fletcher el al, 2010).

In this study, the prevalence of marital dissatisfaction experienced by the participants was reported to be 55%. The score on marital dissatisfaction was found to be inversely associated with sexual dysfunction score with r= -0.49. This would indicate that women who experienced greater marital dissatisfaction would have lower FSFI score, indicating a greater severity of sexual dysfunction. From the multivariate linear regression analysis done in this study, this association was found to be statistically significant with p< 0.001. This confers with the evidence from previous studies that found women who relatively have poorer relationship with their spouse would report more sexual problems (Dow et al, 1996; Ganz et al, 1996 & 1998; Kornblith and Ligibel, 2003).

This finding substantiate to the observation made in a study conducted by Kinsinger and colleagues (2011) which found that perceived greater levels of support, both emotional and informational, from the spouse at baseline were associated with less sexual problems amongst breast cancer women concurrently and 6 months after surgery. Bre´dart and colleagues (2011) in their study also found that there was an association between absence of sexual activity and sexual dissatisfaction with the feeling of emotional separation in the couple or of spousal fear of sexual intercourse amongst women with breast cancer.

6.7 ASSOCIATION OF DEPRESSION WITH SEXUAL DYSFUNCTION

Depressive symptoms in this study were assessed using the depression sub-scale of the Hospital Anxiety and Depression Scale (HADS-D). A score of ≥ 8 is indicative of a possible case of depression.

In cancer patients, depression was found to be 15% to 25% more prevalent compared to the healthy general population (Massie and Popkin, 1998). Depression is usually diagnosed after therapy of breast cancer. There are wide variations observed in the prevalence of depression in breast cancer, which very much depended on the study population. The prevalence rate ranges from 3% to 55% (Fulton, 1997). In this study, we found the prevalence of possible depression cases amongst breast cancer survivors to be 9% using the depression sub-scale of the HADS questionnaire. This finding is similar to the prevalence of depression in breast cancer survivors when HADS were used that ranged from 1% to 22%, with a median of 10%, in a systematic review of observational studies conducted recently (Zainal et al, 2013).

Most of the literature concluded that 20% to 30% of these women had depressive symptoms that led to significant impairment, even though the prevalence of major depressive disorder is possibly low (Schou et al, 2004). This disorder has an adverse impact on all facets of quality of life in cancer patients as a whole and is also associated with reduced medical compliance, diminished understanding of treatment recommendations and worries about negative implications of therapies (Ayres et al, 1994; Ell et al, 2005). It also leads to a greater morbidity and possibly mortality in cancer patients (Hjerl et al, 2003).

Many factors can lead to depression in breast cancer patients. Psychosocial factors that may be associated with an increased risk of the disorder are previous history of depression, poor social function, and existence of any other stressful live events. Pain, disability, and poor body image are amongst somatic factors that showed modest associations with the disorder (Bardwell et al, 2006). On a contrary, disease and treatment variables that include stage of cancer, modality of treatment received and Tamoxifen use are not consistently associated with depression (Bardwell et al, 2006). These evidences point towards strong influence of psychosocial and physical factors on depression amongst breast cancer patients instead of disease severity or treatment modalities (Kim et al, 2012).

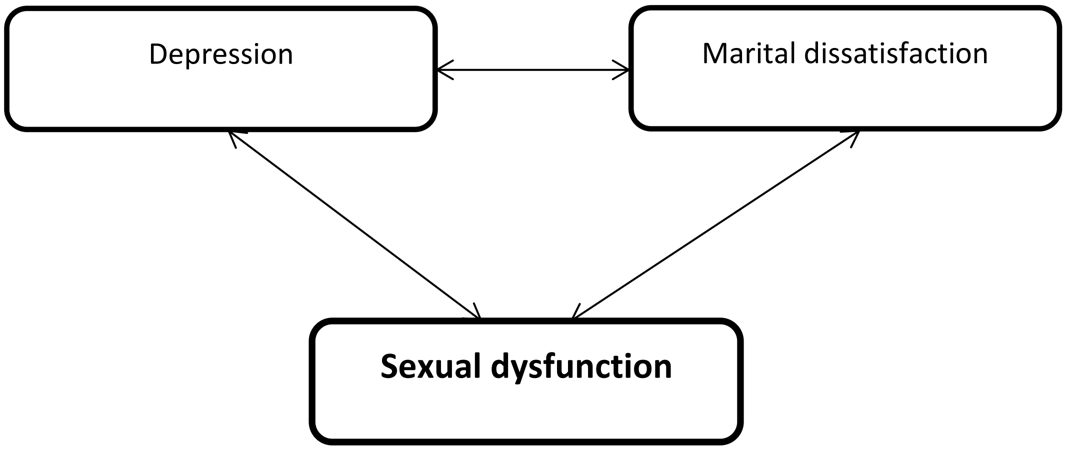
Depression is a psychological disorder not only characterized by mood disturbances but also involves loss of interest (anhedonia). It is also associated with biological symptoms such as sleep difficulties, appetite and weight disturbances, lethargy and reduced sexual libido. Both anhedonia (which may lead to decreased sexual pleasure), and reduced sexual desire can play an important role in sexual dysfunction experienced by breast cancer survivors. These depressive symptoms also could possibly exacerbate sexual problems secondary to breast cancer therapies experienced by these women.

Depression in breast cancer patients can have tremendous implication on the quality of life and also may lead to changes in the marital relationship (Kim et al, 2012). In a study conducted by Milbury and Badr (2013) examining the associations between sexual difficulties, depressive symptoms and two types of couple communication patterns (mutual constructive and demand-withdraw), 191 couples were included in which the patient was starting treatment for metastatic breast cancer. The study found that greater levels of sexual difficulties were strongly associated with more depressive symptoms in patients who experienced low levels of mutual constructive communication ($p < 0.01$) and high levels of demand-withdraw communication ($p < 0.0001$). On a contrary, greater sexual problems were associated with more depressive symptoms irrespective of the communication pattern reported amongst the spouses of these patients.

From this study, we found that there was a statistically significant inverse correlation between the measure of depressive symptoms as assessed by the total HADS-D sub-scale score and the measure of sexual dysfunction as assessed by the total FSFI score ($r = -0.34$, $p < 0.001$). From the multivariate linear regression analysis conducted, this association was found to be statistically significant, with $p = 0.022$. The evidence is in support of studies done elsewhere around the world justifying the negative impact of depressive symptoms on sexual functioning of women with breast cancers (Kim et al, 2012; Webber et al; 2011).

This study has found that marital dissatisfaction and depression are significantly associated with sexual dysfunction in breast cancer survivors. These associations can be multi-directional, the findings of which are illustrated below:

Figure 6.1 Association between marital dissatisfaction and depression with sexual dysfunction in breast cancer survivors



CHAPTER SEVEN

LIMITATIONS AND STRENGTHS

7.1 LIMITATIONS

This study had limitations that should be taken into consideration when evaluating the results.

1. This was a cross-sectional study, which hindered us from evaluating the consistency of sexual dysfunction, body image distress and marital dissatisfaction over time and across the disease trajectories. The observations were only carried out at a particular time. Thus, the findings of this study were only related to one point of time, and we could not conclude that the observations made were a constant factor in the study population.

2. The study was conducted in a single, tertiary care hospital, in an urban setting. Thus, the results were not an accurate representation of the whole Malaysian population.

3. Patients who could not understand and read English were excluded from the study and this further limits the generalization of the results. However, the number of breast cancer patients that were excluded from the study was relatively small.

4. The total sample of 100 women with breast cancer was relatively small.

5. Depressive and anxiety symptoms were assessed using a self-report questionnaire which served as, a screening tool instead of criteria from the Diagnostic Statistical Manual-IV-TR (DSM-IV-TR). As a result, we could not estimate the number of diagnosable disorders.

6. Past psychiatric history may have influenced sexual dysfunction and marital dissatisfaction experienced by the participants. We did not have access to the data concerning the patient’s past psychiatric history.

7. The use of self-reported questionnaires to assess sexual dysfunction, body image distress, marital dissatisfaction, depressive and anxiety symptoms, and quality of life may cause recall bias.

8. Participants reported that a number of items in the questionnaire to measure body image distress (Breast Impact of Treatment Scale (BITS)) were difficult to understand, thus 9 out of the 100 patients did not answer the questionnaire completely. Hence, they were excluded in the assessment of body image distress.

7.2 STRENGTHS

1. The questionnaires used in this study were validated and widely used.

2. Stronger associations were observed by conducting multivariate analysis.

3. This study looked at sexual dysfunction, body image distress and marital dissatisfaction in breast cancer patients which is the first one conducted in Malaysia.

CHAPTER EIGHT

CONCLUSIONS

Breast cancer is still known to be the commonest cancer and common cause of cancer-related death amongst Malaysian women. Early detection through improved public awareness and early screening programs plus the advances in treatment modalities for breast cancer had resulted in an improvement of the survivorship from the disease. However, the improvement in the survivorship of breast cancer were also associated with delayed and long term implications, either from the disease itself or as a result of negative effects of breast cancer therapies. These implications include sexual dysfunction, body image distress, marital dissatisfaction, psychological disorders such as depression or anxiety and disturbances in the survivors' quality of life.

In this study, the prevalence of sexual dysfunction was high amongst breast cancer patients recruited in the study who attended follow up at the breast clinic in UMMC. Factor that was identified to be significantly associated with sexual dysfunction in these women with breast cancer is younger age at the time of disease onset (≤ 50 years of age).

The prevalence of body image distress was moderate. More than half of these breast cancer survivors reported marital dissatisfaction. The prevalence for probable cases depression was considerably low, but anxiety was noted to have moderate prevalence.

In assessing sexual dysfunction against the independent variables (body image distress, marital dissatisfaction, depression, anxiety and quality of life), marital dissatisfaction and depression were found to be significantly associated with sexual dysfunction.

Women with breast cancer should be made aware of these possible late and long term implications of the disease and its treatment modalities. This would give them ample time and would allow them to cope and handle the matter better if it arises. These findings advocate the need for doctors treating breast cancer patients to routinely assess and discuss matters related to sexual functioning, marital relationship, depression, anxiety and body image as part of a holistic management of these women. Health care providers themselves should not feel uncomfortable discussing these intimate and private issues. The discussion should be conducted in a professional and yet sensitive manner as many of Malaysian women are embarrassed and reluctant to discuss these matters openly, due to their cultural and religious boundaries.

Cancer care services should be made accessible and affordable throughout the country. Management of breast cancer patients should involve a multidisciplinary team which may consists of oncologist, surgeon, radiologist, palliative care physician, psychiatrist, psychologist, nurses and social worker. This would cover all aspects of the management of breast cancer patients and would in hand provide a better quality of care.

Although the number of patients with depression and anxiety in this study is between low and moderate, the need for routine psychological assessment and intervention when indicated could not be put aside. Psychological comorbidity could have negative consequence to the outcome of breast cancer and the patients' quality of life, in general. It can possibly occur at any trajectory of the disease. Hence, it should be recognized early and prompt referral when appropriate, to the psychiatric services should be made for further assessment and management.

Educational and awareness programs should be conducted consistently to encourage these women to come forward for help when appropriate and also to reduce the stigma associated with sexual difficulties and psychological disorder. Breast Cancer Support Group should be available in all hospitals to help these patients in coping with their illness, dealing with emotional problems and changing of experiences and advise on practical issues related to breast cancer.

Breast cancer does not only affect the patient but also the spouse and the entire family as a whole. From this study, the prevalence of marital dissatisfaction was noted to be high amongst breast cancer survivors. This finding emphasizes the need for the treating doctors to also engage the spouse in their routine assessment for any possibility of sexual difficulties, marital and psychological problems faced by them. Carer burnt out and other factors that could lead to strain or dissatisfaction in a marriage should not be missed out as spousal support is vital in battling with breast cancer.

CHAPTER NINE

RECOMMENDATIONS & CLINICAL IMPLICATIONS

9.1 RECOMMENDATIONS

The recommendations for future studies are as below:

1. Longitudinal cohort study should be done in the future in order to obtain stronger findings and associations between the socio-demographic, clinical, disease and marital variables with sexual dysfunction, body image distress and marital dissatisfaction amongst breast cancer survivors.

2. Similar study involving data collection from other hospital settings in Malaysia could be conducted to make the findings more representative of and applicable to the country's population.

3. The power of the study could be increased by a larger sample size. Thus, the study findings would have greater clinical impact to the population.

4. To use a healthy match control groups.

9.2 CLINICAL IMPLICATIONS

The findings in this study serve as an alarm for the surgeons and the physicians who are treating breast cancer patients about the importance of issues related to sexual function, body image, marital dissatisfaction and psychological distress that may be experienced by these women. Sexual and marital issues are considered intimate and private matters amongst Malaysian women. Some even considered discussing these issues as taboo and would feel uncomfortable or ashamed to talk about them. Hence, the surgeons or physicians should be able to discuss and assess these matters in a very professional and sensitive manner. Early detection could lead to prompt and appropriate referral to the psychiatric services for further assessment and treatment if needed. Sexual dysfunction, body image distress, marital dissatisfaction and psychological distress should not be ignored or go unrecognized or untreated as these could have tremendous effect on the breast cancer survivor's quality of life. These issues should be discussed routinely with the patients and also their partners in order to provide a holistic management. Physicians must not feel uncomfortable themselves when discussing these sensitive issues.

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APPENDIX 1

PATIENT INFORMATION SHEET

Please read the following information carefully, do not hesitate to discuss any questions you may have with your Doctor.

Study Title

Sexual Dysfunction, body image distress and marital dissatisfaction in breast cancer patients attending follow up at the breast clinic in University Malaya Medical Centre (UMMC)

Introduction

Breast cancer is one of the commonest cancers seen in woman. It is also the commonest female malignancy in Malaysia and all over the world. Sexual dysfunction, body image distress and marital dissatisfaction are frequent adverse effects of cancer treatment.

What is the purpose of this study?

To study sexual dysfunction, body image distress and marital dissatisfaction in breast cancer patients attending the breast clinic in University Malaya Medical Centre.

What are the procedures to be followed?

A Patient’s Information Sheet will be given to participants who are willing to participate in this study and explanation about the study will be given by the doctor in charge. The participant will need to fill in a consent form prior to the commencement of this study. The participants will then be asked to fill in 5 sets of questionnaires and the doctor will also interview the participants. All the information will be strictly confidential.

Who should enter the study?

Breast cancer patients who are in clinical remission- 3 months or more after any active treatment other then endocrine treatment.

What will be benefits of the study:

(a) to you as the subject?

The standardized interview format in this study can be used to assess sexual dysfunction, body image distress and marital dissatisfaction among affected patients. Therefore, early intervention can be offered.

(b) to the investigator?

This study may help to identify the percentage of patients with breast cancer experiencing sexual dysfunction, body image distress and marital dissatisfaction. Also to investigate whether sexual dysfunction and body image distress buffers depression or anxiety symptoms.

What are the possible drawbacks?

Nil

Can I refuse to take part in the study?

Yes. However, your contribution will be much appreciated. This study will not affect your medical treatment.

Who should I contact if I have additional questions during the course of the study?

Doctor's Names:

Prof. Dr. Nor Zuraida Zainal	***Tel: 03-79493152***
Dr. Norley binti Shuib	***Tel: 03-79492629/2432***

BK-MIS-1116-E01

APPENDIX 2

UNIVERSITY MALAYA MEDICAL CENTRE
CONSENT BY PATIENT FOR CLINICAL RESEARCH

I, ………………………………………………………………… Identity Card No………..……………………………….
(Name of Patient)

of……...
(Address)

hereby agree to take part in the clinical research (clinical study/questionnaire study/drug trial) specified below:

<u>Title of Study:</u> **Sexual dysfunction, body image distress and marital dissatisfaction in breast cancer patients attending follow up at the breast clinic in University Malaya Medical Centre (UMMC)**

the nature and purpose of which has been explained to me by Dr………………………………………………….

and interpreted by ……………………..………………………………..…..…………
(Name & Designation of Interpreter)

to the best of his/her ability in …………………….…………… language/dialect.

I have been told about the nature of the clinical research in terms of methodology, possible adverse effects and complications (as per patient information sheet). After knowing and understanding all the possible advantages and disadvantages of this clinical research, I voluntarily consent of my own free will to participate in the clinical research specified above.

I understand that I can withdraw from this clinical research at any time without assigning any reason whatsoever and in such a situation shall not be denied the benefits of usual treatment by the attending doctors.

Date: ……………...……….. Signature or Thumbprint ……………..……………………………
(Patient)

IN THE PRESENCE OF

Name ……………………………………..….…….…..…

Identity Card No. …………………………..…….…… Signature ……………………………………………
(Witness for Signature of Patient)

Designation ……………………………..……………

I confirm that I have explained to the patient the nature and purpose of the above-mentioned clinical research.

Date ……………………………. Signature …………………………………………..
(Attending Doctor)

CONSENT BY PATIENT FOR CLINICAL RESEARCH	R.N. Name Sex Age Unit	

APPENDIX 3

Serial No. :
Date :

Sexual dysfunction, body image distress and marital dissatisfaction in breast cancer patients attending follow up at the breast clinic in University Malaya Medical Centre (UMMC)

Socio-demographic Data Sheet

All information obtained is strictly confidential and will only be use for the purpose of this research.

Section 1: Basic Information

UMMC RN :

Age :

Contact number :

Race	:	1- Malay 2- Chinese	3- Indian 4- Others
Religion	:	1- Islam 2- Buddhism 3- Hinduism	4- Christianity 5- Others
Educational level	:	1- Nil 2- Primary	3- Secondary 4- Tertiary
Employment status	:	1- Unemployed 2- Part time 3- Full time	4- Housewife 5- Pensioner
Household income (per month)	:	1- < RM 1, 000 2- RM 1, 000 – RM 2, 000 3- RM 2, 001 – RM 3, 000 4- RM 3, 001 – RM 4, 000 5- RM 4, 001 – RM 5, 000 6- RM 5, 001 – RM 10, 000 7- > RM 10, 000	

Section 2: Relationship or Marital Information

Age of partner :

Duration of relationship :

Presence of relationship or marital problem :
1- No
2- Yes (specify) ___________________

Section 3: Illness Information

Date of diagnosis :

Age of onset :

Duration of illness :

Clinical staging at first contact :

Treatment received : Surgery
1- Mastectomy
2- Lumpectomy
3- Nil

Chemotherapy regime
1- Chemo FEC
2- Chemo TAC (toxotere)
3- Others
4- Nil

Radiotherapy
1- Yes
2- No

Current hormonal Treatment :
1- Tamoxifen
2- Femara (letrozole)
3- Arimidex (anastrozole)
4- Aromasin (exemastane)
5- Others ____________________________

Date commenced _____________
Date discontinued _____________

Metastasis	:	1- Bone 2- Liver 3- Lungs	3- Brain 4- Nil
Other medical co-morbidity	:	1- Diabetes 2- Hypertension 3- Asthma	4- IHD 5- Others 6- Nil
Menopause	:	1- Yes	2- No
If yes, duration	:	__________________	

Section 4: Topometry Measurements

Weight (kg) :

Height (cm) :

BMI :

Waist circumference (cm) :

APPENDIX 4

Female Sexual Function Index (FSFI)

INSTRUCTIONS: These questions ask about your sexual feelings and responses during the past 4 weeks. Please answer the following questions as honestly and clearly as possible. Your responses will be kept completely confidential. In answering these questions the following definitions apply:

Sexual activity can include caressing, foreplay, masturbation and vaginal intercourse.
Sexual intercourse is defined as penile penetration (entry) of the vagina.
Sexual stimulation includes situations like foreplay with a partner, self-stimulation (masturbation), or sexual fantasy.

CHECK ONLY ONE BOX PER QUESTION.

Sexual desire or interest is a feeling that includes wanting to have a sexual experience, feeling receptive to a partner's sexual initiation, and thinking or fantasizing about having sex.

1. Over the past 4 weeks, how often did you feel sexual desire or interest?
☐ - Almost always or always
☐ - Most times (more than half the time)
☐ - Sometimes (about half the time)
☐ - A few times (less than half the time)
☐ - Almost never or never

2. Over the past 4 weeks, how would you rate your level (degree) of sexual desire or interest?
☐ - Very high
☐ - High
☐ - Moderate
☐- Low
☐- Very low or none at all

Sexual arousal is a feeling that includes both physical and mental aspects of sexual excitement. It may include feelings of warmth or tingling in the genitals, lubrication (wetness), or muscle contractions.

3. Over the past 4 weeks, how often did you feel sexually aroused ("turned on") during sexual activity or intercourse?
☐ - No sexual activity
☐ - Almost always or always
☐ - Most times (more than half the time)
☐ - Sometimes (about half the time)
☐ - A few times (less than half the time)
☐ - Almost never or never

4. Over the past 4 weeks, how would you rate your level of sexual arousal ("turn on") during sexual activity or intercourse?

☐ - No sexual activity
☐ - Very high
☐ - High
☐ - Moderate
☐ - Low
☐ - Very low or none at all

5. Over the past 4 weeks, how confident were you about becoming sexually aroused during sexual activity or intercourse?

☐ - No sexual activity
☐ - Very high confidence
☐ - High confidence
☐ - Moderate confidence
☐ - Low confidence
☐ - Very low or no confidence

6. Over the past 4 weeks, how often have you been satisfied with your arousal (excitement) during sexual activity or intercourse?

☐ - No sexual activity
☐ - Almost always or always
☐ - Most times (more than half the time)
☐ - Sometimes (about half the time)
☐ - A few times (less than half the time)
☐ - Almost never or never

7. Over the past 4 weeks, how often did you become lubricated ("wet") during sexual activity or intercourse?

☐ - No sexual activity
☐ - Almost always or always
☐ - Most times (more than half the time)
☐ - Sometimes (about half the time)
☐ - A few times (less than half the time)
☐ - Almost never or never

8. Over the past 4 weeks, how difficult was it to become lubricated ("wet") during sexual activity or intercourse?

☐ - No sexual activity
☐ - Extremely difficult or impossible
☐ - Very difficult
☐ - Difficult
☐ - Slightly difficult
☐ - Not difficult

9. Over the past 4 weeks, how often did you maintain your lubrication ("wetness") until completion of sexual activity or intercourse?

☐ - No sexual activity
☐ - Almost always or always
☐ - Most times (more than half the time)
☐ - Sometimes (about half the time)
☐ - A few times (less than half the time)
☐ - Almost never or never

10. Over the past 4 weeks, how difficult was it to maintain your lubrication ("wetness") until completion of sexual activity or intercourse?

☐ - No sexual activity
☐ - Extremely difficult or impossible
☐ - Very difficult
☐ - Difficult
☐ - Slightly difficult
☐ - Not difficult

11. Over the past 4 weeks, when you had sexual stimulation or intercourse, how often did you reach orgasm (climax)?

☐ - No sexual activity
☐ - Almost always or always
☐ - Most times (more than half the time)
☐ - Sometimes (about half the time)
☐ - A few times (less than half the time)
☐ - Almost never or never

12. Over the past 4 weeks, when you had sexual stimulation or intercourse, how difficult was it for you to reach orgasm (climax)?

☐ - No sexual activity
☐ - Extremely difficult or impossible
☐ - Very difficult
☐ - Difficult
☐ - Slightly difficult
☐ - Not difficult

13. Over the past 4 weeks, how satisfied were you with your ability to reach orgasm (climax) during sexual activity or intercourse?

☐ - No sexual activity
☐ - Very satisfied
☐ - Moderately satisfied
☐ - About equally satisfied and dissatisfied
☐ - Moderately dissatisfied
☐ - Very dissatisfied

14. Over the past 4 weeks, how satisfied have you been with the amount of emotional closeness during sexual activity between you and your partner?

☐ - No sexual activity
☐ - Very satisfied
☐ - Moderately satisfied
☐ - About equally satisfied and dissatisfied
☐ - Moderately dissatisfied
☐ - Very dissatisfied

15. Over the past 4 weeks, how satisfied have you been with your sexual relationship with your partner?

☐ - Very satisfied
☐ - Moderately satisfied
☐ - About equally satisfied and dissatisfied
☐ - Moderately dissatisfied
☐ - Very dissatisfied

16. Over the past 4 weeks, how satisfied have you been with your overall sexual life?

☐ - Very satisfied
☐ - Moderately satisfied
☐ - About equally satisfied and dissatisfied
☐ - Moderately dissatisfied
☐ - Very dissatisfied

17. Over the past 4 weeks, how often did you experience discomfort or pain during vaginal penetration?

☐ - Did not attempt intercourse
☐ - Almost always or always
☐ - Most times (more than half the time)
☐ - Sometimes (about half the time)
☐ - A few times (less than half the time)
☐ - Almost never or never

18. Over the past 4 weeks, how often did you experience discomfort or pain following vaginal penetration?

☐ - Did not attempt intercourse
☐ - Almost always or always
☐ - Most times (more than half the time)
☐ - Sometimes (about half the time)
☐ - A few times (less than half the time)
☐ - Almost never or never

19.Over the past 4 weeks, how would you rate your level (degree) of discomfort or pain during or following vaginal penetration?

☐ - Did not attempt intercourse
☐ - Very high
☐ - High
☐ - Moderate
☐ - Low
☐ - Very low or none at all

APPENDIX 5

Breast-Impact of Treatment Scale

Please mark X at the appropriate answers.

	Not at all **0**	Rarely **1**	**2**	Sometimes **3**	**4**	Often **5**
1. How my body has changed pops into my mind.						
2. I have waves of strong feelings about the way my body looks.						
3. I think about how my body used to look.						
4. Things I see or hear remind me that my body is different now.						
5. When I see other women, I think that my body appears different than theirs.						
6. I feel uncomfortable about being seen naked.						
7. I am bothered by feelings or thoughts of body disfigurement.						
8. I am reminded of my breasts when I pick out clothes to wear.						
9. I don’t want to deal with how my body looks.						
10. I avoid letting myself get emotional when I think of how my body has changed.						
11. I try not to think about the size and shape of my breasts.						
12. I avoid looking at and/or touching my breasts.						
13. I feel self-conscious about letting my partner (person with whom I am sexually intimate) see my breasts. (Even if you do not have a partner now, rate how you believe you would feel.)						

APPENDIX 6

Golombok Rust Inventory of Marital State (GRIMS)

We would like to ask you questions regarding your relationship with your spouse mainly on your marital satisfaction. Please tick the appropriate box that described you best.

		Strongly disagree	**Disagree**	**Agree**	**Strongly agree**
1.	My partner is usually sensitive to and aware of my needs.				
2.	I really appreciate my partner's sense of humour.				
3.	My partner doesn't seem to listento me anymore.				
4.	My partner has never been disloyal to me.				
5.	I would be willing to give up my friends if it mean saving our relationship.				
6.	I am dissatisfied with our relationship.				
7.	I wish my partner was not so lazy and didn't keep putting things off.				
8.	I sometimes feel lonely even when I am with my partner.				
9.	If my partner left me, life would not be worth living.				
10.	We can't agree to disagree with each other.				
11.	It is useless carrying on with a marriage beyond a certain point.				
12.	We both seem to like the same things.				
13.	I find it difficult to show my partner that I am feeling affectionate.				
14.	I never have second thoughts about our relationship.				
15.	I enjoy just sitting and talking to my partner.				

		Strongly disagree	**Disagree**	**Agree**	**Strongly agree**
16.	I find the idea of spending the rest of my life with my partner rather boring.				
17.	There is always plenty of ‘give and take’ in our relationship.				
18.	We become competitive when we have to make decisions.				
19.	I no longer feel I can really trust my partner.				
20.	Our relationship is still full of joy and excitement.				
21.	One of us is continually talking and the other is usually silent.				
22.	Our relationship is continually evolving.				
23.	Marriage is really more about security and money then about love.				
24.	I wish there was more warmth and affection between us.				
25.	I am totally committed to my relationship with my partner.				
26.	Our relationship is sometimes strained because my partner is always correcting me.				
27.	I suspect we may be on the brink of separation.				
28.	We can always make up quickly after an argument.				

HOSPITAL ANXIETY AND DEPRESSION SCALE

Patients are asked to choose one response from the four given for each interview. They should give an immediate response and be dissuaded from thinking too long about their answers. Instruct the patient to answer how it currently describes their feelings.

1. I feel tense or 'wound up'
    a. Most of the time
    b. A lot of the time
    c. From time to time, occasionally
    d. Not at all

2. I still enjoy the things I used to enjoy
    a. Definitely as much
    b. Not quite so much
    c. Only a little
    d. Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen
    a. Very definitely and quite badly
    b. Yes, but not too badly
    c. A little, but it doesn't worry me
    d. Not at all

4. I can laugh and see the funny side of things
    a. As much as I always could
    b. Not quite so much now
    c. Definitely not so much now
    d. Not at all

5. Worrying thoughts go through my mind
    a. A great deal of the time
    b. A lot of the time
    c. From time to time, but not too often
    d. Only occasionally

6. I feel cheerful
    a. Most of the time
    b. Sometimes
    c. Not often
    d. Not at all

7. I can sit at ease and feel relaxed
    a. Definitely
    b. Usually
    c. Not often
    d. Not at all

8. I feel as if I am slowed down
    a. Nearly all the time
    b. Very often
    c. Sometimes
    d. Not at all

9. I get a sort of frightened feeling like 'butterflies' in the stomach
    a. Not at all
    b. Occasionally
    c. Quite Often
    d. Very Often

10. I have lost interest in my appearance
    a. Definitely
    b. I don't take as much care as I should
    c. I may not take quite as much care
    d. I take just as much care as ever

11. I feel restless as I have to be on the move
    a. Very much indeed
    b. Quite a lot
    c. Not very much
    d. Not at all

12. I look forward with enjoyment to things
    a. As much as I ever did
    b. Rather less than I used to
    c. Definitely less than I used to
    d. Hardly at all

13. I get sudden feelings of panic
    a. Very often indeed
    b. Quite often
    c. Not very often
    d. Not at all

14. I can enjoy a good book or radio or TV program
    a. Often
    b. Sometimes
    c. Not often
    d. Very seldom

APPENDIX 8

Psychological General Well-being Index (PGWBI)

This section of examination contains questions about how you feel and how things have been going with you. For each question check the answer which best applies to you.

1. **How have you been feeling in general? (DURING THE PAST MONTH)**
   - ☐ In excellent spirits
   - ☐ In very good spirits
   - ☐ In good spirits mostly
   - ☐ I have been up and down in spirits a lot
   - ☐ In low spirits mostly
   - ☐ In very low spirits

2. **How often were you bothered by an illness, bodily disorder, aches or pains? (DURING THE PAST MONTH)**
   - ☐ Every day
   - ☐ Almost every day
   - ☐ About half of the time
   - ☐ Now and then, but less than half of the time
   - ☐ Rarely
   - ☐ None of the time

3. **Did you feel depressed? (DURING THE PAST MONTH)**
   - ☐ Yes- to the point that I felt like taking my life
   - ☐ Yes- to the point that I did not care about anything
   - ☐ Yes- very depressed almost every day
   - ☐ Yes- quite depressed several times
   - ☐ Yes- a little depressed now and then
   - ☐ No- never felt depressed at all

4. **Have you been in firm control of your behaviour, thoughts, emotions or feelings? (DURING THE PAST MONTH)**
   - ☐ Yes, definitely so
   - ☐ Yes, for the most part
   - ☐ Generally so
   - ☐ Not too well
   - ☐ No, and I am somewhat disturbed
   - ☐ No, and I am very disturbed

5. **Have you been bothered by nervousness or your “nerves”? (DURING THE PAST MONTH)**
   - ☐ Extremely so- to the point where I could not work or take care of things
   - ☐ Very much so
   - ☐ Quite a bit
   - ☐ Some- enough to bother me
   - ☐ A little
   - ☐ Not at all

6. **How much energy, pop, or vitality did you have or feel? (DURING THE PAST MONTH)**
   - ☐ Very full of energy- lots of pep
   - ☐ Fairly energetic most of the time
   - ☐ My energy level varied quite a bit
   - ☐ Generally low in energy or pep
   - ☐ Very low in energy or pep most of the time
   - ☐ No energy or pep al all- I felt drained, sapped

7. **I felt downhearted and blue DURING THE PAST MONTH.**
   - ☐ None of the time
   - ☐ A little of the time
   - ☐ Some of the time
   - ☐ A good bit of the time
   - ☐ Most of the time
   - ☐ All of the time

8. **Were you generally tense or did you feel tension? (DURING THE PAST MONTH)**
   - ☐ Yes- extremely tense, most or all of the time
   - ☐ Yes- very tense most of the time
   - ☐ Not generally tense, but did feel fairly tense several times
   - ☐ I felt a little tense a few times
   - ☐ My general tension level was quite low
   - ☐ I never felt tense or any tension at all

9. **How happy, satisfied, or pleased have you been with your personal life? (DURING THE PAST MONTH)**
   - ☐ Extremely happy- could not have been more satisfied or pleased
   - ☐ Very happy most of the time
   - ☐ Generally satisfied- pleased
   - ☐ Sometimes fairly happy, sometimes fairly unhappy
   - ☐ Generally dissatisfied, unhappy
   - ☐ Very dissatisfied or unhappy most or all the time

10. **Did you feel healthy enough to carry out the things you like to do or had to do? (DURING THE PAST MONTH)**
    - ☐ Yes- definitely so
    - ☐ For the most part
    - ☐ Health problems limited me in some important ways
    - ☐ I was only healthy enough to take care of myself
    - ☐ I needed some help in taking care of myself
    - ☐ I needed someone to help me with most or all the things I had to do

11. **Have you felt so sad, discouraged, hopeless, or had so many problems that you wondered if anything was worthwhile? (DURING THE PAST MONTH)**
    - ☐ Extremely so- to the point that I have just about given up
    - ☐ Very much so
    - ☐ Quite a bit
    - ☐ Some- enough to bother me
    - ☐ A little bit
    - ☐ Not at all

12. **I woke up feeling fresh and rested DURING THE PAST MONTH.**
    - ☐ None of the time
    - ☐ A little of the time
    - ☐ Some of the time
    - ☐ A good bit of the time
    - ☐ Most of the time
    - ☐ All of the time

13. **Have you been concerned, worried, or had any fears about your health? (DURING THE PAST MONTH)**
    - ☐ Extremely so
    - ☐ Very much so
    - ☐ Quite a bit
    - ☐ Some, but not a lot
    - ☐ Practically never
    - ☐ Not at all

14. **Have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel or of your memory? (DURING THE PAST MONTH)**
    - ☐ Not at all
    - ☐ Only a little
    - ☐ Some- but not enough to be concerned or worried about
    - ☐ Some and I have been a little concerned
    - ☐ Some and I am quite concerned
    - ☐ Yes, very much so and I am very concerned

15. **My daily life was full of things that were interesting to me DURING THE PAST MONTH.**
    - ☐ None of the time
    - ☐ A little of the time
    - ☐ Some of the time
    - ☐ A good bit of the time
    - ☐ Most of the time
    - ☐ All of the time

16. **Did you feel active, vigorous, or dull, sluggish? (DURING THE PAST MONTH)**
    - ☐ Very active, vigorous every day
    - ☐ Mostly active, vigorous- never really dull, sluggish
    - ☐ Fairly active, vigorous- seldom active, vigorous
    - ☐ Fairly dull, sluggish- seldom active, vigorous
    - ☐ Mostly dull, sluggish- never really active, vigorous
    - ☐ Very dull, sluggish every day

17. **Have you been anxious, worried, or upset? (DURING THE PAST MONTH)**
    - ☐ Extremely so- to the point of being sick or almost sick
    - ☐ Very much so
    - ☐ Quite a bit
    - ☐ Some- enough to bother me
    - ☐ A little bit
    - ☐ Not at all

18. **I was emotionally stable and sure of myself DURING THE PAST MONTH.**
    - ☐ None of the time
    - ☐ A little of the time
    - ☐ Some of the time
    - ☐ A good bit of the time
    - ☐ Most of the time
    - ☐ All of the time

19. **Did you feel relaxed, at ease or high strung, tight, or keyed-up? (DURING THE PAST MONTH)**
    - ☐ Felt relaxed and at ease the whole month
    - ☐ Felt relaxed and at ease most of the time
    - ☐ Generally felt relaxed but at times felt fairly high strung
    - ☐ Generally felt high strung but at times felt fairly relaxed
    - ☐ Felt high strung, tight, or keyed up most of the time
    - ☐ Felt high strung, tight, or keyed up the whole month

20. **I felt cheerful, lighthearted DURING THE PAST MONTH.**
    - ☐ None of the time
    - ☐ A little of the time
    - ☐ Some of the time
    - ☐ A good bit of the time
    - ☐ Most of the time
    - ☐ All of the time

21. I felt tired, worn out, used up, or exhausted DURING THE PAST MONTH.

- ☐ None of the time
- ☐ A little of the time
- ☐ Some of the time
- ☐ A good bit of the time
- ☐ Most of the time
- ☐ All of the time

22. Have you been under or felt you were under any strain, stress, or pressure? (DURING THE PAST MONTH)

- ☐ Yes, almost more than I could bear or stand
- ☐ Yes, quite a bit of pressure
- ☐ Yes, some- more than usual
- ☐ Yes, some- bout about usual
- ☐ Yes, a little
- ☐ Not at all