

**UNDERSTANDING FACTORS ASSOCIATED WITH
DELAY IN SEEKING TREATMENT AMONG LOCALLY
ADVANCED AND METASTATIC BREAST CANCER IN
HOSPITAL RAJA PEREMPUAN ZAINAB II**

DR MOHD FIRDAUS BIN A. KARIM

**DISSERTATION SUBMITTED IN PARTIAL FULLFILMENT
OF THE REQUIREMENTS FOR THE DEGREE OF MASTER
OF MEDICINE
(GENERAL SURGERY)**



UNIVERSITI SAINS MALAYSIA

2020

TABLE OF CONTENTS

ACKNOWLEDGEMENTS.....	ii
ABSTRACT.....	iii
ABSTRAK.....	iv-v
1. INTRODUCTION	
1.1 Introduction.....	1
1.2 Literature Review.....	2
1.3 Justification of Study.....	4
2. STUDY PROTOCOL	
2.1 Document Submitted for Ethical Approval.....	5
2.2 Ethical Approval Letter.....	31
3. BODY CONTENT	
3.1 Introduction.....	35
3.2 Methodology.....	36
3.3 Results.....	39
3.4 Discussion.....	48
3.5 Conclusion.....	52
3.6 References.....	53

ACKNOWLEDGEMENTS

Alhamdulillah. My greatest gratitude to The Almighty ALLAH s.w.t. I would like to extend my most gratitude and appreciation to those who have contributed to the success of this study and helped me from the beginning until the completion of my dissertation.

□ My gratitude and appreciation to both my Supervisor, Dato Dr Imi Sairi Bin Hj Ab Hadi, Breast and Endocrine Consultant Surgeon from Department of Surgery, Hospital Raja Perempuan Zainab II and Dr Rosnelifaizur bin Ramely, lecturer and Vascular Surgeon from Department of Surgery, School of Medical Sciences, Universiti Sains Malaysia, and my Co-Supervisor, Dr Junaidi Bin Isa, Breast and Endocrine Surgeon from Department of Surgery, Hospital Raja Perempuan Zainab II for their priceless scientific guidance and advices for my research.

□ Cordially appreciate the invaluable help from the biostatistics and clinical research teams for their contribution in generating the research methodology, sample size calculation and data analysis of this study from Department of Community Medicine and Biostatistics & Research Methodology unit, Hospital Universiti Sains Malaysia.

□ Special thanks to the staffs of Surgical Out Patient Department of Hospital Raja Perempuan Zainab II and Surgical Wards of Hospital Raja Perempuan Zainab II , for their kindness assistance and cooperation.

Most importantly, I would like to thank both my parent A Karim A Bakar and Norainah Ismail, my dearest wife Nur Naazira Iman Song, my lovely childrens (Arsyad, Aisyah, Aliyah and Auliya) and beloved friends for their endless support, understanding and love throughout the study.

Without them, none of these would be meaningful.

Abstract

Background: Breast cancer is the second most common cancer detected in the world, as reported by GLOBOCAN in 2012 and contribute about 25% of overall cancer worldwide. In Kelantan, it had been reported by Cancer Registry 2006, up to 34.9% cases presented at stage 4, comparing only 20.7% in stage 3 and 19% in stage 1. The aim of this study is to understand the factor associated with delay in seeking treatment for patient presented with locally advanced and metastatic breast cancer in HRPZ II.

Methods: This is a cross-sectional study regarding patient who are being diagnosed as locally advanced and metastatic breast cancer in HRPZ II, Kelantan from January 2016 till December 2019. Patients were interviewed face to face using a standardized questionnaire. We exclude patient who had cognitive impairment, or who had early breast cancer but presented with recurrence disease or did not have proper documentation of investigation.

Results: A total of 111 patients are diagnosed as either locally advanced or metastatic breast cancer were interviewed. Patients thought that the breast lump will disappear by itself and afraid of the pain related to cancer and operation found to be the factors associated with delay in seeking treatment among locally advanced and metastatic breast cancer. The adjusted odds ratio for both factors was 3.13 (95% CI 1.19 – 8.20) and 0.37 (95% CI 0.16 – 0.88) respectively.

Conclusion: Patient thought that the breast lump will disappear by itself and afraid of the pain related cancer and operation are the significant independent factors that associated with delay in seeking treatment among locally advanced and metastatic breast cancer.

Keyword: Delay locally advanced breast cancer, metastatic breast cancer

Abstrak

Latar Belakang: Mengikut kajian GLOBOCAN pada tahun 2012, kanser payudara merupakan kanser yang kedua terbanyak dikesan di dunia dan merangkumi 25% dari jumlah keseluruhan kanser di dunia. Di Kelantan, mengikut laporan Pendaftaran Kanser 2006, sebanyak 34.9% pesakit kanser payudara hadir ke hospital pada tahap 4, berbanding 20.7% pada tahap 3 dan 19% ada tahap 1. Tujuan kajian ini adalah untuk mengenal pasti faktor-faktor yang berkaitrapat dengan kelewatan pesakit mendapatkan rawatan di Hospital Raja Perempuan Zainab II (HRPZ II).

Kaedah Kajian: Ini adalah kajian rentas bagi pesakit kanser payudara “locally advanced” dan “metastatic” yang didiagnos di HRPZ II dari Januari 2016 sehingga December 2019. Pesakit di temuduga menggunakan kertas soal-selidik yang diseragamkan. Pesakit yang mengalami kecacatan kognitif atau kanser payudara peringkat awal tetapi kembali kerana kanser berulang atau pesakit tidak mempunyai nota rawatan yang lengkap akan dikecualikan dari kajian ini.

Keputusan Kajian: Sejumlah 111 pesakit kanser payudara “metastatic” dan “locally advanced” telah di temuduga. Tanggapan pesakit yang ketumbuhan payudara akan hilang sendiri dan ketakutan mengenai kesakitan berkaitan dengan kanser dan pembedahan merupakan factor yang tidak bersandar menyebabkan kelewatan mendapatkan rawatan. Nisbah kebarangkalian yang disesuaikan bagi kedua-dua factor tersebut adalah 3.13 (95% CI 1.19 – 8.20) dan 0.37 (95%CI 0.16 – 0.88).

Konklusi: Anggapan pesakit yang ketumbuhan payudara akan hilang sendiri dan ketakutan mengenai kesakitan berkaitan dengan kanser dan pembedahan merupakan faktor yang tidak bersandar menyebabkan kelewatan mendapatkan rawatan bagi kanser payudara “metastatic” dan “locally advanced”.

Keyword: Delay locally advanced breast cancer, metastatic breast cancer

1.1 Introduction:

Breast cancer is the second most common cancer detected in the world, as reported by GLOBOCAN in 2012 and contribute about 25% of overall cancer worldwide.¹ It expected to increase every year as a lot of promotion had been done to increase breast cancer awareness. Despite the public awareness and education regarding breast cancer, patient with locally advanced breast cancer or metastatic breast cancer are till commonly seen in our community.

In Kelantan, it had been reported by the National Cancer Registry 2006, up to 34.9% cases presented at stage 4, comparing only 20.7% in stage 3 and 19% in stage 1.² Breast cancer is a disease that has good survival rate if detected early as delay in seeking treatment associated with the larger tumour, more advanced stage and subsequently poorer prognosis. Locally advanced breast cancer can be defined as breast cancer that have more than 5 cm in size with regional lymphadenopathy, or tumour that have direct extension to the chest wall or skin or both, or presence of regional lymphadenopathy (clinically fixed or matted lymph nodes or infraclavicular, supraclavicular, or internal mammary involvement). Whereas metastatic breast cancer is defined as any breast cancer that have spread to other organ.

Breast cancer delay can be defined as more than 12 weeks between the discovery of the symptom by the patient and the beginning of the definitive treatment. This can be further classified as patient delay (waiting 3 months or more before seeking treatment) or Health provider delay (one month or more from first patient presentation till the beginning of treatment). MA Richard et all had analyzed 2964 patient with a different stage of breast cancer, shown that the survival after 10

years for patient presented less than 12 weeks after the first symptom was 52% and 47% for longer delays.³

According to The Clinical Practice Guidelines (CPG) on the management of breast cancer in Malaysia, it is recommended that breast cancer patient should receive primary treatment within 2 months of presenting symptom.⁴

Breast cancer has a good prognosis and outcome if presented early to health care provider. 5 years survival rate for stage 1 and stage 2 are 100% and 93% respectively, whereby stage 4 disease only about 20%.⁵ This study will provide insight and understanding reason why there are still numbers of patient seeking treatment late for breast cancer.

The aim of this study is to understand the factors associated with a delay in seeking treatment for patients presenting with locally advanced and metastatic breast cancer in HRPZ II. Thus, by understanding the reasons and its factor, a corrective action can be suggested, thus perhaps the rate of advanced breast cancer in HRPZ II can be reduced in the future.

1.2 Literature Review.

Literature search and review in regard to factor for delay in seeking treatment for advance breast cancer has been done using search engine such as SpringerLink, ScienceDirect, PubMed, Clinical Key, Wiley Online Library and Google Scholar. Most of the search is filtered according

to its relevance and date of publish between 2006 to 2018. The use of connectors (AND, OR, NOT) with the combination of terms “delay”, “advance breast cancer”, and “factor”, has been applied in the searching strategy to ensure that every search is specific and effective.

In year 2011, Norsa'adah et al published a cross sectional design, multicenter epidemiological study of delay in diagnosis of breast cancer in Malaysian woman. This study had shown about 49% of breast cancer patient presented at stage 3 and stage 4 disease. A median range for Malaysian woman who have breast cancer symptoms seek health care consultation are 2 months. The study also found that more than half of patient (55.7%) who delay in seeking treatment seek alternative therapy.⁶

Mao Li Cheng et al (2015) found that about 59.5% of patient presented at late stage of breast cancer. This retrospective descriptive study also shown that only 10 patient who had diagnose with breast cancer had first degree relative with breast cancer, and only 4 of them had delay in consultation.⁷

Yusra Elobaid et al (2016) had found that the lack of knowledge with complex array of personal, social and cultural factors appear to influence a woman decision to seek clinical advice. This qualitative study had analyzed total of 19 patient who presented to Tawam Hospital from January 2010 till December 2011. The median range of consultation in 10 months while the frequency of diagnosis delay more than 6 months wass 52.6%.⁸

Mehreen Baig et al (2018) had done a cross-sectional study among breast cancer patient who presented to a tertiary care center in Pakistan. A total of 89 patient had being analyzed and 55.1% of patient presented at stage 3 while 14.6% presented at stage 4. Approximately 43.8% patient had medical consultation within 3 to 6 months after first symptom. This study had concluded that lack of knowledge about breast cancer was the most reason of delay in seeking treatment (41.6). this followed by non- availability of health care services near their hometown were second most popular reason (32.6) in delay seeking treatment.

1.3 Study justification:

Breast cancer have good prognosis and outcome if presented early. 5 years survival rate for stage 1 and stage 2 are 100% and 93% respectively, whereby stage 4 disease only about 20%.⁵ This study will provide insight and understanding reason why there are still numbers of patient seeking treatment late for breast cancer.

Thus, by understanding the reasons and its factor, perhaps the rate of advanced breast cancer in HRPZ II can be reduce in the future.

2.0 STUDY PROTOCOL

2.1 Document Submitted for Ethical Approval



**RESEARCH PROPOSAL FOR MASTER OF MEDICINE
PARTIAL REQUIREMENT FOR MASTER OF MEDICINE (SURGERY)
PROGRAMME
UNIVERSITI SAINS MALAYSIA**

**TITLE:
UNDERSTANDING FACTORS ASSOCIATED WITH DELAY IN SEEKING
TREATMENT AMONG LOCALLY ADVANCED AND METASTATIC BREAST
CANCER IN HOSPITAL RAJA PEREMPUAN ZAINAB II**

DR MOHD FIRDAUS BIN A. KARIM (MMC No. 55979)

STUDENT ID: P-UM0137/16

Principal Investigator

Coordinating Investigator:

DATO DR IMI SAIRI BIN HJ. AB. HADI (MMC No. 31761)

DEPARTMENT OF SURGERY

HOSPITAL RAJA PEREMPUAN ZAINAB II,

KOTA BHARU, KELANTAN

CO- Investigator:

DR ROSNELIFAIZUR BIN RAMELY (MMC No. 39506)

DEPARTMENT OF SURGERY,

HOSPITAL UNIVERSITY SAINS MALAYSIA,

KUBANG KERIAN, KELANTAN

Topic:

Understanding factors associated with delay in seeking treatment among locally advanced and metastatic breast cancer in Hospital Raja Perempuan Zainab II

INTRODUCTION:

Breast cancer is the second most cancer common detected in the world, as reported by GLOBOCAN in 2012 and contribute about 25% of overall cancer worldwide.¹ It is expected to increase every year as a lot of promotion had been done to increase breast cancer awareness. Despite the public awareness and education regarding breast cancer, patient with locally advanced breast cancer or metastatic breast cancer is still commonly seen in our community.

In Kelantan, it had been reported by Cancer Registry 2006, up to 34.9% cases presented at stage 4, comparing only 20.7% in stage 3 and 19% in stage 1.² Breast cancer is a disease that have good survival rate if detected early as delay in seeking treatment associated with larger tumor, more advanced stage and subsequently poorer prospect of survival.

Breast cancer delay can be defined as more than 12 weeks between discovery of the symptom by patient and the beginning of the definitive treatment. This can be further classified as patient delay (waiting 3 months or more before seeking treatment) or health provider delay (one month or more from first patient presentation till beginning of treatment). MA Richard et al had analyzed 2964 patient with different stage of breast cancer, shown that the survival after 10 years for patient presented less than 12 weeks after first symptom was 52% and 47% for longer delays.³

According to The Clinical Practice Guidelines (CPG) on management of breast cancer in Malaysia, it is recommended that breast cancer patient should receive primary treatment within 2 months of presenting symptom.⁴

The aim of this study is to understand the factors associated with delay in seeking treatment for patient presented with locally advanced and metastatic breast cancer in HRPZ II.

PROBLEMS Statement:

Generally, there are a lot of health promotion and breast awareness campaign that being held every year in Malaysia. Despite all of effort being given, there are still numbers of patient presented with locally advanced breast cancer or metastatic breast cancer. Thus, this study conducted to understand the reason why there are still patient who delay in seeking treatment and its related factor that associated with it.

Study justification:

Breast cancer have good prognosis and outcome if presented early. 5 years survival rate for stage 1 and stage 2 are 100% and 93% respectively, whereby stage 4 disease only about 20%.⁵ This study will provide insight and understanding reason why there are still numbers of patient seeking treatment late for breast cancer.

Thus, by understanding the reasons and its factor, perhaps the rate of advanced breast cancer in HRPZ II can be reduced in the future.

Research Question

1. What are the sociodemographic details for patient with delay diagnosis of locally advanced breast cancer and metastatic breast cancer and its relationship with duration of delay in diagnosis
2. What are the mean of duration of symptom before seeking treatment among locally advanced breast cancer and metastatic breast cancer
3. What are the factor influencing in delay seeking treatment among locally advanced breast cancer and metastatic breast cancer.
4. Are the patient aware regarding breast cancer during first symptom and what are reason for seeking treatment.

GENERAL OBJECTIVE:

To study the factors that associated with delay in seeking treatment among advanced breast cancer/metastatic breast cancer.

Specific objective:

1. To determine the sociodemographic data associated with delay in seeking treatment in advanced and metastatic breast cancer patient in HRPZ II.
2. To determine factors that have associated with delay in seeking treatment among patient with advanced breast cancer and metastatic breast cancer in HRPZ II
3. To evaluate association between delay in diagnosis with specific breast cancer's receptor positivity.

Research Hypothesis

- Low educational level, single, unemployed, seeking alternative therapy and family influence are an important factor that lead to delay in seeking treatment for locally advanced breast cancer and metastatic breast cancer.

Literature Review.

Literature search and review in regard to factor for delay in seeking treatment for advance breast cancer has been done using search engine such as SpringerLink, ScienceDirect, PubMed, Clinical Key, Wiley Online Library and Google Scholar. Most of the search is filtered according to its relevance and date of publish between 2006 to 2018. The use of connectors (AND, OR, NOT) with the combination of terms “delay”, “advance breast cancer”, and “factor”, has been applied in the searching strategy to ensure that every search is specific and effective.

In year 2011, Norsa'adah et al had release a cross sectional design, multicenter epidemiological study of delay in diagnosis of breast cancer in Malaysian woman. This study had shown about 49% of breast cancer patient presented at stage 3 and stage 4 disease. A median range for Malaysian woman who have breast cancer symptoms seek health care consultation are 2 months. The study also found that more than half of patient (55.7%) who delay in seeking treatment seek alternative therapy.⁶

Mao Li Cheng et al (2015) found that about 59.5% of patient presented at late stage of breast cancer. This retrospective descriptive study also shown that only 10 patient who had diagnose with breast cancer had first degree relative with breast cancer, and only 4 of them had delay in consultation.⁷

Yusra Elobaid et al (2016) had found that the lack of knowledge with complex array of personal, social and cultural factors appear to influence a woman decision to seek clinical advice. This qualitative study had analyzed total of 19 patient who presented to Tawam Hospital from

January 2010 till December 2011. The median range of consultation in 10 months while the frequency of diagnosis delay more than 6 months was 52.6%.⁸

Mehreen Baig et al (2018) had done a cross-sectional study among breast cancer patient who presented to a tertiary care center in Pakistan. A total of 89 patient had being analyzed and 55.1% of patient presented at stage 3 while 14.6% presented at stage 4. Approximately 43.8% patient had medical consultation within 3 to 6 months after first symptom. This study had concluded that lack of knowledge about breast cancer was the most reason of delay in seeking treatment (41.6). this followed by non- availability of health care services near their hometown were second most popular reason (32.6) in delay seeking treatment.⁹

Methodology:

Study Design	<u>Cross-sectional Study</u>
Study Area	Hospital Raja Perempuan Zainab II (HRPZ II), Kota Bharu, Kelantan, Malaysia.
Reference Population	Locally advanced and Metastatic Breast cancer patient at HRPZ II
Source population	Locally advanced and Metastatic Breast cancer patients who are diagnosed at HRPZ II
Sampling Frame	Locally advanced and Metastatic Breast cancer patients who are diagnosed at HRPZ II from January 2016 till December 2019
Study subjects	Locally advanced and Metastatic Breast cancer patients who are diagnosed at HRPZ II from January 2016 till December 2019

Inclusion Criteria

Patient who presented first time to Hospital Raja Perempuan Zainab II (HRPZ II) or being referred from other Health Care Centre with locally advanced or Metastatic Breast cancer from 1 January 2016 till 31st December 2019. Patient must be aged more than 18 years old and must be consented before conducting the interview.

Exclusion Criteria

Patient who being diagnosed earlier than January 2016 will be excluded as prior to this date the computerized result not yet established. Patient who did not had proper documentation of investigation result also will be excluded. Patient that being diagnosed as early breast cancer but presented again due to recurrence breast cancer also will be excluded. Patient whom did not consented for interview also will be excluded.

Sample Size

Sample Size Estimation

1. Objective 1: Sample size being calculated using single proportion equation.

a. Sample size =

$$\frac{\frac{z^2 \times p(1-p)}{e^2}}{1 + \left(\frac{z^2 \times p(1-p)}{e^2 N} \right)}$$

N = population size

e = Margin of error

z = z-score

Calculated sample size = 92 patients

2. Objective 2:

Sample size is calculated using pocock's formula

$$N = \frac{p_1(1-p_1) + p_2(1-p_2)}{(p_2 - p_1)^2}$$

With: Alpha : 0.05 , Power : 0.8 , Po : 0.6 P1 : 0.4

(percentage according to incidence in Kelantan, Bachok norsa'adah et al(2010))

N = 97

Risk factor	P0	P1	N+10%	Author, year
Age	0.15	0.83	8	Bachok norsa'adah et al(2010)
Marital status	0.19	0.8	10	Bachok norsa'adah et al(2010)
Ethnicity	0.19	0.8	10	Bachok norsa'adah et al(2010)
Family history	0.73	0.27	19	Bachok norsa'adah et al(2010)
Alternative therapy	0.64	0.30	37	Bachok norsa'adah et al(2010)

We are planning a study of independent cases and controls with 1 control(s) per case. Prior data indicate that the probability of exposure among controls is 0.6. If the true probability of exposure among cases is 0.4, we will need to study 97 case patients and 97 control patients to be able to reject the null hypothesis that the exposure rates for case and controls are equal with probability (power) 0.8. The Type I error probability associated with this test of this null hypothesis is 0.05. We will use an uncorrected chi-squared statistic to evaluate this null hypothesis.

In conclusion the largest sample size needed = 110 patients with 10% drop out

Workflow Of The Study

Source Population: Locally advance Breast cancer patients who are diagnosed at Hospital Raja

Perempuan Zainab II



Sampling frame: Locally advance Breast cancer patients who are diagnosed at Hospital Raja

Perempuan Zainab II



Inclusion criteria fulfilled



Study Sample



Data entry, analysis and interpretation using SPSS



Write up and research paper preparation



Submission of research paper

GANTT CHART

Activity	2020										
	1	2	3	4	5	6	7	8	9	10	11
Proposal and ethical clearance											
Data collection and entry											
Data analysis and interpretation											
Research report writing up											
Submission of research study											

DATA COLLECTION

1. Data Collection Method

Request for permission will be sent to Hospital Director of HRPZ II for permission to start data collection for the study with the attachment of ethical clearance. Initial data will be collected from operation theater (OT) book from Surgical Department, medical records from Record Unit and histopathology result (HPE) from Pathology Unit.

Proforma checklist will be used to extract only relevant data for this study as this study involves secondary data collection. Latest patients' status (alive or death until 31st December 2019) will be determined through Patient Management System (SPP) for those who are still having follow up after 2019, case notes and phone call. Data collection will be done after MREC approval.

Patient will be selected through convenience sampling method as they come to hospital for monthly clinic follow up or being admitted to surgical ward for any reason. Informed consent will be taken from patient before starting the interview. The interview will take about 30 minutes. After completion of this study, the study result will not be reveal to the participant directly. Prior to starting the interview, patient will be asked either to conduct the interview alone or together with her relatives.

2. Research Tool

Data extraction from HRPZ II's Record Unit and Pathology Unit

The list of patients, who diagnosed to have advance breast cancer, will be attached with verified questionnaire, adopted from *Bachok norsa'adah et al questionnaire*(Appendix 1) and used to identify clinicopathological characteristics of each breast cancer patient. The list will then be exported to SPSS software for statistical analysis purposes.

The questionnaire has been validated and its reliability were satisfactory (Cronbach’s Alpha 0.63-0.92). The permission to use questionnaire from Bachok Norsa’adah et al will be sent through email to its author. The letter approval from the author as per attachment in Appendix 2.

Data Analysis

Data will be entered and analyzed using SPSS version 22. Continuous data will be summarized as mean (standard deviation (SD)) or median (interquartile range (IGR)) depending upon the normality of distribution, whereas categorical data will be presented as frequency (percentage (%)). We will divide the diagnosis time into a binary i.e delay and non-delay, by using a 3-month cut off point.

Multiple logistic regression will be use to identify the factors associated with diagnosis delay. A stepwise backward selection, forward selection and enter method will be use to select the significant variables in the model.

The interaction terms and multicollinearity problem of the final model will be check. The final model will be tested for fitness using the homer-lemesshow goodness of fit test. Result will be presented as crude and adjusted odd ratio (OR), 95%confidence interval (CI) and p-value. The p-value <0.05 will be considered to indicate statistically significance.

Expected result as follow:

Associated factor		Delay (%)	Nondelay (%)	Crude Odd ratio (95% CI)	Adjusted Odd ratio (95%CI)	P value
Occupation	professional					
	Non professional					
Marital status	Single					
	married					
	divorce					

Educational level	None					
	Primary school					
	Secondary school					
	University/college					
Ethnicity	Malay					
	Indian					
	Chinese					
	Others					
Family history of cancer	Yes					
	No					
Number of children	None					
	Less than 4					
	More than 5					
First symptom	Breast lump					
	Breast pain					
	Others					
Awareness regarding cancer during first symptom	Yes					
	No					
History of alternative therapy	Yes					
	No					
Factor that lead to delay	Patient					
	Family factor					
	Neighbor/ colleague pressure					
	No nearby health care facilities					
	Others					

ETHICAL CONSIDERATIONS

Subject vulnerability

This study involves secondary data, which is data from breast cancer patients, in the HRPZ II Record Unit, Surgical Department and Pathology Department.

Prior to conducting the interview, patient will be given patient information sheet in language that understood by the patient and to be read by them. The patient will be informed again that this study

will not interfere with current patient management and there will be minimal risk by joining the study.

Declaration of absence of conflict of interest

No conflict of interest.

Privacy and confidentiality

Confidentiality of the data will be maintained at highest level as possible which only researcher will have the access to the data.

All forms are anonymous and will be entered into SPSS software. Only research team members can access the data. Data will be presented as grouped data and will not identify the responders individually.

Patient's names will be kept on a password-protected database and will be linked only with a study identification number for this research. The identification number instead of patient identifiers will be used on subject data sheets. All data will be entered into a computer that is password protected. On completion of study, data in the computer will be copied to CDs and the data in the computer erased. CDs and any hardcopy data will be stored in a locked office of the investigators and maintained for a minimum of three years after the completion of the study. The CDs and data will be destroyed after that period of storage. Subjects will not be allowed to view their personal study data, as the data will be consolidated into a database. Subjects can write to the investigators to request access to study findings.

Publication Policy

No personal information will be disclosed and subjects will not be identified when the findings of the survey are published.

Sponsorship and honorarium

This study is fully funded by Dr Mohd Firdaus Bin Akarim and patient will not receive any payment to involve in this study.



BORANG KAJI SELIDIK KAJIAN KELEWATAN MENERIMA DIAGNOSIS DAN RAWATAN DALAM KALANGAN WANITA KANSER PAYUDARA

Nombor Kajian:.....

A: SOSIO-DEMOGRAFI

Umur: tahun

Tarikh lahir:

Bangsa: Melayu Cina India Siam Lain-lain, nyatakan.....

Tahap pendidikan: Tiada Sekolah rendah Sekolah menengah Universiti / Institut

Pekerjaan: Suri rumahtangga Tidak bekerja Kerja kerajaan Kerja swasta Kerja sendiri

Pendapatan keluarga: RM

Bilangan ahli keluarga serumah: orang

Status perkahwinan: Tidak pernah berkahwin Berkahwin Bercerai Balu

Sejarah Keluarga kanser payudara: Ya Tidak

Jika ya, siapa? ibu kakak adik lain-lain, nyatakan

B: SEJARAH OBSTETRIK

Bilangan anak: orang

Umur semasa melahirkan anak pertama: tahun

Menyusukan anak dengan susu dada: Ya Tidak

Umur mula datang haid: tahun

Pusingan haid: teratur tidak teratur

Putus haid: belum sudah

Umur semasa putus haid: tahun

Pengambilan pil perancang keluarga: Ya, berapa lama Tidak

Pengambilan hormon selepas putus haid: Ya, berapa lama Tidak

Pernah mengalami penyakit payudara bukan kanser: Ya, jenis..... Tidak

Mempunyai penyakit lain: Ya, nyatakan Tidak

Merokok: Ya, berapa lama, berapa batang sehari

bekas perokok, berapa lama, berapa batang sehari

Tidak pernah

C: SOALSELIDIK KELEWATAN

Tarikh mula perasan gejala kanser payudara:

Apakah gejala kanser payudara yang pertama anda alami?

Benjolan Sakit Lelehan puting Puting tertarik Kudis

lain-lain, nyatakan

Tarikh mula mengadu kepada seseorang mengenai gejala kanser payudara:

, siapa.....

Tarikh pertama kali berunding dengan doktor mengenai gejala kanser payudara:

, siapa.....

Doktor beritahu ia adalah kanser infeksi ketulan susu Tidak diberitahu apa-apa

lain-lain, nyatakan

Doktor telah beri ubat beri temujanji doktor pakar ambil tisu tunggu dahulu

lain-lain, nyatakan

Saya mengambil keputusan berjumpa doktor berkenaan masalah payudara kerana:

Benjolan semakin besar Ya Tidak

Perubahan bentuk payudara Ya Tidak

Terdapat tanda baru Ya Tidak

Saya kehilangan berat badan Ya Tidak

Saya tidak lalu makan Ya Tidak

Saya semakin tidak bertenaga Ya Tidak

Saya tidak dapat menjalankan tugas di rumah dengan baik lagi Ya Tidak

Saya tidak dapat menjalankan tugas di tempat kerja dengan baik lagi Ya Tidak

Dinasihati oleh kawan-kawan Ya Tidak

Dinasihati suami Ya Tidak

Dinasihati keluarga lain Ya Tidak

Saya telah mengambil tindakan berjumpa doktor dengan segera Ya Tidak

Siapa yang membuat keputusan untuk berjumpa doktor? Diri sendiri Suami ahli keluarga, nyatakan.....

Saya mengikuti rawatan kanser payudara dengan segera Ya Tidak

Siapa yang membuat keputusan untuk mendapatkan rawatan kanser payudara:

Diri sendiri Suami ahli keluarga, nyatakan.....

Mendapat rawatan alternatif: Ya, nyatakan..... Tidak

Tarikh kemoterapi:

Tarikh radiasi:

a. Interpretasi tanda penyakit

Tidak tahu ia adalah kanser Ya Tidak

Tiada siapa beritahu itu kanser Ya Tidak

Ingat ia tidak bahaya Ya Tidak

Ingat ia akan hilang sendiri Ya Tidak

Saya rasa ia tidak merbahaya kerana ia tidak sakit Ya Tidak

b. Sikap terhadap perundingan perubatan

Tidak tahu siapa hendak mengadu Ya Tidak

Takut dimarahi doktor Ya Tidak

Tidak mahu menyusahkan doktor dengan masalah kecil Ya Tidak

Doktor tidak ramah Ya Tidak

Tidak kenal mana-mana doktor Ya Tidak

Tidak mempunyai doktor keluarga Ya Tidak

Malu untuk periksa payudara Ya Tidak

Suami tidak izinkan periksa payudara Ya Tidak

Tidak percaya rawatan moden Ya Tidak

Walau apa pun rawatan yang dilakukan, penyakit kanser payudara tidak akan sembuh Ya Tidak

Percaya rawatan alternatif (tradisional) lebih berkesan Ya Tidak

c. Takut dengan akibat kanser

Takut kesakitan Ya Tidak

Takut kehilangan payudara Ya Tidak

Saya takut ditinggalkan suami apabila membuat pembedahan payudara Ya Tidak

Saya takut hilang sifat kewanitaan apabila membuat pembedahan Ya Tidak

Saya takut keguguran rambut apabila membuat rawatan kemoterapi Ya Tidak

d. Persepsi persaingan mana yang lebih utama

Tidak tahu dimana klinik / hospital Ya Tidak

Klinik / hospital jauh dari rumah Ya Tidak

Tiada masa kerana sibok kerja Ya Tidak

Tiada masa kerana sibok dengan rumahtangga Ya Tidak

Terpaksa menguruskan anak-anak di rumah Ya Tidak

Tiada kenderaan untuk berjumpa doktor Ya Tidak
Tidak ada wang yang cukup untuk rawatan dan kos lain Ya Tidak

e. Perkara mencetuskan tindakan

Suami mendesak saya mendapatkan rawatan Ya Tidak
Ahli keluarga mendesak saya mendapatkan rawatan Ya Tidak
Kawan-kawan mendesak saya mendapatkan rawatan Ya Tidak
Ada pengalaman waris/kenalan mengidap kanser payudara Ya Tidak
Apabila terdengar mengenai kanser payudara dimedia Ya Tidak
Apabila terbaca mengenai kanser payudara dimedia cetak Ya Tidak

f. Kepercayaan

Kanser payudara berlaku pada diri saya kerana:

Kecederaan pada payudara Ya Tidak
Simpulan urat Ya Tidak
Pemakanan yang tidak baik Ya Tidak
Sistem badan yang lemah Ya Tidak
Stress Ya Tidak
Keturunan Ya Tidak
Asyik berkata mengenainya Ya Tidak
Disumpah Ya Tidak
Dibuat orang Ya Tidak

D: PERFORMA REKOD

Status: hidup mati tidak diketahui

Tarikh status: □□/□□/□□□□

Jika status tidak diketahui, tarikh terakhir masih hidup: □□/□□/□□□□

a: Keadaan klinikal semasa diagnosa

Berat badan: □□. □ kg

Tinggi: □.□□ m

Mammogram: Ya, bila Tidak

Kanser payudara dikesan oleh: pesakit sendiri kakitangan perubatan mammogram
 lain-lain, nyatakan.....

Lokasi : Kanan Kiri Kedua-dua UOQ UIQ LOQ LIQ Tengah

- Benjolan: Ya, besarnya semasa diagnosis: cm Tidak
- Banyak benjolan: Ya Tidak
- Sakit: Ya Tidak
- Lelehan puting: Ya Tidak
- Puting tertarik: Ya Tidak
- Payudara lekuk Ya Tidak
- Terlalu bengkak: Ya Tidak
- Fungating: Ya Tidak
- Ruam kulit: Ya Tidak
- Peau de orange: Ya Tidak
- Kudis: Ya, besarnya semasa diagnosis: cm Tidak
- Tiada selera makan: Ya Tidak
- Hilang berat badan: Ya Tidak
- Cachexia: Ya Tidak
- Axillari limfa: Ya Tidak
- Supraclavikel limfa: Ya Tidak
- Sakit tulang: Ya Tidak
- Patah tulang: Ya Tidak
- Masalah penafasan: Ya Tidak
- Batuk: Ya Tidak
- Kuning: Ya Tidak
- Lemah anggota: Ya Tidak
- Bengkak tangan: Ya Tidak

b: Rawatan

Jangkamasa gejala: bulan

Tarikh gejala kanser payudara bermula: (tarikh interview tolak jangkamasa symptom)

Tarikh pertama kali berjumpa doktor di HUSM kerana kanser payudara:

Di HUSM di mana? Kecemasan Pesakit luar Klinik pembedahan Klinik onkologi

Tarikh pertama kali berjumpa pakar bedah:

Tarikh pertama kali berjumpa pakar onkologi:

Tarikh diagnosis: Diagnosis dengan: Klinikal FNAC Trucut Biopsi

Masalah diagnosis: FNAC tak cukup tisu FNAC benign

Berlaku misdianosis: Ya Tidak

Jenis pembedahan: lumpectomy quadrectomy mastectomy
Menolak rawatan Tidak boleh dibedah

Tarikh pembedahan:

Kemoterapi: Rawatan sempurna Rawatan tidak sempurna Tidak dicadangkan Menolak rawatan

Jenis kemoterapi: CMF CEF CAF lain-lain, nyatakan Menolak rawatan

Jenis kemoterapi: Adjuvant Neoadjuvant Paliatif

Tarikh mula kemoterapi: Bilangan kemoterapi:

Radiasi: Rawatan sempurna Rawatan tidak sempurna Tidak dicadangkan Menolak rawatan

Tarikh mula radiasi:

Pesakit mungkir janji >sekali : Ya Tidak

Tamoxifen: Ya Tidak

Femara: Ya Tidak

Brachytherapy: Ya Tidak

Oophorektomi: Ya, bila _____ Tidak

c: Patologi

Tarikh lapuran HPE:

Jenis histo-patologi: Ductal Lobular Medullary Mucinous Tubular Lain-lain, nyatakan

Gred: 1 2 3 Peringkat: T N M

Axillari limfa dlm patologi: Positif Negatif Tidak diketahui / sampel tidak mencukupi

Bilangan limfa nodus yang diperiksa: Bilangan limfa nodus yang positif:

Margin: Terlibat / sangat hampir Tidak terlibat

Telah merebak: Paru2 Tulang Otak Hati Lain-lain, nyatakan.....

Estrogen Reseptor: Positif Negatif Tidak diketahui

Progesteron Reseptor: Positif Negatif Tidak diketahui

C-erb B₂: Positif Negatif Tidak diketahui

Appendix 2

Sekretariat,
Jawatankuasa Etika Penyelidikan Manusia,
Universiti Sains Malaysia,
Kampus Kesihatan,
16150 Kubang Kerian, Kelantan

7hb April 2020

RE: KEBENARAN MENGGUNAKAN SOAL SELIDIK

1. Adalah seperti maklumat di atas, saya membenarkan pelajar yang bernama seperti di bawah menggunakan soal selidik kepunyaan saya yang telah disahkan bertajuk "**BORANG KAJI SELIDIK KAJIAN KELEWATAN MENERIMA DIAGNOSIS DAN RAWATAN DALAM KALANGAN WANITA KANSER PAYUDARA**" dalam kajian:

Tajuk: **UNDERSTANDING FACTOR ASSOCIATED WITH DELAY IN SEEKING TREATMENT AMONG LOCALLY ADVANCED AND METASTATIC BREAST CANCER IN HOSPITAL RAJA PEREMPUAN ZAINAB II**

Penyelidik Utama: Dr Mohd Firdaus Bin A Karim (P-UM0137/16 , MMC 55979)
Supervisor : Dato Dr Imi Sairi Bin Ab Hadi (MMC: 31761)
Co-Supervisor : Dr (Mr) Rosnelifaizur bin ramely (MMC 39506)

2. Jika sekiranya pihak tuan mempunyai sebarang pertanyaan , sila hubungi saya di talian/email berikut:

No : 09-767 3000, ext:6827
No telefon: 019-746 9520
Email: norsaadah@usm.my

Sekian, terima kasih.

Yang benar,



Professor Norsaadah Bachok
Unit of Biostatistics & Research Methodology,
School of Medical Sciences,
Universiti Sains Malaysia,
Kampus Kesihatan,
16150 Kubang Kerian, Kelantan

Reference:

1. Torre, L. A., Bray, F. , Siegel, R. L., Ferlay, J. , Lortet-Tieulent, J. and Jemal, A. (2015), Global cancer statistics, 2012. *CA: A Cancer Journal for Clinicians*, 65: 87-108.
2. Fauzia MN, mS Norazmi : Cancer Registry Report Kelantan 1999-2003, Report no 1/2006 Kota Bharu Kelantan Health State Department 2006.
3. Richards MA, Smith P, Ramirez AJ, Fentiman IS, Rubens RD. The influence on survival of delay in the presentation and treatment of symptomatic breast cancer. *Br J Cancer*. 1999 Feb;79(5-6):858-64. doi: 10.1038/sj.bjc.6690137. PubMed PMID: 10070881; PubMed Central PMCID: PMC2362673.
4. Ministry of Health Malaysia, Academy of Medicine Malaysia, 2010. Clinical Practice Guidelines: Management of Breast Cancer, 2nd ed. MOH, Putrajaya
5. Unger-Saldaña, Karla & Infante, Claudia. (2011). Breast cancer delay: A grounded model of help-seeking behaviour. *Social science & medicine* (1982). 72. 1096-104. 10.1016/j.socscimed.2011.01.022.
6. Bachok norsa'adah, Krishna G rampal, mohd a rahmah, nyi N naing, biswa M biswal: Diagnosis delay of breast cancer and its associated factors in Malaysian woman (2010), *BMC cancer* 2011 11:141
7. Cheng ML, Ling D, Nanu P, Nording H, Lim CH. Factors influencing late stage of breast cancer at presentation in a district Hospital-Segamat Hospital, Johor. *Med J Malaysia*. 2015 Jun 1;70(3):148-52.
8. Elobaid Y, Aw TC, Lim JN, Hamid S, Grivna M. Breast cancer presentation delays among Arab and national women in the UAE: a qualitative study. *SSM-population health*. 2016 Dec 1;2:155-63.

9. Baig M, Sohail I, Altaf HN, Altaf OS. Factors influencing delayed presentation of breast cancer at a tertiary care hospital in Pakistan. *Cancer Reports*. 2019 Feb;2(1):e1141.