

**PERCEPTIONS, PROBLEMS FACED AND
COPING BEHAVIOUR: A QUALITATIVE
EXPLORATION AMONG PATIENTS WITH
BREAST CANCER ATTENDING HOSPITAL
USM, KUBANG KERIAN, KELANTAN**

by

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LIST OF ABBREVIATIONS

CAM	Complementary Alternative Medicine
HRQOL	Health-Related Quality of Life
QOL	Quality of Life
USM	Universiti Sains Malaysia
MAKNA	Majlis Kanser Nasional

**PERSEPSI, MASALAH YANG DIHADAPI DAN TINGKAH LAKU DAYA
TINDAK: EKPLORASI KUALITATIF DALAM KALANGAN PESAKIT
BARAH PAYUDARA DI HOSPITAL USM, KUBANG KERIAN, KELANTAN**

ABSTRAK

Pesakit kanser payudara berdepan dengan pelbagai cabaran termasuk menerima hakikat sebenar apabila disahkan menghidap penyakit, menguruskan regimen rawatan, berdepan dengan kesan sampingan rawatan, penjagaan sendiri dan pemulihan. Di samping itu, kepercayaan asas terhadap penyakit mempengaruhi tingkah laku pencarian kesihatan. Setiap individu mungkin mempunyai strategi daya tindak yang berbeza untuk menangani masalah mereka. Kajian ini bertujuan untuk menerokai persepsi, masalah, dan tingkah laku daya tindak dalam kalangan pesakit kanser payudara, dan untuk menghasilkan modul sendiri pendidikan kesihatan untuk pesakit kanser payudara. Pesakit dipilih secara sengaja daripada Klinik Onkologi Pesakit Luar, Hospital Universiti Sains Malaysia, Kubang Kerian, Kelantan, Malaysia. Pesakit yang terpilih telah ditemuramah secara mendalam sehingga data telah mencapai ketepuan. Semua temubual telah dirakamkan dan disalin kata demi kata. Data kualitatif telah diuruskan oleh perisian NVivo 10.0. Analisa deskriptif dilakukan dengan menggunakan perisian SPSS versi 22. Seramai 34 pesakit telah mengambil bahagian dalam kajian ini. Kebanyakan pesakit telah berkahwin (85.3%), Melayu (88.2%), berumur di antara 40 hingga 59 tahun (70.6%), mempunyai pendidikan sekolah menengah (73.5%), surirumah (61.8%), disahkan menghidap kanser payudara kanan (52.9%) dan mempunyai pendapatan bulanan kurang dari RM 1500 (67.6%). Keputusan data kualitatif telah dibahagi kepada tiga bahagian iaitu persepsi pesakit mengenai kanser payudara, masalah dan tingkah laku daya tindak dalam kalangan pesakit menghidap kanser payudara. Tema-tema yang terhasil daripada persepsi

pesakit mengenai kanser payudara adalah kanser dilihat sebagai hukuman mati, rawatan kanser menakutkan dan penyakit kanser boleh dirawat. Tema-tema yang muncul mengenai masalah yang dihadapi di kalangan pesakit kanser payudara adalah perubahan emosi, fizikal, dan hubungan sosial, kekangan ekonomi dan utamakan kaedah rawatan traditional berbanding rawatan moden. Tiga tema utama yang muncul mengenai tingkah laku daya tindak adalah daya tindak yang berfokuskan-emosi, daya tindak berfokuskan-rohani dan daya tindak berfokuskan-masalah. Berdasarkan dapatan kajian dan carian kesusasteraan, satu Modul Pendidikan Kesihatan sendiri yang baru telah dihasilkan. Sebelas orang pakar menilai modul ini sebagai baik, sangat bermaklumat, berguna, sesuai untuk dilaksanakan dan mudah difahami. Skor min penilaian adalah 3.5 (grafik menarik) hingga 4.2 (modul selaras dengan objektif). Sepuluh orang pesakit melihat modul ini sebagai yang baik, sangat menarik, jelas, berguna, dan mudah difahami. Skor purata penilaian adalah dari 4.2 (gambar yang menarik) hingga 4.8 (maklumat adalah mencukupi, bermanfaat). Pakar kesihatan juga perlu meluangkan lebih banyak masa untuk kaunseling, mengadakan seminar dan lain-lain aktiviti untuk mendidik dan meningkatkan kesedaran mengenai kanser payudara.

Kata kunci: Persepsi, tingkah laku daya tindak, kanser payudara dan kajian kualitatif

**PERCEPTIONS, PROBLEMS FACED AND COPING BEHAVIOUR: A
QUALITATIVE EXPLORATION AMONG PATIENTS WITH BREAST
CANCER ATTENDING HOSPITAL USM, KUBANG KERIAN, KELANTAN**

ABSTRACT

Patients with breast cancer face many challenges which include coming to terms with the diagnosis, managing treatment regimens, dealing with the side effects of treatment, conducting self-care and rehabilitation. In addition, the underlying belief of the disease influenced their health seeking behaviours. Each individual may have different coping strategies in order to overcome her problem. The study aimed to explore perceptions, problems, and coping behaviours among patients with breast cancer, and to develop Self-study Health Education Module for patients with breast cancer. Patients were purposively recruited from the Outpatient Oncology Clinic, Hospital Universiti Sains Malaysia, Kubang Kerian, Kelantan, Malaysia. Selected patients were interviewed in-depth until saturation were achieved. All interviews were tape-recorded and transcribed verbatim. Qualitative data were managed by Nvivo 10.0 software. Descriptive analysis was performed using SPSS version 22. A total of 34 patients took part in the study. Majority were married (85.3%), Malay (88.2%), age between 40 to 59 years old (70.6%), secondary school education (73.5%), housewife (61.8%), diagnosed with right breast cancer (52.9%) and with monthly income of less than RM 1500 (67.6%). The qualitative findings were divided into three sections which included patients' perceptions regarding breast cancer, their problems and coping behaviours in patients with breast cancer. The themes raised from patients' perceptions regarding breast cancer were cancer is viewed cancer as a death penalty; cancer treatment is terrifying and cancer as curable disease. The themes emerged regarding problems faced among patients with breast cancer were emotional, physical, and social

relationship changes, economical restraint, and prioritise traditional over modern medicine. Three main themes emerged regarding coping behaviours were emotional-focused coping, spiritual-focused coping and problem-focused coping. Based on the study findings and literature search, a new Self-study Health Education Module was developed. Eleven experts viewed the module as good, very informative, helpful, suitable to implement and easy to understand. Mean scores of evaluations ranged from 3.5 (graphics are interesting) to 4.2 (module in line with objectives). Ten patients viewed the module as good, very interesting, clear, helpful, and easy to understand. Mean scores of evaluations ranged from 4.2 (pictures are interesting) to 4.8 (information are sufficient, beneficial). Health professional should also spend more time on counselling, conducting seminar and others activities to educate and improve awareness regarding breast cancer.

Key words: Perception, coping behaviour, breast cancer, and qualitative study

CHAPTER 1

INTRODUCTION

1.1 BACKGROUND OF THE STUDY

Breast cancer is the most common cancer among women in both developed and developing countries (WHO, 2012). According to the global cancer project (GLOBOCAN 2012) which estimated the cancer incidence, mortality and prevalence worldwide, 1,671,149 new cases of breast cancer were being diagnosed with 521,907 deaths in 2012, accounting for 25% of all cancers (Ghoncheh et al, 2016), and the fifth cause of death globally (Ferlay *et al.*, 2015). In Malaysia, according to the National Cancer Registry (2007), the incidence of breast cancer is 18.1 %. The incidence varies in different ethnic groups, one in 16 Chinese and Indian women, and one in 28 Malays will develop breast cancer (Yip *et al.*, 2006).

Breast cancer is defined as a cancer that affects breast tissue (National Cancer Institute, 2014). There are several types of breast cancer and the most common is ductal carcinoma that begins in the lining of the milk ducts. Another type of breast cancer is lobular carcinoma that begins in the lobules of the breast (NCI, 2014).

Having breast cancer was perceived as having a positive or negative impact in life. Patients with breast cancer experience positive impacts to their diet, physical activities, and religious beliefs (Ganz *et al.*, 2002). On the other hand, breast cancer also give negative impacts to patients' love life, career, and financial status (Ganz *et al.*, 2002).

In developing countries, patients perceived breast cancer as a frightening disease with fear and myths (Errico and Rowden, 2006). Furthermore, many women did not perceive themselves as susceptible to develop breast cancer (Rahman and Rahman, 2008), being worried and depressed if they were diagnosed with breast cancer (Rahman and Rahman, 2008), regarded breast cancer treatment as a long and painful process (Abdul Hadi *et al.*, 2010), and did not believe in surgery for treatment (Rahman and Rahman, 2008).

Upon diagnosis, there were many problems or challenges faced by patients with breast cancer. These include their acceptance of the diagnosis, dealing with numerous treatment regimens and adverse effects, conducting self-care, and rehabilitation (Aziz, 2002; Rowland *et al.*, 2006; Jones, 2008). They might suffer various treatment side-effects, which altered their psychological, medical and social wellbeing that affected their Quality of Life (QOL). Appropriate coping strategy is important when dealing with breast cancer, especially during treatment period such as chemotherapy, radiotherapy and surgery (Saniah AR, 2010). Patients may use different coping strategies to cope with their problems, even when they were presented with similar situations (Aziz *et al.*, 2016).

According to Folkman and Lazarus (1984), coping is defined as continually changing cognitive and behavioural efforts as a stressor to manage specific external or internal demands. Many studies were performed to determine coping behaviour among patients with breast cancer in various populations. Numerous coping strategies were reported and the most common coping behaviour identified was turning to religion (Taleghani *et al.*, 2006; Lauver *et al.*, 2007; Goldblatt *et al.*, 2013; Al-Azri *et al.*, 2014).

In America, patients coped with their breast cancer illness by journaling their daily activities and participating in various fun activities (Williams *et al.*, 2016), accepting, turning to religion and distraction (Lauver *et al.*, 2007), relying on prayer, avoiding negative people, developing positive attitude, having a will to live, and receiving support from family, friends, and support group (Henderson *et al.*, 2003). Iranian women with breast cancer coped by using religious approach, thinking about the disease, accepting their disease, hiding the disease, and finding support from their spouse and relatives (Taleghani *et al.*, 2006). Interestingly, Arab women in Israel coped with breast cancer by preserving daily family life, disguising their disease, strengthening their faith with the God, and constructing new meanings in their life after recovery (Goldblatt *et al.*, 2013). In Oman, patients with breast cancer coped with their disease in many ways which include Islamic beliefs and practices, denial, optimism, withdrawal, and support from family members and health-care providers (Al-Azri *et al.*, 2014).

Local studies focused more on the knowledge and risk factors for breast cancer (Hadi *et al.*, 2010; Kirubakaran *et al.* 2017; Shah *et al.*, 2017), experience of newly diagnosed patients with breast cancer (Yusuf *et al.*, 2013), delays in seeking help or treatment (Yusoff *et al.*, 2011; Norsa'adah *et al.*, 2012), religious and spirituality coping (Ahmad *et al.*, 2011), spirituality and mental adjustment coping (Lexshimi *et al.*, 2014), and coping during chemotherapy (Saniah & Zainal, 2010)

The overall total knowledge score of breast cancer among Surgical Patients in a Tertiary Hospital in Malaysia was average (Kirubakaran *et al.*, 2017) and patients' knowledge on breast cancer risk factors is still poor (Kirubakaran *et al.*, 2017; Shah *et al.*, 2017), Kirubakaran *et al.* (2017) reported that patients were unaware that complex risk factors such as early menarche (before the age of 12 years old), late menopause (after the age of 55 years old), oral contraceptive users and those with large breasts could increase their risk of getting breast cancer.

Previous studies on breast cancer awareness among healthy women of various ethnic groups in the state of Penang, Malaysia showed majority of them had serious knowledge deficit (Hadi *et al.*, 2010; Abdul Hadi *et al.*, 2010). Abdul Hadi *et al.* (2010) added that poor knowledge regarding symptoms and risk factors are the main reasons for the delayed presentation of breast cancer patients to the hospital. Consistently, another local study reported that awareness on breast cancer was average which could potentially contribute to delay in seeking medical assistance (Kirubakaran *et al.*, 2017). Thus, awareness programs and education module regarding breast cancer are very important to educate the public, improve knowledge, and promote early breast cancer detection.

A systematic review by Azeem *et al.*, (2015) concluded that the current and future healthcare providers in Malaysia have moderate knowledge on breast cancer. They have positive attitude to be involved in breast cancer education but had poor involvement due to numerous organizational barriers (Azeem *et al.*, 2015). Health education module is appropriate way to deliver health information, health education is designed to protect, promote, and enhance the health literacy, attitudes, skills, and

well-being (Joint Committee on Health Education Terminology, 2000). Health education has the potential to help patients to maintain and improve their health, prevents or delayed disease, and reduces health-related risk behaviours (Indiana Department of Education, 2007). While module is refers to an instructional unit that focuses on a particular topic. Although the details and activities vary according to the specific context, most educational modules include information about the topic, focus on learning activities and to demonstrate understanding (Kristie Sweet, 2014).

1.2 PROBLEM STATEMENT

In developing countries, patients perceived breast cancer as a frightening disease with fear and myths (Errico and Rowden, 2006). There are limited studies on patients' perception about breast cancer, especially in Malaysia. For instance, one study on cervical cancer has been performed in Malaysia (Wong *et al.*, 2009). They identified cervical cancer as a horrible disease and one that often incurred tremendous stress, emotions and physical suffering on both the patients and family members. A study conducted at Kuala Lumpur regarding breast cancer perception and its treatment reported that treatment of breast cancer could enjoy good quality of life without embarrassment, breast cancer treatment is a long and painful process and it did not result in loss of physical beauty (Shah *et al.*, 2017). Another study reported that patient with breast cancer in Penang, perceived they can enjoy a good quality of life after receiving the treatment, did not believe that breast cancer treatment results in loss of physical beauty and However, more the treatment is a long and painful process (Hadi *et al.*, 2010). Experienced on local women perception regarding breast cancer in East Malaysia especially Kelantan are very limited. Exploration of breast cancer

perceptions in the East Coast of peninsular Malaysia are very importance since they could not associate their symptoms with breast cancer and believe in complementary alternative medicine (Norsa'adah *et al.*, 2012).

African American women coping strategies were through prayer, avoiding negative people, having positive attitude and willing to live with the disease as well as getting support from family, friends and support group (Henderson *et al.*, 2003). Until recently, most research on patient's problem and coping regarding breast cancer has been conducted in the western countries, limiting our understanding on the local breast cancer life experience among differences of ethnic groups and underlying culture. It is important to understand person's social and cultural life context helps in understanding their subjective experience of health, illness, and sense of well-being, which shaped their help seeking behaviour (Kleinman and Benson, 2006). Therefore, qualitative research is required to give a better understanding on perception, problems and how patients cope with cancer. The qualitative approach can allow an understanding on how people interpret their experiences which cannot be achieved by quantitative approach.

Tools and modules related to breast cancer are very limited. Module for the assessment of Health-Related Quality of Life (HRQOL) and patient satisfaction following breast surgery (Saiga *et al.*, 2017), Preventive Module to increase breast health awareness among young females in Malaysia (Akhtari-Zavare *et al.*, 2016) and reliability and validity of the brief cope scale undergoing adjuvant chemotherapy (Yusoff *et al.*, 2010). To date, module for health education in patients with breast cancer is still not available. Thus, the study going to explore how patients with breast cancer cope with

their problem in order to develop module. Thus, the information from the study findings was applied in Self-study Health Education Module.

1.3 SIGNIFICANCE OF THE STUDY

This study is very important to the researchers and health professionals to obtain detailed information on perceptions, breast cancer problems and how they cope with their problems. Collecting data on perception is very essential in developing an effective and focussed educational module is very important to improve knowledge, in patients with breast cancer.

Studies had reported that local knowledge regarding breast cancer were poor to average (Kirubakaran *et al.*, 2017; Shah *et al.*, 2017). Furthermore, education modules regarding breast cancer were limited and not focussed on health education (Saiga *et al.*, 2017, Akhtari-Zavare *et al.*, 2016, Yusoff *et al.*, 2010).

Health education module is an appropriate way to deliver health information and education. It is designed to protect, promote, and enhance the health literacy, attitudes, skills, and well-being (Joint Committee on Health Education Terminology, 2000). A module is refers to an instructional unit that focuses on a particular topic. Although details and activities may vary according to the specific context, most educational modules include information about the topic, focus on learning activities, improve knowledge, and to demonstrate understanding of the given information (Kristie Sweet, 2014). Furthermore, health education module has the potential to help patients to maintain and improve their health, prevents or delayed disease, and reduces health-related risk behaviours (Indiana Department of Education, 2007).

Based on the true patients' experience and suggestions, a Self-study Health Education Module was developed for patients with breast cancer. The module can act as a source of information and guide to improve knowledge for patients in dealing with their disease. This module also provides information support for health professionals to educate patients on the psychological, physical, economical issues, as well as promote effective health seeking behaviours, and therefore, improve the quality of life of the breast cancer survivors.

1.4 RESEARCH QUESTIONS

1. What is patient's perception about breast cancer?
2. What are the problems associated with breast cancer?
3. How patients cope with their problems?

1.5 OBJECTIVES

1.5.1 General Objective

To explore the perceptions, problems and coping behaviours among patients with breast cancer and to develop a Self-study Health Education Module for patients with breast cancer.

1.5.2 Specific Objectives

1. To explore patients' perceptions about breast cancer.

2. To explore problems associated with breast cancer.
3. To study coping behaviour in patients with breast cancer.
4. To develop Self-study Health Education Module for patients with breast cancer.

CHAPTER 2

LITERATURE REVIEW

2.1 ANATOMY OF FEMALE BREAST

Women's breasts (Figure 2.1) are made of glands, called lobules and ducts. Breast tissue also contains fat and connective tissue, lymph nodes, and blood vessels. The lobule is placed for milk production and ducts are thin tubes that carry the milk from the lobules to the nipple (National Cancer Institute, 2014).

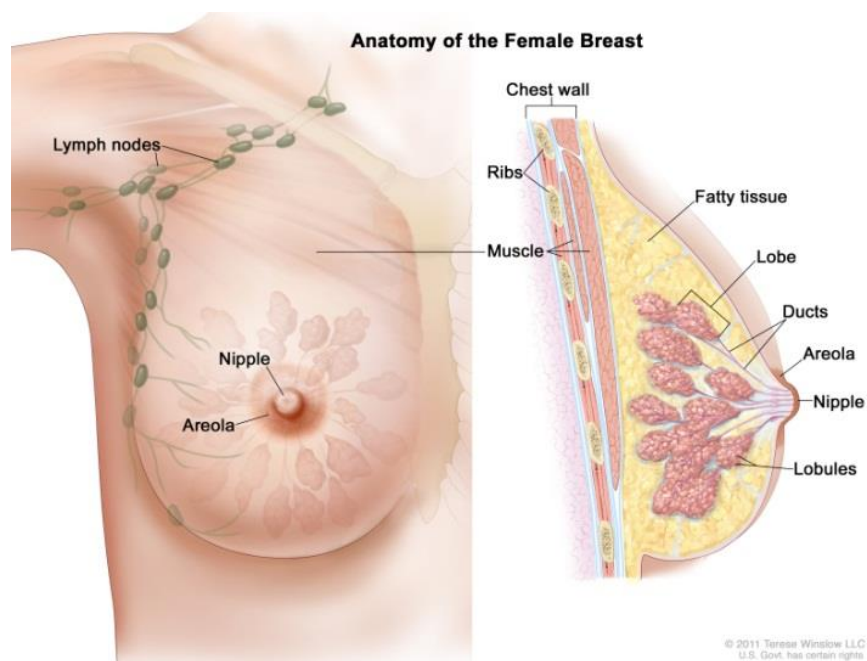


Figure 2:1 Anatomy of the female breast.

(Source with permission: National Cancer Institute © 2011 Terese Winslow).

2.2 PREVALENCE OF BREAST CANCER

Breast cancer is defined as the formation of cancer in the tissue of the breast, or a malignant cell growth in the breast. The most common type of breast cancer is ductal carcinoma, where cancer begins in the cells of the duct. Ductal carcinoma in situ is abnormal cells found in the lining of the ducts that have not spread to other parts of the duct. Invasive breast cancer is abnormal cells that have spread from the duct and into surrounding tissue (NCI, 2014).

In the year 2016, the estimated number of newly diagnosed cases of breast cancer was 246,660, and there were more than 40,450 deaths in the United States (NCI, 2016). According to GLOBOCAN 2012, about 14.1 million new cases and 8.2 million cancer deaths were estimated. This number is estimated to rise up to 19.3 million by the year 2025 (Ferlay *et al.*, 2015).

According to the National Cancer Registry of Malaysia (2016), the three most common types of cancers (Figure 2.2) among the Malaysians were breast cancer (18,343 cases, 17.7%), followed by colorectal cancer (13,693 cases, 13.2%), and lung cancer (10,608 cases, 10.2%). The incidence of breast cancer was highest among Chinese citizens, followed by Indian and Malay. The lifetime risk was 1 in 22 for individuals of Chinese, Indian, and Malay descent (NCR, 2016).

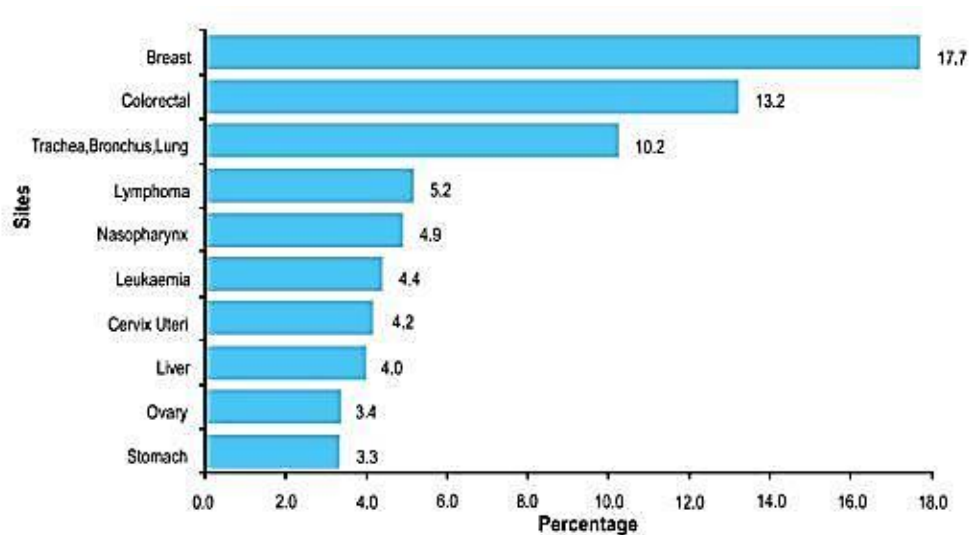


Figure 2:2 Percentage of ten most common cancers all residents, Malaysia.

2007-2011

(Sources: National Cancer Registry of Malaysia, 2016).

2.3 DIAGNOSIS OF BREAST CANCER

When patients reported their symptoms, doctor may order laboratory testing, imagery scans, or other procedures to confirm the disease. Three common diagnostic tests for breast cancer are laboratory tests (such as a blood and urine test), imagery procedures (such as CT scans, ultrasounds, MRIs, and X-rays), and biopsies. A biopsy is a procedure where the doctor removes a sample of breast tissue with a needle, endoscope, or surgery. A pathologist then looks at the tissue under a microscope to see if it is cancer (NIH, 2015).

2.4 PERCEPTIONS ABOUT BREAST CANCER

Many studies were performed regarding breast cancer risk perception (Evans *et al.*, 1993; Lloyd *et al.*, 1996; Metcalfe and Narod, 2002), ethnic risk perception (Hughes *et al.*, 1996; Berry *et al.*, 2016), genetic risk perception (Watson *et al.*, 1999), public

perceptions of cancer (Robb *et al.*, 2014; Jedrzejewski *et al.*, 2015), and perceptions towards disease treatment (Hadi *et al.*, 2010).

Perception is defined as a direct, phenomenological presence of the mind or the immediate knowledge or belief of an object (Smith, 2001). On the other hand, Lacey (1996) defined perception as the faculty of apprehending the word, specifically through the senses.

Patients perceived stress as one of the causes of breast cancer (Baghurst *et al.*, 1992; Willcox *et al.*, 2011). Almost half of Western Australian women related their breast cancer with stress. In a qualitative study, women with breast cancer in Ireland blamed stress as the reason for their cancer (Jassim and Whitford, 2014). In addition, onset of cancer may be associated with a stressful experience in Britain, France, and the United States (LeShan, 1959).

Furthermore, in Hong Kong, stress (Lam and Fielding, 2003), diet, exercise, genetics, and fate were perceived to be the causes of breast cancer (Simpson, 2005). In another study, women perceived that there was a link between stress and other factors, such as poor diet, and a lack of exercise or sleep (Thomson *et al.*, 2014). For many participants, specific stressful life events, such as family-life or work-life, were conceptualised as ‘trigger’ events. Other research indicates that stressful events have adverse effects on the immune response (Segerstrom and Miller, 2004).

Cancer is generally perceived as the most painful, least understood medically and deadliest diseases (Katz *et al.*, 1987). In cervical cancer, it was perceived as a horrible disease that is often related to emotional and physical suffering (Wong *et al.*, 2009). In lung cancer, the disease was perceived as a severe disease with the worst prognosis compared to the other cancers (Mazieres *et al.*, 2015). Compared to breast cancer, lung cancer was associated with a greater feeling of guilt since the disease was usually more associated with unhealthy lifestyle such as smoking. Another author (Wang *et al.*, 2009) compared breast cancer with heart disease and reported that many women felt more worried about breast cancer.

Having breast cancer was perceived as having a positive and negative impact in life. Patients with breast cancer perceived positive impacts to their diet, physical activities, and religious beliefs (Ganz *et al.*, 2002). On the other hand, breast cancer also gave great negative impacts to their love life, career, and financial status (Ganz *et al.*, 2002).

A study (Abdul Hadi *et al.*, 2010) was conducted in the state of Penang, Malaysia to study perceptions of breast cancer management and treatment outcomes. The author reported that majority of patients perceived breast cancer treatment as a long and painful process. These authors also reported that the respondents did not believe that breast cancer treatment resulted in the loss of physical beauty. These personal perceptions were shaped by previous experiences with family or their friends. (Jassim and Whitford, 2014).

2.5 FACTORS ASSOCIATED WITH BREAST CANCER

Many risk factors for breast cancer have been identified such as genetic, environmental, and lifestyle factors. Factors associated with the highest risk for development of breast cancer are inheritance of certain genetic mutations (*BRCA1*, *BRCA2*, *TP53*, *ATM*, *CDH1*), advanced age of 65 years and older, family history of early ovarian cancer, multiple first degree relatives with breast cancer, atypical hyperplasia of breast, and exposure to ionizing radiation before the age 30 (Katz, 2016). Other factors include high endogenous oestrogen or testosterone level, pregnancy after age 35 years, very dense breasts (>50%, compared with 11-25% mammographic ally), one first degree relative with breast cancer, proliferative breast diseases (such as atypical ductal hyperplasia) and certain inherited genetic mutations (*CHEK2*, *PTEN*), but the risks are moderate (relative risk of 2.1-4).

Factors associated with the lowest risk (RR 1.1-2.0) of breast cancer are alcohol consumption, age 30-35 at first full term pregnancy, diethylstilboestrol exposure in utero, early menarche (age <12 years), height (>5 feet 3 inches), high socioeconomic class, Ashkenazi Jewish heritage, dense breasts (25-50% compared with 11-25% mammographically), benign breast conditions such as non-atypical ductal hyperplasia, fibroadenoma, or radial scar (Katz, 2016).

Factors that can reduce the risk of breast cancer (RR <1) include Asian, Hispanic, or Pacific Islander race, breastfeeding, age <20 at first pregnancy, tamoxifen use, prior risk reduction breast surgery, history of cervical cancer, history of oophorectomy, exercise or active lifestyle, and low bone mineral density (Katz, 2016).

2.6 PROBLEMS RELATED TO BREAST CANCER

There are limited studies regarding the problems experienced by patients with breast cancer. A study found that during diagnosis, women did not experience a significant change in depressive symptoms compared with before diagnosis (Jones *et al.*, 2015b). Before diagnosis, patients with breast cancer reported an uncertainty about breast symptoms (Yusuf *et al.*, 2013a). Similarly, once patients noticed lumps in their breast, they were uncertain whether it would be problematic or not (Lam and Fielding, 2003). Patients might perceived that the symptoms were related to benign disease, such as a cyst or milk duct clot (Lam and Fielding, 2003; Yusuf *et al.*, 2013a).

This uncertainty contributes to the delay in seeking health care (Burgess *et al.*, 2001). Many other factors may contribute to the delay in seeking help such as personal factors (patients' knowledge, perceptions, and cultural and religion beliefs) and strong belief on complementary and alternative medicine (Khan *et al.*, 2015). Lack of awareness of breast symptoms (Elobaid *et al.*, 2016), never doing a breast self-examination (Ghazali *et al.*, 2013), attitudes towards seeking healthcare professional, and fear because of previous experience of loved one with cancer also potentially play a role (Burgess *et al.*, 2001). Non-modifiable factors that contribute to the health seeking process delay include age (i.e. older than 60 years), advanced clinical stage (Gangane *et al.*, 2016), late stages, and marital status (divorced or widowed) (Ghazali *et al.*, 2013). Modifiable factors were a negative social perception about breast cancer and financial problem (Khan *et al.*, 2015).

In Malaysia, the majority of women who delayed their treatment were Malays (Cheng *et al.*, 2015). Seeking traditional healers was one of the factors that delayed treatment

among patients with breast cancer (Hisham and Yip, 2004a; Norsa'adah *et al.*, 2011a; Norsa'adah *et al.*, 2012) since traditional treatment was strongly embedded in the Malay culture (Yusuf *et al.*, 2013a).

Traditional healers are local non-biomedical health practitioner who try to treat physical, psychological, social diseases, and conflicts in the community by using botanical, animal, and mineral products, or symbolic methods and ingredients (McMillen, 2004). There were two definitions of traditional healers among Malay society. First, Islamic healers whom applied Islamic spirituality and use verses from the Al-Qur'an (Holly book for Muslim) as source of treatment. Second is "*Bomoh*" (traditional healers) who claimed to know the disease causation, treatment, and prevention. They use a variety of treatment methods such as "herbal" remedies, ceremonial rites, incantation, exorcism, and sorcery (Razali and Najib, 2000). Strong belief in traditional medicine results in a negative perception of cancer.

Factors such as poverty, poor education, fear, and denial about cancer diagnosis were the primary reasons for patients to choose alternative and traditional medicine (Hisham and Yip, 2004b; Norsa'adah *et al.*, 2012). Recommendations from family and friends, permission from family, perceived benefit, trust in the compatibility and credibility of the traditional healer, reservations with modern medicine, and system delay were other factors for patients seeking traditional healers (Mazanah Muhamad, 2012).

After diagnosis with cancer, the main concerns for patients were overall health condition, emotional problems, physical changes, and social relationships (Ussher *et al.*, 2012; Ashing-Giwa *et al.*, 2004). A study that compared three cultural groups of

Americans, Indians and Chinese found that treatment side effects were the major concern. The Indian and Chinese were also concerned with financial problems, while the American couples were more concerned about the changes in their relationship, such as sexual life, social life, communication, closeness, and interdependence of the couples. For the Chinese couples, conflict with their in-laws and spouse regarding treatment decisions were identified as the most stressful (Kayser *et al.*, 2014).

2.6.1 Emotional problems

In a qualitative study (Ussher *et al.*, 2012), emotional problems was reported to arise after patients being diagnosed with breast cancer. In another study (Lethborg *et al.*, 2000) of women with early stage breast cancer, it was reported that there are three distinct time points for women with breast cancer. The first point was at the time of diagnosis and patients experienced shock and bewilderment. The second time point was during treatment, where patients reported having trauma. The final time point was after treatment, where patients reported feelings of relief, ambivalence, and fear. According to Redhwan *et al.*, (2009), patients diagnosed with breast cancer for at least one year reported stress from the time of cancer diagnosis until the interview was conducted. They also felt sad, angry, and sometimes felt like they were going to die early.

In the USA, patients reported that they were shocked and scared when informed about their cancer diagnosis (Williams and Jeanetta, 2016). In Taiwan, when patients received their cancer diagnosis, their level of shock increased. The authors also reported that there was no easy way for patients to accept their cancer diagnosis.

Patients usually felt anger, sense of unfairness, stigma, and loss of hope (Chen and Chang, 2012).

In Malaysia, after receiving a cancer diagnosis, patients were faced with a dilemma on choosing a cancer treatment that will enable them to survive and maintain their quality of life (Yusuf *et al.*, 2013a). They were confused about whether to choose conventional or alternative treatments. Close relatives such as parents, family, in-laws, siblings, and friends played important roles in encouraging patients to choose alternative treatments. They perceived that traditional treatments would cure cancer without undergoing surgery and consequently, suffering from the dreadful side effects of chemotherapy and radiotherapy treatments. Another study found that patients experienced feelings of fright and pain, which was long and difficult while they were awaiting primary surgery (Drageset *et al.*, 2011).

Some Asian-American and Latina women reported fear about the effects of chemotherapy and surgery (Ashing-Giwa *et al.*, 2004). In the early days following the completion of chemotherapy, breast cancer patients experienced several unexpected emotional changes (Costanzo *et al.*, 2007). Fear of cancer recurrence was the greatest source of stress at three weeks and three months after treatment. The stress level was reduced after three weeks to three months of treatment.

Patients also felt sad and lost because of sexual changes such as a loss of interest in sex or not feeling pleasure during sex, after completing chemotherapy. In another study, patients reported negative emotional feelings about their bodies after breast cancer and its treatments, such as a decreased self-worth and attractiveness, feeling

deformed, inadequate, sad, embarrassed, frustrated, or a sense of loss (Ashing-Giwa *et al.*, 2004).

After their breast cancer treatments, patients were uncertain about their health, future, and about being breast cancer survivors (Yusuf *et al.*, 2013a). A number of emotional problems such as fear of cancer recurrence or metastases, fear about the illness affecting their roles as caregivers, and fear of burdening the family were identified (Ashing-Giwa *et al.*, 2004).

2.6.2 Physical problems

Breast cancer treatments can have adverse impacts on physical health such as tiredness, feeling unattractive or lack of femininity, and self-reconciliation to changes (Ashing-Giwa *et al.*, 2004). Symptoms that appeared after being diagnosed with cancer were hot flashes, vaginal dryness, pain with sexual intercourse, and difficulty with bladder control when laughing or crying (Ashing-Giwa *et al.*, 2004). These symptoms significantly increased with age among patients with breast cancer. Other reported physical problems were general aches and pains, unhappiness with appearance, and weight gain (Avis *et al.*, 2005).

Cancer treatment can change sexual experiences such as a decrease in frequency, energy, sexual desire, and satisfaction with sex (Ashing-Giwa *et al.*, 2004). However, patients were able to cope with these problems by talking to their husband, using lubricants or sexual aids, exercise, reading information booklets, talking to health professionals, taking antidepressants, and counselling (Ussher *et al.*, 2012). Lower global QOL was associated with problems like sexual dysfunction and not feeling

prepared (Avis *et al.*, 2005). Sexual problems were associated with vaginal dryness, poorer psychological health, being married, partner's difficulty in understanding patient's feelings, and body image problems (Fobair *et al.*, 2006).

According to a study among breast cancer survivors, the author identified that patients who have a poor body image after breast cancer diagnosis were more likely to have low sexual satisfaction in their relationship. The author also reported that older patients had significantly more concerns about vaginal lubrication and pain (Speer *et al.*, 2005). Another study in United States (Fobair *et al.*, 2006) found that body image problems were associated with a mastectomy and possible reconstruction, hair loss from chemotherapy, concern with weight changes, poorer psychological, low self-esteem, and partner's difficulty understanding the patient's feelings.

Common physical changes experienced after being diagnosed with cancer were loss of sleep that usually continued for the entire treatment. Some patients continued to have insomnia after the treatment was completed. This caused anxiety and discomfort in the patients' daily lives. Patients also reported a decrease physical strength, and loss of appetite after chemotherapy (Chen and Chang, 2012). According to another study, the major side effect of chemotherapy reported by patients was hair loss. Arm pain and swelling also impaired daily activity (Jassim and Whitford, 2014).

2.6.3 Prioritise traditional over modern medicine

In a study, it was indicated that the reasons patients do not seek health care professional were personal belief, general practitioner (GP), and cultural belief (Whitaker *et al.*, 2015; Mitchell *et al.*, 2002; Lannin *et al.*, 1998).

2.6.3.1 Personal belief

Personal factors that cause prioritise traditional over modern medicine were due to existing beliefs among patients with breast cancer, such as the belief that breast cancer symptoms are normal. Some patients may also be stoic and just tolerate the symptoms, while others have a fear of getting a cancer diagnosis, the treatment, and its effect on daily life (Whitaker *et al.*, 2015). In another study, it was indicated that personal factors that cause the delay included the lack of knowledge about breast cancer and beliefs about the ailment (Ashing-Giwa *et al.*, 2004). The author reported that patients believed cancer can spread, that the use of wired bras can cause breast cancer, that breast cancer was always associated with loss of breasts, and cancer was looked at as a death penalty.

However, several patients had spiritual beliefs to cope with negative belief, such as a cancer diagnosis was willed by God or was God's punishment, or that one's fate, including the illness outcome, was under the God's control. However, another study found that the majority of patients with breast cancer believed that the God's will can cure breast cancer, with the remaining minority believing that medical treatment or the health seeking process was unnecessary because only the God could cure breast cancer (Mitchell *et al.*, 2002).

In another study, it was reported that patients believed breast cancer was deadly in nature since cancer is associated with pain and suffering, unlike other diseases. They also believed that cancer was seen as hidden within the body and unobserved, thus, having a mystery and fear surrounding it (Bottorff *et al.*, 1998). Another study revealed personal beliefs of patients with breast cancer. Their beliefs about breast lump

seriousness, beliefs about the consequences of cancer treatment as influenced by past experiences of cancer in relatives or friends, and perceptions that they were too busy to arrange a medical appointment were associated to health seeking treatment (Burgess *et al.*, 2001).

2.6.3.2 Cultural belief

According to a study in the United Kingdom, health behaviour and perceptions of cancer were influenced by cultural beliefs (Karbani *et al.*, 2011). Another study showed that help-seeking behaviour was influenced by cultural beliefs (Norsa'adah *et al.*, 2012). For instance, negative information, like side-effects of chemotherapy, can contribute to fear and cause some patients to refuse treatment.

Women with great culture beliefs were more likely to delay seeking a health professional compared with women who had two or fewer beliefs (Tejeda *et al.*, 2016). According to Tejeda *et al.*, (2006) most women had a cultural belief that their faith in God can protect them from breast cancer. They also believed that if a breast lump is touched often, the lump will become worse. Another belief was if breast cancer was cut open in surgery, it will grow faster.

Prioritise traditional over modern medicine also resulted from a host of cultural and ethnic beliefs and taboos. These beliefs were not based on patients' experiences, but based on the pre-existence of beliefs in the general population. For instance, it was believed that cancer can be spread through air, the devil can cause cancer, breast cancer surgery causes women to no longer become attractive to men, and chiropractic care is an effective treatment for breast cancer (Lannin *et al.*, 1998).

2.6.3.3 General practitioner (GP) associated behaviour

The GP factor is associated with prioritise traditional over modern medicine where patients worry about wasting their doctor's time (Burgess *et al.*, 2001), and have a lack of confidence in the healthcare system (Whitaker *et al.*, 2015). In another study, it was found that patients felt they should wait to seek medical care until they were very ill, since they did not want to waste both the doctor's time and their own (Kohler *et al.*, 2017a).

Furthermore, patients prioritise traditional over modern medicine because they find difficulties with booking GP appointments and worried about wasting the doctor's time (Jones *et al.*, 2015a). The author found patients had challenges in booking appointments, discomfort with disclosing symptoms to the receptionists, inconvenient surgery opening hours, and limited emergency appointments.

2.6.4 Economical problems

Financial problems in cancer survivors were linked to a worse health-related quality of life (Meneses *et al.*, 2012; Fenn *et al.*, 2014). The effects of the cancer diagnosis forced some patients to leave their jobs (Yusuf *et al.*, 2013a; Chen and Chang, 2012) and cause financial problems among patients with breast cancer (Arozullah *et al.*, 2004; Hayman *et al.*, 2001). This was due to the illness or their treatment side-effects (Yusuf *et al.*, 2013a).

Financial problems arise from direct and indirect cancer treatment. Direct costs include medications, physician fees, hospitalizations, and office visit. Indirect costs include transportation, dietary supplements, labour costs, and loss of salary (Hayman *et al.*,