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## Abstract

**Background:** Delayed presentation affects breast cancer survival. The prevalence of advanced presentation remains a large obstacle to achieving lower mortality rates in low and middle resource countries. Research on the reasons for late presentation is scarce in the Asia Pacific region. This thesis aims to clarify in the reasons why women present their breast cancer at an advanced stage.

**Methods:** This study used a concurrent embedded qualitative quantitative mixed methods study. The qualitative portion used purposive sampling of 19 breast cancer patients presenting with delayed treatment and/or advanced cancer diagnosed within two years at the University Malaya Medical Centre (UMMC), Kuala Lumpur. In-depth interviews were conducted using a topic guide. The audio-recordings were transcribed verbatim. NVivo 8 qualitative software was utilised for data management. Triangulation with patients' medical notes was done. The sample size was determined by theoretical sufficiency. Analysis utilised a constructivist grounded theory method. Reflexively the main researcher is a breast surgeon who was not involved in the medical care of the patients. The survey involved 261 consecutive women with breast cancer attending outpatient services in UMMC. This survey was conducted to determine the socio-demographic factors, treatment, social support, sources of information and patients' coping strategies employed during when they were newly diagnosed with cancer. This survey also measured the current needs of the patients.

**Results:** The constructs were derived from the journey of the patients. Through an iterative process, evidenced by thick description in Chapter 4, two models emerged.

The first was the stages of breast cancer delay (SBCD) model where four concepts emerged :- i) pluralistic health systems; ii) stages or points of delay; iii) presence of patient or system delays and lastly iv) patient decision making at each stage. Eight points or stages of delay were found :- (i) Appraisal delay; (ii) Disclosure delay; (iii) Illness delay; (iv)Behavioural/Referral Delay; (v) Scheduling delay; (vi) Diagnostic delay and (vii)Treatment decision delay and viii) Treatment delay. At each stage, a patient decision making model emerged, the breast cancer delay explanatory (BCDE) model, which was the process of assessing severity, understanding and selecting options. Four main constructs found to be operational here were; i) knowledge on disease and disease outcomes, ii) knowledge on treatment and treatment outcomes, iii) psychological and physical resources and support and lastly iv) roles in patient and medical decision making. The quantitative survey found that the breast cancer patients in UMMC had high needs in financial and hospital systems and information, but very low needs in sexuality issues. Acceptance and religion are common methods of coping. Surgeons, oncologists and nurses were perceived to provide good support to women. Family doctors were an irrelevant source of support for the majority. Important sources of information after their diagnosis were from doctors, books on breast cancer, women with breast cancer, family members, nurses and newspapers. Survivor support group was found to be an irrelevant source of information in a third of the women.

**Conclusions:** The SBCD and BCDE models emerged from this exploratory research. These models clarifies the complex reasons for delayed presentation of women with breast cancer to medical authorities.

#### Abstrak (Malay Language)

**Latar belakang:** Menangguh untuk mendapat perhatian dari pihak hospital memberi kesan buruk terhadap kemandirian seseorang yang menghidap kanser payudara. Kelewatan tersebut adalah sesuatu halangan besar untuk mengurangkan kadar kematian akibat kanser payudara di kalangan negara berpendapatan rendah dan sederhana. Kajian berkenaan penyebab kelewatan ini di kawasan Asia Pasifik adalah terhad. Tesis ini bertujuan untuk menjelaskan mengapa wanita hadir ke hospital pada tahap kanser yang lewat.

Kaedah: Kajian ini menggunakan pendekatan kajian campuran kualitatif dan kuantitatif yang dilakukan secara serentak. Pendekatan kualitatif menggunakan pensampelan 'purposive' di kalangan 19 pesakit kanser yang hadir ke Pusat Perubatan Universiti Malaya, Kuala Lumpur dengan kanser yang lewat ataupun mereka yang menangguh rawatan. Mereka didiagnos dalam jangkamasa dua tahun sebelum kajian ini dilakukan. Temubual yang mendalam dilakukan menggunakan bimbingan 'topic guide'. Perbualan direkod dan disalin kata demi kata.Perisian Nvivo8 digunakan untuk mengurus data. Triangulasi dengan nota perubatan pesakit telah dilakukan. Saiz sampel ditentukan oleh 'theoretical sufficiency' berasaskan teori konstruktivis. Penggunaan 'reflexivity' iaitu penyelidik utama adalah seorang pakar bedah payudara yang mengambil kira pernannya walaupun tidak langsung terlibat di dalam rawatan pesakit yang dikaji. Kaji selidik kuantitatif pula, melibatkan 261 pesakit kanser payudara yang hadir berturut-turut ke bahagian pesakit luar, klinik onkologi di PPUM. Kajian yang dijalankan meliputi faktor-faktor sosio-demografi, rawatan, sokongan sosial, sumber maklumat dan strategi mereka menangani diagnosis kanser. Kaji selidik ini juga mengukur keperluan semasa pesakit.

Penemuan: Konstruk dibina dari pengalaman pesakit. Melalui lelaran proses dan dibuktikan dengan huraian padat dalam Bab 4, dua model muncul. Yang pertama adalah peringkat model kelewatan kanser payudara (SBCD) di mana empat konsep muncul: - i) Sistem kesihatan majmuk; ii) Peringkat-peringkat kelewatan; iii) Penyebab kelewatan, yakni pesakit atau sistem; dan akhir sekali iv) Proses membuat keputusan oleh pesakit pada setiap peringkat kelewatan. Lapan peringkat kelewatan ditemui: - (i) Kelewatan menilai simtom; (ii) Kelewatan mendedah simtom; (iii) Kelewatan hidapan; (iv) Kelewatan tingkah laku / merujuk; (v) Kelewatan mendapat tarikh temujanji; (vi) Kelewatan diagnostik ; (vii) Penangguhan membuat keputusan untuk menerima rawatan dan viii) Kelewatan dirawat. Pada setiap peringkat, proses membuat keputusan pesakit muncul. Untuk menerangkan penyebab kelewatan tersebut, model BCDE ditemui. Ianya, merupakan proses menilai keadaan, mengetahui pilihan dan memilih pilihan. *Empat konstruk utama didapati beroperasi iaitu i) Pengetahuan mengenai penyakit serta penghabisannya;* ii) Pengetahuan mengenai rawatan serta hasilnya; iii) Sumber sokongan psikologi dan fizikal dan akhir sekali iv) Peranan dalam membuat keputusan. Kaji selidik kuantitatif pula, mendapati bahawa pesakitpesakit kanser payudara di PPUM mempunyai keperluan yang tinggi dalam kewangan dan sistem hospital dan maklumat. Akan tetapi keperluan mengenai isu-isu seksualiti didapati sangat rendah. Penerimaan dan pendekatan agama adalah kaedah biasa yang dilakuan oleh pesakit untuk mengatasi tekanan. Pakar bedah, pakar onkologi dan jururawat dilaporkan memberi sokongan yang baik kepada pesakit. Doktor keluarga adalah sumber sokongan yang tidak relevan untuk kebanyakan pesakit. Sumber-sumber maklumat selepas diagnosis yang didapati penting adalah dari para doktor, buku-buku mengenai kanser payudara, wanita yang menghidap kanser payudara, ahli keluarga, jururawat dan surat khabar. Organisasi bekas pesakit didapati sebagai sumber maklumat yang tidak relevan dalam satu pertiga daripada pesakit yang disoal selidik.

<u>Kesimpulan:</u> Kajian eksploratori ini menghasilkan dua model : model SBCD dan BCDE untuk menerangkan mengapa sesetengah wanita hadir ke pihak hospital dengan kanser yang telah melarat.

# **Original literary work declaration**

Name of candidate: Nur Aishah Mohd Taib (IC/passport no:700924-10-5230)

Registration/matric no: MHB 080001

Name of degree: Doctor of Medicine

Title of thesis ("this work"):

Why women present with advanced breast cancer- A mixed methods study

Field of study:

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# **Publications**

1. Taib, N. A.; Yip, C. H.; Low, W. Y. Recognising symptoms of breast cancer as a reason for delayed presentation in Asian women - the psycho-socio- cultural model for breast symptom appraisal: opportunities for intervention. Asian Pac J Cancer Prev 2011; 12 (6): 1601-8.

### Submitted for publication

 The Validity And Reliability Of The Supportive Care Needs Survey Short Form-34 (SCNS-SF34), SCNS-SF34-Mandarin And SCNS-SF-34 Malay Versions In Malaysia.

2. The SBCD (Stages of Breast Cancer Delay) to explain the breast cancer patients journey towards delaying presentation.

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# **Chapter 1 Introduction**

#### 1.1 Background

In recent years, steep increases in breast cancer incidence have been reported in Asian countries (Sankaranarayanan et al., 1996), including Malaysia. Breast cancer is now the leading cause of cancer deaths among Malaysian women (Narimah, 1999). The Malaysian National Cancer Registry, launched in April 2003, reported an age-standardized incidence rate of 52.8 per 100,000 for the year 2002. In other words, a woman in Malaysia has a 1 in 19 chance of getting breast cancer in her lifetime (Lim, S Rampal, & Halimah, 2008).

In the first half of the 20th century, clinicians became aware of the variability in prognosis amongst breast cancer patients. Attempts were then made to differentiate and categorise patients so that aggressive treatment could be instituted to those who required it. Among these, in 1904, a German physician Steinthal proposed a three stage prognostic groups system (Singletary et al., 2003). This simple staging system was further refined by Greenough, who based his classifications on microscopic examination of breast cancer specimens. The four-stage Columbia Clinical Classification System for breast cancer, with stages A through C corresponding to Steinthal's stages, and stage D representing disease that has metastasized throughout the body, was introduced in 1956 by Haagensen and Stout. The tumour-node-metastasis (TNM) system was developed by Pierre Denoix in 1942 and represented an attempt to classify cancer based on the major morphological attributes of malignant tumours that were thought to influence disease prognosis. These are: size of the primary tumour (T), presence and extent of regional lymph node involvement (N), and presence of distant metastases (M). The Union for International Cancer Control (UICC) presented a

clinical classification of breast cancer based on the TNM system in 1958 and the American Joint Committee on Cancer (AJCC) published a breast cancer staging system based on TNM in their first cancer staging manual in 1977. Since then, regular revisions have been issued to reflect major advances in diagnosis and treatment. In the 1987 revision, differences between the AJCC and UICC versions of the TNM system were resolved(Singletary et al., 2003). For the clinician, breast cancer staging is useful because of its ability to estimate prognosis. The standardised definitions allows for valid comparison.

A 10-year relative survival study in breast cancer patients, adapted from a report by Bland and colleagues that used data from 1.3 million cases (1985 to 1996) in the national cancer data base (NCDB) shows significant differences in survival rates. Specifically only 5% to 12% of stage I/II patients die in the first 10 years after diagnosis, compared with over 60% of stage III patients and over 90% of stage IV patients (Singletary, et al., 2003).

In turn, the staging depends greatly on the size of the tumour. In the University Malaya Medical Centre (UMMC), Kuala Lumpur from 1993 to 2002, the mean size of tumour at presentation was 4.2 cm (median 3cm), whereas, in Hospital Kuala Lumpur the mean size was 5 cm (Hisham & Yip, 2003). Furthermore, in UMMC about 22% of women present with stage III and IV (Taib et al., 2007). Although there is no nation-wide statistic on the stage of presentation for Malaysia, the Penang cancer registry in 2008 reported 17.3% presenting with stage III and 13.1% stage IV, and in UMMC, the respective figures were similar ie. 17.7% and 12.0% (Taib et al., 2011).

The overall 5-year survival of breast cancer patients in UMMC approached 76% for women diagnosed between 1998 to 2002. Specifically, 5-year survival rates were 100%

for stage 0, 95% for stage I and 88% in stage II compared to 51% for stage III and 20% for stage IV (Taib, et al., 2011). In contrast, the 5-year overall survival rate in the United States was higher ie. 88% for women diagnosed between 2001 and 2002 (Singletary, 2003). The higher overall survival was due to the fact that most patients present with early breast cancer.

The other phenomenon is that in addition to this phenomenon of late presentation, there are women diagnosed with early stage breast cancer who refuse treatment and then progress to locally advanced breast cancer. It has been noted that seven percent of women abscond treatment after diagnosis (Taib & Yip, 2009). It would be useful to know the reasons for refusing or discontinuing treatment, as other treatments sought by the patient may be detrimental to health. In fact, studies in UMMC (Taib &Yip, 2009) and in Europe (Verkooijen et al., 2005) have shown reduced survival time when patients default treatment.

Access to health care, health education and health behaviour may be the basis for delayed presentation in Malaysia. Unlike developed nations, population-based mammographic screening program is not feasible in this country due to its high running cost. Research in disparities in outcomes between whites and blacks in the USA found various factors affecting health-seeking behaviour, such as, failure to identify symptoms, especially non-lump breast symptoms; lower personal risk perception; negative beliefs about breast cancer and its treatment; concerns of disability, disfigurement and adverse economic consequences; non-disclosure; needing prompting from others for non-breast problem and reluctance to bother their GPs and older age (Bish et al., 2005). In this regard, Asian women have been found to be

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fearful and embarrased in seeking treatment related to the breasts (Lam et al., 2009) Gender-sensitivity, namely, reluctance to consult with a male doctor, may be a possible reason although this has not been demonstrated in any study in Malaysia.

On the other hand, in rural Kelantan (a northern state in Malaysia)a survey of 328 women found that delayed diagnosis was more likely among women who had more children, self-detected symptoms, non-cancer interpretation of symptoms, fear and negative attitudes towards treatment. In addition inappropriate action by their initial medical doctors also led to delays. There were also treatment delays among pregnant women, women who initially refused mastectomy, and those taking alternative treatment (Norsa'adah et al., 2011).

However, in an urban practice, little is known on what causes a woman to delay seeking treatment. Information on access to timely diagnosis in Malaysia is not available. Thus, there is a genuine need to understand why women present with advanced breast cancer to enable specific interventions in this population with its unique health beliefs and practices.

1.2 Statement of purpose

Breast cancer is not only the commonest cancer amongst women but the commonest cancer in Malaysia. It is a fact that women can survive the cancer, but there is a subgroup of women in this country who are at higher risk of dying because they present with an advanced stage. The main issue for further research is why women in Malaysia present late with this treatable disease.

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### 1.3 Justification for this study

There are gaps in the literature on why women present with advanced disease at diagnosis. In Malaysia, there is a paucity of information on the reasons why women delay diagnosis as well as treatment. Since delayed diagnosis and treatment are linked to higher mortality risk, an understanding of this issue will contribute towards improving breast cancer survival. The research method that is suitable, to address this would be a qualitative approach to explore the nuances of this phenomenon. In an article on gap analysis for breast cancer research in the United Kingdom National Health Service, one of the key areas recommended is psychosocial research. The key recommendations include encouragement of cross-specialty collaboration to incorporate psychosocial issues and psychological theories. This is to develop and evaluate psychosocial interventions and to ensure researchers give greater attention to all stages of breast cancer and that the needs of older women and those from a range of ethnic groupswere included(Thompson et al., 2008).

Research in this area could directly improve the experience of patients, their families and those at increased risk of breast cancer because their psychosocial needs would be more appropriately and effectively met at all stages of their cancer journey (Thompson, et al., 2008).

In Malaysia, psychosocial support is not available in most hospitals catering to the care of cancer patients. A Medline search in September 2009 using the keywords, "psychosocial", "breast cancer" and "Malaysia", gleaned only three psychosocial papers published in Malaysia. The unmet needs of women with breast cancer in Malaysia constitute an issue that has long been overlooked and could be a reason why women delay presenting to the hospital with a breast symptom.

Recognising this need, this commitment and dedication of four years of my career as a breast surgeon is a gift to my patients and myself. I have felt saddened and frustrated and had difficulty understanding reasons for what may seem to be self-destructive behaviour. Their own lives and their dependents' lives are put in jeopardy when a crucial decision is made that contribute greatly to their survival.

The aim of the study is to delve deep into the depths of the perception of women who have presented with advanced breast cancer, to explore the innermost feelings and experience of women facing this predicament, and to develop our understanding and open windows of opportunities to improve the status quo.

## 1.4 Research question

Why do women present with advanced breast cancer in the University Malaya Medical Centre?

#### 1.5 Aims and objectives

### 1.5.1 Primary objective

Why women present with advanced breast cancer.

## 1.5.2 Secondary objectives

- i. To identify the sociodemographic characteristics of breast cancer patients attending outpatient services in UMMC
- ii. To identify the clinico-pathological and treatment characteristics of breast cancer patients
- iii. To identify the social support during period of diagnosis
- iv. To identify sources of information after diagnosis of breast cancer
- v. To identify coping mechanisms of women after a diagnosis of breast cancer
- vi. To identify the needs of women with breast cancer

I have chosen the qualitative approach to answer the main research question as it requires in-depth analysis. Hence, the study weighs heavily on the qualitative approach using constructivist grounded theory. Women who have been diagnosed with advanced stage breast cancer were invited to participate in in-depth interviews to explore the reasons for presenting at a late stage to UMMC. Concurrent with this qualitative data collection, a survey on the breast cancer presentation and journey, sources of information, sources of social support, supportive care needs and coping mechanisms were also studied. The reason for collecting both qualitative and quantitative data is to consolidate the strengths of both forms of enquiry to answer different research questions. Justification for choosing the mixed method research method to answer the research questions will be discussed in more detail in Chapter 3 and 6.

### 1.6 Reflexivity

The researcher is the research tool in a qualitative inquiry. The pursuit to understand this phenomenon, was borne out of my own frustrations with managing women who presented with advanced cancer. These frustrations include a feeling of helplessness
and not having the resources to deal with women who are not keen on treatment provided by mainstream hospitals. In addition, there is overt competition with alternative health providers who are able to convince women to have alternative treatment.

The feeling of helplessness has dissipated, with maturity and the understanding that decisions by these women are made autonomously, and should be respected. However, there is still suspicion that women are not making informed decisions due to a skewed view of the disease. After extensive cross-disciplinary reading, there are ways that could change this phenomenon. Therefore, it can be taken as a challenge that can be met with help from psychologists and social scientists.

The researcher in this study is a breast surgeon with ten years' experience committed to treating breast cancer patients as well as a trained genetic counsellor. Being the main research tool, the breast surgeon has to be open and upfront in terms of the perception of the study participants towards the researcher. During the period of data collection, the main researcher was not actively involved in the clinical management of the patients participating in the research although they were made aware of her professional background from the start. Although this disclosure may introduce some bias, participants were surprisingly frank during the interviews and open to sharing.

# 1.7 Scope of the research

This study specifically looks at women who present with advanced disease in UMMC. A survey was also carried out on women using oncology outpatient services in UMMC, to study the demographics of women attending our services as well as to understanding their needs. From the perspective of a breast surgeon, it is hoped that this research will offer some insight for policy makers, non-governmental organisations, healthcare providers and researchers to concentrate their efforts to improve the well-being of Malaysian women with breast cancer.

This study is important in investigating the underlying reasons for late presentation. Women who present with advanced breast cancer are just human. Understanding their needs and difficulties may assist future patients in presenting and having treatment at an earlier stage. This is a cross-discipline study incorporating medical practitioners who are experts in the disease and psychological, social sciences and behavioural science experts in the perception of illness. Experiencing the illness is the reality of the patients. Their stories may give clarity and novel insights into this problem.

Results from this study will inform policy makers so that appropriate interventions and programmes can be put in place by the hospital authorities, and other discerning health care providers in Malaysia for the betterment of health care provision.

### 1.8 Outline of the thesis

The thesis is divided into eight chapters.

# Chapter 1 - Introduction

Introduces the central phenomenon being studied and the intent of the study.

# Chapter 2 - Review of the literature

- Section 2.1 of this chapter describes the present situation on breast cancer. The history of breast cancer, its epidemiology, biology, management and the impact

of delay and advanced breast cancer at presentation are presented. An introduction to the gravity of the problem faced in UMMC and other centres in Malaysia paints a backdrop to why this study is important.

- Section 2.2of this chapter is a literature review defining delay and association with socio-demographic variables. Generic health behaviour theories and the bio-psychosocial model of health care are presented.
- Section 2.3 of this chapter gives a more structured view of patient delay by detailing known explanatory delay theories.

# Chapter 3 - Research methods

- Section 3.1 of this chapter details the purpose of the study
- Section 3.2 details the mixed-method study design
- Section 3.3 discusses the theoretical framework
- Section 3.4 describes the study site
- Section 3.5 details the ethical considerations of this research
- Section 3.6 details the qualitative research procedures
- Section 3.7 details the quantitative survey methods

# Chapter 4 - Results

- Section 4.1. reports the quantitative analyses of the survey.
- Section 4.2. displays the profile of women with advanced breast cancer who participated in this study
- Section 4.3. displays the health care utilisation of the women who presented with advanced breast cancer
- Section 4.4. displays the temporal journey of the women with advanced breast cancer

 Section 4.5. displays the explanatory themes of why women present with advanced breast cancer

# Chapter 5 -Discussion

This chapter discusses the emergent models in this study and its' relation to what is already known

# Chapter 6- Limitations

Discussion on research methods and limitation of the study are detailed in this chapter

# Chapter 7 - Contribution and Implications

This chapter discusses the contribution of the emergent models in clinical practice and research

Chapter 8 - Conclusion

This chapter concludes why women present with advanced breast cancer

# **Chapter 2 Literature review**

2.11ntroduction to literature review 2.1.1 The literature review in grounded theory

Literature review in grounded theory is often disputed. Glaser & Strauss (1967) advocated delaying the literature review to the end because of received theory bias or forcing data in preconceived theories, thus, avoiding imported ideas and imposing into one's work (Charmaz, 2009).

2.1.2 Approach towards the literature review

Reflexivity of researcher is important so as not to have a biased outlook. Reflexively, I am a breast surgeon. However, as a novice researcher in the area of psychology, sociology or anthropology, it gives an advantage of theoretical agnosticism; a term coined by researchers. It is a useful stance, congruent with the original Glaser stance on delaying literature review to the end (Bulmer 1979, Dey 1999 and Layder 1998), quoted by Charmaz (Charmaz, 2009).

I used theoretical sensitivity from Glaser 1978 (Charmaz, 2009) during data analysis to acquaint myself to sociology, psychology language and concepts by reading widely and going back to text books to render explicitly the ability to notice the subtleties of relationships in the data. In keeping with the tradition of grounded theory where this study aims to explore and generate models or theories. Hence, this thesis does not provide a theoretical framework but will generate a model to explain why women present late.

#### 2.1.3 Outline of this chapter

Section 2.1 of this chapter describes the present situation on breast cancer. The history of breast cancer, its epidemiology, biology, management and the impact of delay and advanced breast cancer at presentation are presented. An introduction to the gravity of the problem faced in UMMC and other centres in Malaysia paints a backdrop to why this study is important.

Section 2.2 of this chapter gives a more structured view of patient delay. Generic health behaviour theories and the bio-psychosocial model of health care and exploratory delay theories are presented here.

Section 2.3 of this chapter is a literature review on the findings of delay research.

# 2.2 Understanding breast cancer and defining the issue of late presentation

## 2.2.1 History of breast cancer

Hippocrates, the father of modern western medicine, documented the concept of cancer using the humoral theory of blood, phlegm, yellow bile and black bile to reflect the four building blocks of nature - air, fire, earth and water. Cancer erupted from an excess of black bile or "melanchole". Hippocrates termed cancer "karkinos", a Greek word for crab which eventually evolved into carcinoma, which is cancer from epithelial cells as we know today. Hippocrates documented the systemic nature of this disease and deemed it an incurable systemic disease (Olson, 2002).

In the book Bathsheba's breast written by Olson in 2002, an extensively referenced history of breast cancer was documented. Herodotus, a Greek historian, documented

the trials and tribulations of Queen Atossa, daughter of the King of Persia. The wife and mother of the Persians' god, for all her power and splendour, harboured a personal terror - a fear of breast cancer. "so long as the sore was of no great size", she (Queen Atossa) hid it through shame and made no mention of it to anyone. She bathed alone without assistance from tale-carrying servants. Finally, she had no choice - worried about death and disfigurement, sexual castration and loss of her allure as the growth continued engulfing much of her breast, Atossa called on her Greek slave Democedes for medical assistance. He lanced the tumour and was rewarded by granting him freedom from enslavement. As for many women with a breast abscess, Queen Atossa was cured (Olson, 2002).

Women today face the same challenges as those faced by women centuries ago. The fear of having cancer and its' treatment may drive women not to seek treatment until the very end.

### 2.2.2 Breast cancer epidemiology

In 2008, some 13 million people (men and women) were diagnosed with cancers worldwide. Cancer of the breast in women is a major health burden, and comprised 12.7% (1.6 million) of all cancers diagnosed in 2008(Ferlay J, 2008). It was the most common form of cancer in both more developed and less developed regions. The incidence of cancer varied from an age-specific rate (ASR) of more than 100 per 100,000 population in North America to less than 23.4 per 100,000 population in the African continent. Fig. 2.1 shows the differences by region, with Malaysia having a moderately low incidence of breast cancer.



Figure2.1 Incidence of breast cancer(World)- Age standardised rates per 100,000 population. Source: Globocan Report 2008, www. globocan.iarc.fr. Accessed online on 27 December 2011.

Breast cancer is also the primary cause of cancer deaths among women globally, accounting for approximately 458,000 (13.7%) deaths in the same year(Ferlay J, 2008). There is a recognised disparity in breast cancer burden worldwide (Sankaranarayanan et al., 1996; Sant et al., 2004; Sant et al., 2009; Shibuya et al., 2002). In less developed regions, the incidence of cancer was 691,281 (49.97%) of the world burden (Ferlay J, 2008). Yet, the mortality was 58.66% of the global mortality, indicating a greater need to improve survival in less developed regions.



Figure2.2 Estimated age-standardised breast cancer mortality rate per 100,000 population. Source:Globocan Report 2008, www. globocan.iarc.fr. Accessed on 27 December 2011.

In the South East Asian region, breast cancer incidence comprised 22.4% (203,778 cases) of the cancer burden in women and mortality was 93,905 (16.6%) of total deaths (Ferlay J, 2008). Fig 2.2 shows the estimated mortality rates globally. The highest age standardised mortality can be seen in the South-east Asian region, Middle-east, South America, Africa and surprisingly the United Kingdom, a developed nation. This indicates the enormous impact of cancer in less developed nations, necessitating

development in the areas of palliative care and strengthening of hospital systems which are geared towards earlier diagnosis and treatment.

Breast cancer is the most common cancer in Malaysia, with an age-standardised incidence rate (ASR) of 47.4 per 100,000 population. Chinese Malaysians have the

highest incidence with an ASR of 59.9 per 100,000 population, followed by 54.2 for Indian Malaysians and 34.9 per 100,000 population for Malay Malaysians (Lim et al., 2008). Overall, this is one of the lower rates in the world, but the ASR is higher for ethnic Chinese in Malaysia compared to ethnic Chinese in Singapore or Beijing (Lim et al., 2008).

An ageing population and industrialisation are projected to increase in less developed regions, thus, increasing the rate of cancer. In fact, there is increasing evidence for a projected rise in the incidence of cancer in Asian countries (Bray et al., 2004; Fischer et al., 2005) necessitating the growth of cancer services. Outcome data for cancer treatment remain scarce in Malaysia. Improved mortality outcome (Ong & Yip, 2003) and also improving survival trends (Taib, et al., 2011) have been reported., in terms of published morbidity outcomes for Malaysian cancer patients, however, there has been only one qualitative focus group study looking at cancer knowledge profile (Loh et al., 2009) and one study on information needs(Gopal et al., 2005).

## 2.2.3 Biology of breast cancer

#### 2.2.3.1 What is breast cancer?

Breast cancer is a disease of uncontrolled cell growth. The cancer develops when there is a mutation in somatic genes. Figure 2.3. below illustrates the progression from normal cells to invasive carcinoma. Understanding that there is a phase of progression from invasive cancer to incurable cancer gives the insight that this process is time dependent and can be arrested at many stages.



Figure 2.3 Pathobiologic events associated with ductal carcinoma in-situ The molecular, cellular, and pathological processes that occur in the transformation from healthy tissue to preinvasive lesions, such as ductal carcinoma in situ, to breast cancer are shown. The majority of the changes that give rise to cancer, including the accumulation of genetic changes, oncogene expression, and the loss of normal cell-cycle regulation, appear to have occurred by the time ductal carcinoma in situ is present. Most of the clinical features of a subsequent invasive breast cancer are already determined at this stage, although additional events, including tissue invasion and changes in the surrounding stroma, characterize the invasive tumour.

Source: http://www.gastricbreastcancer.com/figures/figure3.htm. Accessed 12 Dec 2010.

Breast cancer is also a heterogeneous disease with differing behaviour and outcomes.

Prognostic subtypes can be divided into hormone-sensitive tumours, triple negative and

Her2 positive tumours. Based on the DNA microarray, the subtypes are divided into

four groups - the luminal or ER positive tumour; normal breast like; Her2 positive; and

basal breast cancer. The hormone sensitive tumours can be further classified into Her2

positive or negative, implying that both diseases should be treated differently (Perou et

al., 2000).

The survival of breast cancer patients have improved in modern times, with the use of appropriate therapies. However, due to the heterogenous nature of breast cancer, individual patients would behave differently, thus delay in presentation in a slow-growing tumour would be less disastrous compared to a fast-growing tumour, as was seen in a study by Bloom who observed that survival was not related to delay alone but to the grade of the tumour (Bloom, 1965). Fig 2.4 and 2.5 show a patient with an aggressive cancer phenotype, inflammatory breast cancer where the tumour had progressed rapidly over two weeks.

Although there is available treatment and breast cancer is known to have good prognosis when detected early, a delay in seeking treatment remains a major obstacle in obtaining better cure rates. Unfortunately, there is no predictive model to identify who would be having the aggressive cancer; therefore, a strategy to reduce delay may prove to be useful.



Figure 2.4 Inflammatory breast cancer



Figure 2.5 Dramatic progression of a biologically aggressive tumour over an interval of two weeks.

Understanding the biology of tumours also allows for better targets to be found, hence, advancing the cure rates of breast cancer. Predictive factors allow prediction to the efficacy of different types of treatment. An example of this would be oestrogen receptor status (ER status) and the use of tamoxifen and aromatase inhibitors and the Her2 status in the use of Trastuzumab (Colleoni et al., 2003).

# 2.2.3.2 Diagnosis of breast cancer

A diagnosis of breast cancer can be made in symptomatic and asymptomatic women. The diagnostic process for symptomatic patients entails the triple assessment which are - clinical examination, imaging and biopsy. The use of fine needle aspiration cytology or core biopsy provides definitive diagnosis for definitive treatment(NCCN, 2011).

#### 2.2.3.3 Breast cancer symptoms

Presentation of breast cancer can be divided to asymptomatic and symptomatic disease. Asymptomatic breast cancer arises from the use of mammographic screening of presymptomatic women. Screening mammography has been found to reduce breast cancer mortality by 30% (de Koning, 2003). Recently, a study in Australia found reductions in mortality of 60% occurred after the introduction of population based mammographic screening in 1991. However the greatest reduction mortality was identified in women 40-49 years old who were not covered by the programme. Hence, the overall reduction was attributed to adjuvant treatment and overdiagnosis (Burton, 2011).

In terms of symptoms, painful lump was experienced in only 6% of symptomatic breast cancer patients (Greenough, 1935). The most common symptom of breast cancer was a painless breast lump. Literature from the pre-screening era reports that 75% of women present with an accidental discovery of a lump. Pain is rarely seen in patients with breast cancer. Other non-lump symptoms such as diffuse hardness, nipple changes and skin changes have been implicated in delay (Andersen & Cacioppo, 1995; Burgess et al., 2001; Meechan et al., 2003; Ramirez et al., 1999). In the absence of the classical symptom of a painless breast lump, many women have a false sense of security and miss other symptoms of cancer (Meechan, et al., 2003).

# 2.2.3.4 Staging of breast cancer

Breast cancer can be divided into early breast cancer, locally advanced breast cancer and metastatic breast cancer. The AJCC (American Join Committee on Cancer) staging provides an avenue for comparisons between different institutions by standardising nomenclature and definitions. The tumour size (T), nodal involvement (N) and metastases (M) are classified into subgroups and in aggregate gives the best staging profile for each patient (Edge et al., 2010). There is no standard agreement on the definition of locally advanced breast cancer. Large primary tumour greater than 5cm (T3) or with fixed skin or chest involvement (T4), and/or fixed axillary (N2) or ipsilateral internal mammary lymph node involvement, when considered would be staged as Stage III are considered locally advanced(Edge, et al., 2010).Inflammatory breast cancer (T4d) as seen in Figure 2.4 and 2.5 are considered locally advanced disease. Locally advanced breast cancer may arise because of neglect or it can develop because the tumour is biological aggressive. Compared to patients with operable primary breast cancer, patients with LABC are at significantly higher risk of local recurrence and distant metastases and have a worse overall survival.

In developing countries, staging of breast cancer patients can reveal epidemiological information relevant to opportunities for improving breast cancer screening and management. Public and private agencies interested in international public health programs can use such information to document needs and to optimize their interventions (Singletary, et al., 2003).

## 2.2.3.5 Survival

Improved survival in developed nations has been documented and attributed to breast cancer screening, advancement in treatment modalities, and better organised health systems (Kingsmore et al., 2003; Thongsuksai et al., 2000).

Causes of this phenomenon include improvement in diagnostics, especially with population mammographic screening, better treatment and improvement of organizational systems (Micheli et al., 2003). The mean European age- and areastandardised 5-year relative survival of women diagnosed with breast cancer in 1995– 1999 (Eurocare-4) was 79%, compared to 76% in 1990–1994 (Eurocare-3). Improvement of breast cancer survival in Europe was 8.9% (Sant et al., 2001).Between countries, survival differences have also narrowed in Eurocare-4 compared to Eurocare-3. However, notable between-country survival differences persist in some cases, e.g. Central Europe had the highest survival (82% and above) and was still slightly lower than the mean (around 77%) for the UK(Sant, et al., 2009).

Cancer mortality and incidence in developing countries have been reported to account for over 60% and about half of the global total, respectively(Shibuya, et al., 2002). The 5-year relative survival for women younger than 75 years with breast carcinoma was 43-84% in developing countries. It seems likely that the survival differences are due to both late stage of disease at presentation well as the availability and quality of adjuvant treatment (Ravichandran et al., 2005)(Sankaranarayanan, et al., 1996)(Fakhro et al., 1999)(Hao et al., 2002)(Son BH, 2006).

There is a disparity between low and high income countries in cancer outcomes (Anderson et al., 2006). However, little is known of the Asia Pacific region. In fact, breast cancer survival information in Malaysia is scarce. However, due to mandatory reporting of deaths in Malaysia, observed survival can be obtained (Mohd Taib et al., 2008; Yip et al., 2006). The 5-year overall survival of breast cancer in women treated between 1993 and 1997 was 58.4%. A more recent cohort showed a vast improvement with a 5- year survival of 75.7%. Independent prognostic factors were found to be age, grade, stage and Malay ethnicity. There was no significant change in stage at presentation and tumour size between the two cohorts (Pathy et al., 2011, Mohd Taib, et al., 2008; Taib, et al., 2011). The use of more efficacious adjuvant treatment, effective multidisciplinary treatment (Bray, et al., 2004; Levine & Eisen, 2001) and realignment of health services (Kingsmore, et al., 2003) have been implicated in the improvement of survival. The overall survival of 75.7% in UMMC seems to be at par with the Eurocare figures. However, this study was based on a hospital cohort which excluded individuals non-adherent to treatment and pre-cancer disease like DCIS and LCIS (Taib, et al., 2011).

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In comparison, the American database of women diagnosed in 2001-2002 showed highly superior 5-year survival rates of 100% in stage 0 or pre-cancer patients, and 92.7%, 87.8%, 81.4%, 74.0%, 66.7%, 41.0%, 49.3% and 14.8% in stages I, IIa, IIb,IIIa, IIIb, IIIc and IV disease, respectively (Edge, et al., 2010).

In Australia, a similar improvement has occurred in terms of downstaging of disease and outcomes spanning a period of 25 years. A study of87 women from the period 1962 to 1963, 103 women from 1981 to 1982, and 50 women from 1986 to 1987 demonstrated a chronologically based improvement in the stage of disease at presentation over the 25 years (Bennett et al., 1990). Specifically, there was a decrease in mean tumour diameter, a reduction in the proportion of patients with involved axillary nodes, and a greater percentage of patients with stages I and II disease. A reduction in the symptomatic period was also noted over this period, and a direct relationship was found between the duration of symptoms and tumour size, nodal status and overall stage of disease (Bennett, et al., 1990).

# 2.2.3.6 Quality of life and breast cancer

Besides the effect of stage and survival, quality of life would be affected in more advanced breast cancer. Cancer outcomes are not just about survival but quality of life. The progression and stage of cancer is inversely correlated with the quality of life (Andersen et al., 1989; Ivanauskiene et al., 2010).

Quality of life is also affected by treatment of breast cancer. Loss of breasts affects the psychological and social well-being of the patient. Losing hair, fatigue and reduced mental alertness have been attributed to chemotherapy. Menopausal symptoms and effects on sexual health related to the use of chemotherapy and Tamoxifen are also

evident (Fallowfield, 2005; Grunfeld et al., 2003; Kirk & Hudis, 2008). Sexual dysfunction hasbeen quoted to be prevalent among breast cancer patients. Socioeconomic factors affect health related quality of life of patients (Ivanauskiene, et al., 2010).Social impact of metastatic cancer on relationships, marriage and family have also been found (Allen, 2010). The impact on survival was seen when poor quality of life in the first year after diagnosis, suggesting support interventions may be of benefit (Epplein et al., 2010). Social support is important in improving quality of life (Trunzo & Pinto, 2003).Little is known in Malaysia with regards to quality of life and association with stage as well as a factors associated with it.

## 2.2.4 Early detection of breast cancer

# 2.2.4.1 Mammographic screening

The detection of breast cancer in asymptomatic women hinges on the effectiveness of a pre-symptomatic screening utility. Figure 2.6 and 2.7 shows a patient with a mammography detected cancer, and a hook-wire localisation biopsy of the lesion was done. Breast cancer is one of the few cancers that have an effective screening procedure. In this regard, large-scale randomised trials on mammographic screening have shown reductions in mortality (de Koning, 2003). Stage reduction with breast mammographic screening has also been demonstrated (Bennett, et al., 1990). Singapore was the first Asian nation to initiate population-based screening. Although early mortality data did not suggest improvement after introduction of mammography, there was a difference in the size of tumour and stage of those detected by screening compared to those detected by symptoms (Chuwa et al., 2009).



Figure 2.6 A non-palpable lesion localised using a hookwire localisation technique



Figure2.7 The specimen removed from the patient

In underserved communities, mammographic screening in insured low socio-economic women showed a benefit in down staging cancers, however mortality benefit was too early to report (Ahmed et al., 2010; Howard et al., 2010; Oluwole et al., 2003). Is opportunistic screening better than no screening? In the US, through insurance coverage, women perform screening but there is no organised population based screening. Despite this US enjoys very good survival rates as compared to Europe. In the United Kingdom (UK), although population based 3 yearly mammogram has been in place, it did not contribute to improved survival. In Denmark, survival was similar to that in the UK, even though nation-wide population based mammographic screening had not yet been implemented (Sant, et al., 2009).

### 2.2.4.2 Breast self examination (BSE)

From a large randomized study in Shanghai on BSE instruction involving 266 000 women who were followed-up for 10-11 years, there is evidence that teaching BSE does not improve survival (Thomas et al.,2002). The failure to observe a difference may be due to the fact that the women in the study were very breast aware and that the overall survival in both the intervention and control arms was above 90%. It was seen that even in the control arm, 44.8% of the women found breast lumps 2 cm or smaller, i.e., almost similar to the intervention group who were taught BSE (48.8%). Therefore in Malaysia, there is still room for the use of BSE to create breast awareness, with the hope that in the future, our women will present with average breast lump size of 2 cm.

#### 2.2.4.3 Clinical breast examination

Clinical breast examination (CBE) is examination of the breasts by trained personnel, i.e., health professionals like general practitioners, gynaecologists, breast surgeons and public health nurses. The effectiveness of CBE versus education alone is currently being investigated in a large randomized trial. This study began accrual in 1998 in Mumbai, India. More than 75 000 individuals were recruited into each arm. The intervention arm was targeted to receive CBE. The study was planned to have yearly rounds for eight years. Interim analysis after three rounds, reported high participation rates, a higher pick up rate of cancer in the CBE arm and high diagnosis and treatment follow-through by the participants. Mortality outcomes have not yet been reported (Mittra et al., 2010). Prior to this, a very important study was conducted in the Philippines (Pisani et al. 2006). This was an epidemiological study employing trained nurses for populationbased clinical breast examination screening. It showed the refractory attitude of the population with respect to clinical follow-up, i.e., despite detecting breast lumps, many women refused further investigations. Initially, 92% of women accepted the invitation to participate, but of the positively detected women, only 35% completed diagnostic follow-up (Pisani et al., 2006).

## 2.2.5 Breast cancer screening in Malaysia

Malaysia does not provide a population-based screening mammogram programme. At best, breast clinics and family general practitioners may provide opportunistic mammographic screening for women.

Opportunistic screening is the effort of either health providers or the women themselves. A study of Malaysian women on knowledge and practice of 425 female school teachers found moderate to low knowledge and breast cancer screening practices. However, 63.6% of the respondents were 40 years and below (Parsa et al., 2008). A study of 269 Malaysian general practitioners (GP) in the Klang Valley who responded to a postal questionnaire also found low rates of reported screening practices - only 58.7% of the GP respondents claimed that they screened asymptomatic women for breast cancer. Reasons why screening was not done were: patients do not come for routine health examinations; patient cannot afford mammogram; and another doctor would have already ordered the mammogram (Taib, et al., 2007). Breast cancer knowledge was also low among GPs who responded - only 54% knew that breast cancer is the most common cancer among Malaysian women and only 54% knew that the prevalent age group was 40-49 years. Among women seen in their clinic, 49% of the GPs agreed that few women would initiate a discussion on breast screening, while 36% agreed that some women would do so. The main reasons why clinical breast examination (CBE) was not performed were: patients do not come for routine health examination; a mammogram is more sensitive than CBE; and patient's culture and religion posed a barrier. (Taib, et al., 2007).

Thus, the success of opportunistic screening in Malaysia hinges on improved patient's as well as health provider's knowledge and uptake of screening. Finding smaller lumps may not translate to better survival, however, as women may still have problems accepting conventional hospital treatment. Thus, we have to understand the health behaviour of our population before employing any mode of screening. Treatment refusal has not been published in Malaysia except in UMMC where an absconder rate of 6.7% has been reported (Taib & Yip, 2009).

Thus, less developed nations need to strategise on cost-effective measures to reduce mortality as setting up a mammographic screening population screening may not be feasible. Cancer centre organizations which provide multidisciplinary care and process matrices were recommended by the BHGI guideline implementation for low and middle income countries to strengthen patient navigation through health systems to ensure timely diagnosis, surgical and adjuvant treatment (Anderson & Jakesz, 2008).

# 2.2.6 Diagnostic breast clinics in Malaysia

Where do women with symptomatic breast disease present and obtain a diagnosis? There is a network of primary health care clinics which serves the population, i.e., the health centres in the country and general practitioner clinics. From this entry-point, patients are referred to surgical outpatient clinics in government as well as private hospitals. Some patients may choose to attend specialist breast clinics in public or private centres. The lump/presenting symptoms will be diagnosed at these clinics. However, these pathways are not explicit and there are no information available for the lay public. Information is obtained generally by word of mouth and referrals from primary care physicians. Access to care and timely diagnosis have not been studied in this country. Measurement of delay in UMMC showed that the majority of women present within three months, but at least a quarter presented beyond three months (Alfiah et al., 2008). In contrast, a study of 328 women in Kelantan showed that 75% of the women presented beyond three months(Norsa'adah, et al., 2011).

In Malaysia, there are only 13 breast and endocrine subspecialty specialists registered on the National Specialist Registry (NSR). Of those registered, five are in private practice. Therefore, the bulk of symptomatic breast patients are seen and diagnosed by generalsurgeons in the public and private sectors. There are no audits available on the diagnostic services provided in Malaysia.

To investigate breast clinic services and the pattern of women presenting with a breast lump, two breast clinics were studied over a period of one month in 2003 by medical students undergoing their electives in UMMC and in Hospital Kota Bharu (HKB) (Taib, et al., 2007). A comparison cross-sectional study showed that there were 103 and 75 new patients seen in UMMC and Hospital Kota Bharu during that time. In UMMC, 48.5% were less than 30 years old whereas 53.3% of the women presenting in HKB were more than 40 years old with the majority (38.7%) between 40 to 49 years of age. Only 24% presented to a GP within two weeks and 76% presented after more than two weeks in HKB. Those presenting within two weeks of discovery was considerably higher in UMMC (63.1%). Only 11.2% waited for more than four weeks. At the same time, more women presenting to HKB used traditional medicine (45.3% vs 15.5%). Furthermore, additional information on knowledge and reported practice showed that only 57.3% of the UMMC patients actually knew how to perform breast self examination (BSE) correctly and only 52.4% practised BSE at home. The majority of them (59.2%) failed to know the main purpose of screening mammogram. Some of the women (15.5%) sought traditional treatment before attending the breast clinic. The final outcome in UMMC showed that only 4.9% of the lumps were confirmed malignant. In contrast, 26.7% of the patients in HKB were diagnosed with cancerous breast lumps. The only factor found to be significant in delaying the presentation to hospital was the women's attribution of whether the lump was cancerous or non-cancerous (Taib, et al., 2007).

### 2.2.7 Management of breast cancer

The management of breast cancer is multidisciplinary in nature involving breast surgeons, radiologists, oncologists, breast care nurse, social worker. Surgery involves mastectomy and axillary dissection with (Fig. 2.9) or without reconstruction (Fig. 2.8) and breast conserving surgery (Fig. 2.10) in selected patients. Breast cancer is a systemic disease that requires systemic therapy. Chemotherapy, targeted therapy and hormonal therapy are used for this purpose. The management intent is important, i.e., whether curative or palliative. In managing women who present at late stages, the intent is usually palliative in nature, though it is important to note that survival for stage III and IV breast cancer in UMMC was 56% and 19% (Taib, et al., 2011) and in USA was

40- 66% and 14.8% (Andersen et al., 2010). This shows that many women are still alive five years after their diagnosis. However, relapses, costs of treatment and quality of life may be impaired in this group of women. There is, however, no documentation of this in the local literature.



Figure 2.8 A simple mastectomy scar



Figure 2.9 Mastectomy and immediate reconstruction with a trans-rectus abdominis musculo-cutaneous flap



Figure 2.10 Breast conserving surgery of the left breast

Currently, there is no evidence to show that psychosocial support of cancer patients improves survival in a biological sense (Stefanek et al., 2009) however, they may have better outcomes by improving adherence to treatment. A recent meta-analysis shows that adherence reduces the risk of poor treatment outcome by 26% (Kissane, 2009). Psychotherapeutic and psycho-educational interventions that promote understanding of the benefits of anti-cancer therapies alongside risks may help to eliminate the social disparities seen currently in oncology through the behavioural mechanism of enhanced treatment adherence. Interventions that have been studied include relaxation techniques, provision of information about cancer, treatments and side effects (Berglund,Petersson, Eriksson, & Haggman, 2003; Petersson et al., 2000). There is a relationship between psycho-educational and treatment satisfaction and adherence, which includes appointment-keeping (Dearing et al., 2005), and compliance with treatment recommendations (Hirsh et al., 2005, Barfod et al., 2005). Linkage of the New Haven epidemiologic catchment area study with the ConnecticutTumour Registry found that patients with major depression were at increased risk in late-stage breast cancer diagnosis compared with their non-depressed counterparts(Andersen et al., 2009). Active treatment of depression improved compliance with anti-cancer therapies and was found to be an important behavioural pathway.In group therapy, higher levels of felt support (group cohesion) was associated with lower distress, improved dietary habits, reduced symptomatology, and higher chemotherapy dose intensity(Andersen, et al., 2009.)

Studies have also shown that implementing institutional changes in multidisciplinary care improves outcomes (Kingsmore, et al., 2003). Delays due to inefficient referral patterns and long workup time to diagnosis may impair outcome (Thongsuksai, et al., 2000). In middle-income countries, psychosocial support has not been incorporated into standard medical treatment as health is still seen in a biomedical model rather than a biopsychosocial model. In addition, the introduction of psychosocial and pharmacotherapy interventions in those with cancer recurrences has been found to reduce distress (Akechi et al., 2007).

In the local context, women's needs within the three areas of medical, emotional and role management in the Klang Valley have been identified. The main themes that emerged as barriers to self-management were poor information, inaccessible health-expertise, i.e., lack of expert information on recurrence of cancer and support, socioeconomic cultural issues and poor patient-provider interaction (Loh et al., 2007). Further, a shortage of oncologists, experienced general practitioners, counsellors and specialized nurses was also found as well as a lack of physicians' sensitivity and empathy, and a lack in addressing patient's anxiety (Loh, et al., 2007).

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There is a changing paradigm from authoritarian to patient-centred care (Kaba & Sooriakumaran, 2007). Communication is the main ingredient to patient centred care - "without communication, there would be no cancer care" (Owen & Jeffrey, 2008). Communication strives to achieve a diverse range of goals in oncology - helping the patient to receive bad news, handle the emotional impact of a life-threatening illness, understand and remember complex information, communicate with multiple health professionals, understand statistics related to prognosis, deal with uncertainty while maintaining hope, build trust that will sustain long-term clinical relationships, and make decisions about treatment, possibly including participation in clinical trials and adopting health-promoting behaviours (Owen & Jeffrey, 2008).

Physician empathy has moderate effects on the quality of life of patients (Neumann et al., 2007) as well as improving adherence to treatment (Squier, 1990). Clinician-patient communication improves patient understanding, trust and clinician-patient agreement, thereby, increasing adherence and better self-care skills (Street Jr et al., 2009).

Historically, doctors have been the primary messengers of bad news to patients but they are often poorly trained and emotionally ill-equipped (buckman, 2005). However, this process can involve a wide range of healthcare professions, such as nurse consultants and clinical nurse specialists.

The NICE guidelines on management of breast cancer in women endorsed the highest grade of recommendation that "psychological support should be available to women diagnosed with breast cancer at the clinic". In the UK, health providers dealing with oncology care have to be trained on communication skills. In the past, training was

mainly for medical staff, but now it is offered to a wider range of healthcare professionals (Blok et al, 1999). The UKNHS plan (United Kingdom Department of Health, 2000) stated that there will be joint training in communication skills across all healthcare professionals, advanced communication skills form part of continuing professional programmes. McCulloch's study (2004) on patients' experiences of receiving bad news from healthcare professionals found that 90% of patients singled out the clinical nurse specialist as the most useful point of contact. One of the key roles of the clinical nurse specialist is to follow up the patient after the news has been delivered to offer emotional support (Mandelblatt et al., 2003).

The above themes converge to the need for a bio-psychosocial model rather than a biomedical model that is currently practiced in many hospital-based breast disease setup. Specifically, breast care nurses and access to psychologists and counsellors would be important as a support system for women to cope when the diagnosis is disclosed and while they undergo treatment.

### 2.2.8 Pluralistic health care

Medical pluralism can be defined as the employment of more than one medical system or the use of both conventional and complementary and alternative medicine (CAM) for health and illness (Shih et al., 2010). Alternative treatment coexists with the conventional health care system in Malaysia(Talib, 2006); (Ariff & Beng, 2006). Complementary treatment, based on CAM, is defined as a broad domain of healing resources that encompasses all health systems, modalities and practices and their accompanying theories and beliefs other than those intrinsic to the political dominant health system of a particular society or culture in a given historical period (Zollman & Vickers, 1999).

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With regards to cancer care, very little has been documented on CAM in Malaysia. A study of traditional healers and health concepts between the three ethnic groups revealed that these therapies could be complementary and integrated into conventional health systems (Ariff &Beng, 2006).

A study on paediatric oncology in Kuala Lumpur revealed that 84.5% of respondents had used CAM, the majority with the intention to complement conventional treatment, and believing that it provides a boost to the immune system. The most frequently used CAM was water therapy (78%), followed by Spirulina (33%), Vitamin C (27%), multivitamin (23%), visit to traditional healers (22%), sea cucumber (Stichopus horrens) (15%), and Chinese traditional medicine (12%). The Malay ethnicity significantly used more CAM then non-Malays (Hamidah et al., 2009). To explain the popularity and supply of alternative health care, it is important to go beyond the culture of each kind of health care itself and to take into consideration the changes occurring at societal, national and global levels. These social conditions influence the choice of health care methods, including herbal/alternative medicine, health foods and, what are often called, new age therapies (Han & Ballis, 2007).

In Malaysia, sales of traditional and complementary/alternative medicines are estimated to be 1000 million Malaysian ringgit annually, compared with a market of 900 million Malaysian ringgit for allopathic pharmaceuticals (WHO, 2001). A google search on 05/02/2011 resulted in 26 700 hits for *"rawatan alternatif kanser payudara"* or breast cancer alternative treatment in the Malay language. Vis a vis a relatively high internet usage in Malaysia, at 14.3 per 100 population in 2007 (Abu Hassan &Omar, 2010), this may represent the norms of the society in accepting alternative treatment as a valid form of treatment.

The medical anthropologist, Castillo (2000), found that there are several reasons why use of CAM is prevalent; namely cultural congruence, orientation to treating illness, and familiarity. Some negative consequences were also mentioned, such as, neglect or delaying "proper" treatment, suffering from financial fraud at the hands of greedy, unethical healers, or other malpractices, including improper sexual behaviour toward female clients by male healers (Tseng, 2001). Thus, there are disadvantages to consulting folk healers. Furthermore, in Malaysia, alternative healers are not regulated (Talib, 2006).

The focus on agricultural sector and development of natural products by funding agencies has encouraged scientists to develop new cancer therapies. In 2005, the Malaysian government launched the national biotechnology policy, which is the core of the government in promoting biotechnology as a source of wealth for the country. One if its objectives was to improve scientific literacy in the community(Lim, et al., 2008). Although the community accepts the relevance of science, many are easily misled due to a poor foundation in the sciences. Reports of cancer cure therapies based on preclinical research data, which are mainly from animal and cell lines studies, and calls for industry to commercialise these products, appear in the local media (Lim, 2011; Unknown, 1998). Unsuspecting members of the public with no knowledge of clinical trials and the need to prove safety and efficacy in human subjects can be easily duped into using these products for treatment of cancer. Furthermore, with the pressure to self-fund, public universities are keen to commercialise their research products quickly (Moynihan & Sweet, 2000), without the rigours of clinical trials.

The pluralistic nature of health utilisation in the society needs to be addressed by health care providers. A study by Nabilla et al in 2002, based on survey of health providers using a postal questionnaire showed that 27.1% of medical practitioners were currently using cam on themselves or their own families, and 22.2% actually have referred patients to CAM practitioners. Analysis showed that only 14.9% of the medical practitioners who responded were exposed to cam during their undergraduate medical programme. There was a significant difference in cam use by which university they graduated. In addition, although only 9.1% of the respondents have attended any training in cam after graduation, 36.8% would like further training on cam and would pay for it. The findings illustrate the need for training in cam in medical undergraduate education, especially in this new age where alternative therapy is in demand by consumers (Nabilla et al., 2002).

### 2.2.8.1 Integrated care

A new model for healthcare has emerged in the US: integrative medicine provides care that is patient-centred, healing-oriented, emphasizes the therapeutic relationship, and uses therapeutic approaches originating from conventional and alternative medicine (Maizes et al., 2009). Driven initially by consumer demand, it is now increasingly being accepted by healthcare providers and institutions. Definitions abound, but the commonalities are a reaffirmation of the importance of the therapeutic relationship, a focus on the whole person and lifestyle (not just the physical body), a renewed attention to healing, and a willingness to use all appropriate therapeutic approaches whether they originate in conventional or alternative medicine.

Integrative medicine represents a broader paradigm of medicine than the dominant biomedical model. In 2008, licensure of the first homeopathic medical college in the united states since the 1800s, development of educational standards for yoga training, and establishment of Ayurvedic and Tibetan medical programs in leading cancer centres in the us, i.e., MD Anderson Cancer Centre, Memorial Sloan Kettering Cancer Centre demonstrate the adoption of the integrated health care model.

A similar paradigm shift is also evident in Malaysia. The registration of traditional and complementary products was legislated in 1992 in Malaysia. The ministry of health traditional and complementary medicine division was created in 2004 to regulate the practice of alternative practitioners. This was followed by eight government ministry of health hospitals offering integrative medicine in 2006(Ministry of Health of Malaysia).

Studies in Malaysia have shown the need for information from hospitals (Loh, et al., 2007). These needs may be different from other countries, thus, would need to be modified (Gopal, et al., 2005). The lack of specialists and long waiting times in public hospitals have also led to further reductions in provider-patient contact, a very important aspect of cancer care as discussed above. Consumers in Malaysia are also sensitive to the way in which the time of utilization is spent, with high travel and treatment time causing reduced demand for services (Heller, 1982). Therefore, with a background of poor understanding of disease, and other competing issues, alternative healers remain a main player for health care in Malaysia.

### 2.2.9 Impact of advanced presentation

#### 2.2.9.1 Cancer burden

As mentioned previously, presentation of advanced breast cancer is common in low and middle income countries (Agarwal et al., 2009; Gorin et al., 2006; Hisham & Yip, 2003, 2004; Omar et al., 2003). The cost of advanced cancer treatment would not just be the economic cost but societal expectation in the use of palliative care (Allen, 2010).

2.2.9.2 Quality of life and the physical and psychosocial impact of advanced cancer Breast cancer symptoms of locally advanced cancer include ulceration, involvement of bony chest wall, which at times may ulcerate through into chest and mediastinal cavity. Cancer en-curasse, swelling in the axillae and lymphoedema of the upper limbs, hoarseness of voice, superior vena cava, spinal cord compression result in malodorous ulcers, pain, paraplegia, seizures, change in behaviour and breathlessness. (Phelan et al., 1992). The risk of relapse and the need for more treatment are higher, than for early staged cancer.

## 2.2.9.3 Financial impact

The financial impact of breast cancer in Malaysia is not known as it had not been studied or published.

## 2.2.9.4 Management of advanced breast cancer in UMMC

Locally advanced breast cancer may be treated primarily by surgery or by downstaging the tumour with systemic therapy for surgery at a later date. Between 1998 to 2002 in UMMC, 155 women presented with locally advanced breast cancer (Fig 2.11) and, of these, 74 underwent primary surgery (Fig 2.12 and 2.13) and 62 underwent primary chemotherapy. The rest underwent hormonal therapy or had best supportive care. Of the women who underwent chemotherapy, 14.5% (9 patients) defaulted on further treatment after completing chemotherapy and the rest had surgery (Chong et al., 2010).



Figure2.11 A 34-year-old lady presenting with a neglected locally advanced tumour



Figure 2.12 Mastectomy and immediate chest wall reconstruction with a latissimus dorsi flap



Figure 2.13 The same patient six weeks later

#### 2.2.10 Impact of defaulting treatment

### 2.2.10.1 Absconder outcome in UMMC

Non-adherence to treatment or access to treatment have consistently been related to a large disparity in survival (Du & Simon, 2005). Patients who refused surgery havea 2.1 fold increased risk of mortality compared to operated women (Verkooijen, et al., 2005). Noncompliance with tamoxifen significantly increased risk of local and distant disease recurrence.

Among the few publications on this issue in this part of the world, a data on 1466 patients on the UMMC breast cancer registry diagnosed between January 1993 to December 2002 showed that 98 patients (6.7%) defaulted therapy. The median follow-up was 53 months (0-107 months) whilst the median survival of the patients who had treatment was 104 months compared to 53 months (log rank p< 0.001). In UMMC, a study spanning 1998 to 2002 showed that out of the 1466 patients studied; 15.6% of Malay, 4.8% of Chinese and 4.3% of Indian breast cancer patients defaulted treatment. Based on age, younger patients were at risk of defaulting treatment. Some 12.4% of those who were 40 years and below, 5.9% of those 41 to 59 years and 3.7% of those 60 years and above defaulted treatment (Taib & Yip, 2009). The 5 year survival rate of those who defaulted was 47.7 % compared to 72.3 % who underwent treatment in UMMC (Taib & Yip, 2009).

## 2.2.11Impact of delaying treatment on survival

Richards (1999) showed that delays in diagnosis do affect survival. Patients with delays of 12 to 26 weeks had significantly worse survival rates than those with delays of less

43
than 12 weeks. The delay in presentation was shown to be associated with more advanced stage. 'Total delay' (i.e., the interval between a patient first noticing symptoms and starting treatment) yielded very similar results in terms of survival to those based on delay to first hospital visit (delay in presentation) (Richards et al 1999).

Naeve (1990) showed that a subgroup of women in their study who had short delay had poorer outcome (Neave et al., 1990). In the same year, Rossi and colleagues, found that diagnostic delay (first symptom detected to first obtaining medical attention) correlated with poorer survival (Rossi et al., 1990).

Metanalysis of 87 published papers found that most patients with breast cancer were detected after symptoms occurred rather than through screening (Richards et al., 1999). The impact on survival of delays between the onset of symptoms and the start of treatment is controversial and cannot be studied in randomised controlled trials. A systematic review of observational studies worldwide on the duration of symptoms and survival found that patients with delays of 3 months or more had 12% lower 5-year survival than those with shorter delays (odds ratio for death 1.47 [95% CI 1.42-1.53]) and those with delays of 3-6 months had 7% lower survival than those with shorter delays (1.24 [1.17-1.30]) (Ramirez, et al., 1999). In studies that controlled for Stage, longer delay was not associated with shorter survival when the effect of Stage on survival was taken into account. In other words, shorter delays of 3-6 months are still associated with lower survival. These effects cannot be accounted for by lead-time bias. Hence, efforts should be made to keep delays by patients and providers to a minimum (Richards et al., 1999).

In another study, 36 222 patients with breast cancer listed in the Yorkshire cancer registry in the UK were studied to audit provider care in terms of referral delays (Sainsbury et al., 1999). In contrast to the study by Richards (1999), there was no evidence that provider delays of longer than 90 days adversely influenced survival. The time from family-physician referral to first hospital visit changed little (median 10 vs 13 days) from 1976 to 1995, whereas time from first visit to first treatment doubled (7 vs 13 days). More than 8% of patients younger than 50 years delayed longer than 90 days, compared with 3% of patients older than 50 years (p<0.001) (Sainsbury, et al., 1999). About 48% of younger patients had their first treatment within 30 days compared with 64% of those older than 50 years. The survival for 5708 patients diagnosed in 1986-90 selected for survival analysis was 63% at 5 years, and 51% at 8 years. An interesting finding was that patients who presented early and were treated in less than 30 days had significantly worse outcomes (Sainsbury, et al., 1999). This could be due to the fact that aggressive cancers tend to present in a shorter time span and have poorer survival, thus, further delay does not affect survival unless grade was taken into account (Bloom, 1965). Sainsbury concluded that a diagnosis of 3 months or more does not seem to be associated with decreased survival in patients presenting with breast cancer and that the drive for all women with possible breast cancer to be seen within 14 days will divert resources from other services (Sainsbury, et al., 1999).

## 2.2.12Financial impact of advanced disease

The cost of treating metastatic breast cancer has increased over time. A study in Canada of two cohorts in two time periods showed a doubling in cost although survival impact was too premature to report (Galy et al., 2010). Out-of-pocket payments are mildly progressive over the years but Malaysians rely heavily on out-of-pocket payments to finance their health care(Yu et al., 2006). Thus, the impact of presenting with advanced cancer requiring a myriad of treatments would affect the financial resource of the individual if most of it are out-of-pocket expenses.

### 2.2.13Section summary

This section of chapter 2 strongly makes a case for the prevalence and impact of advanced presentation locally and abroad. This section presented its impact on survival, economic burden and quality of life justifying the need to further understand reasons for delay or advanced presentation. One wonders whether it's a women's choice to behave in this manner, or are there barriers that prevent women from seeking treatment early.

To understand breast cancer and its presentation, it is important to understand the process a person experiences when she first notices the symptoms, seeks help in getting a diagnosis and finally undergoes treatment. It is pertinent to understand the biology and how intrapersonal factors as well as extra-personal factors interplay. Therefore, to measure delay, be it intrapersonal reasons i.e., help-seeking behaviour or extra-personal reasons, i.e., social support, network, access and financial reasons, it is important that delay is first defined. This leads us to section 2.3 of this chapter which includes a literature review of health behaviour and available delay theories and other underlying fundamental health behaviour theories. Relevant theories on motivation and behaviour of women facing a life threatening event will also be presented.

2.3 Defining delay in breast cancer

### 2.3.1 Defining delay

Delay was first defined as "an interval between the onset of symptoms and first visit to the physician" (Pack & Gallo, 1938). The emphasis was on patient delay before entering into health systems. Interestingly, in the early literature on descriptive essays on presentation of breast cancer, many mentioned the documentation of more advanced disease in textbooks at that time and the absence of advanced features of cancer is important to diagnose the cancer early (Eberts, 1934). Concept of delay hinges on the course of the disease rather than from the time the patient noticed symptoms (Greenough, 1935). The concept of delay was noted early literature and the role of public education in improving the status quo where a gradual decline the node positivity from 76% in 1914 to 60% in 1926. The overall 5 year survival was only about 50% in the US in that era (Greenough, 1935) compared to 89% in USA and 79% in Europe in the 1990s (Sant, et al., 2004).

Delay intervals and impact on survival were presented in the previous section of this chapter, where studies showed a significant reduction in survival if the patients had symptoms of breast changes beyond three months.

An estimated 16 to 34% of patients in the western world delayed beyond three months of finding a breast symptom (Bish, et al., 2005; Facione, 1993; Meechan, et al., 2003; Rauscher et al., 2010). There were also reports that 25% delayed beyond six months (Facione, 1993; Richards, et al., 1999). A study in Iran found 25% of women presented

beyond 3 months (Montazeri et al., 2003) and in sub-Saharan Africa, 15 % of women with breast cancer presented beyond a year since symptom discovery (Anyanwu, 2000). Delay was usually found in lower socioeconomic groups and ethnic minorities in America where 45% may delay beyond 6 months (Friedman et al., 2006) and in those with lower education level (Montazeri, et al., 2003).

In Malaysia, research on access to health care and timely diagnosis of breast cancer is scarce.

In the 1990s, delay was defined not only from the patients' aspect (known as patient delay) but attention was also given to health provider delays (known as provider delay (Facione, 1993), system delay (Caplan & Helzlsouer, 1992), physician delay (Goodson & Moore, 2002) and diagnostic delay (Gorin SS et al., 2006). Facione et al (2002) had separated those who were affected by factors influencing symptom appraisal from those influencing delay in diagnosis (Facione et al., 2002). Gorin et al (2006) distinctively separated diagnostic delay and treatment delay, and combined these delays into clinical delay (Gorin SS, et al., 2006). System delays were found to be longer in blacks compared to whites in a study of 900 women in the us with a median of 2.7 weeks to 2.1 weeks, and system delays beyond three months were shown to reduce survival (Caplan et al., 1995). The leading factors that affected physician delay was belief that a malignant palpable lump was benign, a falsely negative mammogram and poor competency in performing fine needle aspiration biopsy (Goodson & Moore, 2002; Jenner et al., 2000). They also noted that with triple assessment, the current diagnostic method for breast problems, an annual diagnostic delay of 4-5% persisted over a decade (Jenner, et al., 2000).

# 2.3.2 Defining periods of delay

Numerous ways of defining periods of delay are evident in the literature, thus, making comparisons quite difficult. One needs to examine the definition of the periods of delay. Safer (1979) (refer Fig 2.14) defined a three staged delay which was updated by Andersen (1995) (refer Fig 2.15) as four stages of delay comprising appraisal, illness, behavioural and scheduling delay. Anderson (1995) called this total patient delay. Figure2.17 illustrates this with an addition of treatment delay. The fifth stage treatment delay was mentioned briefly in the text which was attributed more towards in-hospital care. These stages or periods of delay were found to be independent of each other. Appraisal delay was found to be the major stage in delay, accounting for 60% of the total delay. Andersen (1995) further described the pre-diagnostic patient delay very well. However, aspects of patient delay after diagnosis was not really elaborated. Both health provider and patient delay may play a role in the post- diagnosis period.



FIG. 1. Decisions to seek or delay care in three stages of an illness episode.

#### Figure 2.14 Safer's three stages of total delay.

Reprint From "Determinants Of Three Stages Of Delay In Seeking Care At A Medical Clinic" By Safer, M. A., Tharps, Q. J., Jackson, T. C., & Leventhal, H. 1979 In *Med Care, 17*(1), 11-29. Copyright ©1979 from Lippincott Williams & Wilkins. Reprinted with permission.

Patients from two tumour sites (gynaecological and breast) were used to test the eight principles of the psycho-physiological theory underlying the process of delay. This will be discussed more in detail later under the exploratory delay models section. Andersen (1995) has improved the clarity of delay periods with the total patient delay model, and this definition of delay periods has been recommended for use in future research (de Nooijer et al., 2001).

Some researchers have used certain periods of delay in relation to prognosis of the cancer and found conflicting results. A review by Richards and colleagues (1999) showed that a delay beyond three months has adverse effect on survival in contrast to a larger-scale review which showed that a shorter diagnostic period has poorer survival (Sainsbury, et al., 1999). As mentioned in the previous section, the biology of cancer is heterogenous with different levels of aggressiveness. Hence, periods of delay from onset of recognised symptom may not be a good indicator of cancer outcomes. But due to delay, even with inherently biologically good prognosis tumours, patients may present at an advanced stage negating the good prognosis of the cancer. Delay has also been implicated in reducing rates of breast conserving surgery (Barber et al., 2004). Specifically, a delay of more than 240 days (8 months) was found to reduce the ability to conserve the breast.

Most recently, a discursive delay theoretical framework paper argued that current studies in delay do not sufficiently consider existing theories on symptom interpretation process (Andersen et al., 2009). Studies on delay are retrospective, hence, after experiencing delay, patients may choose to divulge or interpret symptom appraisal using social and cultural interpretation of symptoms (Fig 2.16).





Source: Reprinted From "Delay In Seeking A Cancer Diagnosis: Delay Stages And Psychophysiological Comparison Processes" By B.L. Andersen & J.T. Cacioppo, 1995. *British Journal of Social Psychology, 34 (Pt 1)*, P. 35.Copyright©1995from Wiley Publishers. Reprinted with permission.



Figure 2.16 Andersen's model of socio cultural interpretation of symptoms. Source: Reprinted From "Patient Delay In Cancer Studies: A Discussion Of Methods And Measures" By R.S. Andersen, P. Vedsted, F. Bro & J.Soendergaard, 2010 In *BMC Health Services Research*, 9(1), P. 5. Copyright© 2009 Andersen et al; licensee Biomed Central Ltd.Open Access.

Thus, to operationalise patient delay, specific symptoms or bodily sensation has to be validated as a suspicious symptom. As such, measurement of the delay period is better done by clinicians to estimate how long the symptoms has really been present (Andersen, et al., 2009). The example given was for a prostate cancer patient where, on further probing, the patient was found, not only, to have had haematuria for six months but nocturia for two years. Thus, clinical knowledge of the symptoms is important to make inferences on what patients report.

Clinical judgement may not be reliable either due to the differing biology of cancer as mentioned in the previous section. That is, a patient may present with a large tumour despite reporting a short period after discovering a lump. Further, patients may not be disclosing accurately if they perceive that they will be judged unfavourably by the clinicians.

The total patient delay is a good model for pre-diagnostic delay. Further work must be done to define post-diagnostic delay. Post-diagnostic delay is the time after diagnosis before patients begins and completes the recommended treatments. Both providers and patients may influence post-diagnostic delays. Diagnostic delays, treatment delays and system delays implying health care provider delays have been described. Work has also been done on patients' decision making process on treatment with regards to adherence and not with regards to delays.

### 2.4 Help-seeking behavioural theories

After defining stages of delay, the fundamental help-seeking behaviour theories that underpin delay research and explanatory delay models are presented as follows.

# 2.4.1 The biopsychosocial model in breast cancer

The bio psychosocial (BPS) model was first introduced by George Engel (1977), putting medical practice into perspective. The biological, psychological and social issues surrounding disease was examined for the first time. First, this change necessarily implies taking into account a much wider spectrum of the factors influencing health and the healing process which, in turn, demands greater knowledge and time investment. Second, the new paradigm implies a new style of the patient– doctor relationship, a style which enables, among other things, the doctor's attention to the patient's psychosocial circumstances in order to better manage his or her situation, and not only his or her illness. Undoubtedly, this kind of interaction requires a greater effort from practitioners, but also from the health care systems, which should provide the necessary context and resources for it, such as communication skills training, adequate settings or sufficient personnel. Despite these hindrances, which will probably continue to relegate the bio-psychosocial model to a secondary place in medical practice, the broadening of the doctor's perspective to encompass psychological and social aspects would be really beneficial for the patient. Engel (1978) pointed out, even though both patient and doctor may culturally adhere to the biomedical model, the patient's needs and ultimate criteria are always psychosocial (Alonso, 2004). A conceptual distinction has been made between "illness" and "disease" where illness is what is experienced by the patient and disease is the condition that inflicts him. Tseng (2001) pointed out that "illness behaviour" as manifested by the patient is going to interact with the "treatment behaviour" undertaken by the therapist, resulting in the clinical phenomena observed. The modern physician is trained to inquire into the patient's symptoms, to detect the manifested signs of his illness, to obtain the needed laboratory data, and, based on this information, to make a clinical diagnosis. Then, the physician is expected to prescribe a treatment plan and predict the course and outcome of the patient's disorder. This "treatment behaviour" is often undertaken by clinicians, particularly those who are biologically medically oriented. Clearly, there is a wide gap between the illness behaviour of the patient and the treatment behaviour of the therapist (Tseng, 2001).

BPS has revived several theories of health behaviour. The oldest is the health belief model developed in the 1950s by US Public Health Service social psychologists who wanted to explain why people were not taking up X-Ray screening for tuberculosis.

They theorised that peoples' beliefs on whether they were susceptible and their perception of the benefits of avoiding influence whether they would act. Following that, the transtheoretical model (TTM) by Prochaska and DiClemente (1991) explains stages of change (Prochaska, 1991). Transtheoretical and stages of change model describes the circular model of interchangeable phases of change - pre-contemplation, contemplation, preparation, action and maintenance.

The theory of planned behaviour (Ajzen, 1991) and theory of reasoned action explore the relationships between behaviour and beliefs, attitude and intentions. Behavioural intention is the most important determinant of behaviour and is influenced by attitude which is the judgment of whether the behaviour is good, neutral or bad. The other factor that influences behavioural intention is the belief that people or persons close to them would approve or disapprove of the behaviour; this is known as subjective norms. The theory of reasoned action (Ajzen and Fishbein 1980, Trafimow 2004) has the additional construct of perceived behavioural control, that is whether one has a choice or has control over the choice (Ajzen & Madden, 1986).

Social cognitive theory (Bandura et al., 1977), which originated from social learning theory, identifies three main factors affecting behaviour change - self efficacy, goals and outcome expectancies. These constructs have been used in other health behaviour theories, such as, the extended health belief mode which include the following constructs benefit finding, role modelling or observational learning, and building self-efficacy in building confidence by promoting learning through skills training. These health belief theories are related to individual behaviour or the internal perspective. As mentioned, based on the theory of planned behaviour, the intention to

act is dependent on the individuals' attitude or evaluation of the situation and other peoples' evaluation or subjective norms. In addition, perceived behaviour control, with the addition of social cognitive theory factors, tries to explain that an individual first needs to be equipped, and needs to find reasons, to perform a behaviour.

# 2.5 The ecological perspective

The ecological perspective is one that examines individuals at the intrapersonal level, as well as their interconnectedness to their social network, be it with other individuals or groups of individuals, or the relationship at the community level, i.e. in the institutional community and in the public domain. This perspective allows one to build into a more holistic theoretical framework of behaviour.

Social network theory was introduced by sociologists from a Norwegian village. Besides individual reason, relationships between and among individuals are important and the nature of the relationships influences beliefs and behaviours. Their social network exposes them to the type of knowledge and the social support available to adhere to treatment recommendations or to cope with serious illness. The important aspects of this theory focuses on the people in the network, frequency of interaction, type of relationship, i.e., family or work colleague, or whether they are part of a larger network, e.g., religious community, clubs, etc. These relationships will show the social influences on their health behaviour. The quality of the network can be described as central versus marginal, reciprocity of the relationship, complexity and intensity, communication patterns, homogeneity or diversity of people in the network. Social control is related to the role of elders, parents, spouse and children and main caregiver, and their power over a woman within her community. Recently, Levanthal and his colleagues described the "society to cell" pathways for health behaviour. Referring to Fig 2.17, three paths exist to health outcomes, namely, socio-cultural, individual/psychological path and physiological path (Leventhal et al., 2006). Understanding the psychology of the individual may not be enough to provide insight as one is interconnected to their community and other factors. However, with a psychological perspective, it can help plan interventions for the individual in the clinical setting (Leventhal, et al., 2006).



Figure 2.17 Three pathways for the study of health and behaviour. Source: Reprinted from "Fig 1. Three pathways for the study of health and behaviour from "Psychological Approaches to The Connection of Health And Behaviour" by H.Leventhal, T.J. Musumeci & E.A.Leventhal, 2006 in *South African Journal Of Psychology, 36*(4), p 668. Copyright © 2008 Psychological Society Of South Africa. Reprinted with permission.

In sum, human behaviour is an area of study that overlaps psychology, sociology and anthropology. Hence, its interpretation may be described differently from the lens of each discipline. In order to be able to explain the phenomenon, and make it clinically relevant, it is important that a cross discipline approach be incorporated with the clinical input (Leventhal & Mora, 2008). This will help in the planning of interventions in the clinical setting.

Understanding what motivates behaviour does not just depend on the intention, but also the enactment itself. Another factor that will affect behaviour is one's decision to do it. The crises in breast cancer are intermittent episodes waxing and waning with the natural history of the illness. The individual may relate a life threatening condition when one discovers a symptom, or upon diagnosis, disclosure, or at a decision to adopt treatment such as surgery, adjuvant chemotherapy, radiotherapy and even during the period of survivorship and future relapses. Decision-making depends on many factors. There are many theories to explain decision-making, for example, the crisis decision theory, a comprehensive theory that incorporates coping, health behaviour and decision making theories.

# 2.6 Decision-making

In the breast cancer journey, decision-making occurs at multiple stages (1) Upon awareness of symptom (2) Upon diagnosis and (3) Decision to have each treatment, namely, surgery, chemotherapy, radiotherapy and hormonal therapy. Assistance to decision-making is an important area. The complexity of the interplay of decision-making communication between the individual and health care provider is such that to have impact on patient's decision making (Polacek et al., 2007). It was found that a large proportion of patients with cancer wanted physicians to decide on treatment, while the remaining, wanted physicians and family to share the responsibility in decision-making (Degner & Sloan, 1992). Shared decision making has been reported in many studies (Charles et al., 1997, 1999; Elwyn et al., 2000; Frosch & Kaplan, 1999). However there is no evidence of the actual contribution of shared decision-making on cancer outcomes (Polacek, et al., 2007).

Decision-making has both cognitive as well as emotional components (Polacek, et al., 2007). The cognitive aspects have both heuristics (see further elaborations) and a logical component (Evans, 2006). The satisficing principle explains by far the most pervasive finding in the psychology of reasoning: that people draw inferences (fallacies) that go beyond the premises given, despite typically being instructed to draw only necessary conclusions (Evans, 2002).

The relevance principle explains the other major finding in the field: the pervasive influence of prior knowledge and belief—for example, in the manifestation of belief, biases that are apparently impossible to suppress by the use of deductive reasoning instructions and are more strongly marked in their absence (Evans, 2006).

The emotional component may be embedded in culture and role theory (Polacek, et al., 2007). Rational thinking may well be supported with information that is culturally appropriate but the not so "rational" is more difficult to support (Polacek, et al., 2007). Providing information is not enough for good decision-making as patients can be emotionally overwhelmed; in fact, decision-making has been described as gambling with their lives (Lam et al., 2005).

Despite these findings, there is still a role for educational materials to help reduce decisional conflict without increasing their anxiety (O'Connor et al., 1999).

2.6.1 Crisis decision theory

The psychological processes when making a decision on a life threatening illness can be best described with the crisis decision theory. Crisis decision theory describes how a decision is made by generating options and choosing options. Crisis decision theory (Sweeney 2008), a logical heuristic model (Fig. 2.18), separates decision making into three stages:

The first is assessing severity; this is part of the health behaviour model. Assessing severity includes compiling information about causes; comparing it with other information, such as past experiences, alternative outcomes as well as social and temporal comparisons, and, lastly, finding future focused information. This helps the person to proceed with an active or passive response to the event.

The second stage is determining response options or generating response options by looking at the controllability of the event, whether or not it is avoidable and the feasibility, i.e., with time, money, social support, strength and ability of the person with regards to the various responses.

The third stage is evaluating response options, as so to choose the best option by looking into required resources, such as time, finances, social support, strength and ability, and emotional suffering. In this stage, direct and indirect consequences of the options are considered. Indirect consequence (i.e., the breadth of effect on the individual) includes emotional consequences, impact on public image and in the areas in one's life. This also includes disappointment when the consequences are out of one's control and regret as a result of action or inaction. If the choices are too overwhelming, Sweeney suggests that one can be paralysed and ineffective in response. Criticism for traditional decision making theories are based on the assumption that it is built on a cognitive model, but feelings, situational cues and satisficing may explain the decision making process rather than rational thinking (McCaul et al., 2005). Decision making is also a form of coping (Luce, 2005). Preconceived ideas from previous experiences may be responsible for individuals to make up their minds (Evans, 2006). These preconceived beliefs are what heuristics is about. The crisis decision theory is superior in that it hinges not only on information and the cognitive process of appraising risk and benefit, but it has a component of affect. Furthermore, health literacy and level of decision-making involvement are both embedded in the social and economic reality of the individual (Polacek, et al., 2007), which have been elegantly added on in this theory.

This theory includes coping theories based on Leventhal's self-regulation theory and other coping theories as well as other decision making theories (Sweeney, 2008). This theory does not only use a cognitive rational stepwise argument as this does not exclusively occur in human making decisions. Then again, this theory has the ability to include the irrational responses as it includes coping theories that are based on patient value-based life goals (Carver & Scheier, 1982) in determining response. Motivational reasoning put forth by Sweeney indicates that information gathered by patients are not just used in an objective way, but is used to arrive at a conclusion. When motivated to reach a conclusion, biased information is used to come to a desired outcome rather than an objective one, thus, at times making decisions maybe irrational depending t on the person's beliefs (Sweeney, 2008). Additionally, it includes social context where feasibility of response would depend on available social support. Furthermore, direct and indirect consequences of disease and treatment would affect one's social standing. This is covered in the third stage of this theory.

By having a theory that is comprehensive, education materials and psychosocial support interventions can be targeted to assist women newly diagnosed with cancer to be informed when making decisions on treatment options.



Figure 1. Crisis Decision Theory.

# Figure 2.18 Crisis decision theory

Source: Reprinted from "Crisis Decision Theory: Decisions In The Face Of Negative Events" by K. Sweeney, 2008, *Psychology Bulletin, 134*(1), p. 62. Copyright © 2008 by American Psychological Association. Permission not required for single and up to three figures reprint.

After being acquainted with the fundamental health behaviour theories, one would like to review the literature on the reasons for delay before looking into explanatory theories of delay.

### 2.7 Factors affecting delay

A Medline literature search on breast cancer delay theories publications of qualitative and quantitative studies that measured delay based on a theoretical framework. Several factors were identified as reasons for delay:-

2.7.1 Sociodemographics

Women are known to seek help more than men. Moreover, women tend to seek help in the elective setting whereas men usually do so at the emergency department. Clearly, in the case of breast cancer, women also delay presenting to health facilities, hence, it is important to know why this is so. Elderly women delaying seeking diagnosis is cited to be the cause of poorer overall survival of breast cancer patients in Europe compared to the US (Sant, et al., 2004). Treatment delays have been documented in ethnic minorities and those of lower socio-economic status in the US. Black American women independently have a higher risk of diagnostic and treatment delay compared to White Americans, and this was seen in an underserved region in South Italy as well (Gorin et al.; Montella et al., 2001). Ethnic minorities are more prone to procrastinate seeking help after detection of a breast symptom (Arndt et al., 2001). In his model, Meyerowitz et al (1998), linked demographic factors, such as ethnicity, to adherence behaviour (Fig 2.19). He pointed out that public health and psychological factors are important in addressing issues on health and cancer related cognitions, adherence behaviour and outcomes (Meyerowitz et al., 1998). Other socio-demographic factors, such as socioeconomic factors and marital status, will be covered later.

#### ETHNICITY AND CANCER



Figure 1. Proposed mediational framework linking ethnicity to cancer outcomes. SES = socioeconomic status.

Figure 2.19Mediational framework linking ethnicity to cancer outcomes. Reprinted from "Ethnicity And Cancer Outcomes: Behavioral And Psychosocial Considerations', by B.E. Meyerowitz, J. Richardson, S. Hudson &B. Leedham, 1998 in *Psychological Bulletin*, *123*(1), p.51.Copyright©1998 by American Psychological Association. Permission not required.

# 2.7.2 Symptom appraisal and recognition

Early literature before the screening era also describes early breast cancer presents as a painless lump in the breast or axilla or nipple discharge and very rarely causes pain (Eberts, 1934). After a symptom is detected, a person would evaluate whether the symptom is something threatening that requires attention which then drives her to obtain professional help (Safer et al., 1979). Based on Safer's work in 1972, Andersen(1995) developed the total patient delay model (see previous section), and found that more than 60% of women who delayed were due to symptom appraisal (Andersen & Cacioppo, 1995).

Poor symptom appraisal, where breast complaints did not trigger a visit to their health providers, has been noted by other researchers as well (Nosarti et al., 2000; Rauscher, et al., 2010). A false negative mammogram in symptomatic women also contributed to delay (Murphy et al., 2007). Studies that have looked at the process of appraisal by Andersen (2009) theorised that bodily sensations are also governed by the social and cultural situation experienced by the individual (Andersen, et al., 2009). Poorer knowledge of symptoms and risks among older women may help to explain the strong association between older age and delay in help-seeking (Grunfeld et al., 2002). A qualitative study in the UK found that one of the main themes for delay was symptom interpretation (Burgess et al., 2008). Factors that contributed to delay were identifying symptoms, i.e., non-lump presentation and risk factors, perceived less personal risk, negative beliefs about breast cancer and its treatment, concerns of disability, disfigurement and adverse economic consequences (Bish, et al., 2005). Symptom appraisal is not just about knowledge, but involves attitude and decisionmaking components. Knowledge of breast cancer symptoms and predisposing risk factors like misunderstanding, the lack of family history and other known risk factors popularly portrayed in the media, including ageing, nulliparity, late first child birth, late menopause and early menarche, may put an individual into optimistic bias. Women with a first-degree relative with breast cancer are less likely to be diagnosed with latestage cancer, a fact that could likely be due to higher breast cancer awareness (Clements et al., 2008; Drossaert et al., 1996). However in Malaysia a study of women with breast cancer with and without family history, show that there is no difference in size of tumour and stage of disease implying that family history does not modify health behaviours (Yip et al., 2008). This was also seen in Mexico (Bird et al., 2011). In Iran, a family history of breast cancer was found in those who delayed beyond 3 months

(Montazeri, et al., 2003). In a qualitative analysis, the lack of family history placed women in an optimistic bias towards having low risk of getting breast cancer (Katapodi et al., 2005). Posttraumatic stress disorder is more prevalent in women with a maternal history of breast cancer which was inversely related to age (Mosher et al., 2005). This may be bring about poor coping and delaying presentation instead (Lerman & Schwartz, 1993).

Symptom appraisal by the patient may not be the only source of delay, misdiagnosis of health providers are also well known, attributing an early presentation of a malignant lump to a benign lump have brought about a rate of 4-5% false negative rate (Goodson & Moore, 2002). Thus symptom appraisal by physicians and other health professionals are important to diagnose symptomatic women early in the course of the disease especially in young "low risk" women, this was seen in very early reports where mammographic screening were not performed in the US (Eberts, 1934; Greenough, 1935; McCarthy, 1948).

# 2.7.3Attitude towards a diagnosis of cancer

Beliefs and knowledge about breast health are important enabling factors for seeking help (Nosarti, et al., 2000). Attributing a breast symptom to cancer may delay presentation (De Nooijer et al., 2001; Ramirez, et al., 1999). This phenomenon was also seen in Malaysia and was mentioned earlier in Chapter 1. The study showed that the pick-up rate for cancer for women presenting to the clinic with a breast lump was 26.7% in Kota Bharu compared to 4.9% in Kuala Lumpur. The only factor that was found to be significant in delaying the presentation to hospital was the women's attribution whether the lump was cancerous or non-cancerous (p= 0.035) (Taib, et al., 2007). In another study, a group of Chinese American women were found to have a sense of invulnerability to breast cancer, linking cancer to tragic luck, preserving modesty and to conserve wealth and time. Many study participants favoured using Chinese medicine and delaying western therapies (Facione et al., 2000).

Psychology literature from the 50s have consistently placed past experience as a central theme in appraising symptoms (Andersen & Cacioppo, 1995). Past experience of others and the individual will form ideas on the causes of the breast symptom. Strong sensory signals, such as pain and bleeding lead to shorter appraisal delay (Safer, et al., 1979). Non-lump symptoms were seen to cause delay (Burgess, et al., 2001) as well as non-specific symptoms, especially if there is no pain, and non-severe symptoms. Misconception of symptoms was more common in ethnic minorities and women of lower socioeconomic status (Rauscher, et al., 2010). At times, due to the different consistency of breast tissue, lumps may be concealed. Authors have tried to describe and categorise the consistency of breast tissue from clinical examination by the "durity" (ability to feel ribs) and "nodularity" (lumpiness of the breasts). However, in a multivariate analysis, these categorisations were not independent reasons for delay (Goodson & Moore, 2002).

Illness coherence is the understanding of the natural history of the disease and treatment outcomes. The well patient gets unwell only after the diagnosis. They may have issues with not being able to transcend into the sick role because there are no overt symptoms and changes in the breast lump occur insidiously. Only when they develop overt symptoms of metastases like loss of appetite, bony pain, breathlessness or sometimes paraplegia, will they be alerted to an illness. Consequences of cancer treatments were found to be a cancer delay theme in some studies (Bish, et al., 2005; Burgess, et al., 2008).

Patient factors that led to why women present late in Africa showed that fatalism played a part in locally advanced breast cancer patients and their spouse. Spouses also tended to be more passive in the women's medical care, and also demonstrated denial (Mohamed et al., 2005).

There is paucity on studies that study appraisal delay and symptom interpretation of a breast symptom in Malaysia. Tumour size and stage can be imperfect surrogates to appraisal delay because of the heterogeneity of individual cancer aggressiveness. Nevertheless, a review looking at tumour size and stage in Malaysia is a good reflection since the breast is a superficial organ large and locally advanced disease especially with overt signs of ulceration or local tissue invasion are not difficult to miss (refer to Fig. 2.20). In Hospital Kuala Lumpur (HKL), from 1998 to 2001, the average tumour size was 5.4 cm in diameter. During the same time, the average tumour size in UMMC was 4.2 cm (Hisham and Yip, 2004). A review of over 10 years from 1995 to 2005 did not show an improvement in clinical down staging of size or TNM staging (Taib, et al., 2007). Malay women presented with the largest tumour size -, the mean size in 1995 was 6.57 cm (SD 6.242cm) and in 2005 was 5.05cm (SD 5.296cm). There was some improvement among Chinese women for whom the average tumour size was 4.23cm (SD3.635cm) in 1995 and 3.64 cm (SD 3.052cm) in 2005. The tumour size for Indian women was 2.99cm (SD 1.073cm) in 1995 and 3.71 cm (SD2.492cm) in 2005. The overall mean size in 2005 was 3.95 cm (SD 3.671cm) which is slightly smaller compared to 4.39cm (SD 3.791cm) in 1995. Over the span of 10 years, the stage of cancer remained almost similar with most women being in Stage 2 (51.8%, 53.9%, and 52.4% in 1995, 2000 and 2005 respectively). The proportions with advanced disease were 15.6%, 11%, 14.7% for Stage 3 and 6%, 10.4% and 7.6% for Stage 4 in 1995, 2000 and 2005, respectively. Very early breast cancer, i.e., Stage 1, was detected in

26.6%, 24.7% and 25.3% in the same years. From the size of tumour and stage of presentation over a decade, an inference can be made that there has been no improvement in the patient delay periods in this urban Kuala Lumpur practice.

Due to the socio-demographics of women attending public hospitals, it is possible that a different demographic group would be seeking diagnosis and treatment in private hospitals. In this regard, a study comparing three centres in the Klang Valley showed differences in the survival of women in three hospitals; a university hospital and tertiary referral centre for breast cancer, a public hospital and a private centre. The best survival rate was seen in the private centre, followed by the university hospital, and lastly, the public hospital with 5-year overall survival rates of 89%, 73% and 61%, respectively (Lim et al., 2010). At the same time, the public hospital received the highest rates of late staged disease compared to the other two. This infers that those with higher socioeconomic status (SES) who can afford private care do not delay diagnosis as much as those from lower SES (Lim, et al., 2010).



Figure 2.20 A 34 year old lady presenting with a fungating 10kg tumor undergoing mastectomy and chest wall reconstruction.

Symptom recognition remains an important aspect of breast health in Malaysia. Due to the opportunistic nature of screening, women will have to inform health care providers if there is a problem. Health care providers, especially in primary care, have to be informed as well on how to identify suspicious symptoms of women with a breast complaint. A review of standard surgical textbooks for medical students and nurses revealed that much emphasis is given to advanced presentation of breast cancer (Black et al., 2008). There is no concerted effort to educate primary care health providers on breast health. The only document that deserves mention is the Malaysian Clinical Practice Guidelines, Management of Breast Cancer,2002 (2002). A study on general practitioners in the Klang Valley revealed that only 27.2% of the GPs were aware of this guideline (Ministry of Health of Malaysia & Academy of Medicine Malaysia, 2002), only 33 or 45.2% have read the guidelines and only 18 found it useful (Taib, et al., 2007).

### 2.7.4 Help-seeking behaviour

"Role" refers to the behavioural expectations of others regarding the individual in question as determined by general cultural norms of proper behaviour and the individual's particular social identity (Twaddle, 1972). When a person suffers from illness, that person, and his society, assign on him/her a "sick role" (Parsons, 1951). If a person becomes sick, it is generally considered necessary for him to seek technically competent help (Tseng, 2001). The issue with breast cancer is that the signs are not severe enough to trigger this phenomenon. In other words, early detection will depend on other factors rather than the woman needing to feel sick.

As indicated by Rogler and Cortes(1993), help-seeking pathways refer to the sequence of contacts made with individuals and organizations by the distressed person and the efforts of his or her significant others in seeking help, as well as the help that is supplied in response to those efforts. As pointed out by Rogler and Cortes, help-seeking pathways are not random: they are structured by the convergence of psychosocial and cultural factors. Multiple pathways are available due to medical pluralism (Rogler & Cortes, 1993).

Help seeking has also been named as care seeking (Lauver, 1992; Reifenstein, 2007). From a qualitative interview of patients, Lauver found many factors that were barriers to help seeking, .ie,, other commitments, financial, time and logistical considerations, such as transport, and no knowledge of where to seek help. Fear was also seen as a barrier to care (Lauver et al., 1995). Attitudes toward GP attendance were also a factor, where women did not want to bother their GPs unnecessarily (Bish, et al., 2005; Burgess, et al., 2008).

# 2.7.5 Intrapersonal factors: psychological factors impacting delay

Psychosocial parameters associated with better breast cancer prognosis are social support, marriage, and minimizing and denial, while depression and constraint of emotions are associated with decreased breast cancer survival (Falagas et al., 2007). How psychosocial parameters affect outcome, in terms of shortening delays or prolonging delays, have been studied. Women who were anxious and fearful seek treatment earlier, and initial emotional distress and panic also brought them sooner (De Nooijer, et al., 2001; Meechan, et al., 2003). In contrast, another study on patients with symptoms of breast cancer did not find that the effect of adverse life experiences nor

mood disorder in the year before symptom discovery increased the risk of delaying their presentation to a general practitioner (Burgess et al., 2000).

# 2.7.5.1 Coping

Individual response to a life-threatening stress, such as, a possible diagnosis of cancer, its outcomes and treatment side effects, is called coping. Stress consists of three processes (Lazarus & DeLongis, 1983). Primary appraisal is the process of perceiving a threat to oneself. Secondary appraisal is the process of bringing to mind a potential response to the threat. Coping is the process of executing that response (Carver et al., 1989). The entire process, then, may cycle repeatedly in a stressful cycle. Some emotion-focused responses involve denial, positive reinterpretation or reframing of events, while others seek out social support. These responses are very different from each other, and may have very different implications for a person's success in coping (Carver, et al., 1989). Those who think a great deal, to the extent of being unable to cope or take action, prevents help-seeking (Levanthal 1970, Safer et al 1979). Cancer patients who have social support reduce their distress and improve optimism. However some studies show close social support had no effect (Trunzo & Pinto, 2003).

A model for individual cancer strategy emerged from a qualitative study by Link (2005). The model showed the stages of choosing and using strategies and constructs that affect each stage (Fig 2.21). Coping style was one of these constructs.



Figure 2.21 The individualized cancer strategies model.

Source: Reprinted from "How do cancer patients choose their coping strategies? A qualitative study", by Link, L. B., Robbins, L., Mancuso, C. A., & Charlson, M. E. 2005 in: *Patient Education and Counseling*, 58(1), p.99. Copyright © 2005from Elsevier. Reprinted with permission.

## 2.7.5.2 Denial

Denial is often put into the context of delay, but not proven to be a factor in delayed help seeking (Wool, 1986). Denial is a maladapted coping mechanism, leading to the inability to cope and take the next step (Phelan, et al., 1992). The opposite of denial is acceptance, and in the grief model, the Kubler-Ross (1969) cycle of grief describes stages in which a person journeys to reach acceptance (Leming &Dickson, 1994). Denial, anger, bargaining, depression and acceptance may occur in succession or, in some cases, they can occur concurrently without any order (Leming & Dickson, 1994). Emotional reactions would be considered part of the ''primary appraisal.'' others have described visceral, emotional reactions of shock and denial which delayed, rather than directly affected, their pursuit of coping strategies (Link et al., 2005). Denial may be detrimental in that important treatment decisions remain undone.

In an underpowered case-control study of 30 women with locally advanced cancer who were randomly matched, all the women claimed to be aware of their diagnosis. Yet,

denial was a common theme in many guises. The study also found that delay occurred more among unmarried women although there was no difference by age, education level, occupation or ethnicity (Phelan, et al., 1992). Another study found that, not only did patients use denial, their spouses also utilized denial as a coping mechanism (Mohamed et al 2005). Without social support from spouses, further delay may occur.

### 2.7.5.3 Maintaining control

Maintaining control so as not to disrupt the individual's, and others' lives without expecting a bad outcome also resulted in delay (Timko, 1987). This concept is also viewed as loss aversion in the crisis decision theory, whereby the patient generally holds on to what they have at present, for fear of losing control over what functions they have (Sweeney, 2008).

### 2.7.5.4 Religiosity

Spiritual support and guidance are well known coping mechanisms. Studies have shown that for some women talking to God alone brought about delay (Gullatte et al., 2009). Studies have also shown that fatalistic belief is different in Asians, among whom, cancer is believed to be pre-ordained or fated, and there is acceptance of their fate (Straughan & Seow, 1998). Meanwhile in African Americans, it has been reported to be a sign of helplessness and hopelessness (Powe & Finnie, 2003).

A strong reliance on God in the midst of a life-threatening illness is often quoted in professional literature as "fatalism" rather than a way to explain daily life (Ohnuki-Tierney, 1984) (Barg & Grier, 2008). A study showed that by being religious and needing ways to find meaning and peace in the world gave a group of African

Americans a sense of being outsiders in the breast cancer world, as these needs were left unacknowledged (Barg & Grier, 2008). Similarly, Malay Muslim women through a qualitative study found that their experience with breast cancer was governed by their cultural and spiritual contexts (Ahmad et al., 2011). Cultural dissonance between the patients and their health care providers remains to be seen in Malaysia, studies have not been done in Malaysia to explore health care providers' perception and practices in terms of validating their patients needs in the meaning of cancer.

# 2.7.5.5 Fear

There are two ways of coping with fear-fight or flight. The avoidance behaviour associated with reduction of fear and anxiety seems to be helpful in the short term because of the reduction of negative feelings but it may be counterproductive in the long run. With cancer, the lack of emotional response on symptom discovery can lead to patient's delay. The level of fear evidently influences the patient's decisionmaking process on help-seeking, hence, this important factor should be taken into account when facilitating help-seeking (Dubayova et al., 2010). Fear of mastectomy was seen globally, including the west (Phelan, et al., 1992), in Ghana (Clegg-Lamptey et al., 2009) and in Nigeria (Ajekigbe, 1991). The literature review on fear intensity as a main reason for delay appeared in 15 publications. Emotion of fear towards help seeking or delay was seen quite extensively (Dubayova, et al., 2010). Fear can be defined at several levels - being worried, having fear, being anxious, in panic, and feeling death anxiety. In this regard, it was found that cancer patients usually experience fear at the lower intensity (Dubayova, et al., 2010). Minimising the seriousness of symptoms, termed defensive bias (Caplan & Helzlsouer, 1992), optimistic bias (Andersen & Cacioppo, 1995) or denial (Moyer & Levine, 1998) can

cause delay. On the other hand, some studies have found that it is indecision, rather than denial, that causes the delay (Dubayova, et al., 2010; Leslie et al., 2000; Temoshok et al., 1984).

2.7.6 Interpersonal factors:-

Distal factors, such as social support, network and social norms, are also known to influence help-seeking behaviour.

2.7.6.1 Social obligation

A woman generally has to play multiple roles and has perceived social obligations to others. She may be the main caregiver in a family, not only taking care of children and spouse but aged parents as well. In addition, she may also be employed. Studies have shown the effects of such competing interests on delay (Safer, et al., 1979; Zola, 1973). Specifically, women without competing personal problems have been found to have short delay periods (Safer, et al., 1979).

### 2.7.6.2 Social support

Social support can greatly modulate cancer patients' distress (Friedman, et al., 2006; Trunzo & Pinto, 2003). The influence of others may play a more important role in cancer patients' use of coping strategies than is recognized in other health behaviour models. For many participants, this was a crucial part of their decision making process. Women confronting various major health-related decisions used ''information seeking'' from social support networks, trusted health care professionals and independent research. (Link, et al., 2005).

# 2.7.6.3 Sanctioning

Sanctioning or permission from significant others to perform help seeking is another important feature (de Nooijer, et al., 2001; Grunfeld et al., 2003; Smith et al., 2005). Women needed to be prompted by others to seek help, (Burgess, et al., 2001). A study also found that perceived sanctioning by others to seek help is enough rather than enacted sanctioning (Timko, 1987). Sanctioning occurs not only from family, but friends and the media (Smith, et al., 2005). The lay referral network may also explain the presence of social permission to seek care (Scambler, 1984). Hence, a pluralistic health utilising community may perpetuate the use of a certain forms of treatment based on this perpetual social network.

# 2.7.6.4 Disclosure

Bish in 2005 placed disclosure within the theoretical model of patient delay (Bish, et al., 2005). Some studies found that it did not matter whether or not there was disclosure (Meechan, et al., 2003), whereas others showed that non-disclosure led to delay (Burgess, et al., 2001; Gullatte, et al., 2009; Ramirez, et al., 1999).

### 2.7.6.5 Marriage

Marital status did not affect delay in one study (Ramirez, et al., 1999). However, Gullate et.al. (2009) showed that unmarried women were more at risk for delay in a study in the US (Reifenstein 2007). Similarly, this was found in a study in Thailand using multivariate data analysis, where unmarried status was the only independent factor for delayed presentation, where unmarried women had 2.8 higher risk of presenting late compared to married women after adjustment with socioeconomic status (Thongsuksai, et al., 2000).

#### 2.7.7Access to care

### 2.7.7.1Financial

Socioeconomic (SES) groupings are important when health care is an out- of-pocket expense. In Malaysia, health expenses are found to be mainly out-of-pocket (Yu, et al., 2006). SES remains associated with survival among patients with cancer in Ontario, Canada. Disparities in outcome were not explained by differences in stage of cancer at time of diagnosis, especially with breast cancer. Thus, financial barriers may exist for treatment rather than the diagnostic process (Booth et al., 2010).

The cost of treating metastatic breast cancer has increased over time. A study in Canada of two cohorts showed a doubling in cost although its impact on survival impact was too premature to report (Galy, et al., 2010).

### 2.7.7.2Health systems

In Thailand, patient delay and system delay in breast cancer care were important weaknesses of disease control (Thongsuksai, et al., 2000). Some 6.6% and 24.4% of the patients studied, respectively, experienced patient and system delay of more than 12 weeks. System delay was seen in patients contacting a provincial hospital instead of a university hospital as the first medical care source. Being given a diagnosis rather than being told nothing; and being given treatment rather than being immediately referred were associated with system delay (Thongsukai et al 2000).

Crispo (2009) looked at characteristics of patient and diagnostic delay in southern Italy where the disadvantaged attend community based hospitals rather than breast health services. They found that these community centres lack strong organisation, infrastructure that is physically attractive to patients and there was limited adherence to updated guidelines. Women who delayed were often self-detected compared to screening mammogram. Faster growing tumours were most likely self-detected and indolent ones via mammogram. The poor less educated and minority groups were less likely to be in the early stages of disease (Crispo et al., 2009). A study of African American women with breast cancer found that a non-caring attitude related to a "wait and see" approach of healthcare providers contributed to delays (Gates et al 2001). Factors such as access to care and previous utilisation of health care patterns were also implicated in delayed presentation (Rauscher, et al., 2010; Reifenstein, 2007), as was perceived prejudiced health care (Reifenstein, 2007).

The literature on delay has many limitations. The studies were exploratory and inductive, i.e., qualitative in nature (Bish, et al., 2005; Burgess, et al., 2001; de Nooijer, et al., 2001). Some were a theoretical discourse on the process of delay (Bish, et al., 2005) and the stages of delay (Andersen, et al., 2009). Very few were conclusive or generalisable to a larger population (Burgess et al., 1998; Burgess, et al., 2000; Meechan, et al., 2003; Mor et al., 1990; Nosarti, et al., 2000). In the literature, the information on delay is usually retrospective, thus, there would be limitations in recall bias and reporting it at period where new perceptions and understanding may have come out of the experience itself (Reifenstein, 2007). On the other hand, prospective hypothetical studies are also problematic. Only one study actually interviewed women
with breast complaints that have not sought professional help (Facione & Facione, 2006).

The complexity of the stages and process of delay whilst using an ecological framework is very challenging and most likely cannot be generalisable to other societies due to the very localized aspects of psychological, social and cultural aspects affecting human behavior. Hence studies to improve disparities will need to be specific to the population that will benefit from the findings. Therefore, breast cancer in Malaysia with disparity in survival of women by stage of disease, ethnicity, socioeconomic group and level of health literacy and educational level in its' multicultural context will benefit from an exploratory study using qualitative grounded theory. Since generalisability will be limited, further studies will need to confirm similarities and differences between the hetergenous groups of women around the world.

# 2.8 Explanatory delay theories

Theories that look into delay in women are constructs derived from temporal events that occur naturally in the process, as discussed previously on stages of delay in the Andersen total patient delay model. However, the discontinued path is where the explanations to delay lie. Now we look upon existing exploratory delay models in cancer.

# 2.8.1 Patient delay

In these delay periods, both patients as well as provider factors play a role. Exploratory delay models in cancer are very much focused on pre-diagnostic delay, especially in the

area of symptom appraisal. Patient delay was explained mainly in the view of symptom appraisal. Less theories or models have tried to explain why women default or abscond treatment or non-adherence. Initial theories from Safer in the 70s, was built on fairly cognitive model of delay where decisions were binary and straight forward (Safer, et al., 1979), in the 80s the recognition of the situational social environment that gives meaning to illness to the person was reported (Andersen, et al., 2010).

#### 2.8.2 Crisis model

In the 90s, the crisis model in cancer delay incorporated personal, social and physical factors (Zervas et al., 1993). Crisis model to resolve or postpone the crisis brought on an individual by the suspicion of terminal illness. The original crisis theory was from Moo and Tsu's writings in 1977 on the crisis of physical illness (Moos & Tsu, 1977). The model was illustrated with two cases of women presenting with advanced head and neck cancer and a breast carcinoma. Zervas et al (1993) argued that patients used maladaptive cognitive appraisal with denial and denial-like processes as ways to avoid the tasks that require mature coping skills (Zervas, et al., 1993). Denial buffers the crisis onset but also increases the likelihood of morbidity and mortality. The crisis model is useful in that it allows the integration of many different theoretical systems and provides a context in which to organize understanding and to strategize interventions. The crisis decision theory has similarities and was discussed in the previous section (Sweeney, 2008). Sweeney's theory was more explicit and refined by having stages.

2.8.3 Total patient delay and psychophysiological comparison theory

In 1995, a clearer definition of the stages of total patient delay (Andersen & Cacioppo, 1995) was put forward by an explanatory theory of psychosocial comparison.

The psychophysiological comparison theory (PCT) has eight principles (refer Fig 2.22) it assumes that human beings have a sense of detecting when something is wrong with his/her body (physiology). At times, it may go undetected and may not be accurate. People are motivated to know what is wrong if it has personal relevance and he/she knows the outcomes of the condition associated with the symptom. Logical consistency governs the interpretation of the symptom as a known disease or condition. An inherent optimistic belief that the problem will be minor, and not due to something dangerous, prevails. The more non-specific the symptom, the higher the likelihood of an erroneous explanation as well as the likelihood of changing one's mind about its causes. The PCT tries to explain total patient delay theory. A cognitive process to appraisal and the vagueness of the physical symptom, prior experience, personal relevance and optimistic bias were used to explain delay. It was quite cumbersome to explain eight principles and designing interventional strategies would be a challenge. Furthermore, there was no incorporation of affective factors therefore the PCT seems incomplete.

Assumptions

- 1. People are motivated to maintain an explicable physiological condition
- 2. Symptoms perception need not be accurate in terms of physiological aetiology

Antecedents:

3. The strength of the motivation to understand and evaluate one's symptoms is a function of their unexpectedness, saliences, personal relevance and perceived consequences

Psychophysiological comparison

- 4. Symptom interpretation involves a comparison of the symptoms with the known consequences of salient situational stimuli (eg. exposure to pathogens, recent medications) and physiological conditions (eg. allergies, diseases that is illness prototypes)
- 5. Symptom interpretation is governed in part by logical consistency. For example, the probability of a specific illness inference is a direct function of its accessibility(familiarity) and inverse function of the discrepancy between the symptom and the disease prototype
- 6. Symptom interpretation is governed in part by an optimistic bias for example. For example innocuous explanations
- The more diffuse the symptom, the greater the potential comparisons and consequently greater likelihood of erroneous interpretations of the symptoms and the more susceptible to change are the interpretations
  Effects of failing to find a comparison
- Effects of failing to find a comparison
- 8. If a situational stimulus or illness prototype cannot be initially identified to account for the symptoms, then the stimuli or prototype(s) which maximizes the logical and optimistic bias will be considered. This will influence the subsequent symptom interpretation process in at least two ways:

A) the implicit theories people have about stimuli or ptototypes will influence the attention to and detection of symptoms and the production of symptoms for interpretation.

B) the particular symptom chosen will influence people's implicit theories about stimuli and prototype.

Figure 2.22. The psychophysiological comparison theory

Source: Adapted From "Delay In Seeking A Cancer Diagnosis: Delay Stages And Psychophysiological Comparison Processes" By B.L. Andersen & J.T. Cacioppo, 1995. *British Journal of Social Psychology*, 34 (Pt 1), P. 35. Copyright © 1995 from Wiley Publishers. Reprinted with permission.

#### 2.8.4 Judgement to delay

Facione (2002) came up with the judgement to delay model (J-delay), again emphasising appraisal of symptoms in patient delay. Facione (2002) studied 699 women from three different ethnic groups in USA who without symptoms to see whether they were likely or not to delay. He found that 23.7% were likely to delay. The study showed that self-reported likelihood of patient delay is measurable in advance before symptom occurrence. This study is the first to examine whether variables believed to predict patient delay can identify women's predisposition to delay even before symptoms occur. The stability of the results on retesting after six months, showed that there are people without symptoms yet who are clear in their intentions to delay. The J-delay model integrated measurements of social and psychological variables reported to be related to patient delay. The addition of socio-demographics and access to health care was very relevant and valid. The study also found that perceived access and prejudice to care exists in the three ethnic groups - black, Latino and white. Fatalism was also seen in all three ethnicities. In fact, this study is the first to show it among Caucasians. Women's roles, social obligations and female sacrifice were seen in this study. This model only predicted those who delayed in 40.6% of the cases and the logistic regression model explained 34% of the variance in delay. There are other important factors influencing delay that could not be measured in this study. The researchers suggested affective responses, normative expectations of when it was appropriate to visit healthcare providers, incorrect estimations of the consequence of delay, feeling invulnerable and cultural-specific modesty may explain the rest of the variance. Fig 2.23 shows the factors that affected delay or non-delayers.



FIG. 1. Judgment to delay model.

Figure2.23 Judgement to delay model Reprinted From "The Self-Reported Likelihood Of Patient Delay In Breast Cancer: New Thoughts For Early Detection" By N.C. Facione, C. Miaskowski, M.J. Dodd & S.M. Paul, 2002 In Preventive Medicine, 34(4), P. 398. Copyright © 2002 American Health Foundation and Elsevier Science (USA). Reprinted With Permission.

2.8.5 Model of understanding delayed presentation with breast cancer

Bish (2005) proposed an explanatory model for understanding delayed presentation

with breast cancer by selecting variables from the literature review and fitting them into

a psychological theoretical model to explain patient delay (Fig 2.24).

Elements of self-regulation theory, theory of planned behaviour and implementation

intentions are evident in this model. The model also draws upon Andersen's total

patient delay model, psycho-physiological comparison theory and social cognition

model. It incorporates stages of symptom appraisal, attitudes towards help seeking and

translating intentions into behaviour. No studies have been done to confirm this

theoretical model



Fig. 1. Model for understanding delayed presentation with breast cancer.

Figure 2.24 Model for understanding delayed presentation with breast cancer. Reprinted From "Understanding Why Women Delay In Seeking Help For Breast Cancer Symptoms" By A. Bish, A. Ramirez, C. Burgess & M. Hunter,2005 In *Journal Of Psychosomatic Research*, 58(4), P 323. Copyright © 2005 Elsevier Inc. Reprinted With Permission.

This model is important in a small segment of patient delay, i.e., it is very clear that it explains the components to enable help seeking behaviour after symptom discovery. Disclosure is needed to obtain social support, which is important to enable and trigger help-seeking. The main criticism, is that it does not have an affective aspect which has been shown to be linked to care-seeking behaviour (de Nooijer, et al., 2001; Meechan, et al., 2003). Although it mentions attitudes, especially towards cancer treatment outcomes, other factors were not mentioned. This model may be too simplistic and empirical research has to be done to measure each component and to see how much each explains help seeking behaviour. Smith (2005) found that sanctioning help seeking was important in help seeking behaviour (Fischer, et al., 2005). Sanctioning can be from the media, friends and family.

#### 2.8.6 Heuristics reasoning

In the same year, Katapodi (2005) examined heuristics and dominant cognitive restructuring in 11 women of diverse backgrounds on their risk assessment of breast cancer (Katapodi, et al., 2005). Predictions and judgments are often mediated by a small number of distinctive mental operations, which are called heuristics. Heuristics are logical as well as affective dependent judgemental shortcuts when a person judges a situation. The affective aspect is more so in situations where uncertainty is prominent, such as in assessing risk of breast cancer. The affective heuristic was described in two ways - firstly, as the affective response to the decision-making and, secondly, as the affective evaluation, i.e. negative or positive of a mental image resulting from the internal and external image of the condition. For an individual, multiple heuristics occur, and dominant restructuring where a few types of heuristics are used more than others, to come to a decision. The judgment uses available information, which the authors found to be from prior experience, especially with family members or friends with breast cancer as well as the stereotypical high risk individual. This is similar to the crisis decision theory where assessing severity includes comparative information from prior experiences.

The four phases of the judging process were (1) pre-editing where individuals consider multiple choices; (2) second phase where they select an alternative more dominant to the other; (3) third phase where they examine the values of each alternative; and the (4) final phase where the drawbacks of the dominant choice are evaluated and the dominance structure is created. The structure selected may not be logical, and independent on the person's cognition. The phases mentioned here are similar to the three stages of crisis decision theory (CDT) - assessing severity, generating options and choosing options. The CDT also expresses the importance of values in life goals, which

Common heuristics				
Affect	(1) Positive or negative feelings that are experienced as a conscious or unconscious feeling state. (2) Positive or negative quality of a stimulus or a mental image.			
Anchoring and adjustment	The estimation of the probability of an event starts from an initial point, which is suggested by the formulation of the problem or is the result of partial computation. Final estimates are adjusted towards initial values.			
Availability	The probability of an event is judged by the ease with which instances of that event come to mind.			
Loss aversion	If choices are framed as gains, people become risk averse and favor the status quo. When choices are framed as losses, people become risk seeking.			
Perceived control	People behave as if chance events are subject to control. Hindsight bias of prior events leads to heuristic assertion of control over "similar" events.			
Representativeness	As long as A is significantly similar to B, the probability that A originates from B is judged to be high and vice versa.			

# Figure 2.25 Common heuristics

Reprinted From "Perceived Breast Cancer Risk: Heuristic Reasoning And Search For A Dominance Structure" By Katapodi, M. C., N. C. Facione, Et Al., In 2005 In *Social Science & Medicine* 60(2) P 421-432. Copyright © 2004 Elsevier Ltd. Reprinted With Permission.

means that it may not be rational decision-making. The dominance structure as a method of decision making by women , is important in designing educational interventions.

In this study, they asked three questions to unearth the heuristics involved. (a) how did you make the decision about whether or when to have your breast symptoms evaluated? (b) have you had any problems with access to health care services? (c) what do you think is your risk for getting breast cancer? They found evidence of optimistic bias in the women's responses, whereby, the women formed beliefs based on prior experience with relatives or friends with breast cancer and had perceived control over the disease, i.e., the ability to adopt healthy lifestyles and trust in their health care provider to overcome the illness. The heuristics in this study were simulation, availability and representative heuristics (refer to Fig. 2.25) (Katapodi, et al., 2005). Facione and Facione (2006) studied women presenting with potential breast cancer symptoms. The study was well planned in that women's decision to delay was studied at the time of the incident. A subsample of 28 women was identified from a larger study looking at asymptomatic womens' intention to seek help (Facione, et al., 2002). The women who had breast changes were studied to see their uptake of seeing a health professional. After recruitment, 13 sought attention, 15 continued to monitor own symptoms for at least three months. Out of the 15, eight reported more than a year or more. Nine women did not disclose to others. None reported lack of confidence. Those with lump symptoms and younger women delayed longer. Heuristic analyses were used on in-depth interviews and heuristic reasoning shortcuts found affect, availability, associational of breast cancer and death, representative or similarity heuristics with benign diagnosis with overconfidence in similarity of two cases, i.e., their own, and someone else in the past. When prompt diagnosis seekers were compared to delayers, prompt diagnosis seekers used the heuristics of women with breast cancer. Although delayers used vivid similar stories and most of the strategies were the same as for those who did not delay, the delayers also used satisficing. This was seen to be in operation, taking an alternative pathway as adequate although it was not the most optimal. Simulating with imagining outcomes was seen as were illusions of control, by overestimating the belief that one could control outcomes, loss aversion was seen, i.e., there was a negative association with loss and risk, thus decisions were aimed at conserving the status quo rather than suffering a loss. The delayers also made confident decisions which failed to foresee the consequences of inaction. More arguments were made against seeking help, and they abandoned sound and compelling arguments to seek diagnosis, relying instead on false information. Decisions to delay were resilient, yet required maintenance to sustain it. Intervention should address the thinking process

by questioning this reliance on mistaken claims of control, satisficing, simulating benign diagnosis rather than preventing late staged cancer. They prioritized control of fear over protection of life. This paper was unique in that they had women with symptoms and were able to track and analyse the heuristics used by these women.

# 2.8.7 Care seeking model

Reifenstein (2007) built a model explicitly including psychosocial constructs based on findings from her study. This is the only explanatory delay theory that explicitly included affect and utility in the model. This study was a descriptive correlation study on 48 participants in the primary care setting. Results showed that denial was significantly correlated to delay. Confrontive coping, seeking social support and planful problem solving had no relationship to delay. This explanatory model modifies Lauver's care seeking behaviour (refer to Fig.2.26). Lauver in 1992 integrates Trandis 's theory of behaviour with psychosocial factors (affect, expectations and values of outcomes, habit and norms) in association with facilitating conditions (e.g., insurance coverage) (Reifenstein, 2007).



Figure 2.26 Reifenstein's modification of Lauver's care seeking model. Reprinted From "Care-Seeking Behaviors Of African American Women With Breast Cancer Symptoms" By K. Reifenstein, 2007 In Research In Nursing And Health, 30(5), P 544. Copyright © 2007 Wiley Interscience. Reprinted With Permission.

# 2.8.8 Prolonged patient delay

More recently, Rauscher (2010) confirmed that interpretation of symptom and utilisation of care were two factors identified in appraisal and illness delay, respectively. The conceptual model was shown in Fig. 2.27. This study was a population based study of 436 symptomatic women. Sixteen percent reported delay beyond three months. The definition of patient delay was from recognition of symptom to the first attempt to contact health provider rather than the first appointment defined in other studies.



Figure 1. Conceptual model for prolonged patient delay before deciding to seek help for a breast problem.

Figure 2.27 Prolonged patient delay. Reprinted From "Misconceptions About Breast Lumps And Delayed Medical Presentation In Urban Breast Cancer Patients" By G.H. Rauscher, C.E. Ferrans, K. Kaiser, R.T. Campbell, E.E. Calhoun & R.B. Warnecke, 2010 In Cancer Epidemiol Biomarkers Prev, 19(3), P. 641. Copyright ©2010 American Association For Cancer Research. Reprinted with permission.

Misconceptions about breast lumps, absent regular provider, lower recency of breast check-up, history of benign breast disease were independent variables to delay. Misconceptions about breast symptoms correlated with advancing age, decreased education, income, lack of private health insurance, lack of regular doctor, ethnic minorities with lower SES and poor access to care. There was no disparity in findings between delay in the three ethnic groups; whites, blacks and Latinos. Lower utilisation rates of health care were seen in delayers. The challenges of a quantitative study to measure a phenomenon were obvious when a Likert scale response was converted to a binary response. The conceptual model was constructed based on the results. Other variables that were not significant were excluded from the model.

#### 2.8.9 Sociocultural interpretation of symptoms

Andersen (2010), used Alonzo's concept of containment supplemented by other anthropological literature on how bodily sensations are interpreted. Symptoms are potentially contained in a dynamic interplay of factors related to social situations, life biographies and life expectations and their accordance with cultural explanations and values (Andersen, et al., 2009). Symptom appraisal is not just a logical process, but rooted in the social and cultural context (Hay, 2008). There is an interaction of individual bodily sensation, social objectication or selection, interpretation and evaluation. Containment is situational, that is, individuals keep body state at a level of side involvement in order to sustain the integrity of self and others (Andersen, et al., 2010). Thus, the theoretical model of delay was further enriched with the recognition of social and cultural dimension of symptom interpretation.

## 2.8.10 Unger's grounded theory

Unger (2011) criticised the simplistic traditional delay model and summarised it in Fig. 2.28.Based on her recent study in Mexico using a qualitative enquiry on 17 women, the researcher identified a grounded model of help-seeking for a breast symptom (Unger-Saldaña & Infante-Castañeda, 2011). The main constructs of symptom interpretation and decision making, social network interaction and health service utilisation were identified. The model presented (Fig. 2.29) was comprehensive and explains the phenomenon in the Mexican setting.





Source: Reprinted From "Breast Cancer Delay: A Grounded Model Of Help-Seeking Behaviour." By Unger-Saldaña, K., & Infante-Castañeda, C. B. In 2011 In *Social Science & Medicine*, *72*(7), 1096-1104. Doi: 10.1016/J.Socscimed.2011.01.022. Copyright © 2011 Elsevier Ltd. Reprinted With Permission.



Fig. 3. Grounded model of help-seeking for breast symptoms

Figure 2.29 Grounded model of help-seeking for breast symptoms. Source: Reprinted from "Breast Cancer Delay: A Grounded Model Of Help-Seeking Behaviour. " By Unger-Saldaña, K., & Infante-Castañeda, C. B. In 2011 In *Social Science & Medicine*, *72*(7), 1096-1104. Doi: 10.1016/J.Socscimed.2011.01.022. Copyright © 2011 Elsevier Ltd. Reprinted With Permission. Explaining human behaviour is very challenging due to the complexities involved. Theories try to explain why people behave as they do. In delay research, several theories try to explain the process that the patient goes through. The exploratory theories actually describe the common pathways, such as, the health behaviour constructs like intention, self-efficacy, decision making aspects, affect and social network and support. However, the explanatory theories are mainly on symptomrecognition and help seeking. Adherence to treatment and maintenance of treatment were found to be lacking, except in the crisis theory.

# 2.2. Chapter summary and theoretical framework

Why do women present with advanced cancer? The theoretical framework belies the complexity of the research question. My constructive grounded theory will be built upon these extant theories. Therefore, the theoretical framework that is eventually constructed will be described in the results section as my constructive grounded theory. Integration of these theories and models will bring about the theoretical framework emerging from this research to understand why women come late from symptom recognition to the completion of treatment.

# **Chapter 3 Research method**

#### 3.1 Introduction and research questions

This chapter details the research questions as well as the justifications and types of research designs chosen in this study.

#### 3.2 Purpose of this study

The central phenomenon being studied is why women present themselves with advanced breast cancer as stated in the primary objectives detailed in Chapter one. The second objective is to understand women using oncological services in UMMC. The secondary objectives were also shown in Chapter 1.

3.3Mixed-method study design

3.3.1 Worldviews and philosophical assumptions

Mixed method is the third methodological movement, the first being Quantitative and the second Qualitative method. It has evolved from paradigm wars as a pragmatic way of using the strengths of both approaches (Tashakkori & Teddlie, 2003). Pragmatic worldview is one of the four different worldviews or paradigms in research methods (Creswell & Plano Clark, 2007). The four are post-positivism, constructivism, advocacy and participatory, and lastly pragmatism. The advocacy and participatory worldview are influenced by political concerns and approaches favour qualitative approach, the need to improve society for marginalised groups. The last, which is the pragmatism, is associated with mixed method where the focus is on the consequences of research and the primary research question rather than methods. Multiple data collection informs the problems under study, thus, it is pluralistic and oriented towards what works in practice (Creswell & Plano Clark, 2007). The key factors in deciding to use mixed method would be the research question, the timing of the methods, weightage of the methods and how the data will be mixed (Creswell & Plano Clark, 2007). The research design of this study weighs heavily on the qualitative design, the emphasis on qualitative design is imperative to answer the main research question.

The study design was a mixed method, concurrent embedded design (Creswell 2003). In other words, it is a single phase and both qualitative and quantitative studies performed at the same time. A single data set was not sufficient to answer different research questions. The notation for this study was QUAL + quant (Morse 2003). Figure 3.1 gives a pictorial view of the study design (Creswell 2007). The embedded terminology introduced by Caracelli & Greene(1997) and that the data are used to answer different research questions within the study (Hanson 2005). Creswell has also been described it as nested (Creswell 2003). The nesting meant that the main research question is addressed by the dominant method, in this case qualitative and when seeking other information, a nested supplementary approach was added. The data is analysed separately but displayed together in the analysis (Morse 2003). The strength of the embedded design is that it can be used when a researcher does not have sufficient time or resources to carry out extensive qualitative and quantitative data collection Creswell (2007) another reason why the concurrent embedded design was employed was due to the limited time available to perform this study in view of the study leave that was for 2 years. This time was used for learning research methods, data collection and analysis, hence having to choose a most time efficient study design was crucial. In this case a choice of having data from different sources and way of analyzing aim to

clarify the main problem of women presenting with advanced disease, one has to understand the population that future interventions are based upon.

To reiterate further, the intent of the mixed study design was not to triangulate the results (Morse 2003) or to converge the findings (Creswell 2007), it is to give a larger interpretation in a purview for understanding the parent population and hence provide a more holistic interpretation of the phenomenon and to suggest interventions.



# Figure 3.1 Embedded design

Source: Reprinted from"Designing and Conducting Mixed Method Research" by J.W.Creswell and V.L. Plano Clark. Copyright© 2007 from SagePublications Inc. Books. Reprinted with permission.

The research question and design of the study are summarised in Table 3.1 below:-

Table 3.1 Research questions, design, tools, sample size and operationalisation methods

Research question	Design	Tools	Sample	Operationalisation				
Primary objective Why women present with advanced breast cancer								
Why women present with advanced breast cancer	Qualitative	In depth interview	Women with advanced breast cancer diagnosed between 2007 to 2009	In-depth interviews				
			Theoretical sufficiency technique (n=19)					

# Table 3.1, continued

question   nalisation     2. Secondary objective:   2.     2.1. To identify the sociodemographic characteristics of breast cancer patients attending outpatient services   Face to face (Self-devised)     Socio- demogra phic   Quantitative   The breast cancer patients urvey questionnaire)   Breast cancer patients     outpatient   questionnaire)   outpatient   face (Self-devised)     -istics   questionnaire)   outpatient   oncology services (n=261)     2.2. To identify the clinico-pathological and treatment characteristics of breast cancer patients   Face to face (Self-devised)   attending     interview   The breast cancer   Breast cancer patients   face     breast   Quantitative   The breast cancer   Breast cancer patients   face     ionamer   questionnaire)   outpatient   oncology services (n=261)   interview     2.3. To identify social support during period of diagnosis   Social   guantitative   The breast cancer   Breast cancer   face     support   Quantitative   The breast cancer   guestionnaire)   guestionnaire)   outpatient   oncology     services (n=261)   2.4. To identify the sources of information after diagnosis of breast cancer   face	Research	Design	Tools	Sample	Operatio				
2. Secondary objective:     2.1. To identify the sociodemographic characteristics of breast cancer patients attending outpatient services   Breast cancer patients attending outpatient face interview     Socio- demogra phic   Quantitative   The breast cancer patients attending outpatient oncology services (n=261)     Phic   (Self-devised questionnaire)   outpatient oncology services (n=261)     2.2. To identify the clinico-pathological and treatment characteristics of breast cancer patients   Face to face interview     The breast Quantitative   The breast cancer patients urvey quatients attending outpatient oncology services (n=261)   Face to face interview     2.3. To identify social support during period of diagnosis   Social support during period of diagnosis services (n=261)   Face to face interview outpatient oncology services (n=261)     2.4. To identify the sources of information after diagnosis of breast cancer patients urvey (Self-devised questionnaire)   Breast cancer patients attending outpatient oncology services (n=261)   Face to face interview     2.4. To identify the sources of information after diagnosis of breast cancer patients survey (Self-devised questionnaire)   Breast cancer patients face interview   Face to face interview     off   Quantitative   The breast cancer patients attending outpatient oncology services (n=261)   Face to face interview     2.4. To identify the coping mechanisms of women with breast cancer patients attending outpatient oncol	question				nalisation				
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#### 3.4 Theoretical framework.

This study's main objective is to iteratively form a theoretical framework of the phenomenon at hand. Hence, the theoretical framework that is eventually constructed will be described in Chapter 6 as models derived from my constructive grounded theory.

## 3.5 The study site and participants

# 3.5.1 The research site

The University of Malaya Medical Centre (UMMC) is a 900-bed tertiary public hospital located in urban Kuala Lumpur. The breast surgical unit in UMMC has been in existence since1993. The development of oncology services has improved over the years with the incorporation of trained oncologists in 1998. In-house radiotherapy and daycare chemotherapy services were started in 1998 and 1999 respectively. Prior to this, patients received chemotherapy in the ward administered by surgeons and radiotherapy services were obtained at a different public institution. Presently, about 300 newly diagnosed breast cancer patients have treatment in UMMC. The issues that have been discussed are issues of late presentation, which comprise about 30% of the cases each year (Taib NA et al. 2011). Furthermore, in other parts of Malaysia, the proportion of patients with delayed presentation is higher, thus, there is a need to address this issue. Knowledge on why women present with advanced disease will fill the gaps in knowledge and provide important information so that interventions can be tailored to address specific issues relevant locally and in other parts of the world.

#### 3.5.2 The participants

In-depth interviews were conducted on 19 women with advanced breast cancer. The survey was conducted on 261 women with breast cancer attending outpatient oncology services in UMMC.

# 3.6 Ethical considerations

Ethical clearance was obtained from the University of Malaya Medical Centre Ethics Committee (Appendix A). Informed and written consent was obtained from all participants prior to the interview.Patient information sheets were provided. Confidentiality in handling sensitive information and anonymity of the participants were ensured.

Participants were aware of my area of expertise; many questions arose during the interviews about their prognosis, and so on. The researcher always answered their questions at the end of the interview and kept contact with them on the phone to answer their queries.

Since the research is really a partnership towards understanding the issues, the researcher offered counselling to some patients and referred when required. When there was any evidence of physical or psychological issues the researcher referred to other health professionals, like the breast care nurse, psycho-oncologist, social worker as well as the breast surgeon.

#### 3.7 Qualitative research procedures

## 3.7.1 My epistemological stand

Ontology is the study of capturing social realities and how to reconstruct them. The original grounded theory method espouses a totally independent interpretation without any biasness placed by the interpreter. A shared reality or normative beliefs can be interpreted by the researcher if she continuously and reflexively puts in check her beliefs and perception of the world. That multiple realities exist and create meaning for the individuals studied is a fundamental belief of qualitative researchers (Streubert Speziale & Rinaldi Carpenter, 2007). Commitment to participants' view-points, unstructured interviews, observations and artefacts ground researchers to the real life of the study participants. The researcher is a co-participant in discovery and understanding the realities of the phenomenon studied. Interviews are done with a semi-structured guide, using open ended questions, to encourage participants to share in their own words, their own experiences (Streubert Speziale & Rinaldi Carpenter, 2007). The insider's view with utmost respect for the participants perspective need to be maintained. Thus, prolonged engagement was undertaken by giving adequate time for building a trusting relationship. The concept that the researcher is the research instrument is also important because the interviewer and observer are always subject to bias.

The researcher's participation can also add to the richness of the data. However, the researcher must keep in mind /her duty to report from the perspectives of the people that have lived those experiences (Streubert Speziale & Rinaldi Carpenter, 2007).

Grounded theory method (GTM) for qualitative design has undergone modernisation since its founders Glaser and Strauss developed it in 1967. A plethora of new GTM students emerged, the most influential being Charmaz in 2006, and Clarke in 2005. A constructivist perspective by Charmaz in 2006 assumes that people construct the realities in which they participate, thus, highlights the researcher-participant connection and the co-construction of the data. Reflexively for a breast surgeon working in the field for more than 10 years brings into the picture a great deal of bias, but by being aware and declaring it upfront, a conscious effort is made not to bring in a priori concepts into the grounded theory. The researcher has therefore taken a constructive grounded theory (CGT) (Charmaz 2006) epistemological stand in analyzing the qualitative results in this thesis. The CGT is a pragmatic approach taking into account the identity of the researcher with her own background knowledge, beliefs etc. We do not exist in a social vacuum (Charmaz 2007) in contrast to an objectivist grounded theory epistemology stand would be following the positivist tradition, that data is real and it is not generated by the process of its production (Charmaz 2007, Corbin and Strauss 1990, Glaser 1978, Glaser and Strauss 1967). The objectivist assumes an unbiased view of the data and claims of value-free neutrality. Paradoxically CGT takes on a value position (Charmaz 2007). Hence, the CGT provides a more realistic approach towards analysis. As explicating oneself from the analyses is never 100%, however as a health professional it is critical that the researcher remains reflexive in the analysis. During the interviews ethical considerations were important. Power relationships were put in check where the participants are explicitly told that they may disclose materials without any fear of reprisal from the treating doctors and that they may refuse or opt out at any time. One participant was not included in the analyses as she opted out after the interview as she was uncomfortable that she had disclosed more

than what she was comfortable with. For the researcher, explicating herself, would mean being non-judgmental and always putting herself in check with regards to the biases a breast surgeon might put into the analysis.

A constructivist grounded theorist would be using her previous understanding to construct a topic guide (Appendix B) that would guide the participants to disclose their reasons for presenting late. A more narrative approach was taken to get the details of her journey to break the ice and to enable a rapport to be built before getting into the details of why she presented late. Many times the women could not tell why she came late. Interview method may not bring out the social and cultural circumstances, because this is accomplished unthinkably and unknowingly as the logic of social life is implicit and often taken for granted (Bourdieu 1980, Andersen, et al., 2010). It was important to be able to probe on the emotions and values women put into their treatments and their knowledge of the disease to be able to clarify reasons for delay or presenting late. Also informants may make connections and associations that may have not been there before the reflective interview session (Kvale 1983, Andersen, et al., 2010). Hence, the journey as expressed by the participants provides clues for their reasons for not presenting earlier to hospital staff.

#### 3.7.2Explicating the researcher's beliefs/ reflexivity

As mentioned in Chapter 1, the researcher is the tool in qualitative research. The researcher's role as a breast surgeon was kept at a minimal as she had no contact on the clinical management of the participants. When researching, questioning and analysing, she had to keep in mind her own biases. A short journal was written to reflect on how the relationship was and her responses to the participants on whether counter transference occurred at times. Biased interpretation of the participants' reality was kept in check.

However, as a novice researcher in the area of psychology, sociology or anthropology, it gives an advantage of theoretical agnosticism; a term coined by researchers. It is a useful stance, congruent with the original Glaser stance on delaying literature review to the end (Bulmer 1979, Dey 1999 and Lyder 1998). Since the researcher has taken a CGT epistemology stand, she used her prior knowledge and by initially not knowing much sociology and psychology allowed herself to explore the data in a more grounded way.

## 3.7.3 Topic guide development

In qualitative research, unstructured interviews usually are more data dense(Corbin & Strauss, 2008). A semi-structured topic guide was constructed in this study because data collection involved more than one researcher. The semi-structured topic guide was constructed and discussed with an expert panel consisting of breast surgeons and a clinical psychologist. Initially the topic guide was all too comprehensive (Appendix B). A 15 core open-ended questions were utilised for the interview. The use of open ended questions and probes was important to allow the interviewees to express the issues in their own words and not be biased towards answering what they think the interviewer would want to hear. In view of Malaysia's multicultural and multilingual society, translating research questions into various local languages was necessary to cater to the multilingual background of the participants. Therefore, it was translated to Malay, Mandarin and Tamil (this method will be elaborated on below under instrument development in Appendix D) and pilot tested to ensure soundness and maintenance of meaning.

# 3.7.4 Sampling

Seven purposive sampling methods have been presented by Onwuegbuzie and Collins (2007); maximum variation, critical case sampling, theory based sampling, typical case sampling, random purposeful sampling, multistage purposeful random sampling and multi-stage purposeful sampling (Onwuegbuzie & Collins, 2007). This sampling method can be used for emergent or constructivist type of qualitative research (Onwuegbuzie & Leech, 2007). The sample size should not be too big to extract rich data (Onwuegbuzie & Leech, 2007). Hence, in this study a purposeful sampling was carried out. The selection of cases was based on women who have been diagnosed with advanced breast cancer (clinical or pathological stage III and IV) within two years of the interview. Women diagnosed from June 2007 to 2009 were selected from the UMMC breast cancer registry as well as those admitted or undergoing treatment during the study period. The participants were contacted by the researcher or the Mandarin or Tamil-speaking research nurse. Women who agreed to participate were scheduled for a two-hour appointment. The in-depth interview was conducted in an appropriate place, i.e. in the hospital or at the participant's home. Another appointment was made for the questionnaire survey by face-to-face interview. The sampling was stopped at 19, when theoretical sufficiency had been achieved (see below for further elaborations).

# 3.7.5 Representation

The researcher strived to obtain representativeness via intra-cultural diversity (Sankoff, 1971). The 19 patients varied in age the extremes of age of 25 to 82 years were represented, the different ethnic groups and different socioeconomic groups were represented as well. They were typical women with advanced breast cancer that was seen in the breast clinic. Each subsamples were abundant, ie 10 Malay women this was

justified as a study in UMMC revealed that Malay women tend to default treatment and present with advanced stages. Five Chinese women and four Indian women were accrued. A good mix of religion, with Muslims, Buddhists, Taoists, Christians and Hindus were represented in the data. The cases were chosen based on their uniqueness and what their stories could inform about reasons for their late presentation.

3.7.6 Saturation of sample size with theoretical sufficiency

A pragmatic approach towards saturation of data was used in this study. Theoretical sufficiency is when the data suggests categories, not saturates the theme as in the theoretical saturation (Charmaz, 2009; Dey, 1999). There is tension in that purist GT methods would require that theoretical sampling is done to achieve theoretical saturation. This was first described by Glaser and Strauss (Glaser and Strauss 1967). To clarify further it is a data collection method based on concepts and themes derived from the data. It is collected from variable sources to maximise the opportunities to develop concepts not persons in terms of their properties, dimensions, variations and relationship between the concepts(Corbin & Strauss, 2008).

Theoretical saturation is defined as the point in analysis when all categories are well developed in terms of properties, dimensions and variations. Further data gathering and analysis add little to the conceptualization, though variations can always be discovered (Corbin & Strauss, 2008).

It was challenging to wait for transcripts after the interviews and the researcher went back to the patients personally interviewed with more specific questions to refine the ideas further by keeping notes. The researcher went to the next patients and probed further on the ideas that she came across during the earlier interviews. She found it very challenging to actually perform theoretical saturation as multiple themes came about in each interview, and reasons for presenting with advanced cancer, appeared to be complex and involved intrapersonal, interpersonal and external factors. Hence, during analysis the theoretical sufficiency approach was more applicable to this research. Furthermore, when using research assistant to do the in depth interviews in other languages, there was a disadvantage of losing the ability to have immediate follow-up questioning to get more information on new ideas. By using culturally and linguistically appropriate research nurses, it was hoped that by communicating well with the participants, the root cause of the phenomenon would be unearthed more efficiently. There were challenges in performing timely analysis when needing transcripts to be translated; this was seen for all non- Malay language transcripts. Only on two occasions the mandarin research nurse went back to probe a patient, the Indian patient interviewed in Tamil was also probed once.

Hence, it was not particularly focused to develop further questioning on each topic or theme for each interview i.e. to understand the mechanics of each theme as described for theoretical saturation. Consequently, the researcher used a pragmatic saturation point described by Dey where categories have been suggested by the data (Dey, 1999).

#### 3.7.7 The in-depth interview

The in-depth interviews were conducted at the convenience of the interviewees, four home interviews were conducted, the rest were opportunistic periods of outpatient visits during treatment or clinic follow-up. Five were interviewed during admission to the ward. Building rapport and trust was placed upmost when planning and scheduling the interviews. The average duration of the interviews was 51.8 minutes (range 35 to 101 minutes).

Non-participants were welcomed during the interviews if the interviewees welcomed it, although this may bring about biasness in the expression of the participants in the presence of a loved one. However, they may need the support of their significant others to feel comfortable at disclosing information to the researcher and to prompt their memory and events that had occurred to them after the diagnosis of cancer. At times, their presence gave away other nuances like their self-efficacy and the importance of spousal and family support. Repeat interviews were conducted when further clarifications were needed.

#### 3.7.8 Managing multilinguistic data

Coding was done in English for all the transcripts. For Malay transcripts, the researcher being bilingual, with a mother tongue in Malay and conversant in English as a second language coded the transcripts directly into English codes. During memo writing and displaying the results, the transcripts were then translated to English, e.g. below is a transcript that was coded under self-efficacy, and how coded data was translated in Malay is shown here. The subtle nuance of this script, where the participant described how life was suddenly challenging for her, and that she felt she was not strong enough to face the problems that befell her.

"sebelum I umur 30, i macam tak pernah ada masalah dari I kecik. I hidup senang masa kecik, I memang hidup sen... Alhamdulillah lah. Allah bagi. Macam, famili I senang, se, sehingga masa I umur 30 tu, ah, macam I kata, I ni, macam tak pernah hidup susah,hidup bagai roda, cheh \*laughs\* I kan... Oh, Alhamdulillah lah, I ni, tak pernah diuji, belajar pun, okey. ERM, hidup pun, senang, anak semua, dapat. I dapat suami, I dapat anak. I happy sangat.oh, tapi, bermula daripada umur 30 tu, lepas tu je, I dah tak senang, sampai sekarang. I tertimpa-timpa, lepas anak kedua, I dah jumpa lump tu, ah, start daripada situ, I dah tak senang dah. Eh, start dari, daripada anak meninggal, masa tu, baru I tahu, ah, dah mula cubaan hidup I.dan dia macam, I rasa dah macam, I dah rasa macam... Dah takde senang dah kat dunia ni.macam tu lah. I rasa macam, kalau Allah bagi kesenangan, insya-allah, kat syurga lah pulak."

Before the age of 30, my life was without any problems. I had an easy life as a child. My family was well off. I was good in my studies. I had a husband, children. I was very happy. But after 30 years old, life was no longer easy, I had a lump, my child died, that was when I knew life challenges had begun. I have gone through so much, it is no longer easy to live in this world, god-willing Allah will provide me an easy life in heaven. (P11)

The excerpt below was coded as poor doctor patient communication and low self-

esteem due to loss of breast.

"it is very important[spiritual support], I rasa.for sure. Yang tu, lacking. Because they are concerned more, concentrate more on, tsk, ni lah. Ah?Ah, physical, chemical \*laughs\* semua tu lah.so, macam tu lah. Spiritual tu, nak kena bina dulu lah, even, tsk, , bukan I nak cakap lah, my... Even psychologist kat sini pun, I tak boleh.you just imagine, doctor. After I kena.....ah, after I kena ni, kan, doctor. After I... Dah breast, kena buang breastnya, kan.one of the psychologists..... Datang and cakap, do you mind? Ah... You takde breast? Cakap macam tu. Lepas tu, dia kata, in front of my husband, I pun... Actually you rasa low self-esteem tau, bila you, bila you, kan, you memang, you tahu you kekurangan lah, kan.but, please don't mention, tau tak?\*\*crying\*\*I just buat senyap je lah.dia cakap masa I masih, healing process. Ja...stitch pun, belum open lagi in front of my husband. You kisah tak, that you takde breast? I kata tak apa lah, at least I feel comfortable, I just console myself. I kata, at least I feel comfortable daripada I ada lump yang besar tu, dah busuk lagi, kan. \*sniff\*and then... \*sniff\* lepas tu, dia kata, no, ah... Your husband kisah, tak? And my husband ada kat situ, my husband senyap je. You husband kisah tak? No, because some, some, some husbands, dia kata, some husbands, dia suka perempuan tu sebab breast.dia kata, tak tahu lah, your husband suka you sebab breast ataupun sebab dia suka you. Dia kata, and I feel very sad. Psychologist cakap macam tu?\*sniff\*I macam... Tak percaya.\*\*sniff\*\*"(p11)

It is very important to have spiritual support, that is lacking in hospitals. They are concerned more on the physical, chemical. The spiritual strength needs to be built first, even the psychologist here was not good. Can you imagine, after I had my mastectomy, one of the psychologists came and said.. Do you mind if I ask, you don't have a breast right? She said it like that! It was in front of my husband. Actually Ii had very low self-esteem, you know you have less. Just don't mention it, you know\*crying\*. So I just kept quiet. She said all this when I was still healing, the stitches have not come off yet. In front of my husband, she asked if I cared that I do not have a breast. I said, it is alright, I feel more comfortable without the huge smelly lump. Then she asked, does your husband care? My husband was there, and he remained silent. She continued to say that some husbands, love their wives for their breasts, she continued to say, I don't know if your husband loves you because of your breasts or because he loves you for you. I felt very sad that a psychologist would say this to me, I could not believe my ears.(P11)

Below, is an excerpt form an interview in Mandarin, translated by the research nurse into English (below the Mandarin script) and coded into husband causing delay and self-efficacy. The final English quotation used was improved upon, and checked with the research nurse on accuracy of interpretation. The nuances recorded by the research nurse, helped to indicate the mood and the non-verbal communication of the participants.

"**甚至我**还骂我老公为什么你没有强逼我来看医生。就是说,如果他强硬一 点,不要只是说(劝告),要硬硬拉我来看哦。I scolded my husband as to why he did not force me to come and see the doctor. In other words, if he was a bit forceful, not just mentioned/advice (about going to see a doctor), must 'drag' me by 'force' to see lah...(see the doctor).

'inside my heart' (I am) still blaming him a little...blaming him for not trying earlier to 'drag' me to see..(the doctor). But i also know it is my own problem lah. Because my husband did ask me to see, only I did not....not like this....in other words...did not...only that I was scared(afraid, fearful...to seek treatment)

**害怕)知道是**这个病啰。害怕又...**又好像,去看医生又好像,就是**觉得很 害羞这样。

Knowing that it is this illness (breast cancer). Afraid....and yet it is like.....(if) go and see a doctor also like.....like feeling very shy.

**害羞。哈哈【笑】,我想,是自己的**问题啦。那个时候的心情是说唯一可 以埋怨的就是先生啦。哈。

Shy..ha..ha...(laugh), I am thinking ....it is my own problem lah. My feeling at that time was that my husband was the only one whom I can blame."【大家一 起笑】

(laughter from all...including husband who sat in)(p13)

In my heart, I am still blaming my husband a little for not trying to drag me to see the doctor earlier. But I also know it is my own problem. Because he did ask me to go, only I did not. I was afraid, knowing that it could be breast cancer. (P13)

Hence, analyzing in different languages had been challenging.

## 3.7.9 Analyses

## 3.7.9.1 Data reduction

In this study, coding was done using the Computer Aided Qualitative Data Analysis Software (CAQDAS) Nvivo 8 software (Bazeley, 2007). CAQDAS, unlike the human mind, can maintain and permit one to organise evolving and potentially complex coding systems into hierarchies and networks for at a glance user reference (Saldana, 2009). The software essentially helps organise the codes and categorisations, but it does not assist in the emergent theory where the main research tool is the researcher herself. The coding was done exclusively by the researcher. Coding is a cycle and not a linear process which previously has been classified by levels, i.e., level I and II (Miles & Huberman, 1994), whereas other authors have used three levels: Level 1- free nodes or substantive codes, Level II- tree nodes or categorizing into obvious fits of level I codes, Level III coding are the titles given to the central themes or basic social process (BSP) that emerge from the data (Streubert Speziale & Rinaldi Carpenter, 2007) Saldana (2009) classified first cycle coding as that which involves many types of initial coding where free nodes are used widely. The understanding of human experience is a matter of chronologies more than of causes and effects (Stake, 1995)(Saldana, 2009). Therefore, coding free nodes according to known coding types such as descriptive, invivo, simultaneous, process, values, affective and versus coding are used. The stance put forth by Saldana (2009) "pragmatic eclecticism" allows the researcher to explore many aspects without being too concerned about the types of coding available. Experiential coding, i.e., according to the background, knowledge and readings of the researcher, allows matching of what is already known in the literature and known theories to interpret out discussions in common research language.

Therefore to understand this phenomenon as other researchers had recommended the chronology of events were analysed. Hence, at which trajectory in the breast cancer journey, where delay took place was coded in relation to time at symptoms recognition, at diagnosis, at contemplating treatment choice. Processes were then dissected to reveal what happened to the patients (Charmaz, 2009). Whole transcripts were read and memos written to catch the essence and patterns of the data, a second round and more was done to code, the initial interview were at times coded in vivo. Coding were done by looking at the emotion/ affective coding (Saldana, 2009) , values coding where value (importance of something is to someone), attitudes (an evaluative or judgment and affective response on an idea, self, thing or someone else) and beliefs (part of a system that includes values and attitudes interpretation or perception of the social world)(Saldana, 2009). First cycle coding helped tremendously in guiding the coding. Simultaneous coding (Miles & Huberman, 1994) was used occasionally when there was an overlap on the chronology and the emotions of patients for example.

3.7.9.2 Identifying themes, constructs and taxonomies to theory development Concept development is derived from three steps:- Data reduction, selective sampling of the literature and selective sampling of the data (Streubert Speziale & Rinaldi Carpenter, 2007). The core variables or constructs for this study were identified from data reduction(Miles & Huberman, 1994). Matrices will evolve with information from other theories from literature review and finally allowed to evolve into an emergent theory (Streubert Speziale & Rinaldi Carpenter, 2007). Diagrams of the phenomena are sketched out to find relationships in the constructs. Besides coding, analytical memos (Clarke 2005, Corbin and Strauss 2008) which are essentially a reflection exercise by the researcher to understand the meaning of the data are also used extensively to gain insight and guide the emergent themes. Selective sampling of the literature and data was done to be able to make sense of the phenomenon and to build plausible models to explain the phenomenon. The researcher had to familiarize herself with new terms to build vocabulary to represent analysis and interpretation of the data.A lot of thinking was required and as described by Jan Hood the corkscrew or hermeneutics spiral to tighten up to have a theory that matches the data(Charmaz, 2009).

Initial models that were built to explain the phenomenon are shown here chronologically.



Figure 3.2 Model development circa January 2010.

Fig 3.2 shows the model development circaJanuary 2010. The model focused on the individual and was found to need an ecological context. Although the model had the chronological process, the model could not explain why women present with advanced disease.


Figure 3.3 Model in development circa May 2010

Fig 3.3 shows the model in development phase in May 2010. This model included the ecological context of individual, social environment and distal factors, pluralistic health systems, but was not clear enough to explain why women present late.



Figure 3.4 Model in development circa November 2010

Fig 3.4 shows the model in development in November 2010. Theoretical sensitivity with the Andersen total patient delay model (Andersen & Cacioppo, 1995) and the Crisis Decision Theory (Sweeney, 2008), brought about the early stages of delay model. This was also presented as an oral presentation at the Asian Regional Union of Psychological Societies meeting in Kuala Lumpur, Malaysia and as a presentation at the United Kingdom, Middle-east, Southeast Asia psychosocial cancer research network in the University of Leeds, United Kingdom.



Figure 3.5 Explanatory model in development circa December 2010

Fig 3.5 shows the Explanatory Model in development Dec 2010. The themes that effect decision making was grouped into an ecological model again. This was accepted and presented as a poster at the San Antonio Breast Cancer meeting in USA in 2010.

The model was further refined with other models, and finally a decision to separate the concepts into two models were made to gain clarity of the phenomenon ie a contextual in the chronology of events and another one was explanatory in nature. These models will be elaborated in section 4.4. and 4.5.

Further discussions on theoretical sensitivity will be done in Chapter 5, section 5.8. where discussion are made on the model and its relationship and comparison with existent theories and models.

## 3.7.10 Results Debriefing

The findings of this study have not been presented to the patients. The reason for this is that many of the participants had since passed away or were too ill to be interviewed again. This somewhat limited the validity of the study. But with evidence of the thick descriptions, this feature of validity can be compensated.

#### 3.7.11 Establishing rigour

The authenticity and trustworthiness of the data were ensured by maintaining an audit trail of all the audio taped interviews, transcripts and journaling (Streubert Speziale & Rinaldi Carpenter, 2007).

The in-depth interviews were audio taped with permission, and transcribed. Malay transcripts were analysed by the researcher and those in Mandarin and Tamil were transcribed in the original language and translated into English for the purpose of analyses. Corroboration of the English transcript was done with the respective Mandarin or Tamil research nurse to ensure accuracy of meaning.

All the data were transcribed into Nvivo 8. For each participant's transcript, a memo on the reasons why they present late was created. The patient's hospital notes were also traced to corroborate the interviews with events that occurred in the hospital. A flow chart of events for each patient was constructed. Memos on themes were constructed and reread to find more general themes. The memos were journaled in Word by date, thus, keeping an audit trail of the process of analysis.

Member checking (Burant 2007, Strauss 1987) or checking the content of the interviews with participants was done with 3 participants. Checking of codes was done with the researcher's supervisor (Low WY).

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3.8 Quantitative survey

3.8.1 Sample size calculation for the survey of breast cancer patients

To understand the characteristics of the breast cancer patients attending University Malaya Medical Centre, consecutive sampling of breast cancer patients attending the oncology outpatient services was done.

The quantitative survey is descriptive in nature. One of the main objectives was to determine the needs of breast cancer patients (Appendix C). The prevalence (P) of needs were estimated to be between 20-80%. At the beginning of this research there was a paucity of prevalence of unmet needs using the SCNS SF-34. Recently, prevalence of 30-50% in Korean cancer patients (Park & Hwang 2012) , about 70% in Japan (Uchida, et al. 2011) and about 40-50% in Australia (Boyes et al.,2012) have been reported. The precision was set at sampling error of 10% and the confidence interval was set as 95%. The sample size was ascertained using the formula below. This is to determine the most adequate and accurate sample size to estimate the prevalence of needs with good precision (Naing et al., 2006; Suresh, 2012)

 $N = (Z^{2} x (P (1-P)) / d^{2})$  Z = 1.96; d=0.05; \*P=0.20 N= sample size Z= 1.96 for 95% confidence level d= precision, expressed as decimal \*P= prevalence: 0.20 (estimated)  $N= (1.96^{2} x (0.20(1-0.20)) / 0.05^{2})$  N= 246

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The estimated sample size was 246 patients, an 8% attrition rate was included giving a sample size of 266. After exclusion of those with significant missing data, 261 women were included in the survey.

## 3.8.2 Research instruments

The instruments chosen for this study are detailed in Table 3.1. Four instruments were used, two of which were developed by the researcher. The breast cancer patient survey included the socio-demographics of the participants, their breast cancer journey, use of alternative treatment, social support and source of information (Appendix D). The background literature on Supportive Care Needs Survey (SCNS) and the Brief Cope, adaptation and validation procedures of the instruments are in (Appendix C).

# 3.8.3 Developing and conceptualising the questionnaire

The breast cancer patient survey was conceptualised using the researcher's background as a breast surgeon. An expert panel of another breast surgeon and clinical psychologist validated the content validity of the survey. Socio-demographic and pertinent information about treatment of patients were included, as well as, social support, source of information, needs and coping mechanisms of women with breast cancer which were deemed important from the literature review and reflection of the researcher.

Thus, Supportive Care Needs Survey (SCNS) and the Brief Cope were chosen to measure needs and coping styles of the participants. Further details on the origin of these intruments were detailed in Section 3.1. and Table 3.1.

# 3.9 Administration of survey

Due to the vast multicultural, linguistic and multi-educational level challenges of breast cancer participants, a face-to-face interview was done with all the questionnaire respondents by the researcher and trained research nurses (RN) to avoid inter-rater biases. Hence, in terms of accuracy, by RN led administration would have been more accurate compared to if it was self-administered. The RNs were trained to ensure meaning of the instruments was preserved. All the instruments except for the SCNS SF34 addressed questions that were specific to their period of diagnosis. It was important to understand the needs of women at the present moment in the oncology clinic, furthermore the instrument was designed to capture their needs in the last one month.

# 3.10 The scoring and analysis of the instruments3.10.1 Likert responses

The responses were in Likert scale of 5. The responses were continuous and ordinal in nature. The Sources of social support and Sources of information Likert scales were presented in 5 ordinal scales, and 1 category of not relevant was used to capture whether it was not just "not important" but it was "not relevant" to the participant.

#### 3.10.2 The SCNS SF-34

The SCNS SF-34 was used to measure needs in the women surveyed. There were 34 items in the survey which were factorised into 5 domains, namely physical and daily living (PDL), patient care and support (PCS), psychological (PSY), hospital systems

and information (HSI) and sexuality (SEX). However, 2 items from the SCNS LF-59, were also included as it was deemed useful by the researcher and content experts although it did not factor into the five domains by the original SCNS authors. These 2 items were on financial needs and transportation needs.

Responses were in Likert scale of 1 to 5 coded as: no needs: 1 for not relevant and 2 for satisfied. Some needs are categorised from 3 to 5, based on low, moderate and high needs.

SCNS SF-34 were scored by the 5 constructs that were confirmed to be valid in this population, the procedure and results of factor analyses and other tests were included in Appendix C.

3.10.3 The Brief Cope

There were 14 coping styles: active coping, denial, substance abuse, emotional support, instrumental support, positive reframing, behavioural disengagement, venting, acceptance, planning, religion, humour, self-blame and self-distraction. These items had 4 ordinal scores which had to be reversed. The responses were graded as follows: 4-I have been doing this a lot, 3-I have been doing this a medium amount; 2- I have been doing this a little bit; 1- I haven't been doing this at all. The maximum

summed score is 8 and minimum is 2. Each construct was formed by 2 items, the total score of the 2 items were used giving a score of 2 to 8.

The higher the score indicates the higher frequency of use of that particular coping mechanism.

The breast cancer patient survey depicting socio-demographic and medical data, sources of information and support were mainly descriptive in nature. The survey was developed by the researcher. Content validation was done with a panel of breast surgeons and psychologist. The face validity was conducted on breast cancer patients.

# 3.11 Analysis plan

The SCNS instrument- responses are ordinal hence, the use of a non-parametric test, Chi square test was used. As for the Brief Cope, the responses were aggregated to a score. Although the responses were originally ordinal in nature, but the research nurses were trained to explain it as an interval score to the respondents. Hence, these scales have been found to communicate interval properties to the respondent, and therefore produce data that can be assumed to be intervally scaled (Madsen 1989; Schertzer & Kernan 1985).

# 3.12 Converting to binary responses3.12.1 SCNS SF-34

The responses were then recategorised to "not having" and "having needs" and were analysed by Chi-square as well as logistic regression to obtain factors that predicted needs. Each item was recategorised by classifying the responses into <u>having needs</u> (responses of "some needs" (3)," moderate needs" (4) and "high needs" (5) were included in the "having needs" category. Those with no needs (1) of having but satisfied (2) were included as not having needs.

# 3.12.2 The Brief Cope

The total scores were re-categorised into binary outcomes- "frequently and moderately used" coping style was scored at 6 and above and "minimally or not used" was scored

at 5.9 and below. The reason 6 was chosen as a cut-off point, was because 3 was scored as "used it moderately", and with two items to each construct, a total score of 6 could be accepted as the least score for "moderately and frequently used" where at least both items were scored 3 each.

## 3.13 Statistical analyses

All categorical variables were described by proportions and compared using the chi square test. This was done for the SCNS SF-34 and the 2 items from SNCS LF-59. Parametric tests were performed on continuous variables that had a normal distribution and were expressed in means and compared using the t-test or the one way Anova test. For the brief cope, all except acceptance and substance abuse were found to have a normal distribution. Therefore, non-parametric tests were used to test for statistical significance between different groups. For those that did not have a normal distribution, Chi-square and Kruskall Wallis tests were performed.

For both SCNS SF-34 and Brief Cope, the responses were re-categorised into binary outcomes. The logistic regression was then used for multivariate analysis. Two-tailed p-values below 0.05 and hazard ratios with a 95% confidence interval which did not include 1.00 was considered statistically significant. Statistical analysis was performed using SPSS v. 16.0 (SPSSinc, Chicago, II, USA).

# 3.14 Chapter summary

This chapter outlines and details the study design with its underpinning philosophy. The study employs embedded mixed-method which weighs more towards qualitative constructivist grounded theory design. The methods for instrument development, measurement were detailed in this chapter and in Appendix B. Further elaborations on the the linguistic and cultural adaptation and test for reliability and validity were also described Appendix B. Mixing of data was used to inform the model that was built and to recommend recommendations for interventions. The systematic methodological approach elaborated in this chapter serves to ensure the rigour and validity of the data collected.

# **Chapter 4 Results**

### 4.1 Introduction

The results of this mixed-method study were based on an integrative logic using data from women with breast cancer and then specifically women with advanced breast cancer. Understanding the population of women attending our services in UMMC is important to inform this study as well as future studies on the population that interventions can be planned for.

To provide clarity and illuminate the reasons for delayed presentation, the study on women attending our breast cancer services looked into supportive care needs of women, coping styles, source of support and information experienced by the women. These are factors known to be important in affecting the timeliness of presentation to the hospital. With this background, it would inform the topic guide to specifically illuminate the reasons for delayed presentation in women with advanced breast cancer. The data was concurrently collected, in view of the limited time allowed for this research. Although the secondary objective of the study was on understanding women attending to breast cancer services in UMMC, this section will be displayed first to ease the qualitative results into the discussions. Hence, Section 4.2 describes women who attended breast cancer services in UMMC. The survey looked into the sociodemographics and duration of symptoms and their presenting complaints. Medical variables like treatment details were shown. Needs of the women, utilizing the supportive care needs survey SF-34 was employed and also the brief cope to measure the coping styles of the women. The social support and source of information at diagnosis was also

collated.

Section 4.3. describes the population of women with advanced breast cancer involved in the in-depth interviews, which was tabulated in Table. 4.19. The impact of cancer was

well described by these women; where the physical, emotional and social impact was seen in these women with advanced breast cancer. The power of hindsight allows a glimpse of women who inadvertently or consciously chose the paths that they did. Some were regretful, but some were satisfied with the choices that were made. Section 4.4 explores the help seeking behavior as well as the utilization of health care among the women with advanced breast cancer. Health pluralism was seen to exist with the use of alternative treatment and conventional medicine. The types and attitudes towards alternative treatment were delved into in Section 4.4.1. Barriers towards health seeking within the conventional health care will be displayed in Section 4.4.2 Section 4.5 develops the stages of delay, a contextual understanding of the delay problem. Grounded in the data, health seeking and utilisation behavior of women were examined through a chronological process. Section 4.6 offers a clarifying view of reasons for delayed presentation and attempts to explain this phenomenon. The breast cancer journey was examined to capture the biopsy experience, surgical, chemotherapy, radiation and hormonal treatment were described by the rich experiences of these women, and to extricate the meanings of these experience to understanding why they present with advanced cancer. The breast cancer diagnosis and factors affecting decision making were explored. Expectant outcomes of the disease and treatment were seen as important factors affecting treatment decision making. Their source of information and resources which included psychological, social and physical support were also found to be important factors. The roles played by the participants were key in understanding why they presented with advanced disease.

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4.2 Results from a survey of breast cancer patients attending outpatient oncology services

# 4.2.1 Survey response

This survey was done on breast cancer patients attending outpatient oncology services to ascertain basic information on: (i) socio-demographics; household income, education level, marital status, occupational history; (ii) current status of patients; cancer status, duration from diagnosis, current use of treatment; (iii) co-morbidities and previous experience with people with cancer and past preventive health behaviours; (iv) the breast cancer journey; first symptoms, duration of symptoms; treatment details and costs; (v) support; current living arrangements, main care giver, disclosure of symptoms, disclosure of diagnosis, main support after diagnosis; (vi) source of information; (vii) use of alternative treatment; (viii) needs of breast cancer patients; and finally (ix) types of coping.

The response rate was 73 % (266 out of 363 women attending oncology services between 1<sup>st</sup>April 2009 to 30<sup>th</sup>November 2009 participated in the survey). A total of 261 participants with complete data was included in the study.

## 4.2.1.1Socio-demographic characteristics of participants

Table 4.1 shows that the median age of the women was 51 years old, the age ranged from 25 to 72 years of age. Majority were Chinese followed by Malays and Indians. Majority were Buddhists, followed by Muslims, Christians, Hindus and Taoists. Most women were married, but about 16% were single women. Majority had upper secondary education; more than 20% had tertiary education. A small proportion (12.6%) of the patient's households did not have income. Some (28.7%) had a household income less than RM

1500. Thirty-six percent of the participants had a monthly household income within the RM1500- 3500 bracket. Some 11.1 % had a household income of beyond RM 5000.00.

As for occupation history, most of the women (87.8%) had worked before, more than a third were currently working (refer to table 4.1). Of those who used to work, slightly under 50% left their jobs due to breast cancer. As per occupation wise, most of the women were blue collar workers: technicians, clerical, and service workers, factory workers and hold elementary occupations. Only those who are currently working (about 11%) hold managerial and professional occupations. Those who worked in the past, tend to continue working. Among the 63 patients who left their jobs due to the cancer, majority were also blue collar workers, technicians and service workers followed by clerical workers and factory workers.

#### 4.2.1.2 Cancer status and medical information

Majority of the women attending out-patient follow-up were women on adjuvant chemotherapy (44.1%), 27.6% (n=72) were in remission and 28.4% (n=74) were in relapsed or metastatic state.

## 4.2.1.3 Co-morbidities and previous experiences and preventive medical care

Very few had previous psychiatric disorders; 4 with anxiety disorder and another 4 with major depression. A significant number 24.1%(n=63) had hypertension and 14.5% (n=38) had hypercholesterolemia and 7.3% (n=19) were diabetics. A large number of women had pap smear (72%, n=188), mean duration to last pap smear was in the past 4 years (mean 52.5 months (ranged 0.4 to 361 months). Quite a high proportion of respondents had experienced cancer in family members (43.3%,n=133) and non-family members (20.8%,n=54).

Characteristics		Ν	%
Age(years)			
(n=261)			
	Mean(SD)	51(9.7)	
	Median(range)	51(25-72)	
Ethnicity			
(n=261)			
_	Malay	66	25.7
	Chinese	155	59.0
_	Indian	35	13.4
	Others	5	1.9
Religion			
(n=261)			
	Islam	67	25.7
	Buddhism	92	35.2
	Taoist/confucianism	22	8.4
	Hinduism	31	11.9
	Christianity	43	16.5
	Others	6	2.3
Marital status			
(n=261)			
	Single	41	15.7
	Married	194	74.3
	Separated/divorced/widowed	20	9.9
Highest educati	ion level		
(n=259)			
	No formal education	3	1.2
	Primary education	45	17.4
	Lower secondary education	39	15.1
	Upper secondary education	107	41.3
	Vocational education	5	1.9
	University/college	60	23.2
Monthly house	hold income (RM)		
(n=261) (usd1=	RM3.10)		
	No income	33	12.6
	< 1500	75	28.7
	1500-3500	95	36.4
	3500-5000	29	11.1
	>5000	29	11.1
Current occupa	tion		
(n=261)			
	Currently working	91	34.9
-	Never worked	32	12.3
	Used to work	138	52.9
	Total	261	100.0
Left job due to	breast cancer		
(n=138)			
(	Ves	63	45 7

Table 4.1 Distribution of participants by socio-demographic data

# 4.2.2Period of diagnosis

# 4.2.2.1 Duration from diagnosis

Table 4.2. shows the most respondents were in the first year after diagnosis, where majority was undergoing adjuvant treatment, it was interesting that few women (4) were still undergoing adjuvant treatment between 1 to 2 years after diagnosis, ie. With the use of adjuvant targeted Trastuzumab. 12% of the respondents were diagnosed with cancer more than 5 years ago. Many women (21.5%) had relapsed or metastatic disease even after 5 years. Some 52.9% (n=138) were currently undergoing chemotherapy.

		Patient status				
		In remission	Adjuvant treatment	Relapsed/ metastatic	Total	
Duration from	0-12 months	15	108	27	150	
diagnosis		20.8%	96.4%	36.5%	58.1%	
	12-24 months	21	4	13	38	
		29.2%	3.6%	17.6%	14.7%	
	24-36 months	10	0	4	14	
		13.9%	.0%	5.4%	5.4%	
	36-48 months	7	0	7	14	
		9.7%	.0%	9.5%	5.4%	
	48-60 months	5	0	7	12	
		6.9%	.0%	9.5%	4.7%	
	> 60 months	14	0	16	30	
		19.4%	.0%	21.6%	11.6%	
	Total	72	112	74	258	

Table 4.2 Duration from diagnosis and cancer status

# 4.2.2.2First symptom of cancer

Table 4.3 shows that majority (59%) presented with a painless breast lump, about 11%

did have painful breast lump. Less than 5% were asymptomatic.

Table 4	.3 Percen	t distribution	of	first	symptoms	of	cancer	experienced	by	the
participa	nts.									

First symptom of cancer	Ν	%
Painless breast lump	153	58.6
Compound		
breast/axilla/nipple	45	17.2
symptoms		
Painful breast lump	29	11.1
Asymptomatic	12	4.6
Nipple complaints	7	2.7
Axillary lump	4	1.5
Other symptom	4	1.5
Mastalgia	3	1.1
Axillary pain	1	0.4
Enlarging breast	1	0.4
Ulcer	1	0.4
Breast dimpling	1	0.4

The median duration of symptoms was 21 days, range (0-9125 days). Comparison made between symptom duration and other socio-demographic characteristic showed that the only factor that was significant was the monthly household income. The Levene's test for homogeneity was significant, thus the Welch test was used, and it showed a significant association F (4,100)= 2.6, p=0.04. Those who had a household income of less than RM 1500 and those with no income had higher duration of symptoms compared to those who earned RM 1500 and above. The mean duration of single women (206 days) was higher than these married (141 days) and separated/divorced (77 days) or widowed (14 days). Although there is a trend this was not significant F(3, 50) = 2.2, p=0.10. 4.2.2.3 Support during the period of diagnosis

Majority of women lived with their family members (92%, n=240). Sixteen of the women (6.1%) were living alone. One was living in a shelter home (0.4%). Eleven (26.8%) of single women, 2(1.0%) of married women, 1(10%) of separated/divorced women and 2(14.3%) of widowed women lived alone. Of those who lived alone, 7(43.8%) had relapsed or metastatic disease.

Table 4.4 showed that the spouses are the main care givers (59.4%), followed by children (12.3%) and self (11.1%). Rarely the main carer was not a relative. Of those who were married (n=194), 79% were cared for primarily by their spouses, 9.8% by their children, 5.7% self-cared and 3.9% by their parents. Single women, were mainly cared for by their parents, self, siblings, relatives and rarely others. Some 82% (n=191) of the women had children. Among these, 43.3% (n=74) still had dependent children (less than 18 years old).

			Main ca	re giver							
		Self	Spouse	Parent	Child	Rel*	Friend	Sibs	Maid	NA#	Total
Marital	Single	11	0	16	0	4	2	6	1	1	41
status		(26.8)	-	(39.0)	-	(9.8)	(4.9)	(14.6)	(2.4)	(2.4)	(100.0)
	Married	11	155	6	19	1	0	3	1	0	196
		(5.6)	(79.1)	(3.1)	(9.7)	(0.5)	-	(1.5)	(0.5)	-	(100.0)
	Separated/	7	0	2	13	0	0	1	0	1	24
	Divorced/ Widowed	(29.2)	-	(8.3)	(54.1)	-	-	(4.2)	-	(4.2)	(100.0)
Total		29	155	24	32	5	2	10	2	2	261
		(11.1)	(59.4)	(9.2)	(12.3)	(1.9)	(0.8)	(3.8)	(0.8)	(0.8)	(100.0)
#not stated											

Table 4.4 Percent distribution of main care giver by participant marital status

\*relative

### 4.2.2.4 Disclosure of symptoms

Majority of participants disclosed symptoms to their husbands (54%, n=141). Next, the respondents confided in female family members, like sisters (12.6%, n=33), daughters (7.3%, n=19) and mothers (4.2%, n=11). Best friends were confided with their symptoms (5 %, n=13). Some women chose to go to their doctors; general practitioners (4.2%, n=11), cancer specialist (1.5%, n= 4). Very rarely symptoms were disclosed to male family members (Fig. 4.1). Few women did not disclose to anyone (2.7%, n=7) and one lady confided in her church pastor.



Figure 4.1 Percent distribution of first person informed of breast cancer diagnosis

# 4.2.2.5 Disclosure of diagnosis

The same people that symptoms were disclosed to were also informed of the diagnosis. Majority of respondents confided in their husbands (59.4%, n=155), female family members; sisters (13.4%, n= 35), daughters (6.9%, n=18), mothers (5.7%, n=15). Best friends (4.2%, n=11), sons (2.3%, n= 6), general practitioners (1.1%, n=3), and one woman, each confided in her cancer specialist and her family friend. (refer fig x) Of the 41 single women, the first person they told of their diagnosis was female family members like sisters (48.8%, n=20), mothers (22%, n=9) and female relatives (4.9%, n=2). Best friends (9.8%, n=4), brothers (4.9%, n=2), boyfriend (2.4%, n= 1), church pastor (4.9%, n=2) and neighbor (2.4%, n=1).

# 4.2.2.6 Main support after diagnosis

Again, spousal support was the commonest main support person (41.9%, n=109), followed by close female family members; sisters (11.5%, n=30), mothers (7.3%, n=19), daughters (6.9%,n=18) and female relatives (3.1%, n=8). Best friends although made up only 4.6% (n=12), were important support of the participants (Fig. 4.2). For single women, the commonest main support was provided by female family members such as mothers and sister, each (26.8%, n=11). One single woman stated that no one provided any support.



Figure 4.2 Percent distribution of main support after breast cancer diagnosis

# 4.2.2.7 Quantifying support

Responses from the Likert scale were analysed and categorised according to very supportive, supportive, neither supportive or not, not supportive and very not supportive. The study found that women received very supportive support from spouse (59.8%, n=156), followed by sisters (58.6%, n=145), surgeons (56%,n=145), and best friends (53.8%,n=140). Some 70.9% (n=185) reported family doctors were not relevant to them.

When the score was re-categorized into 3 categories, very supportive and supportive into supportive, not relevant to the same category and the rest into not supportive, it was found that amongst married women (fig 4.3), spouse (87.6%, n=170) and female family members played a major role in supporting these women.



Figure 4.3 Perceived support amongst family and friends amongst married women Amongst single women, sisters (70.7%, n=29), best friends (75.6%, n=31), brothers 63.4%, (n=25), friends (65.9%, n=27) and other female (58.5%, n=24) and mothers 48.8%, (n=20) were their main support (Fig 4.4). To a lesser extent, male relatives 36.6%, (n=15) and fathers 24.4%, (n=10) also provided support.



Figure 4.4 Perceived support from family and friends amongst single women Single women like their married counterparts, also had support from their health care providers, namely surgeons, oncologists, nurses and to a lesser extent hospital staff (Fig. 4.5).

A sizable number of women did get support from food supplement salespersons (married: 13%, (n=25) and single women: 9.8%, (n=4)) and alternative healers (married: 76.4%, (n=42) and single: 19.5%, (n=8)) (Fig. 4.5). However, alternative healer support was found to be irrelevant in 68.3%, (n=132) in married women, 63.4%, (n=26) in single women and food supplement salesperson in 60.0%, (n =116) in married women and 65.9%, (n= 27) in single women.

The supportive role of the family doctor was also found to be low at 24.7%, (n=48) in married women and only 17.1%, (n=7) in single women.



Figure 4.5 Perceived support from health care providers amongst married women



Figure 4.6Perceived support from health care providers amongst single women

Table 4.5 shows that the most important source of information was from doctors (71.4%), books on breast cancer (56.9%), women with breast cancer (56.2%), family members (50.0%) and nurses (48.3%) and newspapers (46.9%).

More than half the women found sources of information from VCD or DVDs (69%), movies (65.9%), alternative complementary therapists (59.4%), internet (53.2%) and survivor support group (35.2%) was not relevant to them as source of information.

	Very important	Important	Neither/nor important	Not important	Least important	Not relevant
Doctor	185	45	12	8	3	6
N=259 (%)	(71.4)	(17.4)	(4.6)	(3.1)	(1.2)	(2.3)
Books on	148	40	18	7	5	42
breast cancer N=260 (%)	(56.9)	(15.4)	(6.9)	(2.7)	(1.9)	(16.2)
Women with	146	58	24	11	6	15
breast cancer N=260 (%)	(56.2)	(22.3)	(9.2)	(4.2)	(2.3)	(5.7)
Family	130	61	37	8	9	15
members N=260 (%)	(50.0)	(23.4)	(14.2)	(3.1)	(3.5)	(5.7)
Nurse	125	63	34	15	9	13
N=259 (%)	(48.3)	(24.3)	(13.1)	(5.8)	(3.5)	(5.0)
Newspaper	122	56	40	8	9	25
N=261 (%)	(46.9)	(21.5)	(15.4)	(3.1)	(3.5)	(9.6)
Survivor	87	40	26	9	5	92
support group N=259 (%)	(33.6)	(15.4)	(10.0)	3.5)	(1.9)	(35.2)
Friends	74	68	62	21	12	22
N=259(%)	(28.6)	(26.3)	(23.8)	(8.1)	(4.6)	(8.5)
Internet	69	31	13	6	2	139
N=260 (%)	(26.5)	(11.9)	(5.0)	(2.3)	(0.8)	(53.5)
Women	60	52	35	16	12	84
magazines N=259 (%)	(23.2)	(20.1)	(13.4)	(6.2)	(4.6)	(32.2)
Television	46	55	44	20	11	85
N=261 (%)	(17.6)	(21.1)	(16.9)	(7.7)	(4.2)	(32.6)
Alternative/co	27	26	22	12	19	155
mplementary therapist $N = 2(1, 0)$	(10.3)	(10.0)	(8.4)	(4.6)	(7.3)	(59.4)
$\frac{N=201(\%)}{Vcd/dvd on}$	21	21	13	8	17	180
breast cancer $N=260$ (%)	(8.0)	(8.0)	(5.0)	(3.1)	(6.5)	(69.0)
Food	12	20	30	22	40	135
supplement salesperson N=259 (%)	(4.6)	(7.7)	(11.6)	(8.5)	(15.4)	(52.1)
Movies	8	14	28	22	17	172
N=261 (%)	(3.1)	(5.4)	(10.7)	(8.4)	(6.5)	(65.9)
	(2.1)	(2.1)	(10.7)	(0.1)	(0.0)	(00.7)

Table 4.5 Percent distribution on the level of importance of varied sources of information after diagnosis

Demographics and medical factors		Internet as source of information		$\chi^2$ value	P-value
		Important	Important Not		
	<u>) ( 1</u>	- 22	Important	4.07	0.12
Ethnicity	Malay	32	34	4.27	0.12
	N=66	48.5%	51.5%		
	Chinese	52	102		
	N=154	33.8%	66.2%		
	Indian	14	21		
	N=35	40.0%	60.0%		
Age	Less than 50	49	58	4.13	0.04
-	N=107	45.8%	54.2%		
	50 years and more	51	102		
	N=153	33.3%	66.7%		
Monthly	No income	6	26	60.17	< 0.001
household		18.8%	81.3%		
income	<rm 1500<="" td=""><td>9</td><td>66</td><td></td><td></td></rm>	9	66		
		12.0%	88.0%		
	RM1500-3500	43	52		
		45.3%	54.7%		
	RM3500-5000	18	11		
		62.1%	37.9%		
	>RM5000	24	5		
		82.8%	17.2%		
Cancer	In remission	30	42	0.56	0.75
status		41.7%	58.3%		
	Adjuvant treatment	44	71		
	5	38.3%	61.7%		
	Relapsed/metastatic	26	47		
	1	35.6%	64.4%		

Table 4.6 Internet as an important source of information by various sociodemographic andmedical factors

\*(very important and important responses were re-categorised to <u>important</u>; and neither important nor not important, not important and least important and not relevant was recategorised to <u>not important</u>).

Table 4.6 shows that women who used internet were significantly younger and have higher monthly household income. There was no significant association between the various cancer status of the patients and the use of internet ( $\chi^2=0.56$ ,df = 2, ns).

Some 52.9% (n=138) were currently having chemotherapy. Majority of women had surgical treatment, more women had mastectomy (64%,n=168), only (18.4%n=48) had breast conserving surgery, lumpectomy (1.9%, n=5) and 8% (n=21) did not have any surgery. Some 6.9% (n=18) were planning for surgery. Very rarely immediate reconstruction was seen in this sample of women (n=1). Some 86% (n=225) of the women had received chemotherapy and 42.5% (n=111) had received radiotherapy.

# 4.2.3.1 Cost of treatment

More than a quarter of the participants had financial support from their employer. Some 11.5% of the participants did not know the cost or that surgery was not recommended. About 10% spent more than RM 10 000 on surgery. About 20% spent between RM 1000 to 2000. The fees varied, indicating the variable fees of surgery for breast cancer due to the different types of surgery, and where the operation was performed (public or private hospitals). Table 4.7 shows that, for chemotherapy slightly more than a quarter have employers that financially supported them. About 12% spent beyond RM 10 000.00.

Cost of surgery	Ν	%
RM1000-2000	52	19.9
RM2001-4000	20	7.7
RM4001-6000	24	9.2
RM6001-8000	14	5.4
RM8001-10000	16	6.1
>RM10000	25	9.6
Payment made by employer	70	26.8
Not known	30	11.5

Table 4.7 Percent distribution of the cost of surgery and chemotherapy to the respondents

#### Table 4.7, continued

Cost of chemotherapy

<rm2000< td=""><td>74</td><td>28.4</td><td></td></rm2000<>	74	28.4	
RM2001-5000	15	5.7	
RM5001-10000	20	7.7	
RM10001-20000	14	5.4	
RM20001-50000	11	4.2	
>RM50000	6	2.3	
Payment made by employer	72	27.6	
Not known	25	9.6	
Not stated	24	9.2	
			-

(USD 1=RM3.10)

# 4.2.3.2 Use of alternative therapy

Some 123 (47.1%) patients used alternative therapies, and among these, 78 (63.4%) paid for the therapies. The median cost was RM 1 200 (range from free to RM 50 000.00). Out of the 108 who used alternative treatment, 63 (58.3%) used only one type of alternative treatment, some 45 respondents used more than one type. One (0.9%) patient used 6 types of alternative medicine, three (2.8%) participants used four types of alternative therapies, eleven (4.2%) used 3 types, 29 (26.9%) used 2 types, one patient did not state what she used. There was a significant difference in the use of alternative treatment amongst the ethnic groups, it was mostly used by the Malays (50%), Chinese (46.5%) and the least in Indians (8.6%) ( $\chi^2$ = 19.02, df=2, p<0.001). There was no significant difference in usage by age ( $\chi^2$ = 2.95, df=1 ,ns), income( $\chi^2$ =0.67, df=4,ns), marital ( $\chi^2$ = 3.15,df=3 ,ns), and cancer status ( $\chi^2$ =2.18, df=2 ,ns).

Usage of Chinese herbs was significantly different between the ethnic groups ( $\chi^2=24.57$ , df=2 ,p<0.001), where the majority of the Chinese patients used it. Qigong was mainly used by the Chinese, blessed water and herbal paste by the Malays. The rest of the alternative therapies were not significantly associated with ethnicity (Table 4.8).

		Alternativ	e therapy use		
		Yes	No	$\chi^2$ values	P-value
Ethnicit	Malay	33	33		< 0.001
у	N=66	50.0%	50.0%	19.02	
	Chinese	72	83	-	
	N=154	46.5%	53.5%		
	Indian	3	32	_	
	N=35	8.6%	91.4%		
Age	Less than 50	51	56	2.95	0.09
	N=107	47.7%	52.3%		
	50 years and more	57	97	-	
	N=153	37.0%	63.0%		
Monthly	No income	12	21	0.67	0.96
household	N=33	36.4%	63.6%		
income	<rm 1500<="" td=""><td>30</td><td>45</td><td>_</td><td></td></rm>	30	45	_	
	N=75	40.0%	60.0%		
	RM1500-3500	41	54	_	
	N=95	43.2%	56.8%		
	RM3500-5000	12	17	_	
	N=29	41.4%	58.6%		
	>RM5000	13	16	_	
	N=29	44.8%	55.2%		
Marital status	Single	17	24	3.15	0.37
	N=41	41.5%	58.5%		
	Married	85	111	_	
	N=196	43.4%	56.6%		
	Separated/divorced	3	7	-	
	N=10	30.0%	70.0%		
	Widowed	3	11	_	
	N=14	21.4%	78.6%		
Cancer	In remission	35	37	2.18	0.34
status	1N-/2	48.6%	51.4%	_	
	Adjuvant treatment	45	70		
	N=115	39.1%	60.9%	_	
	Relapsed/metastatic	28	46		
	N=74	37.8%	62.2%		

Table 4.8 The use of alternative therapy by various socio-demographic factors

	Ν	Chinese	Malay	Indian	$\chi^2$	p-value
Chinese herbs	45	42(93.3%)	2(4.2%)	1(2.1%)	24.57	<0.001
Qigong	46	40(93.0%)	3(6.5%)	0	23.16	< 0.001
Direct selling products*	31	14(45.2%)	17(54.8%)	0	4.48	0.11
Blessed water	25	1(4.0%)	24(96.0%)	0	71.05	<0.001
Traditiona l massage	17	7(41.2%)	9(52.9%)	1(5.9%)	2.63	0.27
Acupunct ure	10	8(80.0%)	2(20.0%)	0	2.21	0.33
Herbal paste	7	1(16.7%)	5(83.3%)	0	10.69	0.01
Spiritual surgery	3	1(33.3%)	2(66.7%)	0	2.76	0.25
Homeopat hy	1	0	1	0	-	-

Table 4.9 The types of alternative therapy used by the various ethnic groups

\*brands recorded by participants: Transfer Factor, EExel, Elken Spirulina, Usana 4 Life, Alfa Lipid, Mangosteen Juice, Jelly Gamat, Wheat Grass, Herbal Life, Melilea Chlorella, Keladi Tikus, Noni Juice, Omx, Angeless, Bioresonanz, health foods.

# 4.2.4 Needs of breast cancer patients

# 4.2.4.1. Items having some needs

Chapter 2 had described the scoring and analysis of the instrument. The first analysis, was done by grouping those categorised from 3 to 5 into one category or having 'some needs'. A description of the percent distribution of the top 10 items of having some needs was tabulated in Table 4.10.

	Having so	ome needs
	Ν	%
Addressing fears about the cancer spreading	205	78.5
Addressing fears about the cancer returning	207	79.3
Being informed about things you can do to help	177	67.8
yourself to get well		
Addressing fears about pain	172	65.9
Having one member of hospital staff with	169	64.8
whom you can talk to about all aspects of your		
condition, treatment and follow-up		
Anxiety about having any treatment	165	63.2
Talking to other people about the cancer	160	61.3
Worry that the results of treatment are	159	60.9
beyond your control		
The opportunity to talk to someone who	159	60.9
understands and has been through a similar		
experience		
Being given written information about the	158	60.5
important aspects of your care		

Table 4.10 Top ten items, expressing some need of breast cancer patients (n=261)

Almost 80% of the participants had 'some needs' in addressing their fears about cancer spreading and returning. Some 65.9% had needs to address their fears about pain. Some 63.2% of the participants had needs to address their anxieties of having treatment. Some 60.9% had needs to address their worry that results of treatment were beyond their control.

Majority had 'some needs' in addressing information needs like being informed about things they can do for themselves. They had 'some needs' in having someone to talk to to, be it a hospital; staff or someone who had been through similar experiences as well as needing written information about their care. Most of these needs fall under the psychological domain, where fears related to cancer and treatment outcomes were expressed. Needs in health systems and information provision were also expressed by majority of women.

# 4.2.4.2. Items having high needs

The Likert response of category '5' (those expressing 'high needs')was taken into account and displayed in Table 4.11. Again, information needs and psychological needs feature prominently. Quite a high proportion (18.4%) had high needs in financial concerns, and more than half had some needs in this area.

	High needs		Some needs	
	Ν	%	Ν	%
Being informed about	61	23.4	177	67.8
things you can do to help				
yourself to get well				
Fears about the cancer	60	23.0	207	79.3
returning				
Fears about the cancer	59	22.6	205	78.5
spreading				
Being informed about	54	20.7	156	60.0
cancer which is under				
control or diminishing				
(that is, remission)				
Having one member of	52	19.9	169	64.8
hospital staff with whom				
you can talk to about all				
aspects of your				
condition, treatment and				
follow-up				
Concerns about your	48	18.4	148	56.7
financial situation				
Being informed about	41	15.7	145	55.6
your test results as soon				
as feasible				
Paing adaguately	12	165	124	51.2
informed about the	43	10.5	134	31.3
honofits and side offects				
benefits and side-effects				

Table 4.11 The 10 commonest items that patients expressed high needs (n=261)

of treatments before you				
choose to have them				
Being given written	39	14.9	158	60.5
information about the				
important aspects of your				
care				
Being given explanations	39	14.9	150	57.5
of those tests for which				
you would like				
explanations				

# 4.2.4.3. The needs by domains

In the previous section, each item in the instrument were analysed, in this section the items were grouped according to the domains. Appendix B details the validity of the 5 domains of the instrument in this study population.

The responses were re-categorised according to 'no needs' and 'having needs'. Where 1 = 'no need', not relevant and 2 = 'no need, satisfied' were categorised to 'no need'; and 3 = 'low', 4 = 'moderate' and 5 = 'high need' categorised to 'having needs'.



Figure 4.7 Percentage distribution of 'having needs' by domain (n= 253) \*SEX= sexuality, PCS=patient care and support, PSY=psychological, TRANS=transport, PDL= physical and daily living, HSI= hospital systems and information, FIN=financial

Figure 4.7 shows the proportion in descending order of 'having needs' by domain. The most common was financial needs, followed by hospital systems and information, physical and daily living, transport, psychological, patient care and support and lastly sexuality needs. The results show that slightly over half the participants had financial issues. A large proportion (>40%) had physical and daily activity (PDL) needs and transport needs. About a third needed psychological (PSY) help. In contrast, only a fifth reported having sexuality needs.

4.2.4.4 Factors predictive of needs by domain

The associations between the various socio-economic and medical variables were shown in Tables 4.12, 4.13, 4.14 and 4.15. Co-variates analysed in this section include sociodemographic factors like age, ethnicity, marital status, religion, income, family history of cancer, non-family (friends or acquaintance) history of cancer, ever-worked and medical factors like cancer status, type of surgery, had chemotherapy, currently on chemotherapy, had radiotherapy and had alternative treatment. Factors predictive of the each domain of need will be shown below.

4.2.4.1 Physical daily living needs

Physical and daily living needs were significantly seen in those currently having chemotherapy and those who use alternative medicine (Table 4.12). Multivariate analysis, confirms this, where those currently on chemotherapy had 3 times more PDL needs than those not on chemotherapy (Table 4.16). Those who used alternative therapy also had 2 times more PDL needs as compared to those not on alternative treatments.

4.2.4.4.2. Psychological needs.

The presence of family history had 2.2 times more psychological needs than those without family history of cancer (Table 4.16).

# 4.2.4.4.3 Patient care and support needs

It was found that there were no independent predictive factor for patient care and support (Table 4.12).
## 4.2.4.4 Hospital systems and information needs

HSI needs were significantly associated with having family history of cancer by univariate analysis and after adjustment for other variables was still significant on multivariate analysis. Those with family history had a 1.7 times more needs than those without family history (Table 4.16).

## 4.2.4.4.5 Sexuality needs

Sexual needs were significantly more seen in women who were married compared to single, widowed and divorced women. However, only 25% of married women reported sexuality needs (Table 4.12). The multivariate analysis showed that marital status, religion of patients and use of alternative treatment to be independent predictive factors to sexuality needs. Married women had 17.5 times more sexuality needs than single women (Table 4.16).