

**DELAY IN SEEKING CARE FOR BREAST
SYMPTOMS AND ITS ASSOCIATED FACTORS**

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**DISSERTATION SUBMITTED IN PARTIAL
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ABSTRAK

Latar Belakang: Kanser payudara adalah kanser yang tertinggi di Malaysia dan di kalangan wanita di seluruh dunia. Insiden kanser payudara ini semakin meningkat setiap tahun. Kehadiran awal ke klinik dapat membantu dalam pengesanan awal kanser payudara, justeru menjadikan prognosis dan kelangsungan hidup yang lebih baik.

Objektif: Tujuan kajian ini adalah untuk menyiasat tahap kelewatan mendapatkan penjagaan untuk gejala payudara dan faktor-faktor yang berkaitannya.

Kaedah: Kajian ini telah dijalankan pada Januari hingga Oktober 2020, melibatkan wanita yang mempunyai gejala payudara baharu telah datang ke klinik buat kali pertama. Temubual dijalankan dengan berdasarkan borang soal selidik piawai bahasa Malaysia. Tarikh bermulanya gejala payudara dan tarikh hari lawatan pertama ke klinik dicatatkan. Bilangan hari untuk hadir ke klinik melebihi 90 hari dianggap sebagai lewat. Faktor-faktor yang mungkin menyumbang kepada kelewatan tersebut dianalisa dengan analisis Logistik Regresi Berganda.

Keputusan: Sejumlah 106 peserta telah terlibat dalam kajian ini. Purata umur peserta kajian adalah 33.99 tahun (Sisihan piawai (SP) 11.21), berumur 39 dan kebawah (73.6%), berbangsa Melayu (98.1%) dan Cina hanya (1.9%). Kebanyakan peserta ini telah mendapatkan rawatan di klinik kesihatan kerajaan (35.8%) untuk gejala payudara. Antara gejala yang dialami adalah benjolan (75.5%), sakit (15.1%), lelehan dari puting (5.7%), perubahan kulit pada payudara (0.9%) dan lain-lain (2.8%). Hanya seramai 10.4% peserta telah mendapatkan perubatan alternatif. Purata bilangan hari yang diambil untuk hadir ke klinik adalah 98.91 hari (SP 323.71) dengan median 14.5 hari. Seramai 61.3% peserta telah datang ke klinik dalam masa kurang dari 1 bulan. Hanya 19.8% peserta yang telah lewat melebihi 3 bulan. Faktor yang bererti dengan kelewatan mendapatkan konsultasi adalah interpretasi gejala sebagai tidak bahaya, nisbah odds diselaraskan OR 3.05 (95% selang keyakinan 1.11, 8.38) dengan gejala benjolan.

Konklusi: Tahap kelewatan mendapatkan penjagaan untuk gejala payudara didapati lebih rendah berbanding dengan kajian yang telah dijalankan sebelum ini di Malaysia. Faktor yang menyumbang kepada kelewatan penjagaan gejala payudara yang bererti adalah interpretasi gejala sebagai tidak bahaya. Program pendidikan bersasaran dan bersesuaian dengan komuniti setempat perlu diadakan pada masa akan datang.

ABSTRACT

Background: Breast cancer is the most common cancer among Malaysian and in women worldwide. The incidence of breast cancer is increasing yearly. Early presentation and thus, early detection of breast cancer will lead to better prognosis and survival.

Objective: This study aimed to investigate the delay of presentation time in women with breast symptom and its associated factors.

Methods: The study was conducted between January to October 2020, recruiting women with new breast symptoms at their first visit to the clinic. Face-to-face interviews using the standardised Malay language questionnaires, and the date of symptom first develop and first visit the clinic was recorded. Presentation time was calculated based on the number of days between the two date. Those with presentation time more than 90 days was considered as a delayed group. Associated factors were recorded, cross-tabulation and multiple logistic regression with the delay presentation for were used for analysis.

Result: In total, 106 respondents were included. The mean age of the respondents was 33.99 (SD 11.207), and most of them (73.6%), were age 39 and younger. The respondents mainly were Malay ethnicity (98.1%) and Chinese (1.9%). Most of the respondents first visited the local government health clinic (35.8%) for breast symptoms. They presented symptoms were breast lump (75.5%), followed by pain (15.1%), nipple discharge (5.7%), skin changes of breast (0.9%) and others (2.8%). Only 10.4% of the respondents went for alternative treatment before for the breast symptoms. The mean of presentation time was 98.91 days (SD 323.71) with median of 14.5 days. Approximately 61.3% of the respondents came within 1-month time. Only 19.8% of the respondents had delay presentation of more than 3 months. The factor that significantly associated with the delay in the presentation was the interpretation of the symptom as not dangerous with adjusted OR 3.05 (95% CI 1.11,8.38) with adjustment of the symptom of breast lump

Conclusion: The percentage of delay presentation was lower compared to the previous local study in Malaysia. The significant factor associated with the delay for breast care was the interpretation of the symptom as harmless. The future education program must be targeted and tailored to the local community.

1.0 INTRODUCTION

1.1 Introduction

Breast cancer is the most common cancer and causes the highest number of cancer death in women worldwide [1,2]. In high-resource countries, the incidence and mortality have been declining while in low-resource countries, the incidence and mortality have been increasing due to the differences in the access to breast cancer early detection [2].

In Malaysia, breast cancer is 19% of all cancer [3]. The incidence of female breast cancer registered in Malaysian National Cancer registry report was increasing, from 18,206 in 2007-2011 to 21,634 in 2012-2016, accounted for 34.1% of all cancer among the females [3]. It is expected that the incidence of breast cancer in Malaysia to increase because of improving life expectancy, better socioeconomic status and changes in lifestyles [4].

Delay in seeking care for breast symptoms is a significant problem[5] and associated with a lower rate of survival from breast cancer[6]. It is important to provide awareness to the community that any breast symptoms should prompt early medical attention as it could be the potential symptoms of breast cancer. There is a high percentage that the breast symptoms may turn out to be a malignancy. A study in London, of 692 women presented to Breast Clinic with breast symptoms found out that 87 (12.6%) of the women had the diagnosis of breast cancer [5].

In this study, the aim is to investigate the delay in seeking care for breast symptoms and the associated factors of our local community. The patients with breast symptoms who attended the Breast Cancer Awareness & Research Unit (BESTARI) clinic, regardless of the type of the symptoms, malignant or benign, were recruited in the study.

1.2 Literature review

Delay can be divided into five stages which is appraisal delay, illness delay, behavioural delay, scheduling delay and treatment delay[7]. The combination of these five stages are known as total patient delay, and the appraisal delay is the major stage, 60% of the total delay[7].

Appraisal delay is the patient's interpretation of her bodily symptoms as an illness or labelling it as serious symptoms [7,8]. Illness delay is the number of days elapsing from the time an individual interpreted that her symptoms are ill to the day she decided to seek medical attention and behavioural delay is the time from her decision and to the time she acts on the decision [7]. These stages of total patient delay are illustrated in Figure 1.

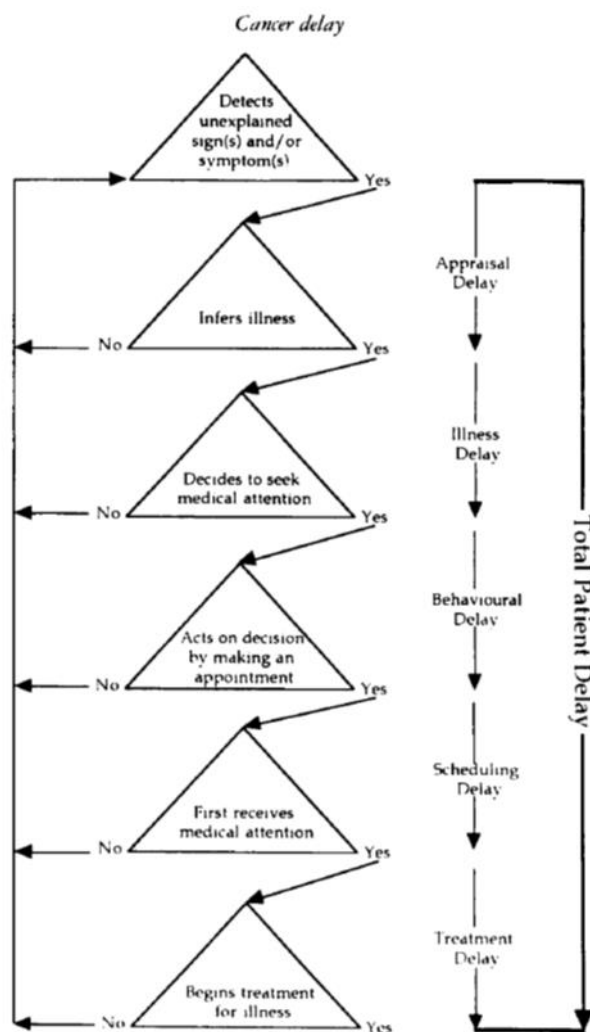


Figure 1 Total Patient Delay by Andersen and Cacioppo, 1995[7]

The first three stages, which are the appraisal, illness and behavioural delay are the patient's related delays. These stages consisted of factors such as patient's social demographics, previous history, interpretation of the breast symptoms, type of symptoms, knowledges, attitude and practices towards breast symptoms, which were analysed in most of the earlier studies [4,6,8–13].

The treatment delay is not of interest in the current study. There was one study which looks into general practitioners (GP) delay in referring the patient to the hospital, 17% of the patients were referred delay by the GP, and the delay was related to the patient's initial symptoms of presentation [14]. Another study found out that physician delay was not significant [15].

A local study published in 2011 by Norsa'adah at el, conducted in multiple centres in the year between 2005 to 2007, found out that there was a high percentage of the patient with delayed presentation time. The presentation time was delayed up to 11 years with a median of 2 months, and 43.4% had delayed by more than 3 months [4]. The study found out that the delay among breast cancer patients are very serious problems in Malaysia and the delay was higher than in other studies in developed and developing countries [4]. The factors that associated with the delay were clinical presentation, patients' interpretation, attitude and alternative treatments [4]. The delay was defined as sixth-months cut off point [4] while most of the other studies categorised delay of three-months cut off point [6,9,11,13,15,16].

Most of the studies were done on the patients that were diagnosed with breast cancer, and the timing of presentation was recalled retrospectively or via the record in medical notes [4,8,10,12,13,15,17], thus contained recall bias and not including the delay of presentation in the patient with benign diseases. A more comprehensive study comprising of patients with breast symptoms, regardless of whether it is benign or cancer with lesser recall bias is needed to properly evaluate and understand the factors leading to presentation delay.

There was a study conducted in New Zealand in 2003, a female patient who have self-discovered breast symptoms, on the first consultation to their breast clinic, was recruited for the study [6]. The breast symptoms experienced by the patients in the study were breast lump, breast infection, breast pain, nipple discharge, nipple indrawn or changes, breast abscess, change in shape or dimpling of the breast. In this study, the median presentation time was 14 days, and 14% of women had delay of more than 3 months. Women that delay more than 3 months were less likely to have a breast lump and had family member previously diagnosed with breast cancer [6].

Another study was conducted by Nosarti et al in London, United Kingdom, looking into the delay in presentation of women with breast symptoms who attended a London breast clinic and the associated factors were analysed. Presentation delay was operationally defined as the time elapsing between symptom self-discovery and the first presentation to a medical provider to seek evaluation. The median presentation time was 13 days and 17% of the women had delay over 3 months. 692 women with breast symptoms were interviewed, and 87 (12.6%) of the women had the diagnosis of breast cancer. Of those 87 women with cancer, 32 (36.8%) thought that they had a less serious condition. This misinterpretation causes a longer presentation time with median of 31 days [5].

1.3 Rationale for the study

It is vital for a woman to be aware that any breast symptoms are potentially the symptoms of breast cancer, thus need to be appropriately assessed at the health care center. It is recommended that patient with breast symptoms to undergo a proper triple assessment which consists of clinical examination, imaging, and tissue biopsy to rule out malignant lesion[18,19].

If the symptoms were to be of breast cancer, and there was delayed in the presentation of three months or more, it was associated with lower survival rates by 10% [8]. It was estimated that 20% to 30% of women wait at least three months before seeking medical help with breast symptoms [10].

Early detection of breast cancer is important because delay is preventable [4]. Earlier detection and hence earlier treatment can improve the survival [20,21]. Patient with late detection would be associated with larger tumour size [15], and will increase on the cost and limit the choice of treatment [4]. Earlier breast screening, diagnosis, and better treatment improved survival [14].

A population-based screening mammogram is not practised in Malaysia, thus getting an early detection of cancer depends on patients' awareness to seek treatment early and health providers that practice opportunistic screening [8]. The mammogram itself does carry benefits of reducing breast cancer death but also harms such as false-positive and overdiagnosis [20]. False-positive may cause anxiety, unnecessary biopsies, and scar [22].

The early access to health care for breast cancer early detection should be highlighted, and any factors leading to the delay need to be studied. The health care service should be easily accessible by the community. Taking an example of our center BESTARI clinic, patient with any breast symptoms can seek treatment directly walk into the clinic without any prior appointment or referral. Prompt clinical examination will be conducted, and

subsequently, early imaging and tissue biopsy will be arranged depending on the clinical findings.

Unfortunately, despite having an easily accessible clinic, several patients presented late at the advanced stage disease. In BESTARI clinic, we actively promote breast awareness via various breast awareness programs, charity programs, local and social media. Strong commitments are made to provide a convenient and friendly channel for those wanting to seek treatment early.

The patients who delay seeking care could be due to various factors, including the type of the symptoms, misconception about the disease, misinterpretation, inconveniency in getting to the hospital facilities due to logistic reasons, opt for alternative treatment, poor awareness, knowledge and attitudes. Thus, a local study is necessary to investigate those factors causing the delay to guide us for better planning and to formulate strategies for more targeted or individualised breast cancer awareness programs in the future. Figure 2 illustrate the framework of the study.

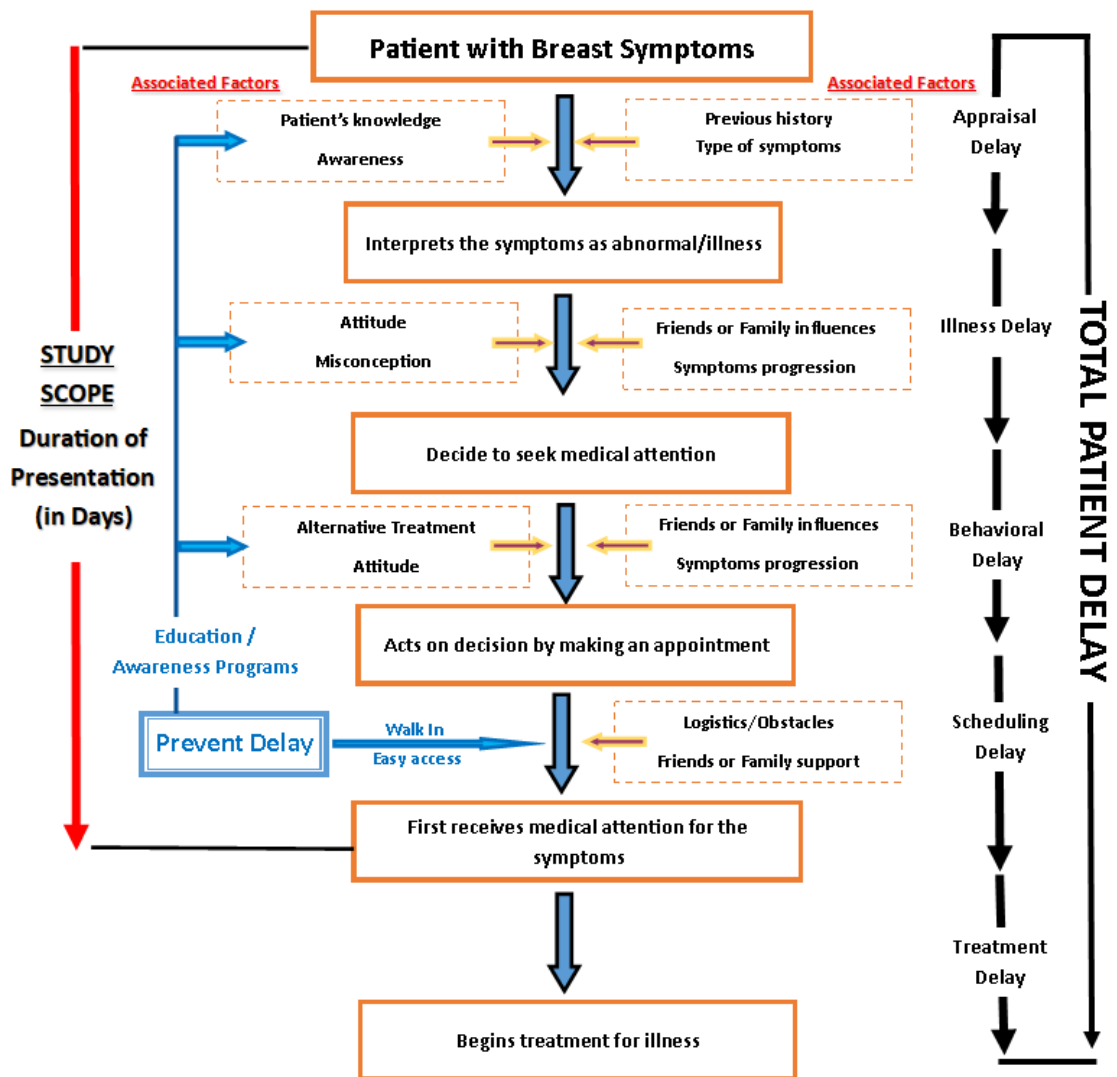


Figure 2 Study Framework integrated with Total Patient Delay by Andersen and Cacioppo, 1995 [7]

2.0 STUDY PROTOCOL

2.1 Document submitted for ethical approval



RESEARCH PROPOSAL

Research title: DELAY IN SEEKING CARE FOR BREAST SYMPTOMS AND ITS ASSOCIATED FACTORS

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Introduction

Breast cancer is the most common cancer and causes the highest number of cancer death in women worldwide (Winters et al., 2017). In high-resource countries, the incidence and mortality have been declining while in low-resource countries, the incidence and mortality have been increasing due to the differences in the access to breast cancer early detection (Winters et al., 2017).

The incidence of female breast cancer registered in the Malaysian National Cancer registry report 2007-2011 is increasing yearly, from 3579 in 2007, gradually increase to 3766 in 2011, accounted for 32.1% of all cancer among the females (Azizah et al., 2015). It is expected that the incidence of breast cancer in Malaysia to increase because of improving life expectancy, better socioeconomic status and changes in lifestyles (Norsa'adah et al., 2011).

Delay in seeking the care of breast symptoms is an important problem (Nosarti et al., 2000) and associated with lower rate of survival from breast cancer (Meechan et al., 2003). It is important to provide awareness to the community that any breast symptoms should prompt early medical attention as it could be the potential symptoms of breast cancer. A study of 692 women presented to Breast Clinic with breast symptoms found out that 87 (12.6%) of the women had the diagnosis of breast cancer (Nosarti et al., 2000).

In this study, the aim is to investigate the associated factors that lead to delay in seeking the care of breast symptoms to Breast Cancer Awareness & Research Unit (BESTARI), Universiti Sains Malaysia. The patient which breast symptoms that attended the BESTARI clinic, regardless of the type of the symptoms, malignant or benign, will be recruited in the study.

Problem statement & Study rationale

It is important for a woman to be aware that any breast symptoms are potentially the symptoms of breast cancer, thus need to be properly assessed at health care centre. It is recommended that patient with breast symptoms to undergo proper triple assessment which consists of clinical examination, imaging, and tissue biopsy to rule out malignant lesion (Kocjan et al., 2008).

If the symptoms were to be of breast cancer and there was delayed in the presentation of three months or more, it was associated with lower survival rates by 10% (Taib et al., 2011). It was estimated that 20% to 30% of women wait at least three months before seeking medical help with breast symptoms (Burgess et al., 2001).

Early detection of breast cancer is important because delay is preventable and earlier treatment can improve survival (Norsa'adah et al., 2011). Patient with late detection would be associated with larger tumour size (Tartter et al., 1999), and will increase on the cost and limit the choice of treatment (Norsa'adah et al., 2011). Earlier diagnosis, breast screening, and better treatment improved survival (Burgess et al., 2001).

Population-based screening mammogram is not practised in Malaysia thus getting an early detection of cancer depends on patients' awareness to seek treatment early and health providers that practice opportunistic screening (Taib et al., 2011).

The early access to health care for breast cancer early detection should be highlighted, and any factors leading to the delay need to be studied. In Universiti Sains Malaysia Hospital, the health care service is easily accessible by the community via the Breast Cancer Awareness & Research Unit (BESTARI) clinic. Patient with any breast symptoms can seek treatment directly walk into the clinic without any prior appointment or referral from another primary centre. Prompt clinical examination will be conducted, and subsequently early imaging and tissue biopsy will be arranged depending on the clinical findings.

Despite having an easily accessible BESTARI clinic, there were several patients that presented late or at the advanced disease. At present, there was no study in BESTARI clinic to investigate the delay and the factors that caused the delay. In average, around 100 patients new case registered in BESTARI clinic per months.

BESTARI clinic is actively promoting breast awareness via various breast awareness programs, charity programs, local and social media. Strong commitments are made to provide a convenient and friendly channel for those wanting to seek treatment early.

The patients that delay in seeking care could be due various factors including the type of the symptoms, misconception about the disease, misinterpretation, inconveniency in getting to the hospital facilities due to logistic reasons, opt for alternative treatment, poor awareness, knowledge and attitudes.

The factors causing the delay in seeking care and need to be studied to guide us for better planning and to formulate strategies for more targeted or individualised breast cancer awareness programs in the future.

Research Question

1. What is the duration of in days, from the day the patient initially aware of breast symptoms until the day the patient presented to the clinic?
2. What is the mean of the days taken by the patients before presented to the clinic?
3. What is the percentage of patients with delayed seeking care to the clinic?
4. What are the associated factors causing the delay in seeking care to the clinic?

Objective

General:

To study on the delay in seeking care for breast symptoms and its associated factors for patient presented to the clinic.

Specific:

- i. To determine the mean of duration in days, from the day the patient initially aware of breast symptoms until the day the patient presented to the clinic.
- ii. To determine the percentage of patients with delayed seeking care to the clinic.
- iii. To study on the associated factors including social demographics, previous medical history, clinical presentation, patient's knowledge, interpretation, attitude and obstacles which causing the delay in seeking care to the clinic.

Literature review

Delay can be divided into five stages which is appraisal delay, illness delay, behavioural delay, scheduling delay and treatment delay (Andersen and Cacioppo, 1995). The combination of these 5 stages are known as total patient delay, and the appraisal delay is the major stage, 60% of the total delay (Andersen and Cacioppo, 1995). Appraisal delay is the patient's interpretation of her bodily symptoms as an illness or labelling it as serious symptoms (Andersen and Cacioppo, 1995; Taib et al., 2011). Illness delay is the number of days elapsing from the time an individual interpreted that her symptoms are ill to the day she decided to seek medical attention and behavioural delay is the time from her decision and to the time she acts on the decision (Andersen and Cacioppo, 1995). These stages of total patient delay are illustrated in Figure 1.

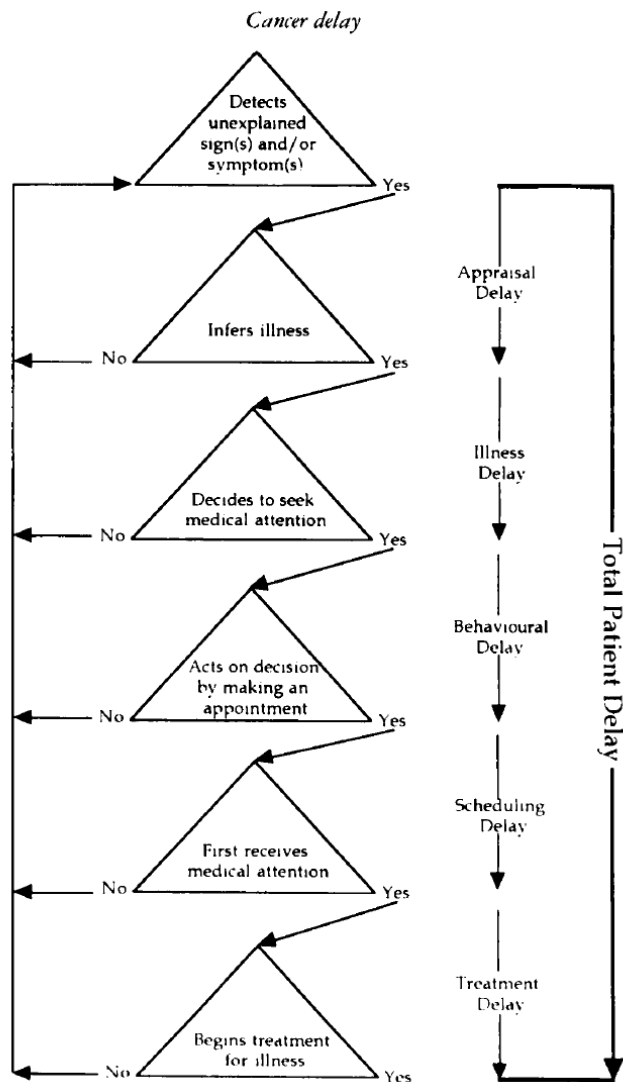


Figure 1 A model of total patient delay (Andersen and Cacioppo, 1995)

The first three stages, which are the appraisal, illness and behavioural delay are the patient's related delays. These stages consisted of factors such as patient's social demographics, previous history, interpretation of the breast symptoms, type of symptoms, knowledges, attitude and practices towards breast symptoms, which were analysed in most of the previous studies (Arndt et al., 2002; Burgess et al., 2001; Galukande et al., 2014; Hisham and Yip, 2004; Lim et al., 2015; Meechan et al., 2003; Norsa'adah et al., 2011; Taib et al., 2011). The treatment delay is not included in the study. There was one study which looks into general practitioners delay in referring patient to hospital, only 17% of the patients were referred delay by the GP, and the delay was related to the patient's initial symptoms of presentation (Burgess et al., 1998). Another study also found out that physician delay was not significant (Tartter et al., 1999).

A local study published in 2011 by Norsa'adah et al., conducted in multiple centres in the year between 2005 to 2007, found out that there was high percentage of patient with delayed presentation time. The presentation time was delayed up to 11 years with median of 2 months and 43.4% had delayed by more than 3 months [3]. The study found out that the delay among breast cancer patients are very serious problems in Malaysia and the delay was higher than in other studies in developed and developing countries (Norsa'adah et al., 2011). The factors that associated with the delay were clinical presentation, patients' interpretation, attitude and alternative treatments (Norsa'adah et al., 2011). In this study, the delay was defined as sixth-months cut off point (Norsa'adah et al., 2011) while many others studies categorised delay of three-months cut off point (Abu-Helalah et al., 2016; Arndt et al., 2002; Galukande et al., 2014; Lim et al., 2015; Meechan et al., 2003; Tartter et al., 1999).

Most of the studies were done on the patients that were diagnosed with breast cancer and the timing of presentation was recalled retrospectively or via the record in medical notes (Burgess et al., 2001; Gould et al., 2010; Hisham and Yip, 2004; Lim et al., 2015; Norsa'adah et al., 2011; Taib et al., 2011; Tartter et al., 1999), thus contained recall bias and not including the delay of presentation in patient with benign diseases. A more comprehensive study comprising of patients with breast symptoms regardless of whether it is benign or cancer with lesser recall bias is needed to properly evaluate and understand the factors leading to presentation delay.

There was a study conducted in New Zealand in 2003, a female patient who have self-discovered breast symptoms, on first consultation to their breast clinic, was recruited for the study. The breast symptoms experienced by the patients in the study were breast lump, breast infection, breast pain, nipple discharge, nipple indrawn or changes, breast abscess, change in shape or dimpling of the breast. In this study, the median presentation time was 14 days, and 14% of women had delay more than 3 months. Women that delay more than 3 months were less likely to have breast lump and had family member previously diagnosed with breast cancer. (Meechan et al., 2003)

Another study was conducted by Nosarti et al in London, United Kingdom, looking into the delay in presentation of women with breast symptoms who attended a London breast clinic and the associated factors were analysed. Presentation delay was operationally defined as the time elapsing between symptom self-discovery and the first presentation to a medical provider to seek evaluation. The median presentation time was 13 days and 17% of the women had delay over 3 months. 692 women with breast symptoms were interviewed and 87 (12.6%) of the women had the diagnosis of breast cancer. Of those 87 women with cancer, 32 (36.8%) thought that they had a less serious condition. This misinterpretation causes a longer presentation time with median of 31 days. (Nosarti et al., 2000)

Conceptual framework

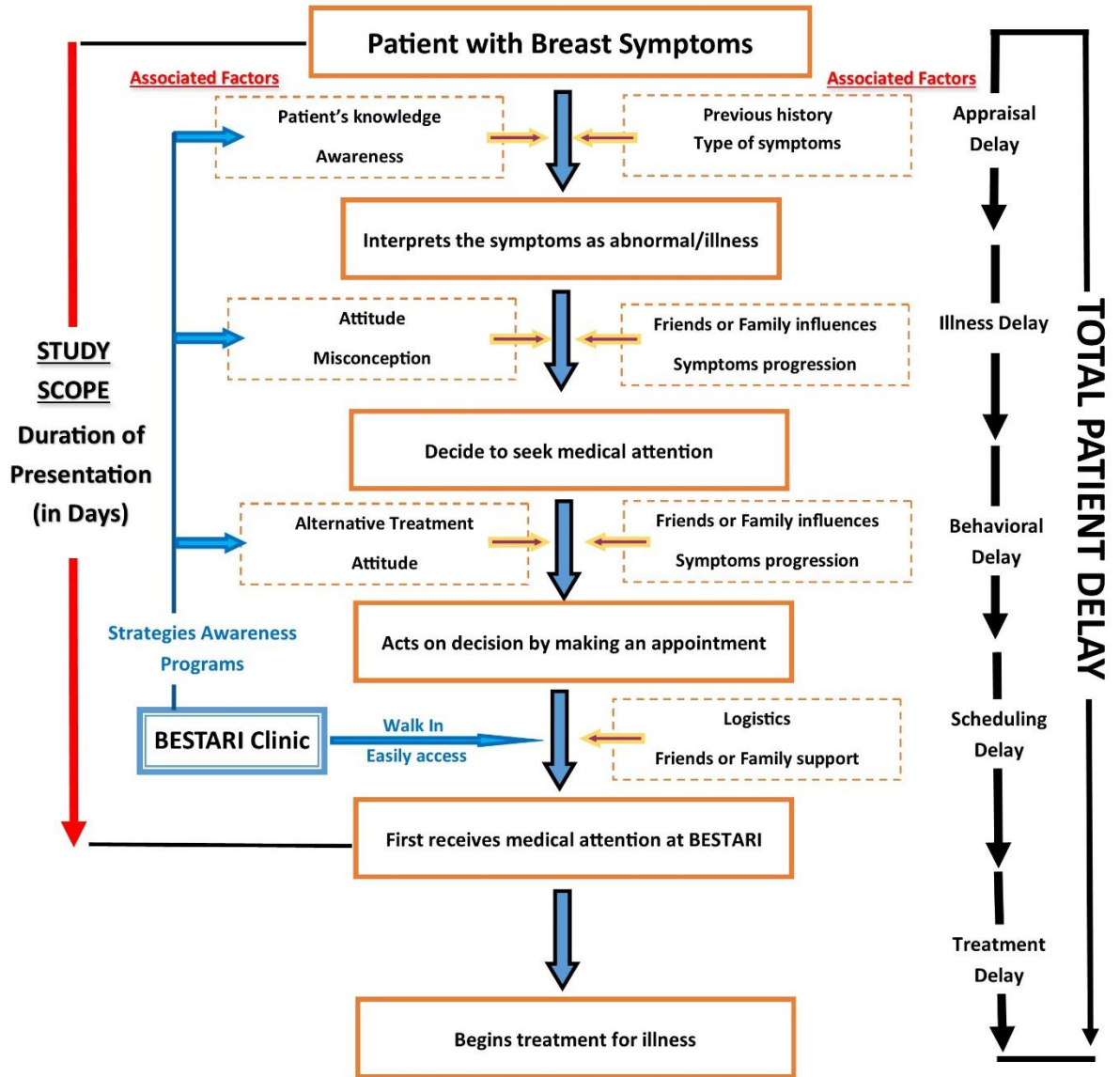


Figure 2 Conceptual Framework adapted from Anderson et al (Andersen and Cacioppo, 1995)

Research design

Cross-sectional study

Patients with breast symptoms at the first visit to BESTARI clinic, HUSM, which fulfil the inclusion and exclusion criteria will be recruited for the study.

Study area

BESTARI clinic, HUSM, Kubang Kerian, Kelantan

Study population

Reference population – Patients with breast symptoms in Kelantan

Target population – Patients with breast symptoms who attended BESTARI clinic, HUSM.

Source population/sampling pool – Patients with breast symptoms attending BESTARI clinic, HUSM

Sampling frame – All patients with breast symptoms attending BESTARI clinic, HUSM which fulfil the inclusion and exclusion criteria from June 2019 to August 2019.

Subject criteria

Inclusion criteria

1. Patient's age 18 years old and above.
2. Female.
3. Patient attending the first visit to BESTARI clinic for the breast symptoms (New case).
4. Patient referred from GP or primary care centres or other breast clinics.
5. Patient with the previous history of breast diseases (benign or cancer), currently with new breast symptoms.

Exclusion criteria

1. The patient comes for screening without breast symptoms
2. Patient with cognitive impairment

Sample size estimation

- i. **Objective 1** To determine the mean of duration in days, from the day the patient initially aware of breast symptoms until the day the patient presented to the clinic.

Using G*Power 3.1.9.4, Statistical test - Means: Difference from constant (one sample case), two tails, effect size $d=0.5$, $\alpha=0.05$, Power 80%.

Sample Size: 34

- ii. **Objective 2** To determine the percentage of patients with delayed seeking care to the clinic.

Using **G*Power 3.1.9.4**, Statistical test - Proportion: Difference from constant (binomial test, one sample case), two tails, effect size $g=0.5$, $\alpha=0.05$, Power 80%, constant proportion 0.434

(43.4% of Women delay in presentation (Norsa'adah et al., 2011))

Sample size=8 (one group)

Sample Size: $8 \times 2 = 16$

- iii. **Objective 3** To study on the associated factors including social demographics, previous medical history, clinical presentation, patient's knowledge, interpretation, attitude and obstacles which causing the delay in seeking care to the clinic.

Using Power and Sample Size Program, under Dichotomous test for Sample Size, Design: Independent, prospective, two proportions study, uncorrected chi-square test, with $\alpha=0.05$, Power 80%, p_0 , p_1 , and m as in the table below.

Associated Factors	P_0	P_1	m	N per group	Sample Size	References
Alternative Therapy	0.351	0.6	1	62	124	Norsaadah et al
Breast ulcer	0.413	0.8	1	24	48	Norsaadah et al
Palpable axillary lymph node	0.386	0.7	1	38	76	Norsaadah et al
Attitude toward treatment	0.419	0.7	1	48	96	Norsaadah et al
Fear of Breast Cancer Treatment	0.577	0.8	1	67	134	G. Meechan et al
Family History with Breast Cancer	0.163	0.5	1	53	106	G. Meechan et al

Highest Sample Size needed: 134

Add on 10% Drop out: $134 + 14 = 148$

Final Sample Size: 148

Sampling method and subject recruitment

Sampling method – All patients with breast symptoms attending BESTARI clinic, HUSM which fulfil the inclusion and exclusion criteria November 2019 to January 2020 will be recruited for the study.

Research tool

Face-to-face interviews will be conducted using standardized questionnaires developed in the previous study (Norsa'adah et al).

The questionnaire was developed in the Malay language based on expert discussions and a literature review. It was pre-tested for face and content validity and reliability, which were satisfactory (Cronbach's Alpha 0.63-0.92). The content included socio-demography, medical and obstetric history, the date of all the chronological events (the first recognition of symptoms, first complain to someone, first doctor consultation, and first meeting with the surgeon/specialist) and the use of alternative therapy.

The questionnaire also included yes-no questions on the interpretation of symptoms, knowledge about presenting symptoms, aetiology and metastatic organs, beliefs about breast cancer and treatment, fear, denial, barriers, healthcare services, husband support, attitude on medical care and treatment, and health care practices.

<u>Domains</u>	<u>Items</u>	<u>Number of Questions</u>
A. Social-Demographic	Address	1
	Age in years	1
	Race	1
	Education level	1
	Occupation	1
	Number of households	1
	Marital status	1
	History of Breast Cancer in Family	1
B. Medical and Obstetric History	Number of Children	1
	Age when first child born	1
	Breastfeeding	1
	Menarche	1
	Menses regularity	1
	Menopause	1
	Age of menopause	1
	Oral contraceptive intake	1
	Hormonal therapy after menopause	1
	History of breast diseases	1
	Other underlying medical illness	1
	Smoking	1
C. Regarding the Delay	Patient Actions and Date of Actions	14
	Interpretation of the symptoms	2
	Attitude on medical care, treatment, and health care practices	11
	Barriers	8

Operational definition

1. Breast symptoms (Lim et al., 2015; Meechan et al., 2003; Norsa'adah et al., 2011) includes (but not limited to):
 - i. Breast lump
 - ii. Breast dimpling
 - iii. Peau de orange
 - iv. Breast infection
 - v. Nipple discharge
 - vi. Nipple indrawn
 - vii. Change in shape of the breast
 - viii. Breast pain
 - ix. Breast ulcer
 - x. Axillary lump
 - xi. Breast rashes
 - xii. Breast itchiness
2. Presentation time: The duration in days, from the first day the patient initially self-discovering breast symptoms until the day the patient presented to BESTARI clinic.
3. Delayed presentation time: Women in the study who had delay more than 3 months(90days) (Abu-Helalah et al., 2016; Burgess et al., 2001; Meechan et al., 2003) before the first visit to BESTARI clinic, were categorised as delayed presentation group.

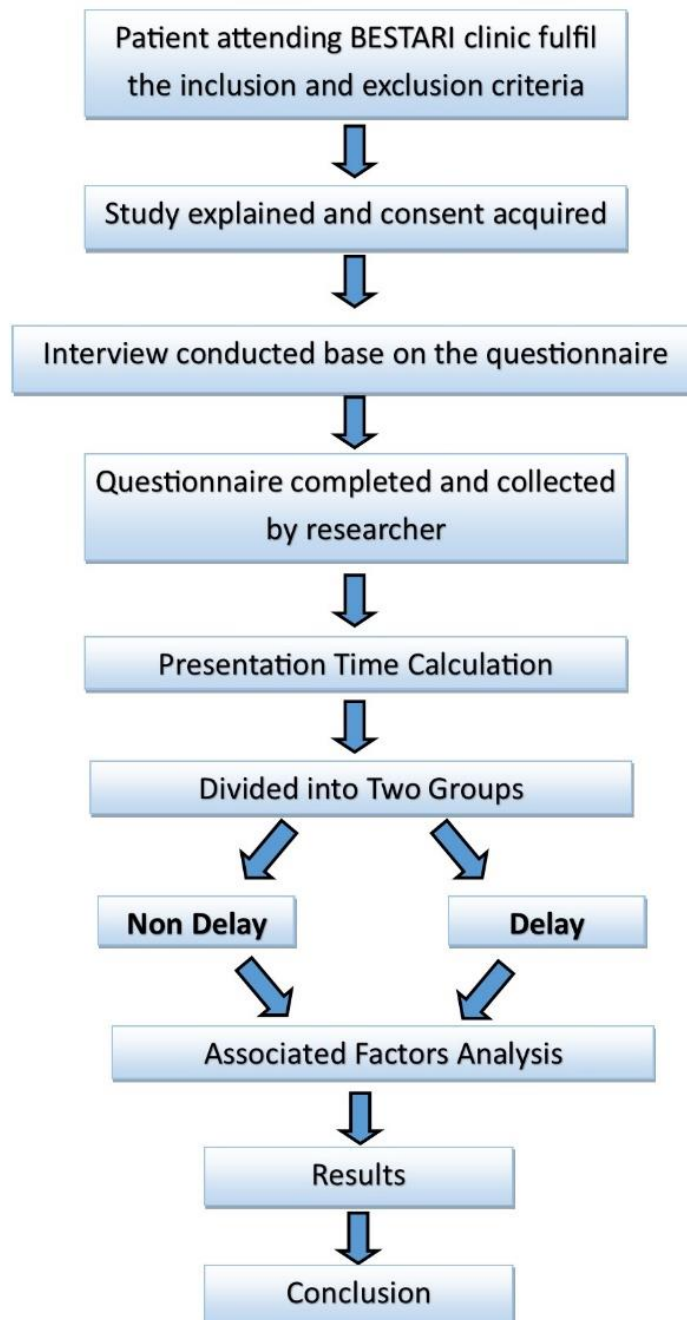
Data collection method

On the first arrival to BESTARI clinic, the patient will be explained regarding the study and will be given full freedom to participate or not without affecting her medical condition management and care. Only the patient who is 18 years and above with no impairment in cognitive function will be enrolled in the study.

After consent obtained, they will be interviewed in the BESTARI clinic based on the standardised questionnaire. The interview will be conducted in the clinic confidentially without collecting the patient name or any identifiable data. The participant can withdraw herself from the study at any time during the interview for any reason.

The interviewer will be the appointed female nurses and medical officers in BESTARI clinic. The appointed interviewer will be given proper training before the study. The recorded questionnaire will be placed in a closed storage box and later collected only by the researcher.

Study flowchart



Data analysis

Data were analysed using SPSS for Windows (version 24, SPSS Inc., Chicago, IL, USA).

Descriptive statistics will be used to summarise the socio-demographic characteristics of patients.

Continuous data will be summarised as mean (standard deviation (SD)) or median (interquartile range (IQR)) depending upon the normality of distribution, whereas categorical data will be presented as frequency (percentage (%)).

The presentation time will be divided into a binary outcome, i.e., delay and non-delay, by using a three-month cut-off point.

Multiple logistic regression will be used to identify the factors associated with diagnosis delay. A stepwise backward selection procedure will be used when selecting significant variables in the model. The interaction terms and multicollinearity problem of the final model will be checked. The final model will be tested for fitness using the Hosmer-Lemeshow goodness of fit test.

Results will be presented as the crude and adjusted odd ratios (OR), 95% confidence interval (CI) and p value. The p value <0.05 will be considered to indicate statistical significance.

Expected result(s)

Table 1 Socio-demographic characteristics of the respondents

Social Demography	Frequency (%) N =	Mean (SD)
Age (years)		
Ethnicity <ul style="list-style-type: none"> • Malay • Chinese • Indian • Others 		
Education level <ul style="list-style-type: none"> • None • Primary school • Middle school • Diploma • Degree 		
Years of education		
Family income (RM)		
Occupation <ul style="list-style-type: none"> • Housewife • Government servant • Private sector • Self-employed • Unemployed 		
Marital status <ul style="list-style-type: none"> • Married • Widow • Single • Divorce 		

Table 2 Medical History of the respondents

Medical history	Frequency (%)
Family history of breast cancer	
History of benign breast disease	
Parity status <ul style="list-style-type: none"> • Nulliparous • Parous 	
Co-morbid chronic disease	
Oral contraceptive pills	
Menopausal status <ul style="list-style-type: none"> • Pre • Post 	
Hormone replacement therapy	

Table 3 Clinical Presentation of the respondents

Clinical Characteristics	Frequency (%)
Symptoms during presentation <ul style="list-style-type: none"> Breast lump Nipple retraction Breast pain Breast ulcer Nipple Discharge Breast dimpling Axillary lump Breast change in shape 	
Location of the symptoms <ul style="list-style-type: none"> Right Left 	
Constitutional symptoms <ul style="list-style-type: none"> Loss of weight Loss of appetite 	

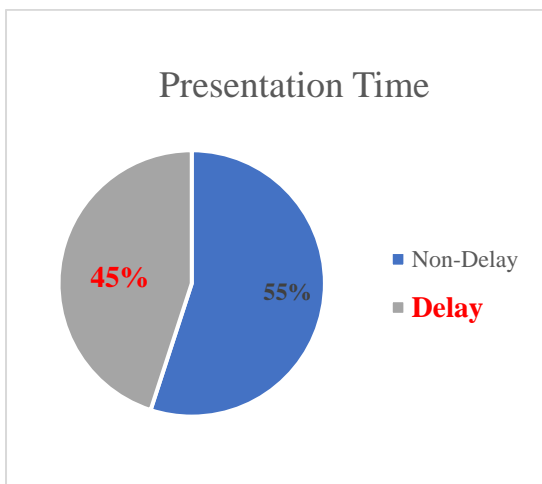


Figure 3 Presentation time of respondents with Breast symptoms

Table 4 Factors associated with presentation delay of breast symptoms

Associated Factors	Frequency (%)		Adjusted Odd Ratio (95% CI)	P value
	Non-delay N=	Delay N=		
Breast Lump				
Breast Ulcer				
Interpretation				
Attitude				
Alternative Therapy				
Family history				
Axillary lymph node				