IDENTIFYING PREDICTORS OF POSTOPERATIVE PERSISTENT PAIN IN WOMEN WITH BREAST CANCER: ASSESSMENTS OF INVESTIGATIVE TOOLS

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Declaration

I hereby certify that this thesis contains original research material. No other person's work has been used without acknowledgement, and has not been submitted at any other university.

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Abstract

Persistent pain after surgery in breast cancer has a significant impact on the patient's survival. The value of escalating research on breast cancer in Malaysia cannot be underestimated. However, it is not known how many of these women experience persistent pain after surgery. This study surveyed previously unknown figures on prevalence, and explored the predictive factors of persistent pain women with breast cancer in Malaysia. There were three objectives. First, to assess the reliability of the already established investigative tools, namely, the Brief Pain Inventory, Distress Thermometer, and Resilience scale RS-14; second, to survey the prevalence of persistent pain; and thirdly to identify predictors of persistent pain in women after breast surgery, using the above measures. A test and retest design with no intervention and a recall period of 3 to 7 days was employed for assessment of the investigative tools. A cross-sectional study, with a prospective, correlational design, a retrospective review of medical records was used to identify predictors of persistent pain. These investigations were conducted in two phases –Section A and Section B – using separate data sets, with different inclusion and exclusion criteria. Participants were recruited from the University of Malaya Medical Centre, Malaysia. Descriptive statistics, a stepwise regression model for reliability testing, Cronbach alpha, and factor analysis were used. This study divided pain into categories 0 = no pain, 1–4 = mild pain, 5–6 = moderate pain, and 7–10 = severe pain. Section A: The tools were found reliable. Section B: A total of 123 participants were recruited; 119 participants remained because 4 of them did not meet the inclusion criteria. A total of 43% of the participants had persistent pain (n = 51). Pain interfered with their work, mood, and sleep. Based on a "Yes" answer for pain today (n = 51), data were analysed to determine predictors. The results revealed three predictors: distress, B = –.911, resilience, B = –.444, and pain interference, B = .309. The model was statistically significant, F (3, 41, 44) = 13.827, R^2 = 0.267,

.381, .467), and adjusted R^2 = .250, .351, .467, p = 0.001. Significant P value ≤ .005. Pain prevalence was 43% in this Malaysian population. This study provided empirical evidence which is an important new knowledge to health care systems, health care providers, policy makers, and future research. The impact of persistent pain on work, mood, and sleep are justifiable medical concerns. The results obtained and identified predictors are catalysts for providing extra support for breast cancer women after surgery. Ideally, all women with breast cancer should have very good life satisfaction.

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Abbreviations

AIHW	Australian Institute of Health and Welfare
AJCC	A Joint American Committee on Cancer
ANU	The Australian National University
ALND	Axillary Lymph Node Dissection
BMI	Body Mass Index
BPI	Brief Pain Inventory
CAM	Complementary Alternative Medicine
CFA	Confirmatory Factor Analysis
CITC	Corrected Item-total Correlation
COMT	Catechol-O-methyltransferase
COX-2	COX-2 inhibitor
DHEA	Dehydroepiandroterone
DT	Distress Thermometer
DV	Dependent Variable
FA	Factor analysis
IAPS	International Association for the Study of Pain
ICC	Interclass Correlation Coefficient
IV	Independent Variable
KMO	Keiser-Meyer-Olkin Measure of Sampling Adequacy
NCCN	National Comprehensive Cancer Network
NPY	Neuropeptide Y
NRS	Numerical Rating Scale
NSAIDS	Nonsteroidal Anti-inflammatory Drugs
OCCAM	Office of Cancer of Complementary and Alternative Medicine
PCA	Principle Component Analysis
P-P plots	Probability-Probability plots
PTSD	Post-traumatic Stress disorder
RMSEA	Root Mean Square Error of Approximation
RS-14	Resilience scale RS-14
RSA	Resilience Scale for Adult
SD	Standard Deviation
TENS	Transcutaneous Electrical Stimulation
TOUS	Theory of Unpleasant Symptoms
UM	University of Malaya
UMMC	University of Malaya Medical Centre
VRS	Verbal Rating Scale
WHO	World Health Organisation

CHAPTER 1
INTRODUCTION OF BACKGROUND

Consider what life would be like if women with breast cancer were free of persistent pain after surgery. However, in an era where there are improved treatment modalities for breast cancer, although survival rates have risen some women still experience delayed side-effects of cancer treatment (Henneghan & Harrison, 2015; Pinto & Azambuja, 2011). Based on research from other countries, it is known for certain that persistent pain is a problem after surgery in women with breast cancer. For instance, one meta-analysis study [(H. S. Smith & Wu, 2012)], found that persistent pain after breast surgery could reach 50% which could last for 5 to 7 years, and in another study (Gartner et al., 2009) found a figure of 25 to 60%. While [(Macdonald, Bruce, Scott, Smith, & Chambers, 2005)] found that persistent pain after breast surgery could last up to 9 years.

1.1 Gaps in knowledge

In Malaysia, studies of breast cancer are on the rise. In one review (Yip, Bhoo Pathy, & Teo, 2014), of 154 articles between 2000 and 2013 were reviewed and comprehensively summarised from two perspectives: the significance of the study to clinical practice, and implications for future research. Some clinically significant themes which emerged were: improvements in surgical techniques; the need for good health care services (ranging from imaging, pathological services and diagnosing equipment for breast cancer); and the late presentation of women seeking treatment (due to lack of knowledge), which lead to poor rates of application of optimum treatments. Due to lack of knowledge, the patients had been dissuaded from conventional treatments and chose complementary and alternative medicine (CAM) instead. Another significant finding was that women had no power or autonomy, and men made decisions for them.

Over time, the survival rate of women with breast cancer has improved. As a result, women now live to experience delayed side-effects from cancer and its treatments. Issues arising include early menopause, sexual issues, lymphedema, fatigue, and

chronic pain among others. Yip et al. (2014) noted these issues and called for future research.

Now it is known for certain that there is a need for studies on postoperative persistent pain in women with breast cancer in Malaysia. Better understanding of persistent pain would help women with breast cancer experience satisfaction in life. Knowledge of persistent pain symptoms would allow physicians, oncologists, and other health care providers establish plans to care for and manage pain. Good evidence and data would allow policy makers and facility managers to allocate finance to improve care for women with breast cancer. The above reasons support this current study, which is a subset of a larger study conducted by Taib et al. (Islam et al., 2015).

1.2 Significance of the study

This study will:

1. Provide informed knowledge on postoperative persistent pain in women with breast cancer in Malaysia,
2. Contribute towards objective data on postoperative persistent pain in women with breast cancer in Malaysia,

It is anticipated that the study will:

1. Act as a bench mark for further research,
2. Generate ideas for planned of care and management of persistent pain in breast cancer and,
3. Provide a baseline for allocation of money to facilities. It is known that in developing Asian countries the allocation of funds for neoplastic diseases are only a small fraction of the total budget of other countries (Agarwal, Pradeep, Aggarwal, Yip, & Cheung, 2007).

1.3 Aims and Objectives of the Study

1.3.1 Research aims

The primary aims are to critically:

1. Survey the prevalence of postoperative persistent pain in women with breast cancer in Malaysia.
2. Investigate the factors that causes postoperative persistent pain in women with breast cancer in Malaysia

A secondary aim is to critically:

1. Assess the reliability of the three investigative tools: Brief Pain Inventory (BPI), Distress Thermometer (DT), and Resilience Scale RS-14 (RS-14). This process is adopted as advocated by Streiner and Norman; each time the instruments are used to survey different population and different culture, it is necessary to assess its psychometric properties to ensure that they measure what they are supposed to measure (Streiner & Norman, 2003).

1.3.2 Research Questions

Section A:

1. Are the investigative tools Brief Pain Inventory (BPI), Distress Thermometer (DT), and Resilience Scale RS-14 (RS-14) reliable? And
2. Can they measure what they are supposed to measure?

Section B:

1. What is the prevalence of postoperative persistent pain in women with breast cancer in Malaysia?
2. What are the factors affecting persistent pain in this breast cancer population in Malaysia? Is age, stage of cancer, or the type of surgery a predictor (or predictors) of persistent pain postoperatively in women with breast cancer?

1.4 Research Methods

There are two sets of data underpinning the study: identifying predictors of persistent pain and assessment of the investigative tools. Thus, the study is divided into two sections – Section A and Section B. Assessment of the investigative tools comprises Section A, and identifying predictors of persistent pain is contained in Section B. The framework of this study is influenced by the Theory of Unpleasant Symptoms or TOUS (Lenz, Pugh, Milligan, Gift, & Suppe, 1997).

Although Section B plays a pivotal role in this study, in principle the investigative tools in Section A also play an important role. Both sections are assessed concurrently. This allows the reliability of the tools to be measured, with the level accuracy of the findings assessed in Section B. Sections A and B differ slightly from each other regarding sample criteria, sample size, and the design of the data, and in fact they were gathered for different purposes. The differences are described below.

1.5 Differences between Section A and Section B

Section A and Section B differ from each other from these perspectives:

1. Section A was for assessment of tools, and Section B was to survey pain prevalence and identify predictors of persistent pain after surgery.
2. Two completely different data sets.
3. Both set of data were obtained from women with breast cancer after surgery, but for Section A the duration of surgery was 6 months to 1 year. Whereas for Section B, the duration of surgery was any time between 3 months to 5 years.
4. Recruitment for Section B did not exclude concurrent pain such as from arthritis, back pain, or chest pain; however, concurrent pain would be documented if present. However, for Section A participants with preoperative pain were excluded. Women with breast cancer were only invited to participate when they had pain or unpleasant sensations due to breast surgery.

This measure was meant to limit bias due to pain prior to surgery because preoperative pain could influence pain intensity postoperatively.

5. The design for Section A was test–retest, although no randomized control or interference was exercised; however, for section B the design was cross-sectional.

The sample size for Section A aimed at a minimum of 200 participants, whereas for Section B was calculated for 92 participants.

1.6 Thesis overview

Chapter 1 includes an introduction to the topic, a brief background to the study (with supporting literature and identifying gaps), significance of the study, the research aims, and research questions. Chapter 2 provides literature review and Chapter 3 describes the methodology of the study. There are two separate studies conducted on women with breast cancer; there are differences between the two samples, which are described in detail in **section 1.5.** Chapter 4 describes an assessment of investigative tools. Chapter 5 is an analysis of the main study which identifies factors underlying postoperative pain and symptom clusters. Chapter 6 gives the results of the assessment of the investigative tools from Chapter 4 and Chapter 5. Chapter 7 concludes the study, highlighting what was achieved, what was new, and what contributions the study has had on practice and research perspectives. It also provides the limitations and strengths of the study, recommendations for future research, and discusses ways of disseminating the results.

CHAPTER 2
LITERATURE REVIEW

The literature reviews for this study is a result of search from 2012, mainly from ANU and UM data bases; Google Scholar, Pro Quest, JSTOR, PubMed, Scopus, Web of Science, CINHL, and books, additionally a few reviews were given by supervisors. The results of the search have been updated periodically. The student saved articles in a file in her computer, sent to EndNote when PDF versions were available, and to ensure safety the articles were also saved in a software called Qiqqa.

The search strategies have been done manually, but only an alert function is used on Scopus, using search term pain AND breast AND surgery AND PUBYEAR>2014 AND PUBYEAR <2018. The articles are sent to personal email. The main search words are breast cancer and pain, predictors of pain and breast cancer, postoperative pain and cancer, psychological distress in cancer, resilience in cancer, from broad term of cancer then the searches are narrowed down to breast cancer; Theory of unpleasant symptom and critiques, Theory of unpleasant symptom and validity, and studies on Theory of unpleasant symptom, symptom clusters and pain, Pierce inductive and abductive reasoning, inductive and abductive reasoning and nursing and inductive and abductive reasoning and clinical practice. For investigative tools, the search terms are associated with psychometric properties with addition of Brief Pain Inventory, Distress Thermometer and Resilience Scale, Resilience Scale RS-14, other terms included are assessment of tools, analytical model and psychometric properties to name a few.

In general, the student sets inclusion criteria: primary source a first choice, quantitative preferred to qualitative, articles with high impact journal but some are also from low impact journal when applicable, articles with many citations, sample size close to 100 minimum, large sample size are preferred. Normally limited search from

year 2000, but not always possible in view of the nature of the arguments, and absolute exclusion criteria from articles of unknown source and incomplete citation.

2.1 Background

According to the World Health Organisation (GLOBOCAN), in 2012 there were 6. 3 million women living with breast cancer 5 years after diagnosis (Ferlay et al., 2012). Asian countries make up 60% of the world's population and account for half the global cancer burden. According to a review conducted by Sankaranarayanan, Ramadas, and Qiao (2014) 2014 the incidence of cancer cases is estimated to rise from 6.1 million in 2008 to 10.7 million in 2030. The incidence of breast cancer is a rising trend in all Asian countries, increasing at a rate of 1% to 3% annually. The increase is not unexpected, as Asian countries now have improved screening equipment, and are therefore able to more effectively detect breast cancer. Based on a study in eight Asian countries (Cambodia, Myanmar, Vietnam, Laos, Thailand, Philippines, Indonesia and Malaysia) conducted in Jan (2015) the socioeconomic disadvantage associated with cancer are early death, premature discontinuation of treatment, and financial catastrophe. This study is a subset of the larger study (n = 9513). This study comprises n = 4584 participants with cancer. The participants were assessed at two points, baseline and 3 months. The assessments made on surgically operable cancer patients related to financial catastrophe, cessation of cancer treatment, and death. The author found that after 3 months 8% of patients had died, 23% had discontinued treatment, 31% experienced catastrophic expenditure, and 38% had avoided catastrophic expenditure and were still hospitalised. Overall, the crux of the problems was financial. Hence the findings provide a perspective for policy makers to address these issues.

A report by the National Cancer Registry of Malaysia from 2007 to 2011 found there were 103,507 new cancer cases diagnosed. The ratio was 1:10 in men and 1:9 in women, accounting for 45.2% and 54.8% respectively. The Age Standardised Rate

(ASR) was found to be 86.9 and 89.0 per 100,000 for men and women respectively. Breast cancer is number one of the five commonest cancers among women; the remainder are colon, cervical and uterine, ovary, and lung cancer. The percentages are 32.1%, 10.7%, 7.7%, 6.1%, and 5.6% respectively (Azizah, Nor Saleha, Noor hashimah, Asmah, & Mastulu, 2016).

The risk factors for breast cancer in females include: history of alcohol consumption, hormonal factors, genetic, physical inactivity, excess body fat, occupational exposure, ionizing radiation, drugs, and pollution of water, soil, and environment (AIWH, 2017). The surgical procedures, type of breast surgery, complications of postoperative breast surgery (such as infection, seroma, haematoma, and axillary web syndrome) were also elucidated as risk factors (K. G. Andersen, Gartner, Kroman, Flyger, & Kehlet, 2012). According to this study, high body mass index (BMI) was an inconclusive risk factor for persistent pain in breast cancer. Similarly, type of surgery and the surgical procedure used were inconclusive in showing that these factors contributed to persistent pain. However, the review did find that many studies pointed to younger age groups as more likely have persistent postoperative pain in breast cancer. Ten studies showed such an association, while only two studies did not show an association between age and persistent pain. Younger patients differed from the older age group in terms of psychological wellbeing and general level of activity. Other studies have focused on different anatomical locations of pain, and assessed pain itself differently (K. G. Andersen & Kehlet, 2011).

A study found living with persistent pain is always associated with poor satisfaction with life (McNamee & Mendolia, 2014), and it is one of the factors that causes comorbidity and mortality (Sibille et al., 2016). Physical comorbidity and impairments may also lead to social isolation. Consequently, it creates a vicious cycle: social isolation leads to a weak social network, and a weak social network can lead to

persistent pain (Duenas, Ojeda, Salazar, Mico, & Failde, 2016; Leung et al., 2015). Kroenke et al. (2013) found that 45% of participants who scored the worst pain experienced anxiety disorders. It has also been found that in 30% to 50% of cases, pain and depression occur together (Kroenke et al., 2011). Social support from outside the households was found to be a predictor to preventing persistent pain (Leung et al., 2015).

The impact of persistent pain has been studied in great extent. A review revealed that persistent pain had both direct and indirect impacts on the health care system Duenas et al. (2016). The work load on the health care system increased due to more visits to seek pain treatment from general practitioners, specialists, and health care professionals. The visits to doctors and health care providers caused work disruptions and absenteeism from the work place. Even when being at the work place, the experience of pain results in lower output and poorer performance.

Regular absenteeism can result in job loss, with repercussions felt by family members. Family members are forced to accept extra burdens such as supervision and assisting in decision making during consultation with doctors, which causes them to experience anxiety, sadness, frustration, and sometimes even impotence. Strong pain in patients has been reported to cause discomfort, anxiety, and depression among family members (Duenas et al., 2016).

Opioids are still the main stay of treatment for persistent pain. Although cancer patients are not exempt from potential opioid abuse, new abuse-deterring opioid formulations are available when needed (Pergolizzi et al., 2016). Opioid naïve patients might also need treatments to relieve their pain, in which case rapid and short-acting opioids are advocated. Proper titration for opioid naive patients is necessary (Swarm et al., 2013). Many cancer patients suffer from depression, physical disability, impaired rehabilitation, and inadequate nutrition due to persistent pain. The aim of analgesia is to

alleviate pain and ensure comfort to patients, and ensuring they experience no adverse effects from their medications (Nersesyan & Slavin, 2007).

Although conventional pain management is the main treatment, survivors still seek unconventional treatments. Weiger et al. (2002**)** have conducted a review that showed that some diets and by supplements are detrimental to cancer survivors. These treatments might have an adverse impact on conventional treatments such as chemotherapy and radiotherapy. For example, the herb called St. John's wort has been associated with reduced efficacy in cancer treatment from chemotherapy. The herb is found to reduce the efficacy of the chemotherapy drug irinotecan, which can result in a failure to achieve a therapeutic dose of chemotherapy (Mansky & Straus, 2002; Weiger et al., 2002). In another study it was concluded that St. John's wort had a wide range of interactions with drug metabolism, reducing efficacy. In Sweden the herb is labelled not to be used concurrently with any medicinal products (Yue, Bergquist, & Gerden, 2000). Therefore, clinicians need to collaborate with survivors to give them informed evidence-based recommendations which will ensure maximum results from conventional treatments (Weiger et al., 2002).

2.2 Overview of Cancer Pain

Defining pain

The International Association for the Study of Pain (IAPS) defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey, 2000). This study has its operational definition: any actual pain or unpleasant sensation, as a result of surgery due to breast cancer. Symptoms can be pricking, sharp pain, unable to mobilise arm easily, or even very undefined pain. Therefore, for consistency this study uses the word pain with this meaning throughout this study.

Persistent pain in this study covers pain that is present for at least 3 months after surgery. Three months is reasonable because it covers the normal healing of tissue within this timeframe (Fine, 2011). A number of other researchers have accepted chronic pain at that exceeding 3 months (Andersson, Ejlertsson, Leden, & Rosenberg, 1993; Blyth et al., 2001; Bouhassira, Lanteri-Minet, Attal, Laurent, & Touboul, 2008; Kaasa, Romundstad, Roald, Skolleborg, & Stubhaug, 2010). Other researchers have accepted persistent pain at being pain lasting at least six months; (Breivik et al., 2009; K. Kwekkeboom, 1996). However, to date there is no standardised definition of postoperative persistent pain (Bruce & Quinlan, 2011; Shipton, 2011).

Pain is immensely a complicated phenomenon (Rosenblum, Marsch, Joseph, & Portenoy, 2008). Failure to manage acute pain could lead to chronic or persistent pain (Chang, Mehta, & Langford, 2009). The existence of persistent pain existence is largely unexplained (R. J. Bell et al., 2014). It is also an unstable symptom, and is influenced by social and cultural factors (Callister, 2003). Culture is associated with physical and psychological factors and it is also a shared knowledge and belief system (D'Andrade, 1987).

Persistent pain after mastectomy with reconstruction can be caused by a type of gene mutation called vall58met polymorphism of catechol-O-methyltransferase (COMT). The A allele gene associated with the pain is also influenced by opioids (Tan, Tan, Karupathivan, & Yap, 2003). Essentially, patients are the expert of their own pain (Mair, 2009), and so “Pain is whatever the experiencing person says it is, existing whenever he says it does” (McCaffery & Pasero, 1999, p. 17) , and it is real (Jacox, Carr, & Payne, 1994).

2.3 Contributory factors in persistent pain

Studies from other countries informed that early stages of cancer, and lack of family support, contribute to persistent pain among women with breast cancer. The impact of

persistent pain can be profound on the individual, family structure, health care system, and community at large (Currow, Agar, Plummer, Blyth, & Abernethy, 2010). McNamee and Mendolia (2014) also made it clear that persistent pain affected the individual economically, as well as their family and, in turn, the health care system.

Improved survival rates are due to better diagnosis and improved treatments. While efforts are being made to improve survival rates, it means that women with breast cancer are living longer and experiencing delayed side-effects of treatment (Henneghan & Harrison, 2015). The time frame may extend out to 10 years (Pinto & Azambuja, 2011). Surgery is the main treatment (Wyatt, Beckrow, Gardiner, & Pathak, 2008). Persistent pain is a common side effect after (Juhl, Christiansen, & Damsgaard, 2016; H. S. Smith & Wu, 2012; Wang et al., 2016). Persistent pain extending up to five years after breast surgery is common (R. J. Bell et al., 2014).

Postoperative pain may be brief or prolonged. Persistent pain may be caused by phantom breast pain, loss of sensation, or sensory changes. Persistent pain can be complicated because of disabilities and psychological distress (Jung, Ahrendt, Oaklander, & Dworkin, 2003). Damage to the intercostobrachial nerve (ICB) has been associated with persistent pain after breast surgery (Kehlet, Jensen, & Woolf, 2006). The ICB nerve may be damaged due to over stretching of retractors during surgery. Usually it involved T1/T2 dermatomes (Levy, Chwistek, & Mehta, 2008).

Macrae (2008) conducted a review and has identified breast surgery involving axillary lymph nodes dissection associated with persistent pain on the ipsilateral arm, and this is assumed have been caused by damaged of the ICB nerve. Gartner et al. (2009) concluded that persistent pain after surgery could be due to ICB nerve injury. Similarly, Henry et al. (2017) reported that injury to ICB nerve fibres was often the cause of postoperative pain in breast surgery. Due to the wide prevalence of ICB injury, knowledge

of anatomy of the region would minimise injury, as would exercising caution during surgery.

Although surgery can be the cause of pain and impairment and limitation to arm movements, the above sequelae could also be due to other side-effects such as radiotherapy and other treatments (Smoot, Wampler, & Topp, 2009). Kehlet et al. (2006) argued persistent postoperative pain is iatrogenic in nature. Taken together, the cause of persistent pain by injury to ICB is still inconclusive. A systemic research of all surgery types conducted by (Bruce & Quinlan, 2011; VanDenKerkhof, Peters, & Bruce, 2013). Using cut-off 3 months duration after surgery, five domains of predictors to persistent pain were uncovered. First, were demographic factors: young age has been always associated with persistent pain after surgery, but sex, education, marital status, socio-economic status, and lifestyle were also found to be predictors of persistent pain after surgery. Second, pain existing prior to surgery has been found to be a predictor of persistent pain after surgery. Third, clinical factors: height, weight, and body mass index (BMI) have been found to be associated with persistent pain after surgery, although the findings were not conclusive. Fourth, surgery-related factors have given mixed results: for example, the experience of the surgeon and the anaesthetic regimes (involving perhaps epidural anaesthesia during surgery), duration of surgery, and type of surgery. Fifth are psychological factors – catastrophizing, depression, anxiety, fear of surgery prior to the actual surgery, low expectation of return to work – are among predictors of persistent pain after surgery. In addition to the five domains, the authors noted there were also genetic and laboratory tests of pain prior to surgery which could predict persistent pain after surgery, although these predictors were not included in the review of in preventing persistent pain (VanDenKerkhof et al., 2013).

According to (Belfer, 2013), genetic factors and young age are predisposing factors to pain. Belfer et al. identified association of persistent pain after breast surgery

with psychosocial factors namely catastrophising, depressive symptoms, anxiety, perceive stress and insomnia, and none of treatment related factors namely surgical factors, chemotherapy, radiotherapy, tumour size and stage of cancer were associated with persistent pain. Miaskowski et al. (2012) also found that belonging to a younger age group was a predictor of pain, and additionally, low education level, low income group, and non-white ethnicity were associated with persistent pain after breast surgery due to cancer. While in a nation-wide large study, demographic factors such as young age, low education, and low income again predicted persistent pain at the start of the study. However, 5 to 7 years later the influence of these predictors changed (Johannsen, Christensen, Zachariae, & Jensen, 2015).Wang et al. (2016)conducted as a systematic review and meta analysis, and confirmed from a range of studies (Bredal, Smeby, Oyttsen, Warnche, & Schlichting, 2014; Miaskowski et al., 2012; Peuckmann et al., 2009; Steegers, Snik, Verhagen, van der Drift, & Wilder-Smith, 2008) that young age was a predictor of pain.

Wang et al. (2016) claimed that high quality evidence had shown that younger age and radiotherapy in the presence of ALND, and preoperative pain were predictors of persistent pain after breast surgery. The authors also claimed that high-quality evidence showed that BMI, type of surgery, chemotherapy, and endocrine treatment were not predictors of persistent pain after breast surgery. A randomised control study found that TARGIT did not modify the occurrence of persistent pain in breast cancer postoperatively. Some 24.6% of participants also reported persistent pain occurred in TARGIT, compared to 36.9% on external radiotherapy treatment.

2.4 Cost of breast cancer treatment and cost of persistent pain to individuals

Persistent pain is common, while rehabilitation programmes, alternative medicine, and pharmacological treatments are very costly (Turk, 2002). In the United States of America, breast cancer causes a significant economic burden (Blumen, Fitch, & Polkus,

2016). Based on data from health claims between 2011 and 2012, this study was a 2-year retrospective study on breast cancer in women. Data from a total of 8360 newly diagnosed breast cancer women who met the criteria revealed that the more advanced the stage of cancer the higher the costs incurred. The highest cost came from radiotherapy. The first year of the disease cost more than the second year. Per individual, the treatment cost in the first year was USD47,452 and for the second year USD5635. The cost in this context included the cost after diagnosis, all treatments such as surgery, chemotherapy, radiotherapy, and all medical costs incurred (both inpatient and outpatient) during the 24 months. Following from the finding that the more advanced the stage of cancer the higher it cost the health system and the individual, the authors strongly advocate that a breast cancer screening programme should be strengthened so that more breast cancers can be diagnosed and treated early.

Capri and Russo (2017) conducted a study similar in principle to a previous study (Blumen et al., 2016), to assess the financial burden on individual breast cancer patients. This study was conducted in Italy. The purpose was the same: to seek a better understanding of the costs incurred by breast cancer patients at specific levels: for diagnosis, treatment, and follow up. The study was a retrospective study using data from the health information system between 2007 and 2011. A total of 12,580 breast cancer patients were included in the study. The study commenced at 6 months from diagnosis and finished 2 years after diagnosis. The mean cost of each patient projected over two and a half years were: for diagnosis, EUR414; treatment, EUR8,780; follow up EUR2,351; and medical costs, EUR10,970. The study isolated the factors that affected the cost into age, stage of cancer, and level of education. Again, it was noted that the more advanced the stage of cancer the higher the cost incurred, consistent with the study conducted by Blumen et al. (Blumen et al., 2016). Capri and Russo (2017) surveyed the cost from six months prior to diagnosis of breast cancer to follow up. Both

studies recommended on early diagnosis by the improved screening facilities. Thus, this would reduce burden of both the patients and the country.

Persistent pain significantly affects an individual economically, as well as family members, the health care system, and the community at large. According to reviews, persistent pain affects 30% of Australian adults. It was estimated at AUD34.2 (USD$30) billion in 2007, and on an individual basis it was estimated as AUD10,847 (USD$9546). Persistent pain also has other economic implications such as an inability to work (McNamee & Mendolia, 2014).

In another study Blyth et al. (2001) found there were strong findings in terms of disability benefits and unemployment benefits due to health and psychological distress. Adjusted odds ratios were OR 3.89, $p \leq 0.001$, adjusted OR 6.41, $p \leq 0.001$, and adjusted OR 3.16, $p \leq 0.001$ respectively. This study highlighted that the elderly aged group was more prone to chronic pain. The most prevalent ages were 65–69 years old and those with no health insurance. Cancer in general is a burden to the health care system of the country (Luengo-Fernandez, Leal, Gray, & Sullivan, 2013; Yu et al., 2014) and also to the world (Jemal et al., 2011). It is also costly for women to pay for cancer treatments to prolong life expectancy.

2.5 Impact of Persistent Pain on Individual

Unrelieved pain can have a disruptive impact on an individual from biological and physiological perspectives. Perpetual pain causes stress. Stress activates the dysregulation of the neuroendocrine system to cause fatigue, myalgia, and dysphoria, among others. Additionally, persistent pain can affect mental and physical performance. Consequently, it can result in unproductive output at work, jeopardise the integrity of the family, and can make an individual become asocial (Chapman & Gavrin, 1999).

An increasing number of studies have found that persistent pain leads to insomnia, catastrophizing, and depression. These are predictors for suicidal ideation and

suicide. The exact number of failed suicides are unknown, and the genesis of the action remains unclear. However, it is a wake-up call for health professionals to be cognizant of the possibility of suicide, and to screen potential cases during regular contacts for prescriptions to pain relief, particularly opioids. Appropriate screening tools may detect some of these candidates. They may need to be treated as inpatients, be treated by psychotherapy, and given support with action plans to prevent suicide (Cheatle, 2011).

Mastectomy is an operation that shows the highest incidence of persistent pain. It affects millions of people every year, and pain can last for months and years (Correll, 2017). The economic costs – including reduced productivity, early retirement, and absenteeism – due to persistent pain call for full rehabilitation and not just pain relief (Breivik, Eisenberg, & O'Brien, 2013).

Pain is a signal that urgent attention is needed, but it loses its usefulness when it becomes chronic (Sturgeon & Zautra, 2010). It is not clear how persistent pain reduces the sense of wellbeing (R. J. Bell et al., 2014). To find meaning and purpose of life, cancer patients often turn to spirituality and religiosity in their coping process. This aspect cannot be ignored (Büssing, Balzat, & Heusser, 2010). Active coping is associated with less disability and vice versa. A study conducted on women with breast cancer who experienced persistent pain found that there was an association between coping and catastrophizing. Preliminary outcomes show that passive coping and catastrophizing are likely to co-occur and this is worth pursuing with further research (Bishop & Warr, 2003).

When cancer patients experience persistent pain, it has negative influence on their wellbeing. For example, persistent pain limits physical activities, which results in loss of staff time at the work place (Blyth et al., 2001). Persistent pain in women after breast surgery is associated with psycho-social distress (Poleshuck et al., 2006). It is now acknowledged that persistent pain and distress can co-exist: in 1997 the NCCN

finally used the word ‘distress’ to address the range of emotional concerns experienced by cancer patients (Holland, Bultz, & National comprehensive Cancer, 2007). The word distress is preferred to other terms because of the stigma associated with many of them.

Persistent pain after surgery in breast cancer is associated with persistent pain before surgery. It occurs more often with the more invasive axillary procedure. However, it is usually not associated with survivors who have a positive and optimistic outlook (Bruce et al., 2014). Hsu, Ennis, Hood, Graham, and Goodwin (2013) in their study found that 79% to 82% breast cancer survivors returned to work within a year of diagnosis, Mujahid et al. (2010) confirmed that loss of work is a potential impact from cancer, and this is under-explored in breast cancer survivorship.

2.6 Persistent Pain and Resilience

Connor (2006) defines resilient as stress coping ability. Resilience is thought to be the moderator between pain and the coping responses of the individual (Graham & Becerril-Martinez, 2014; Sturgeon & Zautra, 2010). Resilience though has its flip side, not all researchers agree that resilience is a positive notion (Reghezza-Zitt, Rufat, Djament-Tran, Le Blanc, & Serge Lhomme, 2012; Zellmer & Gunderson, 2008). The above researchers argue that resilience is an essential signal of an illness, that could lead to patients’ depression and other health problems.

Lightsey (2006) in a meta-analysis reported that resilience is a generalized self-efficacy, a process that leads to strength awareness. It allows one to acquire strength to cope better with stressors and able to use available resources. Globally, researchers have different connotation regarding its definition, such as concept (Earvolino-Ramirez, 2007), and theory (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014). Apparently, its definition varies according to the particular domain of research or discipline (Lightsey, 2006).

Resilience was defined according to adversity and positive adaptation (Southwick et al., 2014; Wright, Kiparoglou, Williams, & Hilton, 2012). Therefore, the experience of resilience varies from time to time and situation, even in the same individual. Another dimension of resilience is self-efficacy, which is a process that leads to strengthened awareness; therefore, post traumatic growth is part of resilience (Wenzel et al., 2002). Resilience can be measured using standardized psychopathological measurement tools such as those for anxiety and depression, or specific resilience tools such as the Connor–Davidson Resilience Scale or the Resilience Scale for Adult (Herrman et al., 2011).

Resilience is known to be intensified by social support. Resilience is believed to be influenced by culture and a supportive environment (Cicchetti, 2010; Wagnild, 2011; Wright et al., 2012). Social support provides a conducive environment for positive emotional growth. However, personal growth needs to come from within the individual because at times the supportive network or social support can have a negative impact, thus reducing resilience in the individual (Wills & Bantum, 2012).

In some cultures, family members are readily available to provide support during adverse situations such as dealing with cancer pain and other symptoms (Muhamad, Merriam, & Suhaimi, 2012 ; Mystakidou et al., 2008). For example, besides providing emotional support family members and significant others can also provide information and tangible help in coping with cancer (B. L. Andersen, Beck, Kobasa, Revenson, & Temoshok, 1989).

In some cultures, patients turn to doctors in dealing with cancer pain, but a significant number of others turn to spirituality and religiosity (Büssing et al., 2010; Delgado-Guay et al., 2011; Padela, Killawi, Forman, DeMonner, & Heisler, 2012). Of a hundred subjects (N=100), there were a variety of religious beliefs and affiliations, including a majority of Christians (88%); the remainder (12%) was made of Muslims,

Atheists, Jews, Buddhists, and others. Some 98% stated they were religious and a similar percentage claimed they were spiritual. Accordingly, spirituality and religiosity gave them strength to cope with their cancer pain (Delgado-Guay et al., 2011).

A community-based research model conducted on Muslims in America was made up of 13 groups, with 6 or 7 participants per group. The study interviewed 102 participants and found that the participants relied directly on God for healing. They said that health care providers and supportive people in the community were instrumental, but essentially indirect agents provided by God. The interviews also revealed that pain was tolerable because they recited the Quran (the holy book) and made supplication to God. The coping process in this context was positive in nature (Padela et al., 2012). On the contrary, in another study on breast cancer the researchers could not confirm an association between religiosity (or nonreligiosity) with resilience (Van Ness, Kasl, & Jones, 2003).

Meanwhile, (Douglas, 2009) stated that some cancer patients are more resilient in confronting health insult than others. They indulged themselves with outlandish remedies to stay alive. Besides conventional treatment they sought alternative or complementary treatment such as meditation and dietary change. He concluded there were possibilities that the "sense of control" which linked resilience and health was important and called for further research on this aspect.

According to Graham and Becerril-Martinez (2014), there are ways of identifying surgical resilience. From a systematic literature review, they identified two biomarkers – testosterone and dehydroepiandroterone (DHEA) – which they found at high level in patients who had post traumatic stress disorder (PTSD). Another biomarker, neuropeptide Y (NPY), was found at high level in patients who exhibited resilience to psychological stress. Based on these two biomarkers, identifying surgical resilience level in patients is possible. By controlling some variables, two approaches

are possible: prospective or preventative. Prospective methods use cognitive behavioural therapy, while preventative methods aim at modifying resilience by using pharmacological or nonpharmacological means (or in combination).

Brief reviews above shed lights on the inconsistency in resilient definition that differ from person to person, culture to culture, researcher to researcher and varied from discipline to discipline. Further, the individual resilience level is also influenced by family support, social support, and community support. Then it is hard to identify a resilience tool that suits everybody in all population and places (Salisu & Hashim, 2017).

Apart from its operational definition, it is also observed that the resilience tools received critiques on the varied ways of validating not in concordance to the methodological quality assessment for example the one set by consensus-based standards for the selection of health measurement scales [COSMIN (Terwee et al., 2007)]. COSMIN methodological quality assessment involved 4 broad aspects: first, reliability-internal reliability, measurement error and reliability test retest, interrater, and intrarater; second, validity-content, criterion and construct; third, responsiveness; and fourth, repeatability (Mokkink et al., 2010).

In relation to validation and methodological quality assessment of resilience tools, there are evidences of inadequacies (Windle, Bennett, & Noyes, 2011). Windle et al. conducted a review of 15 original validation papers on resilience scales and found that only three tools were considered to receive best psychometric evaluation, those tools were Connor-Davidson Resilience Scale (CD-RISC) being the best of the three, The Resilience Scale for Adults, and The Brief Resilience Scale. According to Windle et al., the items have issues surrounding them, which includes the absence of content validity, pilot study, while for the internal consistency, studies did not report alpha for subscales of the tools. For criterion validity, most authors did not provide “gold

standard" information, and evidence of construct validity was lacking. Windle et al. also found none of the papers presented information on agreement test, to denote reproducibility, even when mentioned the type of ICC was not specified. It was evident that only CD-RISC examined changes over time, and according to Windle et al., none of the tools reported floor and ceiling effects, and poor reporting in interpretability was detected. None of the measures reported the minimal important change (MIC), although effort was made to report means and standard deviations in most of the studies. Windle et al. concluded that recommendations to employing resilience tools were difficult to make due to the lack of documented psychometric properties for review.

In another review, the sound psychometric properties of CD-RISC was supported , but the tool lacked cultural adaptation (Scoloveno, 2017). The Resilience Scale (RS), did not qualify for the best methodological quality assessment (Windle et al., 2011), Scoloveno acknowledged that RS has some flaws in reliability. However, Wagnild and Young 1993 achieved reasonable validity in the initial study. Scoloveno, argued that the Wagnild and Young had followed the right procedures for the initial study in concordance to qualitative process, and further in the second phase they employed two psychometricians and two nurses to validate the content validity, although the process of validating was not documented (Scoloveno, 2017).

On the contrary, in validating resilience construct, researchers should not rely on statistical significance validity alone, but to consider the magnitude of the correlation also, because a low statistical correlation of the instrument does not necessarily indicate poor validity. The phenomenon could arise due to curvilinear rather than linear association (Luthar & Cushing, 1999, p. 131).

2.7 Persistent pain and distress

In 1997, the NCCN defined the word "distress" which was accepted and perceived as no stigmatisation attached, to address the range of emotional concerns that was experienced

by cancer patients (Holland, 1997). In oncology, pain and distress can co-exist, and are highly prevalent. As such, the fifth vital sign has been designated to be pain, while the sixth vital sign has been allocated to distress (Bultz, 2016). It has been observed that persistent pain before surgery in breast cancer is associated with negative outcomes such as insomnia, impairment in range of motion and poor life satisfaction, and psychological symptoms; therefore, it is worth considering the assessment to commence from the beginning, because in addition women who were experiencing pain before surgery were at risk of experiencing persistent pain after surgery (Langford et al., 2015).

Research has found that psychological intervention is the best way to alleviate stress symptoms. Symptom is defined "as a subjective experience reflecting changes in biopsychosocial function, sensation, or cognition in individuals" (Campbell & Happ, 2010). Perception of symptoms refers to whether one notices a change from the way one usually feels or behaves. Symptoms are evaluated according to their severity, cause, treatability, and effects of the symptoms on daily life (Dodd, Cho, Cooper, & Miaskowski, 2010). Distress symptoms are defined in terms of the degree of discomfort experienced by patients. It is often measured in terms of symptom occurrence (frequency), characteristics (severity), and distress ("bothersomeness") (Apfelbaum, Gan, Zhao, Hanna, & Chen, 2004).

Family support plays an important role in alleviating distress. Breast cancer women are expected to be more stressed than their partners. Meta-analysis has revealed that female gender was a predictor of distress regardless as whether the subject was a patient with cancer or played the role of a partner who had cancer (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). On the contrary, Baider, Ever-Hadani, Goldzweig, Wygoda, and Peretz (2003) found no correlation between psychological distress and whether the cancer patient or their partner were male or female. However, the study confirmed that family support reduces the level of stress experienced. Baider

et al. (2003) found that family structure and marital status were indices of positive family support. As such, both members of a couple would benefit from counselling.

Social support also plays a vital role in reducing stress, and there are also mixed results (Trunzo & Pinto, 2003). In a longitudinal study on breast cancer, these authors obtained a very strong negative association between social support and distress at baseline level with beta=-.55, $p<.0001$ but failed to show similar results at repeat study at 6 month and 12 months. A contrary result was obtained by Lepore, Glaser, and Roberts 2008, in that not all social supports are helpful to individuals. A longitudinal study on breast cancer at 3 and 18 months gave insight into when it is appropriate to provide social support. This study utilised two models: a triage model and a self-esteem threat model. The triage model showed a positive correlation between received social support and negative affect. A higher level of negative affect was associated with a higher level of social support. However, the self-esteem threat model highlighted that social support could be associated with lower self-esteem, personal incompetence, or loss of independence. This phenomenon could have detrimental effects on psychological health. The researchers further recommended that it is imperative to select individuals before offering support in order to avoid awkward unsuccessful attempts (Lepore, Glaser, & Roberts, 2008).

Distress symptoms have been associated with suppression of the cellular immune system. The process was found to decrease lymphatic proliferation response (LPR) and reduce natural killer cell toxicity (NKCC) which predicts poor outcome of diseases such as breast cancer. This review has highlighted evidence of the effect of psychological intervention in reducing psychological distress in women with breast cancer from a biological perspective (McGregor & Antoni, 2009).

In a randomised clinical trial, on stress related Andersen et al. 2008 divided women with breast cancer after surgery into two groups (N=227); the first group had no

intervention, and the second had intervention. The intervention group was given psychological intervention by a psychologist over a period of 1 year and assessed at a median of 11 years later. Cox propositional hazard analysis was employed for analysis. The participants' mood was altered and found to lean towards better adherence of medication in the intervention group. The Hazard Ratio showed the intervention group did better in terms of survival; HR 0.55, p = .034 for the intervention group, and HR of 0.44, p = .016 for the control group. A follow up analysis showed the intervention group had a reduced risk of death (HR of 0.51; p = .028). Taken together, recommendations from the study were summarised as: psychological intervention reduces stress, improves mental health, physical health, and treatment-related behaviour; at the same time biological effects reduce inflammatory processes and therefore interrupt disease progression and improve survivorship (B. L. Andersen et al., 2008).

Particular attention is needed to alleviate distress at an early stage (Lazenby, Tan, Pasacreta, Ercolano, & McCorkle, 2015). They advocated five steps of psychological screening by cancer care professionals – in summary: screening, evaluating, referring, follow up, documenting, and quality improvement. Hammonds (2012) utilised the distress thermometer to investigate, in a randomised controlled group, the difference between simple observation and using the thermometer to measure Absolute risk to participants (AR) from distress. The study revealed in the non-intervention group (N=1291), only 8 participants were identified as AR. However, in the control group (N=104), the study found 55 participants fell into the category of AR. The study promoted the idea that by employing the distress thermometer, more patients could be identified as AR compared to mere observation.

2.8 Impact of Persistent Pain on Family Structure

Persistent pain is more prevalent than heart disease, diabetes and cancer combined (M. P. Jensen & Turk, 2014). It is not only having an impact on the individual but also on

people close to them (Turk, 2002). For example, the spouse of people who experience persistent pain experience higher stress than that those of people free from pain (M. P. Jensen & Turk, 2014).

Persistent pain and chronic illness share many similarities (West, Usher, Foster, & Stewart, 2012). Persistent pain forces the family and partners to change roles, especially their caring roles. Family care givers are informal and unpaid (Reinhard, Given, Petlick, & Bemis, 2008). Informal care givers, including spouse, family members and friends play significant role in supporting people with cancer (Shilling, Matthews, Jenkins, & Fallowfield, 2016). The change caused them to grieve of the loss of the former roles. They expressed sadness and frustration, given that they too tried to find ways to cope with the situation. Hence health care providers needed to include family members in the plan of care and treatments of the patients (West et al., 2012).

Caring for patients who required pain management are categorised as intractable. Regardless of pharmacological or nonpharmacological pain management, the procedure caused substantial stress to the carer. Disruptions to their sleep patterns that lead to negative impacts (Reinhard et al., 2008). Knowledge of pharmacokinetics, pharmacodynamics, and drug interactions with commonly used opioids help balance the pain management process (Leppert, 2011). However, carers often feel inadequate to perform the task of administering analgesia and associated medication. In this situation, education and support from health care providers has proven beneficial (Latter et al., 2016).

Among physicians, some conflicts and confusion exist in giving information to patients. Some are not competent in prescribing analgesia (O'Brien et al., 2017). An utmost priority is to keep close clinical observations and not burden patients with undesirable adverse effects from medication. Hence educating the clinical community, patients, and family about drug–drug interactions, for example, is a necessity to

overcome exaggerated fears about legitimate and scientific use of opioids. In this matter, respect between medical professionals, patients, and family is a corner stone for successful pain management in persistent pain (O'Brien et al., 2017).

A review reported a positive experience of carers in their role despite they had received little or no training (Girgis, Lambert, Johnson, Waller, & Currow, 2013). However, caring for cancer patients can be challenging to carers, some having unmet needs greater than the patients themselves. Some said the role had an impact on their physical, psychological, economic, social, and functional relationship. The most cited instances were pain, sleep deprivation, fatigue, diminished physical strength, loss of appetite, and weight loss. Over time, some of them reported increased physical disability, increased fatigue, decreased concentration, and consequently reduced motivation. In another review, Reinhard et al. (2008) uncovered declined in health and premature death has been recorded among carers.

The relationship between the carer and the patient fluctuates over time, either improved or deteriorated. It is reported that carer experienced hostility and irritability from the patient during the caring process (Stamataki et al., 2014). Accordingly, it was revealed, up to 44% of the carers were verbally or emotionally abused, and 28% experienced physical and violence attacks (Simons, 2011).

Azzani, Roslani, and Su (2015) had reviewed cancer related hardship to patients and their family, and had revealed that even in some high-income countries, cancer patients and their family struggled to meet the high cost of cancer treatment. Imagine then how low-income households cope with escalating costs. The coping measures they resorted to included incurring debts, borrowing money, avoiding the purchase of items just to save for cancer treatments, selling properties, and some even discontinued cancer treatment. The financial burden was the consequence of the cancer itself, or a side-effect of its treatment. It caused patients to discontinue working or choose early retirement,

and long-term cancer treatments can drain them financially. Family members lose out financially because they have to become the carer to the cancer patient.

Reduced hospital stay had given the family an important role to support the patient after discharged. A review conducted by Stenberg, Ruland and Miaskowski 2010, revealed that, there were substantial evidence showing family who were caring for cancer patients were taking on a complex and huge responsibility. Their daily life was often interrupted. Hence, health care providers need to consider counselling these people as well as the patient (Stenberg, Ruland, & Miaskowski, 2010).

Especially so in advanced cancer the family as carers was found to experience reduced functional activity and declined in mental power, and experienced economic impact in dealing with the patients declining condition. Hence, professional helps is needed to reduce their psycho social, economic and physical burden associated with being a carer (Grunfeld et al., 2004). Another study found that 20% of the carer experienced financial burden. It was also confounded by loss of one third of their working time. The authors called for policy makers to reduce this gap (Longo, Deber, & Williams, 2006).

2.9 The impact of Persistent Pain on the Health Care System

Psychosocial issues such as insomnia, anxiety, depression, somatization, catastrophizing was associated with persistent pain post mastectomy. Persistent pain after mastectomy is a public health problem (Schreiber et al., 2013). It is imperative to treat persistent pain adequately. Patients with unrelieved pain perpetually bounce back to the health care system for pain relief. In this way, they consume more resources from the health care system (Phillips, 2009).

Persistent pain is believed to be due to lack of knowledge among the health care providers (Chow, Saunders, Burke, Belanger, & Chow, 2017; Lynch, 2011). Therefore, education is a priority. Importantly, the pain management be managed by inter-

disciplinary professionals. Also, the assessment of pain need to be through. In using opioids, one needed to be aware, understand, that some patients could abuse the privilege. Accordingly, compared to normal population who were on prescribed strong opioids (0.16%), the true addiction was only a small fraction of this percentage (Breivik et al., 2013). The inadequate education had caused patients unnecessary suffering. Due to lack of education, physicians were unable to make the right treatment of choice, which resulted in inadequate pain management. Probable reasons were: first, their fear of malpractice suit and second, fear of patients experiencing tolerance to opioid use and dependence. These excuses were not acceptable any longer (Furrow, 2001). Further persistent pain should be viewed as a public health rather than just medical priority (Goldberg & McGee, 2011).

Barriers to effective pain management can also derive from patients. Patients may have inadequate knowledge to manage their pain. Targeted education for pain management has been proven to alter patients' attitude towards pain management. For example, a randomised control trial has shown that, after intervention, patients reported improved knowledge and reduced willingness to tolerate pain for fear of addiction, and a reduction in addiction to analgesia was reported (Yates et al., 2004). A review by Bennett, Bagnall, and Jose-Closs also revealed that education provided significant benefit to patients in their cancer pain management (Bennett, Bagnall, & José Closs, 2009).

The monetary impact of persistent pain, directly or indirectly, on the health care system cannot be underestimated. It is evident that persistent pain costs the health care system from a loss of productivity. A medical record review found that the cost of persistent pain derived substantially from outpatient services (Park et al., 2015). There are strong association between persistent pain and payment for disability (Blyth et al., 2001). There is evidence that persistent pain constitutes economic burden directly or

indirectly on the health care system. Hence, Duenas et al. (2016) recommended that health care policy makers pay attention to persistent pain; the aim is to prevent and manage pain while preventing disability and reducing the economic burden.

In cancer survivors, pain treatments need to meet expectations. Opioids are still the main drugs prescribed. In view of the risks of overuse of opioids, balanced against the positive benefit to survivors, this creates a real challenge to the health care system and health care providers. The risk of potential abuse will always be there (Pergolizzi et al., 2016). Boscarino et al. (2010) found evidence that 36% of patients met criteria for a life-time opioid dependence, and 26% met criteria for current opioid dependence. These data are in contrast to contrast results by Breivik et al. (2013) who found a .03% to .08% risk of dependence (J. S. Lee et al., 2017).

Given the cost issue, there is only a modest difference between the cost of inadequate analgesic treatment and the cost of effective pharmacological treatment in relieving pain. It is important to integrate a psychological model of treatment. The goal of psychological treatment should be diverted away from focusing on reducing pain, but rather on improving strength, mobility, and tolerance of activity. The model demands a collaborative effort between patient, significant others, and health care providers (M. P. Jensen & Turk, 2014).

Katz et al. (2015) planned a design of a multi-disciplinary team approach – by physicians, nurses, psychologists, physiotherapists, and psychotherapists as a preventative measure to prevent long term postoperative pain. This team approach was to commence from preoperative period, continue during hospitalisation, and follow through after discharge. The criteria for the programme were: those patients who use large doses of opioids, patients with disability due to persistent pain, and negative emotions such as depression, anxiety, and pain catastrophizing. These measures were

aimed at reducing hospital stays, reducing readmission, and reducing overall cost to the health care system.

Structured, comprehensive, and multidisciplinary approaches improve skills and help patients regain autonomy to deal with persistent pain throughout their life. This will relieve undue emotional stress, improve coping capacity, reduce pain-related disability, and consequently improve financial status (Roditi & Robinson, 2011). Integrated treatments such as massage, acupuncture, and mind and body techniques like meditation and hypnosis are evidence-based in relieving cancer pain. The efficacy of such treatments cannot be denied. Further, these techniques are inexpensive, safe, and have no side-effects. In view of the accumulating evidence, these techniques have proven to reduce cost. Therefore, adopting integrated treatment into conventional treatment is not a bad option after all (Cassileth & Keefe, 2010).

In summary, the emergence and existence of cancer itself is a public health problem (Sankaranarayanan et al., 2014). The most utilised resource is the outpatients' visits. Among others, persistent pain utilised the outpatients' resources of the health care system. Since cost appears to be the highest concern, research should aim at lowering costs while retaining the effective outcome of relieving persistent pain in patients (Park et al., 2015).

Further, obstacles to effective pain relief include a lack of education by health professionals, limited availability of analgesia provided by the government, fear of litigation suits by health professionals, and the inflated cost of pain management. All of these should not be the barrier for effective pain management. Failure to provide pain relief may be perceived as a violation of protecting humans from suffering, is inhumane, and degrading (Lohman, Schleifer, & Amon, 2010).

2.10 Pain theory and Theory of Unpleasant Symptom

Pain is very subjective; and complex. Experiencing pain need not be from nociceptive input. In fact, the aetiology remained unknown (T. S. Jensen et al., 2011). Persistent pain is taken as iatrogenic in nature (Kehlet et al., 2006). Patients also complain of pain when there is no actual physiological evidence; for instance in phantom breast syndrome, participants experienced the weight the size and shape of the breast (Markopoulos, Spyropoulou, Zervas, Christodoulou, & Papageorgiou, 2010), compounded the complexity by noting the roles of genetics, culture, and previous experiences (Macrae, 2008). While the research community is still researching the aetiology of pain, two of the pain theories – the gate control theory and neuromatrix pain – are selected to shed light on understanding the phenomena underpinning the existence of pain. These theories, however, may not explain the total phenomenon of pain because it is unknown and undefined, and its aetiology is unclear.

2.10.1 Gate control theory

The aetiology of persistent pain after breast surgery is still unclear (Schreiber et al., 2013), and unknown (Vilholm, Cold, Rasmussen, & Sindrup, 2008). However, the emergence of gate control theory and the neurometrix theory encapsulate the notion of pain experience by the breast cancer survivors in this study. (R. Melzack & Wall, 1965) stated in the gate control theory of pain, put forward the idea that physical pain is not a direct result of activation of pain receptor neurons, but rather its perception is modulated by interaction between different neurons. This theory explains how a pain-modulating system – a neural gate in the spinal cord – can open and close and modulate the perception of pain. Both large and small fibres play a role in the transmission of pain. Three systems located in the spinal cord act to influence perception of pain: the substantia gelatinosa in the dorsal horn, the dorsal column fibres, and the central transmission cells. Noxious impulses are influenced by the gating system, so that

stimulation of the large diameter fibres (normal receptors) inhibits the transmission of pain and thus closes the gate; on the other hand, stimulation of the small diameter fibres opens the gate. When the gate is closed, signals from the small diameter fibres (pain receptors) do not excite the dorsal horn transmission neurons. When the gate is open, pain signals excite the dorsal horn transmission cells. The factors that influence the opening and closing of the gate are the amount of activity in the pain fibres, the amount and activity in other peripheral fibres, and the messages that descend from the brain (Dickenson, 2002). The theory is validated by transcutaneous electrical nerve stimulation (TENS). TENS is one of the procedures which are based on the gate control theory concept. It is used in treatment of acute and chronic pain today (D. Melzack & Katz, 2004, p. 17).

The gate control theory has been a major concept and has had a powerful impact on research, theory, and treatment in pain clinics. The theory has been tested on post-hepatic neuralgia using TENS, where the participants had failed treatment with other modalities. Although mixed results had been obtained by using this method, the actual mechanism was still unclear (Nathan & Wall, 1974). Meanwhile, another study used acupuncture and TENS to test the gate control theory (E. J. Fox & Melzack, 1976). According to this theory, there is a grey region situated in the brain-stem which is able to inhibit pain. The suggested mechanism was that acupuncture inflicted pain on the cutaneous nerves which triggered the small fibres and communicated with the brain, which translated it as pain. However, cells in the grey region include projections to the brain and spinal cord. In the event of pain, these small fibres would also send messages to the inhibitory fibres in the brain stem to block the pain to other areas.

2.10.2 Neurometrix pain theory

Why do patients experience pain without any pathophysiological basis? After convincing people with the gate control theory, R. Melzack (1999), argued that injury,

inflammation or other tissue pathology does not necessarily produce pain. He came up with another theory: the neuromatrix theory. According to neuromatrix theory, an experience of pain is determined by a complex synaptic architecture, influenced by genetic and sensory factors. Pain may occur as a result of stress – psychological or physical. The end products of the process could produce lesions in the muscles, bones, and nerve tissues, and hence can cause chronic pain (R. Melzack, 1999). Dismissing the concept of pain caused by noxious stimuli, he accepted that pain was influenced by psychological variables. This theory explains the phantom pain effect. This phenomenon is based on the assumption that the brain can generate the perception of pain without any external stimuli. It is based on memory; the network in the brain continues to send messages even in the absence of a corresponding body part. It assumes that the location, intensity, and degree of pain rely on the cognitive-affective factors (Weich & Tracey, 2009).

2.10.3 Theory of Unpleasant Symptoms

The frame work of this study is influenced by Theory of Unpleasant Symptoms (Lenz et al., 1997). It is chosen because, based on the nature of this research, the theory and practice would complement each other. In this study the researcher intends to rationalise the results obtained in concordance to inductive-abductive reasoning enquiries developed by a philosopher, Pierce, which consequently was explored, expended, popularised and criticised (Haig, 2008; Ketokivi & Mantere, 2010; Mirza, Akhtar-Danesh, Noesgaard, Martin, & Staples, 2014; Raholm, 2010; Woo, O'Boyle, & Spector, 2017).

According to Pierce inductive is evident, and abductive can be taken as inferences in the best explanation, conclusion occurs as a surprise, Pierce further argued that this process the researchers could not have a complete control over the study (Pierce, 1934-1935, pp. 99-113). Woo et al. explained in details the differences in

deductive and inductive reasoning (Woo et al., 2017), while Haig described explicitly the abductive reasoning in clinical setting. Currently, no direct comparisons of studies are possible to project this study, but two studies found to be of similar notion (Dickinson, 1998; Dong, Lovallo, & Mounarath, 2015).

Dong, Lovallo and Mounarath have utilised abductive reasoning and deductive reasoning to prove hypothesis of a project recruiting 105 participants, in which deductive reasoning group showed 28 of 105 of participants accepted the project, whilst in an abductive reasoning group it showed 54 of 105 participants accepted the project (Dong et al., 2015). In a clinical scenario, for diagnostic treatment, as an example, Dickinson gave emphasis on adductive reasoning in dealing with a man with terminal liver cancer, he made the dialogue constructive by using abductive reasoning in the presence of existing data (Dickinson, 1998). The flow of the study is expected to flow as tabulated in figure 1a:

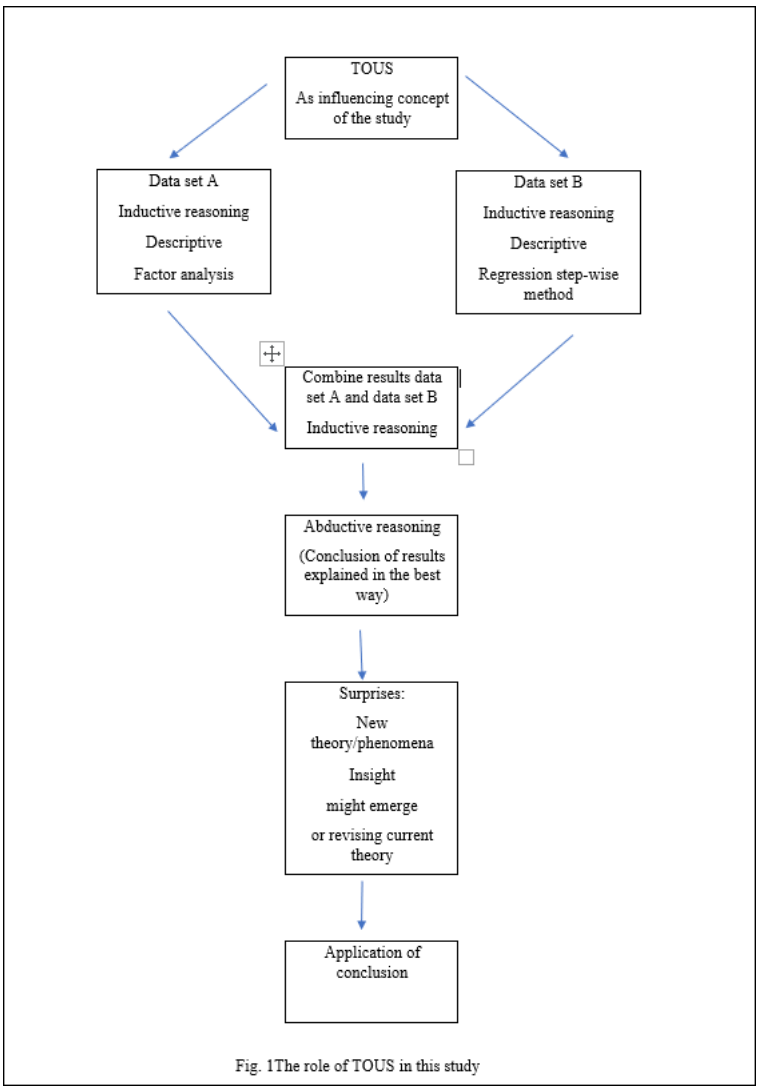

Fig. 1The role of TOUS in this study

Figure 1a Flow of the study utilised TOUS as an influencing/focus Theory

Pain, as the main focus of the thesis, could fit into the experiencing factor. Pain could occur singly or as clusters, such as with insomnia and fatigue. From a psychological perspective, there are two sides the woman with breast cancer can potentially lean, either positive or negative psychology. Distress or resilience are interchangeable, due to the nature of pain, which is unstable.

The theory describes an influencing factor. The wide range of symptoms from the five problem domains listed from the Distress Thermometer certainly capture this component. The influencing factor described by TOUS encompasses physiological, psychological, and situational factors. Fatigue, tingling in hands and feet, and memory loss come under the umbrella of physiological factors. Items such as hopelessness,

sadness, guilt, loss of meaning, or purpose in life would qualify for the psychological component. Items such as caring responsibility, work and education, and appearance could occupy the situational component. The performance factor as mentioned above could be the resilience, and also interchangeable with distress or other constructs like fatigue. Taken together this theory is seen to sit well with the current study.

Not forgetting the other additional factors might influence the process. According to Leininger (2001, pp. 5-68) his culture-orientated theory argues that humans are also influenced by a holistic biopsychosocial realm that differs depending on cultural perspectives. However, he believed that these entities are embedded and can deal with any relevant factors that may arise. Theory evolves over time, and history brings valuable knowledge for future improvement. Taken together, there are three main classifications of theories that emerged: grand theory, also known as meta theory; middle range theory; and practice theory or micro theory. The classification is based on abstract levels.

Grand theory is the most abstract level. Middle range theories are less abstract, and limited in scope, based on reflection and the phenomena covered by broad nursing disciplines; and practice theory or micro theory is the least abstract. It is more reflective and developed from clinical experience. Theory of unpleasant symptoms (TOUS) is one of the middle range theories. TOUS was first developed in 1995 (Lenz, Suppe, Gift, Pugh, & Milligan, 1995). The original version was a unidimensional path between antecedent factors (physiological, psychological, and situational factors) and further improved in 1997 (Lenz et al., 1997). The improved version described the multidimensional as in shown in Figure. 1b (page 35). The purpose of its development is to improve understanding on symptoms experience. It is intended for nurses and researchers [(Lenz, Gift, Pugh, & Milligan, 2013 pp. 165-195)], and this was the first

theory that allowed multiple symptoms together. The focus was on intensity, symptoms, quality, distress and duration.

TOUS is a parsimonious theory, it describes distinctly the multiple symptoms and visual process of its interactions and influencing factors and performance factors. Influencing factors are also called as antecedents. The antecedents are noted to be ill defined. The limitations include; it does not consider more than one performance factor, the exacerbation of symptoms and intervention component despite TOUS does consider possibility of recurrence of symptoms (Brant, Beck, & Miaskowski, 2010). Therefore, the theory needed to be complemented by another specific theory such as the Conceptual Model of Chemotherapy-Related Changes in Cognitive Function (Myers, 2009); the Model in Cognitive-Behavioural Intervention in Cancer Pain Management (K. L. Kwekkeboom, 1999), and Symptoms Experience Model (Armstrong, 2003). In this study, the variables selected from DT, RS-14, and BPI are used.

The TOUS is viewed as a sound theory (Lee, Vincent, & Finnegan, 2017). It has been evaluated in term of significance, internal consistency, testability, parsimony, and empirical adequacy. However, there is still room for improvement in its clarity of terminology. Examples here are concepts such as interchange of symptoms, experience of symptoms, situational factors, and situational conditions, which are often interchangeable. TOUS explicitly describes the process of living but not the process of dying. Overall, TOUS places emphasis on multiple symptoms experienced with influencing factors such as physiological, psychological, and situational factors, all of which are reciprocal with the performance factor. Indeed, it has been shown that TOUS can be employed on patients with breast cancer (Thompson, 2007).

Regarding the analytical models, TOUS could handle multiple symptoms, varied analytical models using varied instruments and has been tested on many types of population across the world. Examples of analysis ranging from chi-square test, *t*-test,

correlation, and regression to complex tests such as exploratory factor analysis (EFA), confirmatory factor analysis (CFA), structural equation model (SEM), mixed effect growth model, and cluster analysis. Inconsistencies in the analyses do affect the results of studies underpinning the Theory of the Unpleasant Symptoms (E. Chen et al., 2011; S. Lee et al., 2017).

Meta-analysis conducted by Fan, Filipczak and Chow (Fan, Filipczak, & Chow, 2007) supported the trend found by Chen and Lin and Lee et al. (M. L. Chen & Lin, 2007; S. Lee et al., 2017) that the studies comprised different combinations of symptom clusters, different tools, various durations of studies, as well as employing different analytical models. In a systematic review of 223 articles, Fan et al. isolated seven articles, of which only six described similar tools and analytical models. In a separate review, it was concluded that the tools, not the methods of the analysis, determined the findings (E. Chen et al., 2011).

Pain is known to co-exist with insomnia and fatigue in cancer survivors (Barsevick, Dudley, & Beck, 2006; Beck, Dudley, & Barsevick, 2005). Beck et al. (2005) conducted a study testing the Mediation model on cancer patients who had pain (n=84), 53% of which were female with a mean age of 54. Total sample size (N) was 214. Brief Pain Inventory (short form), the Pittsburgh Sleep Quality Index, and fatigue subscale of the Profile of Mood States questionnaire were used, to gauge the relationship between pain, fatigue, and insomnia. A multistage linear regression model was employed. It showed that pain had a direct effect on fatigue, but an indirect effect on insomnia. When insomnia was used as a mediator, pain explained some of the effect of fatigue. However, pain also had a direct effect on fatigue.

When two symptoms or more occur at the same time it is also known as a symptom cluster. (Dodd, Miaskowski, & Paul, 2001) defined as three or more symptoms, which may or may not be interrelated as asserted by Fan et al. and Fox and

Lyon (Fan et al., 2007; S. W. Fox & Lyon, 2007). Symptom clusters vary in their definition. Knowing the strength and the weaknesses of TOUS, this study employs TOUS, with attention to any new features that may emerge.

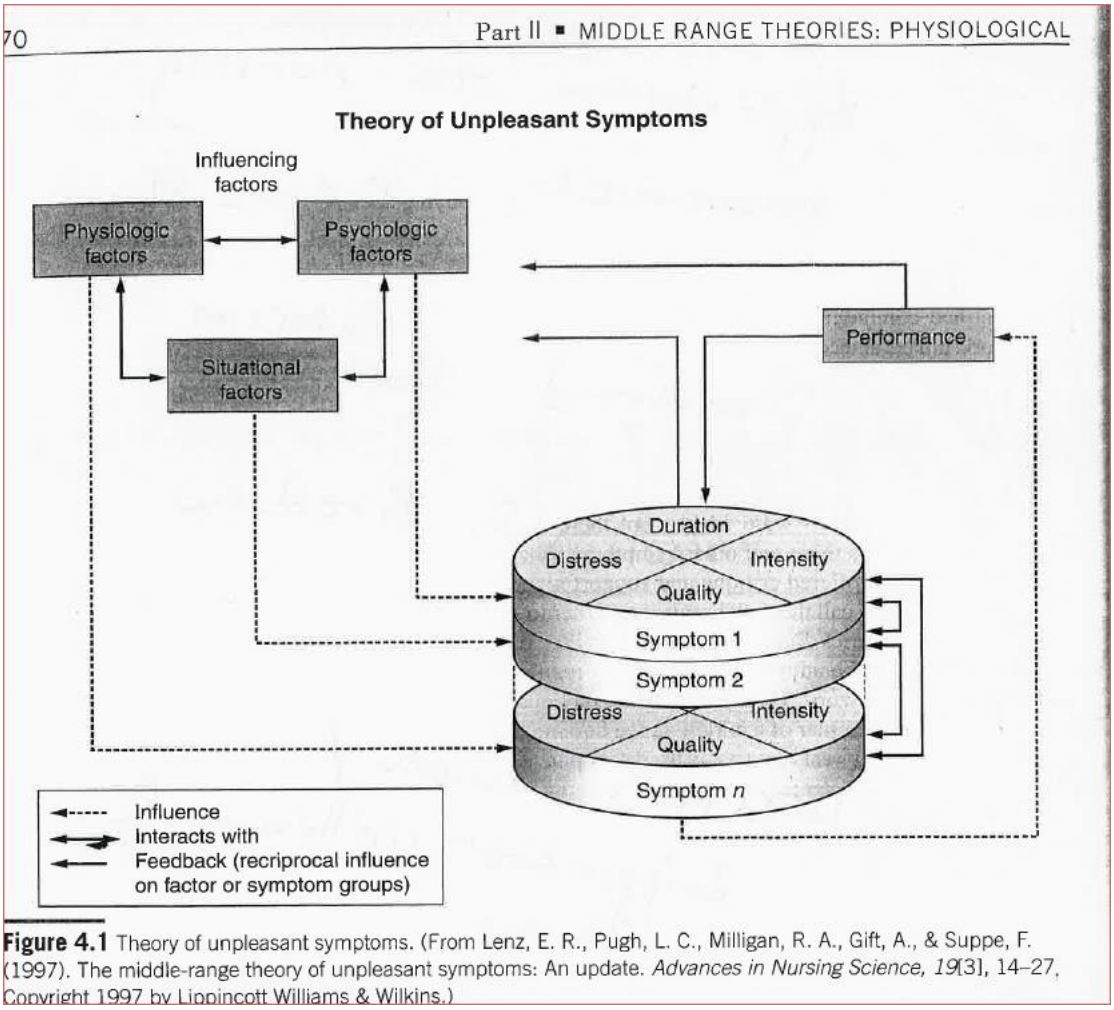

Figure 4.1 Theory of unpleasant symptoms. (From Lenz, E. R., Pugh, L. C., Milligan, R. A., Gift, A., & Suppe, F. (1997). The middle-range theory of unpleasant symptoms: An update. *Advances in Nursing Science, 19*[3], 14–27. Copyright 1997 by Lippincott Williams & Wilkins.)

Figure 1b: Theory of Unpleasant Symptom

2.11 Pain management

Pain is experienced by cancer survivors at any junction of their cancer journey. The percentage experience could reach up to 90% (Vardy & Agar, 2014). It is known that most specialist and oncologist are aware of the importance of adequate pain management, yet more than 50% of cancer patients did not receive adequate pain relief, and approximately 25% of them died while in pain (Nersesyan & Slavin, 2007). Cancer patients could experience pain from more than one source. Because cancer patients may have pain from disease progression or treatment side effects (Jacox et al., 1994). Thus, through assessment is imperative prior to treatment (You, Habiba, Chang, Rodriguez-bigas, & Skibber, 2011).

The purpose of pain management should be targeted at rehabilitation rather than just to relieve the pain In managing pain, health care providers should consider that people from different cultural backgrounds perceive pain differently. For example, in Chinese culture, there are issues of stoicism which emphasise that patients should not show emotion from pain. To followers of Buddhism, pain is taken as part of living, which they need to endure (Breivik et al., 2013).

Health care providers are expected to handle these situations and not assume that patients do not experience pain (Tung & Li, 2015). Opioids are accepted as effective drugs to treat pain (Collett, 2001). Physicians should follow WHO analgesic ladder as a guideline in treating cancer related pain with appropriate analgesia (Urban et al., 2010). Poorly managed persistent pain control may results in post discharge visits at the emergency departments as well as repeat hospitalization (Lynch, 2011).

In the long term, opioids treatments have been documented to adequately relief pain in cancer as much as 70 to 90%. It is traditionally believed that opioids cause dependence, and review of tolerance levels is needed. From extensive experience and observations , this phenomenon did not manifest either as a physical dependence, analgesic tolerance, or other significant clinical problem in cancer treatment (Portenoy, 1996). However, over time, pain survivors change their opioid consumption. In a large controlled randomised study of opioid use (*N*=68,463) conducted by Lee et al., naïve patients and chronic opioid users were studied after curative surgery for various type of cancer, including breast cancer. The study found that 10% (*n* = 4159) of the opioid naïve patients developed persistent opioid dependence; these patients were found to continuously apply for prescriptions for hydrocodone, 30mg daily after one year postoperative. This amount of hydrocodone was as much as the chronic opioid-dependent patients. Hence, the authors recommended that only physicians who were used to prescribing large doses of opioids treat opioid-dependent patients. Further, the

treatment and management of pain should be delivered by multidisciplinary health care providers, and opioids should be prescribed only after weighing up the benefits and the risks (J. S. Lee et al., 2017).

2.11.1 Pain assessment

Pain has a prognostic value that should be assessed, treated, and considered before making treatment decisions (You et al., 2011). The assessment of pain and its associated factors are important aspects of effective pain management. Reviews of Numerical Rating Scale (NRS), Verbal Rating Scale (VRS), and Visual Analogue Scale (VAS) have all been shown to be valid and reliable for clinical practice. However, for practicality and simplicity NRS and VRS are the two instruments most commonly used.

On the other hand, VAS has shown difficulties in clinical practice as it differs in outcome when administered in vertical or horizontal view. It was found that the concordance in repeat measures accounted for 20%. Hence VAS has the highest failure rate among the three. However, the scales have their own strengths and weaknesses. For example, NRS tends to be used for research purposes because of its good sensitivity (Williamson & Hoggart, 2005). Taken together, screening tools cannot replace the skills of clinical judgment in pain assessment by a health professional (Sheridan et al., 2012).

Similarly, self-administrated questionnaires are not without their drawbacks. This method is claimed to be inferior when used to explore sensitive responses such as job satisfaction, organisational policies, and leaders' behaviour. As such, drawing conclusions from the results of self-administered questionnaires could be biased and the interpretation could be inflated or underestimated. By the same token, these researchers are reluctant to dismiss the self-report method either. Hence, they advocate that when obtaining sensitive responses such as the above it is better to use other questionnaire methods, for example longitudinal design or physiological design. Perhaps checking blood for catecholamine to exclude working long hours because long working hours has

physiological effects (Spector, 1994). A similar notion was raised, the athletes would not disclose their consumption of illicit drugs. Also reports on sexual behaviour and abortion would be edited due to embarrassment (Tourangeau & Yan, 2007).

Thorough assessment is crucial prior to pain management. In optimising pain management, the ultimate goals are to identify the contributory factors, avoid them, or treat them when possible (Poleshuck et al., 2006; Siddall & Cousins, 2004). To make a successful assessment, an assessor needs instruments that can accurately determine the phenomenon –for instance, breakthrough pain or pain resulted from inadequate analgesia. In addition, the assessment should include the location of the pain, its intensity, quality, and what activities or factors bring about the pain.

Psychological application is needed in the assessment of pain in specific groups, such as nonverbal patients, children, the elderly, and the cognitively impaired. In order to achieve the best responses, the choice of instruments used is very important to ensure optimal and economical pain management. Additionally, the use of validated instruments is strongly recommended, and accurate and up to date documentation is imperative in these cases. (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011) explicitly advocate a hierarchy of pain assessment techniques for people who are unable to self-report pain.

Their technique should be attempted when a modified self-report technique is impossible. For example, responses can be obtained by asking for yes or no type of responses to such people. The use of behavioural instruments in neonates or in children or adults who are paralysed and intubated and very ill are described very explicitly and comprehensively by Herr and colleagues. The use of resources that ensure psychological alertness and cooperation is really crucial in pain assessment of this group of patients. Gestures, history, behaviour, and reports from carers and family members are useful with such conditions. The assessor needs to gather all information

about the condition, including vital signs, prior to recording the pain symptoms. Analgesia should be administered as if in a trial: the dosage is adjusted in a titrating manner. Documentation and assessment are a continuum in this group of patients.

Neuropathic and visceral pain present in different ways. Women are more susceptible to visceral pain in their reproductive organs. In some instances, it could denote tumour growth (Sikandar & Dickenson, 2012).

Unlike neuropathic pain, visceral pain can originate from organs such as the bladder, heart, and gall bladder; these viscera are solid in nature, and hence do not produce pain when cut, but may produce pain on stretching, such as with the bladder. Usually visceral pain presents as a diffuse type, poorly defined and may be referred in nature. It is often accompanied by autonomic phenomena such as nausea, vomiting, sweating, pallor, and tension in the lower back in response to renal colic (Cervero & Laird, 1999; Sikandar & Dickenson, 2012).

McMahon, Dmitrieva, and Koltzenburg (1995) described visceral pain is normally modest in nature, it occurs in waves such as in labour pain, and can be distant in nature such as appendicitis pain or unpleasant such as in cystitis pain. However, ischemic pain originating from the heart can be differentiated quite well. Contrary to visceral pain, somatic pain is localised in nature. Pain is distinguished and aggravated by movement. In cancer it affects the bones and connective tissues as in osteoporosis, pericarditis, and septic femoral heads (Levy et al., 2008).

The assessment is a continuum until such time that the patient feels comfortable. Assessment of pain also covers the quality of pain, such as being sharp, dull, burning, or aching in nature. The pain in cancer is normally divided into three categories: neuropathic, visceral, and somatic pain. For example, neuropathic pain, also known as nociceptive pain, arises from damage to the central or peripheral nervous system. The pain is characterised by a stabbing, shooting, dull, or burning hyperesthesia in nature

(Backonja & Glanzman, 2003; Kaasa et al., 2010; Seto, Sakamoto, Furuta, & Kikuta, 2011). Using a validated tool for pain assessment, such as BPI, is a crucial prerequisite in order to successfully manage pain. Adequate and systematic assessment of cancer pain is a prerequisite for improving cancer pain management (Breivik et al., 2008). Studies have found that health care providers generally underestimate cancer pain. For pain above moderate intensity, discrepancies often occur between pain as assessed by the patient and by the health care provider (Yun et al., 2003).

A review by Deandrea, Montanari, Moja, and Apolone found similar findings. When there was impaired communication between patients and physicians, under-treatment of pain occurred. Additionally, patients with early stage cancer were often judged as not in pain because they did not look ill. On the other hand, advanced cancer patients were attended by a pain team on a regular basis. The authors concluded that under-treated pain in cancer remains high, reaching nearly half the patients in their review. A marked demarcation was apparent according to geographical area and wealth of a country: European countries and Asian countries differed in terms of wealth, and the wealthier the country the better the pain management available. This data was meant to inform policy makers that they should pay attention to reducing the prevalence of pain in patients with cancer (Deandrea, Montanari, Moja, & Apolone, 2008).

Assessment of pain should be treated as the fifth vital signs besides temperature, pulse respiration, blood pressure (Bultz, 2016; Williamson & Hoggart, 2005). The assessor needs to report the clinically significant difference in pain intensity for the titration of the analgesia. However, just relying solely on the vital signs could be misleading. The assessor's role is central, and they need to use psychology, especially on nonverbal patients, dementia patients, or critically ill patients. The difficulty is that pain can temporarily elevate in intensity when behaviour changes. Other factors that can affect pain assessment are physiological factors and the medication used. All these

patients are considered vulnerable to misdiagnosis. The assessment needs to be accurate or the patients may have to endure pain due to suboptimal pain management (Herr et al., 2011).

2.11.2 Pharmacological pain management of cancer pain

The World Health Organisation (WHO) had devised a three steps ladder for pharmacological pain management in patients with cancer (Nersesyan & Slavin, 2007). Currently, WHO analgesic ladder is the main stay of management of cancer pain (Mercadante & Fulfaro, 2005; Vardy & Agar, 2014). Although three steps ladder has achieved up to 90% satisfactory level, being efficacious and feasible, however it has been criticised for the lack of supporting data. Due to an uncertainty in the percentage of people who fail to benefit from it, and the directions about how adjuvants are used remain unclear, this leads to different practices about how the WHO three-step ladder is used in each country depending on the availability of the drugs (Mercadante & Fulfaro, 2005). For example Vagas-Schaffer (2010) had added another step, making it four steps ladder. The forth steps is for the adjuvants medications such as steroids, antidepressant and anxiolytic. WHO three steps ladder is approached based on the severity of pain. These authors advocated proper pain assessment using a validated tool is pivotal for effective management of pain. For chronic pain they advocated the physicians to prescribe regular doses of analgesia, and not when required. The pain management are summarised as follows, mild pain, scores <3 out of 10, to use first step ladder, analgesic of choice is paracetamol, another name is acetaminophen, and NSAIDS, moderate pain, scores 3-6 out of 10, employ the second step of the ladder, the drugs of choice are weak opioids, with or without, paracetamol and NSAIDS, and severe pain, scores 6 and above out of 10, to use the third step of the ladder, which includes strong opioids with or without paracetamol, and NSAIDS (Ripamonti, Bandieri, Roila, & Group, 2011)

Acetaminophen (paracetamol) is always initiated first. Despite of its unknown mechanism; it still yields the effect of antipyretic and analgesic effects. In cancer pain paracetamol works better when combined with opioids such as codeine and hydrocodone. It can be on the hepatotoxic when taken in excess; >.4000mg a day. Aspirin on the other hand is an antipyretic, analgesic and anti-inflammatory drug. It has side effects of tinnitus and vertigo, and gastro intestinal bleeding. Not allowed to be taken more than 325 to 650 mg and up to maximum of 1000 mg every 4 to 6 hours, which is already a high dose to obtain maximum pain control. In addition, a COX-2 inhibitor drug, for example celecoxib (celebrex), is also used to treat pain in cancer. It also has side-effects. The usual dose is 200 mg BD and no more than 400 mg per day. It is known to cause gastro-intestinal bleeding and heart attacks. Therefore, the COX-2 inhibitors are drugs to be taken cautiously. Tramadol is another commonly used drug for cancer pain. It is effective for mild to moderate pain. Its side-effects can be somnolence and fatigue. The normal dose for tramadol is 50 to 100 mg per day, and a maximum of 400 mg per day. It can cause liver toxicity when taken in excess (Nersesyan & Slavin, 2007). When nonopioid drugs prove insufficient, WHO advocates a second step of treatment, such as weak opioids like codeine; failing that, the third step is stronger opioids. Opioids work well in combination with non-opioid drugs such as NSAIDS, especially in treatment of neuropathic pain (Nersesyan & Slavin, 2007).

There is no ceiling dose for morphine. However, administration of morphine to renally and hepatically impaired patients requires observation and monitoring because morphine can cause renal toxicity. Hence monitoring with a renal function test is required, and the morphine dose can be adjusted at 6 to 8-hour intervals. Side-effects of opioids are many, and not limited to nausea, vomiting, constipation, respiratory depression, sedation, urine retention, and myoclonic jerks (Hall & Sykes, 2004).

Adjuvant drugs are also used in combination of the first line and opioid. Example of adjuvant drugs are antidepressant, antiepileptic, antispasmodic and steroid (Hall & Sykes, 2004). Anticonvulsive or anti-epileptic includes gabapentin and pregabalin, and anti-depressants include tricyclic, example amitriptyline and imipramine. Antidepressant takes two weeks to be effective as analgesic, therefore patients need to be informed regarding this in order to ensure compliance (Moulin et al., 2007; Segman, Shapira, Gorfine, & Lerer, 1995). As for antiepileptic adjuvants with gabapentin and pregabalin it was found that the effect of pain relief occurred between 4 to 8 days (Vardy & Agar, 2014).

The mainstay of persistent pain treatment is morphine; however, its onset is relatively slow. The emergence of rapid formula such as Fentanyl (synthetic opioid) had rapid onset and half-life of 1.6 to 6 hours. It is efficient for break through cancer pain. Fentanyl could be administered via parenteral routes, spinal, transdermal, transmucosal, buccal, and intranasal route. Fentanyl reliefs pain within five minutes by spray to sublingual; one dose could sustain relief up to one hour. It has similar side effects like other opioids, but minimal to moderate and tolerable, and it is effective (Taylor, 2013).

Additionally, topical application; 5% lidocaine patches were proven effective for short term pain relief (Rodriguez, Reise, & Haviland, 2016). It had shown to be effective on scar pain; post- mastectomy and post-thoracotomy scar pain. The result showed there were clinically and statistically significant improvement, mean before and after treatment, 7.1 (SD 1.89) and 4.25 (SD 1.83) respectively. A total of 65% of participants reported they were satisfied with the treatment.

In treating cancer pain the physicians need to be aware of drug-drug interaction. For example in the presence of antidepressant and tamoxifen, some of the antidepressants would interact and reduce the efficacy of the latter (Swarm et al., 2013).

It is also recommended that the patients should be treated either in combination of anti-depressant or anti-convulsive and be closely monitored for side effects (Ripamonti et al., 2011) and also should be titrated from lower dose until efficacy is achieved (Mitra & Jones, 2012).

2.11.3 Complementary and Alternative Medicine

Although complementary therapies are said to be prevalent, reliable prevalence rates are not available (Ernst & Cassileth, 1998). Complementary or unconventional therapies include any treatments that are used apart from pharmacological or conventional therapies. Some methods have been shown to be efficacious while others are not. Despite these inconclusive assessments, patients often claim such treatments improve outcomes in dealing with cancer-related side effects (Munshi, Ni, & Tiwana, 2008; Wong-Kim & Merighi, 2007).

Many breast cancer patients and survivors turn to CAM for pain and psychological wellbeing (Astin, Marie, Pelletier, Hansen, & Haskell, 1998; Hann, Baker, Denniston, & Entrekin, 2005; Henneghan & Harrison, 2015; Montazeri, Sajadian, Ebrahimi, Haghighat, & Harirchi, 2007; Xue, Zhang, Lin, Da Costa, & Story, 2007). Notwithstanding, the participants still believe in conventional medicine. However, CAM provides an active coping mechanism, and dispels passivity and helpless attitudes in dealing with cancer (Sollner et al., 2000). While some people used CAM for fear of recurrence of cancer (Simard et al., 2013), a significant number of cancer patients use CAM to cope with symptoms and manage side-effects from cancer-related treatments (Ku & Koo, 2012), they believe it reduces stress, strengthens inner feelings, and also cures (Shaharudin, Sulaiman, Emran, Shahril, & Hussain, 2011).

CAM is not based on scientific evidence. Therefore, in 1998 the National Cancer Institute established the Office of Cancer of Complementary and Alternative Medicine (OCCAM) to continuously support the scientific study of the role of CAM in

cancer diagnosis, prevention, treatment, side-effect management, and survivorship (W. Smith, 2007).

Regardless of evidence status, cancer patients in countries such as Europe, America, Australia, and Asia use CAM. CAM had grown in popularity, usage, and the approaches are nearly identical from country to country. Going forward, CAM should be acknowledged by physicians, and its benefits and potential harms should be analysed in cancer patients (Ernst & Cassileth, 1998).

2.12 Summary

In 2016 National Cancer Registry Malaysia reported that breast cancer is the commonest cancer in women in Malaysia, which made up of 32.1% (Azizah et al., 2016). Although studies on women with breast cancer in Malaysia are on the rise, it is not known the predictors of persistent pain on these women neither its prevalence. Literature searchers have identified mastectomy shows the highest incidence of persistent pain (Correll, 2017) and occurs in women after breast surgery from 25% to 60% (Gartner et al., 2009; Mejdahl, Andersen, Gartner, Kroman, & Kehlet, 2013; H. S. Smith & Wu, 2012). It can persist normally to five years (R. J. Bell et al., 2014) but can be experienced up to 10 years (Pinto & Azambuja, 2011). Further, persistent pain is also associated with comorbidity and mortality (Sibille et al., 2016). Accordingly, pain can be modulated and intervened (Bennett et al., 2009; Yates et al., 2004).

It is the intension of this study to survey persistent pain in these women in relation to its prevalence and predictors. Data obtained is anticipated to provide towards prevention strategies, plans for treatments and consequently aimed at improves their life satisfaction.

There are mixed results from various studies in regard to predictors of persistent pain, however, younger age is found to be the main predictor (Belfer et al., 2013; Johannsen et al., 2015; Miaskowski et al., 2012; Wang et al., 2016), other predictors

found by the above studies includes axillary lymph node dissection, radiotherapy, and preoperative pain (Wang et al., 2016). Psychosocial factors namely depression, anxiety, insomnia was associated with persistent pain after breast cancer surgery. Conversely treatment factors namely type of surgery, chemotherapy, radiotherapy, tumour size and stage of cancer were not associated with persistent pain after breast cancer surgery (Belfer et al., 2013).

Persistent pain not only causes physiological and biological disruption, it causes stress, and also affect physical and mental performances (Blyth et al., 2001; Chapman & Gavrin, 1999; Poleshuck et al., 2006) and the least to mention the disease is costly to live with (Blumen et al., 2016; Blyth et al., 2001; Capri & Russo, 2017; McNamee & Mendolia, 2014). Persistent pain also impacts other people around the survivor, for example the spouse and family (M. P. Jensen & Turk, 2014). They undergo little or no training, and due to the lack of knowledge in playing a supporting role, they experience some impact on their wellbeing, more so in term of pain, insomnia, fatigue and diminished physical strength (Girgis et al., 2013). It was found that they experienced stress, sometimes experienced verbal abuse, and physical abuse from the survivors (Simons, 2011; Stamataki et al., 2014), and further confounded by loss of their working time, in which consequently results in loss of income, incurring depts, subjected to early retirement, and to the extent of discontinued work (Azzani et al., 2015).

Additionally, persistent pain after mastectomy is a public health problem (Schreiber et al., 2013). Despite there is a lack of scientific evidences cancer patients still chose CAM to ease their pain and sustain psychological wellbeing (Ernst & Cassileth, 1998; Montazeri et al., 2007; Sollner et al., 2000). Opioid is the main stay of the treatment of pain, however, the lack of education from patients and health care providers results in inadequate pain management (Furrow, 2001). Therefore, education is a priority (Chow et al., 2017; Lynch, 2011). For effective pain management, it is

advocated to approach as a multi-disciplines, proper treatment of patients and aims are always to reduce hospital stays, readmissions, and overall cost to health care system (Katz et al., 2015). One has to remember that failure to provide adequate pain relief may be perceived as a violation of protecting humans from suffering, is inhuman and degrading (Lohman et al., 2010).

The International Association for the Study of Pain (IAPS) defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey, 2000). Pain is an indicator of injury or disease, and performs many valuable functions (R. Melzack, 2001). However, it starts to lose this important role when it turns persistent (Chang et al., 2009; Sturgeon & Zautra, 2010). This study has researched persistent pain after surgery in women with breast cancer. The study has accepted the definition that persistent pain is an unpleasant sensation related to breast surgery which lasts beyond 3 months postoperatively. In many countries, persistent pain after surgery in breast cancer women has been acknowledged and widely researched.

Based on single studies, meta-analysis, and systematic reviews, persistent pain in women with breast cancer is indeed a complex symptom (Wiech, Ploner, & Tracey, 2008), which is ill understood Macrae (2008), and unclear of its aetiology (T. S. Jensen et al., 2011). Pain can co-occur with other symptoms such as fatigue, insomnia, and can cause multitude of sequelae (Barsevick et al., 2006). Perhaps by appreciating the concepts behind gate control theory and neuromatrix theory earlier in the reviews, health care providers, breast cancer survivors, and their significant others might more easily understand the complexity of pain and its sequelae. In view of complexity of pain and the symptoms that are occurring at the same time, TOUS is suitable to be utilised as a theory. TOUS was developed in 1995, and consequently was revised in 1997 by Lenz et. al (Lenz et al., 1997; Lenz et al., 1995). According to reviews TOUS is a sound

theory, and empirically confirmed its internal consistency, testability, and confirmed parsimony adequacy (S. Lee et al., 2017). Together it has been tested with study on breast cancer (Thompson, 2007). Variables from three investigative tools, BPI (C. S. Cleeland & Ryan, 1991), modified Distress Thermometer by NCCN which was approved in 2013 (personal communication 2013), and Resilience Scale RS-14 (Wagnild & Young, 1993) then these tools will be integrated into TOUS.

Unlike many studies this study is utilising TOUS not as a guidance, rather it is there to play as a focus theory or influencing theory, because the researcher intends to analyse the study using inductive and abductive enquiry reasoning which was developed by Pierce, inductive means evident, and abductive means conclusion or inference occurs as a surprise, whereby the researcher has no complete control (Pierce, 1934-1935, pp. 99-113). Pierce's inductive and abductive enquiry reasoning has been critiqued, further developed and promoted by other researchers (Haig, 2008; Raholm, 2010; Woo et al., 2017). Currently, no direct comparisons are available for this intended nature of study, however two studies are available to provide similar concepts (Dickinson, 1998; Dong et al., 2015).

Notably, the three integrative tools mentioned above are established tools, which have been widely employed in studies all over the globe. This study seeks to reassess these tools to ensure that they measure what they are supposed to measure (Streiner & Norman, 2003). Further, in health related patient-reported outcomes is necessary to possess a high methodological quality assessment (Mokkink et al., 2010). Taking for an example, reviews found that tools such as resilience scales did not meet the methodological quality assessment criteria, such as validity, reliability, responsiveness, and interpretability. Some tools missed out essential criteria, on the whole, of 15 studies of original resilience tools, only three scored the best, these were Conor-Davidson

Resilience scale, Resilience Scale for Adult and Brief Resilience Scale (Windle et al., 2011).

Pain has a prognostic value (You et al., 2011) which must be assessed by using valid and reliable tools. However, a good sensitive tool cannot replaced clinical judgement by health professionals (Sheridan et al., 2012). Even then studies found discrepancies between pain assessment by patients and that of the health professionals (Yun et al., 2003). Persistent pain is found to be associated with psychosocial distress (Poleshuck et al., 2006). Conversely persistent pain also leads to positive adaptation called resilience (Southwick et al., 2014; Wright et al., 2012).

Taken as whole, after reviewing the literatures the researcher has confirmed there is legitimate reason to proceed with the study entitled: *Identifying predictors of postoperative persistent pain in women with breast cancer: Assessments of investigative tools.* This study is the first in Malaysia. The working pain definition in this study is an unpleasant sensation or pain related to breast surgery which lasts beyond 3 months postoperatively. Two data sets will be collected, the assessment of tools (set A) and the main study (set B). Set A data will be analysed using descriptive analysis for demographic features, test of reliability using Cronbach alpha, test for repeatability or agreement using ICC, and factor analysis, exploratory type, to establish construct validity. While for set B data, descriptive analysis for the demographic features and prevalence, and regression analysis for predictors of persistent pain. The results from both data sets will be merged together using TOUS as a focus or influenced theory, consequently the inferences will be presented in the best explanation using inductive and abductive reasoning. The results may be a surprise whereby the researcher is unable to control prior data analysis (concept mapping is shown in figure 1a).

CHAPTER 3
METHODOLOGY

The current study has been guided by previous studies from other countries. The gap of these studies was established, and a design chosen (a longitudinal and mixed methodology) suitable for the study of persistent pain and its progression. In summary, recognition of the gap has led to this study – Identifying Predictors of Postoperative Persistent Pain in Women with Breast Cancer: Assessment of investigative tools. In view of time constraints and for economic reasons, a cross-sectional study has been used to identify factors affecting persistent pain, and it uses a test–retest design for assessing investigative tools. The study has been divided into two sections, A and B. The findings from this study are designed to answer the following questions:

Section A:

1) Are the investigative tools; BPI, DT, and RS-14 reliable?
2) Do they measure what they are supposed to measure?

Section B:

3) What is the prevalence of postoperative persistent pain in women with breast cancer in Malaysia?
4) What are the factors affecting persistent pain in this breast cancer population in Malaysia?
5) Is age, stage of cancer, or type of surgery a satisfactory predictor (or predictors) of persistent pain postoperatively in women with breast cancer?

The findings are expected to provide informed and empirical data on persistent pain in women with breast cancer in Malaysia, a bench-mark for future research, and provide policy makers with objective data for financial planning and distribution of funds for management of breast cancer and related issues. Most importantly, it is hoped that the outcome of this research will benefit women with breast cancer, so that they can live

without pain and therefore have a sense of satisfaction with their life. A summary of the flow of the study process is shown in Flow chart 1

Flow Chart 1:

Summary of research process: Identifying Predictors of Postoperative Persistent Pain in Women with Breast Cancer: Assessments of Investigative Tools

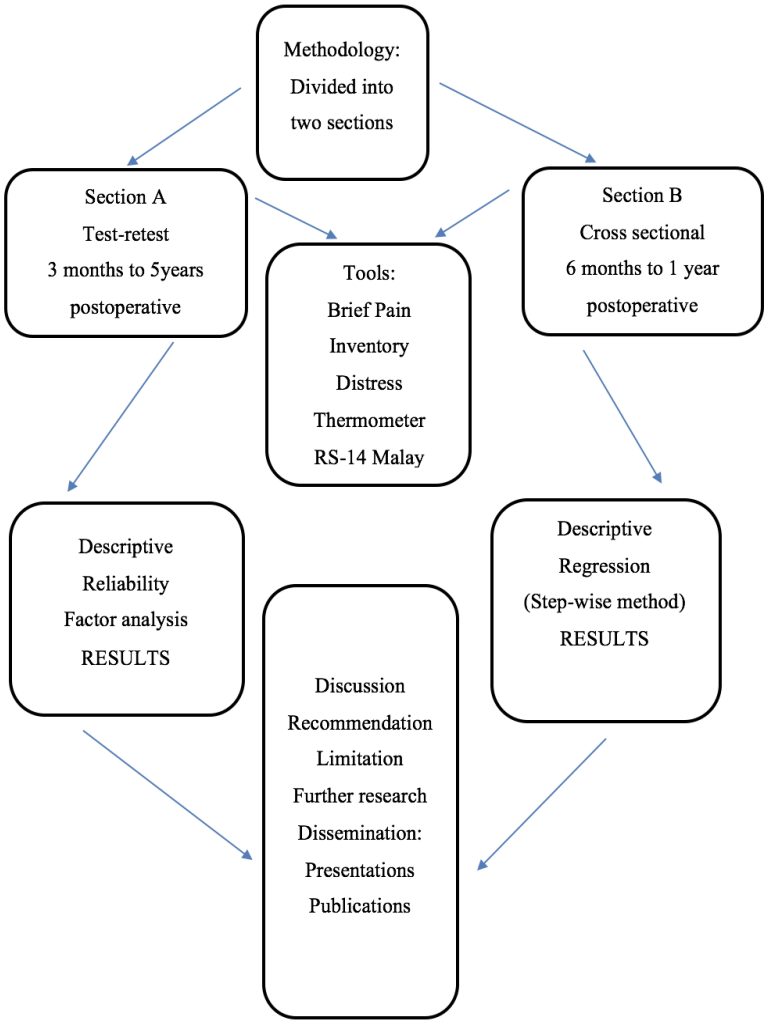

Figure 2: Summary of the research process

This was a quantitative study based on two separate data sets. The first data set is in Section A, which describes the assessment of investigative tools. It was a test–retest method, with no intervention. The second data set is in Section B, which describes the method to obtain a prevalence rate of persistent pain and to identify factors affecting postoperative persistent pain in women with breast cancer in Malaysia. Both Section A and Section B used similar investigative tools: The Brief Pain Inventory (BPI), Distress Thermometer (DT), and the Resilience scale RS-14 (Malay version). Here, the ethical implications are discussed, shared by both Section A and Section B.

SECTION A

3.1 Research design and rationale

The tools underpinning this study were established tools: The Brief Pain Inventory (BPI), Distress Thermometer (DT), and Resilience Scale RS-14 (RS-14), the Malay version. These tools were obtained from the respective research centres. The design for tool assessment was test and retest, and the recall period was 3 to 7 days. This timeframe is in accordance with (Marx, Menezes, Horovitz, Jones, & Warren, 2003; Paiva et al., 2014). Marx et al. (2003) showed no significant difference in test–retest reliability between 2 days and 2 weeks. Paiva et al. (2014), demonstrated that when evaluating cancer symptoms, a 2 to 7 day interval was adequate for reliability of test and retest. Although this study used a test and retest approach, there was no actual intervention at all, and the aim was merely to compare two successive responses of these tools and investigate their reliability. According to Berchtold (2016), when measured twice under the same conditions the tools should replicate the responses. However, this study accepted the notion that nature is so intricate that it is almost impossible to achieve such a thing as a “replicate” (Flora, Labrish, & Chalmers, 2012). It is worth noting that DT was only assessed on face validity.

3.2 Inclusion criteria for Section A (tool assessment):

- Over 18 years old and a maximum of 80 years old
- The subject had experienced unpleasant sensations or ill-defined pain sensations due to breast surgery (not limited to numbness, unable to move arm easily, pulling or burning sensation)
- Confirmed diagnosis of breast cancer on histopathology results, unilateral or bilateral breast cancer
- Any type of breast surgery or lumpectomy with axillary involvement
- Understand either the Malay or English language
- Malays and Chinese Malaysian
- No metastases evident on first contact
- May have undergone treatments such as chemotherapy, radiotherapy, or hormone therapy
- Elapsed time after surgery: minimum 3 complete months and maximum of 5 years.

3.3 Exclusion criteria for Section A (Tool Assessment):

- Non-Malay or non-Chinese Malaysian
- Cognitively impaired and cannot respond to the questionnaires and interview
- Confirmed and documented psychiatric history
- Concurrent chronic pain not related to cancer such as back pain, sciatica, rheumatoid pain, or arthritis prior to cancer diagnosis
- Documented stage 4 breast cancer on first contact
- Only had simple lumpectomy with no axillary involvement
- Breast cancer in males.

3.4 Ethical considerations

Ethical approval was obtained from ANU and UM to conduct both the studies in section A and section B. In addition, permission was also obtained from various heads of department and clinic managers. This was a non-invasive study involving breast cancer survivors. Despite the study's non-invasive nature, participants might have cause to reflect on their cancer journey which could cause stress. This study received ethical approval from the Australian National University, the University of Malaya, and the University of Malaya Medical Centre. Approvals were: ARIES protocol 2013/412, MECID NO 2013120569, and MECID NO 20148-449 respectively.

The study conformed to the Declaration of Helsinki. Other researchers have also advocated strict adherence to ethical considerations in research (Broom, 2006; Kimmelman, Lemmens, & Kim, 2012). The primary researcher was always careful not to breach the research protocols. The enumerators were also constantly reminded.

3.4.1 Provision of privacy

The breast clinic sessions were always crowded. Despite the crowded clinics, privacy and confidentiality were provided by either waiting for the crowd to clear or conducting the interview at the most conducive spot possible. The researcher would organise the timing to the respective sites. The mammography suite was good for interviewing participants at any time due to its space and its system of calling participants for the procedure. Privacy issues did not arise. The interview location was determined by the participants. To maintain privacy, the researcher usually scheduled recruitments to occur in the mammography area in the first part of the morning. By mid-morning recruitment shifted to the breast clinic or the oncology clinic. There were no issues of privacy in the sport and exercise clinic.

3.4.2 Qualified enumerators

Enumerators and research associates were graduates from the University of Malaya. They had gone through research ethics considerations prior to their graduations. They were thus qualified to recruit participants, and their activity was always monitored. The researcher maintained good communication with the enumerators.

3.4.3 Anonymity

Participants were assured that their identity would not be revealed at any time. Although the research outcome would be used for teaching, presentations, and for the thesis, at no time would their identities be revealed. Their names were changed to numbers. The data was kept in a password protected computer. Hard copies were kept in the research room, with card or password access. Some hard copies were kept in locked cupboards at the secure mammography suite. The key to the room was kept by the management.

3.4.4 Consent

Every participant was given information regarding the research and an explanation about free consent. They were each given a participant information sheet and encouraged to take it home. They had the choice to sign the forms either in English or Malay. Most of the participants signed the consent forms. However, some participants did not sign, this action is in accord with the consent forms, they could still participate even without a written consent; by returning the complete responses.

3.4.5 Protection from harm

Some participants were on emotional roller coasters, and sometimes informed the researcher that they could not proceed with the responses. The researcher would reassure them not to worry about the responses. Perhaps they just received news about metastasis or suspicion of metastasis, denoting the progression of their disease. The researcher encouraged these participants to consult the “Breast Team” for distress assessment. The researcher referred many participants due to distress. However,

throughout the data collection there were no occasions of reported distress induced by the study process itself.

3.4.6 Data storage

Some of the hard copies were locked in the research room by the student researcher. The rest of the hard copies were kept by Taib and colleagues in the Breast Cancer Research Centre. No identifiable responses were left unattended. All responses were returned to designated counters such as the Oncology clinic or the Surgical clinic, and the mailed responses arrived at the department of surgery Medical faculty of the University of Malaya. Those responses were kept in a cupboard at the Department of Surgery until collection by either the researcher or the enumerators. Participant data was stored in a password operated computer. On completion, all hard copies were locked in the research room, tentatively for 5 years after publication in accordance with ANU policy.

3.4.7 Dissemination of Findings

The findings of the study will be handed to UM and UMMC authorities. Permission will be obtained for presentation and publication from ANU and UM. This research will be published with a referee from either ANU or UM.

3.4.8 Sample size determination

In factor analysis, sample size is a debatable issue among researchers, and remains unresolved. In order to obtain a stable factor solution Arrindell and Vanderende (1985) suggested that the total number of factors be 20 times the number of participant. Barrett and Kline (1981) concluded that a minimum of 50 is adequate to yield a recognisable factor pattern. Adequate sample size is indicated by a high communalities – at least .7 and preferably higher (MacCallum, Widaman, Zhang, & Hong, 1999). Further, (Costello & Osborne, 2005) argued that virtual EFA by nature and design is exploratory. So even with a larger sample size, EFA is an error-prone procedure, and

the authors advocate Confirmatory factor analysis (CFA) instead. Based on some of the above references, and reinforced by Gorsuch that absolute minimum is 100. Therefore, the sample size for this study is aimed at 200, and thus deemed adequate (Gorsuch, 1983, p. 332).

3.5 Data Collection Procedure for Assessment of Tools

Although the data used for this study were separate sets, on occasions the same participants volunteered to participate for Section B. These participants were allowed, if they had pain or unpleasant sensation due to side-effects of surgery and met the other criteria of the study. The names of the potential participants for the day were obtained at the admission counter. The potential participants were approached individually. In that brief period, the researcher established rapport before the recruitment process commenced. They were first screened for eligibility. The researcher asked whether they had any unpleasant sensation or pain due to breast surgery, which was the first operational question. If pain was present the researcher proceeded to ask the other standard questions for this research, such as age, time since their surgery, any chronic pain prior to surgery (for instance, arthritis, chest pain, sciatica, gout, back pain, or any other chronic pain). If their response was “yes” to the last question, the researcher excluded them from our study of the assessment tools. The researcher also excluded participants who did not meet our inclusion criteria (50).

For those who were eligible, the researcher explained the aims of the research. They were informed that this research was a subset of a larger research program conducted by Taib and colleagues at UMMC. It was emphasised that participation was on a voluntary basis. They could leave if they were not comfortable, and they were reassured that their treatments and management of their cancer would not change. In the event of emotional stress, they were reassured that they could get assistance from the

psycho-oncologist who was on the team. Contact numbers were given to them so that they could contact the researcher or supervisors or even the ethics committees if needed.

The Participant's Information Sheet was given to every participant to read and they were encouraged to take it home. Not every participant was able to provide their contact numbers, therefore only 65% of the participants were given a reminder message, and a thankyou message was sent in gratitude for their attempts. A thankyou message was sent to everyone regardless of whether they returned or failed to return their responses. The participants were well respected; no calls were made without their permission.

Cancer participants had different experiences in their journey. They might request the researcher to be with them the whole time they were responding. At times, they requested the researcher to read and tick for them. It was an experience to the researcher to find these women who were willing to participate but tried to minimise their emotion by going through what they experienced, but not too brave to proceed with the responses alone. These participants, especially, were reassured that there was a psycho-oncologist in the team. Failing that, on their request they could choose any other psycho-oncologist by special arrangement.

3.6 Analytical methods

Analysis was performed using IBM Statistical Package for Social Science (SPSS) version 24. There were three stages to this process. The first was to use descriptive statistics to establish means and standard deviations (SD), and to see the overall normality distribution of the data. The second was a reliability test using Cronbach alpha and ICC to survey the internal reliability and reproducibility of the tools. The third was factor analysis to reduce the large data and establish construct validity.

SECTION B

3.7 Research Design and Rationale

This study was a prospective, correlational, cross-sectional, and retrospective record review design. Prospective data collections obtained by self-reported responses used three tools, similar in nature to those in Section A. the tools were BPI, RS-14, and DT. Retrospective data were extracted from the participant's record. Some were clinical data, such as type of surgery and stage of cancer, while marital status, education level, employment status, and household income were traced from a larger study named MYBCC.

This study commenced after ethical approval from the Australian National University, University of Malaya, and University of Malaya Medical Centre. Approvals were: ARIES protocol 2013/412, MECID NO 2013120569, and MECID NO 20148-449 respectively.

The study conformed to the Declaration of Helsinki. Other researchers have also advocated strict adherence to ethical considerations in research (Broom, 2006; Kimmelman et al., 2012). The ethical aspects were described in section A, and although it may be repetitive it is worth repeating. The primary researcher was always took care not to breach the ethical guidelines of research, and the enumerators were also constantly reminded.

3.8 Inclusion criteria (main study):

- Over 18 years old and a maximum of 80 years old
- Surgery 6 months to 1 year ago. If it was found that they experienced concurrent pain such as arthritis, gout, and back pain, these were documented.
- Confirmed diagnosis of breast cancer on histopathology results, unilateral or bilateral breast cancer

- Had undergone any type of breast surgery or lumpectomy with axillary involvement
- Understood either Malay or English
- Malays and Chinese Malaysian
- No evidence of metastases
- May have undergone treatments such as chemotherapy, radiotherapy, and hormone therapy.

3.9 Exclusion criteria (main study):

- were non-Malays or non-Chinese Malaysian
- were cognitively impaired and could not respond to the questionnaire or interview
- Had confirmed and documented psychiatric history
- Documented stage 4 breast cancer
- Only had simple lumpectomy with no axillary involvement
- Breast cancer in males.

3.10 Data collection procedure

Data collections shared many similarities with procedures described earlier as Section B and Section A. Only procedures that were specific to each section were documented separately. The Flow Chart 1 displayed just at the beginning of this chapter gives a better understanding of this research process.

Many of the participants were approached during hospitalisation after surgery. Their names were recorded as potential participants for the study. However, some names of potential participants were obtained on the day of the interview from the admission counter. The potential participants were approached individually. In that brief period, the researcher established rapport with them. They were first screened for

eligibility. The first question was whether they had had surgery in the last 6 months to 1 year. If so, the researcher proceeded to enquire about other standard questions for this research such as age or any chronic pain prior to surgery (for instance, arthritis, chest pain, sciatica, gout, back pain, or any other chronic pain). If their response was “yes”, the researcher documented this information. This pain question was asked because when the researcher obtained results on pain levels she would need to interpret this as existing pain or new onset of pain. For example, if the pain symptoms were significant while there was no other experience of concurrent pain such as arthritis or gout, the researcher would be sure that the result did not happen by chance.

Most participants completed all questionnaires on their own. The onsite researcher and enumerator only assisted them on request. In the event that they had forgotten to bring their reading glasses or were keen to participate but not keen to read on their own, the researcher or enumerator would assist them. On occasions, some participants requested clarity about the questionnaires.

3.11 Sample size calculation

The sample size calculated using a Cohen’s significant level = 0.05, power = 0.8, and f^2 (effect size 0.15) shows that 92 participants are adequate. This study obtained 121 (N = 121) participants.

3.11.1 Analytical Models

Analysis was performed using IBM Statistical Package for Social Science (SPSS) version 24; Section B, descriptive statistics were used to describe demographic features and the prevalence of persistent pain. Standard simple regression was used to assess the assumptions of both pain intensity and pain interference, and Multiple regression using a stepwise method was used to identify predictors of persistent pain.

SECTION A and B

Outcome Measures for both Section A and Section B

The following measures were established measures, and hence were assessed and concurrently utilised on identifying factors affecting postoperative persistent pain in this study. The assessment used the Malay version of Resilience Scale RS-14. As for the Brief Pain Inventory (BPI), both languages were assessed as one because the Malay version has been validated (Abdullah, Lin, & Abdul, 2006). In contrast, the Distress Thermometer (DT) was assessed in English version due to limitation and conditions set by the NCCN (personal communication in 2013).

3.12 Outcome Measures:

3.12.1 The Brief Pain Inventory (BPI)

BPI was developed in 2009 (C. S. Cleeland, 2009) and will be validated in this study. The BPI is a 9-item questionnaire that assesses pain intensity and how much pain interferes with function. Ratings of present, least, average, and worst pain are obtained using 0 (no pain) to 10 (worst pain imaginable). The degree to which pain interferes with seven activities is rated 0 (no interference at all) to 10 (complete interference). A cut-off point of 5 requires revision of analgesia and referral to a specialist (Holland et al., 2007). A total interference score is calculated by summing the responses and calculating the mean for the seven interference items (C. S. Cleeland, 2009). In this study the pain intensity and pain interference were divided into four categories: 0 (no pain); 1 to 4 (mild pain); 5 to 6 (moderate pain), and 7 to 10 (severe pain) [(Serlin, Mendoza, Nakamura, Edwards, & Cleeland, 1995)]. These levels accord with (Serlin et al., 1995), who studied cancer populations with different language backgrounds, and they had used cut-off points for both pain intensity and pain interference as described above. However, other researchers catagorise pain intensity and pain interference differently: 0 (no pain); 1–3 (mild pain); 4–6 (moderate pain); and 7–10 (severe pain)

(Mikan et al., 2016)]. The BPI has been used to assess pain in cancer patients (Anderson, 2011). The Malay version of the PBI has been used to assess pain in cancer patients in Malaysia (Abdullah et al., 2006). Both pain intensity and pain interference loaded as a factor each with 62% (*N*=113). In term of correlation, the Karnofsky Performance Scale (KPS) was employed. Pain intensity was shown to negatively correlate with KPS (–0.520, $p<0.001$). In a similar fashion, pain interference showed a strong negative correlation (–0.732, $p<0.001$). Test–retest on Intra-class correlation coefficient (ICC) highlighted that this version had a reasonably good psychometric property with $\alpha= 0.72$ and $\alpha= 0.88$ for pain intensity and pain interference respectively.

3.12.2 Distress Thermometer (DT)

Pain is the fifth vital sign after temperature, pulse, respiratory rate, and blood pressure. (Holland et al., 2007) proposed distress as a sixth vital sign to be integrated into the psychological assessment of patients with cancer. The Distress Thermometer was developed by the National Comprehensive Cancer Network (NCCN) in the United States of America (USA) (Holland, 1997). This study used a modified version which was endorsed by the NCCN in 2013. DT is used to assess recall of distress in the past week (including the day of response). There are 48 *Yes* and *No* responses questions in total. In addition to the above, there are four more questions. First, a qualitative response; Other concerns? Second, a question requiring the ranking of responses. Third, a question with response *Yes*, *No*, or *Maybe* (Would you like to talk to someone about your problems?). Fourth, a question with multiple-choice responses to follow the previous question (If yes with whom?); options included nurse, dietitian, physiotherapist, social worker, pastoral worker, psychologist, patient association, or another, namely: __ (The DT questionnaire is attached as an appendix).

The first question of DT has a picture of a thermometer, used as a Likert scale. Scores on an 11-point visual analogue scale range from 0 (no distress) to 10 (extreme distress). The rest of the questions were binomial Yes and No responses.

Problem lists are designed to define the nature of the problems which possibly caused the reported distress (Iskandarsyah et al., 2013). In order to achieve the best results, five steps were proposed (Lazenby et al., 2015): step 1, screening; step 2, evaluating; step 3, referring; step 4, following up; and step 5 documenting and quality improvement. To enable evaluation of patients, prompt referral is necessary at the referral stage patients are explored at the peak of their distress. The assessor should document the findings because poor documentation might lead to missing links, such as suicidal ideation and severity of distress. Documentation acts as both the baseline for follow up as well as for quality assurance purposes (Lazenby et al., 2015). The core questions are divided into five problems lists: first, Practical problems; second, Family problems; third, emotional problems; fourth, Spiritual/religious concerns; and fifth, Physical problems. Other questions include the four described above.

DT has been used as a tool to measure distress by other researchers. The features are nearly similar. In Malaysia, the original version of DT was translated into Mandarin and Malay (Yong, Zubaidah, Said, & Zailina, 2012), and took a cut-off point of ≥5, which was different from NCCN, with a cut-off of 4. It was different to another study where the cut-off score was ≥ 3 (Boyes, D'Este, Carey, Lecathelinais, & Girgis, 2013).

3.12.3 The 14 item Resilience Scales (RS-14)

RS resilience scale is a robust instrument commonly used in psychology research (Damasio, Borsa, & da Silva, 2011; Losoi et al., 2013). The original scale consisted of 50 items, but was then reduced to 25 and subsequently to 14 items (Wagnild, 2011). This research used the 14-item version (RS-14) to measure resilience in participants. The RS-14 is a short form of the RS-25 (Abiola & Udofia, 2011; Wagnild, 2011). The RS-14 measures five domains: meaningfulness in life (purpose), perseverance, self-reliance, equanimity, and existential aloneness. After its original publication in 1993, the Resilience Scale has been translated and published in various languages including Russian (Aroian, Schappler-Morris, Neary, Spitzer, & Tran, 1997), Italian (Girtler et al., 2010), Spanish (Heilemann, Lee, & Kury, 2003), Swedish (Lundman, Strandberg, Eisemann, Gustafson, & Brulin, 2007), Japanese (Nishi, Uehara, Kondo, & Matsuoka, 2010), Brazilian (Damasio et al., 2011), Dutch (Portzky, Wagnild, De Bacquer, & Audenaert, 2010) German (Rohrig, Schleussner, Brix, & Strauss, 2006) Nigerian (Abiola & Udofia, 2011), Losoi et al. (2013) as cited in (Wagnild, 2011).

The RS-25 has been empirically tested for its psychometric properties and has been used extensively worldwide in populations including cancer patients. Responses are provided using a 7-point Likert scale from 1 (strongly disagree) to 7 (strongly agree). Higher scores indicate greater resilience. Similarly, RS-14 has been widely used. For RS-14, the lowest possible score is 14, while the highest possible score is 98. The RS-14 has good internal consistency and reliability (Cronbach's alpha ranging from 0.91 to 0.93). The RS-14 correlates well with the RS-25; $r = 0.97$, $p<.001$ (Wagnild, 2011).

There is limited knowledge concerning its test and retest reliability (Damasio et al., 2011; Losoi et al., 2013). RS-25 and RS-14 were tested on people from the general population, and people affected by adverse situations. Although Damasio et al. (2011)

had found significant findings, their study was done on well-educated people, and so the results must be interpreted with caution. Unlike those studies, this study utilised homogenously women with breast cancer.

The Finnish versions of the RS-25 and RS-14 have demonstrated good psychometric properties and correlate well on both scales. The Cronbach's alpha was 0.90 for the RS-25 and 0.87 for the RS-14 RS-25 and RS-14 scores were well correlated (*r* =.95**).** Losoi et al. (2013) suggested that, further research on test-retest reliability of both RS scales was needed. Resilience scale RS-25, the German version, has been reduced to RS-11. The RS-11 was consequently reduced to RS-5 to test on the elderly (von Eisenhart Rothe et al., 2013). A total of (*N*= 4127), response rate was 69%. After exclusion, finally 3712 participants were analysed. Ages ranged between 64 to 94 years. RS-11 yielded one factor structure. Their sample violated the normality assumptions; hence the Shapiro-Wilk test and Kruskal-Wallis test were used to survey differences between the age groups, which showed that the older groups were less resilient compared to the younger ones. The reliability and validity tests showed on EFA a one factor structure. On a model fit test, the CFA showed the model did not show a good fit although the RMSEA value was .090.

Although the RS-14 has established internal and external consistency in other studies, it has not been tested in Malaysia. Similarly there has not been documentation on validation of the existing RS-25 Malay version (Arokiaraj, Nasir, & Wan Shahrazad, 2011). This study extracted an RS-14 Malay version from the RS-25 Malay version, and assessed it for reliability and construct validity.

CHAPTER 4
ASSESSMENT AND EVALUATION OF INVESTIGATIVE TOOLS

This chapter describes the pilot study of the assessment tools, its implementation, and the challenges faced. The pilot study rectified issues concerning the efficiency of data collection during the final assessment of the tools. The chapter also describes assessments of the Brief Pain Inventory and the Resilience Scale RS-14. However, the Distress Thermometer had its validity assessed only on face value.

4.1 Pilot Study

Introduction

The pilot study was conducted between 24th October and 29th December 2014. Ethical approval was obtained from The Australian National University and the University of Malaya (ARIES protocol: 2013/412 and UMMC MEC IC No 2013120569). This study used already established and validated tools: The Brief Pain Inventory, Distress Thermometer, and Resilience Scale RS-14, so none of the tools needed translation into Malay. However, the participant's information sheet and consent form were translated by the researcher and reviewed by peers; later the translations were confirmed by a senior lecturer who had a PhD in Malay–English languages. None of the participants expressed any concerns regarding the translated information sheet or consent form after receiving them.

The study took place in clinics at the University of Malaya Medical Centre, Kuala Lumpur. The participants were women with breast cancer who had had surgery at least 3 months before. Only women who met the selection criteria were recruited. The aim of the pilot study was not to establish the statistical significance of the data but to survey the following:

1. The response rate
2. Attrition rate
3. The time each participant took to complete the questionnaires

4. Whether the participants were able to understand the questionnaires
5. How best to interact with the participants during busy clinic sessions.

4.2 Methodology of the Pilot study

The methodology involved self-reported questionnaires, with a test and retest design. No interventions were involved. The retest responses were returned either personally or by post. The recall period was 3 to 7 days. According to Paiva et al. (2014), this duration is adequate to yield good reliability when investigating cancer symptoms. The pilot study recruited 44 participants, a fraction of the total sample size of 200 participants aimed for in the actual study. It is normal in a pilot study for a 20–30% sample size to be used in comparison with the actual sample size (Baker, 1994, p. 152). This study also aimed for at least a 60% response rate (Fincham, 2008).

4.3 Results and discussion of Pilot Study

A total of 44 participants were recruited. The study labels the first test as T1 and the retest as T2. A total of 19 participants returned the T1 response, while a total of 15 participants returned the T2 response. The responses represent response rates of 43% for T1 and 34% for T2, which was much below expectation. The high attrition rates were a challenge to this study. A brief meeting with Professor Taib, and on a few occasions consulting with peer researchers helped improve the situation.

The time taken for responses very much depended on the participants' understanding of the questionnaires and their concentration, and so the researcher was relaxed about that. Every participant was observed to have different levels of experience, emotion, and power of concentration. Most participants understood the questionnaires, but a few did ask for assistance.

In the pilot study the participants highlighted question number one in the questionnaire from the Malay version of the Brief Pain Inventory. It was apparent that

the question included redundant words, and when compared to the English version those words should not have been included. After discussion with the advisor, Professor Taib, these words were deleted. Since then, no issues have been raised by the participants.

The pilot study informed the researcher that a few adjustments were necessary in order to ensure efficient data collection. The low response rate and the high attrition rate were examined. It was suspected that the participants might have forgotten to answer the T2 questionnaires. At that point, there were no telephone numbers documented, and hence no means of contacting them for a reminder. For subsequent recruitments, participants were asked to leave their phone numbers and were informed that a reminder message would be sent for the T2 responses. The reminders worked well and enabled the participants to respond to T2 on time.

Regarding the time spent answering the questionnaire, the researcher assessed each individual participant. Depending on their abilities, the recruitment was modified to allow participants to take extra time for assistance and supervision if required. When contacting the participants, the researcher scheduled the timing so that appointments took place in the early part of the morning in the mammography suites, and at the breast clinic for appointments in the mid-morning and later parts of the evening. Similarly, adjustment was made when recruiting participants from the radiotherapy department and chemotherapy clinic. On Saturday in the sport and exercise clinic there was a unique situation in which the participants were always in a hurry to be with their family. Hence recruitment had to be modified so that the participants took both T1 and T2 questionnaires at the same time. Proper explanations and telephone messages were important to ensure they returned both responses.

The pilot study gave a good insight into the participants' characters, the clinic activities, and the staff responses to the presence of ongoing research. The pilot study had support face validity for the three investigative tools. The researcher experienced

the dynamics of the situation and adjusted to the needs of the participants. The outcome was an improved data collection and improved response rate, as seen in subsequent data collections for the actual assessment tools. The data allowed the factors surrounding postoperative persistent pain in women with breast cancer to be identified.

Brief Pain Inventory

4.4 Brief Pain Inventory: Assessment

4.4.1 Design

This was a prospective study measuring two times points, a test–retest situation, but with no intervention involved. Although a self-reported questionnaire was employed, the participants could request for assistance from the primary researcher or the enumerators if required. All the questionnaires were compiled into a booklet. There were three investigative tools included in the booklet: The Brief Pain Inventory (BPI), the resilience scale RS-14, and the Distress Thermometer (DT). The BPI and RS-14 were a Likert Scale, while the DT uses a binomial scale with Yes and No responses.

4.4.2 Sample size and sampling methods

Data collection commenced on 24th October 2014 and proceeded until the first week of May 2017. The last responses were collected on 30th May 2017. The total recruitment was 274 participants. Each tool was administered twice to the same participants with the recall time being between 3 and 7 days. The student excluded all data that were not in pairs, (must be test and retest). Hence the numbers were not similar between tools. This phenomenon is only limited to Section A, the assessment of tools.

A sample size of 200 was desired. After the data were cleaned the sample size was found to be 172 participants, and justified adequate (Arrindell & Vanderende, 1985). The potential participants were approached individually. Those approached were women with breast cancer who had had surgery at least 3 months before and at most 5 years. The participants' ages were from 25 to 78 years. All participants met the

operational definition of this study. Participation was on a voluntary basis. The process strictly adhered to the Declaration of Helsinki.

A total of 274 samples were obtained for the first responses, and a total of 214 for the second set of responses. Thus, the response rate was 78.1%. According to Fincham (2008), a response rate for research should be about 70%, while for schools or colleges of pharmacy it should be at least 80%. For convenience, the study refers to T1 and T2 for the test and retest respectively.

4.4.3 Data Analysis

Descriptive statistics was used to describe the basic demographics features. As a reliability test (a test for internal consistency) the study used the Cronbach alpha test. Factor analysis statistics were used to reduce the large number of variables, extract factors, and then change them derive composite scores for future analysis. Data were analysed using the Statistical Package for the Social Sciences (SPSS) version 24.

Data were cleaned. Using SPSS package data were checked for missing variables, variables outside the range, example responses from 0 to 10, any value 11 would have been rectified by checking the actual responses from the hard copies. Further, the data were established missing at random or not at random. These data were found missing at random. Missing in a random pattern is less serious (Tabachnick & Fidel, 2014, p. 97).

There was some missing data which was noted, but not imputed. In factor analysis (FA) the assumption of normality is not compulsory (Tabachnick & Fidel, 2014, p. 666). All data from T1 and T2 that were not paired were deleted, and found 214 participants, however, only data ranged from 3 months to 5 years ago were required for analysis. Therefore, 172 participants were eligible for analysis, Finally, our working sample size was 172 (N=172). This size was to avoid imbalance in the data that could cause reduced statistical power (Batterham & Atkinson, 2005).

Variables for BPI were continuous in nature and in Likert Scales; the researcher therefore chose Cronbach alpha to test for reliability, followed by Factor analysis. The primary aim was to ensure that BPI remained reliable and measured what it was supposed to measure. Therefore, the study sought 1) to assess reliability by examining the alpha values to see if they had the same weight and measured the same construct, and 2) to establish construct validity using factor analysis.

4.4.4 Results of demographic data for BPI

A total of 275 participants; after data cleaning the study retained 214 participants (N = 214). Those subjects where surgery occurred > 5 years ago were 19.6% (n = 42); for < 5 years, the figure was 80.37% (n = 172). However, the researcher analysed only the data for < 5 years. The reason was that as the duration after surgery progresses, the tendency of comorbidity rises, which would jeopardise the results obtained.

The demographic features are described as follows. The participants' ages ranged from 25 years to 78 years old, with a mean of 53.9 years. Participants aged 20–39.9 made up 8.1%; 40–59.9 made up 51.2%; and 60 years and above made up 40.7%. There was 45.3% and 54.7% participation from Malay and Chinese ethnicity respectively. More Malay version questionnaires were chosen than the English version – 61% and 39% respectively. All participants had breast surgery. For 17.8% of them it had occurred more than 5 years ago, and for 79.9 % it had been less than five years ago. Some 27.9% of participant reported they did not experience other pain except pain from surgery; others had concurrent pain that included: arthritis (6.4%), gout (0.6%), chest pain (9.3%), back pain (9.9%), sciatica (1.2%), or other pain (37.8%). 7.0 % did not report their status of comorbidities. None of the participants had mental illness. A total of 65.1% of the participants scored Yes pain today. These results are summarised in Table 1.

Table 1: Demographic features of the participants

Demographic data for assessment of Brief Pain Inventory (N = 172)

Variable name	Group	Number	%
Age	20–39.9	14	8.1
	40–59.9	88	51.2
	60 and above	70	40.7
Range 25–78 years	Mean age (53.9)		
Ethnicity	Malay	78	45.3
	Chinese	94	54.7
Languages	English	67	39
	Malay	105	61
Mental illness	None	100	100
Comorbidities	None	48	27.9
	Arthritis	11	6.4
	Gout	1	.6
	Chest pain	16	9.3
	Back pain	17	9.9
	Sciatica	2	1.2
	Others*	65	37.8
	Missing	12	7.0
Postoperative time (years)	<5	172	100
Pain today	Yes	112	65.1
	No	58	33.7
	Missing	2	1.2

*Breast-numbness, tingling, scar pain, inflammation; arm-lymphedema, numbness, pain, tingling, tightness, joints-pain; neck pain, heel pain, eczema and diabetes.

4.5 Assessment of Reliability

Unlike the study conducted by Abdullah et al., and Uki, Mendoza, Charles, and Cleeland (Abdullah et al., 2006; Uki, Mendoza, Charles, & Cleeland, 1998), this study utilised Q8, the percentage of pain relief received after treatment. Thus, although the above papers studied 11 items, this study conducted the analysis using 12 items. In principle, Q8 measures pain intensity. The scale for Q8 was originally from 0% to 100% relief, referring to the level of pain after receiving pain management. The scale

was originally a Likert scale of 0%, 10%, 20%, 30%, 40%, 50%, 60%, 70%, 80%, 90%, and 100%, 0% means no relief, and 100% complete relief. But was consequently recoded to 0 1, 2, 3, 4, 5, 6, 7, 8, 9, and 10 respectively. The Likert scale was finally reversed, and recoded to 10, 9, 8, 7, 6, 5, 4, 3, 2, 1, and 0 respectively because pain relief describes the opposite of pain intensity, although it still measures pain levels.

Using SPSS version 24, Cronbach alpha was assessed. The aim was to assess internal reliability and the association between items, as well as the approximate weight of those items. From this test the potential factors were extracted. The study aimed at a Cronbach alpha >.7 (as a guide, Cronbach alpha ranges from 0 to 1, with the closer to 1 the more reliable the items). Cronbach alpha provides a unique estimate that shows the average value of the reliability coefficient, with only a single test administration being required (Gliem & Gliem, 2003).

4.5.1 Results of reliability test

As summarised in Table 2, this current study and placed against other work in Table 6, despite Table 6 only showed the overall means and SD values, on detailed appraisal of all the cited studies, there was a common result; that the mean and SD values were arranged in similar order with the current study. The current study yielded both T1 and T2, mean values, highest to lowest in the following order: worst pain, average pain, pain right now, and least pain, similar arrangements were seen in (Abdullah et al., 2006; Zalon, 2006), and (Uki et al., 1998; Yun et al., 2004).

The current study, showed pain intensity item Q8, percentage relief, the highest mean score both times. To the researcher's knowledge this is the first BPI tool assessed 12 items, instead of 11 items. For pain interference, the highest score for T1 was in this order: mood, enjoyment, work, activity, sleep, and walk. Unlike T1, the T2 highest mean scores were as follows: enjoyment, mood, sleep, activity, work, and walk. But the order in pain interference differed from that of (Abdullah et al., 2006; Uki et al., 1998;

Yun et al., 2004; Zalon, 2006). On the whole, the only items that showed higher mean and SD were Q8 both at T1 and T2. Excluding Q8, however, the current study mean and SD values were still lower than the other papers referred to.

Table 2: Descriptive statistics for BPI items T1 and T2 (*N* = 172)

Variables	Mean	SD	Mean	SD
Severity items				
Worst	2.39	2.579	2.48	2.557
Least	1.56	1.833	1.70	1.747
Average	1.88	1.966	2.09	1.952
Right now	1.61	2.164	1.81	2.122
ReversedQ8	7.40	3.469	6.80	3.6
Interference items			Interference items	
Activity	1.91	2.414	2.06	2.484
Mood	2.01	2.490	2.13	2.486
Walk	1.46	2.137	1.73	2.385
Work	1.91	2.420	2.02	2.433
Relation	1.33	1.968	1.50	2.050
Sleep	1.83	2.337	2.08	2.458
Enjoyment	1.94	2.633	2.17	2.640

The Cronbach alpha for reliability for T1 and T2 covering all items was .900 and .908 respectively. A Cronbach alpha above .8 (Pallant, 2011, p. 100) on both occasions showed that the data had good internal reliability. As for the correlations matrix, the output table for all items showed positive correlations. No items correlated >.3. However, for T2, the items mood and general activity correlated >.9 and .952, respectively. These items were also observed in subsequent analysis.

Table 3 shows the corrected item–total correlation (CITC) and alpha if an item was deleted. Both T1 and T2 showed alpha at excellent values, indicating the items contributed towards the reliability of the scales. T1 showed alpha was between .881 and .964 if an item was deleted, while for T2 if an item was deleted alpha was between.887

and .969. As such none of the items were deleted. The subscales Cronbach's alpha for BPI T1 and T2 were .898 and .899 respectively, which were acceptable although value above.8 was preferable (Pallant, 2011, p. 100).

Table 4 summarises the reliability and agreement test. The correlation coefficients were very good, ranging from .784 to .885. This showed that the T1 and T2 responses were replicable (reproducible). Values of .81 to 1.00 are generally considered excellent (Kottner et al., 2011). For subscales test retest (ICC) T1 and T2 .729 and .696 respectively.

Table 3: Reliability of BPI T1 and T2 (*N*=12 items)

	Corrected item–total correlation	Cronbach's alpha if item deleted	Corrected item–total correlation	Cronbach's alpha if item deleted
Worst	.906	.876	.798	.892
Least	7.82	.887	.799	.896
Average	.862	.883	.825	.894
Right now	.787	.885	.875	.890
Reversed Q8	–.534	.964	–.499	.969
Activity	.869	.879	.897	.887
Mood	.827	.881	.900	.887
Walking	.742	.887	.734	.896
Work	.888	.878	.888	.888
Relation	.736	.888	.823	.893
Sleep	.789	.884	.827	.891
Enjoy	.796	.883	.838	.890

Table 4. Reliability and agreement test of BPI questionnaire (*N* = 12 items)

	Names of items	ICC
Q3	Worst pain	.866
Q4	Least pain	.791
Q5	Average pain	.861
Q6	Pain right now	.842
Q8	**Percentage pain relief**	**.876**
Q9a	Activity	.863
Q9b	Mood	.870
Q9c	Walking ability	.848
Q9d	Work ability	.885
Q9e	Relation with others	.784
Q9f	Sleep	.829
Q9g	Enjoyment of life	.838
Subscale	intensity	.729
Subscale	interference	.696
Methods: Two way mixed, absolute agreement		

4.6 Factor Analysis

The reliability test provided the insight that the items were somewhat correlated and so could be subject to factor analysis. Thus, all the 12 items were subjected to analysis. Since Cronbach alpha does not provide a unidimensional view of the items, a factor analysis was conducted (Gliem & Gliem, 2003).

4.6.1 Assumptions for data analyses

Assumptions for data analyses have been met. Sample size for BPI was adequate (*N*=172). Each item was in a Likert scale; there were twelve numbers. A reliability test for Cronbach alpha showed there was a relationship among the items and they shared nearly similar weight.

4.6.2 Factor rotation

Initially, all the 12 items were subjected to factor analysis. The goal of this analysis was data reduction, and the Principal Component method was employed (Fabrigar, MacCallum, Wegener, & Strahan, 1999).

An orthogonal rotation was adopted, assuming the factors were not related. Varimax was the choice of rotation because it yields more interpretable clusters of factors (Field, 2013, p. 681).

Keiser's criterion technique, using as default eigenvalues above one, and a fixed number of factors were employed. A Scree plot was also done. The coefficient was suppressed to .4.

Preliminary analysis

Correlations

Based on the Correlation Matrix output, the one-tailed significant coefficient table for T1 showed significant values for all items; $p \leq .001$. All items correlated positively to one another (ranging from .381 to .901). Overall, correlations were above .5. None of the loading was less than .25, so all items were retained. Based on a determinant test, multicollinearity is not expected (determinant = 8.850E-7). Similarly, for T2 one-tailed coefficient was significant <.001, and all items showed positive correlations (ranging between –.493and .952). Visual inspection showed that overall correlations were above .5 and the highest correlation was .952. The analysis results therefore need caution. However, the determinant value did not show potential collinearity despite the high correlations (determinant = 2.003E-007).

4.6.3 Factor Extractions

Based on KMO, .911 and .921 for T1 and T2 respectively (> .6) showed measured sampling adequacy. Bartlett's Test of Sphericity was significant, >. 001 and >.001 for T1 and T2 respectively. The items met assumptions, and the values showed these items were factorable. Factors from T1 and T2 are presented in Table 5.

Initially one factor was extracted for T1. A scree plot provided visual confirmation. The variance explained was 70.91%. The second component explained .75, thus the 12 items were returned for factor analysis a second time. The 12 items once

again were subjected to factor analysis using a similar rotation, but the items were cross-loading. Therefore, a third attempt was made employing direct oblimin rotation, which yielded more interpretable factors. Only two items were cross loading (walking ability and worst pain). The result was accepted, and it was found that Q8 attached to the pain intensity items. Therefore, it was apparent that Q8 belongs to the pain intensity construct. The final two factors explained 77.16% of the variance. At the same time, the communalities of Q8 showed a value of .534; the second lowest communality was .624 and the highest was .865, which was acceptable (a value of .7 is desired) (MacCallum et al., 1999).

The T2 showed one factor extracted, and the single factor was confirmed visually by a scree plot. An attempt was made to extract two factors. However, for the second attempt, the second factor was made up of only two items; with one cross loading and another one item (Q8) emerging alone with a strong loading of –.942. Hence, one factor was accepted for T2. Communalities overall were good: the lowest Q8 (.544); the second highest was .807; and the highest was .925 (which was acceptable, >.7).

Table 5. The factors extracted and the communalities from T1 and T2.

Items	F1	F2	Communalities	Items	Factor 1	Communalities
Enjoyment	**1.002**		0.850	Work	**0.925**	0.741
Relation	**.951**		0.751	Activity	**0.923**	0.852
Work	**.753**		0.865	Mood	**0.918**	0.843
Sleep	**.706**		0.734	Right now	**0.901**	0.812
Mood	**.689**		0.763	Average	**0.878**	0.771
Activity	**.617**		0.843	Enjoyment	**0.866**	0.750
Walking	**.467**		0.624	Reverse Q8T2	**0.544**	0.296
Least		**.734**	0.784	Sleep	**0.861**	0.741

Average	**.658**	0.873	Worst	**0.861**	0.855
Right now	**.696**	0.777	Relation	**0.859**	0.738
Reverse Q8T1	**.807**	0.534	Least	**0.850**	0.723
Worst	**.482**	0.862	Walking	**0.807**	0.651
			Q8T2	**–0.544**	0.296
Eigenvalue	8.500	.751	Eigenvalue	8.774	
% of variance	70.910	6.257	% of variance	73.117	
Cumulative %	70.910	77.167	cumulative %	73.117	

(All figures above .4 are shown in **bold**)

4.6.4 Factor labelling and interpretation

Using data set T1 and T2 on separate occasions, 12 items were subjected to factor analysis. Both times orthogonal rotation and principal component extraction was used. However, T1 yielded better results by oblique rotation than by orthogonal rotation, hence results were from pattern matrix. While T2 yielded a factor from component matrix (although attempts to obtain more factors were made but there were cross loadings, and the second factor was not recognisable). Accordingly, it is not possible to obtain a perfect statistical model, there will always be some imperfections due to the complexity of nature. However, researchers need to obtain a model that can yield approximate results that can answer research questions and provide useful results (Flora et al., 2012).

The first factor was represented by items from enjoyment of life, relations with other people, working, sleep, mood, general activity, and walking activity. Enjoyment of life led the list, as so the first factor is labelled *Life satisfaction*. The second factor was represented by items from pain intensity; the least pain, average pain, pain right now, pain relief, percentage of pain relief, and worst pain, which was cross loaded,

sorted to pain intensity construct. In view of the chronological order of the nature of pain the second factor is labelled *Less Pain*.

As for T2, the factor was shown in the component Matrix table because only one factor was extracted. One factor structure showed very high loading; only one of the items was low in its loading (–.544). The highest loading was .925; the rest of the items showed more than .8. Because the first three items factors loaded highly, accompanied by pain intensity loaded in between pain interference and not in chronological order, which means they do not cling to each other and the presence of pain relief Q8 showed negative loading, which it was supposed to do, therefore the factor is labelled as *Physical-psychological relief.*

4.7 Composite scores

The large number of variables had been reduced to two factors from BPI T1, and one factor was obtained for BPI T2. Therefore, the aim was met. All the three factors were converted into composite scores using the non-refined method. All the loadings were added then averaged. This measure is applicable when the factors consist of different numbers of items (DiStefano, Zhu, & Mindrila, 2009). Factor scores for *Life satisfaction, Less Pain,* and *Physical-psychological relief* were converted to composite scores. The composites scores of BPI were retained for regression analysis at a later stage.

4.8 Comparison between five studies from 1998 to 2017

Similarities and differences and strength in mean and SD of the five studies, has been partially discussed in **Section 4.5** and **4.5.1.** Comparison of other aspects are summarised in Table 6. Based on pain intensity and pain interference, this study showed lower scores than shown in previous studies (Abdullah et al., 2006; Uki et al., 1998; Yun et al., 2004; Zalon, 2006).

The results were not unexpected because Abdullah et al. (2006) recruited participants with all types of cancer and within one month after surgery. They also controlled the analgesia: no administration for 24 hours prior to recruitment. One month after surgery meant that wounds were still in the healing process. Healing time has been estimated at about 12 weeks (Nixon, Doll, Kerr, Burge, & Naegeli, 2016). Controlling the analgesia for 48 hours would have contributed to substantial pain because a half-life of 2 to 3.5 hours for oral analgesia gives a normal duration of action ranging from 3 to 6 hours, depending on the analgesia used (Urban et al., 2010). These factors could explain the higher mean than seen in the current study.

Yun et al. (2004) recruited all cancer cases who had metastasis or were recurrent. The participants were still taking their medications during recruitment. Their

study showed a higher mean than the current study, which might have been due to the late stage of cancer; pain was forthcoming. Depending on the regimen given, the participants might have been interviewed at the cessation of the effectiveness of the analgesia. Similarly, Uki et al. (1998) recruited participants with metastatic or recurrent cancer. They were also under active pain management. The higher mean result when compared to the current study is reasonable.

Zalon (2006) on contrary had chosen emergency surgery patients including open heart surgeries, hip replacements, laparotomy, laminectomy, joint replacement, neck surgery, other orthopaedic surgery, and hysterectomy. He recruited at three points: first post-operative day; second; and third post-operative day. Similar principles applied. Depending on the analgesic regimens, based on anecdotal experience these participants would not have been without pain. After three days the surgical sites would still be very raw. The manipulation during surgery could have a residual impact on the pain scores. Hence, the increased means were not unexpected.

The current study scored the lowest overall means (compared to the above-cited studies) because the participants were ambulant, and there had been 3 months to 5 years since surgery; this meant that healing would have taken place (unless there were complications such as infections or some comorbidities – for example diabetic participants or those recruited just after 3 months). The current study excluded stage 4 and recurrent cancer. However, the current study did not involve any intervention. Table 6 summarises the participants and results: mean alpha if deleted and factor extracted, and also gives the methodology of recruitment for the cited studies.

In terms of the alpha if item deleted, the current study scored the highest among all the cited studies. There is a common result shared by all studies: the number of factor scores obtained from BPI, where all the studies yielded two factors. This showed

the tool was repeatable across culture – Malaysia, Korea, Japan, and America, and over time (1998, 2004, 2006, and 2017).

Without involving mathematical and computational methods, the tool was also confirmed sensitive to detecting different pain intensity and interference, based on evidence provided by the cited studies and the current study. The means and alpha values varied across the studies according to timing of the interview and acuteness of the participants. In acute participants, the mean was high and alpha value was lower, as compared to the current study (in which the participants were in the non-acute category). The current study scored the highest alpha values among all the other studies.

It is worth noting that the current study included Q8 (pain relief in relation to analgesia) into the pain intensity group. In fact, it does belong to this group but in a reverse manner – correlating negatively with all the other items. This was a new factor, since the all above studies employed only 11 items. Although the correlations were >.3, the communalities were lower than the other items sharing similar factors. The inclusion of Q8 might not produce a perfect communality; however, the fact that it clung to items in pain intensity, makes this result seem reasonable. First, it could be due to inconsistent responses from participants, and second in real life there is no perfection (Flora et al., 2012). The researcher strongly believes that the role of Q8 revealed in this study should be tested in further studies.

Table 6: Comparison between five studies from 1998 to 2017

Author/year	Participants/*N*	Time	Mean/SD Highest/lowest	Versus current study	Alpha if item deleted	Factors	comments
Current Study/2017	Breast cancer/172	3 months to 5 years post surgery	2.39(2.58)* 1.56(1.83)* 2.60(3.47)** 1.33(1.97)** retest 2.48(2.56)* 1.70(1.75)* 3.20(3.6)** 1.50(2.50)**	L> than all above studies	.95 to .97	2	Test–retest
Abdullah/ 2006	various type of cancer/113	One month post surgery	6.1(2.80)* 2.0(1.186)* 6.7(3.18)** 3.3(2.97)**	H>Current study	.77 to .91	2	Cross-sectional
Zalon/ 2006	Various type of surgery/137	Within 3 days post surgery	Average 7.0(2.5)* 2.9(2.4)* 6.6(3.3)** 2.9(3.7)**	H>Current study	NA (ICC .59, .78, .93	2	Test–retest 3 times
Uki /1998	Metastatic Lung, stomach Breast cancer /121	Ongoing pain treatment	4.89(2.60)* 1.93(1.59)* 4.31(2.76)** 2.97(2.96)**	H>Current study	.78 to .80	2	Cross-sectional
Yun/ 2004	Various advanced cancer/132	Ongoing pain treatment	6.2(2.3)* 2.0(1.7)* 6.2(3.4)** 4.8(3.3)**	H>Current study	.85 to .93	2	Cross-sectional

Pain intensity*
Pain interference**

4.9 BPI tool: Conclusion

In sum, the results obtained from Cronbach alpha reliability and factor analysis provide evidence to support that BPI tool has excellent internal reliability, with overall alpha values .900 and .908, and proved its repeatability, ICC, average value of .85. Additionally, it has revealed good construct validity using the three factors obtained. The first factor was labelled *Life satisfaction*, the second was labelled as *Less pain*, which explained 77.167% of the variance. Meanwhile, for T2, the third factor was labelled as *Physical-psychological* pain, which explained 73.117% of the variance. Taken together, the BPI tool in this study is as reliable as other studies, such as the ones

cited, even if it was not better. Last, but not least, the potential role of Q8 should not be underestimated, prior to replication using a similar study.

Resilience Scale

4.10 Assessment of Resilience scale RS-14 Malay version

4.10.1 Introduction

Study of resilience has gained popularity. It has remained a debatable issue among researchers as regard to its definition. Reghezza-Zitt et al. (2012) deduced that the definition of resilience is equivocal, and means different things to different people from different discipline. In simple words, we stumble and fall from time to time, but we have the ability to get up and move on, and the ability to do so is called resilience (Wagnild, 2011).

There are many resilience scales available, such as the Connor–Davidson Resilience Scale (10-item CD-RISC), the Resilience Scale for Adult (RSA), the Ego Resilience Scale, the Bandura Self-efficacy Scale, the Resilience Scale RS-25, and the Resilience Scale RS-14.

In Malaysia, resilience studies are on the increase. However, the studies have focussed more on hardship from other perspectives but not breast cancer, pain, and surgery. For instance, the Brief Resilience Scale for Adults (Amat, Subhan, Wan Jaafar, Mahmud, & Ku Johari, 2014), conducted on international students who pursued their studies in Malaysia, the Resilience Scale, (Zamani, Nasir, Desa, Khairudin, & Yusooff, 2014) focussed on substance addiction. Similarly, Narayanan and Onn (2016) had recruited university students to employ RS-14 Malay version, the version similar to this study. The researcher acknowledges the authors as the first to publish a paper using RS-14 Malay version. It is also noted that the authors explicitly found a Cronbach alpha of 0.86 for the bilingual version, the English and Malay version. To our knowledge, this study is the first to assess the Malay version of RS-14. Hence this study should

complement the already known findings from the study conducted by (Narayanan & Onn, 2016).

RS-14 Resilience Scale is a subset of RS-25. The 25-item Malay version of RS-25 was provided by the author, G. Wagnild, who allowed it to be reduced to 14 items. The tool as originally developed by Wagnild and Young (1993). The scale is a Likert Scale of 1 to 7, where a score of 1 means completely disagree and a score of 7 means completely agree. The higher the score the more resilient is the person. For RS-14 the lowest score is 14 and the highest score is 98. There are five constructs that make up the questionnaire. First, Equanimity, means the balance of life; second, Meaning, means meaningful life, a sense of purpose in life; third, Perseverance, the ability to continue with life despite setbacks; fourth, Essential aloneness, the ability to recognise and accept a unique life path; and Self-reliance, means belief in oneself. Both RS-25 and RS-14 have been translated and validated in many languages, including the Malay language spoken in Malaysia. However, there is lack in information about its assessment.

4.10.2 Aims of the study

This study aims are:

1. Assess RS-14 Malay version for reliability, and
2. Assess its construct validity.

4.10.3 Material and Method

This was a prospective observational study employing test and retest design. Data collection was from 24th October 2014 to 5th May 2017. Approvals were obtained from the Australian National University, Canberra, Australia, and the University of Malaya, Kuala Lumpur, Malaysia. Participants who met the inclusion criteria were recruited. All participants had breast surgery due to cancer. This study accepted all type of breast cancer surgery, except lumpectomy with no axillary involvement.

4.10.4 Subjects and sampling methods

A total of 274 participants were recruited. 62 of them did not respond to the retest, and 2 participants did not respond to the first test, an attrition rate of 23.4% and leaving 210 participants. There was a further reduction of 4 participants due to no documentation of the time of surgery, leaving 206 participants. These were a mixture of responses in both Malay and English (most Malaysians speak two languages in their daily life). There were 121 responses in Malay, and 85 in English. The researcher also decided to analyse only participants whose surgery was less than five years ago. A total of 16 participants were above 5 years, leaving 105 participants below five years and this number were consequently analysed.

4.10.5 Sample size

Preliminary Analysis had shown the sample size of 105 was adequate for the factor analysis. This decision was in concordance with (Arrindell & Vanderende, 1985), who suggest a factors and variables ratio of 1:20, meaning that a sample as small as 50 would be adequate, since a maximum of three factors were extracted from our sample. While (Barrett & Kline, 1981) stated the model should yield recognisable factors, while Fabrigar et al. (1999) recommended that the communalities should be .7 or above, so that the sample size can be as small as 100. Additionally, Flora et al. (2012) supported the notion, saying that nature was intricate and it was impossible to achieve a perfect statistical model. Assumptions always tend to be violated, and as long as the model can still provide useful results, to a certain extent the violation of assumptions can be overlooked.

4.10.6 Data Cleaning

Data cleaning was done. In the T1 there were three cases missing, while in the T2 four cases missing. The percentage of missing cases were very small 1.0 to 1.9%. So, no imputation was necessary. Using SPSS version 24 package data were checked for

missing values, values outside the range, for example responses from 0 to 10, values such as 11 or 12 would have been rectified by checking the actual responses from the hard copies. This step was performed periodically. Further, data were established missing completely at random. The pattern for missing completely at random is less serious (Tabachnick & Fidel, 2014, p. 97).

4.10.7 Assumptions for data analyses

Sample size was considered adequate. The total number analysed was 105 (n = 105). This number refers to the Malay version of the resilience scale and the data were for subjects less than 5 years after their operation. Although a minimum of 200 is considered the rule of thumb, the researcher considered sample size (n = 105) as adequate for high communalities (.6) and well determined factors (Tabachnick & Fidel, 2014, p. 666).

Multicollinearity was excluded by using a determinant test which showed a value of 4.98E-005 for T1 and 6.26E-005 for T2, meaning that inter-item correlation should be >.3 for most items (and not >. 9), Bartlett's Test of Sphericity should be <.001, and the minimum KMO should be .5. After extraction of communalities, our study qualifies for the value of sample size recommended by (Field, 2013, p. 706). Further, according to Tabachnick and Fidel (Tabachnick & Fidel, 2014, p. 666) , if FA is used descriptively, the assumptions of normality do not need to be enforced.

After this assessment, the researcher proceeded to test agreement as advocated (Polit, 2014), to establish whether the RS-14 Malay version is reproducible. Although there was no intervention, the values were a baseline for future comparison. Further, Kottner et al. (2011), asserted that test of agreement is important not only for completeness of the reporting.

It is important in clinical practice, for the assessment of error that allowed in making clinical decision. Depending on the issue of concern, such as pressure ulcer, the

reliability value should be at least 0.90. However, for research purposes values of 0.60, 0.70, or 0.80 are sufficient. Therefore all 14 items from both T1 and T2 were analysed for interclass correlation coefficients (ICC) using two-way mixed effect model, and using absolute agreement definition as default analysis, the average score was, .85 which was good (Koo & Li, 2016), which exceeded .80 as recommended by (Polit, 2014).

4.11 Analytical method

Descriptive statistics was used to describe basic demographics features, and to establish the mean and standard deviation of each item. The Cronbach alpha was assessed to examine the internal consistency or reliability. RS-14 items were in Likert scales, so it was imperative to report internal consistency (Gliem & Gliem, 2003). The stability of items over a recall period 3 to 7days was assessed using ICC, two-way mixed effect model, and absolute agreement methods. Two way mixed effect model was chosen because test retest samples were not random (Koo & Li, 2016), and with assumption there were no variance from the enumerator but focus was on the pooled data (Shrout & Fless, 1979). Despite no intervention being involved, this study still used a test–retest design. For convenience, the two points are referred to as T1 and T2. Lastly, Factor analysis (FA) was performed to reduce the large data as well as to confirm construct validity. This study had no intention to proceed to a confirmatory factor analysis (CFA), after FA. It is based on reviews, not all FA followed by CFA. After all, these three investigative tools have been translated into Malay language and the English version has been widely employed throughout the globe. Data were analysed using Statistical Package for the Social Sciences (SPSS) version 24.

4.12 Results of the RS-14 Malay version Questionnaire

4.12.1 Results of the demographic features

The demographic features of the Malay version came from two ethnic groups in Malaysia, Chinese and Malay. The highest participation was from women aged 40 to near 60 years old (69.5%), second highest were from age 60 and above (21.9%), and the lowest participation from 25 to near 40 years old (8.6%). Some 40% of the women stated they had experienced comorbidities acquired during their cancer journey, apart from the listed ones. These women showed they had comorbidities ranging from arthritis, 7.6%, gout, 1.0%, chest pain, 12.4%. back pain, 9.5%, and sciatica, 1.9%. These are summarised in Table 7.

Table 7: Demographic features of the RS-14 Malay version questionnaire

Demographic features of the RS-14 Malay version questionnaire (N = 105)

Variable names	Groups	Frequency	Percentages
Age in years	25 to 39.9	9	8.6
	40 to 59.9	73	69.5
	60 and above	23	21.9
Age range 29 to 70	Mean 53.1 (SD 8.80)		
Ethnicity			
Mental illness	None	105	100
Comorbidities	Arthritis	8	7.6
	Gout	1	1.0
	Chest pain	13	12.4
	Back pain	10	9.5
	Sciatica	2	1.9
	Others	42	40.0
	Missing	1	1.0
	Total	105	100

Participants were those who had had breast surgery less than 5 years previously

4.12.2 Internal consistency using Cronbach alpha and Intercorrelation coefficient

Cronbach alpha reliability test was performed on both T1 and T2, and overall descriptive values did not show any significant outstanding value, and the resilience level of the women was moderate (T1: 75.43 considered an average score; and T2, score of 74.99, also considered an average score, summarised in Table 8). While the Cronbach alpha values for reliability were excellent for both T1 and T2 (.923 and .932 respectively), all

items scored .90 and above, and therefore no items were deleted. The results are summarised in Table 9a. As for the agreement test, the values were acceptable – ICC values ranged from .622 to 754, as summarised in Table 9b.

Table 8: Descriptive statistics of the RS-14 Malay version questionnaire

		T1		T2	
		Mean	SD	Mean	SD
Q2	I usually managed one way or another	5.37	1.04	5.32	1.05
Q9	I feel that I can handle many things at a time	5.01	1.28	4.88	1.23
Q13	I can get through difficult times because I have experienced difficulty before	5.39	1.15	5.35	1.09
Q18	In an emergency I am some one people can generally rely on	5.07	1.16	5.11	1.17
Q23	When I am in a difficult situation, I can usually find my way out of it	5.41	1.03	5.43	.970
Q6	I feel proud that I have accomplished things in my life	5.42	1.12	5.48	.952
Q15	I keep interested in things	5.35	1.03	5.41	.979
Q21	My life has meaning	5.84	.865	5.74	.889
Q7	I usually take things in a stride	5.46	1.05	5.38	.934
Q16	I can usually find something to laugh about	5.12	1.27	5.08	1.26
Q10	I am determined	5.43	.917	5.33	1.06
Q14	Self discipline is important	5.48	.952	5.53	.920
Q8	I am friend with myself	5.32	1.20	5.33	1.28
Q17	My belief in myself gets me through hard times	5.76	.914	5.62	.964
	RS-14 items	75.43	14.978	74.99	14.748

Table 9a: Cronbach alpha reliability statistics for RS-14 Malay version questionnaire

Cronbach alpha T1	Cronbach alpha T2	Item Deletion	Number of items
.923	.932	None	14

Table 9b: Reliability and agreement test of RS-14 Malay version questionnaire

	Items	ICC values
Q2	I usually managed one way or another	.680
Q9	I feel that I can handle many things at a time	.754
Q13	My belief in myself gets me through hard times	.717
Q18	In an emergency I am someone people can generally rely on	.746
Q23	When I am in a difficult situation, I can usually find my way out of it	.704
Q6	I feel proud that I have accomplished things in my life	.751
Q15	I keep interested in things	.700
Q21	My life has meaning	.622
Q7	I usually take things in a stride	.698
Q16	I can usually find something to laugh about	.664
Q10	I am determined	.737
Q14	Self discipline is important	.689
Q8	I am friend with myself	.683
Q17	My belief in myself gets me through hard times	.676
Methods: two-way mixed, absolute agreement		

4.13 Factor analysis (FA) procedure and Results

All 14 items of RS-14 Malay version from T1 were subjected to factor analysis using principal component method for extraction, and Varimax method for rotation. Based on an eigenvalue of 1 and factor loading suppressed to .4, and scree test was ordered.

Screening through the output, there were some large or contrasting mean and standard deviation values, and the correlation matrix was above .3, but none >. 9. Based on determinant value, there was no multi collinearity detected (D = 4.98E). Keiser Mayer Olkin (KMO) was .868 and Bartlett's Test for Sphericity was significant, although the rest of the values appeared good; however, the rotated component matrix summarised many cross loadings for T1, Q16 (I can usually find something to laugh about), Q10 (I am determined), and Q15 (I keep interested in things). Hence the RS14 items from T1 were again subjected to factor analysis using the same extraction method, principal component, but the rotation method was changed to direct oblimin. After comparing the two different rotation methods, this study chose the direct oblimin for the explicit factors obtained, which were confirmed by visual inspection of scree plots.

After 10 iterations, three factors were produced. Results showed one cross-loading item (Q18, In an emergency I am someone people can generally rely on). The result also showed the mean and standard deviation were very similar to the varimax rotation, the mean ranging from 5.01 to 5.84, and SD .917 to 1.28; the KMO, .868 (well above .5) (Field, 2013, p. 706); and Bartlett's sphericity test were significant, with *p* value of .001, which showed factor analysis was possible.

There were three factors produced, as presented in Table 10a. The first factor explained 51.345%, the second 10.011%, and the third 8.262%, for a cumulative total of 69.698%. Overall communalities were good – lowest .471, highest .801, and the

average .708. The reliability values for individual factor scored well: Cronbach alpha for T1 F1, T1 F2, and T1 F3 being .705, .870, and .795 respectively.

The first factor consisted of four items and related to accomplishment and taking it easy, which was named *Compose*. The second factor was made up of six items and related to believing in oneself and discipline, named *Confident*, and the third factor was composed of four items concerning an ability to find ways of handling issues, so was named *Capable*.

4.14 Factors obtained from T2 RS-14 Malay version questionnaire

In similar fashion, the RS-14 Malay version T2 was subjected for a second time to principal component extraction and direct oblimin rotation. After six iterations, two factors were obtained. Although on visual inspection, the second and the third scree plots were very close to one another; the fact that the second factor only explained 1. 028, the third factor was not considered. Results were Mean 4.88 to 5.68, and SD from .889 to 1.28. Correlations between items were examined, and the lowest was .346 and highest.780; although multicollinearity was not suspected, a determinant test was done, and yielded a value of D=6.26E-005, which confirmed multicollinearity was unlikely.

The result obtained after the items were subjected to direct oblimin rotation were: based on KMO, .897 for T2, (> .6); and Bartlett's' Test of Sphericity significant >.001, hence the data were fit for FA. The first factor was established for 10 items, while the second factor for 4 items. The factors for T2 are presented in Table 10b.

The variance explained gave, for the first factor, an eigenvalue of 7.637, which explained 54.551% of the variance. The second factor had an eigenvalue of 1.028 and explained 7.340%. Together they explained 61.891% of the cumulative total variance. The reliability for F1 and F2 were alpha .909 and .784 respectively. The communalities average was .739, where a value of at least .7 is desired (MacCallum et al., 1999).

Consequently, the factors were given names according to the highest loadings for each score and for other items that looked significant. Factor 1 was named *Composed*, because the highest loading came from Q21 (my life has meaning), Q7 (I usually take things in a stride), and Q23 (when I am in a difficult situation, I can find my way out). Factor 2 was comprised of Q8 (I am a friend with myself), Q2 (I usually managed one way or another), Q9 (I can handle many things at a time), and Q10 (I am determined), and so Factor 2 was named *Optimism.*

Table 10a: Factors extracted from RS-14 Malay version questionnaire

Items of RS-14 Malay version T1	F1	F2	F3	Communalities
I feel proud that I have accomplished things in my life	**.874**			.751
I keep interested in things	**.862**			.727
I can usually find something to laugh about	**.718**			.744
In an emergency I am someone people can generally rely on	**.556**			.704
My belief in myself gets me through hard times		**.905**		.769
Self discipline is important		**.793**		.743
I am friend with myself		**.728**		.471
I am determined		**.646**		.711
I usually take things in a stride		**.558**		.699
My life has meaning		**.547**		.573
I feel that I can handle many things at a time			**-873**	.801
I usually managed one way or another			**-.830**	.711
I can get through because I had experienced difficulties before			**-.812**	.633
When I am in a difficult situation, I can usually find my way out of it			**-.601**	.708
Cronbach alpha	.705	.870	.795	
Eigenvalues	7.188	1.402	1.157	
% of variance	51.345	10.011	8.262	

NB: Factor loading over .40 are **bolded**

Table 10b: continued Factors extracted from RS-14 Malay version questionnaire

Items of RS-14 T2	F1	F2	Communalities
My life has meaning	**.959**		.745
I usually take things in a stride	**.945**	.	.774
When I am in a difficult situation, I can usually find my way out of it	**.817**		.645
I feel proud that I have accomplished things in my life	**.773**		.606
My belief in myself gets me through hard times	**.732**		.632
I can get through difficult times because I have experienced difficulty before	**.656**		.532
In an emergency I am someone people can generally rely on	**.644**		.527
Self discipline is important	**.520**		.433
I can usually find something to laugh about	**.448**		.460
I keep interested in things	**.447**		.607
I am friend with myself		**.918**	.712
I usually managed one way or another		**.744**	.683
I feel that I can handle many things at a time		**.667**	.570
I am determined		**.555**	.739
Cronbach alpha	.909	.784	
Eigenvalues	7.637	1.028	
% of variance	54.551	7.340	

NB: Factor loading over.40 are **bolded**

4.15 Table 11. Comparison of RS-14 Malay version questionnaire with other studies

The current RS-14 Malay version questionnaire was compared with five other studies as summarised in Table 11. The studies comprised of, the original study by the author of resilience tool Wagnild (2011), which was the original assessment of RS-14, assessment on Japanese population (Nishi et al., 2010), assessment on African population (Abiola & Udofia, 2011), assessment on Finnish population (Losoi et al., 2013), and lastly, (Aiena, Baczwaski, Schulenberg, & Buchanan, 2015) had done assessment on American population.

Similarities, were found from mean and standard deviation values across six studies. Cronbach alpha values for current study, .92 for T1 and .93 for T2 which were in concordance with Wagnild (2011), .93, and Aiena et al. (2015) .93, while other studies (Abiola & Udofia, 2011; Losoi et al., 2013; Nishi et al., 2010), scored .81, .87 and .88 respectively. However, all studies had Cronbach alpha more than cut off point of .70, the value which was endorsed by the original author (Wagnild, 2011).

Nonetheless, the studies varied from other aspects such as analytical models. The current study, and the original study conducted by the author utilised factor analysis. Both employed Principle Component Analysis (PCA) as an extraction method, and direct oblimin as the rotation method. As a result, the current study had extracted 3 factors for T1 and two factors for T2, which explained 51.345% for first factor, 10.011% for second factor and 8.262% for the third factor. For T2 the variance explained was 54.551% for the first factor and 7.340% for the second factor. While the original study had extracted a one factor, and the variance explained was 53%, which was less than the current study. Perhaps the current study utilised samples from the homogenous group that bounced back from adversity, cancer survivors, that explained the extra factors obtained as well as the higher percentages of the variance explained, as opposed to samples from general populations. Conversely, Nishi et al. (2010) had utilised PCA with varimax as the method of rotation, which was different from the current study and that of the original study, they obtained a single factor that explained only 39.4%. On the other hand, (Aiena et al., 2015) had obtained reasonably high percentage of variance explained for the cohort that were comprised of students, 67.6% and the other population that had gone through the adverse event, 53.2%.

Studies by Losoi et al. (Losoi et al., 2013) utilised Pearson correlation, however, Losoi et al. had additional analysis, factor analysis, which yielded single factor, and

explained 39% of the variance. Consequently, had proceeded to Confirmatory Factor Analysis (CFA), that showed RMSEA border line value of .101, similarly, (Aiena et al., 2015) had obtained RMSEA, .11 for the student sample, which was borderline too. Worth to mention, the results were concordance to each other perhaps both studies recruited students as samples.

Taken together, the current study had scored similar weight in term of means and standard deviation values with the referred studies. In similar fashion, the Cronbach alpha values were as strong as other studies. The ICC values were in good range, and particularly, the current study had obtained more factors compared to all other referred studies. Further, the current study had scored strong percentages of variance explained when compared to other studies. When appraised from these perspectives, it is envisaged that RS-14 Malay version questionnaire tool is competitive with other established tools and had fulfilled requirements for good internal consistency and the construct validity, and reproducible. Hence, the RS-14 Malay version questionnaire it is indeed a reliable tool. Simultaneously, it is the first resilience RS-14 tool in Malay version, a language spoken in Malaysia.

Table 11: Comparing RS-14 Malay version questionnaire with other studies

Author & Year	Population N=	Results RS-14				Designs		Comments
		Mean/SD highest/lowest	α	Factor T1	Factor T2	Cross sectional	Test retest /ICC	
Current study 2017/	Breast cancer N=105	4.88 (1.229) 5.74 (.889) 75.45 (10.665) 75.01 (10.795)	.92 .93	3	2		x ICC .70	Malay PCA Direct oblimin loading =>.4 moderate Resilience scores 75.43/74.99
(Wagnild, 2011)	General population Middle aged and older adults N=776	NA	.93	1	-	x	-	Initial RS-14 vs RS25 loading .4, 53% variance PCA direct oblimin r=.97correlate with RS25
(Nishi et al., 2010)	Nursing student n=229 Laboratory student n= 268	63.78 (13.03)	.90 .88	1	1	x	x .84	Japanese 1factor 39.4% variance
(Abiola & Udofia, 2011)	Clinical students (male and female) N=91	74.17 (10.17)	.81	-	-	x		Nigerian Pearson Correlation
(Losoi et al., 2013)	Psychology students Male and female N=243	6.22/4.48	.87	1	-	x		Finnish Pearson correlation 39% variance
(Aiena et al., 2015)	Student N= 1765 Clinical N= 1032 CFA split half Student= 883 Clinical= 516	74.88 (17.05) 63.11 (19.87)	.96 .93	1/1	-	x		United states of America 67.6% variance student 53.2% variance clinical RMSEA-student=0.11 Clinical=0.09

NB RMSEA: Root Mean Square Error of Approximation

Distress Thermometer

4.16 Assessment of Distress Thermometer

The study recruited a total of 230 participants. 53 participants did not respond both time, therefore were excluded. Additionally, 14 participants were found missing, and 3 participants did not know the period of surgery. At last the total number of participants was 159, of which 34 participants were more than five years, and 125 participants were within 5 years duration of surgery.

Distress thermometer questionnaire was not assessed statistically at this stage, since the tool was assessed by NCCN prior to this study. Special permission was given just to conduct the study in English version. Prior to the actual study, the questionnaire was piloted; participants were encouraged to give their feedback on the questionnaire. But, none of the participants raised any issue, neither during the actual data collection.

The nature of its *Yes* and *No* responses; with no intervention, it was anticipated that it would yield bias result. However, the researcher takes it as it is reliable from face validity perspective. Although the face validity may seem trivial to some researchers, face validity has its legitimate weight in research. Face validity is actually content validity that provides assessment of common sense in research conclusion (Gaber & Gaber, 2010). Further, the researcher believed the DT was suitable for this study because, similar questionnaires were tapping the predictors of persistent pain. In future a more structured study to be conducted using DT, perhaps on cognitive intervention study. Besides, Polit (2014), strongly recommended that in clinical practice, the tool should be able to detect the smallest detectable change. On careful appraisal, to the researcher's knowledge, DT had shown that it was robust enough to be employed in this study.

CHAPTER 5
IDENTIFYING FACTORS OF POSTOPERATIVE PERSISTENT PAIN

This chapter describes the methodology used to obtain pain prevalence rates and identify predictors of postoperative persistent pain in women with breast cancer. The data on which it is based is a separate set from that used in Chapter 4. At the same time, resilience level and distress level were investigated to see whether any of the variables were predictors of persistent pain symptoms. The results are compared with findings from previous studies conducted in other countries. The chapter also highlights what is new to the research, and finally the findings are integrated into the Theory of Unpleasant Symptoms (TOUS).

Keywords

predictors, stepwise regression, dependent variables (DV), independent variables (IV), women with breast cancer, duration of six months to one year postoperatively, symptoms clusters, TOUS, prevalence.

5.1 Aims of the study

- To survey the prevalence of persistent pain in women with breast cancer
- To identify predictors of persistent pain experienced between 6 months and 1 year after the operation
- To attempt to integrate the findings into a Theory of Unpleasant Symptoms (TOUS)

5.2 Research questions

- What is the prevalence of pain?
- Is the woman's age, stage of cancer, type of surgery, or other factor a good predictor for postoperative persistent pain in women with breast cancer?
- Can any of the findings be integrated into the TOUS model?

5.3 Methodology

5.3.1 Participants and settings

This was a cross-sectional, prospective, and correlational study with retrospective review of medical record. The participants were women with breast cancer who had had surgery 6 months to 1 year previously. One hundred and twenty-three participants were recruited (*n*=123). Four participants did not meet the study criteria (refer **57-58**) and were excluded: two of them were aged over 80 (83 and 84 years old); one of them did not have cancer, and in one woman only a simple lumpectomy was done. Thus, one hundred and nineteen participants were analysed (*n*=119).

The age of the participants ranged from 25 to 80 years old. The mean age of participants was 56.7 (SD=11.0). The two main ethnic groups of Malaysia were chosen: Malay and Chinese. The Malay population, as in the 2017 census, is approximately 68.8%, and the Chinese makes up 23.2%. The remaining 7.0% is made up of Indians and other ethnic groups (https://en.wikipedia.org/wiki/Demographics_of Malaysia#Etholingistic_groups). These women were those who had been receiving medical attention at the University at Malaya Medical Centre (UMMC). UMMC is a tertiary referral centre from all over Malaysia.

5.4 Measures

5.4.1 Brief Pain Inventory (BPI)

This study had chosen to survey the prevalence of pain intensity and interferences by using BPI. This tool was developed in 1993 by Cleeland, to assess cancer pain (C. S. Cleeland, 2009). The BPI is a 9-item questionnaire, with seven additional sub-items in Q9. The questionnaire seeks to assess pain intensity on a 4-item scale, namely worst pain, least pain, average pain, and pain right now. The items to measure how pain interferes with daily life consist of general activity, mood, walking ability, normal work, relations with others, sleep, and enjoyment of life. Both pain intensity and interference

with life were ranked on a Likert scale: 0 (no pain) to 10 (pain as bad as can be imagined). The ratings were 0 (no pain), 1–4 (mild pain), 5–6 (moderate pain), and 7–10 (severe pain), the same cut off points as used by (Serlin et al., 1995).

Definition

The operational definition of pain in this study was any pain, unpleasant sensation, or ill-defined pain due to side-effects of surgery. It was a self-reported pain. For consistency, all sensation experienced was referred to as pain. This definition is reasonable because the pain in breast cancer after surgery cannot be described objectively. People identify pain and unpleasant sensations interchangeably. Therefore, responses to pain were very much open-ended questions. The pain could perhaps be influenced by culture, as in Malaysia this aspect has not been well explored. Studies have found that culture plays an important role in the perception of pain symptoms (Lasch, 2000). However, this study did not explore the area of culture.

5.4.2 Resilience scale RS-14

A 7-point Likert Resilience Scale, RS-14, was used (Wagnild, 2011). The scale ranges from 1 (strongly disagree) to 7 (strongly agree). The tool has five domains: self-reliance, made up of five items; meaning, consisting of three items; equanimity, comprising two items; perseverance, a combination of two items; and existential aloneness, another combination of two items. The higher the score the more resilient was the person.

5.4.3 Distress thermometer

A binomial-response questionnaire, a modified ‘Distress thermometer’, was also used. It was adopted with permission from NCCN (V.2.2013). The tool covers five domains called problem lists: practical problems, consisting of four items; family problems, made up five items; emotional problems, comprising eight items; spiritual/religious concerns, comprising three items, and physical problems – are total of 23 items.

Similarly, prior to analysis, the DT variables were recoded from the original (1 = Yes, 2 = No) to 1 = Yes and 0 = No and then summed.

5.5 Ethical approval

The data were collected after ethical approval from both ANU, Australia, and UM, Malaysia. Data collection commenced on 24th June 2015 and finished on 5th May 2017. All participants were recruited by trained enumerators and research associates according to research ethical guidelines. The current study recruited 123 participants but only 119 participants met the criteria for analysis.

5.6 Data analysis

There were three stages to data analysis. The first stage was to use descriptive statistics to calculate the frequency and percentages of the demographic features of the participants, followed by the frequency and percentages of items in the medical history of the participants. The second stage was a simple linear regression to investigate interaction between pain intensity and pain interference with life, and proceeded with a stepwise multiple regression analysis to identify predictors for pain intensity and interference with life.

A stepwise method of regression was performed to identify the predictors affecting persistent pain postoperatively in these women with breast cancer. The analysis was divided into two segments: pain intensity and interference with life due to pain. Pain intensity and interference with life were considered as two dependent variables throughout the process of identifying predictors. This study was based on the actual data collected, and no imputations were made. All analyses were done using IBM SPSS (version 24) for descriptive analysis, assessment of assumptions, and regression.

5.7 Sample size and number of IVs

There are many rules of thumb regarding sample size for regression analysis. Tabachnick and Fidel (2014, p. 159) advocated $N \geq 50$ for 8 IVs, so if 6 IVs are used, then $8 \times 6 = 98$ participants are needed. However, in a small sample size instead of using R^2 one should use an adjusted R^2 for variance explained by the population model (Austin & Steyerberg, 2015). These authors had shown that two participants per variables was adequate. In linear regression, this ratio 1:2 ratio yields adequate estimates of regression coefficients, standard errors, and confidence intervals, and guarantees unbiased estimates of coefficients and adjusted R^2 values. For 119 participants, this study used factor size n=5 to reliably identify factors affecting pain. This study used composite scores for testing the Resilience scale RS-14 and the Distress thermometer, and ensured that the model reliably fitted the data before making a final interpretation.

A stepwise method of regression was used for this research because, first, it uses an iteration process to obtain the best predictors (that is, those which contribute the most variance to the model) and excludes the rest (Field, 2013, p. 322). Also, the researcher used a small sample size which is only suitable for exploratory studies rather than strong hypothesis testing, and stepwise regression is able to be used in this situation (Steyerberg, Eijkemans, & Habbema, 1999). All data were assessed for normality, multicollinearity and heteroscedastic, and found, assumptions seemed reasonable.

5.8 Preliminary data analysis

Prior to the actual analysis, data from RS-14 were assessed for reliability using Cronbach alpha. The data were found to have nearly similar weight: alpha value = 0.911 and all items showed .900 to .911. Hence the data were combined and placed in the respective constructs: self-reliance, meaning, equanimity, perseverance, and existential aloneness. The binomial responses from the Distress Thermometer were recoded (the

initial responses were 1 = Yes and 2 = No, and they were recoded as 0 = No and 1 = Yes). Therefore these became new variables and were renamed (Pallant, 2011, p. 92).

The data for descriptive analysis was screened for missing values. No real issues with missing values were found, probably because all errors were addressed at intervals during data entry. All demographic features – ethnic group, age, marital status, education status, employment status, and household income/month – were screened for normality, and there was no departure from normality.

Due to the small frequencies, changes were made to a few items prior to running the analysis. For example, concurrent comorbidities – which included arthritis, chest pain, back pain, and others – were combined and converted into Yes and No responses. Similarly, for marital status, widowed and divorced were combined; no formal education and primary level of education were combined; and stages of cancer stage 0 and stage 1 were combined.

Using the data based on pain today (n=51), the data were subjected to simple regression and stepwise method of regression. All data were assessed for normality, multicollinearity, and heteroscedasticity.

Stepwise method of regression is a sensitive test for noisy data (Burkholder & Lieber, 1996). Preliminary analysis found data was normally distributed. The values as guidelines for this study were: Tolerance test > .1 and VIF < 10; visual inspection; histograms followed a bell curve; P–P plots were positively linear and the standard residual was within ±3; and Durbin–Watson was not <1. When the majority of criteria were met, analysis proceeded, with efforts to use stepwise method of regression analysis to fit models to the data. Throughout this study the dependent variables were either pain intensity (Pain intensity) or interference with life caused by pain (Pain interference).

5.9 Results of demographic features overall

In addressing pain prevalence, a total of 43% of the women were found to have had pain on that day, which means the rest either had no pain or just experienced unpleasant sensations. The questionnaires only asked to recall pain over the last 24 hours. The demographic features of the women with breast cancer are summarised in **Tables 12.**

The participants' ages ranged from 25 to 80 years. This study divided their ages into three groups, and 51.3% of them were aged 40 to nearly 60 years, the highest number of participants, the second biggest age-group was 60 years and above, 42.9%, and the smallest group of participants were aged from 25 to near 40 years, 5.9%.

The study participants came from different sections of the population, ranging in education level from no formal education to a higher degree. The majority of the participants were married (67%), with a small percentage single, divorced, or widowed. It was very clear that most (67%) were not working. Many participants earned less than RM5000 per month. Only 21% earned more than RM5000, which could potentially impact on their choice of treatment, since many treatments are expensive.

The women in the current study had various types of breast surgeries, for example lumpectomy with axillary clearance, lumpectomy with sentinel lymph node biopsy, mastectomy with axillary clearance, mastectomy with axillary dissection, breast conserving surgery, or breast reconstruction, which can be either LD flap (latissimus dorsi flap) or TRAM flap (transverse rectus abdominis muscle flap). None of the participants had undergone GAP and TUG (gluteal free flap) or TUG (transverse upper gracilis flap). For operational reasons, the surgeries were grouped into three: mastectomy and reconstruction; mastectomy with no reconstruction; and lumpectomy with breast conservation surgery.

The surgery type was determined by individual situations, such as stage of cancer, and the choice being made by the participants. Most of participants had

mastectomy with no reconstruction (65%). The current trend is breast reconstruction surgery, and this study showed that 13% of the participants had mastectomy and reconstruction. 23% of the participants had lumpectomy and breast conservation surgery. Apart from surgery, there were additional treatments received by participants; chemotherapy, radiotherapy and hormonal therapy. However, this study did not survey the details of those treatments received at individual basis.

UMMC has an up-to-date screening facility, and the stage of cancer is based on the American Joint Committee on Cancer (AJCC, 7th edition). Some 5% of participants were picked up early, at stage 0; 37% who were detected at stage1, and 34% at stage 2. Although the government advocates early screening, there were 23.5% of participants who presented at hospital at stage 3. This study excluded stage 4.

The initial pain scores ranged from 0 to 10, with the higher the score the more intense the pain. For operational reasons and future reference, this study divided the pain intensity and pain interference into four categories: 0, no pain; 1 to 4, mild pain; 5 to 6, moderate pain; and 7 to 10, severe pain (Serlin et al., 1995). The pain reported in this study was pain as a side-effect of breast surgery. Summary of the findings are in **Table 13.**

Pain prevalence was 43%. Using this percentage, the pain intensity construct was taken to be worst pain, least pain, average pain, and pain right now. Similarly, the pain interference construct was framed in terms of general activity, mood, work, relationship, sleep, and enjoyment of life. For pain intensity, the participants' responses scored no pain in all domains, demonstrating that pain was not a stable symptom. Only in least pain did the participants not give a severe pain response, whereas in other domains the participants scored moderate (7.8%) to severe (19.6%) pain. Based on these categories, there is evidence that pain occurs at a level of concern.

In all domains, most participants scored no interference (31.4% to 52.9%). However, there was a significant proportion of others who rated that their pain did interfere moderately (9.8% to 21.6%) or severely (5.9% to 25.5%).

5.10 Identifying factors affecting persistent pain

The pain reported in this study was pain as a side-effect of breast surgery. Summary of the findings are given previously in **Table 13.**

The factors identified as contributing to persistent pain are tabulated in **Table 14**. A simple regression analysis was conducted to identify predictors for pain intensity and pain interference. Out of 119 participants, only 51 participants reported pain for the current day. Data were sorted separating pain today (42.9%) and no pain today (56.3%). To investigate predictors, only those data showing pain today were used for analysis.

Pain intensity comprised categories of worst pain, least pain, average pain, and pain right now, and pain interference comprised combinations of general activity, mood, walking ability, normal work, relationship with others, sleep, and enjoyment of life.

5.11 Assessment Pain intensity as dependent variables and Pain interference as a predictor

A total of 26.9% of the variance for pain intensity was explained by pain interference. When the model was fitted to the data, ANOVA output revealed $p \leq .005$. The resulting coefficient confirmed that pain interference had a positive impact on pain intensity, each unit increase in pain interference providing a .38 increase in pain intensity. The regression results can be statistically summarised as $F(1,49) = 19.386$; $p \leq .005$, $R^2 = .283$.

The initial pain scores ranged from 0 to 10, the higher the score the more intense was the pain. For operational reason and future references, this study had divided the pain intensity and pain interference into four categories, 0, no pain, 1 to 4, mild pain, 5 to 6,

moderate pain and 7 to 10 severe pain. The pain reported in this study was pain as a side effect of breast surgery, and are summarised in Table 13.

5.11.1 Results of Identifying Factors affecting persistent pain

The results of identifying predictors of persistent pain are summarised in Table 14. A descriptive statistic was used to identify pain intensity and pain interference, and prevalence of participants who stated "Yes" for the question do you have pain today? Out of 119 participants, only 51 participants reported pain for the day. Data were sorted separating pain today (42.9%) and no pain today, (56.3%). Only those data that were responded to have pain today were utilised for all analysis to investigating predictors. Pain intensity comprised of worst pain, least pain, average pain and pain right now items, and pain interference were the combinations of general activity, mood, walking ability, normal work, relationship with others, sleep and enjoyment of life items.

5.11.2 Stepwise regression results

Model for identifying predictors affecting pain in this study:

$$y = a + bx_1 + bx_2 + \cdots + e,$$

where $a = \ intercept, b = slope, \ e = error,$ and y is dependent variable and x is independent variable.

Adjusted R^2 was used to assess the percentage of variance

Table 14, Results: The predictors of pain using stepwise regression model.

Segment 1: When pain intensity was the dependant variable, there were nine independent variables from, the demographic and clinical variables, namely, age of participants in groups, marital status, education level, employment status, household income, surgery type, stage of cancer, concurrent pain, and pain interference. The iteration was completed after one step. Only pain interference was the predictor of pain intensity. The remainder eight variables were removed. Pain interference was a strong predictor, 0.749. For each increment of pain interference there was positive linear

increase in pain intensity of 0.749. The model showed a good fit to the data. It explained 26.9% of the variance, and was statistically significant, $F(1, 49) = 19.386$, $p = 0.001$, R^2 =. 283, adjusted R^2 = .269.

Pain intensity remained the dependant variable, but ten composites scores were independant variables: self-reliance, meaning, equanimity, perseverance, and existential aloneness from the RS-14. From DT the independent variables were: practical problems, family problems, emotional problems, spiritual problems/religious concerns, physical problems, and pain interference. The independent variables were subjected to regression analysis using the stepwise method. The process ended after three iterations. However, the spiritual problems/religious concerns did not fit the model, and the process was repeated after excluding this factor. The model was stopped after two iterations. Three predictors were identified: pain interference, perseverance, and practical problems, explaining 26%, 35%, and 47% of the variance respectively. The rest of the independent variables were excluded. The result suggest that practical problems is the strongest predictor, suggesting that every unit increased in distress level, pain intensity reduced (B=- .911), and for the resilience level, every unit increased in perseverance, pain intensity reduced (B=- .444). Lastly, for pain interference, when it increased, pain intensity also increased (B = .309). The model was found to be statistically significant [$F(3,41,44) = 13.827$, $R^2 = 0.267, .381, .467$), and adjusted R^2 = .250, .351, .467, p value = 0.001].

Segment 2: Pain interference as dependent variables

When pain interference was the dependant variable, the demographic and clinical variables were subjected to stepwise regression in similar fashion to obtain predictors. A total of nine independent variables from demographic and clinical features were used: age of participants in groups, marital status, education level, employment status, household income, surgery types, stage of cancer, concurrent pain, and pain

interference. The iteration was completed after one step. Only pain intensity was found to be a predictor of pain interference. The remaining eight independent variables were removed. Pain intensity was a strong predictor (0. 749). For each increment of pain interference there was positive linear increase in pain intensity of 0.749. The model showed a good fit to the data, explaining 27% of the variance, and was statistically significant [$F(1,49) = 19.386$, $p = 0.001$, $R^2 =$. 283, adjusted $R^2 = .269$].

While pain interference remained the dependant variable, the predictor variables were self-reliance, meaning, equanimity, perseverance, and existential aloneness from the RS-14, followed by variables from DT, practical problems, family problems, emotional problems, physical problems, and pain intensity, and they were subjected to regression analysis using the stepwise method. The process ended after single iteration. However, this time the spiritual problems/religious concerns were not subjected to analysis because they did not fit the model. Pain intensity was the only predictor identified. The participants experienced an increase in pain intensity when there was an increase in pain interference of .749. It explained 25% of the variance in pain interference. The model was found to be statistically significant [$F(1,43) = 15.646$, $R^2 = .267$, and adjusted $R^2 = 0.250$, $p = 0.001$].

Table 12: Demographic features of women with breast cancer (*N*=119)

Variable	Group	Frequency	%
Ethnicity	Malay	52	43.7
	Chinese	67	56.3
Age	25 to 39.9	7	5.9
	40 to 59.9	61	51.3
	60 and above	51	42.9
Marital status	Single	24	20.2
	Married	80	67.2
	Widowed	12	10.1
	Divorced	3	2.5
Education status	No formal education	4	3.4
	Primary school	26	21.8
	Secondary school	55	46.2
	University/college	32	26.9
Employment status	Working	39	32.8
	Not working	80	67.2
Household income/month	<RM1500	27	22.7
	RM1501–RM3499	38	31.9
	RM3500–RM 4999	13	10.9
	>RM5000	34	28.6

Variable name	Group	Frequency	%
Group of surgery	Lumpectomy +conserv	27	22.7
	Mastectom + reconst	15	12.6
	Mastectomy + no reconst	77	64.7
Stage of cancer	0	6	5.0
	1	44	37.0
	2	41	34.5
	3	28	23.5
Other treatments	Chemotherapy	79	66.4
	Radiotherapy	75	63.0
	Hormonal therapy	93	78.2
Duration after surgery	>6 months	103	86.6
	<1 year	16	13.4
Concurrent comorbidity	Arthritis	2	1.7
	Chest pain	5	4.2
	Back pain	6	5.0
	Other*	7	5.9
	None	80	83.2

*Lymphedema, hypertension, hypercholesterolemia, diabetes, chronic cardia failure, gastritis, and thalassemia

Table 13. Pain prevalence: Pain intensity and pain interference in women with breast cancer (*N*=119)

Variable	Group	Frequency	%
Pain today	Yes	51	43
	No	67	57
Pain intensity and pain interference shown by participants who scored "Yes" for pain today (*n*=51)			
Worst pain	No	7	13.7
	Mild	24	47.1
	Moderate	10	19.6
	Severe	10	19.6
Least pain	No	15	29.4
	Mild	29	56.9
	Moderate	7	13.7
	Severe	0	0
Average pain	No	6	11.8
	Mild	32	62.7
	Moderate	10	19.6
	Severe	3	5.9
Right now	No	17	33.3
	Mild	25	49.0
	Moderate	5	9.8
	Severe	4	7.8
General activity	No	16	31.4
	Mild	18	31.4
	moderate	9	17.6
	Severe	8	15.9
Mood	No	15	29.4
	Mild	16	31.4
	Moderate	11	21.6
	Severe	9	17.6
Work	No	16	31.4
	Mild	17	33.3
	Moderate	5	9.8
	severe	13	25.5
Relationship	No	27	52.9
	Mild	14	27.5
	Moderate	7	13.7
	Severe	3	5.9
Sleep	No	18	35
	Mild	16	31.4
	Moderate	7	13.7
	Severe	10	19.6
Enjoyment	No	20	39.2
	Mild	14	27.5
	Moderate	8	15.7
	Severe	9	17.6

Formula

$Y = a + bx_1 + bx_2 + ...+ e$

Table 14: Summary of Predictors of persistent pain in women with breast cancer

Dependant/Independent variables	Percentage explained variance	B	B Std error	Coefficient *p*
Model 1				
Y = Pain intensity X = Demographic variables				
Pain intensity		1.721	.329	.001
Pain interference	26.9	.378	.086	.001
Model 2 Y = Pain intensity X = RS-14 and DT variables				
Pain intensity		7.325	1.482	.001
Pain interference	25.0	.309	.077	0.001
Perseverance	35.0	–.444	.126	0.001
Physical problems	47.0	–.911	.287	0.003
Model 1 Y = Pain interference x = Demographic variables				
Pain interference		.789	.567	.170
Pain intensity	26.9	.749	.170	.001
Model 2 Y = Pain interference x = RS and DT variables				
Pain interference		.707	.652	.284
Pain intensity	25.0	.749	.189	.001

Significant P value ≤.005
CI = 95%

Table 15: Removed IVs when DV= Pain intensity when practical problems, perseverance and pain interference were predictors.

Excluded Variables[a]

Model		Beta In	t	Sig.	Partial Correlation	Collinearity Statistics		
						Tolerance	VIF	Minimum Tolerance
1	Prac	-.295[b]	-2.377	.022	-.344	.997	1.003	.997
	Fam	-.133[b]	-1.016	.315	-.155	.988	1.012	.988
	Emo	-.059[b]	-.449	.656	-.069	.998	1.002	.998
	Physi	-.068[b]	-.512	.611	-.079	.997	1.003	.997
	Self reliance	-.247[b]	-1.955	.057	-.289	1.000	1.000	1.000
	Meaning	-.148[b]	-1.133	.264	-.172	.991	1.009	.991
	Equanimities	-.171[b]	-1.319	.194	-.199	.997	1.003	.997
	Perseverance	-.340[b]	-2.777	.008	-.394	.984	1.016	.984
	Existential aloneness	-.130[b]	-.998	.324	-.152	.998	1.002	.998
2	Prac	-.354[c]	-3.177	.003	-.444	.974	1.026	.962
	Fam	-.015[c]	-.116	.908	-.018	.865	1.157	.861
	Emo	-.011[c]	-.092	.927	-.014	.978	1.022	.964
	Physi	-.068[c]	-.552	.584	-.086	.997	1.003	.982
	Self reliance	-.118[c]	-.862	.394	-.133	.792	1.263	.780
	Meaning	.132[c]	.811	.422	.126	.562	1.780	.558
	combined Equanimities	.024[c]	.159	.874	.025	.690	1.448	.682
	Existential aloneness	.102[c]	.677	.502	.105	.656	1.524	.647
3	Prac	-.099[d]	-.814	.421	-.128	.826	1.210	.826
	Fam	-.045[d]	-.397	.693	-.063	.970	1.031	.946
	Emo	-.028[d]	-.248	.806	-.039	.984	1.016	.962
	Self reliance	-.077[d]	-.612	.544	-.096	.783	1.278	.754
	Meaning	.154[d]	1.049	.300	.164	.561	1.784	.547
	Equanimities	-.017[d]	-.124	.902	-.020	.684	1.462	.678
	combined Existential aloneness	-.099[d]	-.657	.515	-.103	.538	1.860	.538

a. Dependent Variable: pain intensity

b. Predictors in the Model: (Constant), pain interference

c. Predictors in the Model: (Constant), pain interference, combined Perserverence

d. Predictors in the Model: (Constant), pain interference, combined Perserverence, SumDT1

5.12 Summary of results

1. A total of 43% of the women experienced pain 6 months to 1 year postoperatively.
2. Evidence showed that pain experienced by these women was unstable, based on the reported pain level today. Considering there were four domains of reported pain intensity, the study found there were some women who scored no pain.
3. The women found that pain interfered with general activity, mood, work, relationship, sleep, and enjoyment. Based on the highest percentage interference in life, three predominant symptoms were identified, work, mood and sleep
4. Women who experienced pain most frequently scored it as moderate to severe. Based on clinical practice, the intensity was significant. Cultural considerations need to be considered, but the levels call for closer investigation.
5. Pain interference in life, resilience, and distress were predictors of pain intensity.
6. Age, stage of cancer, co-morbidities, type of surgery, marital status, education level, employment status, and household income were not significant contributors to pain intensity or interference of pain with daily living these items were excluded in stepwise method multiple regression as presented in Table 15.

CHAPTER 6
DISCUSSION

This chapter amalgamates discussions of results from Chapter 4 and Chapter 5, which each dealt with separate data sets. The combined results are compared with the findings from previous studies conducted in other countries. The chapter also highlights new findings, and their implications. Finally, the results are integrated using TOUS.

6.1 Prevalence Pain intensity and pain interference

Despite increasing research interest in Malaysia about breast cancer, this study is the first to survey persistent pain in women with breast cancer over the period 6 months to 1 year postoperatively. The study found that 43% of women experience persistent pain after breast surgery, a substantial figure. The percentage of persistent pain found in this study is in agreement with other studies (Gartner et al., 2009; Mejdahl et al., 2013; H. S. Smith & Wu, 2012). Given the high prevalence of pain, more attention is needed to reduce comorbidities and other burdens experienced by women with breast cancer.

Across this study, 10–20% of women experienced pain which fell in the moderate category (scores 5–6), while 6–20% experienced severe pain (scores 7–10). In clinical practice, moderate pain is taken as significant and should be managed and documented. In fact, Pereira et al. (2017) considered severity score of pain ≥3 is a clinically relevant outcome. Although the cut-off point for persistent pain may be disputed by some researchers [Ojeda et al. (2016)], a cut-off point acts as a baseline for action in pain management.

A large percentage of the women responded that pain did not interfere with their general activity, mood, working ability, relationship with others, sleep, or enjoyment of life. However, there was substantial evidence across all domains that pain did interfere with the women's lives. Pain interfered significantly with **work, mood, and sleep**, which are important components of sustaining a sense of well-being. Although pain is unstable and complex, it might be a good idea to improve on the current pain-

management medication that the women had been prescribed (paracetamol, celecoxib, and tramadol, and at times pregabalin and gabapentin), making sure they take their medication as advised by their doctor. Education and supervision of analgesia is deemed necessary so as to alleviate levels of suffering and prevent further comorbidities.

The current study found a unique situation in which, among the women who scored "Yes" pain today, there were still responses as "No" pain in all the four categories of pain intensity. At first glance, the responses were thought to lack coherence. Instead, this phenomenon may have shown that pain was unstable, and possibly they had taken some pain relief or been distracted (K. L. Kwekkeboom et al., 2012). There is an implication here for health care providers, that they should ensure adequate pain assessment and not disbelieve patients, which might consequently deprive the women of pain relief.

6.2 Discussion of the assessment of the resilience scale RS-14

The main aim of this study was to assess the RS-14 Malay version questionnaire. This tool was an extraction of the Malay version RS-25.

6.2.1 Reliability

This study had provided evidence that the RS-14 resilience scale Malay version questionnaire is a reliable tool, in terms of both its internal consistency and construct validity. Based on Cronbach alpha, the 14 items scored highly. Overall Cronbach alpha values were .923 and .932 respectively, with no items deleted, a very favourable outcome. (Field, 2013, p. 709) cautioned about the interpretation of high Cronbach alpha values). To confirm the outcome, the reliability test was also calculated for individual factors. These showed the average Cronbach alpha ranged from .705 to .909. The ICC confirmed the reliability of the tool, revealing an average value of .70, which is acceptable (Field, 2013, p. 712; Kottner et al., 2011, p. 100; Pallant, 2011).

6.2.2 Construct validity

Regarding the construct validity, there was only one cross-loading on each of the questions on the T1 data set (Q18, in an emergency I am someone people can generally rely on). Similarly, for T2 (Q15, I keep interested in things). However, the factors were easy to identify. The factors were strong and explained 55–70% of the data. Additionally, overall communalities were good, ranging from an average .708 to .739 (Field, 2013, p. 698; MacCallum et al., 1999) which is acceptable. Cronbach alpha was calculated for all factors, and the results were as follows. For T1: F1, F2, F3 were .705, .870, and .795. For T2, the values were: F1, .909 (considered an excellent value), and F2, .784, (categorised as a good value) (Field, 2013, p. 709; MacCallum et al., 1999). Overall, these features revealed the level of rigorousity of this study. Worthy to note, the measures was adopted as advocated by Field (2013, p. 706).

6.3 Comparison of RS-14 Malay version questionnaire with cited papers

6.3.1 Factor structure, culture, and resilience

The current study used the RS-14 Malay version of the questionnaire, and here the researcher looks at similar studies from other countries where the issue of culture is raised. For example, Nishi et al. (2010) raised the issue in their study to explain low values of test–retest and the concurrent validity. Nishi et al. (2010) stated that Japanese people are inclined to suppress their expression of positive affect. Diverse factor structure could also be due to how resilience is interpreted, since it could depend on culture and context (G. T. Ruiz-Párraga, López-Martínez, & Gómez-Pérez, 2012). In the view of Lundman et al. (2007), resilience was a construct highly valued by western cultures.

Considering the above, the current study extracted five factors in total, which possibly means that Malaysians were expressive in their affect. However, this researcher's view is that there the good values obtained in the current study could be

due to multifactorial effects. It happened that the participants of this study had gone through a very bad scenario, being diagnosed with breast cancer. The impact of this might be too much for many people to handle – adjustment to life expectations, support needed physically, psychologically, and financially from families and community – such a situation might cause survivors to respond in a way shown in the current study. To be certain, the issue needs to be confirmed with further research.

All studies have their limitations. For example, one of the cited studies, Abiola and Udofia (2011), obtained relatively low concurrent validity despite high internal reliability. Further, although the sample comprised intelligent students, the authors underlined that the sample size might not represent all the ethnic groups in the Nigerian population. Similarly, although the study of Losoi et al. (2013) achieved good consistency and reliability, the sample comprised highly educated participants, which could have created some bias in the results. Although Aiena et al. (2015) had a large sample size and possessed several major strengths, the researchers still reported some limitations: for example, there was a lack of ethnicity diversity, with participants coming from a predominantly white population.

The current study has its own limitations. Apart from the relatively small sample size, the sample was from one centre. The site was a tertiary referral centre and is well regarded in terms of good facilities, as it is a teaching hospital. Therefore, the current study may not represent the resilience level of women with breast cancer in another centre. Nonetheless, the resilience shown by the women in the current study cannot be underestimated. At the very least, it may be a catalyst for a replicate study with a bigger sample size and from multiple sites, making the findings more generalisable.

In conclusion, all the above tools have shown satisfactory psychometric properties, despite various samples, sample sizes, and analytical models. In research there are always variables that researchers cannot control.

Having given a general impression of pain intensity and interference with life in these women, it is important to ascertain whether some variables acted as predictors. It is also important to extract constructs such as distress and resilience level and see whether these constructs play a role as predictors. Hence the next section is an analysis which identifies factors behind postoperative persistent pain in women with breast cancer.

6.4 Discussion of results on identifying predictors of persistent pain

The prevalence of persistent pain for the women under study was 43%, as has been established and discussed earlier. This study utilised stepwise analysis to identify predictors of persistent pain after surgery in women with breast cancer. Distress, resilience, and pain interference in life were found as predictors of pain in these women. The following paragraphs discuss the above predictors.

6.4.1 Predictors of persistent pain, distress, and resilience

The women experienced low distress and low resilience in the presence of a high intensity of persistent pain. When the pain level increased, so did the interference level. This connection agrees with Sturgeon and Zautra (2010), who found that pain and distress tend to affect each other (although the impact of overall persistent pain was probably influenced by demographic factors). Individuals who experience persistent pain, but adopt a coping attitude, were found to experience less pain (Roditi & Robinson, 2011). When an individual adapts to pain, it is called coping, and is influenced by other psychological resources, for instance, the one related to this study, resilience. This contrasts with a study (Eccleston, 2001) found increased pain was associated with increased emotional distress, and normally occurred in individuals with a catastrophising attitude. Perhaps the women under study had adjusted their coping mechanisms to deal with high pain.

The connection between low resilience and high pain found in this study is consistent with Zautra, Johnson, and Davis (2005), where the authors found that positive affect led to lower pain. The result is also supported by Souza, Vasconselos, Caumo, and Baptista (2017), in their study of noncancer persistent pain, which revealed that those with low-grade pain showed higher resilience. According to Min et al. (2013) resilience may independently contribute to lower distress, and similarly in another study (Friborg et al., 2006), patients who reported high resilience experienced less pain and less distress. The connection is significant in clinical practice because a resilient response to pain can be described as a confrontational style which leads to better adjustment to pain, and can be made use of in making adjustments to pain management (G. T. Ruiz-Párraga et al., 2012).

One of the important elements is education for patients to understand their pain. Health care providers acknowledge that resilience is a very complex construct, and is influenced by personal experience, culture, environment, and genes; hence, it may need multidisciplinary professional collaboration (Souza et al., 2017). Of course, pain and distress are complex constructs too. Taken together, the results of this study are potentially useful for pain management; by intervening appropriately, it might improve the well-being of women with breast cancer or with other types of cancer in general.

6.4.2 Predictors of persistent pain, Demographic features

The results of the current study was in concordance with (Belfer et al., 2013) who found that age and surgery were not predictors of persistent pain. On the contrary, Wang et al. (2016) found that there was high evidence that young age and axillary dissection were predictors of persistent pain. Persistent pain has also been reported in younger age groups in the general population (Rustøen et al., 2005); however, possibly only 5.9% of the young age group participated in this study, so their presence did not contribute to statistical significance.

The current study also revealed that marital status and employment status were not predictors of persistent pain, which is in accordance with a study conducted by Miaskowski et al. (2012). Similarly, this study was in agreement with Rief et al. (2011) who found that the stage of cancer and its type were not predictors of persistent pain. The present study combined comorbidities – such as arthritis, gout, sciatica, chest pain, and back pain – into concurrent pain, and this construct was not the predictor of persistent pain either. According to (G. T. Ruiz-Párraga et al., 2012) individuals with persistent pain from comorbidities learn to adjust their life to it, acknowledging its presence but not paying too much attention to it. Due to their experience of cancer, many survivors adjust their outlook on life, and personal growth is a term to describe this strategy. Mystakidou et al. (2008) found that a younger age group adjusted more than an older age group in terms of adjustment to breast cancer.

Although this study did not survey pain management in depth, based on documentation, responses to the BPI questionnaires, and retrospective reviews of medical records, the participants were prescribed analgesics to take home. Paracetamol, celecoxib, and tramadol were regularly prescribed. Perhaps these women achieved good pain control by taking those analgesics. These women were under periodic review, routinely at 3, 6, and 12 months then 3 and 5 years after surgery. Therefore, psychological factors could have affected their experienced of pain. Possibly too the participants received adequate family support because in Malaysia strong family support is part of the culture (Muhamad, Afshari, & Kazilan, 2011). In this context, lack of family support has been associated with persistent pain (Currow et al., 2010).

6.5 Integration into the Theory of Unpleasant Symptoms (TOUS)

Introduction

Most of us wish life would run in an orderly manner. But in reality, life is not so linear. Breast cancer patients rarely present with single symptom and usually experience many residual side-effects from their treatments. Health care providers have a tendency to focus on and treat just one symptom, but the focus of care should shift to a multiple-symptom approach.

This section discusses this study's findings in terms of the TOUS model, which was developed by Lenz and colleagues. TOUS focuses on the individual level, but the developers acknowledge that other aspects of life can affect the individual such as social support, experience, and environmental factors. TOUS has been expanded from looking at a single symptom to multiple symptoms (Lenz et al., 2013 ; Lenz et al., 1995).

6.5.1 Objectives:

1. The primary objective was to examine the prevalence of a single symptom, or multiple symptoms or clusters that emerged from the two data sets of the study.
2. A secondary objective was to simulate the interaction of the symptoms in accordance with the TOUS model developed and revised by Lenz and colleagues.

6.5.2 Methods

Sample and characteristics

The samples were women with breast cancer who had surgery from 3 months to 5 years ago. After analysis based on descriptive statistics, factor analysis, and regression using the stepwise method, the two data sets had yielded multiple symptoms. All data were analysed using SPSS version 24.

6.6 The merged multiple symptoms clusters uncovered from the study

The results uncovered four clusters of multiple symptoms. For T1 (data from Section A), Factor analysis (FA) revealed that **work, sleep, and mood** formed the first cluster. In T2, **general activity and mood** formed a second cluster. Descriptive statistics using data from Section B yielded a similar cluster, **work, mood and sleep;** stepwise regression formed third cluster, **pain interference in life, resilience** (perseverance), **and distress** (practical problems).

The multiple symptoms above were chosen because apart from occurring close to one another, the loadings from factor analysis were rather high. From T1, work, sleep, and mood were found to have F1 loadings of .753, .706, and .689 respectively. From T2, general activity and mood were identified to have loadings of .923 and .918 respectively. The third multiple cluster – made of work ability, mood, and sleep – emerged from descriptive statistics and showed that pain intensity caused interference with daily life. These three constructs were found to score the highest in severity. Finally, the fourth multiple cluster was found as a result of stepwise regression.

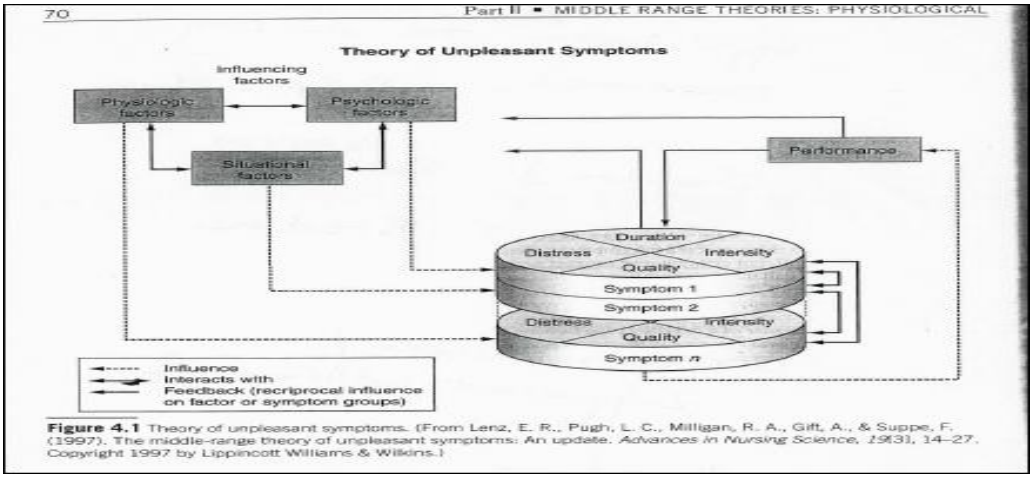

Figure 4.1 Theory of unpleasant symptoms. (From Lenz, E. R., Pugh, L. C., Milligan, R. A., Gift, A., & Suppe, F. (1997). The middle-range theory of unpleasant symptoms: An update. *Advances in Nursing Science, 19*(3), 14–27. Copyright 1997 by Lippincott Williams & Wilkins.)

Figure 3a: The original Theory of Unpleasant Symptom

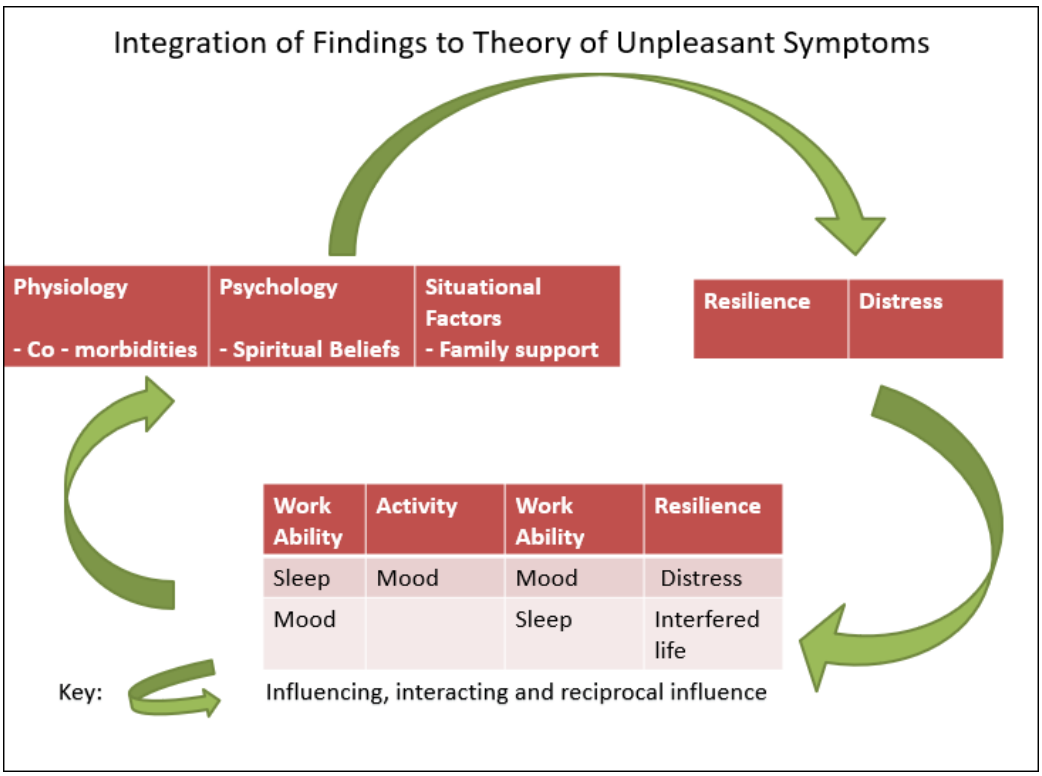

Figure 3b: The Modified Theory of Unpleasant Symptoms

The four symptom clusters prompted this researcher to compare the clusters with other studies to see whether they had found similar multiple symptoms. The five other studies are tabulated in Table 16, and the clusters of multiple symptoms are presented in the form of a pie chart in Figure 4. The author acknowledges that there are many other studies of a similar nature, but the intention is just to give a broad illustration, rather than look at all the details of findings from other researchers.

Based on the five studies chosen for this illustration, the most prevalent symptom was pain, which occurred in all the five cited studies. In all the studies there were other symptoms present, one or possibly more, but only the commonest ones are considered. It was found that in any research design the symptoms of pain, sleep deprivation, and fatigue were common. The current study uncovered pain, sleep, and mood from its cross-sectional and test–retest design, which the researcher will proceed to compare with other studies. The following studies used specific tools to uncover the multiple symptoms of pain, fatigue, and insomnia. Dodd et al. (2001), studied pain, and

fatigue, using longitudinal design, M. L. Chen and Lin (2007) obtained pain, sleep, and fatigue, from prospective study, using secondary data, K. L. Kwekkeboom et al. (2012), employed randomised controlled design, and isolated pain, sleep, and fatigue, (Buffum et al., 2011) conducted a intervention, and longitudinal study design focussed on pain, and sleep, and (Ma, Chang, & Lin, 2014), looked at pain symptom at three time points (three nights of pain and sleep).

Table 16: Comparison of Current Study with Five Studies: Multiple Symptoms Co-occurred with Pain

		Breast cancer	Surgery	Pain	Sleep	Mood	Fatigue	Experimental	Test retest	Theory	Survey prospective	Retrospective	
This study 2017	Identify Predictors of persistent pain	x	x	x	x	x					x	x	**Immerged** Two data sets Tested twice/cross sectional N=172/N=119
(Dodd et al., 2001)	Effect on symptom cluster on functioning	Mixed cancer		x			x				x		**Targeted** Longitudinal Hierarchical specific tools N=93
(Chen & Lin, 2007)	Ca symptom clusters; a validation study	Mixed cancer		x	x		x						**Targeted** Secondary samples MD Anderson Symptoms inventory CFA N=321
(Kwekkeboom et al., 2012)	RCT pts control cognitive behavior	Mixed cancer advanced		x	x		x	x					**Targeted** Psychoeducation Covariance using effect **size** N=78
(Buffum et al., 2011)	Pain,gender age sleep/wake circardian rythm	Mixed Including breast		x	x			x					**Targeted** Pittsburg sleep quality index Regression model Actigraph N=with pain =69 Without =113
(Ma et al., 2014)	Rest activity rhythm pain and sleep disturbance	Mixed cancer		x	x			x					**Targeted** Descriptive statistic Pearson correlation Sobel test Actigraph Pittsburg sleep quality index BPI N=68

Visually, the multiple symptoms are presented as a pie-chart in Figure 4. The pie-chart illustrates that pain, sleep, and fatigue co-occur almost at the same time. According to K. L. Kwekkeboom et al. (2012), pain, insomnia, and fatigue are known to frequently occur together. These features have implications for clinical practice.

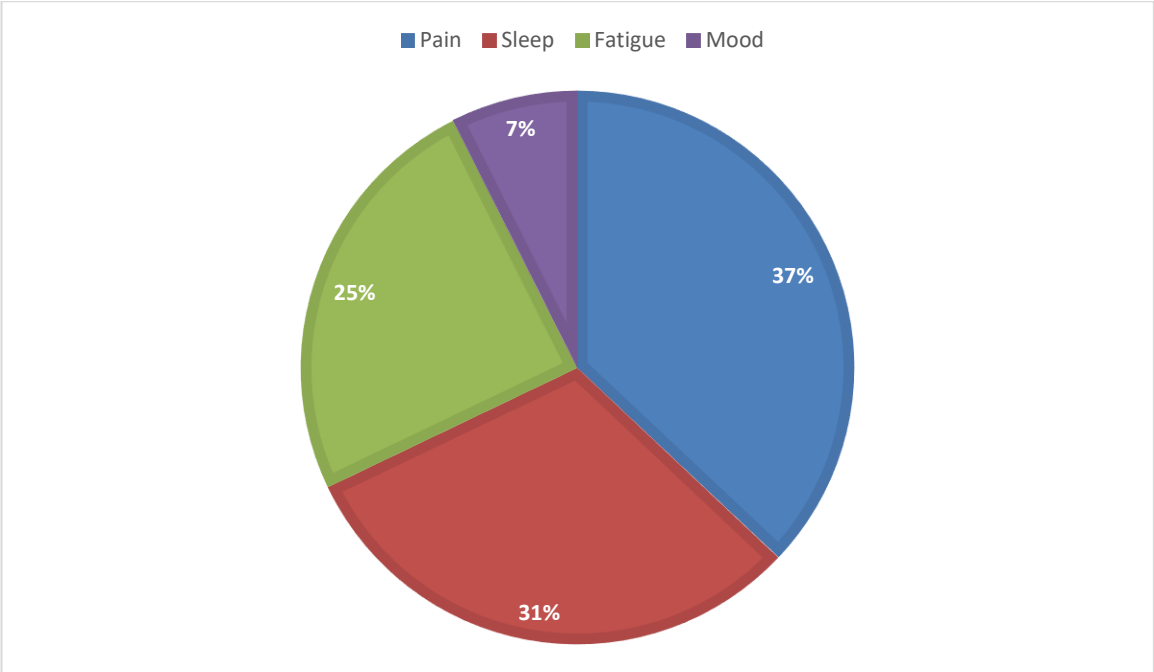

Figure 4: Illustration of commonly occurred multiple symptoms based on 6 studies

6.7 TOUS in Action

By looking at all the four clusters of multiple symptoms in Figure 3a, imagine that the three arrows are a continuum, so that pain causes lack of sleep, lack of sleep causes low mood, leading to unproductive work, reduced activity, leads to distress but resilience, comorbidity, family support, spirituality, and religiosity could buffer the worst scenario in certain individual.

From this study's perspective, the three concepts are in concordance with Lenz and colleagues. Firstly, experiencing factors primarily pain symptoms, co-occurring symptoms, insomnia, and fatigue. Secondly, consequences or outcome, women with breast cancer tend to lean towards resilience or distress. Thirdly, the distress level and resilience level are influenced by comorbidities as the physiological variable, spiritual belief and religious concerns, psychological variables, and family support as the situational variable.

The role of spiritual/religious concerns, family support, and comorbidities are significant. Spirituality and religiosity is a resource to cope with confronting issues associated with chronic diseases such as cancer (Büssing et al., 2010). The Malays in Malaysia are synonymously Muslims. Muslims believe in God as a fundamental concept. All events such as cancer or chronic diseases are fated and determined by God, therefore the individual needs to accept that fact and move on (Nabipour et al., 2016). The Malaysian Chinese believe in spirituality and religiosity for healing psychological ailments rather than believing in bio-medical means of treatment. Apart from stigmatisation, by adopting a religious-spiritual approach, individuals retain autonomy throughout the healing process (Ting & Ng, 2012). Another study found that prayer, spirituality, and religiosity played important roles, perceived as comforting and supportive in cancer patients during chemotherapy. Notably, spirituality and religiosity are part of complementary and alternative medicine (CAM) practice in Malaysia (Gan, Leong, Bee, Chin, & Teh, 2015). Possibly, religiosity and the spiritual world isolated survivors from their existing pain. Researching this issue would provide concrete and rational findings because currently this issue is considered vague and abstract. Possibly in the future, the role of distraction and imagery might benefit women with cancer who do not believe in spirituality or religiosity.

It is known that the level of social support affects the level of anxiety and depression in women with breast cancer in Malaysia (Ng et al., 2015). Perhaps family support and social support were able to reduce the pain experienced in this population. This is an aspect requiring further research. However, other studies have found that Malaysians in general are family orientated, providing support, relationship, and family cohesiveness, which extends to village level and social group level. The relationship is reciprocal and accompanied by a sense of obligation (Sharan & Mohamad, 2000). A study on breast cancer (Muhamad et al., 2011) revealed strong cohesiveness within the

family and there was collaborative decision-making among the family. The support extended to emotional support, managing health, life style, and dietary practice. Based on these studies, which show that breast cancer survivors experience strong family support, it is therefore not unexpected that family support was not a predictor of persistent pain in this research.

Although this study had been restructured to minimise bias in term of comorbidities (for instance, limiting the age to a maximum of 80 years old and restricting participants to those who had had surgery 3 months to 5 years ago), the researcher acknowledges that comorbidities in the current study in fact worked to the advantage of these participants. The chances were that the comorbidities they experienced had given them means to make adjustments to their lives. Studies have found that people with pain comorbidities experience some form of adjustment (Bendayan, Esteve, & Blanca, 2012; G. Ruiz-Párraga, T., López-Martínez, Esteve, Ramírez-Maestre, & Wagnild, 2015). Therefore, comorbidities did not appear as a predictor of persistent pain.

Resilience is a set of adaptive responses to pain and pain related to life's adversities. The interaction involves social support, such as from family, relationships, and any interpersonal factors that contribute to pain adaptation. The adaptation does not necessarily mean getting back to a premorbid status; rather it is an adjustment to new plans in life, learning and growing, improving social support, and understanding one's own ability to withstand pain (Yeung, Arewasikporn, & Zautra, 2012).

From a provider's clinical view, cancer is associated with distress. From a survivor's perspective, it has been shown that 45% of survivors do not report distress, because they do not consider themselves in distress either physically or emotionally. They have learned to cope, and moreover, in the presence of resilience, the level of distress declined (Min et al., 2013). Similarly, distress and pain coexist. An increasing

number of studies on Cognitive Behavioural Therapy have informed researchers that it works to deescalate distress symptoms (Okifuji & Turk, 2015; Syrjala et al., 2014; Tatrow & Montgomery, 2006). Based on this evidence, a psychological construct can be modulated by intervention, which is a good thing.

The phenomena found by other studies, spontaneously explained the findings of this study, the negative linear association of distress and pain was not extraordinary after all. Although the negative linear association of resilience fits the normal norm, perhaps due to pain the women had adjusted their responses to pain and pain related to life adversity. Probably the support from family, and community that is exclusive culture to Malaysian contributed to the positive adjustment, and the role of religiosity and spirituality believes could not be underestimated. To appraise the women under pinning this study is to look at all the above in a holistic view.

6.8 Implication in clinical practice

Certainly, the findings here have implications for clinical practice. The notion of treating pain as a symptom with no further investigation would give surprises at times. Women with breast cancer after surgery can complain of back pain. The analgesia may be effective for pain relief, but it would be better to ask the women specifically after surgery if, for example, the pain was related to the unequal weight of the breasts, which might be the actual problem. Unequal weight causes a posture change, which over time leads to back pain. Hence, a solution may be to refer her for a breast prosthesis or advice. Possibly she needs a physiotherapist to ease her pain rather than perpetually giving her analgesics to treat a single symptom.

This study has highlighted that pain is a common symptom in cancer, irrespective of cancer type. The pie chart of Figure 4 illustrates results from only five papers (plus the current study), and the symptoms chosen were the three common symptoms fairly close to those in the current study. This illustration gives an insight into

the prevalence of pain compared to other symptoms such as mood, insomnia, and fatigue. The moral here is, when patients present with fatigue, health care providers need to enquire from a holistic perspective, such as asking, do you have pain? How are your sleeping patterns? Moreover, when someone is in a low mood, there is likely to be other symptoms that are co-occurring, perhaps lack of sleep due to pain. The one arrow in Figure 3b represents three factors: influences, interactions, and reciprocal influences – in short, the participant's life cycle. The cycle is active, far from stagnant, and is driven by attributes in the world around them, which is always a continuum.

It is acknowledged that other factors, such as the presence of comorbidities, spiritual belief, and family support can be the cause of the presenting symptoms. Treatments and care need to be refocussed towards a holistic perspective. This new approach is the concept behind TOUS, that there are always outside factors, interactions, and feedback. This is represented by the arrows in the modified TOUS diagram. Figure 4 aims to show how TOUS can express the findings of multiple symptom clusters found during the study.

In summary, it should be mentioned that there were cross-domain influences, as illustrated by the directions of the arrows in the original figure of Lenz and colleagues, and by the arrows in the modified theory, which has three functions: influences, interactions, and reciprocals. This study has aimed to give insight to health care providers, especially in Malaysia, that persistent pain in women with breast cancer after surgery is a real medical problem. Pain occurs in all types of cancer. Pain can occur singly, or in multiple symptoms, as in this study. The symptoms need to be addressed in a holistic manner. Therefore, using psychology, cultural practices, and beliefs, treatment and care can be prioritised and tailored at the individual level by establishing a collaboration between women with breast cancer and health care providers.

The strength of the modified TOUS is that all the symptoms emerge naturally. Can that be by chance? This seems unlikely, given that the modified theory – involving pain, sleep, and work ability – emerged twice: once, from the factor analysis in data set A and another time from the descriptive analysis from data set B. Certainly, however, replication of the research is imperative.

From a research perspective, although the current study did not intend to validate TOUS, this theory was found to be very flexible. It can accommodate both abstract and quantitative data. Therefore, it is of benefit to both inductive and deductive orientated researchers. Ultimately, it displays a holistic concept underpinning the study. Its role in bridging the gap between research and practice is very evident. For example, it allows the research findings from the current study to be integrated into practice. Additionally, the concept of TOUS allows management from various disciplines in clinical practice: the medical teams, nursing teams, and rehabilitation teams would be able to provide services aimed towards the same goal using the theory as a guide. It is envisaged that survivors would then receive holistic care, promptly and effectively, and therefore improve their satisfaction with life.

CHAPTER 7
CONCLUSION

This study had identified six significant results. These included: Data from main study that confirmed prevalence of persistent pain as 43%, and together it confirmed the predictors of pain were not age, stage of cancer, neither type of surgery, but the interplay of resilience and distress in the presence of persistent pain. The study has demonstrated the successful assessment of 12 items BPI, as opposed to the previous11 items. This study concluded that the Malay version of RS14 resilience scales has sound psychometric properties, and abled to measure resilience in the main study. DT items have confirmed its face validity. Lastly, the study has supported the agility of TOUS as an influence/focus theory of this study.

The, BPI, DT, and RS-14 can be used in future studies as these are the already established tools and have been reassessed because they were employed in a new population and a new environment (Streiner & Norman, 2003). These tools achieved sound reliability, validity and repeatability.

In a break of the tradition, the BPI-12 items instead of 11 items yielded a benchmark to enhance its already established psychometric properties. This achievement is a great benefit to clinicians, nurses, and other health care providers because the 12th item is a question to measure the percentage of pain relief after pain management (Q8 of BPI), which is the integral part in pain management. The item was found to clump with other items in pain intensity, predictability in a reverse direction.

Equally important is the DT tool which has been assessed and has been modified and tailored to Malaysian population with approval from the developers (NCCN) in 2013. Although, DT did not go through major analysis because of its binomial responses and the study was not an experimental study, its face validity was confirmed.

The Malay version of RS-14 has confirmed its validity, reliability and repeatability after it has been employed in women with breast cancer. It is suggested for

further testing on other populations and different situations. The availability of a validated Malay version RS-14 is important for future research to reduce the bias gap by allowing participants to use the language that is comfortable to them.

The originality of this study lies on the emergence of the results which were obtained from the data set A (assessment of investigative tools) and data set B (the main study). Persistent pain has shown its impact on the women within the study in the clusters of symptoms; work ability, sleep and mood emerged from both from data set A and data set B, this replication was natural, and in a way it was naturally validated, and highly unlikely this phenomenon had occurred by chance. Other symptom clusters include, activity and mood, resilience, distress, and interference with daily life (work ability, activity and interference with daily life are treated as symptoms because these are components of pain interference).

The study also uncovered the women under study scored moderate resilience. The stepwise method of regression showed increase pain / reduced resilience, and increased pain / reduce distress, this is not unexpected as many reviews have confirmed that is due to adjustment from a survivors' perspective. Analysis has confirmed comorbidities, spiritual beliefs, and family support are not significant outcomes, then these are influencing the final inferences of this study. The inferences were also based on findings from other studies which include Malaysian studies. Comorbidities make people adjust themselves (Bendayan et al., 2012; G. Ruiz-Párraga, T. et al., 2015), social support is able to reduce pain experience (Muhamad et al., 2011; Ng et al., 2015; Sharan & Mohamad, 2000), and religious and spiritual belief give comfort and sense of empowerment (Büssing et al., 2010; Gan et al., 2015; Nabipour et al., 2016; Ting & Ng, 2012). According to Mirza 2014, in abductive reasoning, clinicians and nurses can formulate inferences through cues of phenomena, using intuition, linking to current and using reflection of past experiences of similar situations (Mirza et al., 2014).

The TOUS has augmented its role in influencing the flow of this study which at the conclusion resulted in interpretation of Pierce's concept of inductive and abductive enquiry. This explanation is enhanced by results of analysis displayed in the modified TOUS figure 3b. Notably, there are no direct comparable studies such as this one.

7.1 Strengths and limitations

No study is without its limitations. The multiple limitations of the current study include the following. First, it was a cross-sectional study which only allowed one-point estimates of the prevalence of persistent pain. Second, because pain is an unstable symptom, a longitudinal study (for instance, 1, 6, and 9 months after surgery) might have allowed the study to track a transition from acute to chronic pain. Third, a combination of quantitative and qualitative aspects would have improved the rigor of the study. Fourth, the sample could have been bigger, because a larger data set improves statistical power and data from more sites strengthens the generalisability of the results. Fifth, there was a lack of some ethnicity groups (for example, Indians and others who were Malaysian citizen). Finally, sampling error could have occurred, despite precautions taken.

Memory problem can occur as a limitation to cancer patients due, to side-effects of chemotherapy (called 'chemo brain'). Chemo brain is a cognitive deficit that is not fully understood. It can occur in up to 50% of patients who have undergone chemotherapy (Staat & Segatore, 2005). This study initially uncovered many participants did not respond to Q7, which required brief documentation on their pain medications. However, after follow-up reminder the responses improved.

The strength of this study lies with its nature, the homogeneity of its population, and its prospective design. For the data set in Section A, the study gauged the pain symptoms of women with breast cancer between 3 months to 5 years after surgery,

controlling for variables such as comorbidity that could arise over a long period. For the data set in Section B, this work surveyed pain symptoms from 6 months to 1 year.

To the researcher's knowledge this study is the first to survey the prevalence of persistent pain in women with breast cancer in Malaysia. The current study is also the first to assess the Malay version of RS-14. Additionally, currently no comparison studies on assessment of the Brief Pain Inventory using 12 items. Multiple symptoms were obtained from data sets A and B, were naturally emerged. Unlike other studies, the symptoms were surveyed and subjected to randomised control studies using specific tools. In this sense, this study is unique.

The literature described earlier found that TOUS is a parsimonious theory. It can handle many analytical models, and emphasis on the multiple symptoms, has been evaluated in terms of its internal consistency significance. This study has proven that TOUS has another additional property that is able to act as influence/focus theory.

Despite limitations that could have occurred, statistics are mere tools to help us interpret the findings. In real life there is no perfect sampling, data structure, and unbiased analysis. For example, in assessment of the tools, the 3 to 7 days recall period could have had the participants recall the first response, thereby creating some bias in their second response. In the work on identifying predictors for persistent pain, the process might also have created bias due to prolonged and repeated questionnaires, not just from this study but there were also many researchers interviewing the same sample using various tools.

Overall, this study has successfully answered the research questions. The three investigative tools were found to be reliable, and adequate to gauge the respective problems. It addressed the prevalence and predictors of postoperative persistent pain in women with breast cancer in Malaysia, and it uncovered multiple symptoms which

consistently occurred in both data sets whereby the outcome after inductive and abductive reasoning revealed its reflection of the already existing TOUS.

On reflection this study has made a reasonable contribution in isolating significant findings, and despite its limitations, the strength of this study can prove to be invaluable, for clinical practice. It is hoped this study will spur future research on persistent pain after surgery in women with breast cancer in Malaysia and allow international comparison.

7.2 Recommendation for future research

- Future studies should replicate this study with a larger sample. The participants should be covered nationwide to ensure that the findings are generalisable and empirically studied. The bigger sample size might tap the demographic features that are predictors, and therefore concentrate on the specific group. This would maximise, time, effort and reduce financial burden by the health sectors.
- It is recommended future research to replicate this study because 43% of prevalence of persistent pain in women after breast surgery is significant high.
- Instead of a cross sectional study, a longitudinal study that surveying patients at one month, three month, and six month would have given this study more accuracy of the occurrence of persistent pain and which group of the participants would be at high risk to experience pain. In this way some form of intervention could take place to prevent rather than rectify the persistent pain issue.
- It is highly recommended that the 12 items of BPI are used in future assessment or validation, and to use as a “gold standard” tool as concurrent validity, and ensure that Question 8 (In the last 24 hours, how much relief have pain treatments or medications provided? Please circle the one

percentage that most shows how much RELIEF you have received), is responded. This response is an instrumental information in pain management, from this response the dosage of analgesia can be adjusted.

- Future study of a similar nature should pay attention to Question 7 of BPI (Please tell us what treatment or medications are you receiving, if any, for your pain?). To improve responses, researchers should give special instructions to encourage participants to document analgesia taken, or if there were none taken to leave indicators of some kind, for example a dash (-), or (NA), for not available. Despite some participants documented the names of analgesia, for example celecoxib, paracetamol, and tramadol, it was found that the rest of the participants left blank spaces, which the researcher could not assume they did not take the analgesia.
- It is also recommended that future research should also investigate employment of DT tool on the experimental study to see the detection of change over time.
- For the Malay version of RS-14 future researcher should consider concurrent validity and CFA in the analysis.
- Specific to Malaysian context, it is recommended to researchers the importance of contact details keeping up to date any correspondence regarding longitudinal study to minimize attrition rate. This study improved from 50% attrition rate in the pilot study to 23.4% in the actual study.

7.3 Recommendation for clinical practice

- Data confirmed 43% prevalence of persistent pain be put on priority list by health care providers to be more vigilant in assessing, planning, implementing, and reassessing patients for optimum care and management of pain.
- It is recommended that the BPI of 12 items be used in the clinical practice.

- Based on the emerged results from this study, the pain is influenced by resilience and distress level. It is empirically stated that working ability, sleep, mood and impaired activity are clusters of symptoms that interfered one's life, and all disciplines could focus on the above symptoms.
- It is strongly recommended that patients be treated in a holistic approach. In doing so, an establishment of care may require a theory, concept, and or a pain management template that fits the establishment.
- It is certainly, worth considering abductive reasoning, renowned as inferences to the best explanation in clinical practice because that is holistic.

7.4 Dissemination

The results of this study will be presented to UMMC for reference. The findings will be published after submission of this thesis and will be presented at conferences for public and professionals in the University of Malaya, Kuala Lumpur Malaysia, and elsewhere as opportunity arises.

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APPENDIX 1 PARTICIPANT'S INFORMATION SHEET AND CONSENT FORM - VALIDATION STUDY (SECTION A DATA SET)

Australian National University

UNIVERSITI MALAYA
PUSAT PERUBATAN UM

Participant Information Sheet

Title of the project: Establishing the responsiveness, reliability and validity of the: Brief pain inventory, resilience scale RS-14, health related questionnaires, QLQ-ORTC C-30 and BR 2-3, and Distress thermometer questionnaires in Malaysia.

1. Invitation

We would like to invite you to take part in a research to study the questionnaires as attached to see that they are good enough to be used to explore breast cancer survivors in Malaysia. You are being invited to participate because you are a breast cancer survivor attending the University of Malaya Medical Centre (UMMC) today for a post-operative review or post-operative counselling or imaging review.

The aim of this Participant Information Sheet is to provide you with information that will help you decide whether to take part in this study. You can discuss this with your family and friends if you wish and ask any questions you might have before you make your decision. You do not have to participate if you don't want to and if you chose not to take part this will not affect your care or your relationship with the researchers, in any way.

2. Who is conducting the research?

We are researchers from Malaysia and Australia. Our team consists of Che Gon Hashim (Principal Investigator and PhD student, Australian National University (ANU)), Associate Professor David Hardman, a vascular surgeon (ANU Medical School), Professor Nur Aishah Taib (Consultant Breast Surgeon at UMMC), Faizah Harun (Associate researcher UMMC), Associate Professor Maznah Dahlui (Social and Preventative Medicine University of Malaya), Associate Professor Ng Chong Guan (psycho-oncologist University of Malaya), Associate Professor Marian Currie (A/g Director Research Centre for Nursing and Midwifery Practice, ANU and ACT Health), Dr. Carol Huang (physician at Canberra Hospital) and Professor Violeta Lopez (Adjunct Professor ANU Medical School).

3. What will I have to do if I chose to take part in the study?

a) Provide us with your written consent to take part in the study. You could also take part in this study **without a written consent by sending back the complete responses.**

b) Complete 8 sets of questionnaires for two occasions. One as soon as you decide, another 3-7 days after. They should take about an hour to complete depending on your understanding of the concepts. The questionnaires are available in English and Malay languages. They contain questions about you and some measures of resilience (the RS-14 & Connor-Davidson resilience Scale), pain (Brief Pain Inventory), distress (Distress thermometer), quality of life and well-being, (European Organisation for Research and Treatment of Cancer - (EORTC QLQ-C30 together with EORTC QLQ BR-23 questionnaires), SF 36 and Hospital Anxiety and Distress questionnaires. You can complete the questionnaires in the clinic, over the phone or by mail. We will ask you for your telephone number and postal address to enable this. If you wish to be mailed the questionnaires we will provide you with self- addressed and stamped envelopes so that you can return them to us.

4. Will I benefit from taking part in the study?

You may not benefit directly from this study. However, it is hoped that the findings will be of benefit to cancer survivors, nurses, doctors and other health professionals involved in the care of women with breast cancer who undergo surgery, particularly in Malaysia. A summary of the study findings will be sent to you after the study is completed.

5. Are there any risks associated with taking part in the study?

It is possible that you may experience some distress when reflecting on the pain you experienced during your cancer journey. If this is the case you will be provided with immediate support by the UMMC staff and offered referral to a counseling service. If you are completing the questionnaires at home you can ring the UMCC for this support.

It is possible that you may have a recurrence of your cancer during the course of the study. If this happens and you feel able to continue in the study we will be grateful. However, if continuing to take part causes you too much distress we will respect your choice to withdraw from the study.

You are free to leave the study at any time and if you chose to withdraw this will not affect your care or your relationship with any of the researchers in any way. We will use the information you have already provided to us in our study. If you do not wish us to use your information please contact the research team (their contact details are listed below). We will destroy your information in accordance with the procedures of the participating universities – the University of Malaya and the Australian National University.

6. What happens to my information?

Questionnaires

Once we receive your questionnaires we will enter the information into an electronic database and you will be given a number. The questionnaires containing your name will be kept in the research department of the UMMC in a locked cupboard in a locked room separate from the electronic database. All electronic data will be stored in the password secured computer. Only the members of the research team will have access to the questionnaires and the electronic data. Only aggregate data will be published and you will not be able to be identified in any publications. Information obtained from you during the study will be used only in research reports and journal publications. All the used data will be stored at the ethic department for seven years.

7. Questions/further information about the study

If you have any questions about the study you can speak with the principle researcher (Che Gon Hashim), Professor Nur Aishah Taib, Associate Professor David Hardman or Associate Professor Marian Currie.

Ms Che Gon Hashim, principle investigator
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If you have any concerns or complaints about how the research is conducted, and you do not feel comfortable communicating with the researchers you can contact:

The Ethics Committee at the University of Malaya	Lembah Pantai 59100 Kuala Lumpur, Malaysia Telephone: 603 79493209 Fax: 603 79494638
The Human Research Ethics Committee	Office of Research Integrity, Research Office Ground floor, Chancelry 10B Ellery Road, The Australian National University Action ACT 0200, Telephone: + 61 (0) 2 6125 3427 Fax: + 61 (0)2 6125 4807 human.ethics.office@anu.edu.au

Thank you for considering taking part in our research study. Please tell the clinic staff if you would like to complete the first questionnaire now.

Australian National University

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CONSENT FORM TO PARTICIPATE IN A RESEARCH PROJECT

Title of Project: Responsiveness, reliability and validity of tools: Brief pain inventory, resilience scale RS 14, health related questionnaires, QLQ-ORTC C30 and BR 23, SF 36, and Distress thermometer questionnaires in Malaysia.

Please tick:

1	I have read and understand the participant information sheet for above project	
2	I have had the opportunity to consider information, ask questions and satisfied with those answers	
3	I understand that my participation is voluntary**,** I also could participate this study by sending back the complete responses without a written consent	
4	I understand that approval has been given by the Australian National University (ANU) and University of Malaya Medical Centre (UMMC) Human Research Ethics Committee.	
5	I understand that the aim of the study is to assess the questionnaires attached to explore its effectiveness on breast cancer survivors after surgery in Malaysia	
6	I understand that the result of the study be of no direct benefit to me	
7	I understand that the project procedure will involve completion of questionnaires that have been explained to me. I am also aware that I could ask the researchers to assist me with the completion of the questionnaires	
8	I understand that it is anticipated to some people there will be no risk or discomfort but to some significant others this research may cause some discomfort. In that event I am free to leave the project at any time. If my discomfort continues despite leaving the project, I am aware that there is counseling available on request. I understand that there will be no changed in the treatment, management and my legal rights to UMMC. I am aware that the data will not be used and will be destroyed.	
9	I understand that my participation in this project will not result in extra medical or hospital cost to me	
10	I understand that while the results of the project will be made accessible my involvement and identity will not be revealed	
11	Should I have any problems or queries about the way in which the project was conducted, and I do not feel comfortable contacting the research staff, I am aware that I may contact the University of Malaya Research Ethics Committee (Tel: 03 79493209) or Human Research Ethics Committee of Australian National University (Tel: 612 6125 3427)	
12	After considering all these points, I accept the invitation to participate in this project	

Thank you kindly for your time to consider participating in this project

Full name:	Date:	Signature:
Witness:	Date:	Signature:
Researcher:	Date:	Signature:

APPENDIX 2 DEMOGRAPHIC DATA AFTER PILOT STUDY

Australian National University

UNIVERSITY OF MALAYA
UM MEDICAL CENTRE

Thank you for taking the time to answer the following questionnaire. If you need assistance please ask the researcher or the assistance researcher. They will be around to assist you

First some questions about you
(*please fill in the blanks*)

Q1. How old are you? *(years)* _____

Q2. What is your ethnic background? _____

Q3. What is your name? _____

Q4. What is your contact number? _____

Now we would like to ask some questions about your medical conditions
(Please circle the answer which best applies to you)

Q5. Did you have breast surgery? **YES** **NO**

Q6. How long ago was your surgery done? _____**days**_____**months**_____**year**

Q7. Are you having pain from: **Arthritis** **Gout** **Chest pain**
(you may circle more than one)
Back pain **Sciatica**
Other pain *(please specify)* _____ _____

Q8. Are you having any treatment for mental illness? **YES** **NO**

Thank you very much for taking the time to complete this form

Please complete the following questionnaires. There are: Pain scale questionnaires; Brief Pain Inventory, questions on symptoms and problems during the past week; (Distress Thermometer), resilience questionnaires; the 14-item resilience scale (RS-14) & Connor-Davidson Resilience Scale 10 (CD-RISC-10), something about your health and well-being, EORTC QLQ-C-30, EORTC QLQ BR-23 and SF-36v2, and lastly Hospital Anxiety and Depression Scale.

APPENDIX 3 BRIEF PAIN INVENTORY

Australian National University

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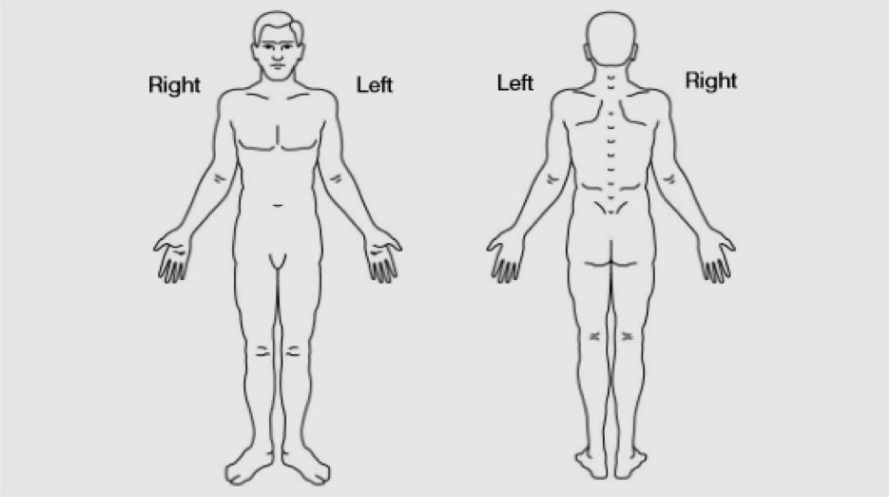
Brief Pain Inventory (Short Form)

Q1. Throughout our lives, most of us have had pain from time to time (such as minor headaches sprains, and tooth aches). Have you had pain other than these every-day kinds of pain today? *(Please circle your response)*

Yes No **(if your answer is no, please proceed to Distress Thermometer questionnaires)**

Q2. On the diagram, shade in the areas where you feel pain. Put an X on the area that HURTS MOST.



Q3. Please rate your pain by circling the one number that best describes your pain at its WORST in the last 24 hours.

0	1	2	3	4	5	6	7	8	9	10
No pain										Pain as bad as you can imagine

1

Q4. Please rate your pain by circling the one number that best describes your pain at its LEAST in the last 24 hours

0	1	2	3	4	5	6	7	8	9	10
No pain										Pain as bad as you can imagine

Q5. Please rate your pain by circling the one number that best describes your pain on AVERAGE

0	1	2	3	4	5	6	7	8	9	10
No pain										Pain as bad as you can imagine

Q6. Please rate your pain by circling the one number that tells you how much pain you have RIGHT NOW

0	1	2	3	4	5	6	7	8	9	10
No pain										Pain as bad as you can imagine

Q7. What treatments or medications are you receiving for your pain?

_____

Q8. In the last 24 hours, how much relief have pain treatments or medications provided? Please circle the one percentage that most shows how much RELIEF you have received.

0%	10 %	20%	30%	40%	50%	60%	70%	80%	90%	100%
No relief										Complete relief

Q9. Circle the one number that describes how, during the past 24 hours, pain has interfered with your:

A. General activity:

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes

B. Mood:

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes

C. Walking ability:

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes

D. Normal work (includes both work outside the home and housework):

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes

E. Relations with other people:

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes

F. Sleep:

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes

G. Enjoyment of life:

0	1	2	3	4	5	6	7	8	9	10
Does not interfere										Completely interferes

Distress Thermometer

Date of today: ……/……/……. (day/month/year)

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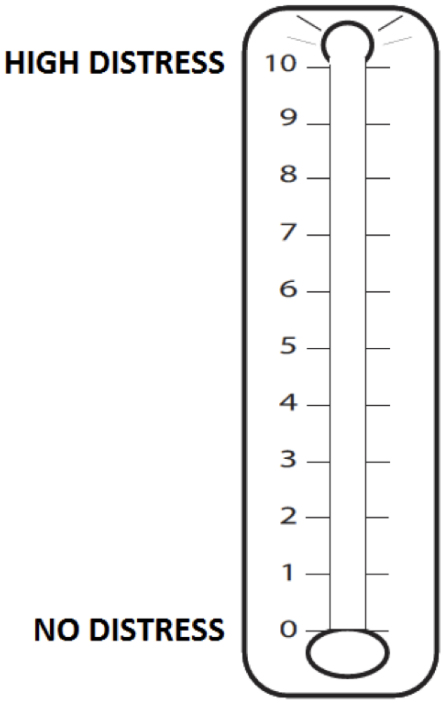
Distress Thermometer

First please circle the number below that best describes how much distress you have been experiencing in the past week (including today) physically, emotionally, socially, practically and/or religiously.



Problem list

Second, please indicate by checking yes or no if any of this following has been a problem for you in the past week (including today). Be sure to check YES or NO for each

Yes	No	(1) Practical Problems
O	O	caring responsibility
O	O	housing and finances
O	O	transport
O	O	work or education

Yes	No	(2) Family problems
O	O	relationship with my children
O	O	relationship with my my partner
O	O	relationship with others
O	O	relationship with relatives
O	O	relationship with friends

Yes	No	(3) Emotional problems
O	O	loneliness or isolation
O	O	sadness or depression
O	O	worry, fears or anxiety
O	O	anger or frustration
O	O	guilt
O	O	hopelessness
O	O	difficult making plans
O	O	sexual concerns

Yes	No	(4) Spiritual/religious concerns
O	O	loss of faith or other spiritual concern
O	O	loss of meaning or purpose in life
O	O	feeling regret of the past

Yes	No	(5) Physical Problems
O	O	my appearance
O	O	bathing or dressing
O	O	breathing difficulties
O	O	passing urine
O	O	constipation
O	O	diarrhea
O	O	eating or appetite
O	O	fatigue, exhaustion or extreme tiredness
O	O	feeling swollen
O	O	high temperature or fever
O	O	getting around (e.g. walking)
O	O	indigestion
O	O	sore or dry mouth
O	O	nausea or vomiting
O	O	pain
O	O	dry itchy or sore skin
O	O	sleep problems
O	O	tingling in hands and feet
O	O	changes in how things taste
O	O	hot flushes
O	O	memory or concentration
O	O	wound care after surgery
O	O	other medical condition or disability

(6) Other concerns?

_____

_____

Thirdly, please rank your top 4 problem categories:

First rank: ☐

Second rank: ☐

Third rank: ☐

Fourth rank: ☐

Would you like to talk with someone about your problems?

O yes O maybe O no

If yes, with whom?

O nurse O pastoral worker
O dietician O psychologist
O physiotherapist O patient association
O social worker O another, namely:

Adapted from NCCN CPG in Oncology

APPENDIX 5 RS-14 ENGLISH VERSION

The 14 item Resilience Scale (RS-14)

SELF RELIANCE	**Strongly Disagree**						**Strongly Agree**
2. I usually manage one way or another.	1	2	3	4	5	6	7
9. I feel that I can handle many things at a time.	1	2	3	4	5	6	7
13. I can get through difficult times because I've experienced difficulty before	1	2	3	4	5	6	7
18. In an emergency, I'm someone people can generally rely on?	1	2	3	4	5	6	7
23. When I'm in a difficult situation, I can usually find my way out of it.	1	2	3	4	5	6	7
MEANING	**Strongly Disagree**						**Strongly Agree**
6. I feel proud that I have accomplished things in my life.	1	2	3	4	5	6	7
15. I keep interested in things.	1	2	3	4	5	6	7
21. My life has meaning.	1	2	3	4	5	6	7
EQUANIMITY	**Strongly Disagree**						**Strongly Agree**
7. I usually take things in stride.	1	2	3	4	5	6	7
16. I can usually find something to laugh about.	1	2	3	4	5	6	7
PERSEVERANCE	**Strongly Disagree**						**Strongly Agree**
10. I am determined.	1	2	3	4	5	6	7
14. Self- discipline is important.	1	2	3	4	5	6	7
EXISTENTIAL ALONENESS	**Strongly Disagree**						**Strongly Agree**
8. I am friends with myself.	1	2	3	4	5	6	7
17. My belief in myself gets me through hard times.	1	2	3	4	5	6	7

1

APPENDIX 6 PARTICIPANT'S INFORMATION SHEET AND CONSENT FORM - MAIN STUDY (SECTION B DATA SET)

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Participant Information Sheet

Project title: A longitudinal study of pain experienced by breast cancer survivors: Effects of pain on distress symptoms, resilience and quality of life

Invitation

We would like to invite you to take part in a research study exploring the effect of pain on the lives of breast cancer survivors. This is the first study to explore this subject in Malaysia. You are being invited to participate because you are a breast cancer survivor attending the University of Malaya Medical Centre (UMMC) today for a post-operative review.

The aim of this Participant Information Sheet is to provide you with information that will help you decide whether to take part in this study. You can discuss this with your family and friends if you wish and ask any questions you might have before you make your decision. You do not have to participate if you don't want to and if you chose not to take part this will not affect your care or your relationship with the researchers, in any way.

Who is conducting the research?

We are researchers from Malaysia and Australia. Our team consists of Che Gon Hashim (Principal Investigator and PhD student, Australian National University (ANU)), Professor David Hardman, surgeon (ANU Medical School), Professor Nur Aishah Taib (Consultant Breast Surgeon at UMMC), Faizah Harun (Associate researcher UMMC), Associate Professor Maznah Dahlui (Social and Preventative Medicine University of Malaya), Associate Professor Ng Chong Guan (psychologist University of Malaya), Associate Professor Marian Currie (A/g Director Research Centre for Nursing and Midwifery Practice, ANU and ACT Health), Dr. Carol Huang (physician at Canberra Hospital) and Professor Violeta Lopez (Adjunct Professor ANU Medical School).

What will I have to do if I chose to take part in the study?

1. Provide us with your written consent to take part in the study.
2. Complete 3 questionnaires - one 6 months, one 9 months and 12 months after your surgery. Each one should take approximately 20 to 30 minutes to complete. The questionnaires are available in English, Malay and Mandarin languages. They contain questions about you and some measures of resilience (the RS14), pain (Brief Pain Inventory), distress (Distress thermometer) and quality of life (European Organisation for Research and Treatment of Cancer - (EORTC QLQ-C30 together with EORTC QLQ BR-23 questionnaires). You can complete the questionnaires in the clinic, over the phone or by mail. We will ask you for your telephone number and postal address to enable this. If you wish to be mailed the questionnaires we will provide you with self-addressed and stamped envelopes so that you can return them to us.
3. Consent to us reviewing your medical records to gather information about you.

Will I benefit from taking part in the study?

You may not benefit directly from this study. However, it is hoped that the findings will be of benefit to cancer survivors, nurses, doctors and other health professionals involved in the care of women with breast cancer who undergo surgery, particularly in Malaysia. A summary of the study findings will be sent to you after the study is completed.

Are there any risks associated with taking part in the study?

It is possible that you may experience some distress when reflecting on the pain you experienced during your cancer journey. If this is the case you will be provided with immediate support by the UMMC staff and offered referral to a counseling service or any other clinical service you may need. If you are completing the questionnaires at home you can telephone the UMCC for this support.

It is possible that you may have a recurrence of your cancer during the course of the study. If this happens and you feel able to continue in the study we will be grateful. However, if continuing to take part causes you too much distress we will respect your choice to withdraw from the study.

You are free to leave the study at any time and if you chose to withdraw this will not affect your care or your relationship with any of the researchers in any way. We will use the information you have already provided to us in our study. If you do not wish us to use your information please contact the research team (their contact details are listed below). We will not use your information in the study and it will be destroyed in accordance with the procedures of the participating universities – the University of Malaya and the Australian National University.

What happens to my information?

Questionnaires
Once we receive your questionnaires we will enter the information into an electronic database and you will be given a number. The questionnaires containing your name will be kept in the research department of the UMMC in a locked cupboard in a locked room separate from the electronic database. All electronic data will be stored in the password protected computer. Only the members of the research team will have access to the questionnaires and the electronic data. Only aggregate data will be published and you will not be able to be identified in any publications. Information obtained from you during the study will be used only in research reports and journal publications. All the used data will be stored at the Australian National University for seven years.

Clinical records
Only the primary investigator and Professor Taib, who is the leader of your treating team, will have access to your clinical records. She will collect the following information from your clinical record: the stage of your breast cancer, the type and date of your breast surgery, your history of any other surgery and any other medical conditions you might have including gynaecological conditions. If you do not wish us to have this information please let the UMMC staff know. We will respect that decision. If you wish, you can still take part in the study by completing the questionnaires.

Questions/further information about the study

If you have any questions about the study you can speak with the principle researcher (Che Gon Hashim), Professor Nur Aishah Taib, Associate Professor David Hardman or Associate Professor Marian Currie.

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Ms Che Gon Hashim, principle investigator
603 79493642 (Research Centre UMMC)
chegon.hashim@anu.edu.au

Professor David Hardman, Vascular Surgeon
Telephone No: +.61 6260 5250
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Professor Nur Aishah Taib, Head of Surgical Department and Head of Breast Unit UMMC
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Email: nuraish@gmail.com, naisha@um.edu.my, nur@ummc.edu.my

Adjunct Associate Professor Marian Currie
A/g Director Research Centre for Nursing and Midwifery Practice, ANU and ACT Health
Telephone: 61 2 62442333 Mobile: 0481010530 Fax: 61 2 62442375
Email: marian.currie@act.gov.au

If you have any concerns or complaints about how the research is conducted, and you do not feel comfortable communicating with the researchers you can contact:

The Ethics Committee at the University of Malaya	Lembah Pantai 59100 Kuala Lumpur, Malaysia Telephone: 603 79493209 Fax: 603 79494638
The Human Research Ethics Committee	Office of Research Integrity, Research Office Ground floor, Chancelry 10B Ellery Road, The Australian National University Action ACT 0200, Telephone: + 61 (0) 2 6125 3427 Fax: + 61 (0)2 6125 4807 human.ethics.office@anu.edu.au

Thank you for considering taking part in our research study. Please tell the clinic staff if you would like to complete the first questionnaire now.

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CONSENT FORM TO PARTICIPATE IN A RESEARCH PROJECT

Title of Project: A longitudinal study of pain experienced by breast cancer survivors: Effect of pain on distress symptoms, resilience and quality of life.

Please tick each point (1-13):

1	I have read and understand the Participant Information Sheet for this study.	
2	I have had the opportunity to consider information, ask questions and have them answered satisfactorily and comprehensively.	
3	I understand that my participation is voluntary.	
4	I understand that approval has been given by the Australian National University (ANU) and University of Malaya Medical Centre (UMMC) Human Research Ethics Committee.	
5	I understand that the aim of the study is to explore the pain experience by breast cancer survivors after surgery in Malaysia.	
6	I understand that the results of the study may not be of direct benefit to me.	
7	I understand that the study will involve completion of three questionnaires. I am aware that I can ask the researchers to assist me with the completion of the questionnaires.	
8	I am aware I will be offered immediate and ongoing support as needed if I find my participation in the research causes me any distress or discomfort.	
9	I am aware that I am free to leave the study at any time and that this decision will not affect my treatment or my relationship with my treating team or the researchers in any way. I also understand that I may chose to have any information I have already provided withdrawn from the study and destroyed.	
10	I understand that my participation in this study will not result in extra medical or hospital costs to me and I will not receive any payment for participating.	
11	I understand that while the results of the project will be made accessible my involvement and identity will not be revealed.	
12	I acknowledge that the researcher will examine my medical records only as they relate to this study.	
13	Should I have any problems or queries about the way in which the project was conducted, and I do not feel comfortable contacting the research staff, I am aware that I may contact the University of Malaya Research Ethics Committee (Tel: 03 79493209) or Human Research Ethics Committee of Australian National University (Tel: 612 6125 3427)	
14	After considering all these points, I accept the invitation to participate in this study.	

Full name:	Date:	Signature:
Witness:	Date:	Signature:
Researcher:	Date:	Signature:

APPENDIX 7 PARTICIPANT'S INFORMATION SHEET AND CONSENT FORM MALAY VERSION - ASSESSMENT OF TOOL STUDY (SECTION A DATA SET)

Australian National University

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Lampiran informasi peserta projek

Tajuk projek: Establishing the responsiveness, reliability and validity of the: Brief pain inventory, resilience scale RS-14, health related questionnaires, QLQ-ORTC C-30 and BR 23, and Distress thermometer questionnaires in Malaysia.

1. Jemputan

Kami ingin menjumput anda untuk menyertai project penyelidikan kami bertajuk seperti diatas. Projek ini adalah untuk mempastikan yang soalan-soalan thema seperti yang dilampirkan adalah cukup baik untuk project meninjau survivors kanser payu dara di Malaysia. Anda dipilih untuk menyertai project ini kerana anda adalah survivor yang membuat temu janji di Pusat Perubatan Universiti Malaya (PPUM) hari ini kerana lepas pembedahan, untuk review,kaunseling atau pengimejan.

Tujuan lampiran ini adalah untuk memberi informasi untuk membantu anda dalam membuat keputusan untuk menyertai projek kami. Jika perlu anda boleh meminta pendapat keluarga atau kawan sebelum membuat keputusan. Penyertaan ini adalah sukarela. Sekiranya anda menyertai project ini kami dahului dengan ucapan terima kasih. Jika anda tidak memilih untuk mengambil bahagian, ini tidak akan menjejaskan penjagaan anda atau hubungan anda dengan penyelidik, dengan cara apa juga.

2. Siapa yang mengendalikan project ini?

Kami adalah penyelidik dari Malaysia dan Australia. Kumpulan kami terdiri daripada Che Gon Hashim (Penyelidik utama dan penuntut PhD, Australian National University (ANU)), Profesor Madya David Hardman, pakar bedah vascular (Sekolah Perubatan, ANU), Professor Nur Aishah Taib (Perunding Pakar Bedah Payu dara di PPUM), Faizah Harun (Penolong penyelidik, PPUM), Profesor Madya Maznah Dahlui (Sosial and Pencegahan Perubatan University of Malaya), Profesor Madya Ng Chong Guan (psiko-oncology Universiti Malaya), Profesor Madya Marian Currie (A/g Pengarah Research Centre for Nursing and Midwifery Practice, ANU dan ACT Health), Dr. Carol Huang (Pakar perubatan di Canberra Hospital) and Professor Violeta Lopez (Adjung Professor Sekolah Perubatan ANU).

3. Apa yang saya perlu buat bila menyertai projek ini?

a) Memberi keizinan dan menandatangani lampiran borang persetujuan untuk mengambil bahagian dalam projek penyelidikan **(BPUMBDPP)**. Anda juga boleh menyertai projek ini dengan menjawab dan mengembalikan soalan-soalan yang telah lengkap tanpa menandatangani lampiran **(BPUMBDPP)**.

b) Lengkap 8 set soal selidik sebanyak dua kali. Pertama kali sebaik sahaja anda membuat keputusan. Kali keduanya dalam masa 3-7 hari selepas yang pertama. Semua soalan akan memakan masa selama lebeh kurang satu jam terpulang pada kepantasan masing-

masing dalam memahami thema soalan-soalan tersebut. Soalan-soalan disediakan dalam dua Bahasa, Bahasa Melayu Malaysia dan Bahasa Inggeris. Soalan-soalan tersebut merangkumi: Thema ketahanan diri (the RS-14 & Connor-Davidson resilience Scale -10), sakit (Brief Pain Inventory), kesusahan (Distress termometer), qualiti kehidupan dan kesejahteraan; Pertubuhan Eropah bagi Penyelidikan dan rawatan Kanser ((EORTC QLQ-C30 bersama-sama dengan EORTC QLQ BR-23 soal selidik), SF 36v2 dan Kebimbangan hospital dan sekala kebimbangan. Anda boleh selesaikan soalan-soalan tersebut di klinik, melalui talipon dan juga melalui pos. Kami akan sediakan bungkusan soalan-soalan dalam sampul surat yang sudah beralamat dan bersetem. Kami meghendaki nombor talipon dan alamat anda untuk mengendalikan proces tersebut supaya anda dapat memulangkan kapada kami.

4. Apakah menafaat yang saya dapat dalam menyertaan projek ini?

Kemungkinan anda tidak dapat menikmati menafaat projek ini secara langsung. Tetapi hasil penemuan dari projek ini akan memberi menafaat kapada pesakit kanser payu dara melalui para doktor, jururawat dan professional perubatan yang lain dalam perawatan, pemulihan wanita terbabit kursusnya selepas pembedahan payu dara akibat kanser di Malaysia. Ringkasan analisa projek akan dihantar kapada anda nanti.

5. Apakah risiko-risiko yang bakal tiba jika meyertai projek ini?

Ada kemungkinan yang anda mungkin mengalami kemurungan ketika merenungkan kesakitan yang anda alami selama perjalanan kanser anda. Jika ini berlaku anda akan disediakan dengan sokongan serta-merta oleh kakitangan PPUM dan menawarkan rujukan kepada perkhidmatan kaunseling. Jika anda melengkapkan soal selidik di rumah, anda boleh menelefon PPUM untuk sokongan ini.

Ada kemungkinan bahawa kanser anda berulang dalam tempoh kursus pengajian itu. Jika ini berlaku dan anda merasa mampu terus menyertai kajian ini kita akan terhutang budi. Namun, jika terus mengambil bahagian menyebabkan anda terlalu banyak mengalami kemurungan kami akan menghormati pilihan anda untuk menarik diri dari penyelidikan ini.

Anda bebas untuk meninggalkan kajian ini pada bila-bila masa dan jika anda memilih untuk menarik diri, ini tidak akan menjejaskan penjagaan anda atau hubungan anda dengan mana-mana penyelidik dalam apa cara juga. Kami akan menggunakan maklumat yang anda telah berikan kepada kami dalam kajian kami. Jika anda tidak mahu kami menggunakan maklumat anda, sila hubungi pasukan penyelidikan (butir-butir hubungan mereka disenaraikan di bawah). Kami akan memusnahkan maklumat anda sesuai dengan prosedur universiti yang terlibat - Universiti Malaya dan Australian National University.

6. Apa yang berlaku kapada maklumat saya?

Soalan-soalan Soal selidik

Setelah kami menerima soal selidik anda, kami akan memasukkan maklumat ke data elektronik dan nama anda akan ditukarkan menjadi nombor. Soal selidik yang mengandungi nama anda akan disimpan di jabatan penyelidikan di PPUM di dalam almari yang berkunci di dalam bilik

yang dikunci berasingan dari data elektronik. Semua data elektronik akan disimpan dalam komputer yang mempunyai kata laluan yang dijamin. Hanya ahli-ahli pasukan penyelidikan akan mempunyai akses kepada soal selidik dan data elektronik. Hanya data bernombor akan diterbitkan dan anda tidak akan dapat dikenal pasti dalam mana-mana penerbitan. Maklumat yang diperoleh daripada anda semasa kajian akan digunakan hanya dalam laporan penyelidikan dan penerbitan jurnal. Semua data yang digunakan akan disimpan di jabatan etika selama tujuh tahun.

Soalan-soalan informasi lanjutan berkenaan projek

7. Soalan-soalan/informasi lain berkenaan projek

Jika anda mempunyai soalan-soalan fasal projek anda boleh bercommunikasi dengan penyelidik utama (Che Gon Hashim), Professor Dr.Nur Aishah Taib, Associate Professor Dr. David Hardman atau Associate Professor Dr. Marian Currie.

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Cik Che Gon Hashim, penyelidik utama
603 79493642 (Pusat Penyelidikan PPUM)
chegon.hashim@anu.edu.au

Professor Dr. David Hardman, Pakar Bedah Vaskular
Telephone No: +.61 6260 5250
Fax: + 6162606240
Email: dtah@webone.com.au

Professor Dr. Nur Aishah Taib, Ketua Unit Payu Dara PPUM
Telephone No: +60379492070, 79493642, +60192405856
Email: nuraish@gmail.com, naisha@um.edu.my, nur@ummc.edu.my

Adjung Profesor Madya Dr. Marian Currie
A/g pengarah Research Centre for Nursing and Midwifery Practice, ANU and ACT Health
Telephone: 61 2 62442333 Mobile: 0481010530 Fax: 61 2 62442375
Email: marian.currie@act.gov.au

Jika anda mempunyai kebimbangan atau aduan berkenaan dengan cara penyelidikkan dijalankan, dan anda rasa tidak selesa berkomunikasi dengan penyelidik-penyelidik anda boleh hubungi:

Jawatankuasa Etika Universiti Malaya	Lembah Pantai 59100 Kuala Lumpur, Malaysia Telepone: 603 79493209 Fax: 603 79494638
Jawatankuasa Etika Penyelidikan manusia Australian National University	Office of Research Integrity, Research Office Ground floor, Chancelry 10B Ellery Road, The Australian National University Action ACT 0200, Telephone: + 61 (0) 2 6125 3427 Fax: + 61 (0)2 6125 4807 human.ethics.office@anu.edu.au

Terima kasih kerana mempertimbangkan untuk mengambil bahagian dalam penyelidikan kami Sila beritahu kakitangan klinik yang anda ingin melengkapkan soalan pertama sekarang.

BORANG PERSETUJUAN UNTUK MENGAMBIL BAHAGIAN DALAM PROJEK PENYELIDIKAN

Tajuk Projek: Responsiveness, reliability and validity of tools: Brief pain inventory, resilience scale RS 14, health related questionnaires, QLQ-ORTC C30 and BR 23, SF 36, and Distress thermometer questionnaires in Malaysia.

Sila tandakan:

1	Saya telah membaca dan memahami lampiran informasi peserta untuk projek di atas	
2	Saya mempunyai peluang untuk mempertimbangkan maklumat, bertanya soalan dan berpuas hati dengan jawapan-jawapan	
3	Saya faham bahawa penyertaan saya adalah secara sukarela, saya juga boleh menyertai projek ini dengan menjawab dan mengembalikan soalan-soalan yang telah lengkap tanpa menandatangani lampiran	
4	Saya faham yang kelulusan telah diberi oleh Australian Nasional University (ANU) dan Pusat Perubatan Universiti Malaya (PPUM) Penyelidikan Manusia Jawatankuasa Etika	
5	Saya faham bahawa tujuan kajian ini adalah untuk menilai soalan-soalan soal selidik yang dilampirkan untuk meneroka keberkesanannya pada pesakit kanser payudara selepas pembedahan di Malaysia	
6	Saya faham bahawa hasil kajian tidak memberi manfaat secara langsung kepada saya	
7	Saya faham bahawa prosedur projek itu akan melibatkan penyelesaian soal selidik yang telah dijelaskan kepada saya. Saya juga sedar bahawa saya boleh bertanya kepada para penyelidik untuk membantu saya dalam penyelesaian soal selidik	
8	Saya faham bahawa adalah dijangkakan bagi sesetengah orang tidak akan ada risiko atau tidak selesa, tetapi bagi beberapa orang signifikan yang lain, kajian ini mungkin akan menimbulkan rasa ketidakselesaan. Dalam keadaan demikian saya bebas untuk meninggalkan projek itu pada bila-bila. Jika ketidakselesaan saya berterusan selepas meninggalkan projek itu, saya sedar bahawa ada kaunseling disediakan atas permintaan. Saya faham bahawa tidak akan ada perubah dalam perawatan, pengurusan dan hak asasi saya dari PPUM. Saya sedar bahawa data tidak akan digunakan dan akan dimusnahkan	
9	Saya faham bahawa penyertaan saya dalam projek ini tidak akan mengakibatkan tambahan kos perubatan atau hospital kepada saya	
10	Saya faham, walaupun hasil projek ini akan dapat diakses, namun penglibatan dan identiti saya tidak akan didedahkan	
11	Sekiranya saya mempunyai sebarang masalah atau pertanyaan tentang cara di mana projek itu dijalankan, dan saya tidak berasa selesa menghubungi kakitangan penyelidikan, saya sedar bahawa saya boleh menghubungi Jawatankuasa Etika Penyelidikan Universiti Malaya (Tel: 03 79493209) atau Jawatankuasa Etika Penyelidikan Manusia dari Australian National University (Tel: 612 6125 3427)	
12	Setelah mempertimbangkan semua butir-butir ini, saya menerima jemputan untuk mengambil bahagian dalam projek ini	

Terima kasih kasih di atas masa anda untuk pertimbangan bagi mengambil bahagian dalam projek ini

Nama penuh	Tarikh	Tanda Tangan:
Saksi:	Tarikh	Tanda Tangan
Penyelidik	Tarikh	Tanda Tangan:

APPENDIX 8 DEMOGRAPHIC DATA MALAY VERSION AFTER PILOT STUDY

Australian National University

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Terima kasih kerana sudi mengambil masa menjawab soalan-soalan di bawah. Jika ada memerlukan pertolongan, sila panggil penyelidik atau penolong penyelidik. Mereka ada berdekatan untuk menolong anda

Kita mulakan pertanyaan berkenaan peribadi anda
(*sila isikan tempat kosong dibawah*)

Soalan 1. Berapakah umur anda? *(tahun)* _____

Soalan 2. Apakah latar belakang ethnik anda?
_____

Soalan 3. Apakah nama anda?_____

Soalan 4. Apakah nombor untuk menghubungi anda?
_____

Sekarang kita ingin bertanya tentang kesihatan anda.
(sila bulatkan jawapan yang terbaik tentang anda)

Soalan 5. Adakah anda penah menjalani pembedahan payu dara? **Ya** **Tidak**

Soalan 6. Berapa lamakah pembedahan tersebut dilakukan
_____Hari_____bulan_____Tahun

Soalan 7. Adakah anda mengalami sakit
(anda bolih bulatkan lebeh dari satu)

Radang sendi (Arthritis) **Penyakit Gout,**

Sakit dada **Sakit belakang**

Sengal pada paha dan pangkal paha (Sciatica)

Lain-lain sakit (*sila jelaskan***)**_____

Soalan 8. Adakah anda dalam perawatan sakit jiwa? **Ya** **Tidak**

Terima kasih diatas masa yang anda berikan bagi melengkapkan borang ini
Sekarang sila jawab soalan-soalan berikut. Soalan tentang sakit; Inventori Ringkas Kesakitan, soalan meninjau kesukaran anda; Distress Thermometer (DT) soalan meninjau ketahanan diri anda; 14-item Scala Ketahan diri (SKD) beserta Connor-Davidson Resilience Scale 10 (CD-RISC10), soalan tentang kesihatan dan kesejahteraan hidup anda;, EORTC QLQ-C30, EORTC QLQ BR-23 dan SF-36v2 dan soal selidik kerisauan dan kemurungan Hospital.

APPENDIX 9 BRIEF PAIN INVENTORY IN MALAY VERSION

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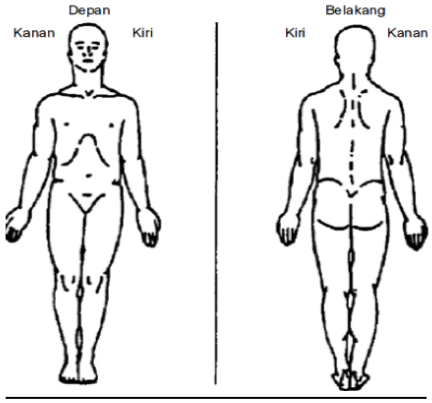
Inventori Ringkas Kesakitan (Format pendek)

Nama: ……Tarikh……..

1. Sepanjang hidup ini kebanyakan kita pernah mengalami kesakitan dari semasa ke semasa (seperti sakit kepala, terseliuh/tergeliat, sakit gigi ~~dan lain-lain~~) Adakah anda mengalami kesakitan selain kesakitan biasa seperti di atas pada hari ini?

Ya Tidak (**jika jawapannya "tidak" sila jawab soal-selidik Distress Thermometer**)

2. Pada gambarajah di bawah, hitamkan bahagian dimana anda merasa sakit. | Tandakan X pada bahagian yang paling sakit



3. Sila bulatkan satu nombor yang terbaik untuk menggambarkan tahap kesakitan yang paling teruk anda alami dalam masa 24 jam yang lalu.

0 1 2 3 4 5 6 7 8 9 10

Tiada Sakit — Amat sakit

1

4. Sila bulatkan satu nombor yang terbaik untuk mengggambarkan tahap sesakitan yang paling ringan anda alami dalam masa 24 jam yang lalu.

0	1	2	3	4	5	6	7	8	9	10
Tiada Sakit										Amat sakit

5. Sila bulatkan satu nombor yang terbaik untuk menggambarkan kesakitan anda pada tahap sederhana

0	1	2	3	4	5	6	7	8	9	10
Tiada Sakit										Amat sakit

6. Sila bulatkan satu nombor yang terbaik untuk menggambarkan tahap kesakitan yang anda rasa sekarang

0	1	2	3	4	5	6	7	8	9	10
Tiada Sakit										Amat sakit

7. Apakah rawatan atau ubatan yang anda terima untuk kesakitan yang anda alami?

---

8. Dalam masa 24 jam yang lalu, berapa banyakkah .kelegaan yang anda alami setelah menerima rawatan atau ubatan? Sila bulatkan satu peratusan yang menggambarkan kelegaan tersebut.

0%	10 %	20%	30%	40%	50%	60%	70%	80%	90%	100%
Tiada Kelegaan										Kelegaan sepenuhnya

2

9. Sila bulatken nombor yang menggambarkan bagaimana kesakitan dalam tempoh 24jam yang lalu mengganggu keadaan berikut:

A: Activiti umum

0 1 2 3 4 5 6 7 8 9 10

Tidak Mengganggu — Mengganggu sepenuhnya

B Keadaan perasaan:

0 1 2 3 4 5 6 7 8 9 10

Tidak Mengganggu — Mengganggu sepenuhnya

C. Keupayaaan untuk berjalan:

0 1 2 3 4 5 6 7 8 9 10

Tidak Mengganggu — Mengganggu sepenuhnya

D. Kerja biasa (termasuk di dalam dan di luar rumah)

0 1 2 3 4 5 6 7 8 9 10

Tidak Mengganggu — Mengganggu sepenuhnya

E. Hubungan dengan orang lain

0 1 2 3 4 5 6 7 8 9 10

Tidak Mengganggu — Mengganggu sepenuhnya

3

F. Tidur:

0	1	2	3	4	5	6	7	8	9	10
Tidak Mengganggu										Mengganggu sepenuhnya

G. Kenikmatan hidup:

0	1	2	3	4	5	6	7	8	9	10
tidak mengganggu										Menggangu sepenuhnya

Distress Thermometer

Date of today: ……/……/……. (day/month/year)

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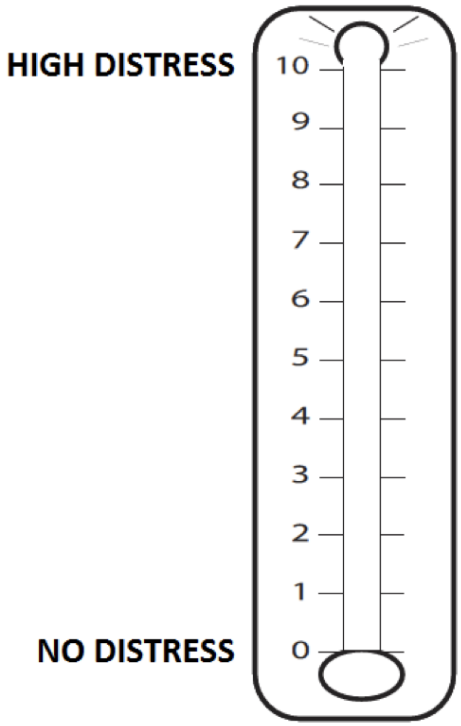
UM MEDICAL CENTRE

Distress Thermometer

First please circle the number below that best describes how much distress you have been experiencing in the past week (including today) physically, emotionally, socially, practically and/or religiously.



Problem list

Second, please indicate by checking yes or no if any of this following has been a problem for you in the past week (including today). Be sure to check YES or NO for each

Yes	No	(1) Practical Problems
O	O	caring responsibility
O	O	housing and finances
O	O	transport
O	O	work or education

Yes	No	(2) Family problems
O	O	relationship with my children
O	O	relationship with my my partner
O	O	relationship with others
O	O	relationship with relatives
O	O	relationship with friends

Yes	No	(3) Emotional problems
O	O	loneliness or isolation
O	O	sadness or depression
O	O	worry, fears or anxiety
O	O	anger or frustration
O	O	guilt
O	O	hopelessness
O	O	difficult making plans
O	O	sexual concerns

Yes	No	(4) Spiritual/religious concerns
O	O	loss of faith or other spiritual concern
O	O	loss of meaning or purpose in life
O	O	feeling regret of the past

Yes	No	(5) Physical Problems
O	O	my appearance
O	O	bathing or dressing
O	O	breathing difficulties
O	O	passing urine
O	O	constipation
O	O	diarrhea
O	O	eating or appetite
O	O	fatigue, exhaustion or extreme tiredness
O	O	feeling swollen
O	O	high temperature or fever
O	O	getting around (e.g. walking)
O	O	indigestion
O	O	sore or dry mouth
O	O	nausea or vomiting
O	O	pain
O	O	dry itchy or sore skin
O	O	sleep problems
O	O	tingling in hands and feet
O	O	changes in how things taste
O	O	hot flushes
O	O	memory or concentration
O	O	wound care after surgery
O	O	other medical condition or disability

(6) Other concerns?

_____

_____

Thirdly, please rank your top 4 problem categories:

First rank: ☐

Second rank: ☐

Third rank: ☐

Fourth rank: ☐

Would you like to talk with someone about your problems?

O yes O maybe O no

If yes, with whom?

O nurse O pastoral worker
O dietician O psychologist
O physiotherapist O patient association
O social worker O another, namely:

Adapted from NCCN CPG in Oncology

APPENDIX 11 MALAY VERSION RESILIENCE SCALE RS-14 (ABSTRACTED FROM ORIGINAL RS-25)

Sekala Ketahanan Diri (SKD)

Sila baca setiap penyataan dan bulatkan nimbor di sebelah kanan yang paling tepat menggambarkan perasaa anda tentang kenyataan tersebut. Sila berikan maklum balas kepada semua penyataan.

Kumpulan satu	**Sangat sangat tidak bersetuju**						**Sangat sangat bersetuju**
2. selalunya saya dapat mengurus sesuatu dengan pelbagai cara.	1	2	3	4	5	6	7
9. Saya merasakan mampu mengendalikan banyak perkara dalam satu masa.	1	2	3	4	5	6	7
13. Saya boleh mengharungi masa-masa yang sukar kerana pernah menagalaminya sebelum ini	1	2	3	4	5	6	7
18. Ketika berlaku kecemasan, saya orang yang boleh di harapkan?	1	2	3	4	5	6	7
23. Apabila saya berada dalamsituasiyang sukar , saya biasanya dapat mencari jalan keluart	1	2	3	4	5	6	7
Kumpulan dua	**Sangat sangat tidak bersetuju**						**Sanagt sangat bersetuju**
6. Saya berasa bangga kerana telah mencapai pelbagai perkara dalam hidup saya	1	2	3	4	5	6	7
15. Saya terus berminat dalam pelbagai perkara.	1	2	3	4	5	6	7
21. Hidup saya mempunyai makna.	1	2	3	4	5	6	7

1

Kumpulan tiga	**Sangat sangat tidak bersetuju**						**Sangat sangat bersetuju**
7. Saya dapat menenang kan diri dan bersikap terbuka sekiranya timbul sesuatu masaalah	1	2	3	4	5	6	7
16 Saya selalunya boleh mencari sesuatu yang berbentuk jenaka walaupun saya berada didalam keadaan tertekan.	1	2	3	4	5	6	7
Kumpulan empat	**Sangat sangat tidak bersetuju**						**Sangat sangat bersetuju**
10. Saya adalah seorang yang mempunyai keazaamman tertinggi	1	2	3	4	5	6	7
14. Saya adalah seorang yang mempunyai disiplin sendiri.	1	2	3	4	5	6	7
Kumpulan lima	**Sangat sangat tidak bersetuju**						**Sangat sangat bersetuju**
8. Saya bersahabat dengan diri sendiri.	1	2	3	4	5	6	7
17. Kepercayaan kapada diri sendiri membolehkan saya melalui masa-masa yang sukar	1	2	3	4	5	6	7

2

APPENDIX 12 MALAY VERSION RESILIENCE SCALE RS-25 (ORIGINAL)

Skala Ketahanan Diri (SKD)

Tarikh_____

Sila baca setiap penyataan dan bulatkan nombor di sebelah kanan yang paling tepat menggambarkan perasaan anda tentang kenyataan tersebut. Sila berikan maklum balas kepada semua penyataan.

Bil	Item	Sila bulatkan nombor di ruang yang sesuai. Sangat Sangat Tidak Bersetuju — Sangat Sangat Bersetuju						
1	Apabila saya membuat perancangan, saya mengikuti perancangan yang dibuat itu.	1	2	3	4	5	6	7
2	Selalunya saya dapat mengurus sesuatu dengan pelbagai cara.	1	2	3	4	5	6	7
3	Saya boleh berdikari daripada bergantung pada orang lain.	1	2	3	4	5	6	7
4	Mengekalkan minat terhadap sesuatu adalah penting bagi diri saya.	1	2	3	4	5	6	7
5	Saya boleh berdikari sekiranya terpaksa.	1	2	3	4	5	6	7
6	Saya berasa bangga kerana telah mencapai pelbagai perkara dalam hidup saya.	1	2	3	4	5	6	7
7	Saya dapat menenangkan diri dan bersikap terbuka sekiranya timbul sesuatu masalah.	1	2	3	4	5	6	7
8	Saya bersahabat dengan diri sendiri.	1	2	3	4	5	6	7
9	Saya merasakan mampu mengendalikan banyak perkara dalam satu masa.	1	2	3	4	5	6	7
10	Saya adalah seorang yang mempunyai keazaman tinggi.	1	2	3	4	5	6	7
11	Saya jarang mempersoalkan tujuan tentang sesuatu perkara itu berlaku.	1	2	3	4	5	6	7
12	Saya mengharungi kehidupan walaupun sukar dari sehari ke sehari tanpa kerisauan yang tinggi.	1	2	3	4	5	6	7
13	Saya boleh mengharungi masa-masa yang sukar kerana pernah mengalaminya sebelum ini.	1	2	3	4	5	6	7
14	Saya adalah seorang yang mempunyai disiplin diri.	1	2	3	4	5	6	7
15	Saya terus berminat dalam pelbagai perkara.	1	2	3	4	5	6	7
16	Saya selalunya boleh mencari sesuatu yang berbentuk jenaka walaupun saya berada dalam keadaan tertekan.	1	2	3	4	5	6	7
17	Kepercayaan kepada diri sendiri membolehkan saya dapat melalui masa-masa sukar.	1	2	3	4	5	6	7
18	Ketika berlaku kecemasan, saya orang yang boleh diharapkan.	1	2	3	4	5	6	7
19	Saya selalunya dapat melihat sesuatu situasi dalam pelbagai cara.	1	2	3	4	5	6	7
20	Kadang-kala saya memaksa diri melakukan sesuatu sama ada saya ingin atau tidak melakukannya.	1	2	3	4	5	6	7

Bil	Item	Sila bulatkan nombor di ruang yang sesuai. Sangat Tidak Bersetuju						Sangat Bersetuju
21	Hidup saya mempunyai makna.	1	2	3	4	5	6	7
22	Saya tidak akan terus memikirkan perkara-perkara yang tidak boleh berbuat apa-apa tentangnya.	1	2	3	4	5	6	7
23	Apabila saya berada dalam situasi yang sukar, saya biasanya dapat mencari jalan keluar.	1	2	3	4	5	6	7
24	Saya mempunyai cukup tenaga untuk melakukan apa yang perlu saya lakukan	1	2	3	4	5	6	7
25	Tidak mengapa jika ada orang yang tidak menyukai saya.	1	2	3	4	5	6	7

APPENDIX 13 PARTICIPANT'S INFORMATION SHEET AND CONSENT FORM MALAY VERSION - MAIN STUDY (SECTION B DATA SET)

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Lampiran informasi peserta projek

Tajuk projek: **A longitudinal study of pain experienced by breast cancer survivors: Effects of pain on distress symptoms, resilience and quality of life**

Jemputan

Kami ingin menjumput anda untuk menyertai project penyelidikan kami bertajuk seperti diatas. Anda dipilih untuk menyertai project ini kerana anda adalah survivor yang membuat temu janji di Pusat Perubatan Universiti Malaya (PPUM) hari ini kerana lepas pembedahan, untuk review ,kaunseling atau pengimejan.

Tujuan lampiran ini adalah untuk memberi informasi bagi membantu anda dalam membuat keputusan untuk menyertai projek kami. Jika perlu anda boleh meminta pendapat keluarga atau kawan sebelum membuat keputusan. Penyertaan ini adalah sukarela. Sekiranya anda menyertai project ini kami dahului dengan ucapan terima kasih. Jika anda tidak memilih untuk mengambil bahagian, ini tidak akan menjejaskan penjagaan anda atau hubungan anda dengan penyelidik, dengan cara apa juga.

Siapa yang mengendalikan project ini?
Kami adalah penyelidik dari Malaysia dan Australia. Kumpulan kami terdiri daripada Che Gon Hashim (Penyelidik utama dan penuntut PhD, Australian National University (ANU)), Profesor Madya David Hardman, pakar bedah vascular (Sekolah Perubatan, ANU), Profesor Nur Aishah Taib (Perunding Pakar Bedah Payu dara di PPUM), Profesor Madya Maznah Dahlui (Sosial and Pencegahan Perubatan University of Malaya), Profesor Madya Ng Chong Guan (psiko-oncology Universiti Malaya), and Professor Violeta Lopez (Adjung Profesor Sekolah Perubatan ANU),. Dr David Larkin (Hospital Canberra, ACT, Australia) and Dr. Jin Hwan Yoon Statistician (ANU).

Apa yang anda perlu buat bila menyertai projek ini?

1. Memberi keizinan dan menandatangani lampiran borang persetujuan untuk mengambil bahagian dalam projek penyelidikan .Anda juga bolih menyertai projek ini dengan menjawab dan mengembalikan soalan-soalan yang telah lengkap tanpa menandatangani lampiran.

2. Lengkap 4 set soal selidik sebanyak 3 kali. Pertama kali bile anda membuat keputusan, kedua kali 3 bulan kemudian dan akhirnya enam bulan selepas kali pertama. Soal-selidik akan mengambil masa kurang dari satu jam terpulang pada kepantasan masing-masing dalam memahami thema soalan-soalan tersebut. Soalan-soalan disediakan dalam dua Bahasa, Bahasa Malaysia dan Bahasa Inggeris. Soalan-soalan tersebut merangkumi: Thema ketahanan diri (the RS-14), sakit (Brief Pain Inventory), kesusahan (Distress termometer), qualiti kehidupan dan kesejahteraan; Pertubuhan Eropah bagi Penyelidikan dan rawatan Kanser ((EORTC QLQ-C30 bersama-sama dengan EORTC QLQ BR-23. Anda boleh selesaikan soalan-soalan tersebut di klinik, melalui talipon dan juga melalui pos. Kami akan sediakan bungkusan soalan-soalan dalam sampul surat yang sudah beralamat dan bersetem. Kami meghendaki nombor talipon dan alamat anda untuk mengendalikan proces tersebut supaya anda dapat memulangkan kapada kami.

3. Memberi keizinan untuk kami mendapat maklumat daripada rekod hospital.anda**, Keizinan terhad untuk mengumpul maklumat tertentu untuk projek ini sahaja.**

Apakah menafaat yang saya dapat dalam menyertaan projek ini?

Kemungkinan anda tidak dapat menikmati menafaat projek ini secara langsung. Tetapi hasil penemuan dari projek ini akan memberi menafaat kapada pesakit kanser payu dara melalui para doktor, jururawat dan professional perubatan yang lain dalam perawatan, pemulihan wanita terbabit kursusnya selepas pembedahan payu dara akibat kanser di Malaysia. Ringkasan analisa projek akan dihantar kapada anda nanti.

Apakah risiko-risiko yang bakal tiba jika meyertai projek ini?

Ada kemungkinan yang anda mungkin mengalami kemurungan ketika merenungkan kesakitan yang anda alami selama perjalanan kanser anda. Jika ini berlaku anda akan disediakan dengan sokongan serta-merta oleh kakitangan PPUM dan menawarkan rujukan kepada perkhidmatan kaunseling. Jika anda melengkapkan soal selidik di rumah, anda boleh menelefon PPUM untuk sokongan ini.

Ada kemungkinan bahawa kanser anda berulang dalam tempoh kursus pengajian itu. Jika ini berlaku dan anda merasa mampu terus menyertai kajian ini kita akan terhutang budi. Namun, jika terus mengambil bahagian menyebabkan anda terlalu banyak mengalami kemurungan kami akan menghormati pilihan anda untuk menarik diri dari penyalidikan ini.

Anda bebas untuk meninggalkan kajian ini pada bila-bila masa dan jika anda memilih untuk menarik diri, ini tidak akan menjejaskan penjagaan anda atau hubungan anda dengan mana-mana penyelidik dalam apa cara juga. Kami akan menggunakan maklumat yang anda telah berikan kepada kami dalam kajian kami. Jika anda tidak mahu kami menggunakan maklumat anda, sila hubungi pasukan penyelidikan (butir-butir hubungan mereka disenaraikan di bawah). Kami akan memusnahkan maklumat anda sesuai dengan prosedur universiti yang terlibat - Universiti Malaya dan Australian National University.

Apa yang berlaku kapada maklumat saya?

Soal-Selidik
Setelah kami menerima soal selidik anda, kami akan memasukkan maklumat ke data elektronik dan nama anda akan ditukarkan menjadi nombor. Soal selidik yang mengandungi nama anda akan disimpan di jabatan penyelidikan di PPUM di dalam almari yang berkunci di dalam bilik yang dikunci berasingan dari data elektronik. Semua data elektronik akan disimpan dalam komputer yang mempunyai kata laluan yang dijamin. Hanya ahli-ahli pasukan penyelidikan akan mempunyai akses kepada soal selidik dan data elektronik. Hanya data bernombor akan diterbitkan dan anda tidak akan dapat dikenal pasti dalam mana-mana penerbitan. Maklumat yang diperoleh daripada anda semasa kajian akan digunakan hanya dalam laporan penyelidikan dan penerbitan jurnal. Semua data yang digunakan akan disimpan di jabatan etika selama tujuh tahun.

Rekod klinikal

Cuma penyiasat utama dan Profesor Taib, yang merupakan ketua pasukan yang merawat anda, akan mempunyai akses kepada rekod perubatan. Hanya maklumat yang berikut akan dikumpulkan dari catatan rekod klinikal: tahap kanser payudara, jenis dan tarikh pembedahan payudara anda, sejarah anda dengan mana-mana pembedahan yang lain dan apa-apa keadaan perubatan lain yang anda mungkin perlu termasuk penyakit sakit puan. Jika anda tidak mahu kita untuk akses kepada rekod perubatan anda, sila beritahu kami. Kami akan menghormati keputusan itu. Anda masih boleh mengambil bahagian dalam kajian ini dengan melengkapkan soalan-soalan soal selidik.

Soalan-soalan/ informasi lanjutan berkenaan projek

Jika anda mempunyai soalan-soalan fasal projek anda boleh berhubung dengan penyelidik utama (Che Gon Hashim), Profesor Dr.Nur Aishah Taib, Profesor Madya Dr. David Hardman

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Cik Che Gon Hashim, penyelidik utama
603 79493642 (Pusat Penyelidikan PPUM)
chegon.hashim@anu.edu.au/0183817300

Profesor Dr. David Hardman, Pakar Bedah Vaskular
Telephone No: +.61 6260 5250
Fax: + 6162606240
Email: dtah@webone.com.au

Profesor Dr. Nur Aishah Taib, Ketua Unit Payu Dara PPUM
Telephone No: +60379492070, 79493642, +60192405856
Email: nuraish@gmail.com, naisha@um.edu.my, nur@ummc.edu.my

Jika anda mempunyai kebimbangan atau aduan berkenaan dengan cara penyelidikkan dijalankan, dan anda rasa tidak selesa berkomunikasi dengan penyelidik-penyelidik anda boleh hubungi:

Jawatankuasa Etika Universiti Malaya	Lembah Pantai 59100 Kuala Lumpur, Malaysia Telepone: 603 79493209 Fax: 603 79494638
Jawatankuasa Etika Penyelidikan manusia Australian National University	Office of Research Integrity, Research Office Ground floor, Chancelry 10B Ellery Road, The Australian National University Action ACT 0200, Telephone: + 61 (0) 2 6125 3427 Fax: + 61 (0)2 6125 4807 human.ethics.office@anu.edu.au

Terima kasih kerana mempertimbangkan untuk mengambil bahagian dalam penyelidikan kami Sila beritahu kakitangan klinik yang anda ingin melengkapkan soalan pertama sekarang.

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BORANG PERSETUJUAN UNTUK MENGAMBIL BAHAGIAN DALAM PROJEK PENYELIDIKAN

Tajuk Projek: A longitudinal study of pain experienced by breast cancer survivors: Effects of pain on distress symptoms, resilience and quality of life

1	Saya telah membaca dan memahami lampiran informasi peserta untuk projek di atas	
2	Saya mempunyai peluang untuk mempertimbangkan maklumat, bertanya soalan dan berpuas hati dengan jawapan-jawapan	
3	Saya faham bahawa penyertaan saya adalah secara sukarela	
4	Saya faham yang kelulusan telah diberi oleh Australian Nasional University (ANU) dan Pusat Perubatan Universiti Malaya (PPUM) Penyelidikan Manusia Jawatankuasa Etika	
5	Saya faham bahawa tujuan kajian ini adalah untuk menilai soalan-soalan soal selidik yang dilampirkan untuk meneroka keberkesanannya pada pesakit kanser payudara selepas pembedahan di Malaysia	
6	Saya faham bahawa hasil kajian tidak memberi manfaat secara langsung kepada saya	
7	Saya faham bahawa prosedur projek itu akan melibatkan penyelesaian soal selidik yang telah dijelaskan kepada saya. Saya juga sedar bahawa saya boleh bertanya kepada para penyelidik untuk membantu saya dalam penyelesaian soal selidik	
8	Saya faham bahawa adalah dijangkakan bagi sesetengah orang tidak akan ada risiko atau tidak selesa, tetapi bagi beberapa orang signifikan yang lain, kajian ini mungkin akan menimbulkan rasa ketidakselesaan. Dalam keadaan demikian saya bebas untuk meninggalkan projek itu pada bila-bila. Jika ketidakselesaan saya berterusan selepas meninggalkan projek itu, saya sedar bahawa ada kaunseling disediakan atas permintaan. Saya faham bahawa tidak akan ada perubah dalam perawatan, pengurusan dan hak asasi saya dari PPUM. Saya sedar bahawa data tidak akan digunakan dan akan dimusnahkan	
9	Saya faham bahawa penyertaan saya dalam projek ini tidak akan mengakibatkan tambahan kos perubatan atau hospital kepada saya	
10	Saya faham, walaupun hasil projek ini akan dapat diakses, namun penglibatan dan identiti saya tidak akan didedahkan	
11	Dalam memberikan kebenaran, saya mengakui bahawa penyelidik akan mengkaji rekod perubatan saya; hanya yang berkaitan dengan projek ini	
12	Sekiranya saya mempunyai sebarang masalah atau pertanyaan tentang cara di mana projek itu dijalankan, dan saya tidak berasa selesa menghubungi kakitangan penyelidikan, saya sedar bahawa saya boleh menghubungi Jawatankuasa Etika Penyelidikan Universiti Malaya (Tel: 03 79493209) atau Jawatankuasa Etika Penyelidikan Manusia dari Australian National University (Tel: 612 6125 3427)	
13	Setelah mempertimbangkan semua butir-butir ini, saya menerima jemputan untuk mengambil bahagian dalam projek ini	

Terima kasih kasih di atas masa anda untuk pertimbangan bagi mengambil bahagian dalam projek ini

Nama penuh:	Tarikh	Tanda tangan
Penyelidik:	Tarikh	Tanda tangan